

ATHABASCA UNIVERSITY

AN EXAMINATION OF BODY WEIGHT, DIET, AND PHYSICAL ACTIVITY
INFORMATION SOURCES AND NEEDS TO INFORM SERVICE PROVISION FOR
RURAL BREAST CANCER SURVIVORS IN NORTHERN BRITISH COLUMBIA: A
CROSS-SECTIONAL STUDY

BY

LINDSAY VAN DER MEER, B.Sc. R.D.

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN
PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF HEALTH STUDIES

CENTRE FOR NURSING AND HEALTH STUDIES

ATHABASCA, ALBERTA
OCTOBER, 2014

© LINDSAY VAN DER MEER



The future of learning.

Approval of Thesis

The undersigned certify that they have read the thesis entitled

“Lifestyle Information Sources and Needs to Inform Service Provision Among Rural Breast Cancer Survivors in Northern British Columbia”

Submitted by

Lindsay Van der Meer

In partial fulfillment of the requirements for the degree of

Master of Health Studies

The thesis examination committee certifies that the thesis
and the oral examination is approved

Supervisor

Dr. Steven Johnson
Athabasca University

Committee members

Dr. Jeff Vallance
Athabasca University

Dr. Geoff Ball
University of Alberta

Dr. Mamdouh Shubair
University of Northern British Columbia

October 9, 2014

Abstract

Breast cancer survivors often seek information about lifestyle behaviours. The objectives of this study were to: 1) determine body weight, diet, and physical activity information sources and needs of rural breast cancer survivors in Northern British Columbia (BC), and 2) describe if and how these lifestyle recommendations are delivered to rural breast cancer survivors in Canada. Two cross-sectional surveys were completed among rural breast cancer survivors in Northern BC and among Canadian nurses and dietitians. Breast cancer survivors (N=132) want to make lifestyle changes to improve their health and are interested in how changes can reduce the risk of recurrence and improve survival. Healthcare providers (N=134) frequently field questions on lifestyle from breast cancer survivors, though few are referred to community programs or services. Opportunities exist to support rural breast cancer survivors in Northern BC including improved awareness of lifestyle information and integration with existing chronic disease management programs.

Dedication

This research is dedicated to breast cancer survivors in Northern BC. In addition to facing the many physical and psychosocial challenges that can accompany breast cancer, many of these women experience cultural, socioeconomic, and geographical barriers that complicate their cancer journeys and make equitable survivorship care less attainable. It is my sincere hope that this research will contribute to improving care for breast cancer survivors in Northern BC and justify the need for rural-focused solutions for rural populations.

Acknowledgements

I would like to thank the following individuals for their guidance, support, and contributions to this research:

My husband, Josh, for helping me to see beyond graduate school and supporting me in finding balance while I juggled school, work, and life. I could not have done this without you.

Dr. Steven Johnson, my supervisor, for patiently and thoroughly answering all of my questions along the way, for helping me navigate the research process, and for ongoing guidance while I carried out my thesis and prepared this document.

Dr. Ryna Levy-Milne, my manager, for her support and assistance with navigating the research process at BC Cancer Agency.

Peggy Lynn M^{ac}Isaac, AU Reference Librarian, for her comprehensive assistance with literature searches.

The other members of my thesis committee: Dr. Jeff Vallance and Dr. Geoff Ball, whose existing work and feedback helped to shape my thesis. And finally, Dr. Mamdouh Shubair, for his role as external committee member.

Table of Contents

Approval Page	ii
Abstract	iii
Dedication	iv
Acknowledgements	v
Table of Contents	vi
List of Tables	xi
List of Symbols, Abbreviations, and Nomenclature	xii
1.0 Introduction	1
1.1 Study Objectives	2
1.2 Definitions	3
1.2.1 Breast Cancer survivor(s)	3
1.2.2 Rural	4
2.0 Review of the Literature	6
2.1 Review of Evidence for the Role of Lifestyle Factors on Breast Cancer	
Outcomes	6
2.1.1 Body Weight	6
2.1.2 Diet	10
2.1.2.1 Dietary Patterns	10
2.1.2.2 Low-Fat Diet	11
2.1.2.3 Phytoestrogens	13
2.1.2.4 Vitamin D	15
2.1.3 Physical Activity	17
2.1.4 Lifestyle Interventions	20

2.1.5 Summary	24
2.2 Information Needs of Breast Cancer Survivors	24
2.3 Defining a Need for Research on Rural Breast Cancer Survivors	26
2.4 Transitioning to Survivorship Care	28
2.5 Summary	29
3.0 Methods	30
3.1 Study Objectives	30
3.2 Study Design	31
3.3 Study Population	31
3.3.1 Part 1: Breast Cancer Survivors	31
3.3.2 Part 2: Cancer Care Providers	31
3.4 Inclusion and Exclusion Criteria	32
3.4.1 Part 1: Breast Cancer Survivors	32
3.4.2 Part 2: Cancer Care Providers	32
3.5 Sampling and Recruitment	32
3.5.1 Part 1: Breast Cancer Survivors	32
3.5.2 Part 2: Cancer Care Providers	33
3.6 Data Collection	34
3.6.1 Part 1: Breast Cancer Survivors	34
3.6.2 Part 2: Cancer Care Providers	35
3.7 Measures	36
3.7.1 Part 1: Breast Cancer Survivors	36
3.7.2 Part 2: Cancer Care Providers	38
3.8 Data analysis	39
3.8.2 Part 1: Breast Cancer Survivors	39

3.8.2 Part 2: Cancer Care Providers	39
3.9 Ethical Considerations	40
4.0 Results	40
4.1 Part 1: Breast Cancer Survivors	40
4.1.1 Body weight, diet, and physical activity changes after diagnosis (objective 1a)	41
4.1.2 Barriers to and interest in body weight, diet, and physical activity changes (objective 1b)	43
4.1.3 Body weight, diet, and physical activity information sources and needs (objective 1c)	45
4.1.4 Reliability of information sources (objective 1d)	49
4.1.5 Program and resource preferences (objective 1e)	49
4.1.6 Proportional differences of demographic variables with information sources, needs and preferences (objective 1f)	51
4.2 Part 2: Cancer Care Providers	52
4.2.1 Knowledge and attitudes (objective 2a)	52
4.2.2 Differences in knowledge and attitudes by discipline (objective 2b)	54
4.2.3 Provision of information and awareness of programs (objective 2c)	54
4.2.4 Differences between discipline and proportion of rural patients, and provision of information and awareness of programs (objective 2d)	56
5.0 Discussion	57
5.1 Part 1: Breast Cancer Survivors	58
5.2 Part 2: Cancer Care Providers	62
5.3 Implications for Practice and Service Delivery	66

5.4 Limitations and Suggestions	69
5.5 Suggestions for Future Research	71
6.0 Conclusion	74
References	76
Appendices	96
Appendix A: Timeline	96
Appendix B: Budget	97
Appendix C: Letter of Initial Contact Part 1	98
Appendix D: British Columbia Cancer Registry Information Sheet	100
Appendix E: Cross-Sectional Survey Part 1	101
Appendix F: Reminder/Thank You Letter Part 1	123
Appendix G: Letter of Initial Contact Part 2	124
Appendix H: Cross-sectional Survey Part 2	126
Appendix I: Reminder/Thank You Letter Part 2	131
Appendix J: Athabasca University Research Ethics Board Approval	132
Appendix K: University of British Columbia BC Cancer Agency Research Ethics Board Approval	133
Appendix L: Table 3	135
Appendix M: Table 4	136
Appendix N: Table 5	137
Appendix O: Table 6	138

List of Tables

Table 1: Characteristics of Breast Cancer Survivors in Northern BC	42
Table 2: Characteristics of Cancer Care Providers	49
Table 3: Characteristics of Body Weight Programming for Breast Cancer Survivors Reported by Cancer Care Providers	135
Table 4: Characteristics of Programming on Diet for Breast Cancer Survivors reported by Cancer Care Providers	136
Table 5: Characteristics of Physical Activity Programming for Breast Cancer Survivors Reported by Cancer Care Providers	137
Table 6: Characteristics of Lifestyle Programming for Breast Cancer Survivors Reported by Cancer Care Providers	138

List of Symbols, Abbreviations, and Nomenclature

ASCO - American Society of Clinical Oncology

AUREB – Athabasca University Research Ethics Board

BC – British Columbia

BMI – Body Mass Index

CANO – Canadian Association of Nurses in Oncology

CON – Communities Oncology Network

DC – Dietitians of Canada

DPP - Diabetes Prevention Program

DRI - Dietary Reference Intakes

HR - Hazard Ratio

IOM – Institute of Medicine

IU – International Units

Kg – kilograms

m² – Metres squared

N, *n* - Number

OR – Odds Ratio

PI – Primary Investigator

RCT – Randomized Controlled Trial

RD – Registered Dietitian

RN – Registered Nurse

TINQ-BC - Toronto Informational Needs Questionnaire – Breast Cancer

WHEL – Women’s Healthy Eating and Living Study

WINS – Women’s Intervention Nutrition Study

UBC BCCA REB – University of British Columbia British Columbia Cancer Agency Research
Ethics Board

An Examination of Body Weight, Diet, and Physical Activity Information Sources and Needs to Inform Service Provision for Rural Breast Cancer Survivors in Northern British Columbia: A Cross-Sectional Study

1.0 Introduction

Breast cancer survivors comprise the largest cancer survivor population in Canada (Smith, Wei, Alexander, & Singh-Carlson, 2011). There are more than 150,000 Canadian women alive today that have had a breast cancer diagnosis in the last ten years (Canadian Cancer Society, 2012). Ongoing advances in breast cancer treatment have led to a growing number of long-term breast cancer survivors living cancer-free, with stable disease, or with advanced cancer (Patterson, Cadmus, Emond, & Pierce, 2010). For example, in the province of British Columbia (BC), 89% of individuals diagnosed with breast cancer are still alive five years after their diagnosis (BC Cancer Agency, 2010a). Breast cancer survivors are often motivated to make lifestyle changes (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005), and seek information to improve their health and assist with coping (Radina, Ginter, Brandt, Swaney, & Longo, 2011). Breast cancer survivors are often interested in accessing information to help them cope and to support lifestyle changes that may improve their disease outcomes (Demark-Wahnefried, et al., 2005). Early research has begun to inform body weight, diet, and physical activity recommendations for breast cancer survivors, and in some large urban centres, programming exists to communicate recommendations and support applying this evidence.

This research was designed to address several knowledge gaps. Firstly, it identifies the body weight, diet, and physical activity (lifestyle) information sources and needs among rural breast cancer survivors in Northern BC, which to date are unknown. Secondly, this research describes if and how evidence-based information on lifestyle behaviour is delivered to breast

cancer survivors living across Canada. Thirdly, findings from this study will inform the provision of evidence-based information on body weight, diet, and physical activity to rural breast cancer survivors in a sparsely populated yet geographically vast area. Overall, the results of this study will help to address a gap for a population considered to be disadvantaged in terms of socioeconomic status, education, and access to healthcare services and providers.

1.1 Study Objectives

1. Among rural breast cancer survivors in Northern BC, the objectives were to describe
 - a. body weight, diet, and physical activity changes since diagnosis;
 - b. barriers to and interest in body weight, diet, and physical activity changes;
 - c. currently available body weight, diet, and physical activity related information sources and needs;
 - d. perceived reliability of available information sources;
 - e. preferences for programs and resources; and
 - f. differences in information sources, needs, and preferences based on selected demographic characteristics.
2. Among cancer care providers the objectives were to describe
 - a. knowledge and attitudes about body weight, diet, and physical activity recommendations for breast cancer survivors;
 - b. if knowledge and attitudes about body weight, diet, and physical activity recommendations for breast cancer survivors differ among Registered Nurses and Registered Dietitians;
 - c. if and how evidence-based recommendations for body weight, diet, and physical activity are being delivered to rural breast cancer survivors in Canada; and

- d. if the provision of information and awareness of programs differs according to demographic variables (discipline and proportion of rural patients cared for).

1.2 Definitions

1.2.1 Breast Cancer Survivor(s)

Despite extensive use of the term in the literature, there is no uniformly accepted definition of a *cancer survivor* or *cancer survivorship* (Doyle, 2008). The Centers for Disease Control and Prevention (CDC) defines an individual as a cancer survivor from the time of diagnosis onward (CDC, 2011). In a concept analysis of the term *cancer survivorship*, Doyle (2008) postulated that survivorship starts after a cancer diagnosis and is characterized by several attributes (uncertainty, a life-altering experience, and both positive and negative aspects) as well as health consequences (physical, psychological, social, and spiritual).

Others have more narrowly defined cancer survivorship as the distinct phase between completion of cancer treatment and recurrent disease or end of life (Grunfeld & Earle, 2010), or more simply as those who have completed cancer treatment (Memorial Sloan-Kettering Cancer Centre, 2011). This phase is considered distinct because individuals in the survivorship phase are often concerned with accessing follow-up care and management of delayed side effects from treatment as well as rehabilitation from their diagnosis, prevention of recurrence and improvement of overall health (Grunfeld & Earle, 2010).

A cancer survivor may have different information needs relevant to their diagnosis at different times during the cancer journey, which may not follow a linear path. For example, a cancer survivor may be actively seeking information about the type of cancer he or she was diagnosed with followed by seeking information specific to side-effects from treatment, and then how to prevent recurrence and improve health related quality of life. The heterogeneity of the

cancer journey makes allocating any specific health and information needs of individuals into distinct categories a difficult task. Therefore, for the purposes of this study, the term breast cancer survivor will apply to any woman who has been diagnosed with breast cancer.

1.2.2 Rural

As there is no uniformly accepted definition of rural in Canada (du Plessis, Beshiri, Bollman & Clemenson, 2002), literature that defined this concept was reviewed in an effort to assist with the selection an acceptable working definition. Most definitions are based on population size, density, or the influence that an urban centre has on its surrounding area (McNiven, Purderer, & Janes, 2000; Olatunde, Leduc, & Berkowitz, 2007). Markey, Halseth and Manson (2010) described the importance of incorporating both spatial and social components into a definition of rural in an effort to incorporate a rural way of living. This way of living has been described by Cloke (1989, as cited in Markey et al., 2010) as small settlements that extensively use land and live a distinct lifestyle based on this land use. Some communities may collectively identify with this concept of rural, regardless of population size, density or distance from an urban centre (Markey et al., 2010).

In a comparison of definitions of rural that have been applied in Canada, du Plessis and colleagues (2002) describe that the choice of definition is important and depends on the question being asked, as no single definition of rural is appropriate for all situations. In the absence of a uniformly accepted definition, it has been suggested to define rural by degrees of rurality that exist on a continuum as opposed to distinct categories (du Plessis et al., 2002). Degrees of rurality are based on identifying relevant parameters such as distance, population density, or availability of a post-secondary institution (du Plessis et al., 2002).

The BC Cancer Agency Centre for the North provides care to the most geographically vast and sparsely populated area in BC. The catchment area for the BC Cancer Agency Centre for the North encompasses the entire NH region and several local health areas that extend into Interior Health. The NH catchment area represents 64% of the overall provincial land mass of BC; however, this region includes only 6.4% of the provincial population (Kashaninia, 2011). Although approximately one third of the 288,570 residents in this area live in Prince George and the surrounding area, the remaining land is sparsely populated, with only four municipalities with populations over 10,000 (Kashaninia, 2011). The local health areas included in the BC Cancer Agency Centre for the North catchment area that extend beyond NH are also predominantly rural areas, with a total population of 43, 937, or 1.0% of the provincial population (British Columbia Statistics, 2012). Separate definitions of rural were selected for each of the two parts of the study to reflect each population and their likely distinct perceptions of rural. For example, a rural way of life is a defining feature for many Northern BC residents, regardless of community size or proximity to healthcare services (Markey et al., 2010). Therefore, the first definition (study part 1) was based on all communities in the BC Cancer Agency Centre for the North catchment area exhibiting varying degrees of rurality. Measurable parameters relating to access to cancer care services were inquired about in the survey. This included distance travelled to location of breast cancer surgery, chemotherapy, and/or radiation therapy.

Healthcare professionals and administrators commonly use population size or the presence the availability of healthcare services when defining an area as rural (Halseth, Helm & Price, 2011). The second definition (study part 2) was adapted from a study of breast cancer survivors in Southern Alberta by Vallance, Lavallee, Culos-Reed and Trudeau (2012a) where the

term *rural and small town* was defined based on Statistics Canada definitions. In this case, Statistics Canada defined rural as any area not within a Census Metropolitan Area (CMA) or Census Agglomeration (CA) defined by population sizes of >100,000 or >10,000 respectively (McNiven et al., 2000). In the study by Vallance et al (2012), *rural and small town* included areas outside of CMA urban cores and CAs of < 20,000. Therefore, for part 2 of this study, rural was defined as areas outside of CMAs, and CAs with populations less than < 20,000.

2.0 Review of the Literature

This section will describe lifestyle factors including body weight, diet, and physical activity, which have been studied in breast cancer survivors in relation to their role in breast cancer outcomes. It will also describe existing research on information needs of breast cancer survivors and how providing information about body weight, diet, and physical activity is an important part of survivorship care. Given that body weight, diet, and physical activity are modifiable, and may influence breast cancer outcomes and risk of other chronic diseases, the need for ongoing research to determine more specific recommendations for these lifestyle factors is significant.

2.1 Review of Evidence for the Role of Lifestyle Factors on Breast Cancer Outcomes

2.1.1 Body Weight

Historically, many cancers were diagnosed at an advanced stage and patients often presented with considerable fat and muscle loss (Rock et al., 2012). Improved cancer screening, detection, and treatment has led to better survival rates from cancer and a growing population of cancer survivors who have unique health and wellbeing needs (Rock et al., 2012). Cancer survivors are often interested in addressing modifiable risk factors for chronic diseases other than cancer (i.e., diabetes and cardiovascular disease) and survival or for simply improving their

quality of life (Jones & Demark-Wahnefried, 2006). Because overweight and obesity are established risk factors for the development of postmenopausal breast cancer (Demark-Wahnefried et al., 2005; Patterson et al., 2010), it is not surprising that many women are overweight or obese at the time of their breast cancer diagnosis (Rock et al., 2012). Furthermore, women with increased body weight are more frequently diagnosed at a later stage of disease and have poorer survival after a breast cancer diagnosis (Kroenke, Chen, Rosner, & Holmes, 2005a). Overweight and obesity not only increase the risk of postmenopausal breast cancer recurrence (Patterson et al., 2010), but also increase the risk of other chronic diseases such as hypertension, cardiovascular disease and type 2 diabetes.

The link between excess body weight and the development of cancer has been studied, but the physiological mechanisms are not fully understood (Renehan, Roberts, & Dive, 2008). Insulin resistance, increased circulating estrogen, as well as chronic inflammation are all present in obesity and are understood to play important roles in creating an environment in the body favorable to the development of cancers such as postmenopausal breast cancer (Renehan et al., 2008). Fluctuating levels of estrogen related to menstruation have made it more difficult to interpret the relationship between estrogen and premenopausal breast cancer risk (Rock et al., 2008). As breast cancer risk increases with age, most research on body weight and breast cancer outcomes has included postmenopausal women. While the relationship between excess body weight and premenopausal breast cancer is less clear (Patterson et al., 2010), all breast cancer survivors should be encouraged to achieve and maintain a healthy body weight regardless of menopausal status (Rock et al., 2012).

The relationship between body weight status at diagnosis, weight gain after diagnosis and breast cancer recurrence has been examined (Caan et al., 2008; Kroenke et al., 2005a). Weight

gain before and after diagnosis and breast cancer recurrence was examined in a cohort of women diagnosed with breast cancer from the Nurses' Health Study (Kroenke et al., 2005a). Although pre-diagnosis body weight was not associated with breast cancer recurrence, weight gain after diagnosis was associated with recurrence when study participants were stratified by smoking status (Kroenke et al., 2005a).

In another prospective study that examined breast cancer outcomes and body weight before and after a breast cancer diagnosis, weight gain after diagnosis did not show any increase in risk of recurrence (Caan et al., 2008). It is noteworthy, however, that an increased risk of breast cancer recurrence was observed among breast cancer survivors who lost $\geq 10\%$ of their body weight after diagnosis (Caan et al., 2008). As decreased appetite and weight loss are commonly observed among individuals with metastatic cancer (Thavarajah et al., 2012), it is possible that some breast cancer survivors who experienced this weight loss already had undetected recurrence and metastatic disease, which could have confounded the results of this study. In addition, poor control of symptoms during cancer treatment such as nausea, vomiting, diarrhea, and mouth sores can lead to changes in appetite and intake and a subsequent decline in nutritional status and quality of life, and poorer tolerance and outcomes from treatment (Robinson, Darling, Brezden-Masley, & Scaffidi, 2008). While a general recommendation exists for breast cancer survivors to achieve and maintain a healthy body weight (Rock et al., 2012), an acceptable amount of weight loss needed to reduce risk of breast cancer recurrence in overweight and obese individuals is not yet known (Befort et al., 2012; Teras, Goodman, Patel, Diver, Flanders, & Spencer Feigelson, 2011).

Weight gain after a breast cancer diagnosis is common, particularly among women who receive chemotherapy (Caan et al., 2008; Demark-Wahnefried et al., 2001; Freedman et al.,

2004). Among 1692 breast cancer survivors followed for almost seven years ($M = 83.9$ months, $SD = 20.2$), 47.3% of women aged 55 years or younger ($n = 651$) gained weight after a breast cancer diagnosis, and 28.4% of these women gained more than 10% of their body weight (Caan et al., 2008). When stratified by age and menopausal status, younger and premenopausal women were more likely than older and postmenopausal women to experience large ($\geq 10\%$ of their body weight) weight gains ($p < 0.0001$). In the study by Kroenke et al (2005a), breast cancer survivors who gained weight after diagnosis tended to be younger on average (58 years for BMI increase of 0.5 to 2.0 kg/m² and 56 years for BMI increase > 2.0 kg/m²) than breast cancer survivors who maintained or lost weight (59 years for weight maintenance and 61 years for > 0.5 kg/m² weight loss). A higher proportion of those who gained the most weight after diagnosis received chemotherapy, though this difference was not statistically significant (Kroenke et al., 2005a). The results of this study are consistent with earlier evidence identifying that weight gain is more common in younger breast cancer survivors who are premenopausal (Goodwin, 2001; Demark-Wahnefried et al., 2001).

Factors known to contribute to weight gain among breast cancer survivors include decreased physical activity levels (Irwin et al., 2003) and fatigue (Demark-Wahnefried et al., 2001). Fatigue may influence eating patterns among breast cancer survivors as was demonstrated in a study by Guest, Evans, and Rogers (2013). Fatigue was assessed using a validated tool and results showed that among breast cancer survivors suffering from fatigue, there was a positive linear association between fatigue and daily percentage of calories from fat ($r = 0.31, p < .05$) and a negative linear association between fatigue and daily grams of dietary fibre ($r = -0.38, p < .05$). Work by Demark Wahnefried et al (2001) identified that weight gain among breast cancer survivors who received chemotherapy was characterized by a loss or maintenance of lean tissue

and an increase in fat mass, which is in opposition to the corresponding increase in lean tissue seen in typical weight gain (Forbes, Brown, Welle, & Lipinski, 1986).

2.1.2 Diet

2.1.2.1 Dietary patterns. The relationship between dietary patterns and breast cancer outcomes is complex and studies have shown mixed results (Goodwin, Ennis, Pritchard, Koo, Trudeau, & Hood, 2003; Izano, Fung, Chiuve, Hu, & Holmes, 2013; Kroenke, Fung, Hu, & Holmes, 2005b; Kwan, Weltzien, Kushi, Castillo, Slattery, & Caan, 2009). For example, Goodwin et al (2003) described a U-shaped association between intake of several nutrients and breast cancer survival. Specifically, extremes in intake of fat, carbohydrate, protein, and cholesterol were associated with poorer survival from breast cancer compared to a more moderate intake of these nutrients (Goodwin et al., 2003). Breast cancer survivors in the Nurses' Health Study who followed a Westernized diet pattern had no higher risk of breast cancer mortality or all-cause mortality compared with breast cancer survivors who followed a plant-based diet (Kroenke et al., 2005b). In contrast, breast cancer survivors in the Life After Cancer Epidemiology study cohort who followed a Westernized diet pattern had an increased risk of overall mortality, whereas those who followed a more prudent diet pattern (whole foods and plant-based) had a lower risk of overall mortality (Kwan et al., 2009). Neither dietary pattern was associated with breast cancer recurrence or breast cancer-specific mortality. More recently, Izano et al (2013) found that among BCS from the Nurses Health Study, those with the highest versus lowest overall diet quality had a lower risk of non-breast cancer-specific mortality. There were no differences found for the risk of breast cancer recurrence or breast cancer-specific mortality.

2.1.2.2 Low-fat diet. The role of a low-fat diet in reducing risk of breast cancer recurrence has been examined in two large randomized controlled trials (RCTs), though results

have not been consistent. The Women's Intervention Nutrition Study (WINS) was a large ($n = 2437$) multi-centre RCT that examined the impact of a low-fat diet (20% of total calories from fat) on relapse-free survival in women aged 48-79 years with early stage breast cancer who had received conventional treatment (Chlebowski et al., 2006). Women in the intervention group received biweekly counselling by Registered Dietitians (RDs) who received specific and ongoing training for the study intervention. The women who were counselled on following a low-fat diet were given a daily goal for the amount of fat to be consumed, as well as a journal to keep track of their food intake. They had face-to-face appointments with study RDs biweekly for eight weeks, followed by follow-up every three months, either in person or via telephone, and the option of attending nutrition classes monthly. It is noteworthy that no counselling was provided on weight loss, as this was not a goal of the study. Women in the control group received a single face-to-face counselling session with a RD at baseline and then follow up sessions every three months. The information provided to women in the control group was general in nature and focused on nutrient adequacy. Assessment of fat intake was carried out with impromptu diet histories conducted by trained interviewers at baseline and twice annually over the course of the median 60 month study duration. At baseline, fat intake was 29.6% of calories for both the intervention and control groups. At one year, fat intake decreased to 20.3% in the intervention group, but stayed stable in the control group at 29.2%. The difference in percentage fat intake between the intervention and control groups was maintained at 9.0% after three years and 8.0% after five years. When relapse events, defined as breast cancer recurrence anywhere (local, regional or distant), were examined between the two groups, the stratified log rank for the adjusted Cox survival analysis revealed no difference in terms of relapse compared to the control group over the 5 year study period (HR = 0.76; 95% CI, 0.60–0.98). Though weight loss was not

an intention of the low-fat diet intervention (i.e., efficacy was based on relapse free survival by intervention), women in the intervention group experienced a modest weight loss of 2.7 kg [95% CI, -4.5, -0.9]. The role of weight loss alone in risk of cancer relapse could not be determined. With this result, the authors concluded that a low-fat diet in combination with modest weight loss may reduce the risk of cancer relapse in postmenopausal women with a history of breast cancer.

The Women's Healthy Eating and Living (WHEL) study was a large ($n = 3088$) RCT that examined if a diet high in fruit, vegetables and fibre, and low in fat could reduce risk of breast cancer recurrence and all-cause mortality among women previously treated for breast cancer (Pierce et al., 2007). Women in the intervention group received an intensive nutrition and counselling program with the goal of changing their diet to include five servings of vegetables daily, one 16oz serving of vegetable juice, three servings of fruit, 30 grams of fibre/day and limiting dietary fat consumption to 15-20% of total calories. The intensive nutrition counselling program included regular phone calls by trained counsellors to guide dietary behavior change, as well as monthly newsletters and optional cooking classes. The control group received only print resources encouraging five servings of fruit and vegetables daily, an intake of at least 20g of fibre, and limitation of fat to no more than 30% of calories. Adherence to recommendations was monitored with several 24-hour dietary recalls over the course of the mean 7.3 year study period. With the exception of caloric intake, adherence to all aspects of the intervention peaked at six months after baseline and showed a declining trend over the course of the study. The authors report that this study showed that there were no differences in the risk of recurrence or all-cause mortality between the intervention and control groups and that "reducing dietary fat intake did not benefit breast cancer outcomes" (Pierce et al., 2007, p. 296).

A notable difference between the WINS and WHEL trials was the efficacy of each approach to achieve the desired 20% of total calories from fat. This target was accomplished in the WINS trial (Chlebowski et al., 2006), but not in the WHEL study (Pierce et al., 2007). Although women in the intervention group in the WHEL study consumed less dietary fat than the control group, dietary fat consumption comprised 24.2 – 30.9% of total calories throughout the study period, never reaching the goal of 15-20% of calories from fat during the 7.3 year study period (Pierce et al., 2007). The current body of evidence suggests a low-fat diet (< 20% of total caloric intake) may be efficacious for reducing breast cancer recurrence. Within this evidence, the behavioural target of consuming 20% of total caloric intake from fat appears feasible (Chlebowski et al., 2006). However, achieving this behavioural goal requires substantial and sustained motivation as well as behavioural support (e.g., intensive dietary counselling via telephone, cooking classes, and newsletters over the course of several years) that may not be easily translated to the real world. These results of the WINS and WHEL studies are of particular importance to other breast cancer survivor outcomes like body weight (BMI) where dietary intake has an important role.

2.1.2.3 Phytoestrogens. Many breast cancer survivors have questions about consuming soy-based foods and foods that contain flaxseed. This is not surprising since animal studies raised concerns about possible breast cancer-promoting effects of these foods (Helferich, Andrade, & Hoagland, 2008). Soy foods as well as flaxseed contain high amounts of phytoestrogens, which are compounds that are chemically similar to estrogen (Helferich et al., 2008). Ongoing research in this area among breast cancer survivors is helping to inform recommendations for consuming these foods.

Several cohort studies that included breast cancer survivors in Asia and North America have demonstrated that soy consumption decreases (Kang, Zhang, Wang, Huang & Jin, 2010; Shu et al., 2009) or has no effect (Caan et al., 2011) on risk of breast cancer recurrence, and no effect on breast cancer mortality (Kang et al., 2010). In addition, breast cancer survivors taking tamoxifen who consumed soy had a decreased risk of recurrence compared to breast cancer survivors who were not on tamoxifen (Guha, Kwan, Quesenberry, Weltzien, Castillo, & Caan, 2009). Results from a recently published meta-analysis of cohort studies on soy food intake after diagnosis and breast cancer survival that included more than eleven thousand patients found that post-diagnosis intake of soy food was associated with decreased recurrence (HR = 0.79, 95% CI, 0.72-0.87) and mortality (HR = 0.85, 95% CI, 0.77-0.93) (Chi, Wu, Zeng, Xin, Liu & Xu, 2013). A subgroup analysis by menopausal status and receptor status (ER/PR) found that postmenopausal women, and ER- or ER+/PR+ may be most likely to benefit from post-diagnosis soy food consumption, as there was no association between recurrence and mortality for premenopausal women, or women who were ER+, ER-/PR+, or ER+/PR- (Chi et al, 2013). While there is still a need for further research in this area, including randomized controlled trials, soy-containing foods are considered safe for breast cancer survivors to consume (Caan et al., 2011; Rock et al., 2012).

The functional potential of flaxseed on modulating breast cancer growth has more recently received attention. Flaxseed is the best-known source of dietary lignans (Thompson, Chen, Li, Strasser-Weippl, & Goss, 2005), which are structurally similar to estrogen and may be protective against breast cancer by binding to estrogen receptors (Peterson, Dwyer, Adlercreutz, Scalbert, Jacques, & McCulloch, 2010). A small study by Thompson et al (2005) showed that the consumption of 25 grams of ground flaxseed per day for 32 days increased breast cancer cell

apoptosis, reduced tumor cell proliferation, and decreased expression of aggressive breast cancer phenotypes. Buck et al (2011) examined serum enterolactone levels among postmenopausal women with breast cancer on overall survival and distant disease-free survival over a median follow-up time of 6.1 years. Serum enterolactone is a biomarker of lignan intake (Patterson, 2011). Those in the highest serum enterolactone quartile (median 64.1 nmol/L) showed a 42% decreased risk of death when compared to those with the lowest level of serum enterolactone (median 3.4 nmol/L) (Buck et al., 2011). A nonsignificant reduction in risk of distant disease-free survival was also seen when the highest and lowest serum enterolactone quartiles were compared (HR = 0.62; 95% CI, 0.35-1.09). Although flaxseed may play an important role in modulating breast cancer growth and recurrence, the evidence is inadequate to recommend flaxseed in large amounts to breast cancer survivors (Patterson, 2011).

2.1.2.4 Vitamin D. Research on the role of vitamin D and breast cancer outcomes has shown inconsistent results (Chlebowski, 2013). Inadequate vitamin D, often measured in the blood as 25-hydroxyvitamin D, is common among women recently diagnosed with breast cancer (Rose, Elser, Ennis & Goodwin, 2013). Breast tissue contains the enzyme 25-hydroxyvitamin D-1 α -hydroxylase, which is responsible for converting 25-hydroxyvitamin D to its active form, 1,25 dihydroxyvitamin D (Holick, 2007). The proposed mechanism for 1,25 dihydroxyvitamin D in modulating breast cancer is through regulation of genes controlling critical phases of the cell cycle including cellular proliferation and apoptosis (Holick, 2007). Twenty-five-hydroxyvitamin D levels are lower in women with more advanced or metastatic breast cancer (stage III and IV) when compared to early stage breast cancer (stage I and II) (Palmieri, MacGregor, Girgis & Vigushin, 2006). It is currently unknown if the reason for lower 25-hydroxyvitamin D levels among women with more advanced breast cancers is due to the cancer or its treatment, or factors

known to be associated with low 25-hydroxyvitamin D levels such as low physical activity and increased BMI (Chlebowski et al., 2008; Chlebowski, 2013). The possible relationship between 25-hydroxyvitamin D and breast cancer incidence or outcomes becomes further complicated when considering that physical activity and a healthy body weight are known to decrease the risk of developing breast cancer (Chlebowski, 2013; Ibrahim & Al-Homaidh, 2011; Patterson et al., 2010).

A recent systematic review and meta-analysis by Rose et al (2013) examined 25-hydroxyvitamin D levels and breast cancer prognosis among 5691 early stage breast cancer survivors. The risk of breast cancer recurrence and death was significantly higher among breast cancer survivors with low versus high 25-hydroxyvitamin D levels (Hazard Ratio (HR) = 2.13, CI [1.64, 2.78] and HR = 1.76, CI [1.35, 2.30], respectively). There are several drawbacks to this meta-analysis that limits its generalizability including a lack of standardized 25-hydroxyvitamin D levels among included studies, and the lack of adjustment for factors known to be associated with lower 25-hydroxyvitamin D levels such as increased BMI. Results of studies examining 25-hydroxyvitamin D levels that do not adjust for factors that can influence 25-hydroxyvitamin D levels including treatment type, physical activity levels, or BMI have been questioned (Chlebowski, 2013). Further, the studies included in this meta-analysis were only observational and therefore a causal relationship between 25-hydroxyvitamin D and breast cancer prognosis is not possible. Unfortunately, there is concern that RCTs to test the effect of 25-hydroxyvitamin D on breast cancer outcomes will likely not be carried out since vitamin D supplementation has become very common, particularly among breast cancer survivors. Participation in a study that may involve being randomized to stop vitamin D supplements, particularly among breast cancer

survivors who are deficient, may be difficult to recruit for and difficult to power adequately to control for factors such as BMI and physical activity.

The Institute of Medicine updated its Dietary Reference Intakes (DRIs) in 2010 for calcium and vitamin D. This included an increase in the DRIs for vitamin D for adult women under seventy years of age from 200 IU/day to 600 IU/day, and for adult women aged seventy and older from 400 IU/day to 800 IU/day. The expert committee concluded that the evidence for increasing the DRI for vitamin D was based on studies examining bone health alone and that more research is needed before the recommendations can be made around vitamin D for other health conditions including cancer (National Research Council, 2011). While adequate vitamin D intake is recommended among breast cancer survivors at risk of, or who have had osteoporotic fractures to optimize 25-hydroxyvitamin D levels (Lustberg, Reinbolt & Shapiro, 2012; Papaioannou et al., 2010), current evidence does not support vitamin D supplementation in breast cancer survivors for the purpose of influencing breast cancer outcomes (Chlebowski, 2013; Rose et al., 2013).

2.1.3 Physical Activity

Physical activity offers many benefits for breast cancer survivors. While physical activity is known to reduce the risk of developing breast cancer (Neilson, Conroy, & Friedenreich, 2014), evidence from prospective studies has also shown positive results for physical activity on breast cancer outcomes among survivors. For example, in a study by Holick et al. (2008), risk of breast cancer mortality decreased as metabolic equivalent task (MET)-hours per week of physical activity increased. Research by Holmes, Chen, Feskanich, Kroenke, and Colditz (2005) showed that risk of breast cancer recurrence decreased by 43% among survivors who engaged in 9-14.9 MET-hours per week of recreational physical activity compared to predominantly sedentary

breast cancer survivors. Results from a recently published meta-analysis on the influence of physical activity on breast cancer outcomes indicated that regular physical activity after a breast cancer diagnosis decreased disease-specific mortality by 34% and breast cancer recurrence by 24% (Ibrahim & Al-Homaidh, 2011). The largest reductions in risk of both breast cancer mortality and recurrence were observed for breast cancer survivors who engaged in 9-14.9 MET-hours per week of physical activity (Ibrahim & Al-Homaidh, 2011). Walking 4 hours per week (MET score of 3 multiplied by 4 hours) is equivalent to 12 MET-hours per week (Holmes et al., 2005). Thus, these data suggest that walking between 3 and 4 hours per week can substantially reduce the risk of breast cancer recurrence among survivors.

Physical activity has been shown to offer numerous health benefits to breast cancer survivors. Physical activity has been shown to reduce cancer-related fatigue (Kangas, Bovbjerg, & Montgomery, 2008) and improve health-related quality of life among breast cancer survivors (Duijts, Faber, Oldenburg, van Beurden, & Aaronson, 2011; McNeely, Campbell, Rowe, Klassen, Mackey, & Courneya, 2006; Vallance, Lavalley, Culos-Reed & Trudeau, 2012a). Aerobic exercise has been shown to improve cardiopulmonary function among breast cancer survivors (Kim, Kang, & Park, 2009). Both aerobic and resistance exercise has been shown to improve body composition by decreasing percentage body fat (Kim, Kang, & Park, 2009; Winters-Stone et al., 2013). Finally, resistance exercise has been shown to have positive effects on bone mineral density among breast cancer survivors with treatment-induced menopause (Winters-Stone et al., 2013).

Current research supports the participation in regular physical activity by breast cancer survivors (Ibrahim & Al-Homaidh, 2011). The American College of Sports Medicine recommends that cancer survivors should follow age-specific physical activity guidelines,

though modifications may be needed particularly after surgery when mobility is often limited (Schmitz et al., 2010). The Canadian Physical Activity Guidelines recommend that all adults should strive to get at least 150 minutes per week aerobic physical activity that is moderate-to-vigorous in intensity, and to engage in strengthening exercises a minimum of twice per week (Canadian Society for Exercise Physiology, 2011). All cancer survivors should be encouraged to limit inactivity, continue participation in normal physical activity during treatment except around the time of surgery, where it is encouraged to restart these activities as quick as possible afterwards (Schmitz et al., 2010). Appropriate planning and guidance of resistance training programs is recommended for breast cancer survivors due to increased risk of osteoporosis and lymphedema as a result of surgery and treatment (Schmitz et al., 2010). Evidence-based lifestyle resources for breast cancer survivors encourage women to participate in, at minimum, two to three hours of moderate to vigorous intensity exercise, such as walking, per week (BC Cancer Agency, 2011; Vallance & Courneya, 2008).

Despite the aforementioned health benefits of physical activity for breast cancer survivors, the overwhelming majority of survivors are not meeting physical activity guidelines. Breast cancer survivors are less likely to meet public health physical activity guidelines than non-breast cancer survivor women of similar age, and physical activity levels among breast cancer survivors tend to decrease after a breast cancer diagnosis (Mason et al., 2013; Vallance et al., 2012a). In a cohort study of breast cancer survivors followed for 10 years, 34.0% of women met physical activity guidelines prior to diagnosis, yet only 21.4% did at 10 years post diagnosis (Mason et al., 2013). Given the benefits of physical activity on cancer outcomes and overall health for the growing population of long-term breast cancer survivors, further research is needed

on strategies to increase physical activity and decrease sedentary behaviour among breast cancer survivors.

2.1.4 Lifestyle Interventions

While research has examined nutrition or physical activity interventions separately on breast cancer outcomes, there is little research on combined interventions on body weight or breast cancer outcomes (Rack et al., 2010). A recently published study by Campbell et al (2012) piloted the feasibility of a 24-week lifestyle intervention on body composition, dietary habits, and biomarkers among a small sample of postmenopausal breast cancer survivors ($n = 14$) who had completed adjuvant treatment for early stage breast cancer. The lifestyle intervention was based on the Diabetes Prevention Program (DPP) study that compared the effectiveness of a lifestyle intervention that combined dietary changes and physical activity with medication to delay or prevent type 2 diabetes (Knowler et al., 2002). While the diet intervention followed the DPP intervention closely, the exercise intervention was altered. The exercise component included a combination of independent and supervised exercise program aimed at meeting 150 minutes per week of moderate-to-vigorous aerobic activity, with progressive increases in intensity level. The diet intervention included individual strategies to promote weight loss and low-fat eating as well as 16 group nutrition sessions facilitated by an experienced oncology dietitian. At the end of the intervention, results showed significant decreases in body weight (-3.8 ± 5.0 kg, $p = .02$), BMI (-1.4 ± 1.9 kg/m², $p = .02$), and percentage body fat ($-2.4 \pm 2.7\%$, $p < .01$), though no significant changes in dietary intake or biomarkers were observed. Twelve weeks after the 24-week intervention ended, anthropometrics were re-measured and further significant decreases in body weight (-0.8 ± 1.2 kg, $p = .03$) and BMI (-0.30 ± 0.5 , $p = .03$) were found when compared to the end of the intervention (at 24 weeks). Although this brief pilot study did

not include breast cancer recurrence or overall survival as outcome measures, it did demonstrate the feasibility of a lifestyle intervention for decreasing body weight and improving body composition among breast cancer survivors; it also provides an example of an intervention that can be provided to breast cancer survivors. Despite the positive results of this intervention, it should be noted that the human and financial resources were extensive, making it highly unlikely to be duplicated in rural settings where the target population is more geographically dispersed and health professionals with the expertise to facilitate such a program are less abundant. Nevertheless, the study results highlight how interventions for the prevention and management of other chronic diseases or conditions can be modified to be appropriate for breast cancer survivors.

A recently published study on a telephone-based group weight loss intervention among rural breast survivors has shown promising results. In this study, 34 rural-living breast cancer survivors, who were treated with a combination of chemotherapy, radiation and/or surgery for breast cancer an average of 3.1 years prior, participated in a 6 month intervention aimed at facilitating a 10% decrease in body weight (Befort et al., 2012). Study participants were postmenopausal, had BMIs between 27 and 45 kg/m² at baseline and lived in one of three degrees of rurality in the state of Kansas: large rural core (10,000 to <50,000 people), small rural core (2,500 to <10,000 people) or isolated rural, which includes anything smaller than small rural core. The intervention consisted of 24 weekly telephone sessions that involved participants attending a conference call. These sessions were led by a dietitian and a clinical psychologist on topics relevant to weight loss such as goal setting, label reading, body image, nutrition and breast cancer, and stress management. Rural-specific components of this intervention included access to healthy foods and opportunities for engaging in physical activity in small centres, recognizing

and discussing the shared culture of rural living, and modifying traditional energy-dense foods to decrease calories. Participants were advised on their individual caloric requirements to facilitate weight loss and collectively required to eat five or more servings of vegetables and fruits daily, two store-bought frozen dinners or approved alternatives daily, and two low-calorie weight-loss shakes daily. Participants were also advised to progressively increase their physical activity to 225 minutes of moderate intensity activity per week and required to keep eating and activity journals. Of the 91% of participants who attended three-quarters of the weekly sessions ($n = 31$), significant reductions in body weight (-12.5 ± 5.8 kg, $p < .001$), waist circumference (-9.4 ± 6.3 cm, $p < .001$), daily calorie consumption (-328 ± 550 kcal, $p < .001$), and percentage calories from fat (-12.6 ± 8.6 %, $p < .001$) were observed. As well, those who attended three-quarters of the weekly sessions increased weekly physical activity (196.5 ± 115.5 min, $p < .001$) and had increased quality of life measures including an increased sense of control over health. Circulating insulin and leptin levels also decreased significantly during the 6 month intervention. High levels of both of these hormones are implicated with the physiological mechanism linking obesity with increased risk of postmenopausal breast cancer (Renehan et al., 2008). There were no correlations between length of time since treatment or extent of rural living and weight loss. With mean weight loss of all study participants at 12.8 ± 6.8 % of baseline weight, this small single-arm study demonstrates the feasibility of a distance-based weight loss intervention among rural breast cancer survivors at achieving a 10% weight loss goal and showed numerous other health and quality of life-related benefits. As more data from randomized controlled trials becomes available, it is hoped that more specific recommendations will follow. In addition, there is a need for research to test the effectiveness of other distance-based communication options, such as the Internet or videoconferencing or determine the appropriate mixture of components

such as telephone and mailed print-based materials that may be more cost-effective and feasible in resource depleted rural areas.

The FRESH START and RENEW trials have both examined the effectiveness of distance-based interventions to improve functional status, or diet and physical activity among breast, prostate and colorectal cancer survivors. The FRESH START trial randomly assigned breast and prostate cancer survivors ($n = 543$) to receive printed mailed materials that were either survivorship-tailored or general consumer diet and exercise information over a 10 month period (Demark-Wahnefried et al., 2007). After 1 year, both groups made improvements in diet (diet quality, percentage calories from fat, vegetables and fruit servings) and total weekly minutes of moderate, hard, and very hard physical activity (≥ 5 MET-hours). While both groups made significant lifestyle improvements, cancer survivors who received the tailored resources made significantly greater improvements in weekly minutes of physical activity, fruit and vegetable servings, total saturated fat and total fat, and BMI.

The RENEW trial randomly assigned colorectal, breast and prostate cancer survivors ($n = 641$) over 65 years of age to either the intervention group or to a wait list control (Morey et al., 2009). Over a 12 month period, the intervention group received a combination of telephone support from counsellors as well as mailed printed materials to improve diet quality, encourage exercise, and facilitate weight loss with the overall intention of mitigating functional decline. After 12 months, cancer survivors in the intervention group experienced a slower decline in functional status when compared to the wait list group. Intervention group participants also significantly improved targets for diet (vegetable and fruit servings, saturated fat intake), physical activity (duration and frequency of strength and endurance exercise), decreased body weight and BMI, and improved health-related quality of life. While the FRESH START and

RENEW trials were not exclusive to breast cancer survivors, they demonstrate the efficacy of distance-based interventions in improving health and slowing functional decline among cancer survivors.

There are several clinical trials currently underway examining the role of lifestyle interventions on breast cancer outcomes specifically. The SUCCESS-C study will measure disease-free survival among overweight breast cancer survivors receiving either a comprehensive weight loss intervention or general lifestyle guidelines (Rack et al., 2010). The weight loss intervention is telephone-based and includes a calorie-reduced, low-fat diet high in fruits and vegetables combined with increased physical activity, with the goal of achieving and maintaining a 5-10% weight loss (Rack et al., 2010). This study is ongoing and scheduled to be completed in 2016.

2.1.5 Summary

There is consistent evidence of the benefits of physical activity for breast cancer survivors, while the evidence for the role of dietary patterns and body weight is less consistent. Unhealthy body weight, unhealthy diet, and physical inactivity are risk factors that breast cancer survivors should be encouraged to modify to improve their health. There is a need for ongoing research to determine more specific recommendations for body weight, diet, and physical activity, and their role on breast cancer outcomes. Furthermore, ongoing research is needed to determine the ideal modality for the provision of this information particularly for rural populations.

2.2 Information Needs of Breast Cancer Survivors

Women diagnosed with breast cancer often actively seek out information about their disease as a coping strategy and as part of the decision-making process about their care (Radina, et al., 2011). This need for information may stem from evidence that many breast cancer

survivors overestimate their potential risk of recurrence (Andersen & Urban, 1999). Healthcare professionals providing information to this population are inclined to offer “quantity” of information over “quality”, instead of taking adequate time to discuss with the patient specifically what information is needed (Jahraus, Sokolosky, Thurston, & Guo, 2002). In addition, the reading comprehension level of print resources is too high for many cancer patients (Hartmuller & Desmond, 2004). In a study that explored information needs of patients undergoing cancer treatment, patients had different needs than what healthcare professionals perceived them to have (Hartmuller & Desmond, 2004). Specifically, cancer patients wanted more information about complementary therapies whereas healthcare professionals believed patients wanted information about management of treatment-related symptoms (Hartmuller & Desmond, 2004). This discrepancy indicates that despite interactions with healthcare professionals, patients may not be receiving the information they are searching for to increase coping with their diagnosis. The provision of appropriate information (i.e., what survivors actually want) may help to assist with coping with a breast cancer diagnosis (Galloway et al., 1997).

Information about breast cancer is widely available in the media and in scientific journals, but not all breast cancer survivors may be able to critically evaluate this information to discern if it is credible. The literacy level of almost half of Canadians has been described as less than the minimum level to function, raising concerns about the effectiveness of health messages that are communicated to Canadians (Rootman & Ronson, 2005). Identifying the specific information needs of breast cancer survivors may help to ensure healthcare providers can meet the needs of this patient population (Jahraus et al., 2002). The Toronto Informational Needs Questionnaire – Breast Cancer (TINQ-BC) was developed to identify the informational needs of

women with a recent breast cancer diagnosis (Galloway et al., 1997). The TINQ-BC does not include any questions related to body weight, diet, or physical activity information needs, nor does it include estimates of health literacy. This leaves a gap in the literature since information about these factors is essential for sustaining or improving overall health and potentially reducing the risk of recurrence and therefore survival (Bosaeus, 2008; Demark-Wahnefried et al., 2005; Hartmuller & Desmond, 2004). Breast cancer survivors often seek out information on how to improve their diets (Rock & Demark-Wahnefried, 2002), but preferences regarding information type and format are unknown. Research to understand the needs and preferred sources of information related to body weight, diet, and physical activity will make it possible to tailor resources and services to meet the needs of this patient population while ensuring that healthcare resources are used most effectively.

2.3 Defining a Need for Research on Rural Breast Cancer Survivors

In general, urban healthcare policies and models of care are inappropriate for the unique issues facing rural communities (Sevean, Dampier, Spadoni, Strickland & Pilatzke, 2009). The provision of healthcare services to rural areas must take into account distance and geographical barriers that residents face, as well as the social, economic and political climate (Sevean et al., 2009). In Northern BC, many communities are reliant upon one or a few resource-based industries such as forestry, mining, or oil and gas to provide well-paying jobs that retain families in the community (Hanlon & Halseth, 2005). Over the past thirty years, industries located in Northern BC suffered because of economic downturn, corporate restructuring and downsizing, replacement of laborers with technology, and expansion of raw materials export (Hanlon & Halseth, 2005). As a result, these changes led to steadily declining populations and the subsequent closure of many services central to communities including schools, post offices,

government buildings and hospitals (Hanlon & Halseth, 2005). More recently, expansion of resource-based industries, including liquefied natural gas and possible oil pipelines have increased the population in several Northern BC communities. This recent influx of temporary and permanent residents has, in turn, placed a strain on many healthcare services in Northern BC communities.

Grafton, Troughton, and Rourke (2004) argued that declining population and the resulting centralization of services is not a sufficient reason to reduce healthcare services because of the central role these rural-specific services have in meeting the unique needs of a community. While many rural residents must travel for even basic health services, it is essential that some healthcare services remain to meet the needs of rural Canadians (Grafton et al., 2004). Because rural Canadians have poorer health than urban Canadians (Karathotuvu, 2004) regardless of the economic climate, creative rural-focused solutions are needed to ensure that changes in access to healthcare services close this gap.

Relatively little research exists on the health of rural women in Canada (Leipert, 2005). The data that do exist demonstrate that women who live in rural settings in Northern BC face numerous health-related challenges (Leipert & Reutter, 2005). Not only do rural women have lower education and socioeconomic status, they also have challenges accessing healthcare services and providers (Leipert, 2005). The transient nature of many healthcare professionals who work for short periods of time in Northern BC communities or provide travelling clinics impacts the ability of rural women to access ongoing care to meet their unique needs (Leipert & Reutter, 2005). Specific to breast cancer, research has shown that women living in rural communities are less likely to participate in screening mammography (McDonald & Sherman, 2010) and are diagnosed at a later stage of disease than women living in urban centers (Olson et

al., 2012). Transportation challenges contribute to isolation among women in Northern BC both physically and socially, particularly during winter months (Leipert & Reutter, 2005). While rural women represent a minority among the provincial breast cancer survivor population, a substantial proportion of breast cancer survivors in Northern BC likely reside in rural settings.

2.4 Transitioning to Survivorship Care

Breast cancer survivors have distinctive health needs including management of latent side effects from cancer treatment, regular follow-up to identify possible breast cancer recurrence, as well as access to credible information about how a past diagnosis impacts other aspects of their health and wellbeing (Burstein & Winer, 2000). The American Society of Clinical Oncology (ASCO) published clinical practice guidelines for follow-up care of breast cancer survivors that included information on the recommended frequency of breast cancer-specific tests and screening measures (ASCO, 2009). These guidelines describe the importance of regular mammograms and physical examinations for breast cancer survivors, both of which may be difficult for rural breast cancer survivors to access in a timely manner.

Although follow-up care for breast cancer survivors has historically been the role of Oncologists, follow-up is increasingly being provided by primary care physicians (Smith et al., 2011). With guidance from Oncologists, primary care physicians can provide recommended follow-up care and help patients to manage existing health conditions (Smith et al., 2011). Success of this model is contingent upon effective communication between the cancer specialist and the primary care physician (Grunfeld & Earle, 2010). The term *survivorship care plan* is used to detail the treatment received, follow-up plans and recommendations to reduce risk of recurrence, and address specific issues that may arise for a particular type of cancer (Grunfeld & Earle, 2010). This emerging model for guiding survivorship care and communication between

the cancer survivor and their healthcare team was derived from Institute of Medicine (IOM) recommendations that highlighted the lack of coordinated care for the growing number of cancer survivors (IOM, 2005). For breast cancer specifically, a survivorship care plan may include information about breast reconstruction, latent effects of cancer treatment (physical and psychosocial), evidence-based lifestyle recommendations that may help to reduce risk of recurrence, and referral to appropriate care providers and resources in the community (Grunfeld & Earle, 2010; Trotter, Frazier, Hendricks, & Scarsella, 2011). Cancer survivors, and in particular breast cancer survivors, are often very keen to implement lifestyle changes to improve health and prevent recurrence (Burstein & Winer, 2000; Rock & Demark-Wahnefried, 2002). In addition to ensuring appropriate follow-up care, survivorship care plans that engage the cancer survivor have the potential to empower because the care plans often require involvement of the cancer survivor to set personalized goals around their health and general well-being (Trotter et al., 2011).

2.5 Summary

The transition of survivorship care from Oncologist to primary care providers is often accompanied by a transition of care from a larger centre to a smaller community where accessing appropriate and specialized care can be more difficult for breast cancer survivors in Northern BC. Research on what breast cancer survivors in Northern BC want to know about body weight, diet, and physical activity and how to meet this need should be a priority.

3.0 Methodology

3.1 Study Objectives

1. Among rural breast cancer survivors in Northern BC, the objectives were to describe
 - a. body weight, diet, and physical activity changes since diagnosis;
 - b. barriers to and interest in body weight, diet, and physical activity changes;
 - c. currently available body weight, diet, and physical activity related information sources and needs;
 - d. perceived reliability of available information sources;
 - e. preferences for programs and resources; and
 - f. differences in information sources, needs, and preferences based on selected demographic characteristics.
2. Among cancer care providers the objectives were to describe
 - a. knowledge and attitudes about body weight, diet, and physical activity recommendations for breast cancer survivors;
 - b. if knowledge and attitudes about body weight, diet, and physical activity recommendations for breast cancer survivors differ among Registered Nurses and Registered Dietitians;
 - c. if and how evidence-based recommendations for body weight, diet, and physical activity are being delivered to rural breast cancer survivors in Canada; and
 - d. if the provision of information and awareness of programs differs according to demographic variables (discipline and proportion of rural patients cared for).

3.2 Study Design

This descriptive study was comprised of two parts. Part 1 involved the completion of a paper-based cross-sectional survey by breast cancer survivors. The purpose of this approach was to determine the current lifestyle information sources and needs of rural breast cancer survivors. The intent of using a cross-sectional survey was to be able to generalize the findings more broadly to all rural breast cancer survivors (Morgan, Gliner, & Harmon, 2006). Part 2 involved the completion of an electronic cross-sectional survey by cancer care providers (RNs and RDs). The purpose of this approach was to explore if and how evidence-based lifestyle recommendations are provided to rural breast cancer survivors across Canada. The timeline and budget for this study are available in Appendices A and B.

3.3 Study Population

3.3.1 Part 1: Breast Cancer Survivors. Women in the Northern Health and/or BC Cancer Agency Centre for the North catchment area who were diagnosed with breast cancer in 2007 or more recently were recruited to participate in the survey. This population was chosen because both the Northern Health region and the BC Cancer Agency Centre for the North draw from the similar predominantly rural catchment areas and represent the breast cancer survivor population in Northern BC. The timeframe of 2007 through 2012 was selected because cancer survivors are often particularly interested in self-management strategies in the time following treatment (Rock et al., 2012).

3.3.2 Part 2: Cancer Care Providers. RNs and RDs working as part of the Communities Oncology Network (CON) clinics in BC were recruited to participate in the survey. In addition, RDs in the DC Oncology Network, as well as RNs who are members of the Canadian Association of Nurses in Oncology (CANO) were recruited to participate. These two

health professions were chosen because RNs generally spend proportionally more time with cancer patients on treatment and often generate referrals to other disciplines while RDs commonly provide lifestyle information and behaviour change guidance. The data collected from these two oncology healthcare provider networks provided information on potential options and partnerships for the provision of information and services to rural breast cancer survivors.

3.4 Inclusion and Exclusion Criteria

3.4.1 Part 1: Breast Cancer Survivors. Any woman ≥ 19 years of age residing in the Northern Health or BC Cancer Agency Centre for the North catchment areas, with a past breast cancer diagnosis between 2007 and 2012, and could read, understand, and complete the paper survey was eligible to participate. Any woman < 19 years, who did not reside within the Northern Health or BC Cancer Agency Centre for the North catchment areas, who did not have a history of a breast cancer between 2007 and 2012, and could not read, understand, or complete the survey was ineligible.

3.4.2 Part 2: Cancer Care Providers. RNs and RDs that were affiliated with the 48 CON clinics in BC, or were members of either the DC Oncology Network or CANO, and had computer and Internet access, were eligible for inclusion in the survey. RNs or RDs not affiliated with the CON clinics, or who were not members of either the DC Oncology Network or CANO, or who did not have computer or Internet access, were ineligible to complete the survey.

3.5 Sampling and Recruitment

3.5.1 Part 1: Breast Cancer Survivors. A random sample of 300 women who were diagnosed with breast cancer between 2007 and 2012 were recruited through the BC Cancer Registry. This sample size was selected because it is approximately one-third of the estimated 1000 women who were diagnosed with breast cancer between 2007 and 2012 in the Northern

Health/BC Cancer Agency Centre for the North catchment area (BC Cancer Agency, 2010a), and it adequately represents the varying degrees of rurality within the region and the different breast cancer treatment options. While the sample provided by the BC Cancer Registry was random for the period of January 1st, 2007 through December 31st, 2012, there was underrepresentation of women diagnosed in 2012 due to data entry delays (BC Cancer Registry, personal communication).

All potential study participants received a mailed letter of initial contact to introduce the investigator and the research project (Appendix C), and describe how contact information was obtained (Appendix D) as well as a copy of the survey (Appendix E). These documents were mailed from the office of the Principal Investigator (PI) in a plain envelope without organizational logos, consistent with BC Cancer Registry requirements (BC Cancer Agency, 2010b). The package also contained a copy of the survey and a postage paid envelope with the return address to facilitate easy return of the completed survey. Consent to participate in the study was implied by completing and returning the survey. A letter was mailed out three weeks after the information and data collection packages to thank or remind participants of the opportunity to participate in the study (Appendix F). A target response rate of approximately 30% was anticipated based on previous research on women and breast cancer using a similar methodology (Vallance et al., 2012a).

3.5.2 Part 2: Cancer Care Providers. A convenience sample of RNs and RDs was recruited via email and snowball sampling. For RNs affiliated with the CON clinics, which include 48 chemotherapy clinics throughout BC, a contact list was created based on email addresses publically available on the BC Cancer Agency CON website service listing. For RDs affiliated with the CON clinics, permission was granted from BC Cancer Agency to recruit

through an existing email list used for communication of monthly education sessions. To improve accessibility of the survey to individuals who may not be on the public listing or on the RD email list, potential participants were asked to forward the informational email and link to the survey to others who met the inclusion criteria (affiliated with the 48 CON clinics in BC). For members of the DC Oncology Network and CANO, permission was granted from the chairs to recruit through an email to all members. The email sent to potential participants included an explanation of the purpose of the study and participant involvement, anticipated length of time to complete the survey, a link to the survey, and a requested date of completion (Appendix G). Three weeks after the initial email distribution, a second email was sent to thank or remind participants of the opportunity to participate in the study (Appendix H). The potential sample size for the survey was estimated to be approximately 1300, which included approximately 130 RNs and RDs from the CON clinics, 1000 RNs from CANO, and 121 RDs from DC Oncology network. The response rate for the survey was difficult to anticipate, as the response rate of Internet-based surveys of healthcare professionals has been highly variable (Braithwaite, Emery, de Lusignan, & Sutton, 2003).

3.6 Data Collection

3.6.1 Part 1: Breast Cancer Survivors. Data collection for part 1 of the study involved the completion of the self-administered cross-sectional survey (Appendix E). The survey was modified from its original form (Paisley et al., 2008) in an effort to make it more appropriate for the study population and to suit the study objectives. Specifically, the survey was expanded to also include questions about body weight and physical activity, as well as additional demographic and programming questions relevant to rural populations. In addition to the existing survey questions, a health literacy question (Chew et al., 2008), a question on weight

management behaviours modified by Kruger, Blanck, and Gillespie (2006), and a question on cultural and/or ethnic identity, were included. To improve content validity, feedback on the survey questions was received from four research and nutrition professionals. This resulted in revisions to the format, wording and response option. A total of 52 questions made up the survey. Questions were split into three sections with themes that included (i) body weight, diet, and physical activity ($n = 33$); (ii) information and services to meet interests ($n = 5$); and, (iii) demographic characteristics of participants ($n = 14$). A closed-ended, nominal response format was used for most questions, though there was space provided for further elaboration in some instances. There were also several interval-level response options (Likert type). The Flesch-Kincaid grade level of the survey was 6.4. The survey took approximately 20 minutes to complete.

3.6.2 Part 2: Cancer Care Providers. Data collection for part 2 involved an online survey for cancer care providers who work with cancer patients. Questions were split into three sections with themes that included (i) demographic characteristics ($n = 3$); (ii) knowledge and attitudes ($n = 9$); and (iii) provision of information and awareness of programs ($n = 13$) (Appendix H). Demographic questions determined the type of cancer care provider completing the survey (RN or RD) as well as information on the proportion of rural patients cared for in their practice. Knowledge and attitude questions determined the extent that participants were aware of evidence for the role of body weight, diet, and physical activity recommendations for breast cancer survivors and their attitudes towards the accessibility of this information to rural breast cancer survivors. The final portion of the survey included questions on awareness of the provision of information on body weight, diet and physical activity recommendations for breast cancer survivors as well as the type, format, and accessibility of programs. This portion of the

survey was structured similarly to an environmental scan of Canadian pediatric weight management programs completed by Ball, Ambler, and Chanoine (2011). Questions included single and multiple closed-ended response options. This survey took approximately 10-15 minutes to complete.

3.7 Measures

3.7.1 Part 1: Breast Cancer Survivors. The full list of measures is available in Appendix E. *Demographic measures* included age range, menopausal status, marital status, language, household income, education, confidence filling out medical forms, ethnic or cultural identity, comorbidities, length of time living in Northern BC, degree of rurality, travel time to breast cancer surgery, travel time to chemotherapy and travel time to radiation.

Behaviour change since diagnosis was assessed with three questions related to 1) changing food choices, 2) changing physical activity habits, and 3) change in body weight. A series of questions ($n = 16$) were used to assess *barriers and opportunities to eating well, being physically active, and managing body weight*. Breast cancer survivors were asked to select the extent they agreed with statements using the following scale: “strongly agree”, “disagree”, “neutral”, “agree”, “strongly agree”, or “don’t know”. Survivors were asked 1) barriers to eating well, 2) factors that make eating well easier, 3) barriers to being physically active, and 4) factors that make it easier to be physically active. If applicable, breast cancer survivors were also asked to describe other factors that made it harder or easier to eat well, be physically active, and manage their body weight in written format.

Barriers for managing body weight were assessed by asking about what makes it difficult for women who have had a past breast cancer diagnosis to manage their body weight in general. Breast cancer survivors were asked to select the extent they agreed with a series of six statements

(e.g., fatigue from cancer treatment, mental health challenges). In addition to these questions, *strategies used to manage body weight* were assessed by asking “do you use any of the following strategies to manage your body weight?” A list of options was provided and breast cancer survivors were asked to select all that apply.

Interest in behaviour change was assessed with three questions asking breast cancer survivors if they would like to make changes to their 1) eating habits, 2) physical activity habits, and 3) body weight. Response options were “yes” and “no”. If the response was “yes”, breast cancer survivors were asked to describe the changes they wanted to make in written format.

Information sources were assessed by asking *who* and *where* breast cancer survivors turn for help for information on 1) eating well, 2) body weight, and 3) physical activity. A list of options was provided and breast cancer survivors were asked to select all that apply.

Information needs were assessed by asking about interest in topics on 1) eating well, 2) nutrition, 3) physical activity and breast cancer, 4) being physically active, 5) physical activity and your health, and 6) body weight. A list of options was provided and breast cancer survivors were asked to select all that apply and include additional information needs in written format.

A series of questions ($n = 9$) were asked to assess *perceived reliability of available information sources on eating well, physical activity, and body weight*. To do this, breast cancer survivors were asked to select from the following response options: “always”, “most of the time”, “sometimes”, “never”, or “does not apply to me”. For *eating well, information sources* included 1) newspapers and magazines, 2) the Internet, and 3) books. For *physical activity, information sources* included 1) newspapers and magazines, 2) the Internet, and 3) fitness instructors or personal trainers. For *body weight, information sources* included 1) newspapers and magazines, 2) the Internet, and 3) staff at weight loss centres.

Three questions were asked to assess *preferred information sources*, and *programs and services* concerning eating well, physical activity, and body weight. A list of options was provided and breast cancer survivors were asked to select all that apply. Additional suggestions could be provided in written format. *Preferred format for programs or services* was determined by asking three questions about 1) mode of delivery, 2) day of week, and 3) time of day.

3.7.2 Part 2: Cancer Care Providers. The full list of measures is available in Appendix H. *Demographic measures* included professional discipline, location (province and health authority), and proportion of rural cancer patients cared for. A series of questions ($n = 9$) about body weight, diet, and physical activity recommendations were used to assess cancer care provider's *knowledge and attitudes* about lifestyle recommendations for breast cancer survivors. Cancer care providers could respond "yes", "no" or "unsure".

Three questions assessed if cancer care providers fielded questions on *body weight, diet, and physical activity* from breast cancer survivors. Response options included "yes", "no" or "unsure". Cancer care providers were asked if they *provided physical activity recommendations* to breast cancer survivors. Response options included "yes", "no" or "unsure". If cancer care providers responded "yes" they were asked to provide information about these guidelines in written format.

Cancer care providers from BC were asked about their 1) awareness, and 2) use of the *Nutrition Guide for Women with Breast Cancer*. Cancer care providers from provinces other than BC were asked about *written materials provided to breast cancer survivors on diet*. Response options included "yes", "no", or "unsure". If cancer care providers responded "yes" they were asked to provide information about these materials in written format.

A series of questions ($n = 7$) were asked to determine if cancer care providers provided *referrals to other healthcare professionals*, and *programs and services* for breast cancer survivors with questions on 1) body weight, 2) diet, 3) physical activity, and 4) making lifestyle changes. Response options included “yes”, “no”, or “unsure”. Of those who responded “yes” to referrals to programs and services, three additional questions were asked to determine 1) *delivery method*, 2) *funding source*, and 3) *accessibility*. Cancer care providers were provided with a list and asked to select all that apply. A written response option was also available for responses that did not fit within the list of options.

Cancer care providers were asked if breast cancer survivors treated at their clinic have *access to sufficient information and support to make lifestyle changes*. Response options included “yes”, “no”, or “unsure”.

3.8 Data Analysis

3.8.1 Part 1: Breast Cancer Survivors. To address objectives 1a through e, descriptive statistics (specifically frequencies) were completed. To address objective 1f, the non-parametric Chi-square test was used to compare if information sources and needs were different according to demographic characteristics including menopausal status, intention to change body weight, and extent of rural living. Responses to open-ended questions were tallied when brief (e.g. specific magazine names) or aggregated by theme when longer (e.g. desired changes to body weight, diet, or physical activity).

3.8.2 Part 2: Cancer Care Providers. To address objectives 2a through c, descriptive statistics (specifically frequencies) were completed. To address objectives 2d, Chi-square test was used to determine if the provision of information and awareness of programs were different according to demographic variables including discipline and proportion of rural patients cared for. Responses to open-ended questions were tallied when brief (e.g. discipline names) or themed

when longer (e.g. program characteristics). For both surveys, data were analyzed using the Statistical Package for the Social Sciences version 14.0 (SPSS Inc., South Wacker Drive Chicago, IL, USA.). An alpha level of < 0.05 was considered statistically significant.

3.9 Ethical Considerations

This study received approval from the Athabasca University Research Ethics Board (AUREB) and University of British Columbia BC Cancer Research Ethics Board (UBC BCCA REB) (Appendices J and K). Guidelines from the Tri-Council Policy Statement for ethical conduct for research involving humans were adhered to (Canadian Institutes of Health Research, 2010). Ethical concerns in the proposed study included ensuring voluntary participation, informed consent, and participant anonymity and confidentiality (Kelley, Clark, Brown, & Sitzia, 2003; Trochim & Donnelly, 2008). No personal identifying information was collected in the completion of the surveys. To ensure confidentiality of information in part 1 of this study, returned surveys have been stored in a locked office at the PI's place of employment and all data (in electronic form) have been stored on a password protected computer. Consistent with the AUREB and UBC BCCA REB, data will be kept for no less than 5 years, after which it will be destroyed. In addition, no questions in either survey were asked that identify the specific location or CON clinic of participants.

Consent to participate for both surveys involved voluntary completion of the data collection tool (consent was implied by completing and returning the survey). Study participants received an explanation of the purpose of the study, and were informed that participation was voluntary. Details of study involvement were provided as well as information about the confidential nature of the data collected. Participants also had the opportunity to provide contact

information if they were interested in receiving a briefing about the study results upon completion.

4.0 Results

4.1 Part 1: Breast Cancer Survivors

The survey was distributed to a random sample of 300 breast cancer survivors in Northern BC. Twenty-five surveys were returned due to incorrect address, 1 was returned blank, 1 survey was completed by a family member and was therefore not included, and 3 family members contacted the PI to communicate that the potential participant was deceased. A total of 132 breast cancer survivors responded to the survey, representing a response rate of 48.8% (132 of 270 received surveys). Overall, 88.6% of the sample reported being over 50 years of age and the majority (98.5%) had experienced menopause. Approximately two-thirds (66.7%) were considered to have high health literacy based on a validated health literacy question (Chew et al., 2008). Nearly all (96.2%) reported residing in Northern BC for more than ten years. Participant demographics are summarized in Table 1.

4.1.1 Body weight, diet, and physical activity changes after diagnosis (objective 1a).

The majority of participants identified changes in their body weight (67.9%) and diet (56.6%) since being diagnosed with breast cancer. Approximately half (49.6%) of participants identified changes in physical activity since being diagnosed with breast cancer.

Table 1

Characteristics of Breast Cancer Survivors in Northern BC (N=132)

Characteristic	n (%)
Age range	
30 - 39 years	4 (3.0)
40 - 49 years	11 (8.3)
50 - 59 years	46 (34.8)
60 - 69 years	35 (26.5)
≥ 70 years	36 (27.3)
Menopausal status*	
Experienced menopause	122 (98.5)
Marital status	
No partner	90 (68.2)
Education*	
≤ high school completed	64 (52.0)
Confidence completing medical forms*	
Extremely	42 (32.6)
Quite a bit	44 (34.1)
Somewhat	27 (20.9)
A little bit	12 (9.3)
Not at all	4 (3.1)
Household income*	
< \$60,000/year	76 (66.1)
Language spoken at home*	
English	119 (96.7)
Extent of rural living* ^a	
In a community	89 (69.5)
Out of town	39 (30.5)
Breast cancer treatment	
Received surgery	127 (97.7)
Received chemotherapy*	69 (56.1)
Received radiation therapy*	68 (53.5)
Ethnic/Cultural group identity* ^b	
Caucasian/European	100 (85.5)
First Nations	13 (11.1)
Other	9 (7.8)
Comorbidities*	
High blood pressure	62 (30.2)
Arthritis	59 (28.8)
Hypercholesterolemia	33 (16.1)
Type 2 diabetes	22 (10.7)
Chronic lung disease	12 (5.9)
Angina	5 (2.4)
Heart attack	5 (2.4)

Stroke	4 (2.0)
Heart failure	3 (1.5)

*Missing data: Marital status ($n = 2$); Education ($n = 9$); Confidence completing medical forms ($n = 3$); Household income ($n = 17$); Language spoken at home ($n = 9$); Extent of rural living ($n=4$); Received chemotherapy ($n = 9$); Received radiation therapy ($n = 5$); Ethnic/Cultural group identity ($n = 15$); Comorbidities ($n = 41$). ^aFive response options determined the extent of rural living which were subsequently stratified into the following two groups: (1) those who live in a community (population < 5000, 5000-10,000, or > 10,000) and (2) those who live out of town (> 10 minutes driving to services) or out in the country (> 30 minute drive to services). ^bWhile $n = 117$, this was a multiple response question and there were 122 total responses. The results presented include the percent of cases based on 117 participants.

4.1.2 Barriers to and interest in body weight, diet, and physical activity changes

(objective 1b). Participants were asked to what extent they agreed with statements about barriers to making healthy lifestyle changes. The majority of participants agreed (i.e., *strongly agree* or *agree*) that not being physically active (81.3%), mental health challenges (68.0%), medication (65.6%), fatigue from cancer treatment (63.4%), and unhealthy eating (61.0%) make it difficult for breast cancer survivors to manage their body weight. Approximately half of participants (52.0%) agreed that an increased body weight before diagnosis makes it difficult for breast cancer survivors to manage their body weight after their diagnosis.

When asked about factors that make it difficult for breast cancer survivors to eat well, approximately half of participants agreed that learning more about how to make their favorite foods healthier (57.7%), eating well at restaurants (52.0%), and planning healthy meals (48.8%) would make it easier to eat well. When barriers to being physically active were explored, the majority of participants did not agree (i.e., *strongly disagree* or *disagree*) that tiredness from cancer treatment (57.4%) or the availability of exercise programs or classes that they could join (57.4%) were factors contributing to inactivity. The majority of participants (69.6%) agreed that they needed to know more about how to be active in the winter months. More than half of participants agreed that the weather makes it difficult to be active where they live (60.9%) and that they need to know how to be active in their home (61.7%).

Nearly three-quarters of participants (72.9%) expressed interest in currently making changes to their body weight to improve their health. Of those who were interested in making changes to their body weight, 81.9% identified the changes they would like to make within the open-ended responses. These responses have been categorized under key themes and are summarized in Figure 1. Participants were asked about strategies they currently used to manage body weight. Of those who responded, the most frequently reported strategies included choosing smaller portions (66.7%), cooking at home (52.1%) and increase activity (48.7%).

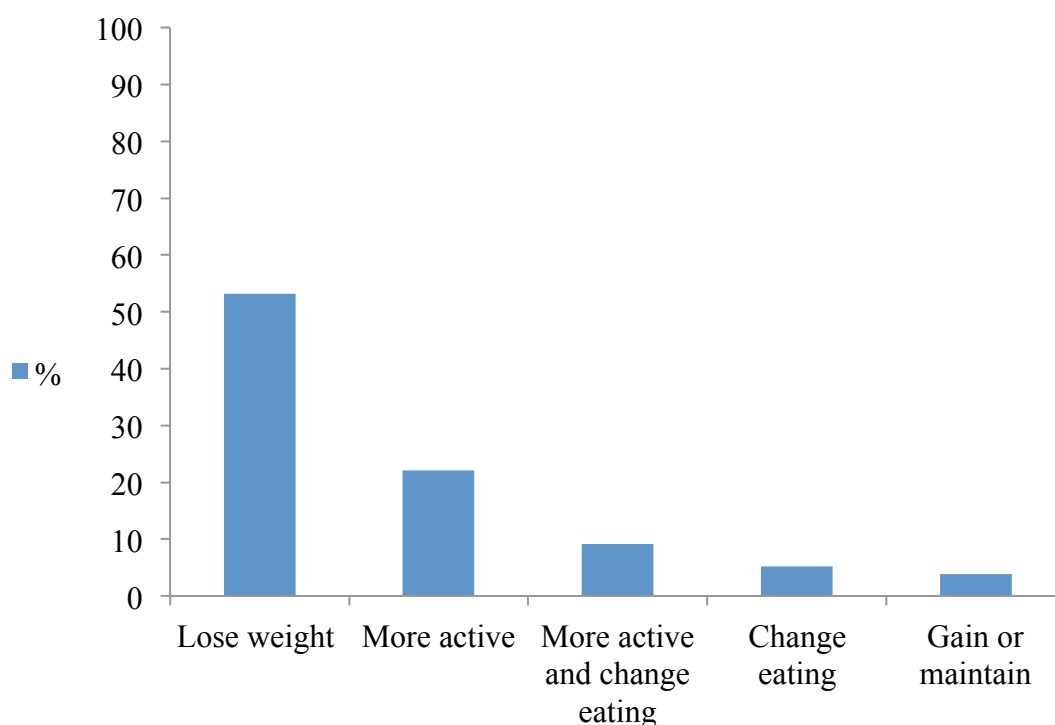


Figure 1. *Most frequently identified themes for changes to body weight among rural breast cancer survivors in Northern BC (n = 77).*

More than half (66.9%) of participants expressed interest in making changes to their diet to improve their health. Of those interested in making changes, 83.9% responded with comments to open-ended questions on the changes they would like to make. These responses

were categorized under key themes. The most frequently identified themes for desired changes to diet are summarized in Figure 2.

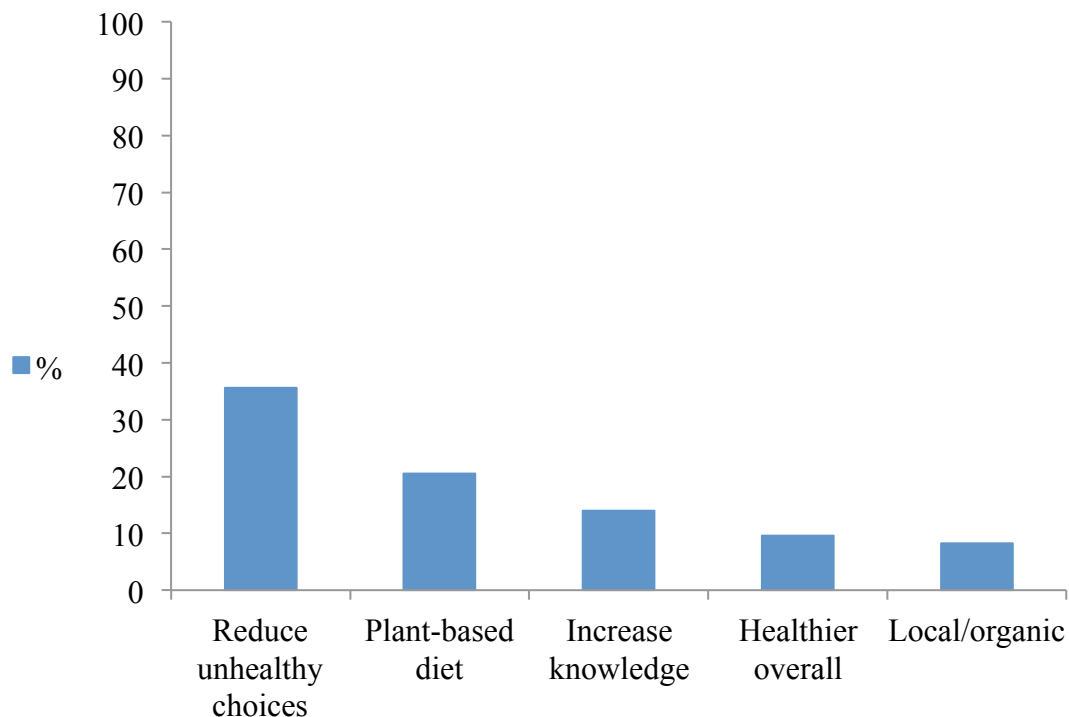


Figure 2. *Most frequently identified themes for changes to diet among rural breast cancer survivors in Northern BC (n = 73).*

More than three quarters of participants (77.4%) indicated an interest in currently making changes to their physical activity to improve their health. Of those who were interested in making changes, 76.0% responded with comments to open-ended questions on the changes they would like to make. These responses were categorized under key themes. The most frequently identified themes for desired changes to physical activity are summarized in Figure 3.

4.1.3 Body weight, diet, and physical activity information sources and needs

(objective 1c). Participants were asked who they turn to for information about body weight, diet, and physical activity. Among those who responded, physicians were most frequently identified (72.9%) as a source of information on body weight followed by friends and family

(42.1%), and dietitians (13.1%). Participants most frequently identified family and friends (59.6%) as a source of information on diet, followed by physicians (35.8%) and dietitians (32.1%). Participants most frequently identified family and friends (65.7%) as a source of information on physical activity followed by physicians (45.7%) and fitness instructors (20.0%).

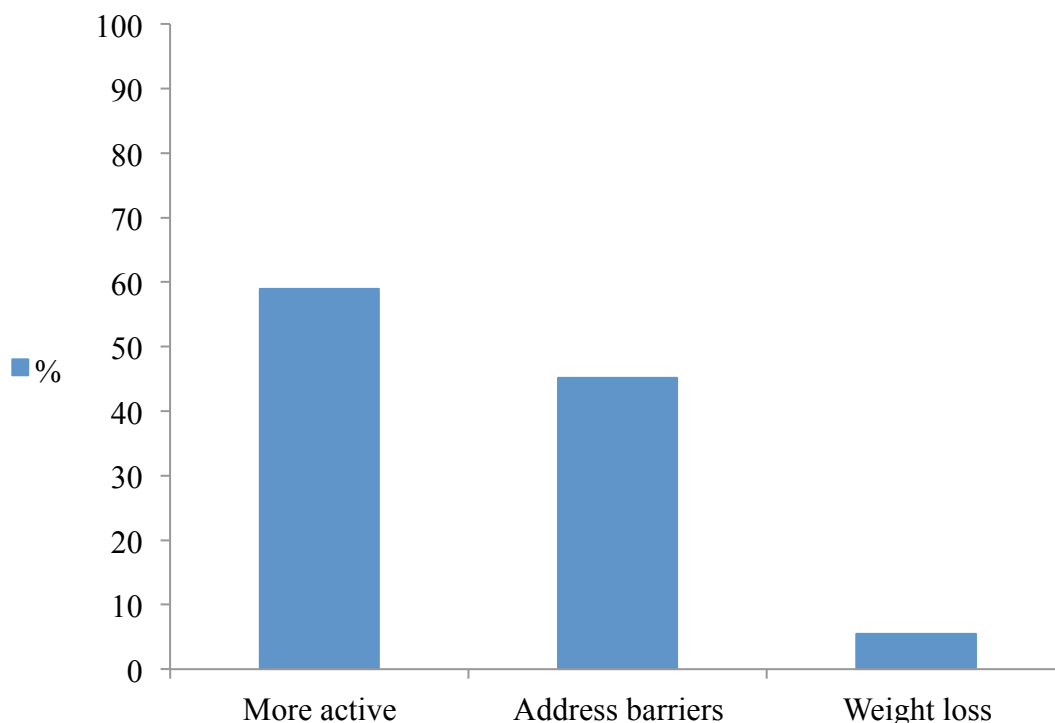


Figure 3. *Most frequently identified themes for changes to physical activity among rural breast cancer survivors in Northern BC (n = 73).*

Participants were asked where they turn for information about body weight, diet, and physical activity. Among those participants who responded, the Internet was most frequently identified (42.9%) a source of information on body weight followed by pamphlets (36.3%) and magazines (31.9%). Participants most frequently identified magazines (53.9%) as a source of information on diet followed by the Internet (44.3%) and books (41.7%). Participants most frequently identified magazines (49.0%) as a source of information on physical activity followed by the Internet (34.4%) and television (30.2%). Though infrequent, when examples of

magazines were provided, *Canadian Living* and *Chatelaine* were most commonly identified for each of body weight, diet, and physical activity. *Dr. Oz* was most frequently listed as the TV program for information about all three topics.

Participants' responded to four questions about topics of interest on body weight, eating well, nutrition, and physical activity. Overall, participants were most interested in information on these topics as means to decrease risk of recurrence or improve survival from breast cancer. Most frequently selected topics about body weight, eating well, nutrition, and physical activity are summarized in Figures 4-7.

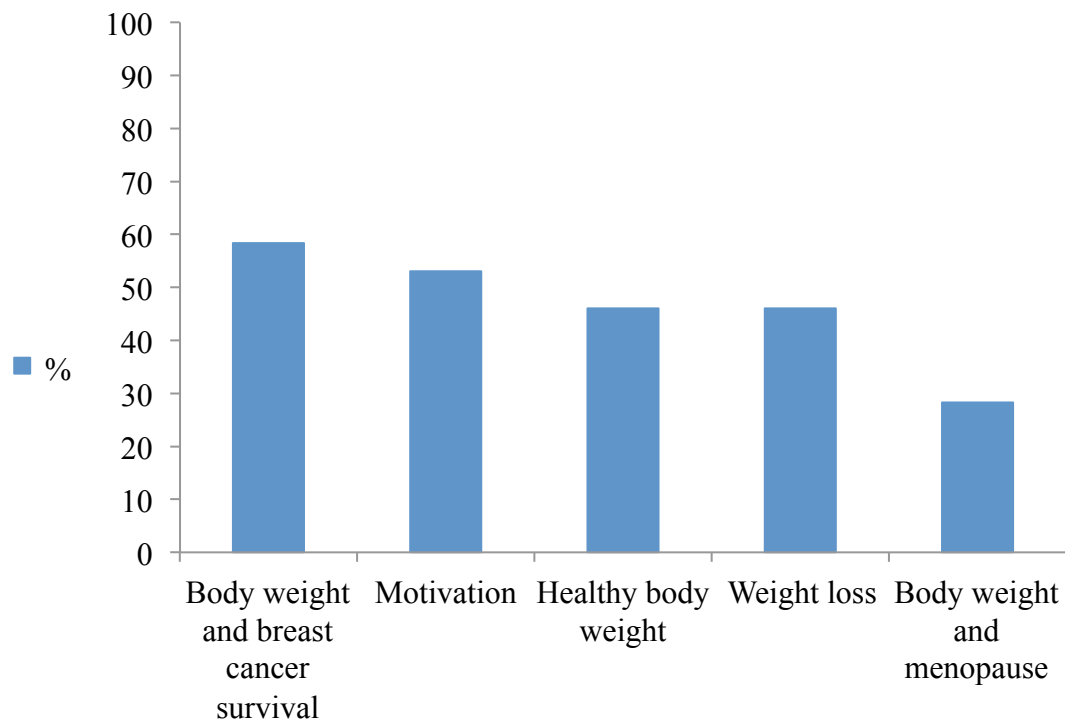


Figure 4. Most frequently reported topics on body weight that rural breast cancer survivors in Northern BC want to know more about ($n = 113$).

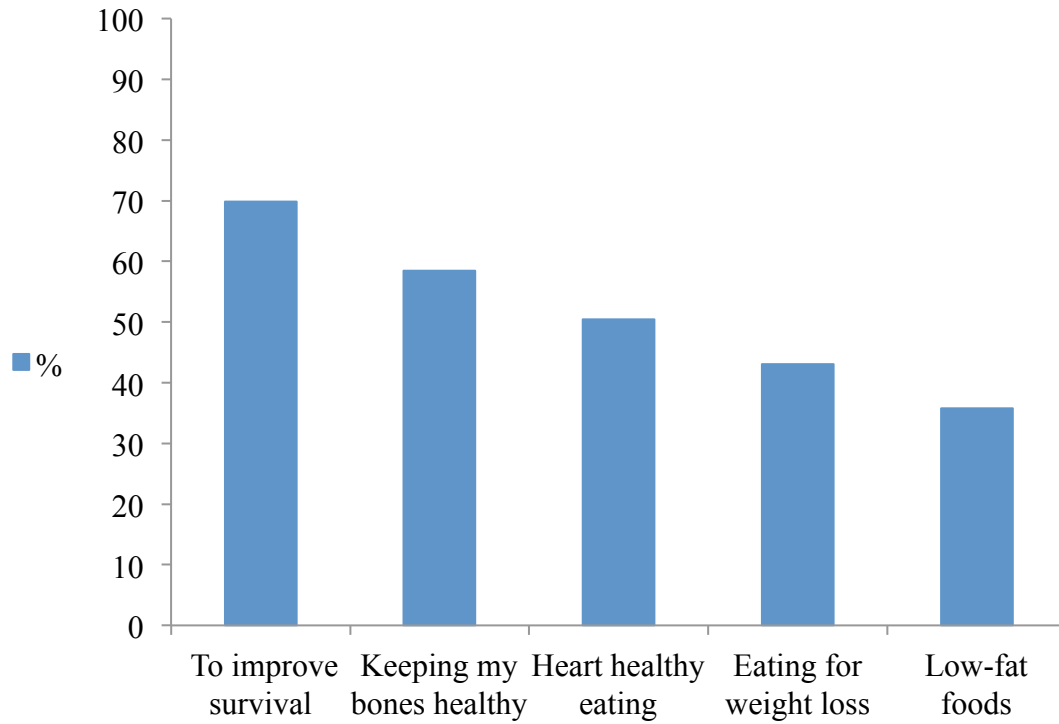


Figure 5. Most frequently reported topics on eating well that rural breast cancer survivors in Northern BC want to know more about (n = 123).

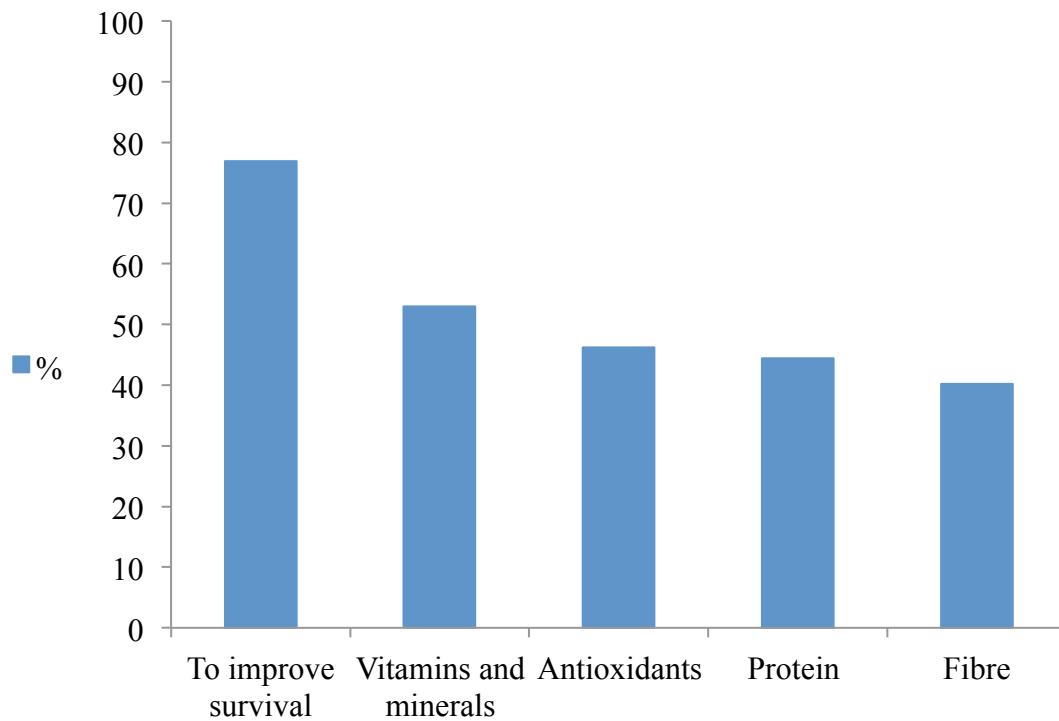


Figure 6. Most frequently reported topics on nutrition that rural breast cancer survivors want to know more about (n = 117).

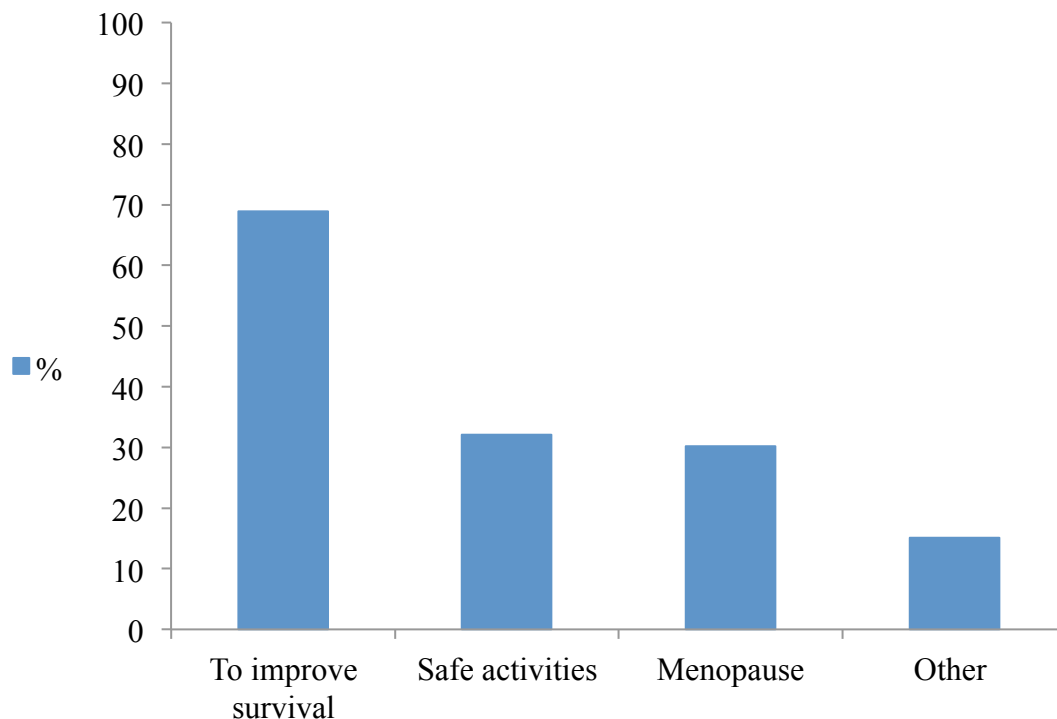


Figure 7. *Most frequently reported topics on physical activity and breast cancer that rural breast cancer survivors want to know more about (n = 106).*

4.1.4 Reliability of information sources (objective 1d). The reliability of body weight, diet, and physical activity information found in common sources was explored. Of sources of information on diet, books were most frequently selected (i.e., *always* or *most of the time*) by participants as being accurate sources of information (35.5%) when compared to newspapers and magazines (21.8%) or the internet (23.4%). Staff at weight loss centres were most frequently (i.e., *always* or *most of the time*) identified to be accurate sources of information on body weight (21.1%) compared to newspapers and magazines (16.9%) or the Internet (15.3%). Fitness instructors or personal trainers (31.5%) and newspapers and magazines (30.6%) were most frequently considered to be accurate sources of information on physical activity.

4.1.5 Program and resource preferences (objective 1e). Participants' were also asked about preferences for body weight, diet, and physical activity programming and resources. For

resources, participants most frequently selected the option of a mailed newsletter (48.2%), followed by lists of reliable books (44.5%) and websites (44.5%).

For program and service preferences, participants were most interested in individual counseling with a dietitian (46.7%), followed by relevant local programs and services in their community (34.8%), and cooking demonstrations (32.6%). The majority (64.0%) of participants preferred a face-to-face format for programs and services. Among distance-based formats, telehealth (videoconferencing) was least preferred when compared to telephone or the Internet. Format preferences are summarized in Figure 8. When considering practical considerations of program delivery, participants preferred weekdays to weekends, with Wednesday being the most preferred day (61.9%). Participants most frequently responded that that mid-morning was a preferred time of day (55.0%).

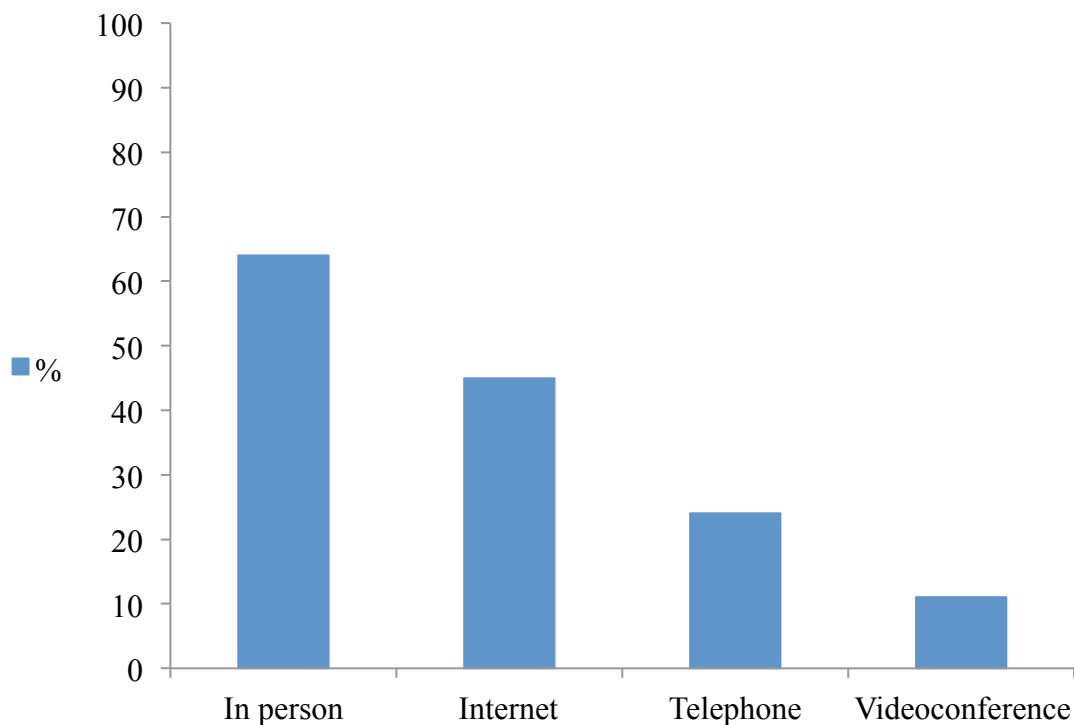


Figure 8. Preferred format of body weight, diet, and physical activity programs or services ($n = 100$).

4.1.6 Proportional differences of demographic variables with information sources, needs and preferences (objective 1f). There was no difference in the proportion of breast cancer survivors living in the most versus least rural locations and access to healthcare and non-healthcare professionals for sources of information on body weight [$\chi^2(df = 1, N = 103) = 3.620, p = .057$], diet [$\chi^2(df = 1, N = 106) = 1.482, p = .223$] or physical activity [$\chi^2(df = 1, N = 102) = 3.241, p = .073$]. There was no difference between the proportion of breast cancer survivors who traveled to surgery (< 1 hour vs. > 1 hour) and access to healthcare professionals and non-healthcare professionals for sources of information on diet [$\chi^2(df = 1, N = 106) = 1.482, p = .223$], or physical activity [$\chi^2(df = 1, N = 102) = 3.214, p = .073$]. Breast cancer survivors who travelled for more than one hour accessed healthcare professionals more than non-healthcare professionals for information on body weight [$\chi^2(df = 1, N = 102) = 4.640, p = .031$]. It was not possible to test if proportional differences existed for distance traveled to radiation or chemotherapy and access of healthcare professionals and non-healthcare professionals for sources of information on eating well, physical activity, or body weight.

It was not possible to test if participants who were interested in changing their body weight had more information needs on body weight, diet, and physical activity than those who were not interested in changing their body weight as the majority of participants (72.9%) were interested in changing their body weight. It was not possible to test if there were differences in information needs amongst premenopausal and postmenopausal breast cancer survivors, as nearly all participants (98.5%) identified themselves as postmenopausal.

There was no difference between the number of breast cancer survivors who live in a community (defined as a community of any size) versus those who live the in the most rural locations (defined as out of town or out in the country, greater than 10 and 30 minutes from

services respectively) in terms of interest in distance-based formats (e.g., Telehealth) for accessing diet, physical activity or body weight related programs and services [$\chi^2(df = 1, N = 99) = 0.366, p = .545$]. There was also no difference between the number of breast cancer survivors who travelled greater distances for breast cancer surgery (< 1 hour vs. > 1 hour) and interest in distance-based formats for future programs and services [$\chi^2(df = 1, N = 95) = 0.297, p = .598$].

4.2 Part 2: Cancer Care Providers

A total of 134 cancer care providers responded to the survey. This survey was distributed to approximately 1300 potential participants, but also included snowball sampling, so it was not possible to determine a true response rate. Although most cancer care providers were from BC, there was representation from most Canadian provinces and territories. Frequencies of cancer care provider demographics are located in Table 2.

4.2.1 Knowledge and attitudes (objective 2a). Cancer care providers were asked if they agreed with nine statements about body weight, diet, and physical activity for breast cancer survivors. All cancer care providers agreed that achieving a healthy body weight is important for breast cancer survivors, while 91.6% felt that breast cancer survivors should have access to weight management counselling and 65.3% indicated that weight gain is common after a breast cancer diagnosis.

The majority of cancer care providers (96.1%) agreed that healthy eating recommendations (such as *Canada's Food Guide*) apply to breast cancer survivors. Less than half (46.3%) of cancer care providers agreed that soy foods (such as tofu, soy milk, and edemame beans) are safe for breast cancer survivors to consume, while approximately one quarter (26.3%) disagreed (i.e., felt that soy was unsafe) or were unsure (27.4%). Nearly all (97.9%) of cancer care providers agreed that breast cancer survivors should have access to

health professionals with knowledge of the physical activity needs and challenges for breast cancer survivors. All cancer care providers agreed that breast cancer survivors should have access to health professionals who can help them to determine if information they seek or receive on diet and breast cancer is accurate/appropriate.

Table 2

Characteristics of Cancer Care Providers (N = 134)

Characteristic	n (%)
Discipline*	
Registered Nurse	53 (50.5)
Registered Dietitian	46 (43.8)
Other ^a	6 (5.7)
Location of Practice*	
British Columbia	48 (47.5)
Ontario	28 (27.7)
Prairie Provinces	13 (12.4)
Quebec	5 (5.0)
Maritime Provinces	6 (5.5)
Yukon Territory	1 (0.7)
British Columbia Health Authority* ^b	
Northern Health	12 (25.5)
Provincial Health Services Authority	9 (19.1)
Vancouver Coastal Health	8 (17.0)
Interior Health	7 (14.9)
Vancouver Island Health Authority	7 (14.9)
Fraser Health	3 (6.4)
Other	3 (6.4)
Proportion of cancer patients cared for who live in a rural setting*	
100%	25 (25.0)
75%	10 (10.0)
50%	15 (15.0)
25%	38 (38.0)
None ^c	12 (12.0)

*Missing data: Discipline ($n = 29$); Location of practice ($n = 33$); British Columbia health authority ($n = 1$); Proportion of cancer patients cared for who live in a rural setting ($n = 34$). ^aIncludes biologist and naturopathic doctor, nurse practitioner (2), registered nurse in academic setting (2), retired registered dietitian (1). ^b $n = 49$ due to a multiple response option question and participants can work for more than one health authority. ^cNo involvement with rural patients.

The majority (92.9%) of cancer care providers agreed that physical activity can reduce cancer-related fatigue, that it is safe for breast cancer survivors to be physically active during

treatment (95.8%), and that breast cancer survivors should have access to health professionals with knowledge of the physical activity needs and challenges for breast cancer survivors (97.9%).

4.2.2 Differences in knowledge and attitudes disciplines (objective 2b). A Chi-square test was used to test if RNs and RDs were equally knowledgeable about lifestyle recommendations for breast cancer survivors. Of the nine statements about body weight, diet and physical activity for breast cancer survivors, seven had too few *no* and *unsure* responses such that the analysis could not be carried out. There was no difference between discipline in terms of the agreement (yes/no) with the statement *weight gain is common after a breast cancer diagnosis* [$\chi^2(df = 2, N = 89) = 4.295, p = .117$]. There was a difference between discipline (RNs and RDs) on agreement (yes/no) with the statement *soy foods are safe for breast cancer survivors to consume* [$\chi^2(df = 1, N = 89) = 31.4934, p = .000$]. More specifically, more RDs agreed (81.6%) that soy foods are safe for breast cancer survivors to consume than nurses (21.6%).

4.2.3 Provision of information and awareness of programs (objective 2c). The majority of cancer care providers (73.1%) reported having fielded questions from breast cancer survivors on body weight, with more than half of participants (67.7%) referring on to other health care professionals for further information. When examples of other health care professionals were provided, the majority of participants (82.8%) referred breast cancer survivors with questions about body weight to RDs or RD services such as Dietitian Services at HealthLinkBC. Less than half (41.9%) of participants refer breast cancer survivors with questions about body weight to programs or services within their community. Characteristics of body weight programs and services for breast cancer survivors are summarized in Table 3 (Appendix T).

The majority of cancer care providers (90.0%) reported having fielded questions from breast cancer survivors on diet, with more than half (68.1%) referring on to other health care professionals for additional information. When examples of other health care professionals were provided, the majority of cancer care providers (96.6%) referred breast cancer survivors with questions about diet to RDs or RD services such as Dietitian Services at HealthLinkBC. A minority of cancer care providers (31.9%) refer breast cancer survivors with questions about diet to programs or services within their community. Table 4 (Appendix U) summarizes characteristics of programs and services on diet for breast cancer survivors.

The majority of cancer care providers (72.7%) provide written material on diet to breast cancer survivors. The most frequently identified categories of written information included BC Cancer Agency materials (49.0%) and *Eating Well with Canada's Food Guide* (25.5%).

Among cancer care providers from British Columbia ($n = 48$), most (72.5%) were aware of *The Nutrition Guide for Women with Breast Cancer*, which is an evidence-based resource that all women diagnosed with breast cancer in the province should receive as part of a new patient information kit (BC Cancer Agency, 2013). A minority of cancer care providers (32.5%) were aware if breast cancer survivors receive this resource where they practice.

The majority of participants (71.3%) reported having fielded questions from breast cancer survivors on physical activity, though less than half (43.7%) refer on to other health care professionals for additional information. When examples of other health care professionals were provided, the most common referral source for questions about physical activity was a physiotherapist (47.2%) or physician (44.4%). The majority of participants (63.2%) did not provide any general guidelines around physical activity, such as *Canada's Physical Activity Guidelines*, to breast cancer survivors. A minority of participants (36.0%) referred breast cancer

survivors with questions about physical activity to programs or services within their community. Characteristics of physical activity programs and services for breast cancer survivors are summarized in Table 5 (Appendix V).

A minority of participants (26.7%) were aware of programs or services in their community specifically for breast cancer survivors who want to make lifestyle changes. Table 6 (Appendix W) summarizes the characteristics of programs and services for breast cancer survivors interested in making lifestyle changes.

4.2.4 Differences between discipline and proportion of rural patients and provision of information and awareness of programs (objective 2d). It was not possible to test if there were differences between in the provision of information or awareness of programs and services in the community on body weight, diet and physical activity. It was also not possible to test if there were differences in the proportion of participants who referred to programs and services for information on body weight, diet and physical activity among those who worked with the highest proportion of rural patients (75% and 100% of patients) and those who worked with the lowest proportion of rural patients (50% or less).

5.0 Discussion

The objectives of this study were:

1. Among rural breast cancer survivors in Northern BC, to describe
 - a. body weight, diet, and physical activity changes since diagnosis;
 - b. barriers to and interest in body weight, diet, and physical activity changes;
 - c. currently available body weight, diet, and physical activity related information sources and needs;
 - d. perceived reliability of available information sources;
 - e. preferences for programs and resources; and
 - f. differences in information sources, needs, and preferences based on selected demographic characteristics.
2. Among cancer care providers to describe
 - a. knowledge and attitudes about body weight, diet, and physical activity recommendations for breast cancer survivors;
 - b. if knowledge and attitudes about body weight, diet, and physical activity recommendations for breast cancer survivors differ among Registered Nurses and Registered Dietitians;
 - c. if and how evidence-based recommendations for body weight, diet, and physical activity are being delivered to rural breast cancer survivors in Canada; and
 - d. if the provision of information and awareness of programs differs according to demographic variables (discipline and proportion of rural patients cared for).

5.1 Part 1: Breast Cancer Survivors

The results of the current study suggest breast cancer survivors in Northern BC experienced changes in their body weight, diet, and physical activity after a breast cancer diagnosis (objective 1a) and are interested in making changes to improve their health (objective 1b). Specifically, breast cancer survivors in Northern BC described wanting to lose weight, reduce unhealthy food choices, and become more active. Many women are overweight or obese when diagnosed with breast cancer and gain weight during treatment and in the years after (Sedjo et al., 2014). In an American study of rural breast cancer survivors, the majority who were above a healthy BMI were trying to lose weight and doing so without any assistance (Befort, Austin & Klemp, 2011). While the current study did not determine body weight status, nearly all breast cancer survivors who provided details about desired body weight changes identified that they wanted to lose weight and very few (7.7%) identified accessing formal weight loss assistance. Research examining dietary patterns among breast cancer survivors has shown that diet quality is generally poor, with less than recommended intake of fruits and vegetables, calcium-rich foods, and grains (Demark-Wahnefried, Peterson, McBride, Lipkus & Clipp, 2000; Potter, Collins, Brown & Hure, 2014). Further, many women are not sufficiently active prior to a breast cancer diagnosis and physical activity levels (i.e., meeting public health guidelines) have been shown to decrease following a breast cancer diagnosis (Irwin et al, 2003; Vallance et al., 2012a).

The majority of breast cancer survivors in Northern BC are interested in information about the role that body weight, diet, and physical activity may have in reducing risk of breast cancer recurrence or improving survival from breast cancer (objective 1c). These results are consistent with similar research among urban cancer survivors (Alfano et al., 2009; Humpel,

Magee & Jones, 2007; Patterson, Neuhouser, Hedderson, Schwartz, Standish & Bowen, 2003) and urban women at risk of breast cancer (Paisley et al., 2008). Research examining the role of cancer-related beliefs and behavior change has shown that women who believe that their lifestyle behaviours may have contributed to their breast cancer diagnosis, or played a role in reducing recurrence, are more likely to show an interest in these topics and adopt changes (Rabin & Pinto, 2006). Maley, Warren, and Devine (2013) explored the meanings of body weight, diet, and physical activity among women ($n = 36$) who had a recent cancer diagnosis, most of whom (86%) were breast cancer survivors. The results from this qualitative study are distinctly similar with results from the current study. For example, they identified considerable uncertainty around the relationship between body weight, diet, and cancer recurrence, which the authors reported seemed to have been responsible for increased feelings of stress and vulnerability. Participants also expressed a desire for better awareness of how common weight gain can be with cancer treatment and wanted dietitian-led nutrition education and weight management sessions. The current study showed study showed nearly three-quarters of those surveyed wanted dietitian-led programming, and identified portion sizes, meals prepared at home, and physical activity as weight management strategies. Participants in the Maley study indicated they were more confident in the relationship between physical activity and cancer outcomes, with many participants identifying the important role of physical activity in their overall health. Eating patterns and physical activity were also identified as central to managing body weight, and were seen as a means to regain a sense of control over their health. It is possible that by meeting the demonstrated need for information and programming around body weight, diet, and physical activity found in the current study, rural breast cancers in Northern BC might gain a sense of

personal control over their health and potentially decrease the feelings of stress and vulnerability as suggested in the current literature.

Breast cancer survivors in Northern BC most frequently seek information about body weight, diet, and physical activity from physicians, friends and family, the Internet, and magazines (objective 1c). These results are parallel to the results of a study that examined lifestyle information needs among urban Canadian women at risk of breast cancer by Paisley and colleagues (2008). Specifically, magazines were also the most frequently identified source of information for diet and physical activity, with *Canadian Living* and *Chatelaine* also being the most frequently identified magazines. Similarly, physicians were the most frequently identified source of information on body weight and family and friends were the most frequently identified source of information on diet and physical activity. In contrast to the current study, the Internet was not frequently identified as a source of information on body weight, diet, and physical activity in the Paisley study. However, the study population was recruited in 2005, which was earlier than the current study. This may indicate that the Internet is more frequently accessed presently or that rural breast cancer survivors in Northern BC frequently access the Internet as a source of health information.

Despite accessing lifestyle information from sources such as magazines or the Internet, breast cancer survivors identified consumer sources of information about lifestyle factors to unreliable (objective 1d). It is known that the credibility of health information in magazines and on the Internet is variable (Bates, Romina & Ahmed & 2007). This combination of demonstrated information needs with consumer health information sources is concerning, as it may be used to inform healthcare decisions (Radina et al., 2011). In the absence of accessible programs or

services, breast cancer survivors in Northern BC may not be exposed to the evidence-based health information they are looking for.

Breast cancer survivors in Northern BC are interested in information on body weight, diet, and physical activity from reliable sources, and prefer a face-to-face format for lifestyle programs and services (objective 1e). These results are similar to research examining lifestyle program preferences among rural women and rural breast cancer survivors. In a qualitative study of obese rural American women, a lack of professional dietary guidance for weight management and need for more intensive weight management programs were major themes (Ely, Befort, Banit, Gibson & Sullivan, 2009). This is consistent with the current study where rural breast cancer survivors in Northern BC most frequently identified an interest individual dietitian counselling and local lifestyle programs or services. The current study identified a strong preference for face-to-face lifestyle programming. Vallance, Lavallee, Culos-Reed and Trudeau (2012b) also identified that a face-to-face modality was strongly preferred over distance-based modalities for physical activity programming among rural breast cancer survivors in Alberta. In addition, breast cancer survivors in rural Kansas showed low interest in Internet-based weight loss programs, which was also not a preferred modality in the Befort (2012) study.

Among distance-based options, telephone and Internet were preferred over telehealth (videoconferencing) (objective 1e). Videoconferencing has been touted as one solution to providing specialized care to rural and remote populations because it can ameliorate many of the challenges faced in providing specialized health care services in geographically vast and sparsely populated regions including financial sustainability, low patient volume, staff recruitment and retention, physical access challenges (Sevean et al., 2009), as well as reduced carbon emissions from patient and clinician travel costs (Ellis, Cheek, Jaffray, & Skinner, 2013). Within Northern

Health and at the BC Cancer Agency Centre for the North catchment area, videoconferencing is used extensively to provide distance-based care to Northern BC residents. It is possible that while videoconferencing is an effective tool for the provision of clinical care to rural locations, an in-person or distance-based format (internet or telephone) seems more preferable for rural breast cancer survivors seeking survivorship programming. Befort et al (2012) demonstrated the effectiveness of telephone-based programming for rural breast cancer survivors in facilitating weight loss and improving quality of life.

There were no differences found among the proportions of breast cancer survivors in Northern BC who travelled the least *versus* the farthest for treatment with regards to access or preferred format for information on body weight, diet, and physical activity (objective 1f). The exception to this was that a greater proportion of women who travelled for more than 1 hour to the hospital where they had surgery for breast cancer appear to access healthcare professionals *versus* non-healthcare professionals for information on body weight (objective 1f). This result is difficult to interpret given that there were no other proportional differences identified between distance travelled for services. However, it is plausible that breast cancer survivors who travel the farthest to access care are more accustomed to accessing available healthcare professionals in a larger centre all at once, sort of a “a one-stop-shop” *versus* seeking this information in their home community or the closest community to their home.

5.2 Part 2: Cancer Care Providers

The results of this part of the study showed that cancer care providers were generally knowledgeable about body weight, diet, and physical activity recommendations for breast cancer survivors and were in favour of services that promote healthy lifestyles among this patient population (objective 2a). Despite this knowledge and support for services of this nature,

lifestyle modification and in particular, weight management, is not routinely part of overall breast cancer care (Demark-Wahnefried et al., 2012).

Among the RNs and RDs there was equal agreement regarding the common nature of weight gain after a breast cancer diagnosis. This agreement indicates that cancer care providers are generally aware that breast cancer survivors often gain weight. Cancer care providers are encouraged to discuss the role of body weight in breast cancer recurrence and survival, and how maintaining a healthy body weight can reduce risk of chronic disease (Rooney & Wald, 2012).

Compared to RNs, more RDs indicated soy foods are safe for breast cancer survivors to consume as frequently (objective 2b). This result is not surprising given that soy consumption for breast cancer survivors is controversial due to inconsistencies in the literature regarding its safety (Helferich et al., 2008). Good quality research has now demonstrated that consumption of soy foods is safe and may in fact decrease risk of breast cancer recurrence (Kang, Zhang, Wang, Huang & Jin, 2010; Shu et al., 2009). However, it's unlikely that RNs are as well-versed in this evidence as RDs are because knowledge of dietary patterns and their health effects are better aligned with a RDs scope of practice.

The majority of cancer care providers surveyed in this study reported fielding questions from breast cancer survivors on body weight, diet, and physical activity (objective 2c). The majority of breast cancer survivors with questions on body weight and diet were referred to other healthcare professionals for further information. However, a minority of those with questions about physical activity were referred on for further information (objective 2c). A possible explanation for this is that the roles of physiotherapists and exercise physiologists are not consistently integrated into cancer clinics in the same way that other clinicians are (e.g., dietitians). While these disciplines are considered to be members of the multidisciplinary team

that provide comprehensive care to breast cancer survivors (Beurskens, van Uden, Strobbe, Oostendorp & Wobbles, 2007; Croke & El-Sayed, 2012; Schmitz et al., 2010), it is possible that fewer referrals happen due to the organization of care and lack of presence of these team members in some cancer care settings. For example, in BC physiotherapy is available to breast cancer survivors through hospital-based programs or through private physiotherapy clinics (BC Cancer Agency, 2010c). Given that the largest proportion of cancer care providers were from BC, it is possible that cancer care providers are not as aware of the role or scope of practice of a physiotherapist for working with breast cancer survivors. Alternatively, a physician referral is required for breast cancer survivors to access physiotherapy free of charge (BC Cancer Agency, 2010c). Therefore it is possible that breast cancer survivors are being referred to physiotherapists, but not by RNs and RDs.

According to the cancer care providers surveyed, a minority of breast cancer survivors under their care are referred to community programs or services for additional information about body weight, diet, and physical activity (objective 2c). Moreover, less than one third of the cancer care providers were able to provide information about the characteristics of body weight, diet, physical activity, or lifestyle programs or services for breast cancer survivors in their jurisdiction. Although these results might seem surprising the lack of referrals to lifestyle-related programs may be due to several factors. In particular, the current study found many jurisdictions do not have programs or services specifically dedicated to breast cancer survivors. In addition, a lack of awareness and/or availability of appropriate programs or services may explain the current study results.

Among those who provided information about lifestyle programs for breast cancer survivors anywhere in Canada, it appears the majority of programs or services are offered in a

group-based format. This result is encouraging because it is consistent with the current literature which suggests weight loss through lifestyle interventions for breast cancer survivors can be achieved through group-based programs (Befort et al., 2012; Campbell et al., 2012). Of the programs and services that were reported to be available, cancer care providers reported less than a quarter were offered in any distance-based format including telephone, Internet, or videoconferencing. Among available physical activity programs and services, no distance-based options were identified. This is surprising considering the known well known benefits of physical activity for breast cancer survivors (Ibrahim & Al-Homaidh, 2011; Schmitz et al., 2010) and that distance-based exercise interventions have been shown to significantly increase physical activity among breast cancer survivors (Pinto, Frierson, Rabin, Trunzo & Marcus, 2005). The lack of distance-based options for physical activity programs or services for breast cancer survivors represents a gap in care given that the majority (77.3%) of breast cancer survivors in Northern BC surveyed want to change their physical activity to improve their health. Further, research among rural breast cancer survivors in Alberta has shown that the majority were receptive to and willing to participate in physical activity programs (Vallance et al., 2012b). While lifestyle programming for breast cancer survivors is available in some large urban centres, the results of this study suggest that this type of programming is not widely available in distance-based formats and thus unavailable for rural populations.

Given the interest in lifestyle information that rural breast cancer survivors have shown in the current study and the apparent lack of service for this population, distance-based modalities, such as videoconferencing, telephone or Internet may be a way to connect rural breast cancer survivors in Northern BC with evidence-based lifestyle information from health professionals with expertise working with this population. Evidence is lacking in Canada to inform distance-

based provision of lifestyle information to rural breast cancer survivors and, more broadly, distance-based provision of weight management programming.

5.3 Implications for Practice and Service Delivery

Study findings have direct relevance to practice and service delivery issues for breast cancer survivors in Northern BC. The results of the current study show that there is an opportunity to improve awareness of existing resources focused on body weight, diet, and physical activity for breast cancer survivors in Northern BC. Specifically, Dietitian Services at HealthLinkBC was identified by cancer care providers as a service breast cancer survivors in BC with questions about body weight or diet were frequently referred to. This service includes a Registered Dietitian who specializes in oncology nutrition and is available either by telephone or by email and requires the user to contact HealthLinkBC to connect with a care provider (HealthLinkBC, n.d.). This service is aligned with the identified preference for individual counselling with a dietitian by breast cancer survivors in Northern BC. Referrals to HealthLinkBC are common for BC Cancer Agency patients who are referred to see a dietitian who are not considered to be at increased risk of malnutrition, which can often includes breast cancer survivors. Without this referral, however, it is not known how aware of this service breast cancer survivors in Northern BC are. Further, it is also unknown how aware physicians are of the availability of Dietitian Services at HealthLinkBC service, as they were identified as the most frequently accessed source of information on body weight by breast cancer survivors in the current study.

Breast cancer survivors in Northern BC frequently seek information about body weight, diet and physical activity from friends and family members, magazines and the Internet, with the accuracy of information from these sources being highly variable (Bates et al., 2007). Further,

breast cancer survivors in Northern BC infrequently sought information from RDs about body weight, diet, or physical activity. This combination of demonstrated information needs with consumer health information sources is concerning, as it may be used to inform healthcare decisions (Radina et al., 2011). Evidence from a study exploring access to survivorship care among residents of Northern BC identified a sentiment that health care professionals in smaller communities do not have adequate knowledge to address the unique needs of cancer survivors (Howard et al., 2014). Access to survivorship care for First Nations cancer survivors in Northern BC is particularly challenging since access to basic care often requires extensive travel, and the necessity to recall medical histories to temporary healthcare professionals in the absence of consistent primary care providers (Howard et al., 2014). Collectively, these findings speak to the need for communication of key messages about the role of body weight, diet, and physical activity for breast cancer survivors through existing channels, and better awareness of services that can be accessed through distance-based services such as HealthLinkBC. In the absence of evidence-based information through existing sources, breast cancer survivors in Northern BC may not be exposed to the accurate health information they are looking for.

Several large urban cancer centres in Canada offer lifestyle programming for breast cancer survivors. Yet the results of this study showed that a minority of programs or services to address lifestyle questions or provide breast cancer survivors with support for behaviour change were available in distance-based formats such as via telephone, the Internet, or videoconferencing. The extension of urban programming using suitable distance-based formats and adapted to the needs of rural populations is an option that should be explored and may offer several benefits. First, it would allow for survivorship care to rural populations that may not otherwise have access. This may have implications for breast cancer outcomes and the

prevention and/or management of chronic diseases that share similar risk factors related to body weight, diet, and physical activity. Second, by integrating research into lifestyle programming for rural breast cancer survivors, an evidence-base could be built to inform care for this population. This may also assist in securing additional funding for further research and programming. Third, to ensure program content is adapted for rural populations, partnerships may need to be created between urban practitioners with research and clinical expertise working with breast cancer survivors and rural practitioners with expertise on the unique needs of rural patient populations. These partnerships could lead to improved integration and shared learning between urban and rural healthcare and research practitioners.

Facilitated group discussions or a series of more structured sessions specifically for rural breast cancer survivors, either via telephone or on the Internet, may help to communicate recommendations and address questions. It may also allow for sharing of similar experiences unique to rural living (e.g., food accessibility in the winter months) as was found in an American telephone-based weight-loss intervention for rural breast cancer survivors (Befort et al., 2012).

Although in-person programming for breast cancer survivors was found to be the most popular, this mode of delivery may not be feasible in many smaller communities within the BC Cancer Agency Centre for the North catchment area due to low patient volume and health human resource challenges. As an alternative, there is an opportunity to integrate cancer survivorship into existing chronic disease management services, which are already in place in many Northern BC communities. Chronic disease management programs aim to increase self-efficacy for the adoption and maintenance of health promoting behaviours among participants who typically benefit from sharing and learning about their individual experiences while learning to manage physical and psychosocial symptoms, engage with their health care team, and adopt health

promoting behaviours (Lorig, Sobel, Ritter, Laurent & Hobbs, 2001). Chronic disease management program content has been described as relevant and helpful for regaining a sense of control among cancer survivors (Beckmann, Strassnick, Abell, Hermann & Oakley, 2007) and may help with self-management (Gerber, Stout, Schmitz & Stricker, 2012). Further justification for this suggestion is based on the fact that advances in breast cancer detection and treatment have improved outcomes from breast cancer (Patterson et al., 2010) and consequently breast cancer survivors are now more likely to die from chronic diseases like cardiovascular disease rather than a recurrence of breast cancer (Patnaik, Byers, DiGuseppi, Dabelea & Denberg, 2011). In addition, public health recommendations for body weight, diet, and physical activity are considered to be appropriate for cancer survivors and for individuals with chronic diseases such as diabetes and cardiovascular disease (Dworatzek, Arcudi, Gougeon, Husein, Sievenpiper & Williams, 2013; Schmitz et al., 2010; Sigal et al., 2013; Rock et al., 2012).

5.4 Strengths and Limitations

There are a number of strengths to this research including registry-based recruitment, the adaptation and use of a data collection tool from a published study, a high survey response rate in study part 1, and the inclusion of both breast cancer survivors and cancer care providers' perspectives. Registry-based recruitment is a strength of part 1 of the study. Sampling by this method allowed for the gathering of a sample of the population of interest that was representative of the diverse demographic area in Northern BC and for those with different treatment options for breast cancer. The survey used for part 1 of this study was adapted from a published study of Canadian women at risk of breast cancer (Paisley et al., 2008). Using this survey allowed for direct comparisons in the results between urban and rural women. Part 1 of this study yielded a response rate of nearly 50%, which is higher than similar research on rural breast cancer

survivors (Vallance et al., 2012a). This response rate may speak to an interest in body weight, diet, and physical activity information among breast cancer survivors in Northern BC as has been observed in similar research with rural women (Befort et al., 2011). Finally, this study is unique in including perspectives from both breast cancer survivors and cancer care providers. Study results can therefore be interpreted in the context of each part and provides a more meaningful description of breast cancer survivorship care in Northern BC.

There are several limitations to the current study. Neither cross-sectional survey used in this study was validated, and while a snap shot of a particular situation was captured, changes or trends over time cannot be described (Kelley et al., 2003). A single validated health literacy question (Chew et al., 2008) was as well as a question on weight management behaviours adapted from Kruger et al (2006) were added to the survey for part 1. This study also did not examine psychosocial factors associated with behaviour change, which have been shown to impact ability and readiness to change (Befort et al., 2011). However, this survey was revised with feedback from research and nutrition professionals to make it more suitable to the study objectives and population and to improve content validity.

Cross-sectional data collection may limit the generalizability of the study results to future women with breast cancer shortly after diagnosis because it is possible that those who were diagnosed closer to 2007 may have different information needs and access different sources of lifestyle information than those diagnosed more recently (i.e., temporal trends). In addition, the sample provided by the BC Cancer Registry included proportionally more participants diagnosed earlier within the 2007 to 2012 time frame due to registry data entry. The online recruitment and data collection used in part 2 of this study yielded a low number of participants that were not

equally represented across Canada. This limits the ability of this part of the study to adequately describe the provision of information on lifestyle to breast cancer survivors in Canada.

Breast cancer survivors are often considered to be active information seekers (Radina et al., 2011), but may also passively access information about their disease (Longo, 2005). The survey for part 1 of this study was aimed at identifying currently available information sources and needs and it is possible that respondents to this survey better represent active information seekers, while those who were not actively seeking for information about their disease were less likely to complete the survey. It is also possible that in both parts of this study, participants may have been inclined to provide socially desirable responses, which is a potential source of bias (Trochim & Donnelly, 2008).

5.5 Suggestions for Future Research

As a result of this research, four recommendations for future research have been generated:

- 1) identify strategies to improve awareness of accessible evidence-based lifestyle information sources for breast cancer survivors;
- 2) discuss the results of the current study and its implications with administrative stakeholders in rural and First Nations communities in Northern BC;
- 3) carry out a feasibility study on the adaptation and extension of urban-based lifestyle programming for rural breast cancer survivors; and
- 4) conduct an environmental scan to explore the integration of cancer survivorship into chronic disease management.

Improved awareness of accessible evidence-based body weight, diet, and physical activity information is needed (recommendation 1). It is currently unknown if and how aware breast

cancer survivors, physicians, and the friends and families of survivors Northern BC are of HealthLinkBC, and that there is a RD with expertise specifically in oncology. It is possible that awareness and visibility of the cancer-specific RD service at HealthLinkBC could be improved in locations where breast cancer survivors are likely to go for information or follow-up appointments, such as physicians offices, mammography clinics, and health region websites and newsletters. A review and critique of lifestyle information in magazines such as *Canadian Living* and *Chatalaine* would help to determine the credibility of the information provided. This information would be helpful for clinicians working with breast cancer survivors in Northern BC who access information about body weight, diet, and physical activity from these sources.

The results of the current study should be communicated with administrative stakeholders in rural and First Nations communities in Northern BC (recommendation 2). Communication of study results and implications could help to build on existing advocacy efforts to expand survivorship care for rural populations, prioritize health care needs, and possibly inform future resource allocation. This communication could also serve as an opportunity to solicit input from stakeholders on interpretation of the study results.

A feasibility study on the adaptation and extension of urban-based lifestyle programming for rural breast cancer survivors is needed (recommendation 3). As lifestyle programming for breast cancer survivors in large urban centres is often carried out as part of research (Campbell et al., 2012; Muraca, Leung, Clark, Beduz & Goodwin, 2011) this serves not only as an opportunity to test the effectiveness of adapted programming for rural populations, but also as an opportunity to test the effectiveness of distance-based modalities, such as telephone or Internet, in the provision of survivorship care.

An environmental scan to explore the integration of cancer survivorship care into chronic disease management (recommendation 4) would help to identify how existing chronic disease management program content and referral criteria can be modified to accommodate an increasing diversity of chronic conditions. In addition, the selection of broadened outcome parameters for program evaluation would need to be carried out. Examples of possible outcome parameters relevant to chronic disease management that includes cancer survivorship includes quality of life, self-efficacy for health behaviour changes (including dietary and physical activity changes), body weight or body composition measurements, and blood biomarkers including blood lipids, insulin and blood sugar control, and inflammation (Campbell et al., 2012; Lorig et al., 2001).

Further research will help to inform the provision of lifestyle information to breast cancer survivors in Northern BC. Through advocacy and communication of research findings with administrative stakeholders, care for breast cancer survivors in Northern BC can be tailored to meet the needs of this unique patient population.

6.0 Conclusion

The results of this study identify a gap in care available for breast cancer survivors living in rural settings. This study found that breast cancer survivors in Northern BC are most interested in information about the role of body weight, diet, and physical activity as means to decrease risk of recurrence or improve survival from breast cancer. Cancer care providers infrequently refer breast cancer survivors with questions about lifestyle to programs or services, and of those who do, accessibility is lacking for those who live in rural settings.

Despite a growing body of literature to inform recommendations on body weight, diet, and physical activity for breast cancer survivors (Rock et al., 2012), very little evidence exists to guide the provision of this information to breast cancer survivors who live in rural settings. Cancer survivors living in rural regions are a unique patient population. Beyond geographic location, rural women in Northern BC have lower socioeconomic status and education when compared to their urban counterparts and face challenges accessing healthcare to meet their needs (Leipert, 2005; Leipert & Reutter, 2005). The social, economic and political climate in a rural region influences healthcare needs and how they can be met (Sevean et al., 2009).

Several opportunities exist to improve access to survivorship care for rural breast cancer survivors in Northern BC. This includes improved awareness of accessible evidence-based lifestyle information, adaptation and extension of urban-based survivorship care to rural settings, and integration with existing chronic disease management programs. Without improvements in survivorship care that meet the specific needs of rural breast cancer survivors in Northern BC and fit the geographic area they live in, the gap in service provision will continue to grow. While knowledge alone does not necessarily lead to behaviour change, addressing the demonstrated need for lifestyle information among breast cancer survivors in Northern BC may help to

improve awareness of the role that body weight, diet, and physical activity can have in improving health, and in doing so, may decrease risk of chronic disease in this population.

References

- Alfano, C. M., Day, J. M., Katz, M. L., Herndon, J. E., Bittoni, M. A., Oliveri, J. M., Donohue, K., & Paskett, E. D. (2009). Exercise and dietary change after diagnosis and cancer-related symptoms in long-term survivors of breast cancer. *Psycho-Oncology, 18*(2), 128-133.
- American Society of Clinical Oncology. (2009). *What to know: ASCO's guideline on follow-up care for breast cancer*. Retrieved from: <http://www.cancer.net/patient/Publications+and+Resources/What+to+Know%3A+ASCO%27s+Guidelines/What+to+Know%3A+ASCO%27s+Guideline+on+Follow-Up+Care+for+Breast+Cancer?sectionTitle=Recommendations§ionId=101150&vgnextrefresh=1>
- Andersen, M. R., & Urban, N. (1999). Involvement in decision-making and breast cancer survivor quality of life. *Annals of Behavioral Medicine, 21*(3), 201-209.
doi:10.1177/1077558708325511
- Ahrendt, A. D., Kattlemann, K. K., Rector, T. S., Maddox, D. A. (2014). The effectiveness of telemedicine for weight management in the MOVE! Program. *The Journal of Rural Health, 30*(1), 113-119. doi:10.1111/jrh.12049
- Ball, G. D. C., Ambler, K. A., & Chanoine, J. P. (2011). Pediatric weight management programs in Canada: Where, What and How? *International Journal of Pediatric Obesity, 6*(2-2), e58-e61. doi:10.3109/17477166.2010.512390
- Bates, B. R., Romina, S., & Ahmed, R. (2007). The effect of improved readability scores on consumers' perceptions on the quality of health information on the internet. *Journal of Cancer Education, 22*(1), 15-20.

BC Cancer Agency. (2010a). *Cancer Incidence Projections: Northern Health 2010-2025*.

Retrieved from http://www.bccancer.bc.ca/NR/rdonlyres/A20EB9FB-0932-4BF4-BA34-141FA6DD5AF6/53195/NorthernHealthAuthority_20102025.pdf

BC Cancer Agency. (2010b). *Guidance note for identification and initial contact of potential research participants*. Retrieved from <http://www.bccancer.bc.ca/RES/REB/ConsentTempl.htm#contact>

BC Cancer Agency. (2010c). *Physiotherapy lymphedema programs in BC*. Retrieved from <http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/Rehabilitation/LocationofLymphapressPhysiotherapyProgramsinBC.htm>

BC Cancer Agency. (2011). *Nutrition guide for women with breast cancer*. Retrieved from http://www.bccancer.bc.ca/NR/rdonlyres/B20CD4F1-25BD-406F-9893-F1CFB4260BD5/54073/Nutrition_2011.pdf

BC Cancer Agency. (2012). *Nutrition Services*. Retrieved from http://www.bccancer.bc.ca/PPI/copingwithcancer/nutrition/Dietitian_Services.htm

BC Cancer Agency. (2013). *Breast cancer information kit*. Retrieved from <http://www.bccancer.bc.ca/PPI/TypesofCancer/Breast/breastcakit.htm>

Beckmann, K., Strassnick, K., Abell, L., Hermann, J., & Oakley, B. (2007). Is a chronic disease self-management program beneficial to people affected by cancer? *Australian Journal of Primary Health, 13*(1), 36-44.

Befort, C. A., Austin, H., & Klemp, J. R. (2011). Weight control needs and experiences among rural breast cancer survivors. *Psycho-Oncology, 20*(10), 1069-1075.

doi:10.1002/pon.1828

- Befort, C., Klemp, J., Austin, H., Perri, M., Schmitz, K., Sullivan, D., & Fabian, C. (2012). Outcomes of a weight loss intervention among rural breast cancer survivors. *Breast Cancer Research and Treatment, 132*(2), 631-639. doi:10.1007/s10549-011-1922-3
- Beurskens, C. H. G., van Uden, C. J. T., Strobbe, L. J. A., Oostendorp, R. A. B., & Wobbes, T. (2007). The efficacy of physiotherapy upon shoulder function following axillary dissection in breast cancer: a randomized controlled study. *BMC Cancer 2007, 7*:166. doi:10.1186/1471-2407-7-166
- Bosaeus, I. (2008). Nutritional support in multimodal therapy for cancer cachexia. *Supportive Care in Cancer, 16*(5), 447-451.
- Brathwaite, D., Emery, J., de Lusignan, S., & Sutton, S. (2003). Using the internet to conduct surveys of health professionals: a valid alternative? *Family Practice, 20*(5), 545-551. doi:10.1093/fampra/cm509
- British Columbia Statistics. (2012). *Socioeconomic profiles*. Retrieved from <http://www.bcstats.gov.bc.ca/StatisticsBySubject/SocialStatistics/SocioEconomicProfiles/Indices/Profiles.aspx>
- Buck, K., Vrieling, A., Zaineddin, A. K., Becker, S., Husing, A., Kaaks, R.,... Chang-Claude, J. (2011). Serum enterolactone and prognosis of postmenopausal breast cancer. *Journal of Clinical Oncology, 29*(28), 3730-3738. doi:10.1200/JCO.2011.37.9669
- Burstein, H. J., & Winer, E. P. (2000). Primary care for survivors of breast cancer. *The New England Journal of Medicine, 343*(15), 1086-1094. doi:10.1056/NEJM200101253440416
- Caan, B. J., Kwan, M. L., Hartzell, G., Castillo, A., Slattery, M. L., Sternfeld, B., & Weltzien, E. (2008). Pre-diagnosis body mass index, post-diagnosis weight change, and prognosis

- among women with early stage breast cancer, *Cancer Causes and Control*, 19(10), 1319-1328.
- Caan, B. J., Natarajan, L., Parker, K., Gold, E. B., Thompson, C., Newman, V.,... Pierce, J. P. (2011). Soy food consumption and breast cancer prognosis. *Cancer Epidemiology, Biomarkers and Prevention*, 20(5), 854-858. doi:10.1158/1055-9965.EPI-10-1041
- Campbell, K. L., Van Patten, C. L., Neil, S. E., Kirkham, A. A., Gotay, C. C., Gelmon, K. A., McKenzie, D. C. (2012). Feasibility of a lifestyle intervention on body weight and serum biomarkers in breast cancer survivors with overweight and obesity. *Journal of the Academy of Nutrition and Dietetics*, 112(4), 559-567. doi:10.1016/j.jada.2011.10.022
- Canadian Cancer Society. (2012). *Canadian Cancer Statistics 2012. Cancer Society's Steering Committee on Cancer Statistics*. Retrieved from [http://www.cancer.ca/~media/CCS/Canada%20wide/Files%20List/English%20files%20heading/PDF%20-%20Policy%20-%20Canadian%20Cancer%20Statistics%20-%20English/Canadian %20Cancer%20Statistics%202012%20-%20English.ashx](http://www.cancer.ca/~media/CCS/Canada%20wide/Files%20List/English%20files%20heading/PDF%20-%20Policy%20-%20Canadian%20Cancer%20Statistics%20-%20English/Canadian%20Cancer%20Statistics%202012%20-%20English.ashx)
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
- Canadian Society for Exercise Physiology. (2011). *Canadian Physical Activity Guidelines*. Retrieved from <http://www.csep.ca/english/view.asp?x=804>
- Centers for Disease Control and Prevention. (2011). Cancer Survivors – United States, 2007. *Morbidity and Mortality Weekly Report*, 60(9), 269-272.

- Chi, F., Wu, R., Zeng, Y., Xing, R., Liu, Y., & Xu, Z. (2013). Post-diagnosis soy food intake and breast cancer survival: A meta-analysis of cohort studies. *Asian Pacific Journal of Cancer Prevention, 14*(4), 2407-2412.
- Chew, L. D., Griffin, J. M., Partin, M. R., Noorbaloochi, S., Grill, J. P., Snyder, A., ... VanRyn, M. (2008). Validation of screening questions for limited health literacy in a large VA outpatient population. *Journal of General Internal Medicine, 23*(5), 561-566.
doi:10.1007/s11606-008-0520-5
- Chlebowski, R. T. (2013). Vitamin D and breast cancer incidence and outcome. *Anti-Cancer Agents in Medicinal Chemistry, 13*(1), 98-106. doi:10.2174/187152013804487362
- Chlebowski, R. T., Blackburn, G. L., Thomson, C. A., Nixon, D. W., Shapiro, A., Hoy, M. K., ... Elashoff, R. M. (2006). Dietary fat reduction and breast cancer outcome: Interim efficacy results from the women's intervention nutrition study. *JNCI: Journal of the National Cancer Institute, 98*(24), 1767-1776.
- Chlebowski, R. T., Johnson, K. C., Kooperberg, C., Pettinger, M., Wactawski-Wende, J., Rohan, T., ... Hubbell, A. (2008). Calcium plus vitamin D supplementation and the risk of breast cancer. *Journal of the National Cancer Institute, 100*(22), 1581-1591.
doi:10.1093/jnci/djn360
- Croke, M., El-Sayed, S. (2012). Multidisciplinary management of cancer patients: chasing a shadow or real value? An overview of the literature. *Current Oncology, 19*(4). e232–e238. doi:10.3747/co.19.944
- Demark-Wahnefried, W., Aziz, N.M., Rowland, J.H., & Pinto, B.M. (2005). Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *Journal of Clinical Oncology, 23*(24), 5814-5830. doi:10.1200/JCO.2005.01.230

- Demark-Wahnefried, W., Campbell, K. L., & Heyes, S. C. (2012). Weight management and its role in breast cancer rehabilitation. *Cancer, 118*(S8), 2277-2287.
- Demark-Wahnefried, W., Clipp, E. C., Lipkuss, I. M., Lobach, D., Snyder, D. C., Sloane, R., Peterson, B., ...Kraus, W. E. (2007). Main outcomes of the FRESH START trial: a sequentially tailored, diet and exercise mailed print intervention among breast and prostate cancer survivors. *Journal of Clinical Oncology, 25*(19), 2709-2718.
doi:10.1200/JCO.2007.10.7094
- Demark-Wahnefried, W., Peterson, B., McBride, C., Lipkus, I. & Clipp, E. (2000). Current health behaviors and readiness to pursue life-style changes among men and women diagnosis with early stage prostate and breast carcinomas. *Cancer, 88*(3), 674-684.
- Demark-Wahnefried, W., Peterson, B. L., Winer, E. P., Marks, L., Aziz, N., Marcom, P. K.,... Rimer, B. K. (2001). Changes in weight, body composition, and factors influencing energy balance among premenopausal breast cancer patient receiving adjuvant chemotherapy. *Journal of Clinical Oncology, 19*(9), 2381-2389.
- Demark-Wahnefried, W., Platz, E. A., Ligibel, J. A., Blair, C. K., Courneya, K. S., Meyerhardt, J. A., ...Goodwin, P. A. (2012). The role of obesity in cancer survival and recurrence. *Cancer Epidemiology, Biomarkers & Prevention, 21*(8), 1244-1259.
- Doyle, N. (2008). Cancer survivorship: Evolutionary concept analysis. *Journal of Advanced Nursing, 62*(4), 499-509. doi:10.1111/j.1365-2648.2008.04617.x
- Duijts, S. F. A., Faber, M. M., Oldenburg, H. S. A., & van Beurden, M. (2011). Effectiveness of behavioral techniques and physical exercise on psychosocial functioning and health-related quality of life in breast cancer patients and survivors – a meta-analysis. *Psycho-Oncology, 20*(2), 115-126. doi:10.1002/pon.1728

du Plessis, V., Beshiri, R., Bollman, R. D., & Clemenson, H. (2002). *Definitions of "rural"*.

Statistics Canada Agriculture Division (Catalogue no. 21-601-MIE — No. 061).

Dworatzek, P. D., Arcudi, K., Gougeon, R., Husein, N., Sievenpiper, J. L., Williams, S. L.

Canadian Diabetes Association 2013 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada: nutrition therapy. *Canadian Journal of Diabetes*, 37(Suppl. 1), S45-S55.

Ellis, I., Cheek, C., Jaffray, L., & Skinner, T. C. (2013). Making a case for telehealth: measuring the carbon cost of health-related travel. *Rural and Remote Health*, 13: 2723(online).

Retrieved from http://www.rrh.org.au/publishedarticles/article_print_2723.pdf

Ely, A. C., Befort, C. A., Banit, A., Gibson, C., & Sullivan, D. (2009). A qualitative assessment of weight control among rural Kansas women. *Journal of Nutrition Education and Behavior*, 41(3), 207-211. doi:10.1016/j.jneb.2008.04.355

Forbes, G. B., Brown, M. R., Welle, S. L., & Lipinski, B. A. (1986). Deliberate overfeeding in women and men: energy cost and composition of the weight gain. *British Journal of Nutrition*, 56(1), 1-9. doi:10.1079/BJN19860080

Freedman, R. J., Aziz, N., Albanes, D., Hartman, T., Danforth, D., Hill, S.,... Yanovski, J. A.

(2004). Weight and body composition changes during and after adjuvant chemotherapy in women with breast cancer. *The Journal of Clinical Endocrinology and Metabolism*, 89(5), 2248-2253. doi:10.1210/jc.2003-031874

Galloway, S., Graydon, J., Harrison, D., Evans-Boyden, B., Palmer-Wickham, S., Burlein-Hall, S., . . . Blair, A. (1997). Informational needs of women with a recent diagnosis of breast cancer: Development and initial testing of a tool. *Journal of Advanced Nursing*, 25(6), 1175-1183. doi:10.1046/j.1365-2648.1997.19970251175.x

- Gerber, L. H., Stout, N. L., Schmitz, K. H., & Stricker, C. T. (2012). Integrating a prospective surveillance model for rehabilitation into breast cancer survivorship care. *Cancer, 118*(8), 2201-2206. doi:10.1002/cncr.2
- Goodwin, P. J. (2001). Weight gain in early stage breast cancer: Where do we go from here? *Journal of Clinical Oncology, 19*(9), 2367-2369.
- Goodwin, P. J., Ennis, M., Pritchard, K. I., Koo, J., Trudeau, M. E., & Hood, N. (2003). Diet and breast cancer: evidence that extremes in diet are associated with poor survival. *Journal of Clinical Oncology, 21*(13), 2500-2507. doi:10.1200/JCO.2003.06.121
- Grunfeld, E., & Earle, C. C. (2010). The interface between primary and oncology specialty care: Treatment through survivorship. *Journal of the National Cancer Institute Monographs, 40*, 25-30. doi:10.1093/jncimonographs/lgq002
- Grafton, D., Troughton, M., & Rourke, J. (2004). Rural community and health care interdependence: an historical, geographical study. *Canadian Journal of Rural Medicine, 9*(3), 156-164.
- Guest, D. D., Evans, E. M., & Rogers, L. Q. (2013). Diet componenets associated with perceived fatigue in breast cancer survivors. *European Journal of Cancer Care, 22*(1), 51-59. doi:10.1111/j.1365-2354.2012.01368.x
- Guha, N., Kwan, M. L., Quesenberry, C. P., Weltzien, E. K., Castillo, A. L., & Caan, B. J. (2009). Soy isoflavones and risk of cancer recurrence in a cohort of breast cancer survivors: the Life After Cancer Epidemiology study. *Breast Cancer Research and Treatment, 118*(2), 395-405. doi:10.1007/s10549-009-0321-5
- Halseth, G., Helm, C., & Price, D. (2011). The Rural Care Needs Index: a potential tool for 'have-not' communities. *Canadian Journal of Rural Health, 16*(4), 134-136.

- Hanlon, N., & Halseth, G. (2005). The greying of resource communities in northern British Columbia: implications for health care delivery in already-underserved communities. *The Canadian Geographer*, *49*(1), 1-24. doi:10.1111/j.0008-3658.2005.00077.x
- Hartmuller, V. W., & Desmond, S. M. (2004). Professional and patient perspectives on nutritional needs of patients with cancer. *Oncology Nursing Forum*, *31*(5), 989-996. doi:10.1188/04.ONF.989-996
- HealthLinkBC. (n.d.). *Cancer*. Retrieved from <http://www.healthlinkbc.ca/healthyeating/conditions/cancer.html>
- Helferich, W. G., Andrade, J. E., & Hoagland, M. S. (2008). Phytoestrogens and breast cancer: a complex story. *Inflammopharmacology*, *16*(5), 219-226. doi:10.1007/s10787-008-8020-0
- Holick, M. F. (2007). Vitamin D deficiency. *The New England Journal of Medicine*, *357*(19), 266-281. doi:10.1056/NEJMra070553
- Holick, C. N., Newcomb, P. A., Trentham-Dietz, A., Titus-Ernstoff, L., Bersh, A. J., Stampfer, M. J.,... Willett, W. C. (2008). Physical activity and survival after diagnosis of invasive breast cancer. *Cancer Epidemiology, Biomarker and Prevention*, *17*(2), 379-386. doi:10.1158/1055-9965.EPI-07-0771
- Holmes, M. D., Chen, W. Y., Feskanich, D., Kroenke, C. H., & Colditz, G. A. (2005). Physical activity and survival after breast cancer diagnosis. *Journal of the American Medical Association*, *293*(20), 2479-2486.
- Howard, F. A., Smilie, K., Turnbull, K., Zirul, C., Munroe, D., Ward, A., ... & Olson, R. (2014). Access to medical and supportive care for rural and remote cancer survivors in Northern British Columbia. *The Journal of Rural Health*. doi:10.1111/jrh.12064

- Humpel, N., Magee, C., & Jones, S. (2007). The impact of a cancer diagnosis on the health behaviors of cancer survivors and their family and friends. *Supportive Care in Cancer, 15*(6), 621-630. doi:10.1007/s00520-006-0207-6
- Ibrahim, E. M., & Al-Homaidh, A. (2011). Physical activity and survival after breast cancer diagnosis: meta-analysis of published studies. *Medical Oncology, 28*(3), 753-765. doi:10.1007/s12032-010-9536-x
- Institute of Medicine. (2005). *From cancer patient to cancer survivor: lost in transition*. Retrieved from <http://www.iom.edu/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx#>
- Irwin, M. L., Crumley, D., McTiernan, A., Bernstein, L., Baumgartner, R., Gilliland, F., D., ... Ballard-Barbash, A. (2003). Physical activity levels before and after a diagnosis of breast carcinoma: the health, eating, activity, and lifestyle (HEAL) study. *Cancer, 97*(7), 1746-1757. doi:10.1002/cncr.11227
- Izano, M. A., Fung, T. T., Chiuve, S. S., Hu, F. B., & Holmes, M. D. (2013). Are Diet Quality Scores After Breast Cancer Diagnosis Associated with Improved Breast Cancer Survival? *Nutrition and Cancer, 65*(6), 820-826. doi:10.1080/01635581.2013.804939
- Jahraus, D., Sokolosky, S., Thurston, N., & Guo, D. (2002). Evaluation of an education program for patients with breast cancer receiving radiation therapy. *Cancer Nursing, 25*(4), 266-275.
- Jones, L. W., & Demark-Wahnefried, W. (2006). Diet, exercise, and complementary therapies after primary treatment for cancer. *Lancet Oncology, 7*(12), 1017-1026.

- Kang, X., Zhang, Q., Wang, S., Huang, X., & Jin S. (2010). Effect of soy isoflavones on breast cancer recurrence and death for patients receiving adjuvant endocrine therapy. *Canadian Medical Association Journal*, 182(17), 1857-1861.
- Kangas, M., Bovbjerg, D. H., & Montgomery, G. H. (2008). Cancer-related fatigue: a systematic and meta-analytic review of non-pharmacological therapies for cancer patients. *Psychological Bulletin*, 134(5), 700-741. doi:10.1037/a0012825; 10.1037/a0012825.supp
- Kashaninia, Z. (2011). *Education and health – an analysis of regions of British Columbia: Part 5 – Northern Health*. Retrieved from <http://www.bcstats.gov.bc.ca/Statistics/BySubject/SocialStatistics/SocioEconomicProfilesIndices/Profiles.aspx>
- Kelley, K., Clark, B., Brown, V., & Sitzia, J. (2003). Good practice in the conduct of reporting of survey research. *International Journal for Quality in Health Care*, 15(3), 261-266. doi:10.1093/intqhc/mzg031
- Kim, C. J., Kang, D. H., & Park, J. W. (2009). A meta-analysis of aerobic exercise interventions for women with breast cancer. *Western Journal of Nursing Research*, 31(4), 437-461. doi:10.1177/0193945908328473
- Knowler, W. C., Barrett-Connor, E., Fowler, S. E., Hamman, R. F., Lachin, J. M., Walker, E. A., & Nathan, D. M. (2002). Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *The New England Journal of Medicine*, 346(6), 393-403.
- Kroenke, C. H., Chen, W. Y., Rosner, B., & Holmes, M. D. (2005a). Weight, weight gain, and survival after breast cancer diagnosis. *Journal of Clinical Oncology*, 23(7), 1370-1379. doi:10.1200/JCO.2005.01.079

- Kroenke, C. H., Fung, T. T., Hu, F. B., & Holmes, M. D. (2005b). Dietary patterns and survival after breast cancer diagnosis. *Journal of Clinical Oncology*, 23(36), 9295-9303.
doi:10.1200/JCO.2005.02.0198
- Kruger, J., Blanck, H., & Gillespie, C. (2006). Dietary and physical activity behaviors among adults successful at weight loss maintenance. *International Journal of Behavioral Nutrition and Physical Activity*, 3(1), 17. doi:10.1186/1479-5868-3-17
- Kwan, M. L., Weltzien, E., Kushi, L. H., Castillo, A., Slattery, M. L., & Caan, B. J. (2009). Dietary Patterns and Breast Cancer Recurrence and Survival Among Women with Early-Stage Breast Cancer. *Journal of Clinical Oncology*, 27(6), 919-926.
doi:10.1200/JCO.2008.19.4035
- Lazarus, R. S. (1993). Coping theory and research: past, present and future. *Psychosomatic Medicine*, 55(3), 234-247.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.
- Leipert, B. D. (2005). Rural woman's health issues in Canada. *Canadian Woman Studies*, 24(4), 109-116.
- Leipert, B. D., & Reutter, L. (2005). Women's health in northern British Columbia: the role of geography and gender. *Canadian Journal of Rural Medicine*, 10(4), 241-253.
- Longo, D. R. (2005). Understanding health information, communication, and information seeking of patients and consumers: a comprehensive and integrated model. *Health Expectations*, 8(3), 189-194.
- Longo, D. R., Patrick, T. B., & Kruse, R. L. (2001). The natural history of the use of healthcare information by women with breast cancer: a conceptual model. *Proceedings of the American Medical Informatics Association symposium*, 413-417.

- Lorig, K. R., Sobel, D. S., Ritter, P. L., Laurent, D., & Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice, 4*(6), 256-262.
- Lustberg, M. H., Reinbolt, R. E., Shapiro, C. L. (2012). Bone health in adult cancer survivorship. *Journal of Clinical Oncology, 30*(30), 2665–3674. doi:10.1200/JCO.2012.42.2097
- Markey, S., Halseth, G., & Manson, D. (2010). Capacity, scale and place: pragmatic lessons for doing community-based research in the rural setting. *The Canadian Geographer, 54*(2), 159-176.
- Mason, C., Alfano, C. M., Wilder Smith, A., Wang, C. Y., Neuhouser, M. L., Duggan, C., ...McTiernan, A. (2013). Long-term physical activity trends in breast cancer survivors. *Cancer, Epidemiology, Biomarkers & Prevention, 22*(6), 1153 – 1161.
- Maley, M., Warren, B. S., & Devine, C. M. (2013). A second chance: meanings of body weight, diet, and physical activity to women who have experienced cancer. *Journal of Nutrition Education and Behavior, 45*(3), 232-239.
- McDonald, J.T., & Sherman, A. (2010). Determinants of mammography use in rural and urban regions of Canada. *Canadian Journal of Rural Medicine, 15*(2), 52-59.
- McNeely, M. L., Campbell, K. L., Rowe, B. H., Klassen, T. P., Mackey, J. R., & Courneya, K. S (2006). Effects of exercise on breast cancer patients and survivors: A systematic review and meta-analysis. *Canadian Medical Association Journal, 175*(1), 34-41.
doi:10.1503/cmaj.051073
- McNiven, C. Purderer, H. & Janes, D. (2000). *Census metropolitan area and census agglomeration influenced zones (MIZ): a description of the methodology*. Retrieved from <http://www.statcan.gc.ca/pub/92f0138m/92f0138m2000002-eng.pdf>

- Memorial Sloan-Kettering Cancer Centre. (2011). *Survivorship FAQs*. Retrieved from <http://www.mskcc.org/cancer-care/survivor/survivorship-faqs#toc-item-0>
- Morey, M. C., Snyder, D. C., Sloane, R., Cohen, H. J., Peterson, B., Hartman, T. J., Miller, P., ... Demark-Wahnefried, W. (2009). Effects of home-based diet and exercise on functional outcomes among older, overweight long-term cancer survivors. RENEW: a randomized controlled trial. *Journal of the American Medical Association*, *301*(18), 1883-1891.
- Morgan, G. A., Gliner, J. A., & Harmon, R. J. (2006). *Understanding and Evaluating Research in Applied and Clinical Settings*. New York: Psychology Press
- Muraca, L., Leung, D., Clark, A., Beduz, M. A., & Goodwin, P. (2011). Breast cancer survivors: Taking charge of lifestyle choices after treatment. *European Journal of Oncology Nursing*, *15*(3), 250-253. doi:10.1016/j.ejon.2009.12.001
- National Research Council. (2011). *Dietary Reference Intakes for Calcium and Vitamin D: Report Brief*. Retrieved from <http://www.iom.edu/~media/Files/Report%20Files/2010/Dietary-Reference-Intakes-for-Calcium-and-Vitamin-D/Vitamin%20D%20and%20Calcium%202010%20Report%20Brief.pdf>
- Neilson, H. K., Conroy, S. M., & Friedenreich, C. M. (2014). The Influence of Energetic Factors on Biomarkers of Postmenopausal Breast Cancer Risk. *Current Nutrition Reports*, *3*, 22-34. doi:101007/s13669-013-0069-8
- Olatunde, S., Leduc, E. R., & Berkowitz, J. (2007). Different practice patterns of rural and urban general practitioners are predicted by the General Practice Rurality Index. *Canadian Journal of Rural Medicine*, *12*(2), 73-80.
- Olson, R. A., Nichol, A., Caron, N. R., Olivotto, I. A., Speers, C., Chia, S., . . . Tyldesley, S. (2012). Effect of community population size on breast cancer screening, stage

- distribution, treatment use and outcomes. *Canadian Journal of Public Health*, 103(1), 46-52.
- Paisley, J., Brown, C., & Greenberg, M. (2008). Information needs of women at risk of breast cancer. *Canadian Journal of Dietetic Practice and Research*, 69(2), 59-64.
- Palmieri, C., MacGregor, T., Girgis, S., & Vigushin, D. (2006). Serum 25-hydroxyvitamin D levels in early and advanced breast cancer. *Journal of Clinical Pathology*, 59(12), 1334-1336. doi:10.1136/jcp.2006.042747
- Papaioannou, A., Morin, S., Cheung, A. M., Atkinson, S. Brown, J. P., Feldman, S., ... Leslie, W. D. (2010). 2010 clinical practice guidelines for the diagnosis and management of osteoporosis in Canada: summary. *Canadian Medical Association Journal*, 182(17), 1864-1873. doi:10.1503/cmaj.100771
- Patnaik, J. L., Byers, T., Diguseppi, C., Dabelea, D., & Denberg, T. D. (2011). Cardiovascular disease competes with breast cancer as the leading cause of death for older females diagnosed with breast cancer: a retrospective cohort study. *Breast Cancer Research*, 13(3), R64.
- Patterson, R. E. (2011). Flaxseed and breast cancer: What should we tell our patients. *Journal of Clinical Oncology*, 29(28), 3723-3724. doi:10.1200/JCO.2011.37.9669
- Patterson, R. E., Cadmus, L. A., Emond, J. A., & Pierce, J. P. (2010). Physical activity, diet, adiposity and female breast cancer prognosis: A review of the epidemiologic literature. *Maturitas*, 66(1), 5-15. doi:10.1016/j.maturitas.2010.01.004
- Patterson, R. E., Neuhouser, M. L., Hedderson, M. M., Schwartz, S. M., Standish, L. J., & Bowen, D. J. (2003). Changes in diet, physical activity, and supplement use among adults diagnosed with cancer. *Journal of the American Dietetic Association*, 103(3), 323-328.

- Peterson, J., Dwyer, J., Adlecreutz, H., Scalbert, A., Jacques, P., & McCullough, M. L. (2010). Dietary lignans; physiology and potential for cardiovascular disease risk reduction. *Nutrition Reviews*, *68*(10), 571-603. doi:10.1111/j.1753-4887.2010.00319.
- Pierce, J. P., Natarajan, L., Caan, B. J., Parker, B. A., Greenberg, E. R., Flatt, S. W., . . . Stefanick, M. L. (2007). Influence of a diet very high in vegetables, fruit, and fiber and low in fat on prognosis following treatment for breast cancer: The women's healthy eating and living (WHEL) randomized trial. *Journal of the American Medical Association*, *298*(3), 289-298.
- Pinto, B. M., Frierson, G. M., Rabin, C., Trunzo, J. J. & Marcus, B. H. (2005). Home-based physical activity intervention for breast cancer patients. *Journal of Clinical Oncology*, *23*(15), 3577-3587.
- Potter, J. L., Collins, C. E., Brown, L. J., & Hure, A., J. (2014). Diet quality of Australian breast cancer survivors: a cross-sectional analysis from the Australian Longitudinal Study on Women's Health. *Journal of Human Nutrition and Dietetics*. doi:10.1111/jhn.12198
- Rabin, C. & Pinto, B. Cancer-related beliefs and health behavior change among cancer survivors and their first-degree relatives. (2006). *Psycho-Oncology*, *15*(8), 701 - 712.
- Rack, B., Andergassen, U., Neugebauer, J., Salmen, J., Hepp, P., Sommer, H., . . . Janni, W. (2010). The German SUCCESS C Study – the first European lifestyle study on breast cancer. *Breast Care*, *5*(6), 395-400. doi:10.1159/000322677
- Radina, E. M., Ginter, A. C., Brandt, J., Swaney, J., & Longo, D. R. (2011). Breast cancer patients' use of health information in decision making and coping. *Cancer Nursing*, *34*(5), E2 – E12. doi:10.1097/NCC.0b013e3181faab7c

- Renehan, A. G., Roberts, D. L., & Dive, C. (2008). Obesity and cancer: pathophysiological and biological mechanisms. *Archives of Physiology and Biochemistry*, *114*(1), 71-83.
doi:10.1080/13813450801954303
- Robinson, J., Darling, P., Brezden-Masley, C., & Scaffidi, D. (2008). Screening for malnutrition risk in cancer outpatients using an abridged PG-SGA. *Journal of the American Dietetic Association*, *108*(9, Supplement 1), A28-A28. doi:10.1016/j.jada.2008.06.372
- Rock, C. L., Doyle, C., Demark-Wahnefried, W., Mayerhardt, J., Courneya, K. S., Schwartz, A. L., ... Gansler, T. (2012). Nutrition and Physical Activity Guidelines for Cancer Survivors. *CA: A Cancer Journal for Clinicians*, *62*(4), 242-274. doi:10.3322/caac.21142
- Rock, C. L., Flatt, S. W., Laughlin, G. A., Gold, E. B., Thomson, C. A., Natarajan, L., ... Pierce, J. A. (2008). Reproductive steroid hormones and recurrence-free survival in women with a history of breast cancer. *Cancer Epidemiology, Biomarkers and Prevention*, *17*(3), 614-620. doi:10.1158/1055-9965.EPI-07-0761
- Rock, C.L., & Demark Wahnefried, W. (2002). Nutrition and survival after the diagnosis of breast cancer: a review of the evidence. *Journal of Clinical Oncology*, *20*(15), 3302-3316. doi:10.1200/JCO.2002.03.008
- Rooney, M., & Wald, A. (2012). Intervention for the management of weight and body composition changes in women with breast cancer. *Clinical Journal of Cancer Nursing*, *11*(1), 41-52. doi:10.1188/07.CJON.41-52
- Rootman, I., & Ronson, B. (2005). Literacy and health research in Canada: where have we been and where should we go? *Canadian Journal of Public Health*, *96*(2), S62-S77.

- Rose, A. A. N., Elser, C., Ennis, M., & Goodwin, P. J. (2013). Blood levels of vitamin D and early stage breast cancer prognosis: a systematic review and meta-analysis. *Breast Cancer Research and Treatment, 141*(3), 331-339.
- Schmitz, K. H., Courneya, K. S., Matthews, C., Demark-Whanefried, W., Galvão, D. A., Pinto, B. M., ... Schwartz, A. L. (2010). American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Medicine and Science in Sports and Exercise, 42*(7), 1409-1426. doi:10.1249/MSS.0b013e3181e0c112
- Sedjo, R. L., Byers, T., Ganz, P. A., Colditz, G. A., Demark-Wahnefried, W., Wolin, K. Y., Azrad, M., & Rock, C. L. (2014). Weight gain prior to entry into a weight-loss intervention study among overweight and obese breast cancer survivors. *Journal of Cancer Survivorship*. doi:10.1007/s11764-014-0351-9
- Sevean, P., Dampier, S., Spadoni, M., Strickland, S., & Pilatzke, S. (2009). Patients and families experiences with video telehealth in rural/remote communities in northern Canada. *Journal of Clinical Nursing, 18*(18), 2573-2579. doi:10.1111/j.1365-2702.2008.02427.x
- Shaha, M., Cox, C. L., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship, 40*(1), 60-67.
- Shu, X. O., Zheng, Y., Cai, H., Gu, K., Zheng, W., Lu, W. (2009). Soy food intake and breast cancer survival. *Journal of the American Medical Association, 302*(22), 2437-2443. doi:10.1001/jama.2009.1783
- Sigal, R. J., Armstrong, M. J., Colby, P., Kenny, G. P., Plotnikoff, R. C., Reichert, S. M., & Riddell, M. C. (2013). Canadian Diabetes Association 2013 Clinical Practice Guidelines

- for the Prevention and Management of Diabetes in Canada: physical activity and diabetes. *Canadian Journal of Diabetes*, 37(suppl. 1):S40-S45.
- Smith, S. L. Wei, E. S., Alexander, C., & Singh-Carlson, S. (2011). Caring for survivors of breast cancer: Perspective of the primary care physician. *Current Oncology*, 18(5), e218-e226. doi:10.1111/j.1365-2702.2008.02427.x
- Teras, L. R., Goodman, M., Patel, A. V., Diver, W. R., Flanders, W. D., & Spencer Feigelson, H. (2011). Weight loss and postmenopausal breast cancer in a prospective cohort of overweight and obese US women. *Cancer Causes and Control*, 22(4), 573-579. doi:10.1007/s10552-011-9730-y
- Thavarajah, N., Chen, E., Liang, Z., Bedard, G., Di Giovanni, J., Lemke, M., ...Chow, E. (2012). Symptom clusters in patients with metastatic cancer: a literature review. *Expert Review of Pharmacoeconomics & Outcomes Research*, 12(5), 597-604. doi:10.1586/ERP.12.41
- Thompson, L. U., Chen, J. M., Li, T., Strasser-Weippl, K., & Goss, P. E. (2005). Dietary flaxseed alters tumor biological markers in postmenopausal breast cancer. *Cancer Therapy: Clinical*, 11(10), 3828-3835. doi:10.1158/1078-0432.CCR-04-2326
- Trochim, W. M. K. & Donnelly, J. P. (2008). *The Research Methods Knowledge Base*. 3rd ed. Mason, OH: Cengage Learning
- Trotter, K., Frazier, A., Hendricks, C. K., & Scarsella, H. (2011). Innovation in survivor care: group visits. *Clinical Journal of Oncology Nursing*, 15(2), E24-E33.
- Vallance, J. K., Lavalley, C. M., Culos-Reed, N. S., & Trudeau, M. G. (2012a). Physical activity is associated with health-related quality of life among rural and small-town breast cancer survivors. *Supportive Care in Cancer*, 20(5), 1079-1087. doi:10.1007/s00520-011-1188-7

- Vallance, J. K., Lavalley, C. M., Culos-Reed, N. S., & Trudeau, M. G. (2012b). Rural and small town breast cancer survivors' preferences for physical activity. *International Journal of Behavioral Medicine, 20*(4), 522-528. doi:10.1007/s12529-012-9264-z
- Vallance, J. & Courneya, K. S. (2008). *Exercise for health: a guide for breast cancer survivors*. Retrieved from http://www.athabascau.ca/cnhs/faculty/publications/Vallance_Guide.pdf
- Winters-Stone, K. M., Dobek, J., Nail, L. M., Bennett, J. A., Leo, M. C., Torgrimson-Ojerio, B., Luoh, S. W., & Schwartz, A. (2013). Impact + resistance training improves bone health and body composition in prematurely menopausal breast cancer survivors: a randomized controlled trial. *Osteoporosis International, 24*(5), 1637-1646. doi:10.1007/s00198-012-2143-2
- Wongkongkul, T., Dechaprom, N., Phumivichuvate, L., & Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing, 29*(3), 250-258.
- Wonghongkul, T., Moore, S. M., Musil, C., Scheider, S., & Deimling, D. (2000). The influence of uncertainty in illness, stress appraisal, and hope on coping in survivors of breast cancer. *Cancer Nursing, 23*(6), 422-429.

Appendix B**Budget**

Item	Expense (\$)	Grant and Award Funds (\$)
Data Collection		
- Paper, envelopes, and printing costs of letter of initial contact, survey, and reminder letter.	450	2000
- Postage	1800	500
- FluidSurveys membership	236	
Dissemination		
- Conference registration	275	400
- Research poster printing	125	
Total	2889	2900

Appendix C

Letter of Initial Contact



LETTER OF INFORMATION

Dear Potential Research Participant,

This letter has been sent as an invitation for you to participate in a research study about what women who have had a diagnosis of breast cancer want to know about eating well, physical activity and body weight.

After your diagnosis, you automatically became part of the BC Cancer Agency's patient records. This information is only available to authorized BC Cancer Agency personnel for specified purposes. In keeping with provincial legislation your right to privacy and confidentiality is protected. This legislation allows BC Cancer Agency researchers to send you information about research opportunities. It is for this reason that you are being invited to participate in this research project.

This research study is part of an Athabasca University Master's thesis. The study aims to find out the current diet, physical activity, and body weight information sources and needs of breast cancer survivors not living in larger centres like Vancouver or Victoria. As well, this research project aims to find out what types of programs that support healthy lifestyle changes are available for women who have had a diagnosis of breast cancer.

Participation includes completing the survey included with this letter. Your involvement in this study is voluntary. No data that would identify you as having filled out the survey will be collected and you will never be identified by name. If the survey is completed, it will be assumed that consent has been given. Completed surveys will be kept in a locked office at a BC Cancer Agency site. Data entered into a computer for analysis will be password-protected. Only the study investigators listed below will be able to access the data. All data collected will be kept for a minimum of 5 years, as per the

Athabasca University and University of British Columbia BC Cancer Agency Research Ethics Board.

This study is supported by a Northern Cancer Control Strategy Discovery Seed Grant and Athabasca University.

In three weeks you will receive another letter to gently remind you to complete the survey if you were planning to but have not yet, or thank you for taking the time to complete it.

Please call 250-645-7300 ext. 687530 if you have any questions about this study, if you do not want to receive a reminder or thank you letter, or would like information about the study results.

Principal Investigator:

Lindsay Van der Meer, BSc. RD
Clinical Coordinator, Oncology Nutrition
BC Cancer Agency Centre for the North
Graduate Student, Health Studies Program
Athabasca University
250-645-7300 ext. 687530
Lindsay.vandermeer@bccancer.bc.ca

Co-Investigators:

Steven T. Johnson, PhD
Centre for Nursing and Health Studies
Faculty of Health Disciplines
for
Athabasca University

Ryna Levy-Milne, PhD, RD
Provincial Director of Clinical
Operations and Practice Leader
Oncology Nutrition
BC Cancer Agency

Appendix D

British Columbia Cancer Registry Information Sheet



BC Cancer Agency
CARE & RESEARCH
An agency of the Provincial Health Services Authority



British Columbia Cancer Registry



What is the purpose of the BC Cancer Registry?

The BC Cancer Registry collects data and generates cancer statistics on the BC population for the purpose of monitoring the burden of cancer in the province. It also serves as a source of information for research.

What information is in the BC Cancer Registry?

The BC Cancer Registry contains personal and demographic information as well as diagnostic and death information on all cases of cancer diagnosed to BC residents.

What is the authority of the BC Cancer Registry?

The BC Cancer Agency is authorized through the BC Health Act (Section 9) and the BC Cancer Agency Research Information Regulation to operate the Cancer Registry for cancer surveillance and research.

How does the BC Cancer Registry protect my privacy?

Confidentiality and security of personal information is protected by compliance with the BC Freedom of Information and Personal Privacy Act (FOIPPA).

Who can use information from the BC Cancer Registry for research?

Access to registry information for research is allowed only with approval by an accredited review board, only with BC Cancer Registry oversight and only under conditions of use that comply with BC Freedom of Information and Protection of Privacy Act (FOIPPA).

Who do I contact to get more information about the BC Cancer Registry?

Director of BC Cancer Registry

Phone: 604-675-8071 (reception)
E-mail: registrydirector@bccrc.ca
Toll Free: 1-888-675-8001 x 8071

Who do I contact to get more information about the study/survey?

Please direct all questions about the study/survey to the Study Coordinator listed the study invitation letter or consent form.

Appendix E**Cross-sectional Survey Part 1****Lifestyle Choices for Rural Breast Cancer Survivors: Current Information Sources and Needs****About This Study:**

This survey is being sent to women like yourself who have had a past diagnosis of breast cancer and live in a rural community. We want to find out what you want to know about eating well and physical activity. We also want to know about where you are currently looking for information on eating well and physical activity.

There are no right or wrong answers to any of these questions.

Please read the questions carefully and answer each one according to what is true for you.

Please answer each question the best that you can.

Please do not write your name on this survey.

If you have any questions as you complete this survey, please call the researcher at
250-645-7300 ext. 687530

How to Record Answers:

For each question, please check the box or circle the number that matches your answer. Please select only **one** answer.

Here is an example of a question answered by checking a box:

1. Do you do like eating vegetables?

- Yes
 No

Checking the “yes” box means that the above statement is true for you.

Here is an example of a question answered by circling a number:

250.	I like trying new recipes.				
1	2	3	④	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

Circling the number 4 means that you agree that you like trying new recipes.

Terms

In this survey, you will see some terms used often. Here is what is meant by these terms:

Eating well – selecting, preparing and eating a healthy diet

Nutrition – facts about the vitamins, minerals, and other things found in foods

Physical activity – movement that makes your heart beat faster and makes you breathe quicker compared to when you are sitting still.

Section 1
Please tell us about your interests

1. Since your diagnosis of breast cancer, do you think you have changed your **food choices**?

- Yes
- No

2. When it comes to **eating well** which of the following topics would you like to know more about? **Check all that apply to you.**

- Canada's Food Guide serving sizes
- Vegetarian eating
- Low-fat foods
- Eating on a budget
- Reading food labels
- Organic food
- Eating for weight loss
- Alcohol
- Keeping my bones healthy
- Heart healthy eating
- Eating patterns that may reduce risk recurrence and survival from breast cancer
- Other: please list

3. Would you like to make changes in your eating habits to improve your health?

- Yes
- No

If you selected **Yes**, please describe the changes you would like to make in the space below

4. When it comes to **nutrition**, what topics would you like to know more about?
Check all that apply to you.

- Fat intake
- Protein intake
- Carbohydrate intake
- Fibre
- Types of fat in my diet
- Cholesterol
- Trans fats
- Omega 3 fatty acids
- Plant estrogens (soy and flax)
- Vitamin and mineral needs
- Antioxidants
- Natural health products (vitamin, mineral, herbal and other supplements)
- Nutrients that may decrease risk of recurrence or survival from breast cancer
- Other: please list

5. For these next statements please describe what **makes it more difficult** for you to **eat well**? **Circle the best response that applies to you**

(a) Messages about what it means to eat well are confusing

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(b) Eating well takes more time than I have

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(c) Healthy foods cost too much money

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(d) Healthy foods are hard to find in my community

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

Other things that make it harder for you to eat well (please list):

6. For these next statements please describe what would **make it easier** for you to eat well? **Circle the best response that applies to you.**

(a) I need more information about what it means to eat well

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(b) I need to know how to make my favourite foods healthier

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(c) I need to know more about eating well at restaurants

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(d) I need to know how to plan healthy meals

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

Other things that make it easier for you to eat well (please list):

7. When you need information about **eating well**, **who** do you turn to for help? **Check all that apply to you.**

- Friends and family members
- Doctor
- Dietitian
- Pharmacist
- Nurse
- Naturopath
- Chiropractor
- Fitness instructor or personal trainer
- Weight loss centre staff
- Health food store staff
- Other: (please list)

8. When you need information about **eating well**, **where** do you turn? **Check all that apply to you.**

- Newspapers: Examples _____
- Magazines: Examples _____
- Books: Examples _____
- TV programs: Examples _____
- Internet websites: Examples _____
- Social Media (such as Facebook): Examples _____
- Radio station: Examples _____
- Scientific journals
- Booklets or brochures
- Other (please list)

9. How often do you feel that you can rely on information about **eating well** that you find in *newspapers and magazines*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

10. How often do you feel that you can rely on information about **eating well** that you find on the *Internet*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

11. How often do you feel that you can rely on information about **eating well** that you find in *books*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

12. Since your diagnosis of breast cancer, do you think you have changed your **physical activity habits**?

- Yes
- No

13. When it comes to **physical activity and breast cancer**, what topics would you like to know more about? **Check all that apply to you.**

- Safety of being physically active after breast cancer
- How activity may lower my risk of breast cancer recurrence or improve my survival from breast cancer
- Physical activity and symptoms of menopause
- Other (please list)

14. When it comes to **being physically active** what topics would you like to know more about? **Check all that apply to you.**

- Which activities are best for increasing my fitness level
- How intense do my activities need to be
- How much activity I need each day
- Sample exercise plans (with photos) that I could do at home
- Ways to make activity a regular part of my life
- How to increase activity without spending a lot of money
- Other (please list)

15. When it comes to **physical activity and your health**, what topics would you like to know more about? **Check all that apply to you.**

- How activity can help with weight loss
- How activity can help with heart disease or diabetes
- How activity can help with my bone health
- How activity can help my quality of life
- Other (please list)

16. Would you like to make changes in your physical **activity habits** to improve your health?

- Yes
- No

If you selected **Yes**, please describe the changes you would like to make in the space below

17. For these next statements please describe what things make it **more difficult** for you to be **physically active**? **Circle the best response that applies to you.**

(a) I am too tired from my cancer treatment to be active

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(b) Other health problems make it hard for me to be active

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(c) It costs too much money to join a fitness club or buy exercise equipment

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(d) The weather makes it difficult for me to be active where I live

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(e) There are no exercise programs or classes that I could join where I live

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

Other things that make it difficult for you to be physically active (please list):

18. For these next statements please describe what things would **make it easier** for you to be **physically active**? **Circle the best response that applies to you.**

(a) I need to know what types of activities are recommended for me

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(b) I need to know how I can be active in my home

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(c) I need to know how I can be active in the winter months

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

Other things that would make it easier for you to be physically active (please list):

19. When you want information about **physical activity**, **who** do you turn to for help? **Check all that apply to you.**

- Friends and family members
- Doctor
- Dietitian
- Pharmacist
- Nurse
- Naturopath
- Chiropractor
- Fitness instructor or personal trainer
- Weight loss centre staff
- Health food store staff
- Other: (please list)

20. When you want information about **physical activity**, **where** do you go? **Check all that apply to you.**

- Newspapers: Examples _____
- Magazines: Examples _____
- Books: Examples _____
- TV programs: Examples _____
- Internet websites: Examples _____
- Social Media: Examples _____
- Radio station: Examples _____
- Scientific journals
- Booklets or brochures
- Other (please list)

21. How often do you feel that you can rely on the information about **physical activity** that you find in *newspapers and magazines*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

22. How often do you feel that you can rely on the information about **physical activity** that you get from *fitness instructors or personal trainers*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

23. How often do you feel that you can rely on the information about **physical activity** that you find on the *Internet*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

24. Since your diagnosis of breast cancer, do you think your **body weight** has changed?

- Yes
- No

25. When it comes to your **body weight**, which topics would you like to know more about? **Check all that apply to you.**

- What a healthy body weight for me is
- Healthy ways to lose or gain weight
- Healthy body weights and menopause
- Safety of popular weight loss methods
- How my body weight affects my risk of recurrence or survival from breast cancer
- How body weight affects heart disease or diabetes
- How to stay motivated to eat well and lose weight
- How to prevent weight gain if I stop smoking
- Keeping a healthy body image
- Other (please list)

26. Do you use any of the following strategies to manage your **body weight**? **Check all that apply to you.**

- Eat smaller portion sizes
- Increase my physical activity
- Eat low-fat foods
- Count calories
- Limit high carbohydrate foods like bread, potatoes and pasta
- Go to formal weight loss program like Weight Watchers®
- Take weight loss supplements like green tea extract or chromium
- Cook more meals at home
- Other (please list)

27. Would you like to change your **body weight** to improve your health?

- Yes
- No

If you selected **Yes**, please describe the changes you would like to make in the space below

28. For these next statements please describe what you believe might make it difficult for women who have had a past breast cancer diagnosis to **manage their body weight**. **Circle the best response that applies to you**

(a) Fatigue from cancer treatment

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(b) Medication

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(c) Unhealthy eating

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(d) Not physically active

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(e) Mental health challenges (such as depression or anxiety)

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

(f) Increased body weight before diagnosis

1	2	3	4	5	6
strongly disagree	disagree	neutral	agree	strongly agree	don't know

Other things that might make it difficult for women who have had a past breast cancer diagnosis to manage their body weight (please list):

29. When you want information about **body weight**, who do you turn to? **Check all that apply to you.**

- Friends and family members
- Doctor
- Dietitian
- Pharmacist
- Nurse
- Naturopath
- Chiropractor
- Fitness instructor or personal trainer
- Weight loss centre staff
- Health food store staff
- Other: (please list)

30. When you want information about **body weight**, **where** do you turn? **Check all that apply to you.**

- Newspapers: Examples _____
- Magazines: Examples _____
- Books: Examples _____
- TV programs: Examples _____
- Internet websites: Examples _____
- Social Media: Examples _____
- Radio station: Examples _____
- Scientific journals
- Booklets or brochures
- Other (please list)

31. How often do you feel that you can rely on dieting and healthy **body weight** information that you find in *newspapers and magazines*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

32. How often do you feel that you can rely on dieting and healthy **body weight** information that you find on the *Internet*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

33. How often do you feel that you can rely on dieting and healthy **body weight** information that you get from *staff at weight loss centres*?

- Always
- Most of the time
- Sometimes
- Never
- Does not apply to me

Section 2

Program and Resource Preferences

In this section we want to know the types of programs or resources you may be interested in.

34. Which of the following **sources of information** concerning **eating well, physical activity and body weight** would you be interested in using? **Check all that apply to you.**

- Mailed newsletter
- Electronic (e-mail) newsletter
- Brochure or fact sheet
- Internet website
- Interactive Internet website where you could ask questions of health professionals
- List of Internet websites that provide accurate information
- List of books that provide accurate information
- Other (please list)

35. Which of the following **programs and services** concerning **eating well, physical activity and body weight** would you be interested in? **Check all that apply to you.**

- Cooking demonstrations
 - Grocery shopping workshops
 - A single workshop
 - A series of workshops
 - Related programs or services in my community
 - Discussion groups organized for patients
 - Individual counseling with a dietitian
 - Group counseling with a dietitian
 - Other (please list):
-
-
-
-

36. What **format would you prefer** for accessing any of the above programs and services? **Check all that apply to you.**

- In person
- Using videoconferencing (telehealth)
- Through an internet website
- Telephone

37. If you were to attend or participate in a program or service **what day of the week would be best** for you? **Check all days that apply to you.**

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday
- Sunday

38. If you were to attend or participate in a program or service, **what time of day would be best** for you? **Check all times that would work for you.**

- Early morning (before 9:00 am)
- Mid-morning (10:30 am)
- Afternoon

- Evening (after 6 pm)

Section 3
Please tell us a little bit about yourself

39. How confident are you filling out medical forms by yourself?

- Extremely
 Quite a bit
 Somewhat
 A little bit
 Not at all

40. How long have you lived in Northern British Columbia?

- Less than 5 years
 5 to 10 years
 More than 10 years
 All of my life

41. What language is most often spoken in your home?

42. How old are you?

- 19 to 29 years
 30 to 39 years
 40 to 49 years
 50 to 59 years
 60 to 69 years
 Over 70 years

43. Have you experienced menopause? That is, have your menstrual periods stopped for 12 months or more?

- Yes → at what age did your periods stop? _____
 No

44. What is your marital status?

- Married
 Common-law
 In a relationship
 Divorced

- Widowed
- Single

45. How would you describe where you live?

- In a community of more than 10,000 people
- In a community of between 5,000 and 10,000 people
- In a community of less than 5,000 people
- Out of town (>10 minutes driving to services)
- Out in the country (>30 minutes driving to services)

46. If you had surgery for your breast cancer, how long did it take to travel to the hospital where you had surgery?

- I did not have surgery
- < 15 minutes
- 15 to 30 minutes
- > 30 to 1 hour
- 1 to 2 hours
- > 2 hours
- I flew

47. If you had chemotherapy for your breast cancer, how long did it take to travel to the clinic where you had chemotherapy?

- I did not have chemotherapy
- < 15 minutes
- 15 to 30 minutes
- > 30 to 1 hour
- 1 to 2 hours
- > 2 hours
- I flew

48. If you had radiation for your breast cancer, how long did it take to travel to the clinic where you had radiation?

- I did not have radiation
- < 15 minutes
- 15 to 30 minutes
- > 30 to 1 hour
- 1 to 2 hours
- > 2 hours
- I flew

49. Altogether, what was the approximate annual income for your **household** last year? (Please include yourself and all other people who live in your home).

- Less than \$20,000
- \$21,000 to \$40,000
- \$41,000 to \$60,000
- \$61,000 to \$80,000
- \$81,000 to \$100,000
- More than \$100,000

50. What is the highest level of education you have attained? **Check the highest level**

- Some high school
- Finished high school
- Some university/college
- Finished university/college
- Some graduate school (such as master's or PhD)
- Finished graduate school

51. To which ethnic or cultural group do you belong? **Check all that apply to you.**

- Arab/West Asian (eg. Armenian, Iranian, Lebanese, Moroccan)
- Black (eg. African, Haitian, Jamaican, Somali)
- Chinese
- Filipino
- Japanese
- Korean
- First Nations
- Metis
- Inuit
- Latin-American
- Caucasian, European
- South Asian (eg. East Indian, Pakistani, Sri Lankan)
- South-Eastern Asian (eg. Indonesian, Loatian, Thai, Vietnamese)
- Other: (please list) _____

52. Has a doctor or nurse ever told you that you have/had the following:

- | | |
|------------------------|----------------------------------------------------------|
| Type 2 diabetes | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| High blood cholesterol | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Angina | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| High blood pressure | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Heart attack | <input type="checkbox"/> Yes <input type="checkbox"/> No |

Stroke Yes No
Arthritis Yes No
Chronic lung disease Yes No
Heart failure Yes No

Thank you for taking the time to complete this survey.

**Please check that you have not missed any pages or questions
and then send this questionnaire back to us in the prepaid
envelope provided.**

**Please call 250-645-7300 ext. 687530 if you have any questions about this
study, or if you would like information about the study results.**

Appendix F**Reminder/Thank You Letter: Cross-Sectional Survey Part 1**

You were recently mailed a survey on eating well, physical activity, and body weight information sources and needs.

Please take a moment to complete and return the survey. If you have any questions about the survey or your participation, please call 250-645-7300 ext. 687530.

If you have already returned the survey, your involvement is appreciated.

Thank you for your participation in this research.

Principal Investigator:

Lindsay Van der Meer, BSc. RD
Clinical Coordinator, Oncology Nutrition
BC Cancer Agency Centre for the North
Graduate Student, Health Studies Program
Athabasca University
250-645-7300 ext. 687530
Lindsay.vandermeer@bccancer.bc.ca

Co-Investigators:

Steven T. Johnson, PhD
Centre for Nursing and Health Studies
Faculty of Health Disciplines
for
Athabasca University

Ryna Levy-Milne, PhD, RD
Provincial Director of Clinical
Operations and Practice Leader
Oncology Nutrition
BC Cancer Agency

Appendix G

Cross-Sectional Survey for Part 2



Dear Potential Research Participant,

This email has been sent as an invitation for you to participate in a research study that aims to determine if there are programs available for rural breast cancer survivors that support healthy lifestyle changes. This research project is part of an Athabasca University Master's thesis.

Your email address was accessed through the BC Cancer Agency's communities oncology network (CON) publically available service listing, your participation in the BC Cancer Agency Oncology Nutrition Lunch and Learn email list, or your membership in either the Dietitians of Canada Oncology Network or Canadian Association of Nursing in Oncology.

Your involvement in this study is voluntary. Participation includes completing the online survey below, which should take no longer than 10-15 minutes. If the survey is completed, it will be assumed that consent has been given.

No data that would identify you as having completed the survey will be collected and you will never be identified by name. Data collected will be entered into a computer for analysis will be password-protected. Only the study investigators listed below will be able to access the data. All data collected will be kept for a minimum of 5 years, as per the Athabasca University and University of British Columbia BC Cancer Research Ethics Board.

To access the survey please click [HERE](#).

In three weeks you will receive another email to remind you to complete the survey if you were planning to but have not yet, or thank you for taking the time to complete it.

Please call 250-645-7300 ext. 687530 if you have any questions about this study, if you do not want to receive a reminder or thank you letter, or would like information about the study results.

Principal Investigator:

Lindsay Van der Meer, BSc. RD
Clinical Coordinator, Oncology Nutrition
BC Cancer Agency Centre for the North
Graduate Student, Health Studies Program
Athabasca University
250-645-7300 ext. 687530
Lindsay.vandermeer@bccancer.bc.ca

Co-Investigators:

Steven Johnson PhD
Centre for Nursing and Health Studies
Operations &
Faculty of Health Disciplines
Nutrition
Athabasca University

Ryna Levy-Milne, PhD, RD
Provincial Director of Clinical
Practice Leader for Oncology
BC Cancer Agency

Appendix H

Cross-Sectional Survey for Part 2

Introductory Questions:

1) What is your role:

Response options: Registered Dietitian, Registered Nurse, Other

Please list: _____

2) Among the cancer patients you care for, please estimate what proportion live in a rural setting (that is, they live in a community of less than 20,000 people, out of town (>10, minutes driving to services), or out in the country (>30 minutes driving to services)?

Response options: none, 25%, 50%, 75%, 100%

3) What province do you provide care to cancer patients in?

Response options: Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland, Northwest Territory, Nova Scotia, Nunavut, Ontario, Prince Edward Island, Quebec, Saskatchewan, Yukon Territory

Additional response options for British Columbia – which health authority is your clinic in: Northern Health, Fraser Health, Vancouver Coastal Health, Vancouver Island Health, Interior Health

The following definitions will explain what is meant by terms used in the survey.

Breast cancer survivor – any woman who has been diagnosed with breast cancer (from diagnosis onward)

Rural – in a community of less than 20,000 people, out of town (>10, minutes driving to services), or out in the country (>30 minutes driving to services).

Overweight or obese body weight status – Body Mass Index (BMI) of 25 – 29.9 kg/m² (overweight) and \geq 30 kg/m² (obese)

Healthy body weight – BMI of 18.5 – 24.9 kg/m²

Diet – eating and drinking patterns over time

Physical activity – Movement that increases heart rate and breathing

Lifestyle changes – changes in diet, body weight, or physical activity levels

Knowledge and Attitudes

Do you agree with the following statements?

- a) Weight gain is common after a breast cancer diagnosis
YES/NO/UNSURE
- b) Achieving and maintaining a healthy body weight is important for breast cancer survivors
YES/NO/UNSURE
- c) I believe all breast cancer survivors should have access to weight management counselling
YES/NO/UNSURE
- d) Healthy eating recommendations (such as Canada's Food Guide) apply to breast cancer survivors
YES/NO/UNSURE
- e) Soy foods (such as tofu, soy milk and edemame beans) are safe for breast cancer survivors to consume
YES/NO/UNSURE

- f) I believe all breast cancer survivors should have access to health professionals who can help to determine if information they seek or receive on diet and breast cancer is accurate
YES/NO/UNSURE
- g) Physical activity can reduce cancer-related fatigue
YES/NO/UNSURE
- h) It is safe for breast cancer survivors to be physically active during treatment
YES/NO/UNSURE
- i) I believe breast cancer survivors should have access to health professionals with knowledge of the physical activity needs and challenges for breast cancer survivors
YES/NO/UNSURE

Provision of Information/Awareness of Programs

- 1) Do you field questions from breast cancer survivors on body weight?
YES/NO/UNSURE

250) Do you refer breast cancer survivors with questions on body weight to other health professionals? YES/NO/UNSURE, If YES, health professionals: _____

250) Do you refer breast cancer survivors with questions on body weight to programs or services within your community? YES/NO/UNSURE, if YES, programs or services within your community _____

- a. How is this service or program delivered? (1:1, group, telephone, internet, telehealth, unsure, other: _____)
- b. How is this service or program funded? (publically through health authority, privately, unsure, other: _____)
- c. How is this service or program accessed? (physician referral, health care professional referral, self-referral, unsure, other: _____).

250) Do you field questions from breast cancer survivors on diet?
YES/NO/UNSURE

- 5) Do you refer breast cancer survivors with questions on diet to other health professionals?

YES/NO/UNSURE, if YES, health professionals: _____

- 250) Do you refer BCS with questions on diet to programs or services within your community?

YES/NO/UNSURE, if YES, programs or services within your community _____)

a. How is this service or program delivered? 1:1, group, telephone, internet, telehealth (videoconferencing), unsure, other: _____

b. How is this service or program funded? Publically through a health authority, privately, unsure, other: _____

c. How is this service or program accessed? Physician referral, health care professional referral, self-referral, unsure, other: _____

BC Specific Questions (only ask to those who select BC)

- 250) Are you aware of the Nutrition Guide for Women with Breast Cancer?

- 8) Do breast cancer survivors in your clinic receive a copy of the Nutrition Guide for Women with Breast Cancer?

Non BC Specific Question (for all respondents that do not select BC)

Do you provide any written materials to breast cancer survivors on diet?

- 9) Do you field questions from breast cancer survivors on physical activity?

- 10) Do you provide breast cancer survivors with any general guidelines around physical activity, such as Canada's Physical Activity Guidelines?

YES/NO/UNSURE, if YES, guidelines: _____

- 11) Do you refer breast cancer survivors with questions on physical activity to other health professionals?

YES/NO/UNSURE, if YES, health care providers : _____

- 12) Do you refer breast cancer survivors with questions on physical activity to programs or services within your community?

YES/NO/UNSURE, if YES, programs or services within your community: _____

- a. How is this service or program delivered? 1:1, group, telephone, internet, telehealth (videoconferencing), unsure, other: _____
- b. How is this service or program funded? Publically through a health authority, privately, unsure, other: _____
- c. How is this service or program accessed? Physician referral, health care professional referral, self-referral, unsure, other: _____

13) Are you aware of any programs in your community specifically for breast cancer survivors who are interested in making lifestyle changes?

YES/NO/UNSURE, if YES, programs or services within your community: _____

- a. How is this service or program delivered? 1:1, group, telephone, internet, telehealth (videoconferencing), unsure, other: _____
- b. How is this service or program funded? Publically through a health authority, privately, unsure, other: _____
- c. How is this service or program accessed? Physician referral, health care professional referral, self-referral, unsure, other: _____

14) Do you think that breast cancer survivors in your clinic have access to the information and support they need to make lifestyle changes?

YES/NO/UNSURE

Appendix I**Reminder/Thank You Email: Cross-Sectional Survey Part 2**

You were recently e-mailed a link to a survey on information about body weight, diet and physical activity recommendations and resources for rural breast cancer survivors.

If you have not already done so, please take a moment to complete the survey. If you have any questions about the survey or your participation, please call 250-645-7300 ext. 687530.

If you have already completed the survey, your involvement is appreciated.

Thank you for your participation in this research.

Principal Investigator:

Lindsay Van der Meer, BSc. RD
Clinical Coordinator, Oncology Nutrition
BC Cancer Agency Centre for the North
Graduate Student, Health Studies Program
Athabasca University
250-645-7300 ext. 687530
Lindsay.vandermeer@bccancer.bc.ca

Co-Investigators:

Steven T. Johnson, PhD
Centre for Nursing and Health Studies
Faculty of Health Disciplines
Athabasca University

Ryna Levy-Milne, PhD, RD
Provincial Director of Clinical
Operations and Practice Leader for
Oncology Nutrition
BC Cancer Agency

Appendix J**Athabasca University Research Ethics Board Approval****MEMORANDUM**

DATE: March 14, 2013
TO: Lindsay Van der Meer
COPY: Steve Johnson, Supervisor
Dr. Simon Nuttgens, Chair, Athabasca University Research Ethics Board
Janice Green, Secretary, Research Ethics Board
Eileen Paluck, Ass't to Dean, CNHS

FROM: Dr. Sharon Moore, Chair CNHS Research Ethics Review Committee

SUBJECT: **Ethics Application CNHS-12-08: An Examination of Body Weight, Diet, and Physical Activity Information Needs to Inform Service Provision for Rural Breast Cancer Survivors in Northern British Columbia: A Cross-Sectional Study**

Thank you for your revised application submitted on March 7, 2013 (and the BCCA REB Approval submitted March 12, 2013) arising from the "Conditional Approval" decision dated January 5, 2013. Your cooperation in revising and furnishing additional information requested is greatly appreciated.

I am pleased to advise that this project has been awarded **APPROVAL TO PROCEED**. **You may begin your research immediately.**

This approval of your application will be reported to the Athabasca University Research Ethics Board (REB) at their next monthly meeting. The REB retains the right to request further information, or to revoke the approval, at any time.

The approval for the study "as presented" is valid for a period of one year from the date of this memo. If required, an extension must be sought in writing prior to the expiry of the existing approval. **A Final Report is to be submitted when the research project is completed.** The reporting form can be found online at <http://www.athabascau.ca/research/ethics/>.

As implementation of the proposal progresses, if you need to make any significant changes or modifications, please immediately forward this information along with an e-mail of support from your research supervisor for the changes, to the CNHS Research Ethics Review Committee via rebsec@athabascau.ca for further review.

If you have any questions, please do not hesitate to contact the Committee Chair (Sharon Moore), or the Research Ethics Administrator at rebsec@athabascau.ca

Athabasca University Research Ethics Board

University Research Services, Research Centre
1 University Drive, Athabasca, AB, Canada T9S 3A3
e-mail: janiceg@athabascau.ca

Appendix K

University of British Columbia BC Cancer Agency Research Ethics Board Approval



University of British Columbia - British Columbia Cancer
Agency Research Ethics Board (UBC BCCA REB)

UBC BCCA Research Ethics Board
Fairmont Medical Building
750 West Broadway, Suite 902
Vancouver, BC V5Z 1H5
Tel: (604) 877-6284 Fax: (604) 708-2132
E-mail: reb@bccancer.bc.ca
Website: <http://www.bccancer.bc.ca> >
Research Ethics
RISe: <http://rise.ubc.ca>

Certificate of Expedited Approval

PRINCIPAL INVESTIGATOR: Lindsay Van der Meer	INSTITUTION / DEPARTMENT: Oncology Nutrition (BCCA)	REB NUMBER: H12-03144
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution		Site
BC Cancer Agency		Prince George BCCA
Other locations where the research will be conducted: Surveys will be completed in participants' homes (Part 1) or in professional offices (Part 2).		
PRINCIPAL INVESTIGATOR FOR EACH ADDITIONAL PARTICIPATING BCCA CENTRE:		
Vancouver:	N/A	Vancouver Island: N/A
Fraser Valley:	N/A	Southern Interior: N/A
Abbotsford Centre:	N/A	Centre for the North: Lindsay Van der Meer
SPONSORING AGENCIES AND COORDINATING GROUPS: Northern Cancer Control Strategy - "Assessing Nutrition Information Needs for Rural Women with Breast Cancer"		
PROJECT TITLE: An examination of body weight, diet, and physical activity information needs to inform service provision for rural breast cancer survivors in Northern British Columbia: A cross-sectional study		

The UBC BCCA Research Ethics Board Chair, Vice-Chair or second Vice-Chair, has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants approval.

This approval applies to research ethics issues only. The approval does not obligate an institution or any of its departments to proceed with activation of the study. The Principal Investigator for the study is responsible for identifying and ensuring that resource impacts from this study on any institution are properly negotiated, and that other institutional policies are followed. The REB assumes that investigators and the coordinating office of all trials continuously review new information for findings that indicate a change should be made to the protocol, consent documents or conduct of the trial and that such changes will be brought to the attention of the REB in a timely manner.

EXPIRY DATE OF THIS APPROVAL: March 12, 2014

DATE DOCUMENT(S) APPROVED: March 12, 2013

LIST OF DOCUMENTS APPROVED:

Document Name	Version	Date
Protocol: Proposal	N/A	December 11, 2012
Questionnaire, Questionnaire Cover Letter, Tests:		

Part 1 Cross Sectional Survey	N/A	December 11, 2012
Part 2 Cross Sectional Survey	N/A	December 11, 2012
Letter of Initial Contact:		
Part 2 Email Invitation	N/A	March 5, 2013
Part 1 Letter of Information	N/A	March 5, 2013
Other Documents:		
DC Oncology Network Support	N/A	December 11, 2012
CANO Letter of Support	N/A	March 4, 2013
BC Cancer Registry Letter of Support	N/A	March 5, 2013
Part 1 Reminder Thank You Letter	N/A	March 5, 2013
null	N/A	December 31, 1969
Confirmation of Oral Proposal Exam	N/A	December 11, 2012
Part 2 Reminder Thank You Email	N/A	March 5, 2013
BCCA Oncology Nutrition Letter of Support	N/A	December 12, 2012
CERTIFICATION:		
<ol style="list-style-type: none"> 1. The membership of the UBC BCCA REB complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations of Canada. 2. The UBC BCCA REB carries out its functions in a manner fully consistent with Good Clinical Practices. 3. The UBC BCCA REB has reviewed and approved the research project named on this Certificate of Approval including any associated consent form and taken the action noted above. This research project is to be conducted by the provincial investigator named above. This review and the associated minutes of the UBC BCCA REB have been documented electronically and in writing. 		
<p>UBC BCCA Ethics Board approval or acknowledgement of the above has been provided by either the full board or where expedited approval is applicable, an authorized delegated reviewer.</p> <p>Electronic verification of appropriate authorization is maintained within a UBC secure encrypted web based system. UBC BCCA REB membership list is available at: http://www.bccancer.bc.ca/RES/REB/members/default.htm If you have any questions, please contact the UBC BCCA REB Administration Tel: (604) 877-6284 Fax: (604) 708-2132 E-mail: reb@bccancer.bc.ca</p>		

Appendix L

Table 3

Table 3

Characteristics of Body Weight Programming for Breast Cancer Survivors Reported by Cancer Care Providers (N = 39)

Characteristic	n (%)
Program elements	
Tailored lifestyle/behavioral counselling	17 (43.6)
Assessment of participant readiness for change pre/post	15 (38.5)
Focused outcome (weight loss or BMI goal)	12 (30.8)
Pre/post measurements (waist circumference, % body fat, body weight)	7 (17.9)
Other ^a	15 (38.5)
Format	
Group	23 (59.0)
Face-to-face	22 (56.4)
Telephone	9 (23.1)
Internet	3 (7.7)
Telehealth/Videolink	0 (0.0)
Unsure	4 (10.3)
Funding	
Publically through health authority	19 (48.7)
Private	8 (20.5)
Unsure	8 (20.5)
Other	3 (7.7)
Access	
Self-referral	25 (64.1)
Health care professional referral	20 (51.3)
Physician referral	12 (30.8)
Unsure	4 (10.3)
Evaluation	
No	6 (15.8)
Yes	4 (10.5)
Unsure	28 (73.7)

^aOf those who provided comments for the *Other* option ($n = 11$), descriptions included the presence of a physical activity component (5), diet program/intervention (4), combined physical activity and diet program (1), and that the program was unstructured (1).

Appendix M

Table 4

Table 4

Characteristics of Programming on Diet for Breast Cancer Survivors Reported by Cancer Care Providers (N = 29)

Characteristic	n (%)
Program elements	
Emphasize healthy eating vs. dieting	22 (75.9)
Tailored lifestyle/behavioral counselling	13 (44.8)
Assessment of participant readiness for change pre/post	10 (34.5)
Target specific nutrients (e.g. < 20% of calories from fat)	9 (31.0)
Detailed diet histories/records	5 (17.2)
Other	7 (24.1)
Format	
Face-to-face	18 (62.1)
Group	13 (44.8)
Telehealth/Videolink	5 (17.2)
Internet	3 (10.3)
Telephone	0 (0.0)
Unsure	2 (6.9)
Funding	
Publically through health authority	17 (58.6)
Private	3 (10.3)
Unsure	5 (17.2)
Other	3 (10.3)
Access	
Self-referral	20 (69.0)
Health care professional referral	18 (62.1)
Physician referral	10 (34.5)
Unsure	4 (13.8)
Evaluation *	
No	2 (6.9)
Yes	2 (6.9)
Unsure	24 (82.8)

* Missing data (n = 1)

Appendix N

Table 5

Table 5

Characteristics of Physical Activity Programming for Breast Cancer Survivors Reported by Cancer Care Providers (N = 31)

Characteristic	n (%)
Program elements	
Promote moderate intensity activities (walking) for at least 150 min/week	14 (45.2)
Tailored lifestyle/behavioral counselling	10 (32.3)
Incorporation of resistance exercise	9 (29.0)
Assessment of participant readiness for change pre/post	6 (29.0)
Detailed activity histories/records	5 (16.1)
Other	3 (9.7)
Format	
Group	19 (61.3)
Face-to-face	13 (41.9)
Telehealth/Videolink	0 (0.0)
Internet	0 (0.0)
Telephone	0 (0.0)
Unsure	5 (16.1)
Other	1 (3.2)
Funding	
Publically through health authority	12 (38.7)
Private	10 (32.3)
Unsure	4 (12.9)
Other	4 (12.9)
Access	
Self-referral	24 (77.4)
Physician referral	9 (29.0)
Health care professional referral	7 (22.6)
Unsure	2 (6.5)
Evaluation	
No	5 (16.1)
Yes	2 (7.4)
Unsure	20 (74.1)

Appendix O

Table 6

Table 6

Characteristics of Lifestyle Programming for Breast Cancer Survivors Reported by Cancer Care Providers (N = 23)

Characteristic	n (%)
Program elements	
Tailored lifestyle/behavioral counselling	12 (52.2)
Combined diet and exercise intervention	11 (47.8)
Focused physical activity outcome (e.g., moderate intensity activities)	10 (43.5)
Assessment of participant readiness for change pre/post	10 (43.5)
Focused body weight outcome (e.g., weight loss or BMI range goal)	6 (26.1)
Pre/post measurement	3 (13.0)
Other	3 (13.0)
Format	
Group	18 (78.3)
Face-to-face	7 (30.4)
Telehealth/Videolink	0 (0.0)
Internet	2 (8.7)
Telephone	0 (0.0)
Unsure	1 (4.3)
Other	0 (0.0)
Funding	
Publically through health authority	8 (34.8)
Private	7 (30.4)
Unsure	6 (26.1)
Other	2 (8.7)
Access	
Self-referral	16 (69.6)
Health care professional referral	9 (39.1)
Physician referral	7 (30.4)
Unsure	2 (8.7)
Evaluation	
Yes	4 (17.4)
No	1 (4.3)
Unsure	15 (65.2)