

A Mixed Method Study of Second Cancer Risk Among Cancer Survivors

by

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ABSTRACT

Recent research shows that cancer survivors are at greater risk of developing cancer than the general population. Knowledge of the magnitude of second cancer risk and cancer-specific deaths among cancer survivors, factors that influence their second cancer risk, cancer survivors' perceptions of second cancer risk and current practices and existing gaps in follow-up care is urgently needed if we hope to prepare survivors and their healthcare providers as to how best to monitor their long-term health. An exploratory mixed method study, guided by Kaplan and colleagues (2000) multilevel approach to the health determinants, was conducted to provide a detailed understanding of second cancer risks among cancer survivors. Data collection methods included: (1) qualitative survey of current practices in the follow-up care offered for cancer survivors across Canada, (2) population-based health databases (cancer registry and health insurance databases), and (3) qualitative interviews on cancer survivors' perceptions of second cancer risks.

Coordinated follow-up services are not universally available across Canada. Yet, cancer survivors have a 4-7-fold increased risk of developing cancer compared to the general population in Nova Scotia and Manitoba. Second cancer risks varied by demographic and disease-related factors such as age at first cancer diagnosis, cancer type, treatment era, and time since diagnosis. Second cancer risk does not exist only as an epidemiological calculation. Second cancer risk, from the perspective of cancer survivors, is shaped by more intuitive conceptual models than statistical models of risk. The theme, *Life After Cancer – Living with Risk*, described survivors' sense that second cancer risk is now a part of their everyday lives.

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CHAPTER ONE: INTRODUCTION

Introduction

Advances in cancer care have transformed the outlook for patients with this disease. Whereas survival from cancer was the exception 40 years ago, the 5-year relative survival for adults and children has steadily risen to 75% and 82%, respectively (Canadian Cancer Society's Steering Committee, 2009). Moreover, it is estimated that 1/640 individuals between the ages of 20 and 39 years is a cancer survivor (Davies, 2007).

Despite these encouraging statistics, progress in survival has come at a cost. Many cancer survivors encounter significant health problems caused by cancer treatment that increase as they age (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). One of the most devastating late effects is the development of a second cancer (Ng et al., 2010). Recent cohort studies show that there is an increased risk of cancer observed in cancer survivors relative to the general population (e.g., Inskip & Curtis, 2007). After recurrence, second cancers represent one of the leading causes of death in cancer survivors (Mertens, 2007), and result in modest yet lasting quality of life deficits in second cancer survivors (Gotay, Random & Pagano, 2007).

While cancer treatments, including high-dose radiation and certain chemotherapies, are recognized as major determinants of second cancers, further research is needed to determine what other factors may influence the occurrence of a second cancer. Also warranted is studying how cancer survivors define second cancer risk and what they do to manage that risk, including the types of decisions they make with respect to follow-up care and cancer screening. The concern is with understanding cancer survivors' knowledge of their second cancer risk so as to determine the best way to help cancer

survivors modify their risk. Identifying cancer survivors' perceptions of second cancer risks is crucial to arriving at a more comprehensive picture of why survivors are at an increased risk of developing cancer compared to the general population.

Improved survival challenges healthcare providers to provide vigilant follow-up care that will promote cancer survivors' health and reduce the burden of second cancers. Coordinated follow-up services are not, however, universally available across Canada (Guilcher, Fitzgerald & Pritchard, 2009; Shaw et al., 2006). Because individual cancer centers implement local policies on follow-up care, not all cancer survivors are offered or attend routine follow-up (Castellino et al., 2005; Nathan et al., 2009). Comprehensive, evidence-based policies for the longitudinal care of survivors are needed so that there will be consistency across the country as to what long-term follow-up care is needed, who delivers it, where, how and how often.

Significance of the Problem

Knowledge of the magnitude of cancer risk among cancer survivors, factors that influence their second cancer risk, survivors' risk perceptions and current practices and existing gaps in follow-up care is urgently needed if we hope to prepare survivors and their healthcare providers as to how best to monitor their long-term health. As Smith and Hare note (2004), the time is ripe to study the fate of cancer survivors. For the growing number of cancer survivors due to improved outcomes and greater life expectancy, there is a need for detailed information about long-term effects demand research attention, particularly from a Canadian perspective.

Studying second cancer risk in cancer survivors underscores the need for a philosophical shift in cancer treatment that looks beyond treatment, reflecting the

importance of both curing the disease and controlling late effects. In order to develop Canadian-specific policies on long-term follow-up care for cancer survivors, it is necessary to better describe and understand the magnitude of risk and predisposing features of second cancers as well as survivors' perspectives on and encounters of risk. Incorporating both quantitative and qualitative components in its design, this comprehensive study may result in foundational knowledge about the nature of second cancer risk that may be used to develop and refine standards for survivorship care including how second cancer risk can be best managed. The knowledge gleaned from this study may help guide and support the work of health professionals, and may ultimately improve the health of cancer survivors.

Purpose of the Study

An exploratory mixed method study was conducted to provide a detailed understanding of second cancer risks among cancer survivors. Population-based epidemiological data were gathered to estimate the magnitude of second cancer risk among cancer survivors relative to the general population at risk. Qualitative data helped to reveal the intricate details of the complex phenomena of second cancer risk and risk assessment that cannot be easily conveyed through quantitative research. New insights, meaningful descriptions, and theoretical relationships about how cancer survivors define second cancer risks and what they do to manage those risks, as well as current practices and existing gaps in follow-up care emerged from the study.

Research Questions

The research questions for this mixed method study are:

1. What are the current practices and existing gaps in follow-up cancer care for cancer

survivors across Canada?

2. In Nova Scotia and Manitoba, what is the risk of developing a second cancer among cancer survivors compared to the general population stratified by age-, sex- and calendar year-adjusted risk estimates?
3. In Nova Scotia and Manitoba, what demographic and disease risk factors are associated with second cancer risk among cancer survivors?
4. What are cancer survivors' understandings of second cancer risk?
5. How do cancer survivors attempt to modify second cancer risk?

Assumptions

Assumptions for this research study are grounded in the beliefs stemming from what Johnson, Onwuegbuzie and Turner (2007) call “pragmatism of the middle”. The assumptions of “pragmatism of the middle” include: (1) knowledge comes from person-environment interactions, (2) knowledge is both constructed and empirically tested, (3) multiple perspectives about phenomena can be true, (4) there are multiple routes to knowledge, and (5) there is no unvarying, eternal truths, just “warranted assertions” (Johnson & Onwuegbuzie, 2004).

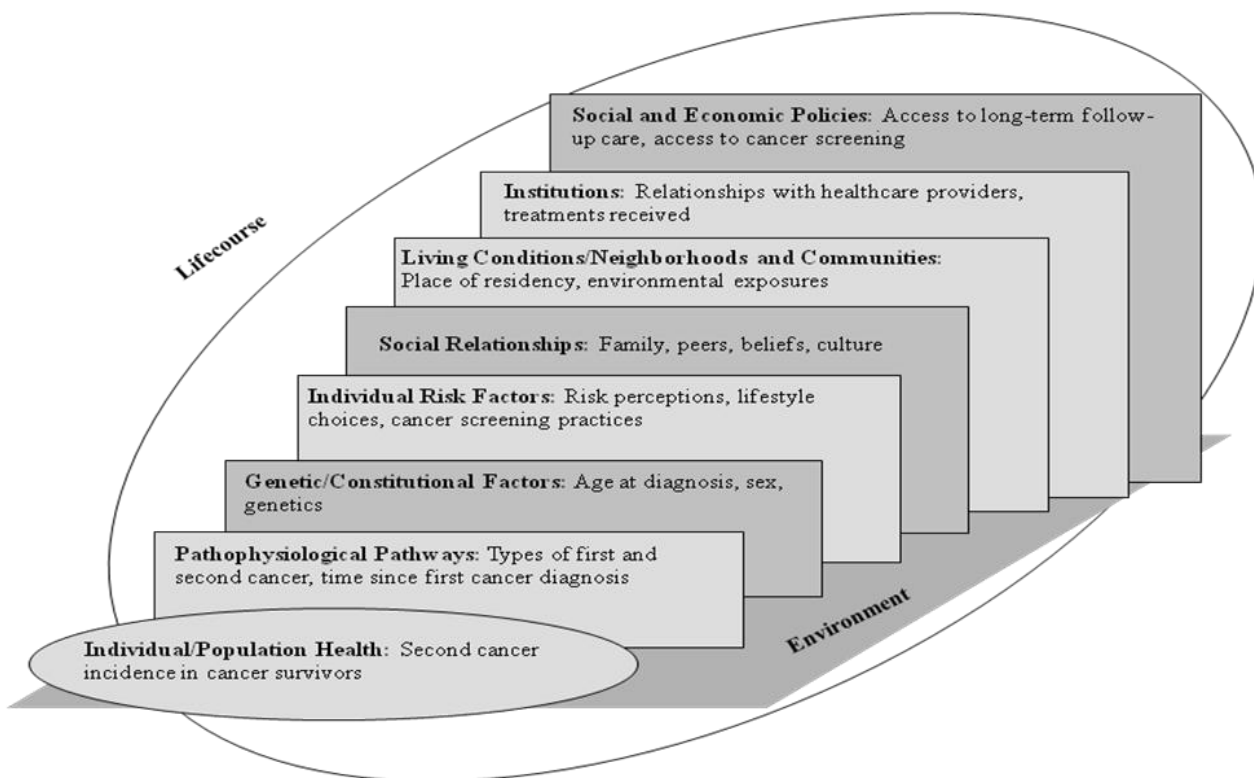
Guiding Conceptual Framework

Mixed methods studies may use a theoretical lens or perspective to guide the study (Creswell, 2003). This study was guided by Kaplan and colleague's (2000) multilevel approach to the health determinants, which emphasizes the linkages and interactions among multiple factors affecting health and unfolding over the lifecourse of individuals, families, and communities. Bridging the biological and the social, this social ecological framework informed the study during the data collection and analysis stages of the study.

Using this model as the guiding framework for this study allowed for the simultaneous incorporation of downstream and upstream variables that may contribute to the risk of developing a second cancer among cancer survivors across the lifecourse (see diagram in Figure 1). Important to understanding variations in second cancer risks are pathophysiological pathways (types of first and second cancer, time since diagnosis), genetic/constitutional factors (age at diagnosis, sex, genetics), individual risk factors (cancer screening practices, risk perceptions, lifestyle choices), social relationships (family, peers, beliefs, culture), living conditions/neighborhoods and communities (place of residency) and institutions (relationships with health care providers, treatment received). Understanding the etiology of second cancers within and across the cancer survivor population also requires an upstream approach which draws attention beyond individual behaviors to the political economy of second cancer risk factors, including access to long-term follow-up care and cancer screening. Embracing a model that includes multiple determinants of health that are linked in many ways, healthcare providers can develop, implement and evaluate the effectiveness of interventions designed to reduce the burden of second cancers among cancer survivors.

Figure 1

Guiding Conceptual Framework: Upstream and Downstream Determinants of Second Cancer Risk Among Cancer Survivors



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Definitions of Key Research Variables

Childhood Cancer Survivor

All individuals with a cancer notified to the Manitoba or Nova Scotia cancer registries before the age of 19 years and more than 5 years ago.

Adulthood Cancer Survivor

All individuals with a cancer notified to the Manitoba or Nova Scotia cancer registries at 19 years of age or older and more than 5 years ago.

Second Cancer

Defined per the International Classification of Diseases for Oncology, second cancers are a (1) a neoplasm in a new location that has not spread or is not a metastasis of the primary cancer, or (2) a neoplasm on the same location of the primary cancer but of different histology (Fritz et al., 2000). Consequently, pre-malignant and benign tumors were not considered second cancers. Cancers diagnosed in the six months immediately after the original diagnosis were not considered second cancers. The minimum interval of six months between the first and second cancer was chosen to exclude second cancers that occur at the same time or very soon after the first, as well as allow for sufficient time for treatment to contribute to the pathogenesis of a second cancer.

Risk

In order to provide direction in the research process, risk was referred to as the “possibility that human actions or events lead to consequences that affect aspects of what humans value” (Renn, 1998, p. 51). However, because one of the research questions was to arrive at an understanding of how cancer survivors define risk and because “risk” is a concept that continues to evolve, this definition was recognized as only one way to define

risk and others emerged from this research.

Chapter Summary

Chapter one provided an overview of the cancer survivorship and the rationale for further research on second cancer risk. With more Canadians surviving cancer, it is reasonable to predict that second cancer risk will become increasingly relevant if we hope to prepare cancer survivors as to how best to monitor their long-term health. Nurses who have a comprehensive understanding of cancer survivors' second cancer risk may be better able to promote positive health outcomes. The next chapter will present a critical review of the literature on second cancer risk among cancer survivors.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter reviews the literature to establish a background that might be useful against which to examine second cancer risk among cancer survivors. The six areas in this review are: (1) cancer survivorship, (2) descriptive epidemiology of second cancers among cancer survivors, (3) risk factors associated with second cancer development, (4) descriptive epidemiology of second cancer mortality among cancer survivors, (5) risk factors associated with second cancer mortality, and (6) what cancer survivors do to manage their risks and what influences their response. By way of conclusion, the discussion turns to a critical assessment of the many studies presented in this review.

Cancer Survivorship

The transformation of cancer from an almost uniformly fatal disease that is now curable in many individuals is one of the greatest success stories of modern medicine. Advances in cancer research and treatment have resulted in the number of Canadians surviving cancer, with relative survival rates rising 4.5 % for all cancers from 1992-1994 to 2000-2004 (Canadian Cancer Society's Steering Committee, 2009).

Although cancer survivorship research appeared before 1985, it is the work of Mullan (1985) that moved cancer care beyond the diagnostic and treatment needs of people diagnosed with cancer to the needs of people who survive the disease. In his seminal work, Mullan (1985) described the "seasons of survival" as three distinct phases - acute, extended and permanent. The acute includes the diagnostic and treatment efforts. Extended survival begins when treatment has completed or remission achieved, and includes recovery and rehabilitation. The final phase, permanent survival, is often called

“cure” although being cancer-free does not mean being free from the effects of cancer or its treatment. What is clear from the cancer survivorship literature is that cancer survivorship is a “lifelong process of adaptation and change” (Naus, Isher, Parrott & Kovacs, 2009). Both positive and negative outcomes may occur as cancer survivors integrate the cancer experience into their evolving goals, meaning and personal identity.

Extending survivors’ lifespan has come at the cost of health problems that occur when they are considered otherwise “cured” of their cancer. Many report having poorer health, lower quality of life and greater lost productivity compared to the general population (Yarbroff, Lawrence, Clauder, Davis & Brown, 2004). Cancer survivors are at risk for late effects of cancer and its treatment that affect growth and development including cognitive deficits, vital organ dysfunction, fertility and reproduction problems, and second cancers (Ganz, 2009; Oeffinger, Hudson & Landier, 2009). Compared to siblings, cancer survivors have 3.3-fold increased risk of chronic health problems and 8.2-fold increased risk of life-threatening health conditions (Meadows et al., 2009; Oeffinger et al., 2006). Cancer survivors with the poorest health typically are those who have had central nervous system or bone tumors, and those with cognitive impairment as a result of their cancer or its treatment (Pogany et al., 2006; Reulen et al., 2007).

Predicting exactly what health problems cancer survivors will encounter is difficult because the type of cancer, treatment intensity and the survivor’s age can all influence the outcome. It is anticipated that these chronic conditions will become more apparent with time because some cancer survivors, particularly survivors of childhood cancer, have not yet reached the age when the risk of chronic health conditions begins to increase in the general population (Meadows et al., 2009; Oeffinger et al., 2006).

Among the potential late effects of cancer and its treatment, the diagnosis of a second cancer is one of the most devastating for cancer survivors. Second cancers are serious events because they predispose cancer survivors to morbidity and early mortality through their effects on general health, quality of life, and long-term survival (Gantz, 2009; Oeffinger, Hudson & Landier, 2009).

Descriptive Epidemiology of Second Cancers among Cancer Survivors

In Canada, it is expected that 40% of women and 45% of men will develop cancer during their lifetimes (Canadian Cancer Society's Steering Committee, 2009). Similarly, at least 750,000 (nearly 8%) of people in the United States have been diagnosed with more than one form of cancer between 1975 and 2001, and it is expected that at least 1 in 9 people will develop two cancers in his or her lifetime (Mariotto, Rowland, Ries, Scoppa & Feuer, 2007). It is also estimated that second cancers account for 16% of all cancer diagnoses reported to the National Cancer Institute's Surveillance, Epidemiology and End Results Program, which is more than 4 times the population-based expected rate (Reis, Melbert & Krapcho, 2007).

When cancer survivors of all ages are considered, population-based studies show that cancer survivors have a 14% higher risk of developing cancer than the general population (Curtis et al., 2006). Survivors of childhood cancer have a 6- to 11-fold increased risk of developing cancer compared to the general population (Cardous-Ubbink et al., 2007; Curtis et al., 2006; Hammal, Bell, Craft, & Parker, 2005; Inskip & Curtis, 2007). Estimates suggest that, following cancer in adulthood, survivors have approximately a two-fold risk of developing cancer, (Curtis et al., 2006; Ng, Kenney, Gilbert & Travis, 2010).

Worldwide Second Cancer Patterns

In general, patterns of second cancer observed in cancer survivors vary between hospital-based and population-based research studies. Hospital-based studies have reported high risks of second cancers among cancer survivors, with standardized incidence ratios (SIR) reaching 11 (Cardous-Ubbink et al., 2007). The largest multi-national cohorts of cancer survivors are the Childhood Cancer Survivor Study (CCSS) and the Late Effects Study Group (LESG). Since 1994, the CCSS has retrospectively evaluated a cohort of about 14,000 5-year survivors diagnosed and treated for their original cancer between 1970 and 1986 in the United States (24 centers) and Canada (Hospital for Sick Children in Ontario) (Robison et al., 2002). Established in 1979, the LESG has collected data from 1,380 children diagnosed with Hodgkin's disease between 1955 and 1986 from 15 institutions within the United States, England and Amsterdam (Bhatia et al., 2003).

Population-based cohort studies report somewhat lower rates of second cancers among cancer survivors. For example, population-based cohorts of childhood cancer survivors in United States, England, Slovenia and Nordic countries have reported comparable SIRs ranging from 4.4 to 6.2 (Garwicz et al., 2000; Hammal et al., 2005; Inskip & Curtis, 2007; Jazbec, Ecimovic, & Jereb, 2004; Jenkinson et al., 2004). The largest published Canadian study of second cancer risk among survivors of childhood cancers indicates that childhood cancer survivors diagnosed between 1970 and 1995 have a 5-fold increased risk of developing cancer compared with the general British Columbia population (MacArthur et al., 2007). Differences in the size and composition of study cohorts, time periods during which the studies were conducted and follow-up

methodologies account for much of the variation in second cancer estimates reported to date (Davies, 2007). Differences in the size and composition of study cohorts, time periods during which the studies were conducted and follow-up methodologies may account for much of the variation in second cancer estimates reported to date (Davies, 2007).

Second Cancer Patterns over Time

Although second cancers may occur at any time during cancer survivorship, secondary leukemias tend to have a short latency of 1-10 years, whereas secondary solid tumors may manifest at 5-10 years after treatment and persist for decades (Kenney et al., 2004; Hodgson et al., 2007; MacArthur et al., 2007). Also of concern is that second cancers often develop at much younger age in cancer survivors than in the general population (Curtis et al., 2006; Bhatia, Blatt & Meadows, 2006). For example, whereas about 51% of breast cancers occur in women older between 50-69 years of age in the general population (Canadian Cancer Society's Steering Committee, 2009), the average age at diagnosis of breast cancer in childhood cancer survivors ranges from 23-29 years (Bhatia et al., 2003; Kenney et al., 2004).

It is still too early to determine cancer survivors' lifetime risk for developing a second cancer because follow-up data in published studies is available only up to 40 years from diagnosis (Hammal et al., 2005; Marees, et al., 2008; Meadows et al., 2009). Only with continued follow-up data will survivors' lifetime risk become evident. That being said, what is known is that the cumulative incidence of second cancers consistently increases with greater time since diagnosis/treatment (Cardous-Ubbink et al., 2007; Curtis et al., 2006). Most recently, Meadows and colleagues (2009) estimated the 30-year

cumulative incidence for second cancers was 9.3% in the CCSSS cohort, indicating that the second cancer risk remains elevated for more than 20 years of follow-up for all first cancer diagnoses.

Second Cancer Patterns Across the Lifespan

Second cancer patterns across the lifespan vary in term of the types of second cancers observed, magnitude of risks and latency periods (Ng et al., 2010). Differences in cancer risk across the lifespan have been attributed to variations in treatment approaches, tissue/organ susceptibility to carcinogenesis based on stage of development and level of tissue maturity, hormone levels, attained age and lifestyle factors (Ng et al., 2010).

Second cancer risks after most commonly occurring childhood cancers. The most second cancers after childhood cancer are radiation-associated solid tumors and chemotherapy-associated hematologic cancers (Curtis et al., 2006). More specifically, second cancers associated with childhood acute lymphoblastic leukemia (ALL) include central nervous system (CNS) tumors, leukemias/lymphomas and skin cancers. Second cancers most commonly reported following hereditary retinoblastoma are soft tissue carcinomas, bone carcinomas, and malignant melanomas, nasal cavity cancers and brain tumors (Kleinerman et al., 2005). Recent research has also found that late onset lung, female breast, bladder, colon and corpus uteri have been observed in survivors of hereditary retinoblastoma (Marees et al., 2008). The most common second cancers following childhood Hodgkin's lymphoma are breast cancer, thyroid cancer and bone/soft tissue sarcomas (Meadows et al., 2009; Constine et al., 2008). An emerging risk for survivors of childhood Hodgkin's lymphoma is the development of cancers of adulthood, including cancers of the genitourinary system, head and neck area and

gastrointestinal tract at ages younger than observed in general population (Bassal et al., 2006).

Second cancer risks after most commonly occurring adult-onset cancers. Among survivors of adult-onset cancers, solid tumors account for 75-80% of second cancers after Hodgkin's lymphoma (Hodgson et al., 2007). Testicular cancer survivors are at increased risk for contralateral testicular cancer, leukemia and solid tumors like malignant mesothelioma, and cancers of the lung, thyroid, esophagus, stomach, pancreas, colon, rectum, kidney, bladder and connective tissue (Travis et al., 2005). Contralateral breast cancer, solid tumors after radiation and leukemia commonly follow breast cancer diagnoses (Curtis et al., 2006; Kirova et al., 2008). Prostate cancer survivors are at increased risk of developing malignant melanomas, and second cancers of the small intestine, soft tissue, bladder, thyroid and thymus (Curtis et al., 2006).

Risk Factors Associated with Second Cancer Development

Although the multi-factorial nature of second cancers makes it difficult to determine the precise etiology of second cancers, researchers have begun to untangle the risk factors linked with second cancers. Among cancer survivors, the risk of developing a second cancer has been linked to the age at diagnosis/treatment of the initial cancer, sex, type of first cancer, radiation therapy, chemotherapy, gene-environment interactions, treatment received for medical complications, and lifestyle choices.

Age at Diagnosis/Treatment of the Initial Cancer

Younger age at diagnosis/treatment has been associated with higher second cancer risk (Bassal et al., 2006; Constine et al., 2008; Curtis et al., 2006; Hammal et al., 2005). The greatest second cancer burden is experienced by cancer survivors whose first cancer

occurred at 30-59 years of age (Curtis et al., 2006). Second solid tumors are most common in people diagnosed at a young age, whereas second leukemias are most common in older adults (Bhatia, Blatt & Meadows, 2006).

Consistent differences in second cancer risk are reported for second cancers of the lung, thyroid and breast. Lung cancer is one of the most common second cancers in survivors of adult Hodgkin's lymphoma, but it rarely follows a childhood cancer (Bassal et al., 2006; Hodgson et al., 2007). Thyroid cancer accounts for 15% of all solid tumors in childhood cancer survivors and only 2.7% in adult survivors (Hodgson et al., 2007; Neglia et al., 2001).

Decreasing risk of second breast cancer has been generally noted for survivors of adult cancers exposure to radiation after 40 years of age (Ng et al., 2010). In contrast, second breast cancer risks are highest among woman treated for Hodgkin lymphoma at \leq 30 years of age (Travis et al., 2005). Most concerning is that cancer survivors who received radiation therapy after 10 years of age have a higher risk of breast cancer than those treated between ages 5-9 (Kenney et al., 2004), suggesting that proliferating and developing breast tissue may be more sensitive to ionizing radiation than pre-pubertal breast tissue (Preston et al., 2002). Other studies have not found an age effect for second breast cancers (Travis et al., 2003; Inskip et al., 2009). One explanation offered for the conflicting findings is that the length of follow-up was not long enough for young survivors to reach an attained age at when breast cancer risk rises. Another reason cited in the literature for the conflicting evidence over the age effect is the use of inappropriate statistical analysis techniques (Bhatia et al., 2003; Neglia et al., 2001; Travis et al., 2003). The standard approach to regression analysis of breast cancer risk has been Cox

regression models that take time since study entry as the time scale. This approach fails to account for increased risk of breast cancer that occurs with aging in the general population (Yasui et al., 2003). Recent research has attempted to correct this oversight by using age as the time scale for the Cox regression model or switching to Poisson regression models (Bhatia et al., 2003; Kenney et al., 2004).

Sex

In general, female sex is associated with increased risk of second cancers (Bhatia, Blatt & Meadows, 2006; Constine et al., 2008; Curtis et al., 2006). Sex differences are primarily due to the excess number of second breast cancers, which have been observed almost exclusively in females (Bhatia et al., 2003; Guibout et al., 2005). In fact, when sex-specific cancers (cancers of the breast and reproductive system) are excluded, there is often no evidence of sex differences in second cancer risk (Curtis et al., 2006; Hammal et al., 2005).

Type of First Cancer

A review of the literature on second cancers following cancer shows that Hodgkin's disease and soft tissue sarcomas are the most common first cancers associated with the development of second cancers (Curtis et al., 2006; Ng et al., 2010). What remains unclear, however, is whether the diagnosis of Hodgkin's disease or soft tissue sarcoma is an independent risk factor for the development of second cancers, or whether cancer treatments and other risk factors are the main contributors to the development of second cancers. For example, one study to date has shown that the excess of breast cancers after Hodgkin's disease is due to "a specific susceptibility" related to the primary cancer diagnosis rather than higher radiation doses and/or chemotherapy (Guibout et al., 2005).

Taking into account age at first cancer, attained age, castration, radiation dose and chemotherapy, Guibout and colleagues reported that a higher risk of subsequent breast cancer was associated with Hodgkin's disease ($RR = 7.0$). Although this study hints that the primary cancer diagnosis is a potential independent risk factor for developing a second cancer, evidence of this association from more than a single study is required.

Radiation Therapy

Radiation can cause most types of cancer, but different organs vary in their susceptibility. The most compelling evidence for radiation therapy in the initiation and promotion of carcinogenesis is the development of a secondary solid tumor notably breast cancer, thyroid cancer, brain tumors and most commonly bone and soft-tissue sarcomas, at or within the margins of the radiation field (Bhatia et al., 2003; Cardous-Ubbink et al., 2007; Inskip & Curtis, 2007). The risk of second cancers is higher if the radiation exposure occurs earlier in life or during periods of rapid growth (Bhatia, Blatt & Meadows, 2006).

Radiation dose is also important in the development of second cancers. The literature suggests a linear dose-response relationship for radiation. The risk of thyroid cancer increases with radiation doses up to 20-29 Gray (Gy) and diminishes at doses greater than 30 Gy (Sigurdson et al., 2005). In the largest international study to date, Travis and colleagues (2003) found that the risk of breast cancer increases with increasing radiation dose to 8-fold at >40Gy. Only one study to date has analyzed the risk of breast cancer according to the estimated dose received by the breasts during radiation therapy (Guibout et al., 2005). Guibout and colleagues found that for each Gy of radiation to the breast, the RR of breast cancer increased by 0.13.

Chemotherapy

Leukemia is the most common cancer following treatment with chemotherapy (Travis, 2006). The risk of leukemia resulting from exposure to alkylating agents increases with age at exposure and higher cumulative dose (Bhatia et al., 2007; Bhatia, Blatt & Meadows, 2006). For example, patients on a clinical trial for Ewing's sarcoma who received high cumulative doses of alkylating agents had a 16-fold increased risk of developing leukemia compared to those who received lower cumulative doses (Bhatia et al., 2007). Likewise, research with ovarian cancer survivors indicates that leukemia risk increases with dose and duration of platinum-based chemotherapy (Travis et al., 1999). Leukemia following exposure to topoisomerase-II inhibitors usually occurs in younger patients with chromosomal translocations and may be related the schedule of drug administration (Bhatia, Blatt & Meadows, 2006).

Exposure to alkylating agents in conjunction with radiation has been implicated as a risk factor for second cancers (Garwicz et al., 2000; Jazbec, Todorovski & Jereb, 2007). It is hypothesized that the use of alkylating agents with radiation might increase tissue sensitivity to cancer development, resulting in the reported increased risk (Bhatia, Blatt & Meadows, 2006). In contrast, other studies have shown that chemotherapy given with radiation reduces the risk of second cancers when compared with the risks after radiation alone (Travis et al., 2003; van Leeuwen et al., 2003). This reduced risk could be due to the reduced radiation therapy dose and field size that chemotherapy allows, or to the occurrence of chemotherapy-induced premature menopause, which has shown to have to a protective effect against carcinogenesis (Travis, 2006).

Gene-environment Interactions

Another factor that contributes to the development of second cancers in cancer survivors is the interaction between genetic susceptibility and environmental exposures (Bhatia, Blatt & Meadows, 2006). It has been hypothesized that an inherited predisposition (i.e., cancer-predisposing genes, genetic polymorphisms) to second cancers may advance the carcinogenesis process by providing the initiating event(s) and that the interaction between inherited familial gene mutations combined with radiation-induced instability may accelerate tumor development (Travis et al., 2006).

An elevated second cancer risk has been found in cancer survivors with such germline mutations as hereditary retinoblastoma, neurofibromatosis, and Li-Fraumeni syndrome (Ng et al., 2010). The finding that almost 25% of second breast cancers were diagnosed in women with not exposed to chest radiation suggests that familial cancer syndromes may play a role in breast cancer risk (Kenney, 2004). Mutations in the breast cancer tumor suppressor genes, *BRCA1* and *BRCA2*, have not been found in survivors of Hodgkin's disease, suggesting that inactivation of *BRCA 1* and *BRAC2* is not a required step in breast carcinogenesis after chest radiation for Hodgkin's disease (Gaffney et al., 2001; Nichols et al., 2003).

Other studies have examined the role of genetic predisposition in the development of a second cancer by measuring family history of cancer. In a study of the Late Effects Study Group survivor cohort, Bhatia and colleagues (1997) did not find any evidence of familial aggregation (breast or otherwise) among family members. However, other research studies have shown that family history of breast cancer in first-degree relatives is independently associated with an increased second cancer risk (Kenney et al., 2004).

Indeed, researchers have found that siblings of cancer survivors are at increased cancer risk compared with the general population (Meadows et al., 2009).

Treatment Received for Medical Complications

Endocrine and metabolic consequences of cancer treatments might also contribute to the development of second cancers in cancer survivors (Bhatia, Blatt & Meadows, 2006). Studies have shown that growth hormone replacement therapy increases the risk of developing secondary solid tumors following radiation therapy in cancer survivors treated with radiation to the brain (Ergun-Longmire et al., 2006). Likewise, among breast cancer survivors, Tamoxifen reduced the risk of contralateral breast cancer, but several large studies have demonstrated a 2- to 4-fold increased risk for a non-aggressive form of endometrial cancer (Fisher et al., 1998; Saadat et al., 2007).

Researchers have also begun to focus on hormonal and reproductive factors that are well established as cancer risk factors for the general population, including early menarche, late menopause, nulliparity, and hormone replacement therapy (Gail et al., 1989). Overall, these risk factors reflect an increased lifetime exposure to ovarian steroid hormones (i.e., estrogen and progesterone) (Ganz, 2001). Reaching menopause before the age of 36 has been associated with a reduction in second breast cancer risk (Travis et al., 2003; van Leeuwen et al., 2003). However, theoretically, hormone replacement therapy (HRT) for premature menopause might counteract this protective effect against second breast cancers (Ganz, 2001).

Lifestyle Choices

Lifestyle choices, such as tobacco, alcohol consumption and excessive sun exposure may enhance genetic and treatment-related risk factors for second cancers

(Bhatia, Blatt & Meadows, 2006). More than 35% of second cancers are observed following cancers typically related to tobacco or alcohol (Curtis et al., 2006). Of particular concern is that cancer survivors use tobacco and alcohol and have inactive lifestyles at higher rates than is ideal (Blanchard, Courneya, & Stein, 2008; Nathan et al., 2009). Hence, it has been hypothesized that lifestyle choices impact second cancer risk by magnifying the risks associated with cancer treatments. For example, survivors of Hodgkin's disease who were treated with radiation and who smoke are at greater risk for lung cancer than non-smokers with the same cancer history (Lorigan, Randford, Howell & Thatcher, 2005).

Descriptive Epidemiology of Second Cancer Mortality

Mortality rates among cancer survivors are 10-20 times higher than expected in the general population (Mertens, 2007). A number of studies have shown that second cancers represent the second leading cause of death, after recurrence of the primary cancer, in 5 and 10-year cancer survivors (Hooning et al., 2006; MacArthur et al., 2007; Meadows et al., 2009; Mertens, 2007). However, in a study of 15+ year cancer survivors, Lawless and colleagues (2007) demonstrated that second cancers were the leading cause of death. Canadian research has shown that the elevated risk of death due to second cancers is evident in survivors diagnosed as recently as 1995 (MacArthur et al., 2007). The poorest prognosis has been reported among survivors of Hodgkin's lymphoma who later developed leukemia or lung cancer with median survival durations of 0.4 and 1 year, respectively (Ng et al., 2010). Overall, death attributable to a second cancer accounts over 15% of cancer deaths among cancer survivors (Meadows, et al., 2009).

Risk Factors Associated with Second Cancer Mortality

Risk of death from second cancers reflects a complex interaction of demographic characteristics, treatment history, and prolonged survival (Lawless et al., 2007). Preliminary research suggests that increased second cancer mortality is highest among cancer survivors treated at a younger age, declines as cancer survivors age and occurs in both sexes (Hoening et al., 2006; Lawless et al., 2007; MacArthur et al., 2007). Increased mortality from solid tumors has been associated with previous radiation therapy, whereas the risk of death from leukemia has been associated with previous chemotherapy (Hoening et al., 2006; Ng et al., 2010). More research is needed to determine whether health behaviors or cancer screening might influence second cancer mortality in cancer survivors.

Management of Second Cancer Risks

Recognizing the potential effects of late morbidity and mortality, the Institute of Medicine released a landmark report in 2003 identifying lifelong follow-up of cancer survivors as a critical priority for cancer control plans (National Cancer Policy Board, 2003). Lifelong follow-up may facilitate the identification and management of late effects including second cancers, and reduce the frequency of severe complications and of morbidity, easing the impact on the healthcare system (Vogel, 2006). Follow-up care also offers an opportunity to provide survivors with information to correct any knowledge deficits, and create a “teachable moment” that facilitates the reception of health promotion messages (Hudson & Findlay, 2006).

Essential to comprehensive long-term follow-up is screening for second cancers. Cancer screening, appropriate for age and sex, is warranted for cancer survivors because

many of the risk factors for second cancers cannot be manipulated or present limited opportunities for change (Ng et al., 2010). Cancer screening can also reduce the risk of dying from second cancers through detection of cancers that are more amenable to effective treatment (Vogel, 2006).

Evidence-based screening for many second cancers, including when screening should be initiated, frequency of screening and corresponding attributes of the tests (e.g., specificity, sensitivity) is lacking (Vogel, 2006). However, the little evidence that does exist has resulted in the development of risk-based screening guidelines for second cancers based on the severity of risk (Klinke & Renn, 2002). For survivors of childhood cancer, the Children's Oncology Group developed long-term follow-up guidelines that match the magnitude of risk with the intensity of the cancer screening recommendations. Recommendations from the American Cancer Society for the general population also serve as the guidelines for at-risk cancer survivor populations (defined as survivors at increased risk for cancer based on risk factors such as age, sex, genetic susceptibility, personal or family history, health-related behaviors or co-morbidities) (Landier et al., 2004). More intense periodic evaluations are recommended for high-risk populations (defined as survivors at significantly increased risk for late effects as result of therapeutic exposures as well as risk factors associated with the at-risk designation) (Oeffinger, Hudson & Landier, 2009).

Current State of Follow-up Cancer Care

Despite the potential benefits of long-term follow-up, recent studies show that as many as 60% of cancer survivors report receiving no regular medical follow-up (Arvidson et al., 2006; Earle & Neville, 2004; Nathan et al., 2009; Nord et al., 2005;

Shaw et al., 2006). Cancer survivors receiving medical care typically visit a general practitioner (GP) rather than an oncologist for care that is neither related to cancer survivors' cancer history nor the specific risks arising from their cancer (Castellino et al., 2005; Nathan et al., 2009). Self-reported healthcare use may, however, underestimate the true prevalence given that audits of administrative databases and chart reviews suggest that nearly 90% of cancer survivors attend follow-up cancer clinics (Johnson et al., 2004).

Regardless of who is responsible for cancer survivors' care, the prevalence of cancer screening in this population is typically below optimal levels recommended for the general population (Findley & Sambamoorthi, 2009; Wilkins & Woodgate, 2008a). What is clear from the literature is that cancer survivors are more likely than sibling controls or population-based non-cancer controls to engage in cancer screening (Wilkins & Woodgate, 2008a). Across the lifespan, research indicates that cancer survivors aged 30 and older are more likely than younger survivors to report having participated in cancer screening (Bloom et al., 2006; Diller et al., 2002; Yeazel et al., 2004). In terms of breast cancer screening, for example, researchers have found that participation rates for mammography are highest among survivors of adult cancer (75%–92%) than survivors of childhood cancer (21-37%) because many of the survivors of childhood cancer have not yet reached the age at which mammography is recommended (Wilkins & Woodgate, 2008a). Most concerning is finding that mammography prevalence rates among women treated with chest radiation, particularly those aged 25-49 (i.e., those most at risk for developing a second breast cancer) is only 30%–37%, (Cox et al., 2009; Oeffinger, Hudson & Landier, 2009).

Factors Influencing Follow-up Cancer Care

The healthcare system, healthcare providers and cancer survivors, themselves, are key determinants of the extent to which cancer survivors participate in long-term follow-up care (Mertens et al., 2004). Barriers and resources within each of these three determinants are described.

Healthcare system-related influences. Cancer survivors' pattern of healthcare use is not surprising given the fragmentation of follow-up services available throughout the industrialized world, including Canada (Oeffinger et al., 2004; Shaw et al., 2006; Taylor et al., 2004). A recent survey of pediatric hematology/oncology programs across Canada found that while 87% of Canadian pediatric oncology centers offer follow-up programs for survivors of childhood cancer, few dedicated programs exist for adult survivors of childhood cancer (Guilcher, Fitzgerald & Pritchard, 2009). Even when cancer centers are able to provide comprehensive long-term follow-up programs, they often do not have adequate staffing and resources for the delivery of follow-up care to the growing cancer survivor population (Aziz, Oeffinger, Brooks, & Turoff, 2006; Guilcher, Fitzgerald & Pritchard, 2009). Additionally, many cancer centers do not have a mechanism for following cancer survivors, and most focus on acute problems and recurrence of disease (Guilcher, Fitzgerald & Pritchard, 2009).

Healthcare provider-related influences. A key barrier to the health care of cancer survivors is the majority of GPs caring for cancer survivors are unfamiliar with the late effects of cancer treatments because they are unlikely to care for more than a handful of survivors in their career (Mertens et al., 2004). Further complicating GP's proficiency in managing cancer survivors' follow-up care is that the heterogeneous nature of cancer

means that there is little similarity in the follow-up required. Cancer survivors and health policy experts have called for improved communication between adult healthcare providers, pediatric oncology experts and survivors to address the reported lack of awareness of survivorship issues (Mertens et al., 2004; Park et al., 2002; Zebrack et al., 2004).

Healthcare providers in the present healthcare environment vary widely in their practices, leading to inefficiencies in care delivery and less than optimal follow-up care for survivors (Taylor et al., 2004). In recent years, models of follow-up care that draw more actively on the skills of GPs, advanced practice nurses and multidisciplinary teams are being advocated to ensure cancer survivors receive education and preventive services as well as ongoing primary healthcare services (Grunfeld, 2005; Oeffinger & McCabe, 2006). Two recent randomized control trials of breast cancer follow-up (one conducted in Canada and one in the United Kingdom) found no differences in rate of recurrence or adverse outcomes based on whether follow-up care was received at a cancer clinic or GP's office (Grunfeld et al., 1996; Grunfeld et al., 2006). These two trials showed that women were more satisfied with care provided by their GP and that GPs were willing to assume responsibility for their care. A related theme arising in the literature is that cancer survivors are more likely to participate in cancer screening practices when recommended by a physician (Bober et al., 2007; Mayer et al., 2007; Oeffinger et al., 2009).

Cancer survivor-related influences. Although cancer survivors generally believe that participation in follow-up care and cancer screening are an integral part of health monitoring, some cancer survivors hold reservations about healthcare utilization because they downplay the possibility of late effects, perceive follow-up care as an interference

with their normal life, or do not know where to seek ongoing care (Earle et al., 2005; Park et al., 2002). Other factors associated with lack of cancer-related follow-up and screening include older age, longer time since diagnosis, lack of health insurance, history of high-risk cancer treatment, and history of central nervous system tumors, retinoblastoma, germ cell tumors or carcinomas (Wilkins & Woodgate, 2008a). Family and social influences are equally important influences on whether or not cancer survivors follow prescribed follow-up regimens. Pressure from family, observing a relative's struggle with cancer and love for their own children have been cited as motivation for female survivors of childhood Hodgkin's disease to participate in breast cancer screening (Crom, Hinds, Gattuso & Hudson, 2005).

The full benefits of follow-up care and cancer screening cannot be realized unless cancer survivors have accurate information about their cancer diagnosis, treatment and potential health risks (Mertens et al., 2004; Zebrack et al., 2004). Previous studies evaluating survivors' health knowledge have shown that about 25% are not aware that they had cancer and 50% are not aware of their increased risk for second cancers (Hudson et al., 2002; Oeffinger et al., 2004; Yeazel et al., 2004). Moreover, a significant proportion of survivors knowledgeable of second cancer risks report on quantified multi-point scales that they are at equal or lower risk than individuals of the same age and thus, are not concerned about their future health (Hudson et al., 2002). The association between perceived risk and screening practices has varied; some studies have found an increased perceived risk resulted in increased screening (Vernon, 1999). Intervention studies aiming to influence cancer screening among childhood cancer survivors have shown that it is feasible to modify cancer screening practices by increasing awareness of

their second cancer risk (Hudson et al, 2002). Moreover, information is most effective in increasing cancer screening practices when it is tailored to individuals' risk factors and behavior change variables, including attitudes, intentions and stages of change (Albada, Ausems, Bensing & van Dulmen, 2009).

What remains largely unknown is the risk judgments that cancer survivors engage in when faced with decisions related to participation in follow-up cancer care and cancer screening (Vernon, 1999). It is unclear as to the influence of the way risk information is presented to cancer survivors on their informed decision-making about cancer screening. An evaluation of second cancer risk requires some technical understanding of risk that allows survivors to discriminate options in managing risks (Edwards & Elwyn, 2001). Cancer risk information is typically presented as percentages or relative risks, but most people are unfamiliar with probabilistic thinking, preferring cancer risk information to instead be conveyed more descriptively and in terms of possible risk factors for cancer (Han et al., 2009).

According to cognitive scientists, cancer survivors' risk judgments may be influenced by cognitive limitations in knowledge and cognitive capacity, affect and emotions, and priorities and values (Taylor-Gooby & Zinn, 2006). Cancer survivors use of mental shortcuts, or heuristics, in processing risk information may cause biases in decision making on risks that results in actions contrary to logic of self-interest (e.g., not participating in cancer screening) (Peters, McCaul, Stefanek & Nelson, 2006). As outlined by Peters and colleagues (2006), heuristics that have been shown to play an important part in risk assessment include: availability heuristic (overestimation of an event because of its vividness and emotional impact rather than on actual probability),

representativeness heuristic (overestimation of an event based on its similarity with a stereotype), anchoring and adjustment heuristic (salient, but not necessarily relevant numbers influence a numerical estimate of risk), and affect heuristic (results from associating positive affect with perceived high benefit and lower risk, even when this is logically not warranted for the situation).

Cancer survivors' risk judgments may be further impaired by treatment-related deficits in information processing (e.g., abstract reasoning, problem solving and planning ability), which have been documented in cancer survivors with a history of cranial radiation (Hollen & Hobbie, 1993). With these deficits, survivors are vulnerable to poor decision-making, and thus, more likely to engage in risk behaviors (Hobbie et al., 2001).

Interventions aimed at refining survivors' decision-making skills show promise in improving decision-making and reducing the risk behaviors of survivors (Hollen, Hobbie & Finley, 1999).

Within the cancer risk perception and prevention decision-making literature, only one qualitative study has explored how personal beliefs and emotions influence cancer survivors' risk perceptions and cancer screening practices. In interviewing Hodgkin's disease survivors about their experiences, Bober and colleagues (2007) discovered that the reasons for women's underestimation of breast cancer risk and avoidance of cancer screening were three-fold. First, women struggled to reconcile messages that they were "cured" with the idea of being at increased risk for second cancers. Second, women expressed a sense of helplessness in preventing a second cancer. Third, women received confusing recommendations over the initiation and frequency of cancer screening.

Literature Critique

The studies reviewed indicate that second cancer risk is not borne equal among cancer survivors. Cancer survivors at greatest risk for the development of a second cancer are those diagnosed with cancer at a younger age, those who have been exposed to high-dose radiation therapy and certain chemotherapies, and those with a known genetic predisposition to cancer, although the latter is small. Dominated by a bio-medical focus, almost virtually nothing exists on psychosocial factors that may influence second cancer risks such as lifestyle choices, knowledge, belief systems, and the availability and uptake of medical surveillance and cancer screening. This is despite the acknowledgement that these risk factors deserve research attention because they can be manipulated and present opportunities for change (Bhatia, Blatt & Meadows, 2006).

A noteworthy deficiency in the epidemiological data published to date is that the majority is based on data collected from co-operative group registration systems or hospital-based cancer registries. Estimates of second cancer risk and second cancer mortality based on these registration systems may be underestimated because they often suffer from an under representation of minority, poor, rural, and other hard-to-reach populations (Pearson et al., 2002). Another challenge in using hospital-based cancer registries is that they are prone to selection biases such as loss to follow-up and participation refusal.

Population-based cohort studies of second cancer risk are rare owing to challenges in following cancer survivors such as name change or address changes. Population-based research is important in monitoring the distribution of second cancers and second cancer deaths across the whole catchment population, achievement of targets for preventing

cancer, effectiveness of cancer screening programs, and assess causes and effects of second cancer as they change over time (Brewster, Coebergh, & Storm, 2005). Further population-based research, particularly from a Canadian perspective, is needed to provide a true estimate of the risks of developing a second cancer and dying from that cancer among cancer survivors, and to elucidate risk factors for second cancer development and second cancer mortality.

Another reason that second cancer risk and second cancer mortality may be underestimated is that the observation periods in most studies start 3-5 years after the initial diagnosis, thus missing cancers that develop shortly after the first, particularly chemotherapy-induced leukemias. Longer follow-up than the typical 20 years is also required for particular exposures, such as radiation therapy, to have its effect on the development on second cancer.

Another problem is that most studies of second cancer risk and second cancer mortality are based on cancer survivor cohorts treated before 1990 and there have been significant changes in therapy for most cancers since that time. At the same time, treatment protocols have been adjusted to incorporate knowledge about the potential for late effects. Thus, different survivors who were treated more recently might have different patterns of second cancer risk and second cancer mortality. Accordingly, future research must include survivors treated with more current therapy than the existing cohorts in order to evaluate the long-term effects of therapy introduced after 1990. Additionally, research conducted to date has been confined to cancers occurring in the first decade following treatment, and only one addresses the risk of cancers typical of later adulthood. Follow-up into second and later decades after treatment is needed to

provide a more accurate estimate of the true incidence of second cancers and second cancer mortality in this vulnerable population.

What is clear from the literature is that much of what is known about the access to follow-up cancer care comes from work conducted in the United States. This raises questions about the relevance of this research in Canada. The most striking difference in healthcare between Canada and the United States is that health care is free in Canada and thus lack of health insurance is not a barrier to follow-up cancer care.

Finally, it is concerning that that few studies have sought how cancer survivors define and interpret second cancer risk, pointing to the need for a greater understanding of how cancer survivors conceptualize and assess risk in relation to having a history of cancer. Existing quantitative approaches to assessing cancer risk perceptions are unable to fully describe the full range of experiences, suggesting the need for approaches that elaborate the multi-dimensionality of the concept of risk in cancer survivors' own voice. A commitment to access and listen to the views of cancer survivors must remain a priority if we are to deliver follow-up based on real rather than perceived or presumed need. Furthermore, to adequately develop and empirically test interventions that seek to modify second cancer risk, it is essential that a multilevel analysis of both individual and contextual variables as they affect behavior be undertaken (Kaplan, Everson & Lynch, 2000).

Chapter Summary

This literature review demonstrates that there is an expanding body of research regarding second cancer risk observed in cancer survivors. The studies reviewed indicate that there is an excess risk of second cancers among cancer survivors, and second cancers

are a common cause of death. Many factors could be responsible for the increased incidence of second cancers and deaths among cancer survivors. Given the lack of studies focusing on the subjective experience using qualitative methodology, little is known about cancer survivors' interpretation of second cancer risk. Approaching second cancer risk from a mixed method approach is warranted to overcome the limitations identified in the literature critique. The next chapter will describe the mixed methods design that was used to provide a multilevel analysis of both individual and contextual variables as they affect second cancer risk among cancer survivors.

CHAPTER THREE: METHODOLOGY & METHOD OF OVERALL STUDY

Introduction

Chapter three describes the methodology of the research study and method used. Methodology refers to the philosophical framework, whereas method is the research technique and procedure for carrying out the research (Wilkins & Woodgate, 2008b). In mixed methods research, methodologies are not mixed, but rather are reflected in what methods are combined, as well as how and why the methods are combined (Sandelowski, 2000). Accordingly, the methodology section of this chapter will introduce the reader to the philosophical framework adopted for this study. In the method section, the research design, design considerations, role of the researcher and dissemination plans are described.

Methodology

The methodology section of this chapter will introduce the reader to the philosophical underpinnings of mixed method research and explain the reasons why pragmatism was embraced as the appropriate methodology for exploring second cancer risk among cancer survivors.

Philosophical Underpinnings of Pragmatism

The methodology used in this mixed method study is what Johnson, Onwuegbuzie and Turner (2007) call “pragmatism of the middle”. Drawn from the ideas of Charles Sanders Peirce, William James, and John Dewey, Johnson and colleagues suggest that classical pragmatism allows mixed method research to coexist with the philosophies of quantitative and qualitative research. Historically, quantitative research has been synonymous with a post-positivist worldview (i.e., reality as singular and objective) and

qualitative research with a constructionist worldview (i.e., reality as multiple and individually constructed) (Giddings & Grant, 2006; Sandelowski, 2000).

A classical pragmatic philosophy asserts that the truth is “what works” for finding answers to the research questions posed (Johnson, Onwuegbuzie & Turner, 2007). A major tenet of classical pragmatism is that quantitative and qualitative methods are compatible, thereby rejecting the incompatibility thesis, that is, it is impossible to mix qualitative and quantitative research methods because they are based on opposing paradigms. According to classical pragmatism, there are multiple routes to knowledge because knowledge is both constructed and the result of empirical discovery. Both numerical and text data can help better understand the research problem. Knowledge comes from the person-environment interaction, thus dissolving the subject-object dualism. Further, knowledge is always changing such that research conclusions are rarely, if ever, eternal truths. Classical pragmatism maintains that truth is what is maintained at the end of history. Another warrant of pragmatism is that theories are not true or false, but rather instrumental in predicting, explain and influencing change.

Appropriateness of Pragmatism for This Study

“Pragmatism of the middle” was chose as the methodology for this study because this philosophy will provide insight into the magnitude of second cancer risk and how cancer survivors interpret and manage second cancer risk, thus providing a more detailed picture of the nature of second cancer risk. Moreover, this philosophy is recommended when the intent is to understand a topic from a pluralistic approach (Johnson & Onwuegbuzi, 2004).

Method

This section details the research design that was applied to obtain information-rich data, design considerations, and procedures. The role of the researcher and plans for disseminating study findings are addressed.

Research Design

The research design was driven by the research questions, which were informed by the theoretical framework for the study. This study used a mixed methods research design, which is a procedure for collecting, analyzing and “mixing” both quantitative and qualitative data at some stage of the research process within a single study, to "combine elements of quantitative and qualitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (Johnson, Onwuegbuzie & Turner, 2007, p. 123).

Analyses were conducted as data became available, and findings informed any subsequent data collection and analyses. The mixed methods approach taken incorporated both quantitative and qualitative data that represented second cancer risk and the management of cancer risk in different ways. These data sets complemented one another, together providing a more complete picture of second cancer risk that could be interpreted in relation to salient features of the context.

The rationale for using a mixed methods research design is that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of the situation, such as a complex issue of second cancer risk in cancer survivors. Mixed methods designs provide a broader focus than a single method design, compensate for

shortcomings in each of the methods used, can reveal researcher assumptions that might not have otherwise been known or biases of ways of measuring or interpreting phenomena, and augments interpretation and usefulness of data (Giddings & Grant, 2006). Moreover, mixed methods research does not attempt to reconcile different epistemological orientations, but rather emphasizes the complementarity of quantitative and qualitative methods. When used in combination, quantitative and qualitative methods complement each other and allow for more complete analysis (Giddings & Grant, 2006).

Design Considerations

While designing a mixed methods study, three issues need consideration: (1) which method, quantitative or qualitative (or both), had more emphasis (*priority*), (2) sequence of the quantitative and qualitative data collection and analysis (*implementation*), and (3) where mixing of the quantitative and qualitative approaches occurred in the study (*integration*) (Wilkins & Woodgate, 2008b). A visual presentation of the study procedures was also developed to ensure better conceptual understanding of the designs by both researchers and intended audiences. All decisions were guided by the purpose of the study, research questions and methodological discussions in the literature (Creswell et al. 2003).

Priority. Priority was given to qualitative methods supporting the ontological belief in multiple realities to achieve a complete picture of the research questions. The qualitative and quantitative methods shared the primary objective to provide a detailed understanding of second cancer risks among cancer survivors, yet answered different research questions. The study involved the following combination of data collection methods:

1) Qualitative survey data (outcome for research question 1)

A survey was used to develop a better understanding of current practices and existing gaps in follow-up cancer care for cancer survivors across Canada (see Chapters 4 and 5 for the methods and results, respectively).

2) Epidemiological data (outcome for research questions 2 and 3)

Population-based health databases (cancer registry and health insurance databases) were used to estimate the extent of the second cancer risk among cancer survivors in Nova Scotia and Manitoba relative to the general population at risk (see Chapters 6 and 7 for the methods and results, respectively).

3) Qualitative interview data (outcome for research questions 4 and 5)

Qualitative interviews were conducted to reveal new insights, meaningful descriptions, and theoretical relationships about cancer survivors' views about their risk of developing a second cancer and how they can best manage that risk (see Chapters 8 and 9 for the methods and results, respectively).

Implementation. Data were collected both concurrently and sequentially. The qualitative survey data and epidemiological data were gathered at the same time in the project and the implementation was simultaneous. The qualitative interview data were collected after the qualitative survey data so as to compare and contrast recommendations for taking care of cancer risk and strategies practices by cancer survivors. The qualitative interview data followed the epidemiological data collection to help explain why certain risk factors are important for interpreting second cancer risk.

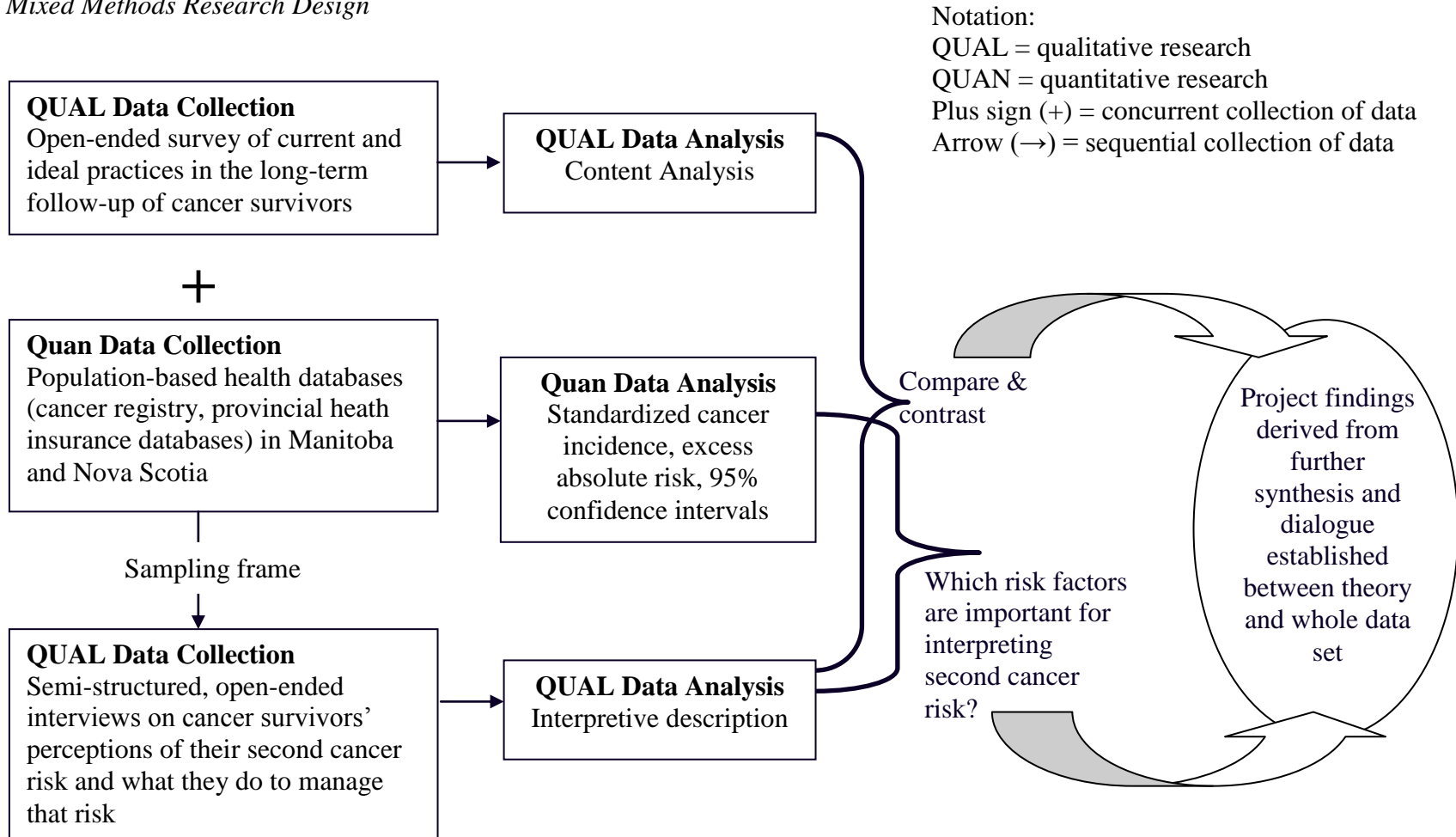
Integration. Integration, or mixing, of the two types of data might occur at any stage of the research process, including data collection, data analysis, interpretation, or

some combination of places (Teddlie & Tashakkori, 2003; Onwuegbuzie & Teddlie, 2003). In this study, the quantitative and qualitative approaches were mixed at the study design stage by introducing both quantitative and qualitative research questions. The epidemiology data and qualitative interviews were linked using nested sampling, whereby a subsample of the individuals with a cancer notified to the Nova Scotia Cancer Registry during the years of 1970 to 2004 were recruited to participate in the qualitative interviews. When the intent is to integrate the quantitative and qualitative data, data can be treated with the techniques usually used with that data (Sandelowski, 2000). For this study, quantitative techniques (e.g., incidence rates) were used with epidemiological data, and qualitative techniques (e.g., content analysis, interpretive descriptive analyses) were used with qualitative survey data and interview data. The results were then combined at the interpretive level of research in the discussion of the outcome of the entire study (see Chapter 10). Integrating the results in the discussion allowed the researcher to develop a more robust and meaningful picture of second cancer risk among cancer survivors.

Visual model. The multi-phase format of the mixed methods research is difficult to comprehend without graphically representing the procedures used in the study. A graphical representation of the mixed methods procedures helps visualize the sequence of the data collection, the priority of the methods, and the connecting and mixing points of the methods within a study. See Figure 2 for an illustration of the sequence of data collection and analysis procedures, priority of the qualitative phases by capitalizing the term QUAL, connecting points between the quantitative and qualitative phases and the related products, and where the integration or mixing of the results of both quantitative and qualitative phases occurs.

Figure 2

Mixed Methods Research Design



Procedures

Ethical approval for the study was granted by the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba, IWK Health Centre Research Ethics Board (IWK REB), Capital District Health Authority Research Ethics Board (CDHA REB), University of New Brunswick (UNB) Faculty of Nursing Research Ethics Committee; and UNB Research Ethics Board. Refer to Appendix A for the approval certificates and renewals from the ENREB for the overall study. Data collection commenced once ethical approval and access was secured. Recruitment, data collection and ongoing data analysis was supervised by the researcher's supervisor, Dr. Roberta Woodgate. The study took three years to complete (see Appendix B for study time line).

Role of the Researcher

The researcher's involvement with collecting quantitative and qualitative data was different. For the quantitative data, the researcher isolated variables and causally related them to determine the magnitude of second cancer risk. The researcher performed rigorous statistical analysis techniques and interpreted the results based on the established values for statistical significance. For the qualitative data, the researcher assumed a more participatory role and became immersed in the survey and interview data.

Chapter Summary

This mixed method study was designed to provide a detailed understanding of the nature of second cancer risk among cancer survivors. The methodology and methods employed in this study were described. The next chapter presents the methods used for collected the survey data.

CHAPTER FOUR: METHOD FOR SURVEY DATA COLLECTION

Introduction

This chapter details the research design that was applied to survey data, study sample, data collection methods, and approach to data analysis. Ethical issues considered during the planning and conducting of this phase of the mixed methods study are addressed.

Research Design

A survey was used to develop a better understanding of current practices and existing gaps in follow-up cancer care for cancer survivors across Canada. A critical analysis of policy documents and guidelines on follow-up cancer care implemented at pediatric and adult cancer centers across Canada was originally planned. However, it came to the researcher's attention that reviewing written policies on follow-up cancer care was not possible because many cancer centers do not have such policies.

Sample Recruitment

Sampling is the process used for selecting participants for inclusion in a study (Speziale & Carpenter, 2003). The process of sample election and participant recruitment are described.

Sample Selection

Medical Directors (or representatives) from cancer centers across Canada were recruited to participate in the study. Medical Directors (or representatives) were eligible to participate in the study if they were able to read, write and speak English, and their mailing address was easily retrievable. It was asked that the questionnaire be completed by the person the Medical Director deemed to be the most appropriate respondent about

the follow-up cancer care provided at their institution.

Sample Size

A convenience sample of 22 healthcare professionals from pediatric and adult cancer centers across Canada participated in the study.

Sample Recruitment

Mailing addresses for Medical Directors (or representatives) were retrieved from internet resources such as the Canadian Cancer Resources Directory, Canadian Association of Provincial Cancer Agencies, and provincial and territorial cancer agency websites. A letter requesting the Medical Directors' (or representatives') participation was mailed directly to them from the research team (see Appendix C). Reminder letters were mailed to non-responders within three weeks of the initial mail-out (see Appendix D).

Data Collection Methods

Data were collected using a survey created for this study by the researcher and Dr. Roberta Woodgate based on (1) key themes identified in a review of the literature on long-term cancer follow-up and (2) their experience in caring for cancer patients (see Appendix E). The survey contained closed and open-ended questions about the long-term follow-up cancer care provided at the participants' institutions (e.g., what follow-up care is provided, who delivers it, frequency and duration of follow-up, and criteria for inclusion in such care) and their ideal model of follow-up cancer care (see Appendix E). Open-ended questions allowed respondents to develop their responses in whichever ways are most relevant to their long-term follow cancer practices. The survey took about 30 minutes to complete.

Data Analysis

All information from the survey was transcribed by the researcher. Descriptive statistics were used for the analysis of the close-ended questions. Content analysis was used to identify categories and themes in the text emerging from the open-ended questions (Speziale & Carpenter, 2003). Themes were co-created by the PI and dissertation supervisor, Dr. Roberta Woodgate. Data emerging on current practices in follow-up cancer care were compared and contrasted with the perspectives of cancer survivors on managing second cancer risk. This comparison helped identify similarities and differences between cancer centers and cancer survivors, but also between cancer centers.

Ethical Considerations

The following ethical issues will be addressed in this section: informed consent, confidentiality, potential harms and benefits.

Informed Consent

Study information accompanied the survey (see Appendix F). Consent was implied by the return of completed surveys to the research team. If potential participants were not interested in participating, their participation in the study was not pursued. Participants were made aware that their participation was voluntary.

Confidentiality

Per request of the IWK REB, the surveys were pre-coded because they were sent out individually. Only the researcher was able to link responses to institutions or individuals. Names of participating institutions were replaced with a code number. Only aggregated data are reported. Only the researcher and Dr Roberta Woodgate reviewed the

surveys. Care was taken to write the findings and data sources in such a way to maintain confidentiality of the participants.

Potential Harms and Benefits

No known risks to study participants were apparent. A summary of the study results was distributed to all participating institutions (see Appendix G). Study participants received no compensation for their participation. A postage-paid envelope was provided for the return the survey to the research team.

Chapter Summary

The survey phase of this mixed method study was designed to gain an understanding of the current practices and existing gaps in follow-up cancer care for cancer survivors across Canada. Data were coded and themes emerged. Ethical considerations were also described. Results of the survey are described in the following chapter.

CHAPTER FIVE: SURVEY RESULTS - LONG-TERM FOLLOW-UP

CANCER CARE

Introduction

In Chapter five, the findings of the surveys on long-term follow-up cancer care are presented. The main findings of the survey address the following research question:

Research Question 1: What are the current practices and existing gaps in follow-up cancer care for cancer survivors across Canada?

Description of Participants

The 22 study participants were from Western Canada ($n = 10$), Central Canada ($n = 7$) and Atlantic Canada ($n = 5$). The majority of respondents were oncologists ($n = 15$). Other respondents were clinic nurses ($n = 2$), nurse practitioners ($n = 2$), nuclear medicine technicians ($n = 2$) and medical administrators ($n = 2$). Of the 22 participating centers, 20 offered follow-up cancer care to cancer survivors, defined as patients greater than 2 years beyond active treatment. The cancer survivor population to whom follow-up care was targeted included childhood cancer survivors ($n = 7$), adulthood cancer survivors ($n = 10$), and both childhood and adulthood cancer ($n = 3$). Table 1 presents a summary of the target population for follow-up care provided by the cancer centers.

Table 1

Target Population for Follow-up Cancer Care

Target Cancer Survivor Population	Region			Total
	Western Canada	Central Canada	Atlantic Canada	
Childhood cancer	3	4	0	7
Adult cancer	5	1	4	10
Childhood & adult cancer	1	2	0	3
No follow-up offered	1	0	1	2
Total	10	7	5	22

Main Findings

Findings emerging from the survey included: (1) present situation on long-term follow-up of cancer survivors and (2) perceptions of follow-up cancer care delivery.

Present Situation on Long-term Follow-up of Cancer Survivors

The present situation on long-term follow-up cancer care refers to the follow-up services offered to cancer survivors who are 2-5 years post-treatment, follow-up services offered to cancer survivors greater than 5 years post-treatment, discharge from follow-up cancer care, and use of guidelines to support follow-up care decisions.

Follow-up care given to cancer survivors who are 2-5 years post-treatment.

Almost all study participants reported that follow-up care for cancer survivors who are 2-5 years post-treatment was provided by multidisciplinary teams with a greater reliance on oncologists. The patient populations most likely to receive follow-up cancer care for the period of 2-5 years post-treatment were: (1) childhood cancer survivors aged 18-25, (2) childhood cancer survivors treated with radiation, (3) adult cancer survivors at high risk of relapse, and (4) adult cancer survivors with history of breast or colon cancer. The primary focus of this follow-up care was surveillance for acute problems and recurrence of disease. Childhood cancer survivors were more likely to receive psychosocial support than adult cancer survivors. The frequency of visits varied from every 3 months to annually. The follow-up care was typically offered in a cancer clinic in a cancer centre or children's hospital.

Follow-up care given to cancer survivors who are greater than 5 years post-treatment. Cancer centres offering follow-up cancer to cancer survivors for more than five years post-treatment used multidisciplinary teams to provide follow-up cancer care

with greater reliance on general practitioners (GPs). The most important determinants as to whether a cancer survivor was followed beyond 5 years were: aged 18-25, at risk of late effects from treatment including new cancers and late relapse, and has no family doctor. The primary focus of follow-up care was surveillance for late effects from treatment. Most centers followed cancer survivors yearly. The follow-up care was typically offered in a cancer clinic or the GP's office.

Discharge from follow-up cancer care. Lifelong follow-up by an oncologist was very rare. When life-long follow-up care was offered, it was primarily for survivors of childhood cancers. When discharged, the care of cancer survivors often reverted to the GP. Cancer survivors discharged to the GP were those who were 10 years post active treatment or 20 years of age, whichever came first, or those identified as low risk for late effects.

Use of guidelines to support follow-up care decisions. Fifteen study participants reported using cancer-specific guidelines to inform the follow-up care provided at their cancer center. Only one participant reported that long-term follow-up care was available according to the judgment/preference of individual oncologists. The remaining four participants did not use guidelines. The guidelines used by study participants included center-specific guidelines, provincial guidelines, national guidelines and international guideline (see Table 2 for examples of the guidelines used). Guidelines used were often augmented by local guidelines and then adapted for use with individual cancer survivors.

Table 2

Examples of Guidelines Used for Follow-up Cancer Care

Target Population	Guidelines
Childhood cancer	<ul style="list-style-type: none"> ▪ Children’s Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers ▪ Pediatric Oncology Group of Ontario Aftercare Guidelines ▪ British Columbia Cancer Agency website
Adulthood cancer	<ul style="list-style-type: none"> ▪ British Columbia Cancer Agency website ▪ Local guidelines published on website ▪ American Thyroid Association British Thyroid Association European Consensus Report on Radio-iodine ▪ Royal College of Radiology Guidelines for breast screening ▪ Cancer Care Ontario Evidence-based Series and Practice Guidelines

Perceptions of Follow-up Cancer Care Delivery

Study participants shared their perceptions on the benefits and challenges of delivering follow-up cancer care. Strategies to deal with the delivery challenges were provided. Study participants also described how they believed follow-up cancer care should be delivered.

Perceived benefits. When asked about the benefits of providing long-term follow-up cancer care, study participants identified the following benefits for cancer survivors:

- Maintain health and well-being
- Early detection of recurrence or late effects
- Provide reassurance
- Counseling
- Satisfy patient preferences
- Health promotion and prevention
- Education

- Research
- Continuity of care
- Psychosocial support

Healthcare providers also benefit from the provision of follow-up cancer care. Study participants reported that cancer survivors are helpful for morale because healthcare providers get to see the “success of cancer treatment.”

Perceived challenges. Concerns about the inconsistency of long-term follow-up care in their cancer centers were noted. Specifically, study participants identified system-driven and survivor-driven challenges to delivering follow-up cancer care.

System-driven challenges. Financial issues were a major challenge in most of the cancer centers. Few resources (e.g., separate, dedicated space and personnel) are available for follow-up cancer care because the primary focus of cancer centers is caring for patients on active treatment. Accessing follow-up care in the acute care setting is particularly challenging for cancer survivors living in rural areas or those who work during the day. Most study participants were concerned that about the limited capacity to provide follow-up care. These participants stated that there was a lack of healthcare providers interested and trained in caring for the growing cancer survivor population. Many cancer survivors are being discharged because most cancer centers do not have the capacity to provide lifelong follow-up cancer care. Study participants reported that successfully discharging cancer survivors to a GP is difficult for two reasons. First, many cancer survivors do not have a healthcare provider to whom they be discharged and thus, receive no follow-up care. Second, it is difficult to establish and maintain communication with GPs.

Survivor-driven challenges. Study participants reported that many cancer survivors missed appointments due to family and work commitments. Another reason offered for why cancer survivors did not return for follow-up care was that cancer survivors experience an identity crisis in which they want to “get on with their lives” upon treatment completion. Cancer survivors’ discomfort with transitioning to a new healthcare provider was also suggested as a barrier to the utilization of follow-up cancer care services.

Strategies to deal with the challenges. To improve or expand follow-up cancer services, most study participants reported that they need more financial resources. Study participants generally supported the need for greater involvement and collaboration with GPs, and expand referral networks to create an integrated network of cancer clinics, including nurse-led clinics and satellite clinics in rural areas. Locating GPs for cancer survivors who have none and scheduling clinics during evenings are much needed services. To facilitate communication between oncologists and other healthcare providers, study participants endorsed using computer charting and providing a discharge letter detailing the cancer diagnosis, treatment regimen and recommendations for follow-up. Outreach to “lost survivors” was identified as an important need. Cancer survivors need education on the benefits of long-term follow-up care and reminder telephone calls or e-mails about appointments. Other strategies suggested by study participants were to offer a “bridging” program to facilitate the transition from a pediatric to adult clinic and provide follow-up for young adults in a separate clinic. See Table 3 and Table 4 for a summary of the strategies offered to deal with system-driven challenges and survivor-driven challenges, respectively.

Table 3

Perceived System-driven Challenges

System-Driven Challenges	Strategies to Address the Challenges
Capacity to provide care	Increased involvement of GP; nurse-led clinics; locate GP for survivors with none
Inadequate resources to sustain programs	Lobby for increased funding
Difficulty accessing care	Create integrated network of cancer clinics; offer satellite clinics in rural areas; schedule clinics in evening; increased involvement of GP
Communication breakdowns between healthcare providers	Provide discharge letter documenting cancer diagnosis, treatment regimen, and recommendations for follow-up; use computer charting

Table 4

Perceived Survivor-driven Challenges

Survivor-Driven Challenges	Strategies to Address the Challenges
Identity crisis (i.e., want to "get on with their lives", so they don't return for follow-up care)	Outreach to "lost survivors"; education on benefits of long-term follow-up care
Missed appointments	Provide reminder telephone calls or e-mails
Transitions in development	Offer "bridging" programs to facilitate transition from pediatric to adult clinic; provide follow-up for young adults in a separate clinic

How follow-up cancer care should be designed. To deliver optimal follow-up care for cancer survivors, most study participants indicated that a multidisciplinary healthcare team dedicated solely to the care of cancer survivors. Study participants reported that follow-up cancer care did not need to be offered at the treating institution. It was recommended that follow-up be situated at the institution closest to where cancer survivors live, preferably with its own dedicated space. In an ideal model, cancer survivors should receive annual follow-up care that includes a comprehensive assessment, evidence-based diagnostic testing and psychosocial support.

Chapter Summary

Canadian pediatric and adult cancer centers have established much needed follow-up care for the first five years post-diagnosis but coordinated follow-up services are not universally available across Canada. Inefficiencies in care delivery and less than optimal follow-up care for cancer survivors most vulnerable to late effects were noted. The next chapter describes the methods used for the epidemiological data of this mixed methods study on second cancer risk.

CHAPTER SIX: METHOD FOR EPIDEMIOLOGY DATA COLLECTION

Introduction

This chapter details the research design that was used to derive population-based risk estimates for second cancer risk among cancer survivors. It presents the setting, cohort characteristics, data collection methods, and approach to data analysis. Ethical issues considered during the planning and conducting of this phase of the study are addressed.

Research Design

A retrospective cohort design was used to identify and describe risk factors for the development of second cancers within the cancer survivor population. This design allowed the researcher to (1) directly calculate the incidence of second cancers, (2) observe the natural history of the development of second cancers and (3) establish temporality (Young, 2005). The cohort study was population-based and relied on existing sources of information such as that which is held by cancer registry and provincial health insurance plan databases.

Setting

Data collection occurred in two provinces; Manitoba and Nova Scotia. Since the number of cancers among cancer survivors was expected to be small, this study required two collection sites to achieve a robust sample size. Two sites were also required to adequately explore associations between risk factors and the development of cancer among cancer survivors. Manitoba and Nova Scotia were selected as the provinces in which to carry out the study for several reasons. First, the cancer registries met data standards on quality, completeness and timeliness outlined by the North American

Association of Central Cancer Registries (NAACCR), and thus are suitable for the calculation of incidence data to measure the burden of cancer by cancer site, sex, age, race, and geography (NAACCR 2004). Second, the registries have similar ways of coding data including second cancers. For every case, the cancer registries include information on cancer diagnoses according to the International Classification of Diseases, 9th edition (ICD-9) code (ICD-10 since 2002). Third, the registries have an ongoing working relationship with facilities housing health care service utilization data in these two provinces, which facilitated efficient data linkage. Fourth, the cancer registries in these two provinces supported this research project.

Identification of the Cohort

A cohort of cancer survivors with a first cancer notified to either the Manitoba or Nova Scotia Cancer Registries during the years of 1970 to 2004 was followed through December 31, 2006. Follow-up was censored, or stopped (Young, 2005), at the following events: diagnosis of a second primary cancer, death, migration out of province, attainment of an upper age limit of 100 years of age if death was not recorded or end of study, whichever came first. Including survivors who were diagnosed with cancer over the past three decades ensured that the data addresses the long-term risks of second cancers. To make the cohort study as accurate as possible, the following exclusion criteria was applied: (1) first cancers diagnosed after December 2004 or second cancers diagnosed after December 2006, (2) first cancers diagnosed before January 1970, (3) first and second cancers diagnosed post mortem, (4) second cancers occurring less than six months after the first cancer, and (5) pre-malignant and benign first and second tumors. First cancers diagnosed after December 2004 were not included to allow sufficient

latency for the development of second cancers. First cancers diagnosed before January 1970 were not included because complete information on cancer cases was only available from 1970 onwards. The minimum interval of six months between the first and second cancer was chosen to exclude second cancers that occur at the same time or very soon after the first, and were not treatment-related.

Data Collection Methods

The sources of data were provincial cancer registries and provincial health insurance databases.

Cancer Registries

The primary source of data on all diagnosed cases of cancer in Manitoba and Nova Scotia was the provincial cancer registries (see Appendix H for fields requested from the cancer registries). Under the authority of Manitoba and Nova Scotia Departments of Health, both cancer registries are legally mandated to collect, classify and maintain accurate comprehensive information on all cancer cases for their respective province. The registries maintain a high level of ascertainment of incident cancer cases through searches of records of hospitals, as well as diagnostic laboratories and other treatment centers. The Manitoba Cancer Registry was started in 1937 and became population based in 1956. The Nova Scotia Cancer Registry has registrations of all cancer diagnoses since 1969, but data before 1971 are considered incomplete. Both cancer registries are linked to the provincial Vital Statistics departments for information on death.

Provincial cancer rates for Nova Scotia and Manitoba by age, time period, sex, cancer type were extracted to calculate the expected number of cases of cancer. Average

annual incidence rates from the middle of each time period were identified for each province. Provincial cancer rates (by age, sex and cancer site) were presented in 5-year groups, starting with 1970, such that 1970-1974 was centered on 1972, 1975-1979 on 1977, 1980-1984 on 1982, 1985-1989 on 1987, 1990-1994 on 1992, 1995-1999 on 1997, 2000-2004 on 2004 and 2005-2006 on 2006.

Year of birth, sex and disease data for both the first and secondary cancer was extracted to describe the population of cancer survivors including those who were diagnosed with a second cancer. Year of death or censoring (i.e., end of follow-up) was required to calculate person-years-at-risk (see data analysis for description).

Provincial Health Insurance Database

A second data source was the provincial health insurance plan database maintained by Manitoba Health. For this study, it was important to access information on registrants' health care insurance eligibility because the data were used to calculate person-years-at-risk. Access to the Nova Scotia provincial health insurance plan database, maintained by Population Health Research Unit (based in the Department of Community Health and Epidemiology, Dalhousie University) was not sought. Accessing this Nova Scotia database for the period of 1970 to 2006 was too expensive and data were not complete, particularly before the late 1980s. For Nova Scotia, it was assumed that between province migration patterns would be small. The Nova Scotia Cancer Registry estimates that only 1-2% of cancer patients die outside of Nova Scotia, suggesting that cancer patients typically remain in Nova Scotia and have few interruptions to the person-years-at-risk they would contribute (Ron Dewar, personal communication, January, 2008).

In Manitoba, the linkage of the cancer registry and provincial health insurance plan

database was carried out by the data custodians to obtain follow-up information for the cohort. The researcher was *not* involved in any stage of the linkage process. The linkage process involved matching records from the cancer registries with the health provincial health insurance databases and merging them such that records referring to the same individual are associated. Several combinations of personal identifiers, including last name, first name, maiden name, last known address, sex, age, and health insurance number were used to ensure follow-up all of survivors in the event of name changes and missed routine matches. The population-based studies conducted to date demonstrate that population cancer registry-based record linkage methodology is robust enough to provide reliable second cancer risk estimates (e.g., Curtis et al., 2006; MacArthur et al., 2007).

Data Analysis

This section presents the procedures for describing the cohort characteristics and conducting the statistical analyses. All data analyses were conducted with STATA SE version 9.0. The cancer datasets from Manitoba and Nova Scotia were analyzed separately because approval was only granted for intra-provincial linkages, not inter-provincial linkages.

Description of Cohort Characteristics

The cohort characteristics were described to put the results of this study into context. Participants for whom data were missing or for whom no risk time (i.e., time into the year after diagnosis) was accumulated were removed from the analysis.

Stratification. Stratification was performed to enable different subgroups of the cohort to be compared (see Table 5 for categories). Five age categories, a variant of the age categories used by the National Cancer Institute's Surveillance, Epidemiology and

End Results (SEER) Program (Curtis et al., 2006), were considered for age at first cancer diagnosis and attained age at end of follow-up: 0-14 years, 15-29 years, 30-49 years, 50-69 years, and ≥ 70 years. To gain insight into different treatment patterns over the course of the study, the participants were classified in four categories by calendar period (1970-1979, 1980-1989, 1990-1999, 2000-2006), with calendar periods corresponding to provincial population cancer rates. Taking into account loss to follow-up, years after the diagnosis of the first cancer (time since diagnosis intervals) were categorized as 1-4 years, 5-9 years, 10-14 years, 15-19 years, and ≥ 20 years. The cancer diagnostic groupings were developed based on those from the diagnostic groupings for adult onset-cancers from the SEER Program (Curtis et al., 2006). Cancer diagnostic groupings were further categorized as solid tumor, hematologic malignancies and other tumors, which included melanoma of skin (see Table 5 for cancer diagnosis categories).

Table 5

Stratification by Cancer Diagnostic Groups

Diagnostic Group	Description
Solid tumors	
Buccal cavity, pharynx	Lip, tongue, salivary gland, mouth, nasopharynx, tonsil, oropharynx, hypopharynx, other
Digestive system	Esophagus, stomach, small intestine, colon, rectum/rectosigmoid junction, liver, anus/anal canal, bile ducts/other biliary, pancreas, other
Respiratory system	Nose/nasal cavity/ear, larynx, lung, bronchus, other
Breast	Breast
Female genital system	Cervix uteri, corpus uteri, ovary, vagina, vulva
Male genital system	Prostate, testis
Urinary system*	Urinary bladder, kidney, renal pelvis, other
Bone, connective tissue	
Melanoma of skin	
Eye, orbit	
Brain, central nervous system (CNS)	Brain, meninges, spinal, other CNS
Thyroid	Thyroid, other endocrine
Hematologic malignancies	
Lymphoma	Hodgkin's lymphoma, non-hodgkin's lymphoma
Leukemia	Acute lymphoblastic leukemia, chronic lymphoblastic leukemia, acute myeloid leukemia, chronic myeloid leukemia
Myeloma, other	Myeloma, other proliferative
Other tumors	
Melanoma of skin	
Unknown	

Note:

* In-situ bladder tumors were included in the urinary system because current Canadian Cancer Registry rules consider in-situ bladder to be invasive (Ron Dewar personal communication, April 23, 2008).

Person-years. Person-years-at-risk (PYR) was used to estimate the time-at risk that each cancer survivor contributed. Each cancer survivor accumulated a different amount of follow-up, depending on the length of time that they were at risk for a second cancer. Cancer survivors contributed person-years as long as they were second-cancer free, and therefore, still at risk of developing a second cancer. Tracking cancer survivors through time was needed to determine if cancer survivors truly had no second cancer diagnosis or if the lack of a second cancer diagnosis occurred because cancer survivors left the province or died. Person-years-at risk began accruing six months after the initial cancer was diagnosed, and ended on the year of a second cancer diagnosis, year of death, attainment of an upper age limit of 100 years of age if death is not recorded, or migration from the province where the initial cancer was diagnosed and treated, or end of study (December 2006), whichever came first. Year of second cancer diagnosis and reports of death registrations were available in cancer registry records. Insured health benefits program eligibility start/end dates were collected from Manitoba Health. Cancer survivors who left Manitoba, but returned after less than one year accumulated person-years throughout their absence. If the absence was more than one year, accumulation of person-years resumed upon their return.

Statistical Analyses

Poisson distribution and confidence intervals. Incidence rates and corresponding confidence intervals were calculated assuming that the number of second cancers occurred following a Poisson distribution (Young, 2005). A Poisson distribution is used when the occurrences of an event occur independently of each other and at random. Confidence intervals (CI) were used to help identify the degree to which random

variability may account for the results observed (Young, 2005). Ninety-five percent confidence intervals were used to determine statistical significant differences in rates. CIs were estimated using the Byar method, and risk estimates were considered significant if its 95% CI did not include one (Breslow & Day, 1987). All statistical tests were 2-sided with statistical significance determined at $p = 0.05$ level.

Standardized incidence ratios and excess absolute risk. The rates of second cancer were expressed as standardized incidence ratios (SIRs). SIRs are descriptive tools in the reporting of second cancer risk that account for the natural increase of cancer risk with age (Yasui et al., 2003). To estimate SIRs, the observed number of second cancer cases was compared to the number of new cancers expected in the general population (Young, 2005):

$$\text{SIR} = \frac{\text{Observed number of events (O)}}{\text{Expected number of events (E)}}$$

The expected number of cases of cancer was determined by multiplying the person-years-at-risk accumulated by the cancer survivor cohort by corresponding age-, sex- and calendar period-specific provincial cancer rates.

SIRs were presented by time since first cancer diagnosis intervals, sex, age at first diagnosis, treatment era, first cancer diagnosis, and second cancer diagnosis. Tests on statistical significance of the SIRs were performed, assuming that the observed number of second cancers followed a Poisson distribution and no variation was associated with the expected number of cases. The SIRs for which 95% confidence intervals excluded 1.0 were designated as statistically significant ($p < 0.05$) (Breslow & Day, 1987).

To calculate the excess absolute risk (EAR), the expected number of second cancers from the observed number and dividing the difference by the person-years-at-risk

(Young, 2005). The excess risk was expressed per 10,000 person years.

$$\text{EAR} = \frac{[(\text{Observed} - \text{expected})/\text{PYR}] \times 10,000}{10,000}$$

Ethical Considerations

The following ethical issues will be addressed in this section: administrative approvals, informed consent, confidentiality, and potential harms and benefits.

Administrative Approvals

Accessing cancer registry and health insurance plan databases required approval from the Director of the Manitoba Cancer Registry, Director of the Nova Scotia Cancer Registry, Manitoba Health, and CancerCare Manitoba's Research Resource Impact Committee (see Appendices I-L).

A written request for cancer registry and health insurance plan data was submitted. A contract, or confidentiality pledge, was signed by researcher, her supervisor and all colleagues with access to the anonymous data. The contract included provisions for safeguards/storage of the data, return/destruction of the data, third party activities, and registry's right to audit and review publications .

Informed Consent

The epidemiological data collection of this mixed method study fulfills all criteria for consent waiver outlined in the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans* (Interagency Secretariat on Research Ethics, 2009).

According to this policy statement, the requirement to seek informed consent may be waived for the collection of epidemiological data because the research involves minimal risk and the waiver does not adversely affect participants. Furthermore, it would be impractical to make all cancer survivors aware of and obtain their consent for all the

secondary uses of data collected to operate the cancer registries and provincial health systems. Among the factors that make seeking consent impractical, impossible or self-defeating with these data are: size of the population studied, number of individuals who have relocated or died, risk of introducing self-selection bias, and creation of greater privacy risks by linking otherwise de-identified data with identifiers in order to communicate with individuals so as to seek their consent (Deapen, 2006).

Confidentiality

Manitoba Health, Manitoba Cancer Registry and Nova Scotia Cancer Registry were the custodians of the information, accessing and linking the cancer registry and health insurance plan database for this study. The minimum cancer registry and health insurance plan data required for the purposes of this research study was requested. The researcher only had access to de-identified data. The use of personal identifiers was kept to an absolute minimum because it may be possible to identify individual indirectly by the use of other person-level identifiers (e.g., combinations of year of birth, sex, or presence of a relatively rare cancer diagnosis). Data were used only for the purpose for which it was requested. Descriptive data analysis and reporting was not allowed for variables with fewer than five cases per cell to protect confidentiality. No institution specific reporting was performed.

One electronic data file was housed on a secure server at the IWK Health Centre, and it was only accessible by the researcher, Dr. Louise Parker and a statistician. The IWK Health Centre server is backed-up daily. The researcher accessed the data through the NSHealth.ca Network. The researcher went through a rigorous application process with the IWK Health Centre Remote Access Committee for access to the data files stored

in wilkkl directory (researcher's directory) of the IWK Health Centre server through the NSHealth.ca Network. Other security features that were implemented included:

- only aggregated results were printed for discussion with supervisor and incorporation into results section;
- researcher was the sole user of the password assigned;
- researcher accessed data files from NSHealth.ca Network from a secure office; and
- computer used to connect to NSHealth.ca Network had the most up-to-date firewall and anti-virus software, as well as latest Windows security patches.

A second copy of the data file was stored at the Manitoba Cancer Registry, and was accessible only to Dr. Roberta Woodgate and Dr. Donna Turner. All data sets were stored unlinked. All data files stored on the hospital server were removed upon completion of the study. Both linked data files were returned to the data custodians when no longer required for this research project.

Potential Harms and Benefits

This study balanced concerns for the protection of privacy and confidentiality with the public health benefits of the population-based data sources. The risk of harm to individuals was considered very small. Accessing population-based data available in the cancer registries and provincial health insurance databases enabled the researcher to draw meaningful conclusions about second cancer risk that are representative of the whole cancer survivor population in Manitoba and Nova Scotia.

Chapter Summary

The epidemiological phase of this mixed methods study was designed to examine the magnitude of second cancer risk among cancer survivors. Epidemiological data were

gathered through population-based cancer registries and provincial health insurance databases. Methods used to describe the cohort and analyses the data are described. Ethical considerations and design limitations are addressed. The epidemiological results on second cancer risk are presented in the following chapter.

CHAPTER SEVEN: EPIDEMIOLOGY RESULTS – DESCRIPTIVE

EPIDEMIOLOGY OF SECOND CANCER RISK

Introduction

This chapter presents the epidemiology findings of second cancer risk.

The main findings address the following research questions:

Research Question 2: In Nova Scotia and Manitoba, what is the risk of developing a second cancer among cancer survivors compared to the general population stratified by age-, sex- and calendar year-adjusted risk estimates?

Research Question 3: In Nova Scotia and Manitoba, what demographic and disease risk factors are associated with second cancer risk among cancer survivors?

A description of the Nova Scotia and Manitoba cohorts is followed by the descriptive epidemiology of second cancer risk in the respective provinces. Differences and similarities in second cancer risk between the two provinces are presented.

Nova Scotia Cancer Data

Cohort Characteristics

All 112,891 residents of Nova Scotia diagnosed with a first cancer between 1970 and 2004 were included in the initial data set. Thirty participants were removed from the analysis because their birth dates were missing. A total of 30,266 participants who did not accumulate any risk time for were removed from the analysis. A total of 82,595 Nova Scotians were included in the final data set (see Table 6 for characteristics of the study cohort).

Table 6

Characteristics of the Nova Scotia Cohort 1970-2004

Characteristic	N
Sex	
Female	40,712
Male	41,883
Age at first cancer diagnosis	
0-14 years	811
15-29 years	1,930
30-49 years	11,813
50-69	37,759
≥70 years	30,282
Calendar period of first cancer diagnosis	
1970-1979	14,866
1980-1989	20,680
1990-1999	29,359
2000-2004	17,690
Time since first cancer diagnosis	
1-4 years	42,523
5-9 years	19,376
10-14 years	9,606
15-19 years	5,320
≥ 20 years	5,770
Attained age at censor event	
0-14 years	325
15-29 years	841
30-49 years	6,166
50-69	28,780
≥70 years	46,483
Person-years of follow-up	525,097
Second cancers included in analysis	8,460
Survival at end of study	
Participants without second cancer	28,091/74,135 (38%)
Participants with second cancer	2,370/8,460 (28%)

The Nova Scotia cancer cohort comprised of 41,883 (51%) males and 40,712 (49%) females. Less than 1% of cohort members were under age 15 at first cancer diagnosis and over 83% were over the age of 50 at diagnosis. The distribution of first cancers across the four calendar periods was highest in the 1990-1999 treatment era with 29,359 (36%) participants. The average time since diagnosis was 6.9 years ($SD = 6.9$, $range = 1-36$) with 42,523 (52%) of cancer survivors 1-4 years from their first cancer diagnosis. A total of 8,460 second cancers occurred in the Nova Scotia cohort. The majority of the second cancers occurred in 50-69 and ≥ 70 age groups, 34% and 62% respectively.

Follow-up

Of the 82,595 members of the cohort, 27,672 (33.5) were followed up until the study end point (December 31, 2006). 54,923 (66.5%) were censored (46,044 died and 419 were over 100 years of age), or diagnosed with a second cancer (8,460) before study completion. The cohort members accumulated a total of 525,097 person-years of follow-up, with a mean of 6.4 years ($SD = 6.9$, $range = 0.5-35.5$ years). The average attained age at the time of the censor event was 70 ($SD = 15$, $range = 1-112$).

Survival

At the end of the study, 52,134 (63%) of the Nova Scotia cohort had died. Survival was lower after a second cancer than after a first cancer; 38% of the cohort without a second cancer was alive at the end of follow-up compared to 28% with a second cancer. The majority (66%) of members of the Nova Scotia cancer cohort died between 50-69 years of age.

Types of First Cancer

The most common types of first cancer were solid tumors, accounting for 87% of the first cancers with hematologic cancers accounting for (6%) (see Table 7 for the distribution of first cancers). There were 4,330 (6%) “other” tumors. The most common types of solid tumors occurring in the cohort were breast cancer (17%), colon cancer (15%), prostate cancer (13%), and lung cancer (11%). Lymphomas accounted for 63% of the hematologic cancers.

Table 7

Nova Scotia Cohort First Cancers 1970-2004

Diagnostic Group	N (all)	N (male)	N (female)
Buccal cavity/pharynx	2,563	1,932	631
Tongue	397	283	114
Lip, mouth, other	1,565	1,200	365
Pharynx, tonsil	601	449	152
Digestive system	16,792	8,786	8,006
Esophagus	558	399	159
Stomach, peritoneum, other	1,867	1,173	694
Small bowel	210	100	110
Colon, rectum	12,733	6,380	6,353
Liver, bile duct	511	251	260
Pancreas	913	483	430
Respiratory system	10,347	7,012	3,335
Paranasal sinuses, larynx	1,156	947	209
Lung, trachea, bronchus, mediastinum, pleural cavity	9,191	6,065	3,126
Breast	13,642	92	13,550
Female genital system	6,488	-	6,488
Body of uterus	2,555	-	2,555
Cervix	1,900	-	1,900
Ovary	1,612	-	1,612
Other	421	-	421
Male genital system	11,910	11,910	-
Prostate	11,143	11,143	-
Testis	607	607	-
Penis, other	160	160	-
Urinary system	7,055	4,977	2,078
Bladder	4,643	3,512	1,131
Kidney, ureter, other	2,412	1,465	947
Bone, connective tissue	758	431	327
Eye, lacrimal gland	226	128	98
Brain, CNS	472	681	1,153
Thyroid, other endocrine	969	351	1,029
Hematologic malignancy	6,362	3,544	2,818
Lymphoma	3,920	1,140	1,780
Leukemia	1,641	948	693
Myeloma, other	801	456	345
Melanoma of skin	2,937	1,409	1,528
Unknown	1,393	733	660
	82,595	41,883	40,712

Types of Second Cancer

The distribution of second cancers by type was similar to that of first cancers. The most common types of second cancer were solid tumors, accounting for 87 % of the second cancers with hematologic cancers accounting for 7% (see Table 8 for the distribution of second cancers). There were 529 (6%) “other” tumors. The most common types of solid tumors occurring in the cohort were lung cancer (19%), colon cancer (18%), breast cancer (13%), prostate cancer (9%), and bladder cancer (6%). Lymphomas (53%) accounted for most of the hematologic cancers.

As would be expected, the most common tumor combination was a solid second tumor occurring after a first solid tumor; representing 79% of the 8,460 second cancers. Fifty-two percent of the second breast cancers occurred following a first breast cancer. The majority of the second colon cancers occurred after a first colon cancer (26%), first prostate cancer (18%), and first breast cancer (13%). Second lung cancer most commonly followed a diagnosis of colon cancer (15%) and prostate cancer (15%).

Table 8

Nova Scotia Cohort Second Cancers 1970-2006

Diagnostic Group	N (all)	N (male)	N (female)
Buccal cavity/pharynx	250	188	62
Tongue	49	36	13
Lip, mouth, other	131	100	31
Pharynx, tonsil	70	52	18
Digestive system	2,159	1,190	969
Esophagus	111	89	22
Stomach, peritoneum, other	221	135	86
Small bowel	42	28	14
Colon, rectum	1,485	794	691
Liver, bile duct	98	56	42
Pancreas	202	88	114
Respiratory system	1,713	1,098	615
Paranasal sinuses, larynx	95	1982	13
Lung, trachea, bronchus, mediastinum, pleural cavity	1,618	1,016	602
Breast	1,079	8	1,071
Female genital system	365	-	365
Body of uterus	184	-	184
Cervix	38	-	38
Ovary	105	-	105
Other	38	-	38
Male genital system	799	799	-
Prostate	774	774	-
Testis	9	9	-
Penis, other	16	16	-
Urinary system	780	550	230
Bladder	512	389	123
Kidney, ureter, other	268	161	107
Bone, connective tissue	51	26	25
Eye, lacrimal gland	17	6	11
Brain, CNS	79	50	29
Thyroid, other endocrine	71	15	56
Hematologic malignancy	568	306	262
Lymphoma	299	164	135
Leukemia	180	95	85
Myeloma, other	89	47	42
Melanoma of skin	233	137	96
Unknown	245	150	95
	8,460	4,555	3,905

Interval Between Cancers

The mean interval from diagnosis of the first cancer to occurrence of the second was 7.8 years ($SD = 6.5$; $range = 1-36$), although it varied by type of first and second cancers (see Table 9). For all first cancer diagnostic groups, second cancers continued for 36 years after the first diagnosis. The average time to diagnosis of second cancer was similar for both solid tumors and hematologic cancers, with a mean time to development of 7.8 years ($range = 1-36$ years) and 8.0 years ($range = 1-34$ years), respectively. The minimum average latency between first and second cancers was 4.9 years, diagnosed after multiple myeloma and other proliferative diseases. The time to development of a second cancer was generally longer following testicular cancer ($mean = 15.8$ years), Hodgkin's lymphoma ($mean = 15.0$ years), tumors of meninges, spinal or other CNS ($mean = 13.3$ years), and cervical cancer ($mean = 12.6$ years). Second small bowel cancers generally occurred after a much shorter period than all other types of second cancers, with a mean time to development of 4.5 years.

Table 9

Nova Scotia Cohort Interval Between Cancers

Cancer Diagnostic Group	Interval (years)					
	First cancer			Second cancer		
	Mean	Min.	Max.	Mean	Min.	Max.
Buccal cavity, pharynx	8.7	1	35	6.6	1	30
Digestive system	7.3	1	34	7.6	1	36
Respiratory system	6.9	1	34	7.7	1	34
Breast	8.4	1	34	7.9	1	35
Female genital system	10.9	1	36	8.6	1	32
Male genital system	6.1	1	34	7.9	1	35
Urinary system	7.0	1	32	7.2	1	34
Bone, connective tissue	9.8	1	30	8.1	1	31
Eye, lacrimal gland	9.0	1	31	9.7	2	34
Brain, CNS	8.9	1	26	8.6	1	33
Thyroid, other endocrine	10.0	1	35	7.1	1	24
Lymphoma	9.0	1	34	8.7	1	34
Leukemia	6.4	1	34	8.1	1	32
Myeloma, other	4.9	1	14	8.7	1	29
Melanoma of skin	7.9	1	31	7.3	1	33
Unknown	6.1	1	27	8.5	1	32

Incidence of Second Cancers

In an overall analysis of second cancers, the SIR for cohort members versus the general Nova Scotia population was 4.3 as of December 2006 (95% CI = 4.2, 4.4) (see Table 10). A total of 8,460 second cancers were observed compared with 1,960 expected. The estimate of the excess absolute risk (EAR) among all cancer survivors was 124 excess second cancer cases per 10,000 person-years.

Second cancer risk was slightly higher among male cancer survivors ($SIR = 5.0$) than among female cancer survivors ($SIR = 3.7$) for all first cancers combined. Similarly, the EAR was higher for males ($EAR = 160$ per 10,000 person-years) than females ($EAR = 96$ per 10,000 person-years), reflecting the overall higher risk of cancer in the male population.

Table 10

Nova Scotia Cohort Risk of a Second Cancer and Absolute Excess Risk by Demographic and Disease-Related Factors

Characteristics	O	E	SIR	95% CI	EAR
All first cancer diagnoses	8,460	1,960	4.3	4.2, 4.4	124
Sex					
Male	4,555	903	5.0	4.9, 5.2	160
Female	3,905	1043	3.7	3.6, 3.9	96
Age at first cancer diagnosis					
0-14 years	16	1	12.5	7.1, 20.3	15
15-29 years	71	6	11.3	8.8, 4.3	27
30-49 years	975	175	5.60	5.2, 5.9	73
50-69 years	4,479	2,155	2.1	2.0, 2.1	94
≥ 70 years	2,919	2,629	1.1	1.1, 1.1	21
Calendar period of first cancer diagnosis					
1970-1979	1,726	377	4.6	4.36, 4.80	97.43
1980-1989	2,571	548	4.7	4.52, 4.88	123.11
1990-1999	3,283	737	4.4	4.30, 4.61	145.17
2000-2006	880	229	3.9	3.60, 4.11	138.82

Note:

O = observed number of second cancer

E = expected number of cancers

SIR = ratio of observed to expected cancers

EAR = excess absolute risk (excess cancers per 10,000 person-years)

CI = confidence interval

$p < 0.05$ for all SIRs.

As shown in Table 11, striking differences in the risk of second cancer were observed by age at first cancer diagnosis. The risk of a second cancer was highest when the first cancer was diagnosed during the 0-14 age group ($SIR = 12.5$) and lowest when diagnosed after the age of 70 ($SIR = 1.1$). Males had the highest SIR in the 0-14 age group ($SIR = 13.9$), while females had the highest SIR in the 15-29 age group ($SIR = 12.8$). The large SIRs for the younger age groups translated into small absolute risks because second cancers were unusual in younger age groups. The greatest burden of second cancers was experienced by all individuals initially diagnosed at ages 50 to 69 years, with $EAR = 94$ per 10,000.

Table 11

Nova Scotia Cohort Risk of Second Cancer After Any First Cancer, by Age at First Cancer Diagnosis

Age at First Cancer Diagnosis	Total			Males			Females		
	O	SIR	EAR	O	SIR	EAR	O	SIR	EAR
All ages	8,460	4.3	124	4,555	5.0	160	3,905	3.7	96
0-14 years	16	12.5	15	10	13.9	18	6	10.7	12
15-29 years	71	11.3	27	29	9.3	23	42	12.8	30
30-49 years	975	5.6	73	320	7.9	81	655	4.3	67
50-69 years	4,479	2.1	94	2,412	2.2	121	2,067	2.0	74
≥ 70 years	2,919	1.1	21	1,784	1.02*	6	1,135	1.1	17

$p < 0.05$ for all SIRs except for males ≥ 70 years.

Risks of second cancers were highest in the first 5 years after diagnosis and tended to decline over time (see Figure 3 and Table 12). There were minimal differences in the rate of second cancers across each of the treatment eras. Differences arose with the EAR, with the highest EAR was highest for second cancers diagnosed during the 1990-1999 calendar period (EAR = 145).

Figure 3

Nova Scotia Cohort SIRs After Any First Cancer, by Calendar Period and Time Since First Cancer Diagnosis

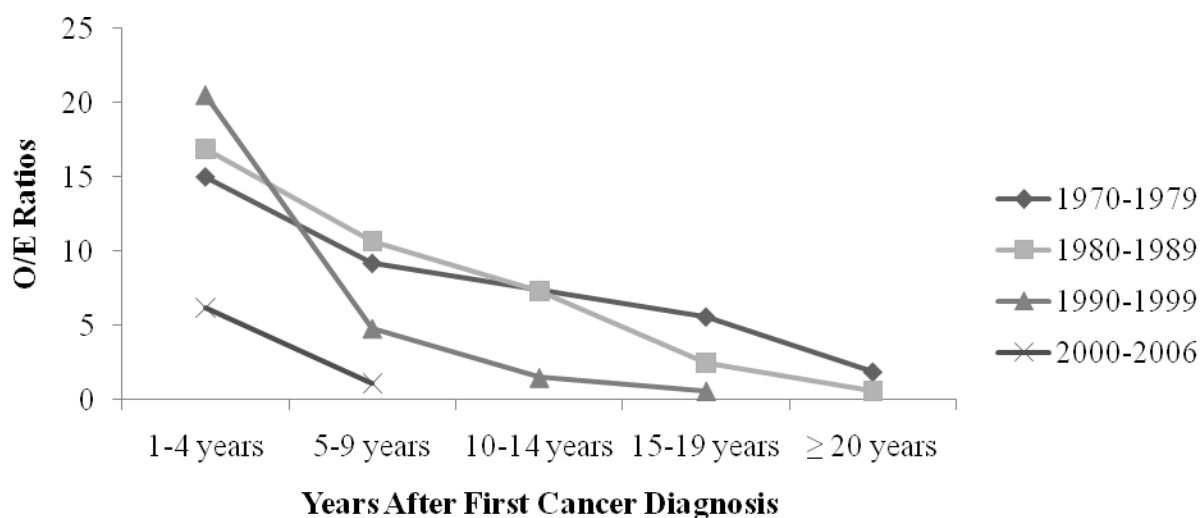


Table 12

Nova Scotia Cohort Risk of Second Cancer After Any First Cancer, by Calendar Period and Time Since First Cancer Diagnosis

Calendar Period of First Cancer Diagnosis	Years After First Cancer Diagnosis											
	Total		1-4 years		5-9 years		10-14 years		15-19 years		≥ 20 years	
SIRs	O	SIR	O	SIR	O	SIR	O	SIR	O	SIR	O	SIR
1970-1979	1,726	4.6	401	14.96	351	9.16	286	7.41	243	5.62	445	1.93
1980-1989	2,571	4.7	766	16.91	752	10.69	539	7.26	392	2.47	122	0.61
1990-1999	3,283	4.4	1,466	20.53	1,293	4.83	465	1.54	59	0.62	-	-
2000-2006	880	3.9	768	6.20	112	1.07*	-	-	-	-	-	-
EARs	O	EAR	O	EAR	O	EAR	O	EAR	O	EAR	O	EAR
1970-1979	1,726	97	401	380.16	351	222.20	286	174.69	243	125.78	445	25.43
1980-1989	2,571	123	766	529.90	752	322.94	539	208.57	392	48.85	122	-12.86
1990-1999	3,283	145	1,466	821.07	1,293	160.91	465	22.68	59	-16.18	-	-
2000-2006	880	139	768	253.49	112	3.36	-	-	-	-	-	-

$p < 0.05$ for all SIRs, except for 5-9 years after first cancer diagnosis in 2000-2006.

Excess of second cancers were observed among all first cancer diagnostic groups compared with that seen in the general Nova Scotia population (see Table 13). Risk of second cancers following solid cancers was over 4-fold higher than expected, with the risk higher for males ($SIR = 5.2$) than females ($SIR = 3.9$). Following hematologic malignancies, the SIR was highest among females ($SIR = 2.8$). The largest second cancer risks were observed following first cancers of the eye ($SIR = 10.6$) and buccal cavity/pharynx ($SIR = 9.2$). The lowest SIR was after first cancers of the brain, CNS ($SIR = 0.3$). Males had the higher SIR s than females for all first cancers, except lymphoma ($SIR = 3.5$ for females compared to $SIR = 0.4$ for males). For all first cancer diagnostic groups combined, the EAR was 124 excess cancers per 10,000 person-years. The highest EAR s were found for first cancers of the breast and digestive system ($EAR = 24$ and 22 , respectively) following the distribution of cancers in the Nova Scotia population. As expected, the highest EAR for males were for first cancers of the male genital system ($EAR = 43$). Likewise, the highest EAR for females was for first breast cancers ($EAR = 41$).

Overall, a significantly higher number of second cancers than expected were observed in every second cancer type (see Table 14). Among the specific types of second cancers, the greatest SIR was for second solid cancers ($SIR = 4.4$), including second cancers of urinary system ($SIR = 5.3$) and buccal cavity/pharynx ($SIR = 5.0$). The risk of second cancers by second hematologic cancers was over 3-fold higher than expected, with the risk higher for males ($SIR = 4.1$) than females ($SIR = 3.4$). Males had the highest SIR s for all second cancer diagnoses except second cancer of the eye ($SIR = 3.0$ for males compared to 5.8 for females) and second cancer of the thyroid ($SIR = 3.1$ compared to 3.5

for females). The highest EARs were for second cancers of the digestive system ($EAR = 33$), followed by second cancers of respiratory system ($EAR = 26$). EARs were also high for sex-specific second cancers, including second cancers of the breast and male genital system ($EAR = 27$ and 26 , respectively).

Table 13

Nova Scotia Cohort Risk of a Second Cancer and Absolute Excess Risk by First Cancer Diagnostic Group

First Cancer Diagnostic Group	Total			Males			Females		
	O	SIR	EAR	O	SIR	EAR	O	SIR	EAR
All cancers	8,460	4.3	124	4,555	5.0	160	3,905	3.7	96
Solid tumor	7,518	4.5	111	4,006	5.2	142	3,512	3.9	88
Hematologic malignancy	508	3.3	7	131	1.8	2	213	2.8	5
Other tumors	434	3.3	6	254	4.4	9	180	2.5	4
Buccal cavity, pharynx	456	9.2	8	360	11.0	14	96	6.8	3
Digestive system	1623	3.5	22	932	4.4	32	691	2.9	15
Respiratory system	752	2.3	8	561	2.8	16	191	1.6	2
Breast	1,514	5.9	24	10	5.8	0	1,504	5.3	41
Female genital system	696	4.9	19	-	-	-	696	4.9	19
Male genital system	1,196	5.8	43	1,196	5.8	43	-	-	-
Urinary system	1,067	7.3	18	844	9.4	33	223	4.7	-2
Bone, connective tissue	71	4.6	1	38	5.0	1	33	4.3	1
Eye, lacrimal gland	42	10.6	1	26	13.1	1	16	8.4	0
Brain, CNS	11	0.3	0	8	0.5	0	3	0.2	0
Thyroid, other endocrine	90	4.5	1	31	6.4	1	59	3.7	1
Lymphoma	336	3.9	6	18	0.4	-1	154	3.5	4
Leukemia	126	2.6	1	84	3.5	3	42	1.8	1
Myeloma, other	46	2.2	0	29	2.8	1	17	1.8	0
Melanoma of skin	360	6.6	6	200	8.6	8	160	5.1	4
Unknown	74	1.0*	0	54	1.6	1	20	0	-1

$p < 0.05$ for all SIRs, except for unknown (total).

Table 14

Nova Scotia Cohort Risk of a Second Cancer and Absolute Excess Risk by Second Cancer Diagnostic Group

Second Cancer Diagnostic Group	Total			Males			Females		
	O	SIR	EAR	O	SIR	EAR	O	SIR	EAR
All cancers	8,460	4.3	124	4,555	5.0	160	3,905	3.7	96
Solid tumor	7,363	4.4	108	3,930	5.1	138	3,433	3.9	86
Hematologic malignancy	568	3.7	8	306	4.1	10	262	3.4	6
Other tumors	529	4.1	8	319	5.6	11	210	2.9	5
Buccal cavity, pharynx	250	5.0	4	188	5.8	7	62	4.4	2
Digestive system	2,159	4.7	328	1,190	5.6	43	969	4.0	24
Respiratory system	1,713	5.2	26	1,098	5.5	40	615	5.3	17
Breast	1,079	4.2	16	8	4.6	0.3	1,071	3.8	27
Female genital system	365	2.6	7	-	-	-	365	2.6	7
Male genital system	799	3.9	26	799	3.9	26	-	-	-
Urinary system	780	5.3	12	550	6.1	20	230	4.7	6
Bone, connective tissue	51	3.3	1	26	3.4	1	25	3.3	1
Eye, lacrimal gland	17	4.3	0	6	3.0	0	11	5.8	0
Brain, CNS	79	2.4	1	50	3.0	1	29	1.9	0
Thyroid, other endocrine	71	3.6	1	15	3.1	0	56	3.5	1
Lymphoma	299	3.5	4	164	4.0	5	135	3.0	3
Leukemia	180	3.8	3	95	4.0	3	85	3.7	2
Myeloma, other	89	4.4	1	47	4.5	2	42	4.3	1
Melanoma of skin	233	4.3	3	137	5.9	5	96	3.1	2
Unknown	296	3.9	4	182	5.3	6	114	2.8	2

$p < 0.05$ for all SIRs.

Manitoba Cancer Data

Cohort Characteristics

All 134,455 participants who were diagnosed with a first cancer between 1970 and 2004, and were residents of Manitoba at the time of diagnosis were included in the initial data set. Two participants were removed from the analysis because their birth dates were missing. A total of 28,469 participants who did not accumulate any risk time were removed from the analysis. A total of 105,984 Manitobans were included in the final data set (see Table 15 for characteristics of the study cohort).

The Manitoba cancer cohort comprised of 53,739 (51%) males and 52,245 (49%) females. Fewer than 1% of cohort members were under age 15 at first cancer diagnosis and over 84% were over the age of 50 at diagnosis. The distribution of first cancers across the four calendar periods was highest in the 1990-1999 treatment era with 35,880 (34%). The average time since diagnosis was 7.2 years ($SD = 7.3$, $range = 1-36$) with 53,428 (50%) of cancer survivors 1-4 years from their first cancer diagnosis. A total of 11,446 second cancers occurred in the Manitoba cohort. The majority of the second cancers occurred in the 50-69 and ≥ 70 age groups, 32% and 64% respectively.

Table 15

Characteristics of the Manitoba Cohort 1970-2004

Characteristic	N
Sex	
Female	52,245
Male	53,739
Age at first cancer diagnosis	
0-14 years	1,025
15-29 years	2,504
30-49 years	13,881
50-69	46,131
≥70 years	42,443
Calendar period of first cancer diagnosis	
1970-1979	21,871
1980-1989	29,000
1990-1999	35,880
2000-2006	19,233
Time since first cancer diagnosis	
1-4 years	53,428
5-9 years	24,050
10-14 years	12,902
15-19 years	6,857
≥ 20 years	8,747
Attained age at censor event	
0-14 years	398
15-29 years	1,169
30-49 years	7,142
50-69	32,898
≥70 years	64,377
Person-years of follow-up	711,207
Second cancers included in analysis	11,446
Survival at end of study	
Participants without second cancer	35,725/ 94,538 (38%)
Participants with second cancer	3,188/11,446 (28%)

Follow-up

Of the 105,984 members of the cohort, 31,706 (30%) were followed up until the study end point (December 31, 2006). 102,701 (76%) were censored (58,338 died; 3,723 were lost to follow-up due to emigration; and 781 were over 100 years of age) or diagnosed with a second cancer (11,436) before study completion. The cohort members accumulated a total of 711,207 person-years of follow-up, with a mean of 6.7 years (*range* = 0.5-35.5 years) from six months post the initial cancer diagnosis. Participants who emigrated accrued a total of 25,122 person-years. The average person-years accumulated before censoring by loss to follow-up was 6.8 years (*SD* = 6.1, *range* = 0.5-33.5). The average attained age at the time of the censor event was 71.4 (*SD* = 15.1, *range* = 1-113).

Survival

At the end of the study, 67,071 (63%) of the Manitoba cohort had died. Survival was lower after a second cancer than after a first cancer; 38% of the cohort without a second cancer was alive at the end of follow-up compared to 28% with a second cancer. The majority (65%) of Manitoban cancer cohort died after the age of 70 years.

Types of First Cancer

The most common types of first cancer were solid tumors, accounting for 87% of the first cancers with hematologic cancers accounting for (9%) (see Table 16 for the distribution of first cancers). There were 4,313 (4%) “other” tumors. The most common types of solid tumors occurring in the cohort were breast cancer (17%), prostate cancer (15%), colon cancer (15%), lung cancer (10%), and bladder cancer (5%). Lymphomas accounted for 53% of the hematologic cancers.

Table 16

Manitoba Cohort First Cancers 1970-2004

Diagnostic Group	N (all)	N (male)	N (female)
Buccal cavity/pharynx	3,936	2,988	948
Tongue	496	312	184
Lip, mouth, other	2,725	2,148	577
Pharynx, tonsil	715	528	186
Digestive system	20,912	11,268	9,644
Esophagus	617	406	211
Stomach, peritoneum, other	2,494	1,556	938
Small bowel	273	144	129
Colon, rectum	15,348	8,051	7,297
Liver, bile duct	867	450	417
Pancreas	1,313	661	652
Respiratory system	11,923	7,747	4,176
Paranasal sinuses, larynx	1,182	969	213
Lung, trachea, bronchus, mediastinum, pleural cavity	10,741	6,778	3,963
Breast	17,544	128	17,416
Female genital system	8,913	-	8,913
Body of uterus	4,244	-	4,244
Cervix	1,953	-	1,953
Ovary	2,251	-	2,251
Other	465	-	465
Male genital system	16,568	16,568	-
Prostate	15,618	15,618	-
Testis	787	787	-
Penis, other	163	163	-
Urinary system	7,902	5,609	2,293
Bladder	5,122	3,885	1,237
Kidney, ureter, other	2,780	1,724	1,056
Bone, connective tissue	952	534	418
Eye, lacrimal gland	331	178	153
Brain, CNS	1,463	841	622
Thyroid, other endocrine	1,380	351	1,029
Hematologic malignancy	9,847	5,393	4,454
Lymphoma	5,224	2,744	2,480
Leukemia	3,155	1,861	1,294
Myeloma, other	1,468	788	680
Melanoma of skin	2,669	1,287	1,382
Unknown	1,644	847	797
	105,984	53,739	52,245

Types of Second Cancer

The distribution of second cancers by type was similar to that of first cancers. The most common types of second cancer were solid tumors, accounting for 87 % of the second cancers with hematologic cancers accounting for 8% (see Table 17 for the distribution of second cancers). There were 512 (5%) “other” tumors. The most common types of solid tumors occurring in the cohort were lung cancer (18%), colon cancer (15%), breast cancer (14%), prostate cancer (10 %), and bladder cancer (6%). Lymphomas accounted for 47% of the hematologic cancers.

As would be expected, the most common tumor combination was a solid second tumor occurring after a first solid tumor; representing 78% of the 11,446 second cancers. Seven percent of the second breast cancers occurred following a first breast cancer. The majority of the second colon cancers occurred after a first colon cancer (21%), first prostate cancer (21%), and first breast cancer (16%).

Table 17

Manitoba Cohort Second Cancers 1970-2006

Diagnostic Group	N (all)	N (male)	N (female)
Buccal cavity/pharynx	419	274	145
Tongue	77	39	38
Lip, mouth, other	255	169	86
Pharynx, tonsil	87	66	21
Digestive system	2,710	1,507	1,203
Esophagus	119	87	32
Stomach, peritoneum, other	329	215	114
Small bowel	58	38	20
Colon, rectum	1,770	929	841
Liver, bile duct	155	86	69
Pancreas	279	152	127
Respiratory system	2,196	1,373	823
Paranasal sinuses, larynx	97	72	25
Lung, trachea, bronchus, mediastinum, pleural cavity	2,099	1,301	798
Breast	1,595	0	1,581
Female genital system	579	-	579
Body of uterus	316	-	316
Cervix	51	-	51
Ovary	168	-	168
Other	44	-	44
Male genital system	1,134	1,134	-
Prostate	1,105	1,105	-
Testis	10	10	-
Penis, other	19	19	-
Urinary system	1,074	752	322
Bladder	672	485	187
Kidney, ureter, other	402	267	135
Bone, connective tissue	88	54	34
Eye, lacrimal gland	22	9	13
Brain, CNS	103	58	45
Thyroid, other endocrine	67	22	45
Hematologic malignancy	947	518	429
Lymphoma	443	222	221
Leukemia	346	204	142
Myeloma, other	158	92	66
Melanoma of skin	176	92	84
Unknown	336	179	157
	11,446	5,986	5,460

Interval Between Cancers

The mean interval from diagnosis of the first cancer to occurrence of the second was 7.9 years ($SD = 6.5$; $range = 1-36$), although it varied by type of first and second cancers (see Table 18). The mean time from diagnosis of the first cancer to occurrence of the second was 7.9 years ($SD = 6.5$; $range = 1-36$), although it varied by type of first and second cancers. For all first cancer diagnostic groups, second cancers continued to be present for over 35 years after the first diagnosis. The average time to diagnosis of second cancer was similar for both solid tumors and hematologic cancers, with a mean time to development of 8 years. The minimum average latency between first and second cancers was 3.9 years, diagnosed after tumors of the mediastinum and pleural cavity. Hodgkin's lymphoma had the longest latency as a first cancer ($mean = 12.6$ years), but had the shortest latency as a second cancer ($mean = 6.6$ years). The time to development of a second cancer was generally longer following testicular cancer ($mean = 12.5$ years), cervical cancer ($mean = 11.9$ years) and ovarian cancer ($mean = 11.0$ years). Second tumors of the larynx generally occurred after a much shorter period than all other types of second cancers, with a mean time to development of 7 years. Tumors continued to develop in all other second cancer groups for at least 17 years.

Table 18

Manitoba Cohort Interval Between Cancers

Cancer Diagnostic Group	Interval (years)					
	First cancer			Second cancer		
	Mean	Min.	Max.	Mean	Min.	Max.
Buccal cavity, pharynx	8.3	1	35	7.6	1	29
Digestive system	7.5	1	34	7.9	1	36
Respiratory system	6.7	1	30	7.8	1	35
Breast	8.8	1	35	8.5	1	34
Female genital system	10.9	1	36	8.3	1	31
Male genital system	6.4	1	33	7.5	1	35
Urinary system	7.1	1	33	7.3	1	33
Bone, connective tissue	10.5	1	31	8.3	1	35
Eye, lacrimal gland	10.8	1	29	8.9	2	17
Brain, CNS	9.4	1	24	8.1	1	31
Thyroid, other endocrine	10.0	1	33	9.0	1	29
Lymphoma	8.7	1	33	8.0	1	33
Leukemia	6.6	1	27	8.0	1	28
Myeloma, other	5.6	1	25	7.4	1	29
Melanoma of skin	8.9	1	33	8.5	1	33
Unknown	7.1	1	25	9.0	1	35

Incidence of Second Cancers

In an overall analysis of second cancers, the SIR for cohort members versus the general Manitoba population was 7.1 (95% CI = 7.0, 7.2) (see Table 19). A total of 11,446 second cancers were observed compared with 1,614 expected. The estimate of the excess absolute risk (EAR) among all cancer patients was 138 excess second cancer cases per 10,000 person-years.

Second cancer risk was slightly higher among male cancer survivors ($SIR = 9.0$) than among female cancer survivors ($SIR = 5.7$) for all first cancers combined. Similarly, the EAR was higher for males ($EAR = 171$ per 10,000 person-years) than females ($EAR = 112$ per 10,000 person-years), reflecting the overall higher risk of cancer in the male population.

Table 19

Manitoba Cohort Risk of a Second Cancer and Excess Absolute Risk by Demographic and Disease-Related Factors

Characteristics	O	E	SIR	95% CI	EAR
All first cancer diagnoses	11,446	1,615	7.1	7.0, 7.2	138
Sex					
Male	5,986	667	9.0	8.8, 9.2	171
Female	5,460	956	5.7	5.6, 5.9	112
Age at first cancer diagnosis					
0-14 years	14	1	13.3	7.2, 22.3	10
15-29 years	87	6	14.4	11.5, 17.7	26
30-49 years	1,260	130	9.7	9.2, 10.2	81
50-69 years	5,906	1,772	3.3	3.3, 3.4	124
≥ 70 years	4,179	2,188	1.9	1.9, 2.0	102
Calendar period of first cancer diagnosis					
1970-1979	2,843	620	4.59	4.4, 4.8	101
1980-1989	3,717	518	7.18	7.0, 7.4	140
1990-1999	3,926	417	9.42	9.1, 9.7	164
2000-2006	960	119	8.06	7.6, 8.6	167

$p < 0.05$ for all SIRs.

As shown in Table 20, striking differences in the risk of second cancer were observed by age at first cancer diagnosis. The risk of a second cancer was highest when the first cancer was diagnosed during the 15-29 age group ($SIR = 14.4$) and lowest when diagnosed after the age of 70 ($SIR = 1.9$). Males had the highest SIR in the 15-29 age group ($SIR = 13.3$), followed by the 30-49 age group ($SIR = 12.1$). Females had the highest SIR in the 0-14 and 15-29 age groups ($SIR = 15.4$ and 14.6 , respectively). The large SIRs for the younger age groups translated into small absolute risks because second cancers were unusual in the younger age groups. The greatest burden of second cancers was experienced by all individuals initially diagnosed at ages 50 to 69 years, with $EAR = 124$ per 10,000.

Table 20

Manitoba Cohort Risk of Second Cancer After Any First Cancer, by Age at First Cancer Diagnosis

Age at First Cancer Diagnosis	Total			Males			Females		
	O	SIR	EAR	O	SIR	EAR	O	SIR	EAR
All ages	11,446	7.1	139	5,986	9.0	171	5,460	5.7	112
0-14 years	14	13.3	10	7	11.4	9	7	15.4	12
15-29 years	87	14.4	26	30	13.3	21	57	14.6	28
30-49 years	1,260	9.7	81	345	12.1	75	915	7.9	83
50-69 years	5,906	3.3	124	3,025	3.6	150	2,881	3.2	105
≥ 70 years	4,179	1.9	102	2,579	1.7	99	1,600	2.1	90

$p < 0.05$ for all SIRs.

Risks of second cancers were highest in the first 5 years after diagnosis and tended to decline over time (see Figure 4 and Table 21). Risks were also higher in the 1990-1999 treatment era ($SIR = 9.42$), followed by the most recent treatment era of 2000-2006 ($SIR = 9.42$). Over the study period, the highest EAR was highest for first cancers diagnosed during the 2000-2006 treatment era.

Figure 4

Manitoba Cohort SIRs After Any First Cancer, by Calendar Period and Time Since First Cancer Diagnosis

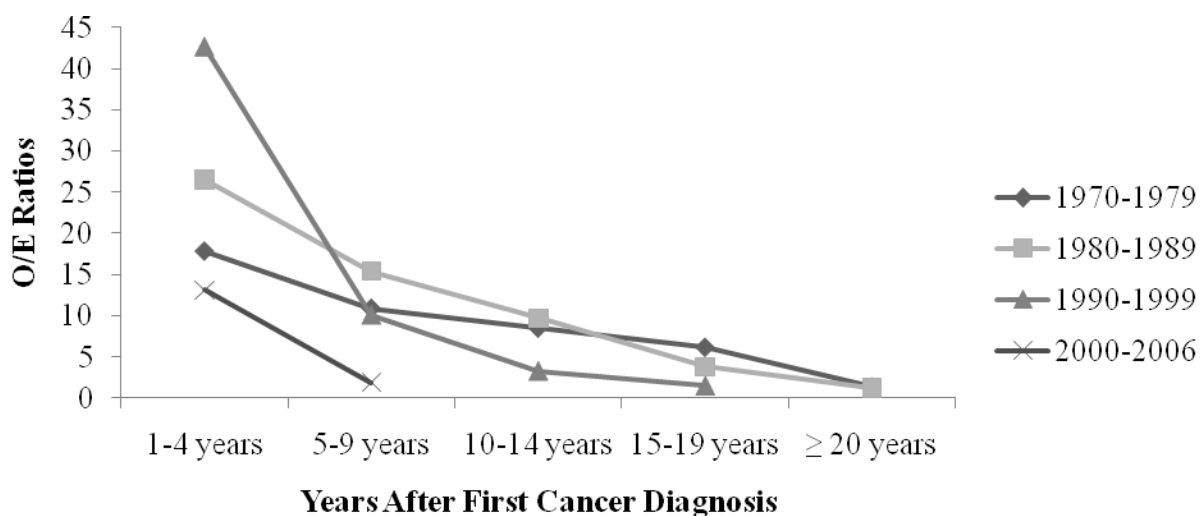


Table 21

Manitoba Cohort Risk of Second Cancer After Any First Cancer, by Calendar Period and Time Since First Cancer Diagnosis

Calendar Period of First Cancer Diagnosis	Years After First Cancer Diagnosis											
	Total		1-4 years		5-9 years		10-14 years		15-19 years		≥ 20 years	
SIRs	O	SIR	O	SIR	O	SIR	O	SIR	O	SIR	O	SIR
1970-1979	2,843	4.59	697	17.78	642	10.87	543	8.52	408	6.20	553	1.41
1980-1989	3,717	7.18	1152	26.48	1080	15.37	725	9.74	535	3.83	225	1.19
1990-1999	3,926	9.42	1789	42.58	1480	10.08	580	3.30	77	1.48	-	-
2000-2006	960	8.06	859	13.13	101	1.88	-	-	-	-	-	-
EARs	O	EAR	O	EAR	O	EAR	O	EAR	O	EAR	O	EAR
1970-1979	2,843	101.32	697	474.17	642	279.04	543	212.55	408	146.86	553	11.58
1980-1989	3,717	140.28	1152	578.43	1080	326.15	725	198.37	535	64.19	225	4.22
1990-1999	3,926	164.44	1789	812.02	1480	177.24	580	44.83	77	9.47	-	-
2000-2006	960	167.06	859	287.82	101	20.90	-	-	-	-	-	-

$p < 0.05$ for all SIRs.

Excess of second cancers were observed among all first cancer diagnostic groups compared with that seen in the general Manitoba population (see Table 22). Risk of second cancers following solid cancers was over 7-fold higher than expected, with the risk higher for males ($SIR = 8.3$) than females ($SIR = 6.7$). Following hematologic malignancies, the SIR was highest among males ($SIR = 7.7$). Among the specific types of first cancers, $SIRs$ were highest following firsts cancers of the thyroid ($SIR = 28.2$), buccal cavity/ pharynx ($SIR = 14.4$), urinary system ($SIR = 10.8$), and breast ($SIR = 10.2$). The lowest SIR , although not statistically significant, was after first melanomas ($SIR = 1.3$). Males had the higher $SIRs$ than females for most first cancers. Females had higher $SIRs$ for first myeloma and other proliferative diseases ($SIR = 9.1$ for females and 5.9 for males) and first cancers of the respiratory system ($SIR = 3.3$ for females and 1.0 for males). For all first cancer diagnostic groups combined, the EAR was 139 excess cancers per 10,000 person-years. The highest $EARs$ were found for first cancers of the breast and digestive system ($EAR = 28$ and 23, respectively). As expected, the highest EAR for males were for first cancers of the male genital system ($EAR = 50$). Likewise, the highest EAR for females was for first breast cancer ($EAR = 49$).

Overall, a significantly higher number of cancers than expected were observed in every second cancer type (see Table 23). Among the specific types of second cancers, the greatest SIR was for second solid cancers ($SIR = 7.4$), including second cancers of the eye ($SIR = 30.9$), thyroid ($SIR = 26.3$), urinary system ($SIR = 10.2$) and respiratory system ($SIR = 9.5$). The risk of second cancers by second hematologic cancers was nearly 7-fold higher than expected, with the risk higher for males ($SIR = 7.8$) than females ($SIR = 6.3$). Males had the highest $SIRs$ for all second cancer diagnoses except second cancers of the

eye ($SIR = 8.9$ for males compared to 10.7 for females) and respiratory system ($SIR = 2.3$ for males compared to 9.7 for females). The highest EARs was for second cancers of the digestive system ($EAR = 33$), followed by second cancers of respiratory system ($EAR = 27$). EARs were highest for second cancers of the digestive system ($EAR = 43$ for males and 25 for females), and for sex-specific second cancers including second cancers of the breast and male genital system ($EAR = 19$ and 31 , respectively).

Table 22

Manitoba Cohort Risk of a Second Cancer and Absolute Excess Risk by First Cancer Diagnostic Group

First Cancer Diagnostic Group	Total			Males			Females		
	O	SIR	EAR	O	SIR	EAR	O	SIR	EAR
All cancers	11,446	7.1	139	5,986	9.0	171	5,460	5.7	112
Solid tumor	10,136	7.4	123	5,208	8.3	147	4,928	6.7	105
Hematologic malignancy	930	6.2	11	556	7.7	16	374	5.0	8
Other tumors	380	4.4	4	222	5.9	6	158	1.5	1
Buccal cavity, pharynx	746	14.4	10	618	18.1	19	128	3.7	2
Digestive system	2,008	5.6	23	1,192	6.9	33	816	4.4	16
Respiratory system	915	3.8	9	612	1.0*	0	303	3.3	5
Breast	2,242	10.2	28	21	15.3	1	2,221	9.1	49
Female genital system	1,000	7.7	22	-	-	-	1,000	7.7	22
Male genital system	1,731	9.3	50	1,731	9.3	50	-	-	-
Urinary system	1,210	10.8	15	896	12.9	27	314	8.4	7
Bone, connective tissue	80	6.3	1	50	7.9	1	30	4.7	1
Eye, lacrimal gland	44	8.4	0	29	15.1	1	15	7.2	0
Brain, CNS	34	4.8	1	24	1.8	0	10	0.8*	0
Thyroid, other endocrine	126	28.2	7	35	8.7	1	91	6.0	2
Lymphoma	521	3.9	3	293	8.2	8	228	5.6	5
Leukemia	303	6.2	4	197	7.7	6	40	1.8	0
Myeloma, other	106	4.7	1	66	5.9	2	106	9.1	2
Melanoma of skin	305	1.3*	0	177	12.4	5	128	6.7	3
Unknown	75	1.4	0	45	2.0	1	30	1.0*	0

$p < 0.05$ for all SIRs except for melanoma (total), respiratory system (male), brain/CNS (female), and unknown (female).

Table 23

Manitoba Cohort Risk of a Second Cancer and Absolute Excess Risk by Second Cancer Diagnostic Group

Second Cancer Diagnostic Group	Total			Males			Females		
	O	SIR	EAR	O	SIR	EAR	O	SIR	EAR
All cancers	11,446	7.1	139	5,986	9.0	171	5,460	5.7	112
Solid tumor	9,987	7.4	121	5,197	8.5	147	4,790	6.7	101
Hematologic malignancy	947	6.8	11	518	7.8	14	429	6.3	9
Other tumors	512	6.4	6	271	8.1	8	241	5.6	5
Buccal cavity, pharynx	419	8.9	5	274	9.0	8	145	5.0	3
Digestive system	2,710	7.8	33	1,507	9.2	43	1,203	6.9	25
Respiratory system	2,196	9.5	27	1,373	2.3	24	823	9.7	18
Breast	1,595	7.6	19	14	17.1	0	1,581	6.8	33
Female genital system	579	4.8	11	-	-	-	579	4.8	11
Male genital system	1,134	6.4	31	1,134	6.4	31	-	-	-
Urinary system	1,074	10.2	14	752	11.6	22	322	9.6	7
Bone, connective tissue	88	8.5	1	54	11.1	2	34	7.4	1
Eye, lacrimal gland	22	30.9	1	9	8.9	0	13	10.7	0
Brain, CNS	103	3.2	1	58	5.8	1	45	4.7	1
Thyroid, other endocrine	67	26.3	6	22	8.3	1	45	3.9	1
Lymphoma	443	5.0	4	222	7.1	6	221	6.2	5
Leukemia	346	4.2	2	204	9.2	6	142	7.3	3
Myeloma, other	158	8.1	2	92	10.1	3	66	7.2	1
Melanoma of skin	176	1.0*	0	92	7.9	3	84	5.4	2
Unknown	336	7.0	4	179	9.0	5	157	6.1	3

$p < 0.05$ for all SIRs except melanoma (total).

Comparison of Nova Scotia and Manitoba Cancer Data

The Nova Scotia cohort ($N = 82,595$) first cancer cases eligible for inclusion in this study was smaller than the Manitoba cohort ($N = 105,984$). Both cohorts had similar characteristics in terms of sex, age at first cancer diagnosis, time since first cancer diagnosis, attained age at censor event and survival at end of study. One difference between the cohorts was that more first cancers were diagnosed in the 1970-1979 calendar period in Manitoba ($N = 21,871$) compared to Nova Scotia ($N = 14,866$); this difference may be attributed to fact the Manitoba Cancer Registry was well established by the 1970s and the Nova Scotia Cancer Registry was relatively new so cancer records may have been incomplete. The Manitoba cohort contributed more person-years of follow-up to the study. Survival rates were similar in both provinces with 63% deceased at the end the study. Breast, colon, prostate and lung cancers accounted for the majority of first and second cancers in both of the provinces. Similar patterns of first and second cancer combinations were found. The average time from first cancer diagnosis to the occurrence of a second cancer diagnosis was nearly 8 years in both provinces, and latencies were similar for both solid and hematologic cancers.

Overall, the second cancer rates were higher in the Manitoba cohort ($SIR = 7.09$) than in the Nova Scotia cohort ($SIR = 4.32$). One possible explanation for the differences in second cancer rates is the age distribution of each cancer cohort. As seen in Figure 5, the Manitoba cancer cohort is older than the Nova Scotia cancer cohort, and thus has longer follow-up, which translates into increased second cancer risk. Another possible explanation for the provincial differences in SIRs was the differences in contribution of person years from different periods of follow-up and treatment eras. As shown in Table

24, although the SIRs are strikingly different between the provinces, the absolute rates were very similar and the contribution of different strata is also very similar. This finding suggests that the differences in second cancer rates must be due the underlying cancer rates in each province; lower cancer rates in Manitoba translate into a higher SIR.

Figure 5

Comparison of Birth Years for Manitoba and Nova Scotia Cancer Cohorts

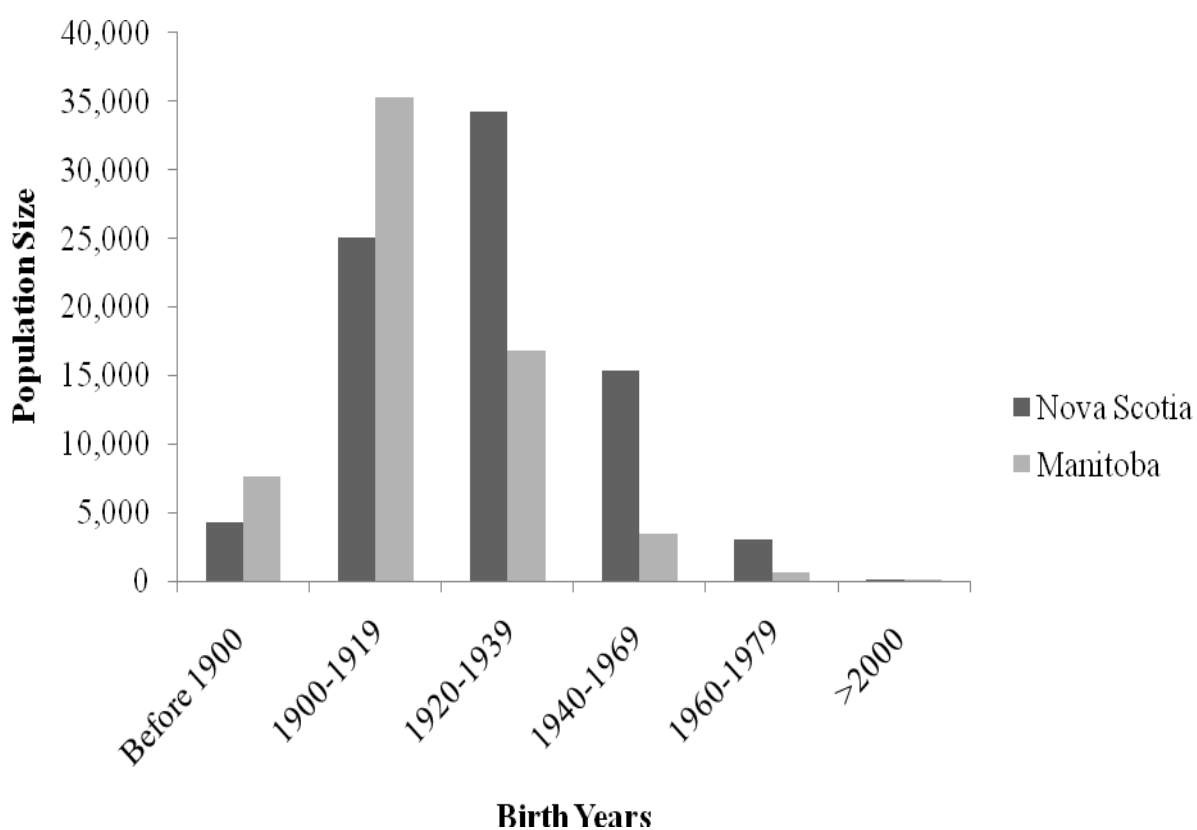


Table 24

Absolute Rates and Contribution of Different Strata to Person Years

Strata	Province							
	Nova Scotia				Manitoba			
	PY	% of PY	O	Absolute rate	PY	% of PY	O	Absolute rate
Calendar Period of First Cancer Diagnosis								
1970-1979	138,443	26%	1,726	0.01	219,403	31%	2,843	0.01
1980-1989	164,365	31%	2,571	0.02	228,063	32%	3,717	0.02
1990-1999	175,365	33%	3,283	0.02	213,402	30%	3,926	0.02
2000-2006	46,925	9%	880	0.02	50,340	7%	960	0.02
Time Since First Cancer Diagnosis								
1-4 years	65,843	13%	3,401	0.05	82,218	12%	4,497	0.05
5-9 years	120,401	23%	2,508	0.02	149,736	21%	3,303	0.02
10-14 years	108,301	21%	1,290	0.01	145,463	20%	1,848	0.01
15-19 years	86,411	16%	694	0.01	111,428	16%	1,020	0.01
≥ 20 years	144,142	27%	567	0.00	222,363	31%	778	0.00
ALL	525,098	100%	8,460	0.02	711,207	100%	11,446	0.02

Note:

PY = person-years-of-risk

N = total number of persons

O = observed number of second cancers

Males had higher second cancer rates than females in both provinces. Second cancer rates were also higher among cancer survivors diagnosed with a first cancer before 29 years of age. The pattern of second cancer rates was similar from 1970 through 2006 for the Nova Scotia cohort, while rates steadily rose in the Manitoba cohort over the same period. Second cancer rates by first cancer diagnostic group and second cancer diagnostic group in the Nova Scotia cohort are generally lower than the Manitoba. When specific first cancers are examined, the Nova Scotia cohort had higher second cancer rates following first cancers of the eye and first melanomas compared to the Manitoba cohort. Cancer rates in the Nova Scotia cohort were also higher than the Manitoba rates for second cancers of the male genital system and second melanomas.

Chapter Summary

Chapter seven presented population-based cancer risk estimates for cancer survivors residing in Nova Scotia and Manitoba. A description of the participants in the Nova Scotia and Manitoba cohorts and descriptive epidemiology of second cancer risk in the respective provinces were. Differences and similarities in second cancer risk between the two provinces are also noted. The methods used for the qualitative interviews conducting with a subset of the Nova Scotia cancer survivor population are described in the next chapter.

CHAPTER EIGHT: METHOD FOR INTERVIEW DATA COLLECTION

Introduction

This chapter details the research design that was applied to obtain information-rich qualitative data for the mixed method study, study sample, setting, data collection methods, and approach to data analysis. Ethical issues considered during the planning and conducting of this phase of the study, and issues of methodological rigor are addressed.

Research Design

A qualitative research design, specifically interpretive description, was undertaken to elicit a thematic description of cancer survivors' reported meanings of, and experiences with, second cancer risk. Interpretive description is a non-categorical qualitative method that has emerged as an alternative way of generating knowledge related to clinical practice (Thorne, 2008). Two key features of interpretive description are: (1) "an actual practice goal" and (2) "an understanding of what we know and don't know on the basis of existing empirical evidence" (Thorne, 2008, p. 35). An interpretive description design departs from traditional qualitative descriptive approaches (used in Phase 1 of the study – see Chapters 4 and 5) in that it encourages the researcher to construct a description of a phenomenon, and then move beyond the initial description, through interpretation, toward developing a comprehensive understanding of the phenomenon.

Interpretive description recognizes the "contextual and constructed nature of the human experience that at the same time allows for shared realities" (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004, p.5). For this study, the researcher was interested in how the descriptive accounts of risk were constructed by cancer survivors and how she

interpreted their experiences. In keeping with interpretive description, the product of this study is “a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied and also accounts for the inevitable variations within them” (Thorne et al., 2004, p.7). In this way, the results of this study are “tentative truth claims” about what is common in cancer survivors’ understanding of second cancer risk (Thorne et al. 2004).

Situated within the naturalistic interpretive paradigm, Thorne, Reimer Kirkham and O’Flynn-Magee (2004) have suggested interpretive description requires a methodologically pluralistic approach to capture the themes and patterns underpinning a phenomenon. In keeping with this thinking, a pluralistic approach which is influenced by grounded theory, phenomenology and ethnography was adopted to interview cancer survivors about second cancer risk (Thorne et al., 2004). A principle from grounded theory informing this study is that research is needed when there is limited knowledge of a phenomenon. The constant comparative analysis of grounded theory was used in recognition that the research is dynamic and continually evolving as new knowledge is discovered. In keeping with phenomenology, the researcher had the opportunity to learn about cancer survivors’ lived experiences of living with second cancer risk, and then reflected upon and interpreted them. The ethnographic component of the study was the interviewing of the members of cancer survivor cultural group to learn of the patterns and behaviors that inform their responses to second cancer risk.

Sampling

The sampling strategy, sample size, criteria for sample selection, and processes for participant recruitment are described.

Sampling Strategy

Purposive sampling techniques were used to capture the “expected and emerging variations within the phenomenon under study” (Thorne et al. 2004, p.6). Purposive sampling proved a useful tool in this study because the concern in recruiting participants was the representativeness of emerging concepts (Speziale & Carpenter, 2003).

Sample Size

Twenty-two cancer survivors participated in the qualitative interviews. The aim of study recruitment was to obtain a large enough sample to realize the richness of the individual experience (Speziale & Carpenter, 2003). Data were collected until redundancy occurred and the researcher found no new or relevant data emerging (i.e., data saturation had been achieved. Only one participant was interviewed twice. A total of 23 interviews were conducted.

Criteria for Sample Selection

Criteria for sample selection guided the recruitment and selection process of eligible participants. In recruiting participants, attention was directed toward selecting individuals based on their knowledge of the experience of being at risk for a second cancer, and their ability and willingness to reflect on and communicate this knowledge.

Participants in this research study met the following criteria:

- 1) Initial cancer diagnosis (at any age) notified to the Nova Scotia Cancer Registry between January 1970 and December 2004 (i.e., currently five or more years from the initial cancer diagnosis);
- 2) Resided in the region where interviews were being conducted;
- 3) At least 19 years of age by December 2008; and

- 4) Able to read, write and speak English.

Exclusion criteria for this study included:

- 1) Second cancer diagnosis notified to the Nova Scotia Cancer Registry;
- 2) Death notified to the Nova Scotia Cancer Registry;
- 3) Pre-malignant and benign tumor diagnoses notified to the Nova Scotia Cancer Registry;
- 4) Unaware of having been diagnosed and treated for cancer;
- 5) Has serious social, mental or medical conditions (e.g., Alzheimer's Disease) that would stop them taking part in the study (e.g., filling out forms); and
- 6) Currently on active cancer treatment.

Sample Recruitment

The sampling frame of individuals who meet the inclusion criteria was developed from the Nova Scotia Cancer Registry. Population-based cancer registries are a largely untapped for recruiting cancer survivors. Population-based cancer registries record information on all new (incident) cancer cases within the boundaries of a geographic location (Parkin, 2006). With more cases registered than hospital-based cancer registries, population-based registries have breadth, providing a sampling frame that represents minority, poor, and other hard-to-reach populations. Using the cancer registry as the sampling frame also ensured that individuals with a second cancer diagnosis, pre-malignant or benign tumor diagnosis or death notified to the cancer registry were excluded from the sampling frame. Another advantage is that population-based cancer registries is that by definition, they eliminate case identification problems related to decentralization of data found with hospital-based cancer registries (Pearson et al., 2002).

For example, with hospital-based registries, approval from each hospital's research ethics committee would be required, delaying research.

Population-based registries were challenging to access and use for participant recruitment. Because the Nova Scotia Cancer Registry did not have complete and accurate contact information for all cancer survivors in the database, additional resources were needed to track tracking survivors whose contact information was not update. For this study, the contact information from the Nova Scotia Cancer Registry was cross-referenced with data from the records of the Nova Scotia Department of Health and IWK Health Centre. Cross-referencing was done by staff of the cancer registry and IWK Health. The researcher was not involved in this process.

According to the recruitment policy of the Nova Scotia Cancer Registry, direct contact with potential participants by the cancer registry, on behalf of researchers, is standard practice for cancer survivors from the adult cancer care system, but is not possible for cancer survivors from the pediatric cancer care system (Maureen McIntyre, personal communication, October 16, 2007). Therefore, recruitment of cancer survivors eligible for this study was achieved in two ways depending on the cancer care system in which the survivors received treatment. For potential participants recruited from the adult cancer system, a recruitment package was mailed directly to them from the Nova Scotia Cancer Registry. Potential participants recruited from the pediatric cancer care system (as documented in the cancer registry records) required additional scrutiny. For these potential participants, pediatric oncologist, Dr. Margaret Yhap, from IWK Health cross-referenced the sampling frame from the cancer registry with the pediatric oncology department's patient database for matches, and revised the sampling frame to include

only cancer survivors who (1) had a current mailing address on record at the IWK Health Centre, (2) were aware of their cancer diagnosis, (3) had no serious social, mental or medical conditions that would preclude study participation, and (4) had completed cancer treatment. Dr. Yhap's administrative assistant mailed a recruitment package to these potential participants.

The recruitment packages included a cover letter from the Nova Scotia Cancer Registry or Dr. Yhap, as appropriate; invitation letter; reply card; and postage-paid return envelope (see Appendices M and N). Letters of invitation described the study and requested that potential participants contact the researcher about their interest in participating in the study. Reminder packages were mailed to non-responders within five weeks of the initial mail-out. To track responders and non-responders, each potential participant was assigned a code, which was marked on the reply card (e.g., CR#, IWK#). If potential participants were not interested in participating, their participation in the study was not pursued. It was only *after* potential participants contacted the researcher for further information, or to set up an interview that names and contact information were collected. The researcher's initial contact with potential participants was by telephone. Telephone contact allowed the researcher to explain the study to potential participants, answer questions, and set-up the interviews. During this initial contact, the researcher determined if potential participants recruited through the cancer registry were on active treatment and excluded those individuals from study participation (see Appendix O for the telephone script).

Recruitment letters were mailed to 100 cancer survivors who met the inclusion. Three recruitment packages were returned as undeliverable. Fifty-six cancer survivors

responded to the recruitment letter, yielding no interest from 26 cancer survivors, interest of 30 cancer survivors and no response from the other cancer survivors. Reasons cited for lack of interest in the study included too busy to participate, feeling uncomfortable talking about second cancer risk, desire to forget they had cancer, and believing they did not qualify as “cancer survivors” because they never had cancer. Of the 30 cancer survivors who were interested in learning more about the study, 3 were never reached and 5 did not qualify for study. Reasons for cancer survivors not qualifying for the study were that they lived outside of the region where interviews were conducted, had been diagnosed with cancer after 2004, or had developed a recent recurrence. All eligible cancer survivors who were contacted (n = 22) agreed to participate in the study.

Data Collection Methods

Data were collected using a demographic form and semi-structured interview format. Interviewing techniques are described. Field notes were also maintained.

Demographic Form

To begin the process of engagement, a demographic form was used to obtain a demographic and health profile of all individuals participating in the study (see Appendix P). Data collected from the demographic form included: age, household, place of residence, education, occupational status, ethnic/cultural background, name of original cancer, year of cancer diagnosis, age at cancer diagnosis, cancer treatments, and relapse status. Questions were adapted from the 2006 Census Dictionary (Statistics Canada, 2007). The demographic form took about 5 minutes to complete.

Semi-structured Interview

Semi-structured interviews are the most common type of interviews (Speziale &

Carpenter, 2003). The purpose of the interviews was to gain an understanding about how cancer survivors perceive and assess second cancer risk. Interviews were used to uncover the perspectives of people who experience the phenomenon under study and generate detailed responses (Speziale & Carpenter, 2003). A person-centered, open-ended interviewing approach engaged the participant as an “informant” who is knowledgeable person about a particular phenomenon and encourages the generation of new knowledge and subsequent interpretation (Levy & Hollan, 1998). That is, an open-ended technique was used in the interview process in order to elicit detailed responses and to focus participants' responses into areas previously not anticipated.

The interviews generally lasted for one hour. Table 25 lists the participant’s pseudonym and total length of the interviews. One participant was interviewed twice because she had to stop the first interview due to childcare concerns. The participants offered the researcher the opportunity of remaining in contact them after the interview so as to clarify what was previously said.

The researcher conducted all interviews. All interviews were digitally recorded in order to preserve their authenticity and to facilitate detailed analysis. Care was taken to minimize errors such as unclear notes and equipment failure. Recording equipment was checked regularly to ensure it was functioning properly, and spare batteries were readily available.

Table 25

Pseudonym and Length of Interviews

Pseudonym	Total Length of Interview(s) (minutes)
Audrey	61
Evelyn	59
Karen	81
Tracey	106
Carrie	66
Helen	32
David	94
Matt	31
Rebecca	49
Brenda	76
Sean	68
Anna	56
Kelly	96
Joe	79
Adam	61
Theresa	92
Brian	58
Sarah	61
Julie	32
Natalie	81
Maureen	50
Laura	25
TOTAL	1414

Interviewing techniques. In semi-structured interviews, questions emerge from pre-planned topics areas which are adapted to suit the pace and mood of individual participants (Speziale & Carpenter, 2003). An interview guide was used to help participants articulate their thoughts and feelings about their personal cancer experience, their second cancer risk, and how they manage that risk. The questions were open enough to allow participants to develop the conversation in whichever ways are most relevant to their situation. Additional questions (i.e., probes) were developed for each main question but were only asked when there was a need to stimulate discussion.

The researcher and Dr. Roberta Woodgate developed an interview guide from (1) key themes identified in a review of the literature on second cancer risk, and cancer risk perceptions and management among cancer survivors, and (2) their experience in caring for cancer patients (see Appendix Q). Two adult cancer survivors reviewed and approved the interview guide. Following the first six interviews, the question requesting participants to speak to the risks they are concerned about for their health was dropped because participants' responses were redundant.

The researcher used various techniques to develop an interactive, trusting researcher-participant relationship. These techniques included giving participants the choice of where the interview took place and asking warm-up questions prior to the interview. Additional interview strategies used to facilitate discussion included: the use of silence, calls for examples, and simple questions to extend something the participant has said (Lincoln & Guba, 1985). The researcher explained to participants her interest in the research problem and importance of the information being obtained. The researcher did not share that she was cancer survivor until after the interview was completed.

Occasionally, this sharing encouraged the participant to further reflect on their understanding of second cancer risk.

Field Notes

The third source of data collection was field notes that the researcher kept throughout the research study to record the setting, nonverbal behaviors, interruptions in the flow of conversations, reminders or critique on the methodology, and patterns discerned from the work in progress. Field notes were made subsequent to each interview.

Setting

Interviews were conducted where the cancer survivors desired so that they were comfortable during the interview process. Fourteen interviews were conducted in the participant's home, 7 in the researcher's office at the IWK Health Centre, and 1 in an office in the participant's workplace.

Data Analysis

In keeping with a qualitative research approach, data analysis occurred concurrently with data collection, allowing data collection and data analysis to mutually inform one another (Speziale & Carpenter, 2003). All interviews and field notes were transcribed verbatim by the researcher and/or transcriptionist, and entered into a computer. Interview transcripts were returned to the participants for their approval. Two participants offered minor changes to their transcripts and one participant wrote a letter to the researcher further explaining a few experiences she had with cancer scares. Interview transcripts were read only by researcher and Dr. Roberta Woodgate. Each interview was listened to following the interview, prior to transcription to review the interview experience, and

after transcription.

A flexible approach to data analysis was adopted in keeping with the naturalistic interpretive paradigm (Thorne et al., 2004). Interpretive description requires that questions such as “what is happening here?” and “what am I learning about this?” be asked to apprehend the overall picture provided by the data (Thorne, Kirkham & MacDonald-Emes, 1997). Immersion in the text began with the identification of words of potential interest. Textual information was categorized and coded based on the study’s guiding framework. In keeping with interpretive description, the researcher searched for and explored “features of a common issue” and rendered “an understanding of them that honors their inherent complexity” (Thorne, 2008, p.75). Constant comparative analysis of grounded theory was used such that data coding was an iterative process of going back to the data and comparing it with emerging codes and creating new codes. Differences and similarities between and within codes and categories were noted, and the underlying meaning of the categories was formulated into themes (Graneheim & Lundman, 2004). Common themes from individual interviews were abstracted and created by the researcher and Dr. Roberta Woodgate.

Basic descriptive statistics, including means, medians, percentages, ranges and standard deviations were used for the demographic data. The small sample size precluded further statistical analyses.

Methodological Rigor

Rigor in qualitative research is important in the practice of good research (Speziale & Carpenter, 2003). While quantitative research relies on measures of reliability and validity to evaluate the utility of a study, qualitative research is evaluated

by its “trustworthiness”, or ability to portray the experience being studied (Lincoln & Guba, 1985). Although proponents of interpretive description are critical of the “litany of attributes such as trustworthiness, transferability or making claims about one’s integrity’ (Thorne et al., 2004, p.15), the guidelines offered by Lincoln and Guba (1985) were helpful to establish the credibility of this study. Lincoln and Guba (1985) have suggested that there are four primary criteria for establishing trustworthiness: credibility, dependability, confirmability and transferability.

Credibility

Credibility is the process whereby the researcher assures that the study findings are meaningful and reflect the current experience (Lincoln & Guba, 1985). In this study, credibility was achieved by:

- Member checking: Interview transcripts were returned to all participants for them to check. Participants were encouraged to comment on the transcripts and make changes. Any comments were added to the transcripts for data analysis.
- Prolonged engagement in the topic: Data collection took place in hours lasting generally about one hour. The researcher engaged in general conversation with participants before and after the interview.
- Reaching data saturation: Saturation or the duplication of information obtained from participants was reflected in the data collection and analysis process of the study. This criterion provided the basis for the researcher’s decision to not seek out additional participants.
- Peer review and debriefing: The researcher and Dr. Roberta Woodgate met periodically discuss findings and impressions. The researcher and Dr. Roberta

Woodgate jointly developed an interpretation of the study findings.

Transferability

Transferability refers to the likelihood that findings of a study may have meaning for others in similar situations (Lincoln & Guba, 1985). For qualitative research, the burden of transferability rests with the users of the research (Lincoln & Guba, 1985).

Transferability in this study was addressed by providing thick and detailed descriptions of the processes used by the researcher, including the time, place and context of interviews, and methodological decisions and impressions.

Dependability

Dependability is concerned with the transparency of the research (Lincoln & Guba, 1985). For this study, dependability has been achieved through a detailed audit trail.

Documentation included in the audit trail was contextual information (setting, behaviors), methodological information, analytical decisions, and personal reflections and a priori thoughts. This audit trail allows another researcher to easily follow the decision trail used by the researcher of the study to arrive at similar conclusions (Lincoln & Guba, 1985).

As part of auditing the study, the researcher and Dr. Roberta Woodgate met independently checking a selection of the interview transcripts to see if there was some initial agreement as to the emerging themes.

Confirmability

Confirmability is concerned with establishing that data and interpretations are derived from the data, not the researcher's personal constructions (Lincoln & Guba, 1985). It assures that interferences made by the researcher are logical. Confirmability of this study was established by (1) using direct quotes, (2) adhering to the analysis process,

(3) validating findings with participants during and immediately following the interviews, and (4) using a journal to record content and process of interactions between researcher and participant as well as the researcher's reactions to events in research.

Ethical Considerations

The following ethical issues will be addressed in this section: informed consent, confidentiality, potential harms and benefits.

Informed Consent

Study information and consent forms were distributed prior to the interview. The consent forms followed the format of the Capital Health District Authority (CHDA) Research Ethics Board for participants recruited through the Nova Scotia Cancer Registry (see Appendix R), and IWK Research Ethics Board for participants recruited through the IWK pediatric oncology department (see Appendix S). Participants were given as much time as needed to review the consent form. The researcher left the room while the participants read the consent form. Participants were encouraged to mark anything they did not understand, or wanted better explained. Participants signed the consent form in front of the researcher and a witness. Ongoing consent was obtained verbally by the researcher at the beginning of each interview. This approach to consent encourages mutual participation and takes into consideration the possibility of unexpected events or changes in circumstances (Speziale & Carpenter, 2003). If potential participants were not interested in participating, their participation in the study was not pursued. Participants were made aware that their participation was voluntary and that withdrawal at any time was allowed without penalty. On the consent form, permission for future contact was requested because the researcher plans to conduct further survivorship research.

Confidentiality

While the names of participants were known in order to secure their written informed consent for the interviews, no names were attached to any of the data collection methods (e.g., demographic form, interview transcripts). Only the researcher had access to participants' names. It was only *after* potential participants contacted the researcher for further information or to set up an interview that names and contact information were collected. Code numbers and pseudonyms were used on all sources of data. Only the researcher and Dr. Roberta Woodgate read the interviews. In presentations and publications, no one will be able to identify any individual study member in any way.

All electronic data files were stored on the secure University of New Brunswick server, and computer protected by a password known only to the researcher. Digital recordings, interview transcripts, and demographic information will be stored in a locked filing cabinet in the researcher's University of New Brunswick office for 7 years. Hard copies of data (e.g., demographic form, interview transcripts) and participant lists (one with participants' names and the other with participants' code numbers) are kept in separate files. After 7 years, all data will be destroyed.

Potential Harms and Benefits

The main risk associated with recruiting potential participants for the interviews through a third party was the potential invasion of privacy. Potential participants may perceive that their privacy has been invaded when a researcher gains access to personal information before they have agreed to participate in the research. To minimize invasion of privacy, sample recruitment took into consideration the potential participants' right to decline without the researcher knowing this decision. Moreover, the research team did

not know who was invited to participate in the study, and neither the cancer registry nor the IWK Health Centre pediatric oncology department knew who did and did not participate in the study. This process allowed potential participants to make autonomous choices rather than imposing choices upon them. Potential participants were contacted by telephone only after receiving an affirmative response on the reply card or through telephone call. A postage-paid envelope was provided for potential participants to return the reply card.

Harm may also occur if new information is introduced as part of the offer to participate in research. For example, because cancer survivors are not always aware of their cancer history, particularly if they were treated at a young age, they could learn of it through researcher contact. For this study, a requirement for cancer survivors to participate in the interviews was that they must be aware of being diagnosed and treated for cancer. The IWK Health Centre pediatric oncology department made this assessment for childhood cancer survivors. Survivors recruited through the Nova Scotia Cancer Registry made make this assessment on the consent form for themselves. Another requirement to participate in the study was that potential participants must be at least 5 years post-diagnosis. This time was chosen to allow cancer survivors enough time to return to their everyday life.

For potential participants recruited through the Nova Scotia Cancer Registry, it was not possible to know their current treatment status. Thus, during the initial telephone contact, the researcher assessed individuals' treatment status and excluded anyone on active cancer treatment.

Because this study is interested in obtaining the views of cancer survivors about

their potential risks for developing a second cancer, cancer survivors who have developed a second cancer were excluded. When a second cancer diagnosis had not been registered in the Nova Scotia Cancer Registry but a participant disclosed during the interview that he/she has had a second cancer diagnosis in describing their health, the interview was stopped.

Some participants became more aware of their feelings given the opportunity to talk about second cancer risk. Respect, caution and sensitivity were exercised when interacting with participants in order to prevent the possibility of undue stress. If participants experience signs of increased distress, the interview was stopped and only resumed if and when the participant felt comfortable to continue. A follow-up telephone call was made to each participant within 24-48 hours of the interview to ensure that all was well. Participants received an information sheet, *Risk of Second Cancers in Cancer Survivors*, to provide them with feedback about second cancer risk and what they might do about it (see Appendix T). This information sheet was reviewed by Dr. Peggy Yhap and Annette Penney, RN of the pediatric oncology department, IWK Health Centre.

Participants were advised that the interviewer cannot tell participants what their personal risk is for developing a second cancer. Participants were referred to their oncologist or family doctor to discuss their personal second cancer risk and what can be done to manage that risk. If they did not have a family doctor, participants were instructed to find a family doctor currently accepting new patients by calling the Physician Information Line at 902-424-3047 or visiting the Nova Scotia Department of Health's website at www.gov.ns.ca/health/physicians/physicians.asp.

Participants received a \$20 bookstore gift card for the inconvenience of

participation. If participants choose to have the interview conducted outside of their home, they were also be reimbursed for parking. A toll-free telephone number linked to the researcher's office telephone number was available so that cancer survivors could contact the researcher directly without incurring any cost.

Participating in the interviews may increase cancer survivors' awareness of second cancer risk and the benefits of maintaining regular follow-up appointments for clinical assessments and participating in cancer screening activities. Participants may then be more ready to make behavioral changes to reduce their second cancer risk and more confident in their ability to make such changes.

Chapter Summary

Qualitative interviews in this mixed method study were designed to gain an understanding of what meaning cancer survivors assign to their second cancer risk and how they manage that risk. Data were gathered through semi-structured interviews, demographic questionnaire and field notes. The research setting was in the participant's home or workplace office, or the researcher's office. Data were coded and themes emerged. In this research, data analysis began with each interview and continued through data collection and writing. Methodological rigor and ethical considerations were also described. The results of the qualitative interviews are described in the next chapter.

CHAPTER NINE: INTERVIEW RESULTS – PERCEPTIONS OF SECOND CANCER RISK

Introduction

In Chapter nine, the findings of the qualitative research interviews are presented. The chapter begins with a description of the participants. The main findings address the following research questions:

Research Question 4: What are cancer survivors' understandings of second cancer risk?

Research Question 5: How do cancer survivors attempt to modify second cancer risk?

Description of Participants

The 22 cancer survivors who participated in this study had an average age of 50 years (*range* = 19-87 years). The majority of survivors were female. Seven survivors lived alone and 14 lived with another family member (e.g., spouse/partner, children, parent), predominantly in urban areas of Nova Scotia. Most study participants had a minimum of high school education. Fifteen participants were employed part-time or full-time, six were retired and one was off work due to a disability. All the cancer survivors who participated in the study were Caucasian. Table 26 presents a summary of participant demographic information.

The cancer history of the participants varied. The first cancer diagnoses included: breast cancer ($n = 4$), lymphoma ($n = 4$), colon cancer ($n = 3$), melanoma ($n = 3$), gynecological cancer ($n = 2$), leukemia ($n = 2$), testicular cancer ($n = 1$), thyroid cancer ($n = 1$), soft tissue sarcoma ($n = 1$) and stomach cancer ($n = 1$). The cancer treatments for these cancers were surgery ($n = 7$), chemotherapy ($n = 2$), chemotherapy in combination with radiation therapy and/or surgery ($n = 9$), and radiation therapy and surgery ($n = 4$).

The average age at time of cancer diagnosis was 40 years (*range* = 2-78 years). At the time of the interview, participants were, on average, 11 years post-diagnosis (*range* = 5-18 years). Two cancer survivors reported having a relapse of their first cancer.

Table 26

Participant Demographic Information

Characteristic	Number (%)
Sex	
Female	16 (73%)
Male	6 (27%)
Residence	
Rural	2 (9%)
Urban/sub-urban	20 (91%)
Household members	
Lives alone	7 (32%)
Lives with spouse	8 (37%)
Lives with parents	3 (13%)
Lives with children only	2 (9%)
Lives with spouse and children	2 (9%)
Highest level of education	
Less than high school	2 (9%)
High school diploma	4 (18%)
University/college degree	11 (50%)
Trade certificate/diploma	5 (23%)
Current employment status	
Working full-time	11 (50%)
Working part-time	4 (18%)
Retired or on disability	7 (22%)

Main Findings

The main findings of the study outline the themes that capture cancer survivors' reported meanings of, and experiences with, second cancer risk. Data analysis revealed that the primary theme is life after cancer - living with risk. No age or sex differences in living with risk were noted. The four sub-themes that emerged from the interviews with cancer survivors were: (1) thinking about second risk, (2) living with risk: a family affair, (3) taking care of second risk and (4) support for taking care of second risk.

Primary Theme: Life After Cancer – Living with Risk

After cancer, the risk of developing a second cancer is a part of everyday life for cancer survivors. When asked to reflect on the meaning of “risk”, study participants, for the most part, struggled to put the meaning of risk into words. Most equated risk with such words “possibility”, “probability”, “chance” or “likelihood” of harm, which in this study was cancer. However, some expressed a more sophisticated understanding of risk that revealed an underlying sense that risk is a personally experienced state of change. One participant explained, using heart health as an example, that a “concern helps prevent the risk.” She said:

I get concerned about my heart health. In terms of me being at risk of developing heart disease, I've never really went that far with it. I do know that chemo drugs are hard on your heart. I have not run out and asked for an EKG or a dye test or anything like that because there is nothing to indicate to me that I would need that. But, I do get my cholesterol checked now every year and I do try, like I said, to eat healthy. I'm aware of fish versus red meat versus whatever. I am trying to educate myself on eating properly so the concern doesn't turn in to a risk I guess. (Carrie, 39-year-old soft tissue sarcoma survivor)

Another participant spoke of risk as a danger in the context of a family history of cancer. Helen, a 82-year-old colorectal cancer survivor, described cancer as a danger in families “riddled with cancer” and as a risk in families, like her own, in which cancer is not

prevalent.

All study participants reported that they were acutely aware of their second cancer risk. When study participants were asked to describe the meaning of second cancer risk, the dominant response was to promptly discuss various possible risk factors for cancer. Given the abstract nature of the concept of risk, the tendency to equate second cancer risk with risk factors seemed to make it easier for participants to conceptualize risk. Participants identified several known risk factors, including diet, exercise, genetics, family history, and surrounding environment, and speculated about many others that play a role in second cancer risk. Some participants recognized that health behaviors, such as eating fruits and vegetables, may decrease the risk of developing cancer after exposure to environmental risks. Some participants noted the salience of the risk factors that would be most relevant in the future, not the present; for example, “I would have to say I’m going to be a big risk in about ten years” and “If I indulge habits like smoking for many, many years, as I get older and my immune system got weaker, it might become more.

Participants adjusted to their perceived second cancer risk in ways that allowed them to incorporate the experience of living with the risks into their everyday lives. For some, second cancer risk was seen as a lived reality that does not define who they are, thus second cancer risk had little impact upon their identity. As Tracey, a 39-year-old endometrial cancer survivor, said:

I had (cancer) but it doesn't own me...it doesn't define me as a person. I don't live my life in fear of developing cancer again. I would not want to use cancer as a crutch...I do what I want to do and I see who I want to see and I have a life I want to live.

A similar sentiment is reflected in the following quotation from Carrie, a 39-year-old soft tissue sarcoma survivor:

I don't actually dwell on the fact that I may get another cancer, because yeah I may get another cancer. Just because I've had chemo doesn't mean I'm never going to get it again. It doesn't mean I am going to get it again. I may live the rest of my life without (developing another cancer). I may be told tomorrow that I have it. I don't believe in living that way. Just whatever happens, happens and you just go with the flow. I can honestly say I don't think about that.

For others, living with second cancer risk was described as a state of permanent threat (or risk) of developing cancer, because “it’s going to be a fact of who I am” (Kelly, 40-year-old HL survivor) or “it’s always there...you are always thinking well you know (cancer) could rise again” (Matt, 37-year-old NHL survivor). Another participant described living with second cancer risk as a dark cloud looming over her, and at any minute, cancer could take away her future.

Accepting second cancer risk within their lives involved a conscious effort to not dwell on that risk. Dwelling on second cancer risk was not an option for many. Moreover, participants did not want to be “paralyzed” by worry arising from changes in their body. Indeed, a clear distinction was made between being aware of one’s body and being paranoid, or constantly worried, about every ache and pain. Thus, living with second cancer risk is a process of learning to strike a balance between inattention to and preoccupation with one’s body.

Common to all cancer survivors’ experience of living with second cancer risk was the constant monitoring of their bodies for signs of disease, for months or even years following cancer treatment. The heightened bodily awareness and associated body monitoring lessened with time as cancer survivors learned to accommodate their second cancer risk within their lives. For example, when probed about the difficulty she experienced in transitioning from cancer patient to cancer survivor, Carrie, a 39-year-old soft tissue sarcoma survivor, reflected that it took her several years to “not live in fear”:

Just sometimes, for the first little while, you didn't believe it. I was sure that they were going to call me and say that it (being cancer-free) was a mistake or we see something... I think it is just time...that you finally believe that okay maybe I'm not going to go back to being a cancer patient, maybe this really is sticking and I am a cancer survivor. Slowly, I just learned to accept it. Going to my doctor's appointment wasn't an experience I feared any more or going to get my MRIs wasn't a big deal anymore. I was satisfied knowing that they are not going to call me telling me I have to come in. I was pretty comfortable with it certainly by the five years. But for the first year or two, it was pretty rough because you know if it is something that is going to reoccur it usually fairly soon after you are declared cancer-free.

Some participants reported feeling relief five years after their initial diagnosis because they conceptualized the “all clear” message from healthcare professionals as no risk of developing cancer again. Moreover, with every additional year that they were cancer-free, participants' confidence that they were free of second cancer risk continued to grow. In the same way, Theresa, a 56-year-old melanoma survivor, spoke of becoming “blasé” about second cancer risk:

After awhile that fear abates somewhat, you're still checking. If you see something that looks a little odd, you make sure you keep an eye on it, but it's not the panic mode of the first couple of years. Once you hit a certain point, the likelihood of that cancer coming back is very, very slim so as time goes on you sort of ease up from that panic mode. You are still concerned, but you don't panic. Since it's been more than 15 years now, I don't panic.

Although the majority of cancer survivors denied feeling particularly worried, many acknowledged increased worry about their health when faced with specific triggers such as when doing a breast self-exam, having a mammogram, hearing about someone else's cancer diagnosis, or experiencing any kind of cancer-like symptoms, particularly pain. Awareness of their physical selves meant that signs and symptoms that might have been ignored in the past had a different meaning for cancer survivors. Interpreted as a potentially threatening experience, lumps or other bodily abnormalities shaped participants' sense of risk for developing cancer. For Rebecca, a 31-year-old cervical

cancer survivor, her cancer worry increased when she encountered problems nursing her son accompanied by breast pain. She worried, “Okay, I had cervical cancer (the first time) and didn’t know I had it, could I have breast cancer now and not know?” Being sent for a mammogram to check her breast tissue added to her worry because “when you hear mammogram, you think okay it screens breast cancer.” Rebecca was relieved when the mammogram results revealed she had unusual breast tissue, but no cancer.

Sub-themes

Four sub-themes emerged from the data in support of the primary theme, life after cancer – living in risk, were: (1) thinking about second risk, (2) living with risk: a family affair, (3) taking care of second risk and (4) support for taking care of second risk. These themes are not mutually exclusive and together they shape how living with second cancer risk influenced cancer survivors’ sense of self (see Table 27).

Table 27

Study Sub-themes and Categories

Sub-themes	Categories
Thinking about second cancer risk	Risk as unpredictable or uncertain; risk as inevitable or certain; risk, I am no worse off than anyone else; risk, I am better off than some; risk, I am worse off than anyone else
Living with risk: A family affair	Shared risk; family empowerment.
Taking care of second cancer risk	Engaging in healthy lifestyle practices; checking for a second cancer or cancer risk; information seeking
Support for taking care of second cancer risk	Recommendations for healthcare professionals; recommendations for the healthcare system

Thinking About Second Cancer Risk

Thinking about second cancer risk refers to the strategies that cancer survivors used to summarize living with their second cancer risk, increasing and/or decreasing attributions to arrive at an overall conception of their second cancer risk. What was clear from the interview transcripts is that thinking about second cancer risk is a dynamic process. Cancer survivors appeared to be continually adjusting their sense of their own second cancer risk over time based on their experiences.

For cancer survivors, the most important component of thinking about their personal second cancer risk was the standard to which the study participants compared themselves. Participants developed a mental image of a person then compared this person's cancer risk to their own real or assumed risk. The comparative person included neighbors, family members, friends, and famous people. The comparative person was an "average risk" person or a "high risk" person who cancer survivors constructed in their mind as a result of information they had received about cancer risk statistics in the general population.

Thinking about second cancer risk involved using knowledge of cancer risk factors and the context of that risk, including the meaning of false alarms and personal behaviors. In this study, four interpretations emerged of the meaning of cancer risk: (1) risk as unpredictable or uncertain (the guessing game), (2) risk as inevitable or certain (the waiting game), (3) risk, I am no worse off than anyone else, (4) risk, I am worse off than anyone else, and (5) risk, I am better off than some.

Risk as unpredictable or uncertain (the guessing game). Risk as unpredictable or uncertain refers to the perception that second cancer risk is unknowable and it is

impossible to predict what will happen in the future. Many cancer survivors described themselves as ready to accept whatever transpired. For instance, Evelyn, a colorectal cancer survivor, said, “I mean who knows whether I’ll get (cancer) again or not. The physicians don’t know. I don’t know.” One participant explained “it hard to know (what my second cancer risk is) because there the common factors of what you can get cancer from, and then, there are the ones that you don’t even know” (Julie, 19-year-old HL survivor). Moreover, there are no guarantees in life, even when one perceives their second cancer risk to be high, as illustrated in the following quotation:

I don’t know actually. I very well could develop another cancer, but I’m not guaranteed to. I know that I probably have a higher risk than anyone else in my family or any of my friends for that matter, but it’s not so high that I’m guaranteed to get it. (Laura, 20-year-old, ALL survivor)

One participant spoke of giving up trying to predict what will happen tomorrow because she learned through her husband’s unexpected death from a heart attack and her own cancer experience that life is unpredictable. She reflected:

On one hand, I think well I’ve had my cancer so statistically speaking, I’m probably not going to get it again. But on the other hand, life is unpredictable. I’m not going to say, there is no chance but I don’t think...I’m not a smoker. I have never smoked. I eat my veggies. I don’t eat a lot of junk food. I try to exercise. I do all the right things. I did that when I was thirty-one. I never smoked. I was a runner. And I still got it. (Carrie, a 39-year-old soft tissue sarcoma survivor)

Study participants described that there is the possibility that they could live cancer-free or there is the possibility of developing another cancer in their lifetime. For instance, Brenda, a 64-year-old breast cancer survivor said, “I might get it and I might not.” Second cancer risk assessments were often prefaced with comments like “you never know” or “you can’t say, never, suggesting that thinking about second cancer risk is a “guessing game.”

In discussing their second cancer risk status, some study participants interpreted their second cancer risk as unpredictable because they were unable to correlate risk factors and future outcomes. Drawing upon their first cancer experience, some participants recounted how they neither fit the profile of what they considered to be a “cancer patient” nor had they done anything they thought would contribute to cancer development.

I don't smoke and I don't go out in the sun, so I don't think I'm at risk for like sun cancer and stuff like that. But who knows? I didn't think I was at risk to get Hodgkin's disease in the first place... So, it's a possibility that it could be anything, and it can happen to anyone. And, just because I've had it, I don't want to rule out the fact that I could have it again. I was young when I had it and who knows what's going to happen? (Julie, 19-year-old HL survivor)

Other participants deferred to what they had been told about their second cancer risk, and used qualifications such as, “they say” “they assume” or “that's what they told me.” Several participants were uncertain about their personal risk of developing a second cancer because they claimed they had never considered it before participating in this research study or they tried to not think about it much.

Risk as inevitable or certain (the waiting game). A sense of inevitability with respect to developing a second cancer permeated some of the interview transcripts. Even in the absence of known cancer risk factors, many survivors were willing to make firm predictions about their second cancer risk. They believed that they would either die of cancer, have cancer again and “beat it”, or not succumb to the disease again. Indeed, cancer survivors often described themselves as playing a waiting game because it was a matter of *when*, not *if*, they develop another cancer sometime in their lifetime. For example, Sean, a 26-year-old ALL survivor, reflected on his second cancer risk:

in my lifetime, I pretty much think I will get some other form of cancer. I just don't

know which one. I just hope it's far enough down the road that they have some sort of cure for it.

One reason offered for the perceived inevitability of second cancer risk was the perception that risk cannot be completely eliminated from our lives. We are living with risk every day. Some perceived their lives as predetermined by forces beyond their control, such as genetics, and this was viewed with a sense of inevitability. Cancer survivors maintained that developing a second cancer was going to happen and they could do nothing about it. One participant described his second cancer risk as a “genetic thing that is just waiting like a time bomb and it may not happen right away” (Sean, 26-year-old ALL survivor). Study participants also cautioned that healthy behaviors, such as eating properly and exercising, are not 100% effective in reducing one’s second cancer risk because “nothing eliminates your risk completely” (Carrie, 39-year-old soft tissue sarcoma survivor). Some participants concluded that they are powerless to control their second cancer risk as evidenced by their first cancer experience whereby they developed cancer despite being very active and healthy. In this way, Kelly, a 40-year old HL survivor, echoed Carrie’s words that she is not able to eliminate all risk factors:

I can't change what is going to happen five years from now. I can do steps to make myself healthier. But, something like cancer, you can't make yourself healthier against necessarily...maybe some types. Like skin cancer, you could limit your sun exposure and (exposure to) smoking. (Kelly, 40-year old HL survivor)

Related to this sense of the inevitability of second cancer risk, many of the cancer survivors spoke about their risk to cancer in comparison to their sense of risk to other diseases. One participant with multiple health problems, including angina, diabetes and arthritis, in the past five years reflected:

My health just went blmpf in the last four or five years. It just went totally down hill...I expect any time I'm going to have a test done and they are going to tell me I

have cancer again; that may not be melanoma, but it's going to be some cancer.
(Theresa, 56-year-old melanoma survivor)

Study participants expressed concern that cancer was more prevalent and appeared to be accelerating through generations in their families and throughout society. They explained that cancer is increasing over time and cancer's position as one of the leading causes of death increases everyone's risk for disease. Thus, they concluded that cancer was inevitable or so highly prevalent in the general population that they would certainly get it sometime in their lifetime. As Theresa, a 56-year-old melanoma survivor, said, "there are so many people out there that have had cancer and ten, fifteen, twenty years later they develop another cancer, so the odds are in favor of me developing something...some sort of cancer." Similarly, Evelyn, a 74-year-old colorectal cancer survivor, observed that:

...at least 12 girls in that age group (40s) have some kind of cancer. They've been dying since they were 22-years-old. Now, something went on...something went on. Twelve girls that I know of...there may be some that I don't know of. And, there are about four of them that are alive and the rest are all dead.

Still others interpreted their second cancer risk as inevitable as a result of information they have obtained from friends about cancer risk. For example, Karen, a 79-year-old breast cancer survivor, commented:

The thing is after (being more than 10 years post-treatment), you don't have to worry about the same location but you are apt to get it somewhere else. In fact, one of my friends doctor's told her that it always goes somewhere; it comes out in your brain or comes out in your liver or comes out somewhere. (Karen, 79-year-old breast cancer survivor)

Risk as certainty was also expressed as the ultimate trump card; study participants were adamant that they were following a certain path of high risk rather than fitting statistical models of second cancer risk. Some perceived that cancer treatment and family

cancer history as more important in conceptualizing second cancer risk than cancer risk statistics and thus, their perceived certain risk took precedence over statistical information. They also maintained that their second cancer risk would not change even when disputed by statistical information.

The doctor can tell me you've only got a 20% chance of developing some other type of cancer. I'm really not going to believe him... While you respect the doctor's opinion and the medical professionals' opinion, you think you know your body better and your fatalistic in some respects about your body...if you were to say to me you know there is only a 10% chance that you are going to develop cancer again, I'd say thank you very much for that statistic...nine out of ten, you know. (Tracey, 39-year-old endometrial cancer survivor)

I've been told that I've leveled off and I should be equal to somebody my age. I personally don't feel that way I feel that I'm still higher. I mean I am grateful they are telling me that, but I still think my potential for developing something is...higher, not significantly. (Kelly, 40-year-old HL survivor)

Risk, I am no worse off than anyone else. Some study participants perceived that cancer is as likely to occur in people who have had cancer as those who have never had cancer. The most commonly held perception was that once someone has cancer, they go back into the “general population risk pot” and their risk for cancer is equal to that of anyone else. For instance, one participant shared that Atlantic Canadians are no more at risk of developing cancer than people living in other parts of Canada, and he assumes his share of that risk.

Another explanation supporting cancer survivors' thinking that their second cancer risk is no worse than anyone else was the belief that once their cancer was over, their cancer risk reverted back to their pre-cancer risk level, which was equivalent to that of the general population. As David, a 67-year-old colorectal cancer survivor, commented, “I'm not aware of there being any greater probability of my having cancer now that I've had it once. I assume my odds are the same now as they were 12 years ago.”

Current good health was another reason espoused by cancer survivors to support thinking about second cancer risk as no worse than anyone else. Most study participants reported being in good health despite managing comorbid chronic illnesses (e.g., arthritis, diabetes, heart disease) and various late effects of cancer treatment such as vitamin deficiencies and lymphodema. In this study, being healthy was described as “feeling well”, “being active” and “being strong”. The linkage of good health and perceived second cancer risk is illustrated in the following quotation:

I think considering the health I have now, I'm probably just thrown back into (the general population pot) ...I have no more or less risk than anybody else. I don't have cancer any more. Like I said, I don't think 8 ½ months of chemo killed off any future little things. It just killed off what was there, but I just think I'm like anybody else now. And I'm glad to say that. I'm glad to say I'm just like everybody else because eight years ago, I wasn't like everybody else. No, I don't think I'm more or less prone to get it than anybody else in the general public. (Carrie, 39-year-old soft tissue sarcoma survivor)

Time since diagnosis was also considered an important factor in conceptualizing second cancer risk as no worse than anyone else. In some cases, the further cancer survivors were from their original diagnosis without developing a second cancer, the more confident participants were about their second cancer risk. For example, Helen, a 82-year-old colorectal cancer survivor, reflected, “I think, after all this time, I'm at a (relatively) low risk because it's been seventeen years.” Similarly, Maureen, a 62-year-old melanoma survivor, reflected:

I remember the surgeon saying after five years that seems to be a good marker...if you haven't had any recurrence of cancer or anything after five years, that's good. And, I think ten years is even better. And I'm coming up to ten years this October, so, it gives me...I think that each year that you live without a recurrence, it gives you hope that you are not going to get another cancer.

Cancer treatments were also considered in participants' determination that their risk was no worse than anyone else. Specifically, the amount of cancer treatment a cancer

survivor received was important in determining one's second cancer risk perception as evidenced in the following quotation:

Like I think if somebody had ten sessions of radiation in the year that I had it, we'd be along the same play field. I wouldn't think...I don't feel like I'm way up there above anybody else. I think if somebody had the similar disease in the same connotation and had the same amount of radiation and stuff, I think we would be pretty equal as far as the potential to develop something further. (Kelly, 40-year old HL survivor)

Lifestyle was another determinant of cancer survivors' second cancer risk as no more than anyone else. When lifestyles were similar, perceived cancer risks are also similar. As Joe, a 58-year-old stomach cancer survivor and ex-smoker, said:

I'd say I'm right in the middle...20 years ago I was a smoker, so you'd have to calculate that in. So, I'd be average for my age of people that used to smoke 20 years ago in this part of the world. So, I guess my chances are the same as everybody else in my position.

Another reason that was offered by study participants for their second cancer risk being no worse than other cancer survivors was the combined influence of their cancer history, time since diagnosis, age and lifestyle. For example, Sean, a 26-year-old ALL survivor, perceived that his cancer risk would be "pretty similar" to another cancer survivors if "we'd gone through similar experiences like both had ALL, the same age, that type of thing. I guess it would also have to depend on their lifestyle too."

The power of positive thinking was also used to explain why some study participants perceived their second cancer risk to be no worse than anyone. Despite being aware that their second cancer risk cannot be completely offset by positive thoughts, some hoped that positive thinking would win out over a more realistic assessment of their second cancer risk. For example, Sarah, a 38-year-old NHL survivor, said, I'm hoping I'm at a lower risk...I hope to God I don't have to go through that again!" When asked to

rate her second cancer risk on a scale of 0-10, her rating reflected her hopes as evidenced by the statement “I’m thinking three. I’m hoping three, really. Yeah that’s what I’m hoping.” Although encouraged to distinguish hopes from thoughts, this finding indicates that for some participants, hopes and thoughts might not be distinct.

Risk, I am worse off than anyone else. Some study participants perceived their cancer risk was higher than the general population. When asked to define “high risk”, participants’ responses revealed an underlying sense that “high risk” for developing cancer means that one needs to more proactive and diligent in taking care of themselves.

It means I need to be...I know myself. I need to be more proactive. I need to take things seriously. I need to be in-tune with my body more. I’m not sure...I don’t know what other people do, but I know for me...just for me, I know to check lymph glands and I know where they are. I know where they check when I go to my appointments so I do the same thing. I know if there is swelling in any areas that I keep a closer eye on it. And, if it doesn’t go away, I consult my doctor or even ask my mom, who is a nurse and say hey is this something that is normal...water retention or whatever, or a cyst or something (Kelly, 40-year old HL survivor)

Means to me that I should be more diligent than I am. (Pause) Sometimes, I feel like I am a turtle and I pull my head in. If I don’t think about these things it’s not going to happen, and then, sometimes I stop, and I think well it’s still going to happen whether you think about it or not, but if you think about it and do something about it, maybe you’ll get it early enough before anything else can happen. That way when you get it early enough your treatment is not as severe, surgery is not as severe, your recovery rate is not as long, so go and get the tests done and find out if there is anything there. (Theresa, 56-year-old melanoma survivor)

Some described their cancer risk as “much higher” or “slightly higher” compared to the general population. For example, David, a 67-year-old colorectal cancer survivor, rated his risk as 6/10 because he perceived that he was more at risk than the “norm”, which he assumed to 5/10. Others had difficulty describing how much higher their risk was than “average risk” as evidenced by the following quotations:

I would say that I’m higher than somebody who has never had anything. By how much? 30% higher kind of thing. Like it’s hard to...it’s hard to put a number on

that. (Kelly, 40-year old HL survivor)

I would say that my risk would be just one peg above (people with a family history of cancer), whatever that means...It just means that I'm basically marginally more likely to get cancer than they are. I don't know whether that means 5%, 10%, 20%. I don't know what the number. (Brian, 33-year-old thyroid cancer survivor)

Still others perceived their second cancer risk to be high but explained their rating was a casual choice as in this response: "What initially popped up in my mind was 80%, but I have no idea of what that number would be comprised of" (Natalie, 58-year-old breast cancer survivor). This type of casual choice might be a manifestation of the participants' preference to avoid detailed thinking about second cancer risk.

A desire to be "reasonable and logical" in their risk assessments was another reason offered to support cancer survivors' perception of their second cancer risk as higher than that of anyone else. For example, Adam, a 38-year old testicular cancer survivor, rated his risk 4/10, which he considered to be higher than the general population. He reported that wanted to give a rating of 1/10 but he thought this rating is "not realistic". Adam further explained "because I have had some exposure to (cancer) in the past, I think regardless of how that occurred, my risk would be higher. I can logically get there, so I think four seems reasonable."

Some participants identified an increased risk for some but not all second cancers. Two men spoke of their higher risk for prostate cancer compared to the general population. One participant attributed his higher risk for prostate cancer to his age given that "it's something that happens to men once they reach a certain age" (Adam, a 38-year-old testicular cancer survivor). Likewise, Sean, a 26-year-old ALL survivor, perceived his risk to be high for lung cancer because of his previous exposures to smoke and other chemicals:

...like I've basically hung out with people who have been heavy smokers, been in smoke filled rooms quite often...not anymore and ever since I've been like 19 or 17 have stayed away from that kind of environment as much as I can. But, I always think to myself okay I've had that in me and I know it was only for like a few years, but still like maybe that already did its damage I don't know. I worked in construction for a little while, I know there were some insulations and stuff like that, not asbestos or anything, umm...that kind of triggered those fears I guess.

Some women expressed concern about their risk of developing breast cancer. For example, Theresa, a 56-year-old melanoma survivor, believes that she is a better candidate for breast cancer than neighbors because she has not had children, she takes birth control medication, and her grandmother had breast cancer.

Age was the most salient consideration in arriving at the conclusion that one's risk was higher than anyone else. One participant was confident in identifying a specific age range (30-50 years) during which he felt he would be at highest risk for developing another cancer. Some study participants maintained that their cancer risk would always be higher than someone their age and who has not had cancer. As Kelly, a 40-year old HL survivor, said, "I would say that I will always be above the norm...always feeling more at risk than somebody my age." In general, study participants thought that their cancer risk increased with age at the same rate as someone of the same age in the general population, but the only difference is that cancer survivors' starting point for their cancer risk is much earlier, as illustrated in the following quotations:

I think that I...I would assume that as I get older and I think as I get older my risks would increase, but I think my risks would increase the same as someone my age naturally. My starting point is just at a different place is what I'd assume. (Adam, a 38-year-old testicular cancer survivor)

I think my risk would increase at the same rate as other people in the general population would. Yeah, but I'm starting out with a slightly greater risk, so I'm always just marginally more likely to develop a cancer just because of my history. Yeah, let's say right now, somebody my same age I think my risk of developing...I say my risk is six out of ten of developing another cancer and I say this other

random person is five out of ten...that seems high, maybe we should say there a one and I'm a two or whatever. I would say, as we age, they would go up to a two, I would go up to a three; they go up to three, I go up to four etc., that's how I see it. (Brian, 33-year-old thyroid cancer survivor)

One process involved in determining the significance of “high risk”, for some cancer survivors, was appraising their own threatening experiences. Typically, this occurred when they discovered a lump and other bodily abnormality. For example, Tracey, a 39-year-old endometrial cancer survivor, reflected on a breast lump she found to conceptualize her lifetime second cancer risk as 9/10.

A common explanation for risk as worse than anyone else is that having cancer exploited a weakness in their body and demonstrated that their body has the propensity to acquire cancer as shown in statements like “my cells got screwed up once before” (Laura, 20-year-old ALL survivor). One participant explained that having had cancer “might be indicative of a greater cancer risk” because of “a quirk of the body as opposed to something that was an influence of external influences, like smoking” (Adam, 38-year old testicular cancer survivor). Another participant explained that she has an “internal feeling that (she is) going to get struck with cancer again, just in another fashion.”

Cells are cells and it doesn't matter if it's in my body or someone on the street's body. But, I just feel that because I've had it once...that I did develop cancer already...there is just something in me... I think that when you are vulnerable to it once you have a susceptibility to be vulnerable to it again. I just feel that if it is going to strike, it is going to strike me better or quicker than the person or it will strike me sooner just because I've had it once. I can't explain to you why that is, it just is. (Tracey, 39-year-old endometrial cancer survivor)

Tracey also associated her increased susceptibility to cancer with not being as being as strong, physically, mentally and emotionally as she could be if she never had cancer.

Another participant perceived that he is at increased risk of developing cancer because of the “unique body qualities that I have that helped incur the first cancer, maybe I will have

that somewhere else in my body” (Brian, 33-year-old thyroid cancer survivor).

Among the many known risk factors for cancer, treatment-related risk factors were used as support for high risk perceptions. One participant, who was treated with chemotherapy and radiation, recognized that “when you get chemo you have a slightly higher risk of developing I think it is of leukemia” (Carrie, 39-year-old soft tissue sarcoma survivor). Another participant explained that she was at higher risk of developing cancer because “radiation is maybe a good thing to treat the cancer at the time, but long-term exposure to radiation is not a good thing” (Kelly, 40-year old HL survivor). Still another participant speculated that radiation therapy changed the structure of her body because:

the radiation to the torso area and of the internal organs were affected...and they told me. And that's what the lead blocks were on the screen...and they repeatedly said these don't protect you fully. They just guide it a little bit away, so you are still getting doses of radiation to your organs, that is unhealthy. And so to me...that was when I was 21 you know, when I'm 41, twenty years later, it's made...it's been around in my body whatever for that period of time, so it's probably changed the structure or whatever. (Kelly, 40-year old HL survivor)

Some participants were not confident in the effectiveness of their cancer treatment and believed that cancer cells still linger in this body. For example, Theresa, a 56-year-old melanoma survivor, concluded “if they take it that far that they won't let me donate blood, because there is a possibility that that one cell is still there, then my odds are higher than somebody that's never had (cancer).”

Several participants constructed their own second cancer risk profiles in terms of personal beliefs about how cancer develops that they felt were relevant. For example, one participant hypothesized she was at more risk for developing cancer than general population because she has scar tissue that “could re-grow itself or something completely

different in your body could happen” (Julie, 19-year-old NL survivor). Another participant explained his immune system is more prone to viruses compared to individuals who have never had cancer and some of the viruses may cause cancer. Participants also speculated about the influence of emotional stress on second cancer risk. For example, Theresa, a 56-year-old melanoma survivor, believes worrying can activate cancer and thus increase her second cancer risk:

There are lots of other things that... (pause)...okay mental health does play a part in cancer, physical health does, what you eat, drink etc., all those things together play a part. If this person is basically the same as me, they may not have the same mental mindset that I do and just simply worrying a lot can sometimes activate things that you don't want to be activated inside your body. So, that might increase my risk compared to them. My uncle who has had melanoma is very carefree, easy going. I don't think he worries about too much of anything, now I worry about a lot of things. I think my risk is a little higher than his.

Risk, I am better off than some. Some study participants perceived that their second cancer risk was much lower than that of others because “some people have stronger bodies than others or inherit things in the family” (Karen, 79-year-old breast cancer survivor). Others shared that, on the grounds of probability, they had a better chance of *not* getting another cancer compared to those who have never had it. The logic behind this assertion was that they did not think their second cancer risk could be so high that they would develop cancer twice before someone else got it once. One participant compared second cancer risk to a lightning strike, saying “(Second cancer risk) is... like getting struck by lightning you don't think you are going to get it twice” (Matt, 37-year-old NHL survivor).

Drawing on observations of the outcomes for other cancer survivors, one participant determined her risk was lower than that of a breast or ovarian cancer survivor. In rating her own second cancer risk, she said:

I'm going to give myself a two (out of 10) because I think with the melanoma once they have gotten it with surgery that your risk is (low)... I think that when somebody has something like breast cancer or cancer of the ovaries or some of those other cancers, I think they have a higher chance. I think some of those would be sort of sevens or eights. (Maureen, 62-year-old melanoma survivor)

The perceived invasiveness of cancer treatments was also considered in study participants' determination that their second cancer risk was lower than other cancer survivors. One participant, who received only radiation, concluded that her second cancer risk was lower than someone who had received chemotherapy because chemotherapy "flows through your whole bloodstream and kills good as well as bad" (Kelly, 40-year old HL survivor). Another participant reflected:

Where mine was surgery only and they got it all and it was contained within the uterus and it didn't spread anywhere or anything, if I were to compare myself to someone who had surgery and maybe had to have chemo or radiation and/or I think they might be more susceptible than I because maybe it was more serious or it was more delicate or something. (Tracey, 39-year-old endometrial cancer survivor)

Similarly, Rebecca, a 31-year-old cervical cancer survivor, explained that her second cancer risk was low because her own cancer was a non-event. She was almost apologetic when describing her second cancer risk. She had not "suffered" as most people with cancer had and actually was embarrassed to identify herself as a "cancer survivor."

I don't necessarily think of myself as a cancer survivor. I don't know because you see people, or you know people, or you hear of people struggling through a serious...like to me a cancer survivor is somebody who has gone through radiation or chemotherapy or whose had a struggle with it. It really wasn't a struggle for me because like I mentioned that surreal feeling of you know you have a pap and a biopsy come back, and that was the scariest part, and then having surgery and you are told that everything is fine now. So, I don't really think about it that way I guess. So, I don't think of myself as being any higher risk than someone else. Maybe, someone who has gone through a lot more of a process of fighting cancer may look at it differently because of their experience with it I guess.

Living with Risk: A Family Affair

Living with second cancer risk is a family affair because cancer runs in families

leaving a cancer risk legacy for family members (past, present and future). In this study, cancer survivors identified the legacy of a family cancer history as (1) shared risk and (2) family empowerment.

Shared risk. Cancer survivors' sense of their second cancer risk was judged against the prevalence of cancer in their family. Study participants with no family cancer history relied on the absence of cancer amongst close family members to rate their second cancer risk as low, thereby distancing themselves from the possibility of developing a second cancer. Knowing that that cancer was not in their family health history was comforting and offered a sense of security to these participants.

For study participants who discussed a family history of cancer (see Table 28), family membership served to engage cancer survivors in an explicit consideration of their own second cancer risk. Some cancer survivors used cancer in their family to construct themselves as individuals at a much higher risk of developing cancer than individuals with no family history. One participant with a strong family history of cancer explained:

If you were to put two people, myself and another lady next to each other with the same circumstances and the same type of cancer, I'd probably say I'd get it quicker, or I would get it more so than she would just because of heredity. I feel that heredity, whether it is correct or not, had such a big part to play. (Tracey, 39-year-old endometrial cancer survivor)

Feeling “doomed”, these cancer survivors positioned themselves at a specific and very real risk due to their cancerous genes. Participants concluded that magnitude of the shared cancer risk is, however, unknown because there is no way of measuring how much genes contribute to a person's risk. For example, David, a 67-year-old colorectal cancer survivor, whose mother had a reproductive cancer followed by an intestinal cancer later in life, believed that “because of my mother's experience, I just think that genetically (my

family) obviously has some risk factor.”

Reaching a critical family age when family members developed cancer acquired particular salience with respect to one’s second cancer risk. When asked about her lifetime second cancer risk, Tracey, a 39-year-old endometrial cancer survivor, speculated that her second cancer risk would increase as she aged based on the following observations:

My mom died in 1980 so she was 42, so five years would put me at 42, but she had cervical cancer which had spread to her lungs...I think I have off-set the fact that she was 42 and I would be 42 with the fact that the type of cancer she had I can’t get, so that’s why I rated it low and the fact that I’m still relatively young and healthy. Ten years, again I’m early fifties, stuff starts to give out. The other part of it is that’s when I started to see my aunts and uncles start to become vulnerable in their fifties. My dad’s brother died a horrible, horrible, painful death. He had had bone cancer. My mom’s brother died in that age range as well, fifties and sixties, stomach cancer, and he was gone in a couple of months. So, that’s where I think I get a bigger number of five.

In this way, reaching a particularly significant birthday also enabled cancer survivors to accommodate their family legacy of cancer into their risk perceptions. One participant explained that her risk of developing colon cancer was low because at 65 years of age she was older than her mother who succumbed to colon cancer at the age 42:

You are constantly, as a young person, you think you’re not going to make 30, but (my mother) died at 42 and I’m 65, so I don’t think lightning is striking twice in this case. I really don’t think that I’m going to develop colon cancer (because) well, just the fact that I’m still here and at 65.

Some cancer survivors rejected their family legacy of cancer and voiced skepticism about relying on family cancer history when determining their second cancer risk. For instance, Theresa, a 56-year-old melanoma survivor, recognized that she inherits a higher risk of developing colon cancer because there is a pattern of colon cancer in her family. However, she holds hope that she will not develop a second cancer because she believes

that her family history is by no means the only risk factor for cancer development.

Likewise, Adam, a 38-year-old testicular cancer survivor, believed that smoking for 20 years contributed to his father's development of lung cancer. Lung cancer for Adam was not a familial disease; it was brought on by life choice. Hence, Adam did not depend on his family history when considering his risk for developing lung cancer. He rated his risk of developing lung cancer low because he is a non-smoker.

Table 28

Family History of Cancer

Participant (Pseudonym)	Family Members with Cancer
Audrey	Sister with breast cancer; brother with prostate cancer; many women on both sides of the family with breast cancer
Evelyn	Five family members with colon cancer; daughter with thyroid cancer
Tracey	Mother died of cervical cancer that metastasized to lungs; father with prostate cancer; grandmother died of cancer; uncle with bone cancer; many other relatives on both sides of the family with various cancers, including endometrial cancer
Helen	Father died of kidney cancer that metastasized to lungs; niece with cancer
David	Mother had gynecological cancer and 30 years later died of intestinal cancer
Rebecca	Grandmother with breast cancer; distant cousin with prostate cancer that metastasized to bone
Anna	Sister with melanoma; mother died of colon cancer; sister with colon cancer
Kelly	Various cancers in family
Joe	Sister died of breast cancer
Adam	Father with lung cancer
Theresa	Grandmother with two reoccurrences of breast cancer; sister with colon cancer; uncle with melanoma
Sarah	Mother with ovarian cancer; father with oral cancer
Julie	Grandmother died of cancer
Natalie	Mother with breast cancer
Maureen	Aunt died of breast cancer that metastasized to brain; aunt and sister with basal cell carcinoma

Family empowerment. The hope of cancer survivors was that they could create a positive family legacy of cancer out of a potentially negative one. They explained that they wanted to arm family members with knowledge of their shared cancer risk so as to empower their family members to change the family legacy.

Study participants were acutely aware of the potential impact of their actions or inaction on others. As illustrated in the following quotation, participants cited altruistic motivations for the changing the family legacy:

My daughter motivates me to be a healthier person, to make sure that I'm around longer for her. I want to see her grow up and be the old grandmother. (Both laugh) And, I just...I live for her...for myself, but for her as well and being healthy and being active and being able to do the things with her that she wants...or needs, then I'm going to work towards that goal. (Kelly, 40-year old HL survivor)

Participants reported feeling obligated to do the 'right thing'. They wanted to do whatever they could to reduce their chances of developing a second cancer so as not to be blamed for causing pain to their family. Laura, a 20-year-old ALL survivor, reflected on taking responsibility so her family would not suffer: "Just because I guess I've already had like a close enough experience. I don't really want to...I just want to live life to the fullest and I don't want to scare my family again." Indeed, some participants engaged in taking care of second cancer risk, even those who were skeptical of their ability to take care of their risk, because they had an obligation to care for others, which meant they had to care for themselves.

Watching each other's health and sharing information were other ways cancer survivors modified their family legacy of cancer. One young mother, a cervical cancer survivor, plans to have her daughter vaccinated with Gardasil® because she wants do what she can to reduce her daughter's chance of developing cervical cancer. Another

participant advised his daughters to go for colon cancer screening earlier than they might otherwise have done because both he and his mother had colon cancer. In this way, Theresa, a melanoma survivor who has a sister diagnosed with colorectal cancer, spoke of the communication she has had with her sisters and mother about their family legacy of cancer:

I had a colonoscopy done last fall...my mother and another sister have been tested (for colon cancer) because we know the risk is there...I try to instill in my sisters that because I've had melanoma, their risk is increased. They go and lay out in the backyard. Do they want big scars all over there face and their arms from having skin cancer removed? I don't think so, not if they are vain enough to lay out and get a suntan so they look better...but I can't get it through their heads. I see one of my sister come in, and she is as red as a beet because she's been out all day gardening or at the beach laying out, and I think you are stupid. I try to tell her, "No, don't do that, you're still at risk (for skin cancer). Your risk might be 10% but now it is 50% simply because I've had it." My mother's risk was increased because her brother had skin cancer and her daughter had it. My mother is out there in the backyard gardening and she comes in and her neck is all red. But then...my mother tells me go get the mammogram done (and I have not yet gone for a mammogram).

As can be seen within this quotation, when family members do not engage in activities to modify their family legacy of cancer, they are seen as selfish or irresponsible, leading to strained relationships and communication difficulties. Like Theresa, Evelyn, 74-year-old colorectal cancer survivor, reported feeling “really quite ticked off with both of my brothers” because her brothers did not follow her advice to get screened for colon cancer and they later succumbed to the disease.

Taking Care of Second Cancer Risk

All of the individuals in this study talked about the responsibility that they, and all cancer survivors, have for making a conscious effort to take care of their second cancer risk – doing something about it. For cancer survivors, taking care of second cancer risk meant living a “good life” so as to lower their risk of developing a second cancer, delay

the onset of a second cancer, and/or prepare their body to be physically able to handle the disease and its treatment should they develop a second cancer.

The most commonly espoused belief was that cancer survivors have a duty to become highly skilled and attentive to monitoring their second cancer risk. As the following quote illustrates, living by the “the rules” entails participating in an endless process of vigilance and lifestyle modification:

I think you have to take care of yourself. I don't think you can do things that are going to harm you or take chances. You are not infallible. You can't walk on thin ice and expect you are not going to fall in. Well, alright...if you were a cancer survivor and you didn't go for your tests or didn't go for your mammogram or stopped taking medications that you were supposed to be taking, that's taking chances. You've got to follow the rules, if you break the rules then you've got to pay the price if you've made a mistake. (Karen, 79-year-old breast cancer survivor)

Taking care of second cancer risk through planning and risk avoidance means that cancer survivors should not take chances with their life because they “dodged the bullet” by having survived cancer once. When asked about why she did not want to “tempt fate”, Laura, a 20-year-old ALL survivor, said:

Yeah, well I've already been given a second chance. Basically, I don't want to screw it up again. Well, I didn't mean that I did anything to get cancer because I know that it was completely out of my control. But, I just...if I can do things to like reduce my risk or anything like that, then I'm going to do all that I can basically.

Indeed, the prevailing norm espoused by study participants was that cancer survivors are expected to “play it safe” by actively pursuing good health or making healthy changes.

As Sean, a 26-year-old ALL survivor, reflected: “I guess the safest thing to do would be just eat well all the time, stay away from people who smoke, limit alcohol.” Study participants perceived any transgression from the status quo or from a state of physical safety as “tempting fate” through unnecessary risk and as something to be avoided.

I would say people have their head in the sand and they are not paying attention,

especially women. It's so important for them to get that yearly testing and a pap smear. I mean I have girlfriends that it's been nine years since they've had one. Well, with people my age, that's foolish, that's foolish. And young people not having them until they are in their 40s and 50s, that's crazy. They are waiting too long. That's the part that is important about looking after your own health, making those appointments, not saying oh I'm fine, I'm healthy because I do this, that, and the other thing.

Study participants with a strong sense of faith espoused the belief that good health was God's reward taking care of second cancer risk, thereby treating the body with respect, and cancer is a punishment from God for not taking care of that risk. For example, Sarah, a 38-year-old NL survivor, was hopeful that the changes she has made her in life will mean that "He's not going to do that (cancer) to me again."

For cancer survivors, taking care of one's second cancer risk contributed to developing a meaningful life. The experience of being able to influence their second cancer risk created a sense of hope and expectation of progress in their cancer survivorship. Furthermore, taking care of their second cancer risk strengthened cancer survivors' self-esteem, enabling to them to take further action.

I think they should be carrying their health record with them, because you are not going to remember everything. They should have that with them at all times. They should be going for their yearly checkups. They should be finding out if they are at risk for certain cancers. If it is in their background, they should check that out. And if there is things wrong with them, it is up to them to tell their doctor and to do the research and to pay attention to what symptoms that they have and deal with it themselves, because your doctor doesn't know what is the matter, she is not going to look at you and say you're fine, when you could be falling apart inside. You have to take responsibility for yourself. (Anna, 65-year-old melanoma survivor)

Despite their awareness of the benefits of taking care of second cancer risk, only a few study participants translated this awareness into action. In this study, cancer survivors attempted to take of their second cancer risk by (1) engaging in healthy lifestyle practices, (2) checking for a second cancer or second cancer risk, and (3) information

seeking. Many cited barriers such as lack of motivation and lack of resources as interfering with their ability to engage in these activities of taking care of second cancer risk. Overall, study participants were at ease with the fact that they could not take care of risk all the time. For cancer survivors, like Rebecca, a 31-year-old cervical cancer survivor, taking care of second cancer risk meant taking “average precautions” but “not on an extreme scale.” Similarly, Tracey, a 39-year-old endometrial cancer survivor, commented that she taking care of herself is a priority and although she is not always vigilant, she tries to do what she can that will “some small way to try to improve my overall health ergo making me stronger so that something such as cancer wouldn’t strike me again.”

Engaging in healthy lifestyle practices. Healthy lifestyle practices are actions that cancer survivors reported engaging in to lead a healthy life. The most commonly implemented healthy lifestyle practices were: (1) well-balanced diet, (2) physical activity, (3) limiting exposure to things known to cause cancer, and (4) taking medications to keep cancer from starting or to keep cancer under control.

Well-balanced diet. Most participants stated that they make a conscious effort to select healthy food choices, paying attention to cholesterol levels, fiber and salt intake.

Only one participant made reference to Canada’s Food Guide in describing his diet:

I never remember the specifics about it, but I just in general try to eat a balance of fruits, vegetables, wheats, whatever the four major food groups are and not very much processed foods. (Brian, 33-year-old thyroid cancer survivor)

Two participants expressed concern about the chemicals present in foods. David, a 67-year-old colorectal cancer survivor, explained that having a garden allowed him to avoid being exposed to additives typically found in store-bought foods. Similarly,

Brenda, a 64-year-old breast cancer survivor, questioned the cleanliness of pre-packaged salads and fruits.

Changes in diet, albeit sometimes small, were commonplace among cancer survivors because of their understanding of the role diet plays in the prevention of illnesses, including cancer. Many cancer survivors were confident that their diet would lower their second cancer risk. They also felt that eating healthy would help them maintain their weight or lose additional weight. Audrey, a 87-year-old breast cancer survivor, emphasized the importance of maintaining her weight to manage her congestive heart failure and keep doing the things she wants to do. Another participant acknowledged that she needed to eat healthier to lose weight but had only made small changes in her diet because she believes these changes are a “life process”.

Family members can be supporters or inhibitors of the dietary habits of cancer survivors. Having support from family in terms of the purchase and preparation of foods made it easier for cancer survivors to eat healthy foods. For example, David, a 67-year-old colorectal cancer survivor, believes his diet is “probably much better than average” because “(his) wife is very astute and she is a very good cook, but she is also conscientious in shopping.” In contrast, Kelly, a 40-year old HL survivor, spoke of the lack of support from her husband to increase her family’s vegetable intake:

When I said that I was going to change my eating habits, when I started this Heart Healthy program, he fired me up two pork chops at night and said here you go and that was that. Just no concept of that’s not really healthy (chuckles)...all meat, no vegetables. He doesn’t do vegetables. My daughter and I we are almost vegetarians (chuckles). We eat meat around my husband...we do eat meat I shouldn’t say it that way, but we tend to be more vegetable people.

Several barriers to eating healthy were identified by participants. One barrier is lack of “personal motivation to choose fresh vegetables as opposed to, I don’t know, a TV

dinner or something like that” (Brian, 33-year-old thyroid cancer survivor). Another participant explained that she did not get the benefits of a glass of wine because she did not like it. Several participants perceived cost to be a barrier to eating healthier. For example, Theresa, a 56-year-old melanoma survivor, said that eating fruits and vegetables is not feasible because they are expensive. Food preparation was also cited as barrier. Some study participants did not know how to prepare or cook foods. One participant explained that she ate food requiring little preparation because she cannot stand for long periods, as a result of chronic arthritis.

Physical activity. Study participants reported a wide range of physical activities in their current exercise patterns. Three activities that were particularly popular were walking, playing sports, and gardening. When asked about what motivated them to be physically active, study participants identified three motivators. Participants spoke of their health as the primary motivator, in that being physically active is “good for my general well-being and if that helps prevent (a second) cancer too that’s great” (Brian, 33-year-old thyroid cancer survivor). Several participants expressed concern about not getting enough exercise. The oldest study participant, Audrey, a breast cancer survivor, spoke of the importance of being active to keep her aging body going. Study participants were also motivated to be physically active to set an example for their children. Being a role model was important to Kelly, a 40-year old HL survivor, who said:

I take my lunch hour at the gym and that’s the way I know that I can get that physical activity in. Now, I’d feel better if my daughter knew more or saw that I was doing the physical activity, but I tell her about it. So, I know seeing is believing for her, but when we get home at night, there is just too much stuff going on. It’s hard to go out for that half hour walk or that 45 minute walk after work as much as I’d like to.

Several health-related barriers to being physically active emerged from the

interviews. These barriers were related to complications from cancer treatment (e.g., lymphedema), other health conditions, or from getting older. One participant with arthritis explained, “My compromised joints mean that I can’t exercise as much and therefore it’s putting risks on other part of the body” (Natalie, 58-year-old breast cancer survivor). Another participant spoke of the difficulty he has in being active due to the way his ankle fused after surgery:

Umm...just my foot, ever since then my foot has never been the same so that makes a few things tricky. Like I want to go skiing and I can't go skiing either really so I'm pretty much limited to hockey, like floor hockey. Running, it can get very sore. (Sean, 26-year-old ALL survivor)

Several of the participants spoke of a lack of time preventing them from being as active as they would like. Many of them had full and busy lives with family commitments, and felt that they could not fit in any more activities.

Limiting exposure to things known to cause cancer. Study participants did their best to limit exposures to things that are known to cause cancer, and if they could, they avoided the exposure completely. The two exposures most commonly discussed were tobacco smoke and ultraviolet rays from the sun.

Two cancer survivors continued to smoke cigarettes. One woman smokes because she believes quitting will not help mitigate her second cancer risk. The other participant rationalized that his doctor gave him “permission” to continue smoking because his doctor told him smoking did not contribute to the development of his first cancer.

Several ex-smokers spoke about quitting many years ago to avoid aggravating other health problems, or to be a role model for their children. For example, Audrey, a 87-year-old breast cancer survivor, said she “gave it up when my kids were 11-years-old and I figured I couldn’t tell them not to smoke.”

Non-smokers did everything they could to avoid cigarette smoke because they were confident that smoking causes cancer. Non-smokers were motivated to not take up smoking and avoid second-hand smoke as a way to take care of their second cancer risk. One non-smoker wondered if he reacted differently to second-hand smoke than before he had cancer:

I think I probably do react differently. I probably do turn around and leave quicker and get mad at the person that's there smoking a little more, and I'm not sure whether that is based on the fact that I had cancer or based on the fact that society reacts that way nowadays...People who are concerned about cancer are more concerned now than ever before. Maybe that's one of the reasons why I am more concerned about it. (Joe, 58-year-old stomach cancer survivor)

Some study participants, particularly those with a history of melanoma, reported taking sun safety precautions, such as using sunscreen, wearing protective clothing (e.g., hat, long-sleeved shirts) and avoiding “sun worshipping”. A common dilemma facing participants was balancing the beneficial and harmful effects of sunlight:

Like for me, to stay out of the sun especially between 11:00 and 2:00; that's the worst time of day for being out in the sun unprotected. Now, I worry about not getting enough Vitamin D because...and that can cause another problem somewhere along the line, but I do go out and walk around the driveway, take a bag of garbage out as often as I can to get some Vitamin D. So, I'm unprotected, no sunscreen on, but there's only my hands and face are exposed and I limit it to a certain time of day, either before eleven or after three. I'm still getting the benefit from the Vitamin D, but I'm not getting the full effects of the sun, but those are things you have to learn, those are things you have to pick up. (Theresa, 56-year-old melanoma survivor)

Taking medications. Several study participants reported using medications to take care of their second cancer risk. At the time of the interview, a breast cancer survivor (Brenda) was taking Femera, after taking Tamoxifen for five years, and a stomach cancer survivor (Joe) was taking Gleevac. Brenda offered the following explanation for how Femera and Tamoxifen offer her “protection”, thereby allowing her to take care of risk:

If the cancer comes back somewhere else, I mean Tamoxifen is supposed to kill off any cancer that is trying to attach, going around in your body if it's there. The Femera...(pause) it's supposed to kill it, I think. If there is something there, it is supposed to kill it so that by the time you finish your Femera, there is not supposed to be any cancer in your body, but again who knows, right?

The biggest concerns raised by participants about taking “protective medications” are (1) what happens when the medications no longer work and (2) what happens when they are instructed by their healthcare provider to stop taking the medications. Both Brenda and Joe reported asking their physician about what, if any, new medications existed to help prevent cancer, but as Brenda said: “I’ve been told nothing new about Femera after five years. What do I do then? You know you worry about it.”

The competing risks of developing a second cancer versus the side effects of medication informed some cancer survivors’ willingness to engage in taking medications. One woman interviewed discontinued taking hormone replacement therapy (HRT) because she feared the risks of developing other types of cancer associated with taking HRT more than the risks of osteoporosis associated with not taking HRT.

Checking for a second cancer or second cancer risk. Checking for a second cancer refers to the strategies that cancer survivors used to look for abnormalities that might be cancerous in its earliest stages or to identify their second cancer risk. Cancer survivors considered active screening an important healthy behavior. They cited early detection through screening as a tool that could detect unobservable, asymptomatic disease including cancer, because “it takes a couple of year for most of those things to grow” (Helen, 82-year-old colorectal cancer survivor). Study participants reported wanting to stay “on top” of their second cancer risk. As Kelly, a 40-year-old NH survivor, said, “I’d want to know in advance before something came out. I procrastinated

enough for the first thing. I don't want to be there again." This statement suggests that checking for a second cancer or second cancer risk procured sense of peace and feeling in control that was lacking when survivors were first diagnosed with cancer. Common strategies used by study participants to check for a second cancer or second cancer risk included: (1) self-examination, (2) examination by a healthcare professional, (3) genetic testing, (4) blood work and (5) cancer screening tests.

Self-examination. Most study participants were aware of the benefits of practicing self-examinations, but only a few translated their knowledge into action. Self-examination was identified as the most effective way that cancer survivors of all ages can become familiar with their bodies so as to recognize any changes. Survivors wanted "to be aware personally (of their body)" (Kelly, a 40-year-old HL survivor) because they believed that they know best when something is wrong with their body. Study participants emphasized that they do not need to go to a healthcare professional and say, "What would you do?" or "I'm in your hands".

Factors which promote and/or inhibit the practice of self-examination emerged in the participants' responses. For example, level of confidence in one's ability to practice self-examination appeared to strongly affect performance levels. Accordingly, participants with high levels of confidence reported practicing more frequent self-examinations. Having been successful in locating past abnormalities also increased study participants' confidence in their ability to find something that was different. Being taught by a healthcare professional appeared to also promote the practice of self-examination. Since being taught, Julie, a 19-year-old NL survivor, practices a thorough examination of the lymph nodes in her neck so "if I feel something abnormal there, I can kind of pick it

out.”

Examination by a healthcare professional. Most cancer survivors in this study reported having a routine physical examinations performed by their healthcare provider. They reported feelings of peacefulness and reassurance when their physician conducted the examination because they believed that their physician was thorough and thus, would more easily detect a health problem. For example, Anna, a 65-year-old melanoma survivor, who practiced infrequent skin examinations, said:

Going once a year to have (my skin) checked out and (my family physician) checks my whole body that's comforting because he knows just by looking at something. We (cancer survivors) don't know by looking at a mole whether it is dangerous or something could be wrong at all and we can't see our backs or anything like that.

Conversely, some study participants believed that a physical examination conducted by a healthcare professional experience is often incomplete. Participants expressed concern that a clinical breast exam had been done for the first five years after their cancer diagnosis, but since then, it has become their sole responsibility to examine their breasts.

Genetic testing. Of the cancer survivors with a family history of cancer, only one has had genetic testing. Evelyn, a 74-year-old colorectal cancer survivor with a strong family history of colorectal cancer, cited an obligation to protect future generations as the primary motivator for seeking genetic testing. Thus far, test results show that Evelyn does not have a gene for colon cancer, but as Evelyn points out “this gene, hasn't been 100% ruled out.” She is concerned about her risk for developing ovarian, uterine and other types of cancer that have been linked to this particular gene, and thus she plans to heed her doctor's advice to seek cancer screening for these cancers in case further genetic testing produces positive results.

Blood work. Blood work was another way that cancer survivors could take care of their second cancer risk. For some, blood work was the only way that they monitored their second cancer risk because it did not take much effort on their part. Some survivors had blood work done when they needed a new medication prescription and others had yearly blood work. For example, Adam, a 38-year old testicular cancer survivor, had yearly blood work through his place of employment, enabling him to participate in a health tracking system that he would never have considered participating in before. Some were confident that the blood tests they had to monitor illnesses, like diabetes, would pick up other problems such as a cancer fairly quickly. Another participant explained that, when she encountered thyroid problems, she had thyroid blood tests performed because she suspected that her risk of developing thyroid cancer was high as a result of the radiation she had and family history of thyroid problems.

Cancer screening tests. Cancer screening tests are recommended for the early detection of breast, colon and cervical cancers in the general population (Wilkins & Woodgate, 2008a). Study participants explained that cancer screening tests, including mammogram, colonoscopy, Pap test, and diagnostic imaging, were something they did regularly to take care of risk because these tests are “an early and easy way to find something out...early on” (Adam, 38-year-old testicular cancer survivor).

Despite participants recognizing the value of screening with respect to one way of taking care of the risk, they expressed difficulty in doing so because of many self-imposed and system barriers. Most study participants reported going for cancer screening tests if such testing was recommended by a healthcare professional. They explained relinquishing decision-making about screening because of trusting relationships. Some

spoke of adhering to age-specific recommendations. For example, Rebecca, a 31-year-old cervical cancer survivor, reflected:

And when I get to the age where it's necessary, I will have a mammogram every year. Just whatever preventative tests are out there I will do that. What is it once you hit 50 you are supposed have a colonoscopy every couple of years? So, I will do those...what is considered the typical screening tests, whatever is available.

Concerns about immediate and future second cancer risk were also cited as a reason for engaging in cancer screening tests. Immediate risk was attended to when abnormalities presented:

And, right now, I have a little node on my thyroid. I have a daughter who has thyroid cancer. And, I have a little lump on one ovary and I'm going next week to see a gynecologist. And then, I go the first week of February for another colonoscopy. So, it seems I get tested and tested and tested. (Evelyn, 74-year-old colorectal cancer survivor)

One participant explained the value of benchmarking her future risk:

I call...all the tests I have and everything I have...benchmarks. So, if something happens tomorrow or whatever, it is in my file from now, a benchmark for procedures, protocols or whatever. (Natalie, 58-year-old breast cancer survivor)

Another spoke about fostering communication about his second cancer risk:

And, it seems to be a good way to get my doctor to think about things with me as well because I go to him...we'll have a conversation about it and sometimes we usually determine it's not necessary, but I think it's just a good way to foster conversation. (Adam, 38-year old testicular cancer survivor)

Cancer screening tests offered cancer survivors reassurance that their health was alright. However, many were often frustrated by inadequate communication about test results. Some participants waited several weeks or months for test results. Others thought (often mistakenly) that their test results were sent to their family physician and that their family physician would contact them if there were any problems, so they assumed no news was good news.

Mammogram. Of the women eligible for mammograms (in Nova Scotia women need to be over the age of 40 to qualify), very few reported engaging in annual or biennial mammograms. The primary motivator for seeking a mammogram was a family history of breast cancer. For example, Audrey, a 87-year-old breast cancer survivor, explained:

I didn't bother with mammograms until my older sister got cancer of the breast and I told my doctor that I would have to start the examinations.... I go for my mammogram every year...My doctor arranges (an annual mammogram) for me. And, I go. No problem. But, that's all I do.

Family history of breast cancer coupled with breast pain served as another reason for seeking a mammogram. Rebecca, a 31-year-old cervical cancer survivor, whose grandmother had breast cancer, reflected:

I only nursed (my son) for eight weeks because it was excruciating. About a year later, I was still having breast pain so I went to the doctor and talked to her about it and she sent me for an ultrasound. They told me that I was old at the same time that they were going to squish my breasts. They said you are close enough to 30, we are going to give you a mammogram instead.

Women reported having to exert much personal effort to access their first mammogram after having had cancer. One woman spoke of the difficulty accessing mammograms before the age 40 despite the test being recommended as part of her follow-up cancer care:

I know when I went to my family doctor, she wasn't aware that maybe I should go earlier for a mammogram, so I had to be the one to bring that to their attention and it was the nurses in the cancer centre that told me that and they have told me over the last 18 years to make sure because obviously they see people and they know what to tell them to look for. So yeah sort of had to fight for...you know this is important to me. (Kelly, 40-year old HL survivor)

Several reasons were cited for not yet having had a mammogram. Some women deferred the responsibility to get a mammogram to their family physician, and if their family physician did not recommend having one, they did not pursue it. The

unpleasantness of procedure caused some, but not all, women to avoid seeking mammograms. As Theresa, a 56-year-old melanoma survivor, noted:

I am a believer in testing, but it's that one test! I haven't gone and had a mammogram done this year, even though I should have. My mother goes every year, my aunt goes every year, but I haven't gone. I know it's going to hurt and I don't do (laughs)...I have enough pain, I don't need more. I know it's only for a short period of time, but I know with me, it's going to really hurt because I do have some pain in that breast. So, I just can't force myself yet to go and have a mammogram done.

Some women indicated that they are overdue for a mammogram and related their delay to concerns with how women's second cancer risk status is defined by health care professionals. For example, Maureen, a 62-year-old melanoma survivor, expressed concern that:

I'm not considered a high risk for mammograms, so they will only give you one every two years now, even though I had an aunt that had breast cancer. It's interesting for awhile I was going for mammograms every year. I don't know if it's because of our health system that they want to save money or...anyway, they will only give...they'll only give me an appointment every two years.

Colonoscopy. Very few of the cancer survivors with a history of personal or familial colorectal cancer reported having a colonoscopy. The frequency of testing varied from every three to five years. The main reason that participants offered for having a colonoscopy was the early detection of polyps.

Diagnostic imaging. Participants sought diagnostic imaging, including x-rays and cat-scans, to investigate unusual lumps, bumps and other abnormalities. There was little concern expressed about the influence of radiation from the tests on cancer survivors' risk of developing a second cancer. Joe, a 58-year-old stomach cancer, explained that he weighed the benefits of detecting a recurrence with the risks of developing a radiation-related cancer. He concluded the tests "might double the odds of me getting cancer from

the radiation, but double the odds...you know the original odds are pretty low odds. It's an issue but it's not something that I worry about."

Pap test. Only a few women reported going for regular pap tests. These women were adamant that all women should have regular pap tests because it is "a simple test (that) can save your life" (Rebecca, 31-year-old cervical cancer survivor). A key message from these participants was that women need to be comfortable with their own body, and shyness should not interfere with getting a pap test.

There are a lot of women who don't do stuff like that (Pap test)...whether it is embarrassment or what I don't know, but I don't believe in that. My mother always raised me that you don't be embarrassed in front of a doctor. (Carrie, 39-year-old soft tissue sarcoma survivor)

Information seeking. Individuals cannot fully take care of their second cancer risk unless they are aware of their risk and all the choices that are available to them to take care of that risk. Cancer survivors acquired second cancer risk information through cognitive and psychomotor learning. This category pertains to quantity of information, type of information, sources of information, and how cancer survivors felt about the information they received.

Quantity of information. The amount of information that cancer survivors wanted about their second cancer risk and its management varied from none to as much information as is available. Study participants who did seek information concluded that information would not make any difference in their second cancer risk. Another reason given for not seeking information was that information could generate unnecessary worry. As Joe, a 58-year-old stomach cancer survivor, explained:

Since I'm kind of a type that worries about details, it's better that I don't get involved in that, because if I did, I'd probably die of a stroke or a heart attack or something worrying about whether I'm going to get cancer or not. So, I know it's better for me, mentally, not to get too worried about it, that maybe the approach that I have taken.

Study participants eager to receive second cancer risk information reported that “the more information, you have about it the better off you are because you can make changes” (Theresa, 56-year-old melanoma survivor). Furthermore, participants did not feel overwhelmed when given large amount of second cancer risk information because they wanted to sift through the information themselves and draw their own conclusions about their second cancer risk from the information.

Type of information sought. Study participants acknowledged that their comprehension of their second cancer risk was affected by the way the second cancer risk information was presented. In this study, most survivors wanted to know that they are more or less at risk for developing a second cancer or they may potentially develop a second cancer, rather than second cancer risk statistics. One reason participants gave for not wanting to quantify their second cancer risk was that second cancer risk statistics scared them, particularly if they were high, so participants indicated they would rather not know their second cancer risk statistics.

In contrast to the majority, a few survivors wanted to know statistics related to their second cancer risk. Numbers were felt by some to be ‘abstract’, ‘scientific’ or ‘data’, and some people felt they were truthful.

Yeah numbers...these are the people who have been involved in this study...have come before us. We've taken the information and these folks at 12% have a) the cancer has come back, but more aggressive or b) they have developed a second cancer. So, I think numbers are a big thing for people. I like numbers because that's reality. (Sarah, 38-year-old NHL survivor)

Percentage-wise yeah you would want to know, not just to say the words yeah you are a high risk or you are low risk, or what are my real chances. Is it a 50% chance? Is it less than that or more than that? (Rebecca, 31-year-old cervical cancer survivor)

Regardless of how second cancer risk information is presented, a key message from cancer survivors was that they wanted to know how their second cancer risk compares to that of other people. The need for information on patterns of second cancer risk in people of similar age is illustrated by the following quotation:

I wish there were studies or whatever that had people that were in the same boat...that I'm in...like 20s year out, not necessarily having Hodgkin's Lymphoma, because you can't lump everybody into one little pot. But, even if they had 100 people that had radiation to their torso 20 years out, what are they dealing with now? And to know okay these people are developing some lung issues or something. (Kelly, 40-year old HL survivor)

Cancer survivors wanted to know what kind of cancer they would be at highest risk of developing. They also wanted to know the risk factors for developing a second cancer. They wanted to know which risk factors were most relevant for their personal second cancer risk and how they could prevent exposure to them. Several participants wanted to know the impact of cancer treatment on their second cancer risk.

What could have made you vulnerable again? So, if radiation on a certain area affected your body in some way, could it then translate in to another type of cancer or make that area vulnerable to another type of cancer?
(Tracey, 39-year-old endometrial cancer survivor)

If Person A has had radiation 20 years ago, what are their experiences currently? What are they dealing with...like is there skin cancer? Is that something...because you think okay radiation directed...I know my skin turned black and peeled and I know that is not a good thing, but that's part of the process. Like 20 years from the time that I had it, what's going on with other people in my situation? (Kelly, 40-year old HL survivor)

Although cancer survivors understood that their future was beset with many unknowns, they wanted information that would support their efforts in taking care of their

second cancer risk. They wanted recommendations about how they could optimize their own health, which in turn, would reduce their second cancer risk. Specifically, study participants wanted to know how a second cancer might present, warning signs to look for and how to look for warning signs.

I suppose I would want to know how it might present itself if it did come back. I've never asked that question. If it would grow back in the same spot or...I've always assumed that if it had come back, it would have come back to an organ it had spread to you know my lung or whatever. (Carrie, 39-year-old soft tissue sarcoma survivor)

Umm...just the kind of things that you should avoid; the warning signs of stuff that could be something if you are not really sure; things to be careful of; more ways to check yourself. (Julie, a 19-year-old NL survivor)

Sources of second cancer risk information. Access to and utilization of second cancer risk information was only possible when cancer survivors were aware of existing community resources and agencies that housed the information. Family physicians, the Internet, Cancer Society and cancer treatment centers were the primary sources of second cancer risk information identified by study participants.

The most trusted source of second cancer risk information was the family physician or oncologist. One study participant shared that he wanted to know “what the healthcare professional perceives as a risk. I guess the best you can do is just trust them, knowing to the best of their knowledge what rough estimates would be” (Sean, 26-year-old ALL survivor). Unfortunately, some participants expressed reluctance to “bother” their physicians with questions about health concerns or second cancer risk, as physician’ time was seen as needing to be used for the more important task of treating people who currently had cancer. For those individuals who did receive information from their physician, it was usually the result of personal effort and agency. One participant shared

that he would see his family physician “if there were risk factors that came up that I wasn’t aware of or just any changes that don’t make sense to me (Adam, 38-year old testicular cancer survivor).

Common to many survivors’ accounts of information seeking were assertions of a lack of satisfactory dialogue about second cancer risk with healthcare professionals. For example, Brenda a 64-year-old breast cancer survivor, commented, “it seems everybody says oh go to the Web you know...can’t even talk to a person on the phone anymore...oh check our website. There’s no real talk, communication is lacking.” In this study, concerns about second cancer risk were exacerbated by an uncertainty about whom to approach for information about second cancer risk. One participant, who was treated at a children’s hospital for his first cancer, reported that he did know if he should take his questions about his second cancer risk to the healthcare professionals at the children’s hospital or adult hospital.

The wealth of information that can be gleaned from the Internet made it the starting point for many study participants who wanted to find second cancer risk information. The Internet was used to prepare cancer survivors for their medical appointments. Information gathered from the Internet gave survivors the opportunity to be “armed with information and then be able to process that (information) and talk about it with the doctor rather than to go into (appointments) blind” (Tracey, 39-year-old endometrial cancer survivor). Participants recognized that information on the Internet may not be trustworthy and reported that they do not believe everything they read on the Internet.

Responses to information received. Study participants suggested that information preserved hope, encouraged accurate risk perceptions, minimized anxiety and

hopelessness, and increased personal control over their risk. However, some cancer survivors reported dissatisfaction with the amount and type of information they received. These cancer survivors had difficulty accessing, gathering and using information to understand their second cancer risk. Frequently, information was fragmented, inaccurate, inappropriate, or insufficient.

I don't have any information nor have I seen any information that says if you had this in this year and you had this treatment here's what you could look in...here's what you are looking at as far as potential, not saying you are going to get this or this is. (Kelly, 40-year old HL survivor)

Support for Taking Care of Second Cancer Risk

Study participants offered many recommendations on how healthcare professionals and healthcare system can help cancer survivors take care of their second cancer risk. When struggling to take care of their risk, cancer survivors sought support information, direction and motivation from healthcare professionals and healthcare system.

Recommendations for healthcare professionals. This category describes the responsibilities of physicians and other healthcare professionals in helping cancer survivors take care of risk. Study participants suggested that healthcare professionals' involved in providing survivorship care should make every effort to be: (1) honest, (2) informative, (3) respectful, and (4) proactive, as illustrated in the following quotation:

Be compassionate, be honest. Assign percentages, just depending on what the person prefers. Know your patient; be aware of what they want to hear. (Carrie, 39-year-old soft tissue sarcoma survivor)

Being honest. Honest communication was highly valued by study participants. Open and honest communication is important to developing a trusting relationship with cancer survivors. Survivors who had trusting relationships with healthcare professionals had a sense of control over their second cancer risk. Furthermore, a trusting relationship

encouraged cancer survivors to explain to healthcare professionals how they were *truly* doing in terms of taking care of their second cancer risk:

I always feel like when I go in to my family doctor...I'll have my regular whatever... I'm having migraines...okay here's your prescription or whatever, but I always feel like I get...like is everything else all right? There always seems to be a little extra making sure I'm all right, that I'm not hiding anything. (Brian, 33-year-old thyroid cancer survivor)

Being informative. Information about second cancer risk is a pre-requisite for making decisions about how to take care of that risk. Important to information sharing is what Tracey, a 39-year-old endometrial cancer survivor described as the “push and pull of information”. The push of information refers to the sharing of risk information that healthcare professionals, as the “experts of information”, deem to be most critical for survivors to take of their second cancer risk. The pull of information is cancer survivors’ ability to use such second cancer risk information, if they want it. This finding suggests that healthcare professionals need to consider survivors’ readiness and desire for second cancer risk information, and enable survivors to take as much or as little information as they wish. Joe, 58-year-old stomach cancer survivor, spoke of the importance of a considering a person’s emotional and intellectual readiness for information:

So, I would say they have to be very careful who they are talking to...how intelligent does the person appear to be that you are talking to? And, how emotional is that person seem to be? If the person seems to be a fairly reasonable, intelligent person, you might as well say everything; here are the possibilities, here's what can happen. But if the person is a wreck when they walk in the door, then I can see very well why they can't be quite honest with that person, or if the person is 95 years old and can't even understand it...or like my aunt, who died in January, she didn't want to know...So, it depends entirely on the person they are talking to...(Healthcare professionals) have got to make their own judgment call on who they are talking to.

Study participants emphasized the importance of individualized risk information, because “people are just different in how they process information and what’s important

to them is different. Important to me is not necessarily what's important to someone else" (Tracey, 39-year-old endometrial cancer survivor). Study participants cautioned that statistics about second cancer risk should be used sparingly for three reasons. First, cancer survivors probably do not understand statistics. Second, cancer survivors do not trust second cancer risk statistics because cancer is unpredictable and "it would be really hard for (healthcare professionals) to predict like this is your exact percent of you getting (cancer) again, or if you do this it will be reduced by this exact percent" (Laura, 20-year-old ALL survivor) because there are too many factors to consider. Three, statistics about second cancer risk may result in unnecessary worry. For example, Evelyn, a 74-year-old colorectal cancer survivor, commented:

As far as saying it's 5% or 80%, the patient doesn't need to know that. Because say it is 80%, are they gonna always have it in their minds? You know, I don't think that's a necessary piece of information. I think they should say the potential for you...like what I'm doing for instance, the potential is there for you to develop renal, ovarian, uterine, all that, so, you check on that. That's all I need to know.

Regardless of how second cancer risk is framed, what is most important for study participants is that the determination of their second cancer risk is supported by evidence.

Another common thread through the interviews was that cancer survivors want to know what they can do to take care of their second cancer risk. As illustrated in the following quotation from Adam, 38-year old testicular cancer survivor, discussing second cancer risk without discussing what cancer survivors can do about that risk is futile.

If someone said you know your risk of relapse is 80%. Would that change my behaviors? Probably, but, I'm not sure where that next step would be. Like maybe I should go to the cancer centre once a year still or something like that, but it would almost have to have some context around it. Here's some things you can do to reduce your risk kind of thing, like they do with heart disease.

Cancer survivors also need reassurance that "what they are doing is correct and that they

are doing everything they can possibly do to make sure it doesn't develop again" (Anna, 65-year-old melanoma survivor).

Second cancer risk information elicited different feelings when received. Most cancer survivors reported that they would take comfort in knowing what their second cancer risk was and what could be done to take care of it. Others cautioned too much information may invoke fear or anxiety. Thus, healthcare professionals must balance providing realistic information with remaining hopeful and reassuring.

Well, I think it would be important to communicate in a way that wouldn't scare a person...so I would say a bit of diplomacy and tact, but not to be afraid to give the people the true risks...any true risk or whatever and give them symptoms they should look for. (Maureen, 62-year-old melanoma survivor)

Being respectful. Being respectful involves careful consideration of a person's cancer history in providing care. Cancer survivors reported that some healthcare professionals treated them in a way that implied that the cancer experience was long over and the disease was successfully treated. When study participants went for a check-up or presented with vague symptoms, healthcare professionals sometimes minimized the likelihood of current or future problems. One participant narrated the experience of her friend, a fellow cancer survivor, whose repeated concerns about pain were all but ignored by her family doctor. The friend later developed a second cancer. Both the participant and her friend think more should have done as far as investigations because the tests might have detected the cancer earlier.

To treat the person, the healthcare professional needs to know why the survivor is asking questions. Fear of developing a second cancer is a normal part of survivorship. Study participants emphasized that they are neither "cancer hypochondriacs" nor paranoid about future second cancer risks. No matter how long a person has survived,

cancer survivors' symptoms need to be taken seriously, not dismissed lightly. Thus, healthcare professionals should avoid "tunnel thinking", that is, thinking that a person can only have one cancer.

Also important in treating the person is assessing a person's cancer history. A recommendation for a quick way of making this assessment is to "red flag" medical charts with a person's cancer survivor status. As Theresa, a 67-year-old melanoma survivor, explained, making her cancer history more prominent on her chart would serve as a reminder to the healthcare professional to enquire about her health concerns.

Equally important to study participant was assessing their family history of cancer. Anna, a 65-year old melanoma survivor with a family history of colon cancer recommended that healthcare professionals ask questions like, "Did your parents have cancer and what kind did they have?" Knowing whether a cancer is sporadic in a family or an inherited predisposition will influence what follow-up care is needed for cancer survivors and their family members.

Being proactive. A common message from cancer survivors was that healthcare professionals need to encourage informed participation, but should not expect survivors to manage their long-term health on their own. Healthcare professionals need to be vigilant in monitoring cancer survivors' long-term health.

Initiated by the healthcare professional, a proactive rather reactive approach to survivorship care is recommended. Proactive care, as described by study participants, includes a plan for the prevention and surveillance of new cancers based on risks associated with survivors' cancer history, genetic predispositions, lifestyle behaviors, and comorbid health conditions. Healthcare professionals are proactive when they

recommend the most appropriate cancer screening tests for the cancer survivor and make arrangements for such testing. For example, Adam, a 38-year old testicular cancer survivor, reported feeling comfortable letting his doctor instruct him on when he needed a prostate exam.

I asked him about a prostate exam or prostate cancer and I said you know I'm getting towards my 40s and is it something I should be starting to think about, should I be doing it now. And, he said well you are in good health and I'll be honest I'm not thinking about it yet for me. So, there has been some of those conversations. He goes I'll let you know when it's time so that kind of thing, which makes...it's a comfort level thing for me I think.

Another component of proactive care that was identified as an area for improvement was the coordination of care between family physicians and specialists. Coordination of care includes the identification of circumstances that require a referral for specialist care and consultation with specialists when uncertainties exist about how to manage a health problem. The benefit of coordinated care is that all of the cancer survivor's health needs are met, including those beyond the scope of the family physician.

It will be two years this summer, and my doctor has not looked at my moles. (My dermatologist) did tell me that he was going to recommend to (my family physician) to do that. She hasn't done it and I've just forgotten to bring it up to her. So, there's got to be a better coordination. (Theresa, 56-year-old melanoma survivor)

Recommendations for the healthcare system. Cancer survivors interviewed emphasized the role of the healthcare system in helping taking care of second cancer risk. The responsibilities of the healthcare system in taking care of second cancer risk include providing: (1) lifelong follow-up to cancer survivors, (2) infrastructure support for lifelong follow-up, and (3) resources to help cancer survivors take care of their risk.

Lifelong follow-up. The majority of study participants reported receiving regular

follow-up check-ups with their oncologist, surgeon or family doctor. Some were told been told that no monitoring of their cancer-related health status was necessary because of the time elapsed since the ending of treatment. Through relocation (of specialist or survivor), several participants lost access to their original oncologist and had not established contact with another.

One of the greatest challenges identified by study participants was the difficulty in maintaining a single source of follow-up care. Continuity of care was not always assured because follow-up care was often delivered by multiple healthcare providers at different sites. Having to “re-educate” each new healthcare provider can be frustrating, even for the most persistent of survivors. For one participant, having no one designated healthcare provider for his long-term follow-up care resulted in different recommendations.

Depending on which doctor I go to see...doctor #1 is really easy going about complaints that I have where doctor #2 is more likely to send me for a bunch of tests. So, I end up having things like PET scan or the upper GI or the colon...I just had a colonoscopy and gastroscopy...all (under) doctor #2's direction, whereas doctor #1 if...you know he didn't want me to have a PET scan. He thought it was kind of a waste of time. (Joe, 58-year-old stomach cancer survivor)

Another challenge was that there was often no clear plan or designated responsibility for cancer survivors' follow-up care. Laura, a 20-year-old ALL survivor, commented that she “wasn't given a plan by anyone...I don't have a specific plan set by a physician, like this is what you need to do.” Thus, what is needed is a collaborative plan between family physicians, specialists and cancer survivors that designates responsibility for taking care of second cancer risk, so that nobody “falls through the cracks.”

Study participants were conflicted about who was the most appropriate healthcare professional to provide survivorship care. Some survivors were convinced that their family physician was in the best position to provide survivorship care because “some of

these questions may come up a year later, and it's not the oncologist that you are going to see at that time, it's the family doctor" (David, 67-year-old colorectal cancer survivor). Others were more confident in the ability of the oncologist to pick up on health problems. Still others did not know which healthcare professional they should consult for routine follow-up visits or if any health problems develop. Not knowing who to turn to left cancer survivors "in limbo", resulting in feelings of frustration and isolation. Adam, a 38-year old testicular cancer survivor, spoke about "finding my way on my own" in terms of navigating his long-term care because he did not know if he was supposed to go the children's hospital, where he was originally treated, or the adult hospital. A related concern expressed by study participants is the accessibility of oncologists:

What access I would have possibly as a cancer survivor? I would have some possible access to the oncologist and then I'm not sure. They are very busy people and whether you could get to see somebody like that without a referral... (David, 67-year-old colorectal cancer survivor)

The frequency with which follow-up care should be delivered also raised disparate perspectives. Recommendations for frequency of follow-up care ranged from every six months, to yearly, to every five years, depending on the participant's confidence in the outcomes of early screening for a second cancer.

I keep pushing for a three month interval on the CAT scan and I've accepted a six month interval, but I refuse to accept a year, which is what my oncologist wants...If (GIST) came back, I'd die in eight months. I say okay a six month interval...the odds are I'm going to know...to give me a few months time versus a year...I may be dead before I get the next CAT scan. (Joe, 58-year-old stomach cancer survivor)

I think it would be good if it was...even if it was like every five years or something, just something to make sure that people are on track and stay on track. (Sean, 26-year-old ALL survivor)

Cancer survivors recognized the need for a paradigm shift in survivorship care, from an illness orientation to a wellness approach. They recommended that healthcare

resources should focus on promoting wellness in survivorship care, rather than reacting to illness including second cancers. A wellness focus to survivorship would also be cost-effective for the healthcare system. A strong message from cancer survivors is that financial costs to the healthcare system should not interfere with cancer survivors' access to lifelong follow-up care.

So, they can say, it's a cost factor. Well, so what! It's your life. There is money for everything else. I think there should be a follow-up and I don't know what the test would be. (Brenda, 64-year-old breast cancer survivor)

Study participants advocated for appropriate use of healthcare facilities, wherein cost and survivorship care are balanced. For example, Kelly, a 40-year old HL survivor, said in relation to accessing mammography at an age younger than recommended for the general population:

I can appreciate this situation where there are cutbacks in healthcare and stuff and they can't get everybody the help that they need, but here is somebody that's saying okay I know what my risk is and I want this one test (mammography). I'm not sure how much it costs whatever, but I'm showing the risk, I've had people tell me that this is something I should do. Please just put me on the list for an appointment or whatever. So yeah, that was rather frustrating and I think it should be more open to prevent cancer from happening...not the treatment part. I'm not taking away from the treatment part, but I think if there was more in the front...like more in the advanced part where you prevent it as opposed to the end, it may be helpful to some people.

Infrastructure support. Inadequate infrastructure for delivering survivorship care is the primary reason study participants identified to explain the fractionated follow-up cancer care that they often received. A common concern raised by study participants was shortage of family physicians.

Study participants' recommended that policy makers and decision-makers need to develop infrastructure to facilitate communication between family physicians, who often assumed much of the responsibility for participants' follow-up care, and specialists to

ensure that cancer survivors receive timely and complete care for cancer-related and other health needs. For example, study participants noted that family physicians have difficulty obtaining documentation of the cancer diagnosis and treatment regimen, and recommended follow-up care including what tests should be ordered and how frequently they are needed. According to study participants, part of the problem is family physicians' lack of power, particularly with respect to their ability to refer cancer survivors to specialists. Improvements in information technology and electronic medical records were recommended to facilitate information sharing.

Insufficient time with healthcare providers was cited by most as a contributing factor to this communication problem. Although cancer survivors believe healthcare professionals are doing the best they can to provide follow-up care and information critical to their health, there was also much discussion about the healthcare system being a 'production' line. Survivors' perceived that healthcare professionals were too busy to respond to survivors' health concerns or questions about second cancer risk, because of an expanded workload that has come from the growing cancer patient and cancer survivor populations. For example, Brenda, 64-year-old breast cancer survivor reflected:

My doctors are all nice I guess, but they are all so busy, and it's hard to get time to discuss anything with them...You know, you go in there. And there are 20 other patients waiting to get in. I don't feel comfortable asking (questions).

A related challenge is the increasingly longer wait times to visit healthcare professionals. Study participants emphasized that lengthy wait times were not the fault of healthcare professionals, but rather the healthcare system. In describing his frustration about having to wait to see his family physician, Joe, a 58-year old stomach cancer survivor, said:

It's irritating to me to have to waste an hour, but I know that's how the system works. I can see what the problems are and it's usually a lack of people and facilities and money, so I don't think the solutions are implementable. If they were then fine, I'd say make it easier to contact the doctor and have the doctor spend more time with the person.

One participant suggested that involving nurse practitioners in the delivery of survivorship care would ease the workload of family physician.

Another recommendation from study participants was the development of infrastructure to support evidence-based practice. Funding and resources to conduct and use research on second cancer risk and its management were considered essential.

And again, like continuing to do research on like what are the numbers, like tracking people throughout their lives, like do these people relapse into their original cancer? Do they ever get cancer again? What type of cancer? (Sean, 26-year-old ALL survivor)

...keep doing research and you know learning new things about people who are relapsing or people who have had one cancer. And, do research and learning about if they get a completely different one and finding patterns and stuff like that. And, that if they learn something, they shouldn't leave these people in the dark, because I would like to know if teenagers my age who were going through the same things, on the same drugs, developed a different type of cancer five years down the road. It would be nice to know about those kind of things. (Julie, 19-year-old NL survivor)

Resources. Cancer survivors identified many ways that the healthcare system can support them in adhering to recommended follow-up care and cancer screening guidelines. Study participants reported that they needed information, automated follow-up appointments, peer support, and cancer prevention messages.

Information. Navigating the current healthcare system requires an educated and empowered cancer survivor. Of particular importance to study participants was access to the most update-to-date and relevant information on second cancer risk. The repository of information needs to be “growing, living, breathing type of thing” (Tracey, 39-year-old endometrial cancer survivor). Having the repository of information will, however, be of

no use to cancer survivors if they cannot access it. Thus, information needs to be readily available.

Automated follow-up appointments. Study participants suggested that appointment reminders and automated visits may be effective in increasing adherence. Using the metaphor of an extended warranty, Natalie, a 58-year-old breast cancer survivor, recommended that there should be automated visits set up in which cancer survivors can receive the follow-up care needed.

Peer support. Peer support may enable cancer survivors to avoid feeling like second cancer risk is “an individual thing”. Meeting other people who have survived cancer could be a way of finding out what other cancer survivors do to manage their risk of developing a second cancer. Brenda, a 64-year-old breast cancer survivor, would like to ask other cancer survivors such questions as “What do they do (to reduce their second cancer risk)? Do they follow a vitamin program? Do they have a particular diet? Where did they go for help?” Peer support may also encourage “people that have had cancer before to keep in touch with their doctor and may be a check-up in some sort of way” (Matt, 37-year-old NHL survivor).

Cancer prevention messages. Study participants spoke about the influence of the social and cultural context in which cancer prevention messages are delivered in terms of how messages are understood and whether they are acted upon. When asked about the value of cancer prevention messages, most participants commented that cancer prevention messages are helpful for everyone, including cancer survivors. When aimed towards the general population, cancer prevention messages should appeal to “as many people as possible, whatever the message” (Rebecca, 31-year-old cervical cancer

survivor). Furthermore, “regardless of whether you’ve had cancer or not, you still have to take care and try to do what you can to not make yourself vulnerable to cancer of various types” (Tracey, 39-year-old endometrial cancer survivor).

Others believed that the cancer prevention messages aimed at cancer survivors should be different than those for the general public. Cancer prevention messages “need to go above and beyond what’s provided to the general populace to find out what exactly they need” (Brian, 33-year-old thyroid cancer survivor). Theresa, a 56-year-old melanoma survivor, echoed these words:

I think there should be two different types; one for people who have never had any kind of cancer and one for people that have had cancer, just to remind them that they are still at risk, maybe a little bit higher than the guy across the street sort of thing. They still...even though it’s gone...they still have to be diligent to watch to make sure they don’t get it back or any other kind. I do think that that should be part of the message. If you can catch somebody’s eye that’s never had it, with a message great, but somebody that has had it really should have a little different message because it may not show itself in the same way. So, if...say when...it might show itself with a little bit different symptoms because you’ve already had it and you might ignore the first symptoms so you might have to be aware that other symptoms would include this.

Another recommendation is that cancer prevention messages directed towards cancer survivors need to be specific to each cancer diagnosis because one message cannot accommodate the needs of all cancer survivors.

In contrast to the majority, a few participants were not convinced of the value of cancer prevention messages for anyone. One participant was skeptical about cancer prevention messages because she did not think there was much that could be done to prevent a cancer, but she was hopeful that it would possible in the future to prevent cancer. Another participant explained that cancer prevention messages are not helpful because society has become blasé about cancer prevention messages. Theresa, a 56-year

melanoma survivor, offered three reasons to explain why society ignores cancer prevention messages:

...(1) there are messages everywhere about everything and you don't see them all, and most of the time after a certain point you turn it all off. So, messages about cancer are not high on people's priority...(2) nobody wants to think about it until you run into it, whether it's you or somebody in your family that has it; you don't really want to think about cancer. It's still the big C. People fear it, even though treatment has come a long way in the last ten years...(3) people that would have died normally are still alive...so, they figure well if I get it, I'll be fine because the treatments are so much better.

When asked about the adoption of cancer prevention messages, most study participants believed that people are more likely to take the messages seriously when they have had experience with illness, cancer or otherwise.

I think that unless you've had someone in your family or yourself who has had some experience with cancer that often times people think it's not going to happen to me. (Maureen, 62-year-old melanoma survivor)

However, having had cancer does not mean one will respond to cancer prevention messages. As Sean, a 26-year-old ALL survivor, summarized, there are two groups of cancer survivors:

...those who want to change their lifestyle and try to eliminate as many risks as they can...to never go through that again, and the other side are the people who say you know what that just showed me how short my life could be I'm going to do whatever I want, whenever I want and if that's it, that's it. So, I think those people who are in the first group will heed that advice and I think it does reach them. I think there is definitely going to be a demographic there that just will ignore it. I'd like to hope that the majority of them listen to it.

One recommendation to encourage cancer survivors to adopt cancer prevention messages is the use testimonials from cancer survivors to reach other cancer survivors.

Chapter Summary

Chapter nine presented the results from the qualitative research interviews. A demographic profile of the participants was presented. This was followed by a discussion

of the themes that captured cancer survivors' perception of second cancer risk. The primary theme, life after cancer – living with risk, was supported by four sub-themes: (1) thinking about second cancer risk, (2) living with risk: a family affair, (3) taking care of second cancer risk and (4) support for taking care of second cancer risk. No age or sex differences in living with risk were noted. The findings from the qualitative survey, population-based databases and qualitative interviews are integrated in following chapter.

CHAPTER TEN: DISCUSSION OF RESULTS

Introduction

The purpose of this chapter is to provide an in-depth discussion of the qualitative and quantitative findings of this mixed method study using Kaplan and colleague's (2000) multilevel approach to health determinants (see Figure 1 discussed in Chapter 1). This chapter will begin with an overview of second cancer incidence in cancer survivors, followed by the contributing factors to the patterns of second cancer risk observed in this mixed method study. This chapter will address the strengths and limitations of this mixed method study. By way of the conclusion, opportunities for nursing practice, education and research are discussed.

Individual/Population Health: Second Cancer Incidence in Cancer Survivors

The Nova Scotia and Manitoba cohorts exhibited a statistically significant 4-fold and 7-fold risk of second cancers compared with their respective provincial populations. The overall SIRs in this study were higher than in other studies of second cancer risk across the lifespan (e.g., SIR = 1.14 in study of cancer survivors of all ages by Curtis et al., 2006). Differences in the size and composition of study cohorts and time periods during which the studies were conducted account for much of the variation in second cancer estimates reported in this study and the Curtis et al. study. For example, this study included first cancer cases diagnosed between 1970 and 2004 and provided rates for second cancers diagnosed 6 or more months after the first cancer diagnosis, whereas the Curtis et al. study included first cancer cases diagnosed between 1970 and 2000 and reported rates for multiple primary tumors occurring two or more months after the first cancer diagnosis.

Upstream and Downstream Determinants of Second Cancer Risk Among Cancer Survivors

Overall, it was clear from the data that second cancer risk is multifaceted, with upstream and downstream issues being important contributing factors to the patterns of second cancer risk in Manitoba and Nova Scotia (see Table 29). In what follows, factors within the individual cancer survivor as well as ecological, or macrolevel, health determinants that influenced second cancer risk are described. These factors include: pathophysiological pathways, genetic/constitutional factors, individual risk factors, social relationships, living conditions/neighborhoods and communities, and institutions/social and economic policies. This section also highlights which risk factors from Kaplan's framework cancer survivors take into account when interpreting second cancer risk, the importance survivors assign to these risks, and perceptions of risk acceptability and courses of action.

Table 29

Combining Survey Data, Epidemiology Data and Interview Data on Second Cancer Risk and Its Management in Cancer Survivors

Downstream and upstream variables	Data Type		
	Survey (QUAL)	Epidemiology (Quan)	Interviews (QUAL)
Pathophysiological pathways	<ul style="list-style-type: none"> Comprehensive follow-up during the first 5 years post-diagnosis may detect second cancers during the early follow-up period 	<ul style="list-style-type: none"> Elevated second cancer risk for all first and second cancer types Average time to development of a second cancer was 8 years Risk of a second cancer decreased with greater time since first cancer diagnosis 	<ul style="list-style-type: none"> Heightened monitoring during the first few years after a cancer diagnosis lessened with time Greater the time since diagnosis, the more likely cancer survivors were to perceive their second cancer risk as no worse than anyone else
Genetic/constitutional factors		<ul style="list-style-type: none"> Younger age at first cancer diagnosis and being male were associated with an increased second cancer risk 	<ul style="list-style-type: none"> With increasing age, the more likely cancer survivors were to perceive second cancer risk would also increase Mixed thoughts on genetic risk factors
Individual risk factors	<ul style="list-style-type: none"> Cancer survivors want to “get on with their lives” so are not always vigilant in taking care of their second cancer risk 		<ul style="list-style-type: none"> Plethora of second cancer risk discourses and heuristics Awareness of benefits of taking care of second cancer risk did not always translate into action
Social relationships			<ul style="list-style-type: none"> Families influence the construction of second cancer risk perceptions, and actions to take care of that risk Cancer survivors perceive cancer prevention messages are successful

Table 29 (Continued)

Combining Survey Data, Epidemiology Data and Interview Data on Second Cancer Risk and Its Management in Cancer Survivors

Living conditions, neighborhoods and communities		<ul style="list-style-type: none"> • Overall second cancer rates were higher in the Manitoba cohort than in the Nova Scotia cohort • About 14% of the second cancers were observed following initial cancers that are typically related to tobacco 	<ul style="list-style-type: none"> • Cancer survivors perceive that Atlantic Canadians are at no higher risk for developing a second cancer than people living in other parts of the Canada • Limiting, or if possible avoiding, exposure to things known to cause cancer is needed to take care of second cancer risk
Institutions, and social and economic policies	<ul style="list-style-type: none"> • Absence of evidence-based policies • Sporadic follow-up care • Transitioning to a new healthcare provider is difficult • Communication breakdowns • Limited capacity to provide care 	<ul style="list-style-type: none"> • Emergence of second cancers as many as 36 years out from the first cancer diagnosis supports the importance of lifelong follow-up 	<ul style="list-style-type: none"> • More invasive the cancer treatments, the more likely cancer survivors were to perceive their second cancer risk as worse off than anyone else • Competing risks of developing a second cancer versus the side effects of medication is needed to take care of second cancer risk • Trusting relationships are important • Inconsistent recommendations • Lack of continuity in care • Timely access to care is needed • Communication needs • Limited capacity to provide care

Pathophysiological Pathways

Shared and distinct pathophysiological pathways to the development of a second cancer identified in this study include: type of first cancer, type of second cancer and time since first cancer diagnosis.

Type of first cancer. The SIR of a second cancer was significantly elevated for all categories of first cancer diagnoses, and incidence ratios varied according to the original cancer diagnosis, although reliability of risk estimated were affected in some categories due to small numbers. The highest risk for second cancers occurred after the diagnosis of cancers of the thyroid and buccal cavity/pharynx as compared with previous studies in which Hodgkin's disease and soft tissue sarcomas were the most common first cancers associated with the development of second cancers (Curtis et al., 2006; Ng et al., 2010). Because there were no analyses in this study to control for other risk factors (e.g., treatment, environment), it is not possible to conclude how much type of first cancer contributes to the magnitude of second cancer risk in cancer survivors. The heterogeneity of the cancer survivors interviewed did not allow for analysis of the interview transcripts by cancer type.

Type of second cancer. Excesses of second cancer were observed for all types of second cancers, particularly second cancers of the male genital system and second melanomas. In contrast, cancer survivors identified an increased risk for some but not all second cancers. Compared to the general population, cancer survivors perceived their second cancer risk to be highest for prostate cancer, lung cancer and breast cancer.

The average time to development of a second cancer was 8 years from the first cancer diagnosis, with a similar latency to development of second solid cancers and

second hematologic cancers. This finding is inconsistent with previous studies which have shown that second leukemias tend to have a shorter latency than second solid tumors (Kenney et al., 2004; Hodgson et al., 2007; MacArthur et al., 2007). One explanation for the difference is that second cancers diagnosed within 5 years of treatment were excluded from other studies, therefore resulting in longer minimal intervals than in the current study.

Time since diagnosis. The risk of a second cancer decreased with greater time since first cancer diagnosis, as supported by findings from previous studies (Curtis et al., 2006). It was expected that the risk of a second cancer would decrease over time because the cancer incidence in the general population increases with age. Longer follow-up is needed to confirm the trend that second cancer rates are higher in more recent calendar periods of first cancer diagnosis compared with earlier periods.

Comprehensive follow-up during the first 5 years post-diagnosis may partly explain the excess of second cancers during the early follow-up period. Heightened bodily awareness and monitoring during the first few years after their first cancer diagnosis lessened with time as cancer survivors accommodated their second cancer risk within their lives. In some cases, the further cancer survivors were out from their original diagnosis without developing a second cancer, the more confident participants were that their second cancer risk was no worse than anyone else.

Genetic/Constitutional Factors

Second cancer risk may be mediated genetic and constitutional factors located within the individual (Travis et al., 2006). The genetic/constitutional factors considered in this study were: age, time diagnosis, shared genes and sex-specific differences.

Age. Younger age at diagnosis of the first cancer has been associated with an increased SIR of second cancers (Bassal et al., 2006; Constine et al., 2008; Curtis et al., 2006; Hammal et al., 2005), as was also observed in this study. The SIRs indicated that cancer survivors diagnosed with a first cancer before the age of 29 years were at higher risk of developing a second cancer than those diagnosed later in life when the underlying population risk was accounted for. Likewise, age was the most salient consideration in arriving at the conclusion that cancer survivors' second cancer risk was higher, or worse off compared to anyone else. In general, study participants thought that second cancer risk increases with age at the same rate as in someone of same age in the general population, but the only difference is that cancer survivors' starting point for their cancer risk is much earlier.

Shared genes. Although there is no genetic information in the Manitoba or Nova Scotia Cancer Registries, future analyses of second cancer risk by age at diagnosis and constellations of multiple tumors may indicate manifestations of familial cancer syndromes (Travis et al., 2006). When determining their individual second cancer risk, cancer survivors spoke of the possible genetic connection in developing a second cancer. Several stated that they would most probably develop a cancer that was present in their family history. However, others denied the possibility of developing a second cancer despite a family history of cancer. This sense of security would seem to be misplaced given the ongoing research demonstrating an association between family history of cancer and development of second cancers (Meadows et al., 2009).

Sex-specific differences. Male cancer survivors in the Nova Scotia and Manitoba cohorts were at a greater risk for developing second cancers than females. These findings,

although seemingly contradictory to many studies, are similar to those of Curtis et al. (2006) when age at diagnosis is considered. In both studies, male gender was generally associated with an increased SIR when cancer was diagnosed before age 60 years. No sex-specific differences in second cancer risk perceptions were identified perhaps owing to the small number of men participating in the interviews. Further research is needed to determine the influence of sex differences in the second cancer risk perceptions of cancer survivors.

Individual Risk Factors

There is ample evidence that the behaviors of individuals are associated with cancer risk (Vernon, 1999). Individual risk factors for second cancer risk explored in this mixed method study were cancer survivors' second cancer risk perceptions and actions for taking care of that risk.

Second cancer risk perceptions. Diverging from previous studies in which as many as 50% of cancer survivors are not aware of their second cancer risk (Hudson et al., 2002; Oeffinger et al., 2004; Yeazel et al., 2004), all study participants in this study reported that they were acutely aware of their second cancer risk. Giving voice to cancer survivors' understandings of second cancer risk shows that there is a plethora of risk discourses that co-exist and compete. What is evident from this study is that second cancer risk does not exist merely as an epidemiological calculation, with actions for taking care of second cancer risk predicated on such calculations. Rather, the data add to accumulating evidence that thinking about second cancer risk is shaped by more intuitive conceptual models than statistical models of risk. For the cancer survivors who took part in this study, a second cancer diagnosis was undoubtedly a real-life danger. The interview

data highlighted that living with risk is often not easy to achieve as second cancer risk is going to always be with cancer survivors. Study participants went back and forth in their minds between being aware of the changes in their self-identity due to their perceived second cancer risk and trying to bracket off their risk status so as to get on with their lives.

Processes that cancer survivors go through in constructing their own risk perceptions can be best explained using the concept of heuristics (Peters et al., 2006). When faced with complex and fragmented information about second cancer risk, cancer survivors used the anchoring and adjustment, representativeness and affective heuristics to help themselves simplify and expedite decision-making processes related to taking care of their second cancer risk.

The anchoring and adjustment heuristic was used when cancer survivors relied on their personal cancer experience and cancer experiences of others as an initial reference point through which interpreted their future with all its risks. Consistent with previous studies (e.g., Han et al., 2009), participants in this study explained second cancer risk in terms of concrete risk factors for cancer, some of which are well known and others were based on personal theories of cancer causation (e.g., having scar tissue that could re-grow as a second cancer).

Cancer survivors used the representativeness heuristic in that they assessed their second cancer risk based on their perception of how similar (or different) they were to the typical person who gets cancer in the general population and within their own family. For example, a common perception was that cancer survivors' risk for developing cancer is equal to that of anyone else because their risk reverts back to their pre-cancer level so

they go back into the “general population risk pot.” This perception that everyone is at risk of developing cancer implies a leveling of one’s personal risk for cancer and a desire to avoid recognizing that one’s actions, such as smoking, may place them at greater risk than the general population.

Through the affective heuristic, cancer survivors with a strong affective reaction to thinking about their second cancer risk demonstrated that experiences of cancer in the family or intense cancer treatment overshadowed the possibility that their epidemiological risk was relatively low. These cancer survivors described risk as certainty because cancer was so highly prevalent in the general population or in their family that they would certainly get it sometime in their lifetime. A sense that second cancer risk is inevitable or certain did not, however, permeate all the interviews with cancer survivors. Indeed, many explained that their cancer risk is a guessing game because it is unknowable and it is impossible to predict what will happen in the future.

Taking care of second cancer risk. Cancer survivors reported engaging in healthy behaviors to take care of their second cancer risk, notably healthy lifestyle practices, checking for a second cancer or second cancer risk, and information seeking. Although aware that that these behaviors might save them from a premature second cancer diagnosis or death, few cancer survivors translated this awareness into action. This finding adds to the mounting evidence that the prevalence of medical follow-up and cancer screening among cancer survivors is below recommended levels (Findley & Sambamoorthi, 2009; Nathan et al., 2009; Wilkins & Woodgate, 2008a).

One reason that cancer survivors espoused for not taking care of their second cancer risk was that they were convinced that a second cancer diagnosis was going to

happen and they could do nothing to influence their second cancer risk. Similarly, some participants were skeptical about the effectiveness of taking care of their second cancer risk because nothing eliminates their risk completely. This sense of helplessness in preventing a second cancer has also been reported by Hodgkin's disease survivors (Bober et al., 2007).

In general, cancer survivors who were less likely to take care of their risk perceived their second cancer risk to be no worse than anyone else. As the survey data suggested, these cancer survivors wanted to "get on with their lives" upon treatment completion and thus, were not vigilant in taking care of their long-term health.

Social Relationships

Differences in perceived risk and on factors that modify its effects are largely determined by patterns of socialization (Vernon, 1999). From a social ecological perspective, habits, norms and beliefs vary between different social groups. In this study, cancer survivors' family played an important role in the construction of second cancer risk perceptions. Living with risk involved cancer survivors making decisions about taking care of second cancer risk in the present which they hoped would prevent a future of suffering from a second cancer diagnosis for their family. In this sense, living with risk was seen as a family affair. Similar to previous studies with cancer survivors (Bober et al., 2007; Crom, Hinds, Gattuso & Hudson, 2005), family relationships influenced in positive and negative directions, the adoption and maintenance of actions to take care of second cancer risk. Taking care of second cancer risk was perceived by many cancer survivors as an obligation not only for themselves but also for family members, particularly in the context of shared risk.

The social and cultural context of second cancer risk is also largely influenced by the risks from the news media, including cancer prevention messages (Vernon, 1999). According to cancer survivors in this study and previous studies (Vernon, 1999), cancer prevention messages have succeeded in raising awareness about cancer and screening in the general population.

Living Conditions/ Neighborhoods and Communities

This mixed method study reports on second cancer risk in two geographically defined populations of cancer survivors – 82,595 first cancer cases in the Nova Scotia cohort and 105,984 in the Manitoba cohort. The overall second cancer rates were higher in the Manitoba cohort ($SIR = 7.09$) than in the Nova Scotia cohort ($SIR = 4.32$) most likely due to differences in underlying cancer rates; Manitoba has lower cancer rates which translate into a higher SIR. These results are comparable to those reported in other population-based Canadian cohorts, including a British Columbia study which recently reported an overall SIR of 5.0 (MacArthur et al., 2007). An interesting finding from the interviews with cancer survivors was that they believe they are at no more risk for developing a second cancer than people living in other parts of the Canada. Future research to compare the second cancer risk perceptions of cancer survivors residing in different provinces is needed to develop interventions best suited to the local cancer survivor population.

In this study, cancer survivors emphasized the importance of limiting, or if possible avoiding, exposure to things known to cause cancer, including tobacco smoke and sun's ultraviolet light. Although the impact of tobacco and other environmental exposures on the incidence of second cancers were not directly measured, it seems likely that these

factors contributed to the excess risk of second cancers observed in this study and previous studies (Curtis et al., 2006). About 14% of the second cancers in the both study cohorts were observed following initial cancers that are typically related to tobacco (e.g., buccal cavity, larynx and lung).

Institutions/Social and Economic Policies

Institutions and social and economic policies are equally important influences on whether or not cancer survivors follow prescribed follow-up regimens to take care of their second cancer risk. Three key variables considered in this section are: treatments received, relationships with health care providers, and follow-up cancer care policies.

Treatments received. The invasiveness of cancer treatments was incorporated into study participants' second cancer risk estimates. As found in the literature reviewed (Cardous-Ubbink et al., 2007; Inskip & Curtis, 2007; Travis, 2006), cancer survivors considered radiation therapy and/or chemotherapy to be invasive cancer treatments that increased one's second cancer risk. Study participants also expressed concern about the competing risks of developing a second cancer versus the side effects of medication. This finding supports the urgent need for information about the influence of treatment for medical conditions on second cancer risk, particularly hormone replacement therapy for premature menopause (Gantz, 2001).

Relationships with healthcare providers. The majority of cancer survivors spoke about the trust they have in their healthcare providers to take care of their second cancer risk so much so that many did not practice self-examinations, preferring to have clinical examinations. Healthcare providers were seen as experts and primary source of second cancer risk information. Having discussions about second cancer risk and its management

with a healthcare provider motivated cancer survivors to take care of their second cancer risk. This finding is similar to the trend seen in previous studies, in which specific recommendations from healthcare providers are associated with higher rate of cancer screening (Wilkins & Woodgate, 2008a). Consistent with results found in survivors of Hodgkin's disease, a more positive perception of healthcare provider interactions also served as a motivator to take care of risk (Bober et al., 2007).

Follow-up cancer care policies. The emergence of second cancers as late as 36 years out from the first cancer diagnosis supports the need for life-long follow-up of cancer survivors. Study findings suggest that the absence of evidence-based guidelines for monitoring and managing second cancer risk of cancer survivors has resulted in sporadic and fragmented long-term follow-up cancer care across Canada.

Inefficiencies in care delivery and less than optimal follow-up care for cancer survivors most vulnerable to late effects were identified. Consistent with previous studies (Earle et al., 2005; Park et al., 2002), cancer survivors reported feeling confused about whom to consult for help in taking care of second cancer risk, as well as the frequency of such consultations. One challenge identified by study participants was the lack of continuity in care, which resulted in much discomfort when transitioning to a new healthcare provider. Another challenge was the long waiting times that interfered with cancer survivors' timely access to follow-up care. A logical first step would be to improve cancer survivors' adherence to cancer screening recommendations for the general population. In a healthcare system with increasing wait times for medical testing, fair queuing is needed. Study participants recommended that fair queuing requires that patients receive care in a timely fashion, with priority determined by factors such as the

person's cancer history, severity of the presenting symptoms and risk of adverse event occurring while waiting. The next step would be to develop comprehensive, evidence-based policies for the longitudinal care of survivors so that there will be consistency in survivorship care across Canada. Another step would be to offer much needed support in the form of information, automated follow-up appointments and peer support.

Effective communication of a cancer survivor's medical history between family physicians, who often assumed much of the responsibility for cancer survivors' follow-up care, specialists and cancer survivors is needed to ensure that they receive appropriate long-term follow-up cancer care (Mertens et al., 2004; Park et al., 2002; Zebrack, et al., 2004). Policies on workload reduction for family physicians and oncologists are needed so that they have sufficient time to respond to cancer survivors' concerns and questions about second cancer risk. Given the growing cancer survivor population, the introduction of nurse practitioner-led follow-up clinics might reduce the workload of family physicians and oncologists. Nurse practitioners are well suited to helping cancer survivors manage their second cancer risk because their education focuses on patient assessment, symptom management, psychosocial care, and care planning (Canadian Nurses Association, 2009).

Methodological Strengths and Limitations

This section includes a discussion of the study's strengths and limitations with respect to conceptualization, research design and research methods. These strengths and limitations were considered in interpreting the study data.

Conceptualization

This mixed method study was guided by Kaplan and colleagues' (2000)

sociological ecological framework for understanding variations in health. This social ecological framework was helpful in developing the data collection instruments, and in informing the study during the data interpretation and integration stages. Bridging the biological and the social, this framework allowed for the simultaneous incorporation of an extensive set of downstream and upstream variables that contributed to second cancer risk among cancer survivors. This framework also serves to help nurses develop, implement and evaluate the effectiveness of interventions designed to improve the health of cancer survivors and reducing the burden of second cancers.

Research Design

The value of using a mixed methods approach in studying second cancer risk among cancer survivors was that the use of quantitative and qualitative methods provided a fuller picture of second cancer risk. The sum was greater than its constituent quantitative and qualitative parts because these parts were linked in the design of the research questions, recruitment of participants for the qualitative interviews and interpretation of study findings. In this way, it was possible to use the quantitative and qualitative data to deepen understanding of the findings emerging from each data set.

The view that was taken for this study was the quantitative and qualitative methods answered different research questions, thereby offering complementary views of second cancer risk among cancer survivors. In this research study, there was clear rationale for the use of survey data, epidemiology data and interview data. The survey data addressed current practices in the follow-up care offered for cancer survivors across Canada (outcome for research question 1). Population-based health databases (cancer registry and health insurance databases) were used to estimate the extent of the second cancer risk

among cancer survivors in Nova Scotia and Manitoba relative to the general population at risk (outcome for research question 2 and 3). Qualitative interview data were collected to better understand cancer survivors' views about their risk of developing a second cancer and how they manage that risk (outcome for research questions 4 and 5). Nested sampling, in which a subsample of the Nova Scotia cohort were recruited to participate in the qualitative interviews, created the integrated sampling identified as important by Teddlie and Tashakkori (2003). The study's research design laid the foundation that facilitated the linking of collected data in the interpretation of the findings.

As with any mixed methods design, it was important to ensure that there was sufficient time and resources to complete the study given the different time lines and rhythms inherent in mixed methods research (Bryman, 2007). The current study required three years to complete. Delays in accessing data were inevitable due to the sheer number of ethical and administrative approvals that were needed. The researcher was able to draw upon the expertise of her dissertation committee members to analyze the qualitative and quantitative data.

Research Methods

Strengths and potential biases that may be introduced by reporting inaccuracies and other methodological limitations must be considered in interpreting the findings.

Qualitative survey data. Healthcare providers from 22 cancer centers across Canada completed the surveys. The participation rate was lower than expected. One possible explanation for the low participation rate is that a similar survey of long-term follow-up programs for childhood cancer survivors in Canada was conducted shortly before the researcher began data collection. Thus, although the surveys were different,

potential participants might have assumed the surveys were the same and chose not to participate in the researcher's survey.

Participants gave responses based on their knowledge of the long-term follow-up programs were available at their cancer centre. Open-ended survey questions allowed the participants to answer in their own words. Open-ended questions required more thought and reflection and thus, may have been more time intensive to answer than closed-ended questions. Not all respondents answered all questions.

Epidemiological data. The epidemiological data covers a defined geographical area; includes details of all cancer types, for both first and second cancers; follow-up is long (up to 36 years) and includes all second cancers diagnosed 6 months or longer following the first cancer diagnosis. It is also the second study to report on second cancers across the lifespan.

Data derived from population-based cancer registries allows detection of even small second cancer risks due to the sizeable number of cancer cases. Another benefit of using population-based data is the opportunity to describe site-specific second cancer risks according to a variety of demographic and disease factors and trends in risk over time as cancer treatments evolve (Travis et al., 2005). Because the observed and expected numbers of second cancers are derived from the same population, the population-based nature of the cancer registries averts the problem of selection or referral biases of hospital-based populations (Pearson et al., 2002).

A key assumption in this study was that the first and second cancers are biologically independent (i.e., the second cancer was not a further manifestation of the first cancer). Provincial cancer registries rely on the pathology report as to whether a new

cancer is a new cancer, metastatic disease, or local recurrence. Histopathologic conformation of the new cancers increases confidence in the diagnosis of a new cancer, but may not provide definitive evidence of cancer independence. Correct classification of a new cancer may also be problematic when it arises at the same anatomic site. A major drawback of using the cancer registries is that cancer treatment data are quite limited and were not accessed for this study. Similarly, information on cancer survivors' culture/ethnicity, screening practices and lifestyle choices is not collected in the cancer registries, thus limiting the conclusions that can be drawn about second cancer risk at the population-level.

Another potential bias is that cancer survivors may undergo closer scrutiny than the general population, which may lead to early detection of cancers that may not be clinically evident for several years. Because multiple comparisons for the presentation of second cancers by sex, age, and time since diagnosis were used, testing may identify statistically significant risks that have occurred by chance alone (Young, 2005). To differentiate real findings from chance, the results were viewed in light of the biological plausibility of the association in the context of previous second cancer studies.

Qualitative interview data. The sample size for the qualitative interviews was small, with 22 cancer survivors participating in a total of 23 interviews. Typically, there are no criteria or rules for sample size in qualitative research (Speziale & Carpenter, 2003). The aim in qualitative research is to recruit a large enough sample to elucidate the richness of the individual experience (Speziale & Carpenter, 2003). Therefore, interviews were conducted until redundancy occurred and the researcher found no new data emerging.

Participants in the interviews included cancer survivors of diverse ages, cancer diagnoses and time since first cancer diagnosis. Regardless of this diversity, no differences in second cancer risk perceptions were noted by these demographic and illness variables. All cancer survivors were Caucasian. It is possible that a sample that included more ethnic variability may have revealed additional information about cancer survivors' second cancer risk perceptions.

Inherent in the qualitative approach to research is the inability to generalize the interview findings to represent the broader population because the results are always contextual (Woodgate, 2000a). There was no expectation in this study that the interview findings would be generalizable to all cancer survivors or that the interviews could be replicated to yield the same data. It was anticipated, however, that the interview data would foster an understanding of cancer survivors' perceptions of second cancer risk, sufficient to form a basis for future research.

Interview data were collected at only one time point. Longitudinal research with multiple data collection points over an extended period of time is needed to capture cancer survivors' multiple and changing realities from various vantage points throughout the course of the cancer survivorship (Woodgate, 2000b). Furthermore, collecting data over time and in a variety of contexts adds breadth to qualitative data and is characteristic of a "good" qualitative study (Woodgate, 2000b).

Because meanings are constructed through interactive experiences, it is the interaction between researcher and participant that created the data (Speziale & Carpenter, 2003). The researcher captured the emic (within) perspective through multiple, in-depth interviews. Interview questions were kept as open as possible to ensure

that the person being interviewed, rather than the interviewer, determined the focus of the discussion.

The risk of bias is present in all human science research studies. The researcher has a responsibility to explicate their assumptions and preconceptions so as to understand their impact on the research process (Speziale & Carpenter, 2003). When collecting the interview data, the researcher made personal and theoretical assumptions regarding second cancer risk explicit in field notes. The aim of this exercise was to not forget about personal biases and feelings but to deliberately hold them at bay.

Recommendations

This study launches future directions nurses can pursue in caring for cancer survivors. Recommendations arising from the study results are presented in the areas of nursing practice, nursing education and nursing research.

Nursing Practice

A key message from the study findings is that nurses need to develop multilevel interventions. Downstream approaches provide tailor-made strategies that are more sensitive to individual second cancer risks. Upstream approaches involve interventions at the policy or community level, leading to reductions in population-level second cancer risks.

Downstream approaches. The assumption that cancer survivors want statistical information about their epidemiological risk was not supported by the qualitative interviews. In this study, having a precise risk statistic is less important to cancer survivors than having a general idea of their second cancer risk and a sense that a system is in place to support them in taking care of their second cancer risk. There is some

information in the literature suggesting that nurses should be focusing more on assessing and understanding how cancer survivors perceive and act on their second cancer risk (Han et al., 2009). Nurses need to do more than ask cancer survivors to assign a numerical value to their second cancer risk as they understand it. Nurses need to ascertain what that second cancer risk means to cancer survivors and how they plan to act upon it because each cancer survivor can hold valid and different risk perceptions and frames of reference for cancer risk factors.

Another effective approach to risk communication is to avoid the typical the one-way, expert-to-layperson communication about cancer risks that involves the nurse correcting cancer survivors inaccurate risk perceptions so as to retain a focus on the actual risk. A key message from the cancer survivors was that nurses cannot assume that all survivors will be swayed to take care of second cancer risk with the same evidence because they interpret risk differently. From the current study and previous research, it remains unclear as to whether or not increasing the accuracy of risk perception will lead to behavior changes such as increased participation in cancer screening (Han et al., 2009; Vernon, 1999).

Another implication of the study findings for nursing practice is that nurses need to consider how living with risk unfolds through cancer survivors' life course and within their social environment. A life course perspective could inform the timing of interventions regarding the needs, risks and opportunities to change at a particular time in the life course. Developmental strategies that match the timing of interventions need to be implemented. Also important is that nurses need to need to connect cancer survivors' past cancer experiences to the present risk assessment so as to examine their second cancer

risk perceptions in their context.

Upstream approaches. Within a healthcare system that obligates individuals to reduce risks and actively pursue good health through individual adherence to cancer screening recommendations, nurses need to examine how wider social forces may hinder an individual's uptake of cancer screening (e.g., access to cancer screening services). Interventions might involve integrating second cancer risk information within organizational activities such as fundraisers, or changing the work environment so cancer survivors can obtain cancer screening.

Nursing Education

This mixed method study contributes to the existing body of knowledge on second cancer risk in cancer survivors by clarifying past findings described in the review of the literature and helping nurses to understand that follow-up cancer care must be based on real need, rather than assumed need. While recognizing that each cancer survivor's second cancer risk is unique, these findings can serve as a starting point for conversations with cancer survivors about their second cancer risk. Nurses may benefit from being taught, that through asking cancer survivors about their perceptions of second cancer risk much can be learned about the interventions that would assist them to take care of that risk.

To ensure the new knowledge is translated into improving how long-term follow-up care, risk-based screening and cancer prevention programs are developed and implemented, a number of knowledge translation activities were planned. Results from this dissertation will be published and presented within and outside of the academic community. Within the academic community the research team plans to publish in peer-

reviewed health journals (e.g., *Journal of Clinical Oncology*, *Oncology Nursing Forum*), cancer survivor journals (e.g., *Journal of Cancer Survivorship: Research and Practice*), and social science journals (e.g., *Qualitative Health Research*). The researcher plans to present the findings at key multidisciplinary national and international conferences that target nurses and other healthcare providers.

Communication of the study's findings outside the academic community is equally important. Summary reports will be distributed to key cancer control institutes and provincial cancer registries. Discussions about the types of data housed in provincial cancer registries will be held. Presentations to professional associations or interest groups who are interested in improving cancer prevention educational materials are planned. Engaging these groups in debate about the need to develop and refine standards for long-term follow-up care and risk-based screening for cancer survivors may lead to reductions in the incidence of second cancers. Further issues and their solutions may emerge.

Nursing Research

Future research on cancer survivors' perceived second cancer risk should explore the views of cancer survivors of different cultural and ethnic backgrounds. Culture and ethnicity are important variables for inclusion in population-based databases so that future research could examine how culture and ethnicity influence second cancer risk at a population-level. The research should also examine the differences among age cohorts. Interviews with GPs and other healthcare providers to explore their views about supporting cancer survivors to take care of risk in their practice would complement the interviews conducted in this mixed method study with cancer survivors.

As cancer treatments evolve, research on treatment-related second cancer risks will

be critical to monitor patterns of excess second cancers. Improvement to the quality and quantity of cancer treatment data recorded in cancer registries is needed to facilitate research on treatment-related second cancer risks. It will be important to examine the effects of age at exposure, gender and other factors on second cancer risk. Another area for future research is identification of subgroups of cancer survivors most at risk of developing second cancers.

The education of cancer survivors and healthcare providers with regard to second cancer risk and taking care of second cancer risk is important. Future research should also address the development of interventions to take care of second cancer risk. Evidence-based cancer screening and risk-reduction strategies for cancer survivors are needed. Where long-term follow-up guidelines have been developed, these should be implemented and evaluated.

Nurses are encouraged to generate knowledge in new and innovative ways. One possible direction for nurses who are interested in second cancer risk research is the pursuit of methodologies that are committed to justice. Research programs adopting a critical social theory approach, such as participatory action research, seeks to empower individuals through critical reflection and consciousness raising (Fontana, 2004). Having an openly emancipatory intent, participatory action research could be used to help cancer survivors become aware of how the world is imbued with meanings of risk and how they can develop the skills necessary to challenge their marginalization in decisions about cancer screening.

Future research is also needed to develop a better understanding of the relationships between perceived second cancer risk and resultant health behaviours of cancer survivors.

Understanding the ways in which perceived risk, attitudes, intentions and stages of change act as a motivator for behaviour change will help tailor second cancer risk information to each cancer survivor (Albada et al., 2009). Theory-guided choices of tailoring variables need to be considered in developing and testing future interventions that promote cancer screening uptake among cancer survivors.

Chapter Summary

An overall picture of second cancer risk among cancer survivors was presented. Six key questions were addressed by linking quantitative and qualitative data and analyses. The identified patterns were discussed, with reference to upstream and downstream factors, and implications for nursing practice, research and education were drawn. The findings were the result of a synthesis of evidence by all data, explored in relation to the study's theoretical underpinnings and other research studies.

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APPENDIX A: ETHICAL APPROVAL, RENEWALS AND AMENDMENTS
FROM THE EDUCATION/NURSING RESEARCH ETHICS BOARD



UNIVERSITY
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OFFICE OF RESEARCH
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Office of the Vice-President (Research)

CTC Building
208 - 194 Dafoe Road
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Fax (204) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

31 July 2007

CIHR

TO: Krista Wilkins (Advisor R. Woodgate)
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2007:052
"A Mixed Method Study of Second Cancer Risks among Childhood
Cancer Survivors"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval: otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.



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AMENDMENT APPROVAL

26 October 2007

TO: Krista Wilkins
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2007:052
"A Mixed Method Study of Second Cancer Risks among Childhood Cancer Survivors"

This will acknowledge your request dated October 10, 2007 requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.

Bringing Research to Life



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AMENDMENT APPROVAL

22 February 2008

TO: Krista Wilkins
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2007:052
"A Mixed Method Study of Second Cancer Risks among Childhood
Cancer Survivors"

This will acknowledge your e-mail dated February 21, 2008 requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.



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RENEWAL APPROVAL

22 September 2008

TO: Krista Wilkins
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2007:052
"A Mixed Method Study of Second Cancer Risks among Childhood Cancer Survivors"

Please be advised that your above-referenced protocol has received approval for renewal by the **Education/Nursing Research Ethics Board**. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Bringing Research to Life



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AMENDMENT APPROVAL

30 September 2008

TO: **Krista Wilkins**
Principal Investigator

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2007:052**
**"A Mixed Method Study of Second Cancer Risks among
childhood Cancer Survivors"**

This will acknowledge your request dated September 24, 2008 requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.

Bringing Research to Life



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RENEWAL APPROVAL

March 2, 2010

TO: Krista Wilkins
Principal Investigator

FROM: Lorna Guse, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2007:052**
"A Mixed Method Study of Second Cancer Risk Among Cancer Survivors"

Please be advised that your above-referenced protocol has received approval for renewal by the **Education/Nursing Research Ethics Board**. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Bringing Research to Life

APPENDIX B: TIME LINE FOR OVERALL STUDY

Date	Activities
June – October, 2007	<ul style="list-style-type: none"> ▪ Meetings with the research team, and appropriate personnel from the Manitoba and Nova Scotia cancer registries to review the study and address concerns and questions ▪ Ethical approval granted by ENREB
October, 2007	<ul style="list-style-type: none"> ▪ Presented study to pediatric oncology department at the IWK Health Centre to ascertain assistance with recruitment ▪ Data access approved by MB Cancer Registry
November, 2007	<ul style="list-style-type: none"> ▪ Meetings with the research team, and appropriate personnel from the Manitoba and Nova Scotia cancer registries to review the study and address concerns and questions ▪ Changes to study approved by ENREB ▪ (Epidemiologic) data access approved by NS Cancer Registry and Manitoba Health
December, 2007	<ul style="list-style-type: none"> ▪ Ethical approval (epidemiological data) granted by Capital Health REB ▪ (Epidemiologic) data access approved by CancerCare Manitoba (RRIC) and Manitoba Health ▪ Policies on long-term follow-up cancer care were sought from cancer centres across Canada
February, 2008	<ul style="list-style-type: none"> ▪ Changes to study approved by ENREB ▪ Changes to (epidemiologic) data access approved by Manitoba Health
March, 2008	<ul style="list-style-type: none"> ▪ Ethical approval (epidemiological data) granted by IWK REB ▪ Preliminary analysis of epidemiological data began
April, 2008	<ul style="list-style-type: none"> ▪ Ethical approval (survey data) granted by IWK REB and Capital Health REB ▪ Surveys mailed
July, 2008	<ul style="list-style-type: none"> ▪ Ethical approval (interview data) granted by IWK REB and Capital Health REB
September, 2008	<ul style="list-style-type: none"> ▪ Changes to study approved by ENREB ▪ Changes to (epidemiologic) data access approved by CancerCare Manitoba (RRIC) ▪ Changes to (epidemiological) data access approved by Capital Health REB ▪ More surveys mailed and analyses began
October, 2008	<ul style="list-style-type: none"> ▪ Changes to (epidemiological) data access approved by Capital Health REB ▪ Ethical approval (interview data) granted by UNB REB ▪ Ongoing preliminary analysis of epidemiological data
November, 2008	<ul style="list-style-type: none"> ▪ Changes to interview data collection approved by IWK REB
December, 2008	<ul style="list-style-type: none"> ▪ Changes to (epidemiological) data access approved by Capital Health REB ▪ Changes to interview data collection approved by Capital Health

Date	Activities
	REB <ul style="list-style-type: none"> ▪ Recruitment for interview data began through the NS Cancer Registry
January, 2009	<ul style="list-style-type: none"> ▪ Recruitment for interviews began through the IWK Health Centre ▪ Ongoing recruitment for interviews through the NS Cancer Registry ▪ Interviews began ▪ Analysis of interview transcripts began
February - July, 2009	<ul style="list-style-type: none"> ▪ Ongoing recruitment for interviews ▪ Interviews were hired ▪ Ongoing analysis of interview transcripts ▪ Hired data transcriber
July, 2009 – April 10, 2009	<ul style="list-style-type: none"> ▪ Ongoing analysis of interview transcripts ▪ Ongoing analysis of epidemiological data ▪ Report writing
May-August, 2010	<ul style="list-style-type: none"> ▪ Defend dissertation ▪ Dissemination activities ▪ Submission of manuscripts for publication ▪ Commence proposal development for future work

APPENDIX C: LETTER TO MEDICAL DIRECTORS FOR THE SURVEY

<Medical Director's Name>

< Medical Director's Mailing Address>

<Date>

Dear <Medical Director's Name>,

My name is Krista Wilkins. I am a nurse currently working in Nova Scotia, and a doctoral student with the University of Manitoba in Winnipeg, Manitoba. I am writing to Medical Directors of all pediatric and adult cancer centers across Canada to invite them to participate in a study titled "*A Survey of Current Practices in Long-term Follow-up of Cancer Survivors across Canada*". This research study is my dissertation research. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this survey study. Dr. L. Parker, Dr. L. Degner and Dr. D. Turner are the other three members of my thesis committee. This study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board. The study is funded by a Canadian Institutes of Health Research studentship.

As part of my doctoral studies, I am surveying Medical Directors from pediatric and adult cancer centers across Canada to better understand current practices and existing gaps in follow-up care for survivors of childhood and adulthood cancers. The survey contains questions about the long-term follow-up cancer care is provided at your institution and your ideal model of follow-up cancer care. The survey will take about 30 minutes to complete.

The information I get from this study will be written up for my doctoral dissertation and for publication in peer-reviewed journals, but in all instances, you and your cancer center's identity would remain anonymous. Only grouped data will be reported. I also plan to present the study results at a health conference. A summary of the study results will be distributed to all participating institutions.

If you are interested in participating in this study, please review the enclosed information. Your consent to participate in this study will be implied by the return of your completed survey. If you have any questions, concerns or need additional information, please contact me at (902) 444-4921 or by e-mail at umwilk04@cc.umanitoba.ca. You may also contact my supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

Sincerely,

Krista Wilkins, RN, MN
Doctoral Student
University of Manitoba

**APPENDIX D: REMINDER LETTER TO MEDICAL DIRECTORS FOR THE
SURVEY**

<Medical Director's Name>
< Medical Director's Mailing Address>

<Date>

Dear <Medical Director's Name>,

A few weeks ago you received a letter from about a research study that you may be interested in participating. If you have already responded, we thank you. If you have not had time to respond or your survey has been misplaced, this letter is to remind you about the study.

My name is Krista Wilkins. I am a nurse currently working in Nova Scotia, and a doctoral student with the University of Manitoba in Winnipeg, Manitoba. I am writing to Medical Directors of all pediatric and adult cancer centers across Canada to invite them to participate in a study titled "*A Survey of Current Practices in Long-term Follow-up of Cancer Survivors across Canada*". This research study is my dissertation research. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this survey study. Dr. L. Parker, Dr. L. Degner and Dr. D. Turner are the other three members of my thesis committee. This study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board. The study is funded by a Canadian Institutes of Health Research studentship.

As part of my doctoral studies, I am surveying Medical Directors from pediatric and adult cancer centers across Canada to better understand current practices and existing gaps in follow-up care for survivors of childhood and adulthood cancers. The survey contains questions about the long-term follow-up cancer care is provided at your institution and your ideal model of follow-up cancer care. The survey will take about 30 minutes to complete.

The information I get from this study will be written up for my doctoral dissertation and for publication in peer-reviewed journals, but in all instances, you and your cancer center's identity would remain anonymous. Only grouped data will be reported. I also plan to publish the report in a professional journal and present it at a health conference. A summary of the study results will be distributed to all participating institutions.

If you are interested in participating in this study, please review the enclosed information. Your consent to participate in this study will be implied by the return of your completed survey. If you have any questions, concerns or need additional information, please contact me at (902) 444-4921 or by e-mail at umwilk04@cc.umanitoba.ca. You may also

contact my supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

Sincerely,
Krista Wilkins, RN, MN
Doctoral Student
University of Manitoba

APPENDIX E: SURVEY

Instructions: This survey asks about your current and ideal practices in providing follow-up care to cancer patients. For this survey, follow-up care refers to the continued care of cancer patients after completion of primary treatment.

1. Survey completed by:

- Oncologist
- Clinic nurse
- Other (please specify your professional designation): _____

2. Which best describes your patient population?

- Childhood cancer
- Adulthood cancer

Please specify the type(s) of cancer:

3. Considering all of your cancer patients who have survived **2-5 years from treatment completion** and for whom there is **no evidence of primary disease**, is it your practice that such patients receive follow-up care?

- Yes → Please describe those groups of such cancer survivors who receive follow-up care

- No → Please describe those groups of such cancer survivors who do not receive follow-up care

4. Considering all of your cancer patients who have survived **beyond 5 years from treatment completion** and for whom there is **no evidence of primary disease**, is it your practice that such patients receive follow-up care?

- Yes → Please describe those groups of such cancer survivors who receive follow-up care

No → Please describe those groups of such cancer survivors who do not receive follow-up care

5. Describe your current practices in providing follow-up care for cancer patients who have survived **2-5 years from treatment completion** and for whom there is **no evidence of primary disease**.

Staffing: _____

Services provided: _____

Timing of visits: _____

Location: _____

6. Describe your current practices in providing follow-up care for cancer patients who have survived **beyond 5 years from treatment completion** and for whom there is **no evidence of primary disease**.

Staffing: _____

Services provided: _____

Timing of visits: _____

Location: _____

7. What cancer-specific and/or cancer non-specific guideline(s) inform follow-up cancer care provided at your institution? Please specify the name and author of the guideline(s):

8. If your institution does not provide life-long follow-up for cancer survivors, describe to whom they are discharged.

9. If your institution does not provide life-long follow-up for cancer survivors, describe what is done to facilitate the transition from your care to the care of another healthcare provider.

10. What are the benefits of providing follow-up care to cancer survivors?

11. What are the challenges of providing follow-up care to cancer survivors?

12. What would you do to address the challenges you have identified in providing follow-up to cancer survivors?

APPENDIX F: INFORMATION LETTER FOR THE SURVEY

Research Title

A Survey of Current Practices in Long-term Follow-up of Cancer Survivors across Canada

Researcher(s)

Krista Wilkins, RN (Doctoral Student)
Faculty of Nursing, University of Manitoba

Dr. Roberta Woodgate, RN, PhD (Chair of Dissertation Committee)
Faculty of Nursing, University of Manitoba

Dr. Louise Parker, PhD (Dissertation Committee Member)
Department of Pediatrics, IWK Health Centre

Dr. Lesley Degner (Dissertation Committee Member)
Faculty of Nursing, University of Manitoba

Dr. Donna Turner (Dissertation Committee Member)
CancerCare Manitoba

Funding

This study is sponsored by a Canadian Graduate Scholarships – Doctoral Award (research allowance) awarded to Krista Wilkins from the Canadian Institutes of Health Research.

Introduction

You are being invited to take part in the research study named above. This form provides information about the study. Before you decide if you want to take part, it is important that you understand the purpose of the study, the risks and benefits and what you will be asked to do. You do not have to take part in this study. Taking part is entirely voluntary (your choice). Informed consent starts with the initial contact about the study and continues until the end of the study. A member of the research team will be available to answer any questions you have. You may decide not to take part or you may withdraw from the study at any time. This will not affect the care you or your family members receive from the IWK Health Centre or any other health centre. This study is being done as part of Ms. Wilkins' doctoral studies.

Why are the researchers doing the study?

The purpose of this study is to better understand current practices and existing gaps in follow-up care available for childhood and adulthood cancer survivors across Canada. This study will result in knowledge that can be used to develop and refine the coordination of long-term follow-up cancer care.

How will the researchers do the study?

Medical Directors from pediatric and adult cancer centers across Canada will be surveyed about the long-term follow-up cancer care provided at their institution and their ideal model of follow-up cancer care.

What will I be asked to do?

You are being asked to complete a written survey on current and ideal practices in the long-term follow-up of individuals who have had a childhood or adulthood cancer. The survey should take you about 30 minutes to complete.

What are the burdens, harms, and potential harms?

There are no known risks for taking part in the study.

What are the possible benefits?

You will receive no direct benefit from participating in the study.

Can I withdraw from the study?

Your participation in this study is entirely voluntary.

Will the study cost me anything and, if so, how will I be reimbursed?

A postage-paid envelope is enclosed for you to return the survey to the researchers.

Are there any conflicts of interest?

There are no conflicts of interest.

What about possible profit from commercialization of the study results?

There is not potential profit from commercialization of the results of this study.

How will I be informed of study results?

A summary of the study results will be distributed to all participating institutions.

How will my privacy be protected?

In all instances, you and your cancer center's identity would remain anonymous. Only grouped data will be reported. All surveys will be stored in a locked filing cabinet and computer protected by a password known only to Krista Wilkins. All data will be destroyed seven years following completion of the study. In any publications or presentations of the study findings, nobody will be able to tell that you were in the study.

Some other people or groups may need to check or see your study records to make sure all of the information is correct. All of these people have a professional responsibility to protect your privacy. These groups and people are:

- The Canadian Institutes of Health Research, the study sponsor, and their assigned representatives
- The Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba, which is responsible for the protection of people in research by students of the University of Manitoba

- The Capital District Health Authority Research Ethics Board (CHREB) which is responsible for the protection of people in research with the Nova Scotia Cancer Registry
- The IWK Health Centre Research Ethics Board (IWK REB), which is responsible for the protection of people in research associated with the IWK Health Centre
- Quality assurance staff including the auditors for the CHREB, ENREB and IWK REB, who ensure that the study is being conducted properly

The information they check may include study results.

You may also be contacted personally by the research auditors for quality assurance purposes.

What if I have study questions or problems?

You may contact Krista Wilkins at (902) 444-4921, Monday to Friday between 9a.m. and 5p.m. or umwik04@cc.umanitoba.ca if I have any concerns, questions, or need additional information. You may also contact Krista Wilkins' supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

What are my Research Rights?

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. The return of a completed survey to the researchers indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator, the research doctor, the study sponsor or involved institutions from their legal and professional responsibilities.

If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Centre at (902) 470-8765, Monday to Friday between 9a.m. and 5p.m.

APPENDIX G: SURVEY SUMMARY REQUEST FORM

A summary of the study results is available to you, if you want one.

Would you like to receive a copy of the study results? Yes___ No___

Please provide your mailing address:

Return in the enclosed envelope or fax to (902) 470-7232.

APPENDIX H: FIELDS REQUESTED FROM THE CANCER REGISTRIES

Field	Purpose(s)
Unique study ID	<ul style="list-style-type: none"> ▪ To link cancer registry data with data from the population health insurance eligibility data (for Manitoba cohort only)
Year of birth	<ul style="list-style-type: none"> ▪ To describe the age of population ▪ To calculate age-adjusted cancer incidence ratios ▪ To determine the risk of developing a second cancer in relation to age at diagnosis
Sex	<ul style="list-style-type: none"> ▪ To describe the sex of the population ▪ To calculate sex-adjusted cancer incidence ratios ▪ To determine the risk of developing a second cancer in relation to sex
First cancer diagnosis (diagnosis of invasive tumor, including tumor of unknown origin)	<ul style="list-style-type: none"> ▪ To describe first cancer characteristics ▪ To determine the risk of developing a second cancer in relation to first cancer diagnosis
Year of first cancer diagnosis	<ul style="list-style-type: none"> ▪ To describe primary cancer characteristics ▪ To calculate person-years-at-risk ▪ To calculate era-adjusted cancer incidence ratios ▪ To determine the risk of developing a second cancer in relation to time since diagnosis
Second cancer diagnosis	<ul style="list-style-type: none"> ▪ To describe second cancer characteristics ▪ To calculate standardized incidence ratios in relation to second cancer diagnosis
Year of second cancer diagnosis (diagnosis of invasive tumor, including tumor of unknown origin that occurs six months or later after the first primary)	<ul style="list-style-type: none"> ▪ To describe second cancer characteristics ▪ To calculate person-years-at-risk
Year of death	<ul style="list-style-type: none"> ▪ To calculate person-years-at-risk
Year of censoring event	<ul style="list-style-type: none"> ▪ To calculate person-years-at-risk

**APPENDIX I: APPROVAL LETTER FROM THE DIRECTOR OF THE
MANITOBA CANCER REGISTRY**



CancerCare
MANITOBA

Action Cancer Manitoba

○ 675 McDermot Avenue
Winnipeg, Manitoba
Canada R3E 0V9

○ 409 Taché Avenue
Winnipeg, Manitoba
Canada R2H 2A6

www.cancercare.mb.ca

October 29, 2007

Ms. Krista Wilkins, RN, PhD(c)
Clinical Trials Research Centre
4th Floor, Goldbloom Pavilion
IWK Health Centre
5850/5980 University Avenue
Halifax, NS B3K 6R8

Re: A Mixed Method Study of Second Cancer Risk Among Cancer Survivors

Dear Ms. Wilkins:

I am pleased to provide a letter of support for your funding application to the Oncology Nursing Society Small Grant Research Program.

CancerCare Manitoba provides services across the cancer control spectrum from prevention and early detection through treatment, palliation and survivorship. As a result we are interested in your project in which long-term outcomes of cancer survivors will be assessed. I appreciate the opportunity to provide input to the development of your study proposal from its inception.

Subsequent to the necessary ethics and data access approvals, staff of the Manitoba Cancer Registry and our Epidemiology Unit will provide the following:

1. identification of cancer cases of interest from the Manitoba Cancer Registry and preparation of the required analytic dataset;
2. linkage to Manitoba Health's administrative databases; and
3. input and feedback into the data analysis process and results.

CancerCare Manitoba is looking forward to this project as it will provide information about risk for second cancers in Canada generally, and in our province specifically. Please let me know if you need anything further for your research.

Yours truly,

Donna Turner, PhD
Epidemiologist / Interim Provincial Director, Cancer Control and Program Planning
CancerCare Manitoba

c.c: Dr. Roberta Woodgate, Faculty of Nursing, University of Manitoba

**APPENDIX J: APPROVAL LETTER FROM THE DIRECTOR OF THE NOVA
SCOTIA CANCER REGISTRY**

October 23, 2007

Ms. Krista Wilkins, RN, PhD(c)
Clinical Trials Research Centre
4th Floor, Goldbloom Pavilion, IWK Health Centre
5850/5980 University Avenue, Halifax, NS B3K 6R8

Dear Ms. Wilkins:

**Re: Letter of Support - A Mixed Method Study of Second Cancer Risk among
Cancer Survivors**

On behalf of the Surveillance and Epidemiology Unit (SEU) of *Cancer Care Nova Scotia* (CCNS), I am pleased to offer the following letter of support for your funding application to the Oncology Nursing Society Small Grant Research Program.

SEU staff have reviewed your study proposal, *A Mixed Method Study of Second Cancer Risk Among Cancer Survivors*, and had input into components related to data acquisition and methodology. Once the study has received appropriate ethics and Department of Health approvals, the SEU will facilitate:

1. Access the Nova Scotia Cancer Registry for identification of the cancer cases of interest and the preparation of the required analytic dataset.
2. Provision of the data to the Population Health Research Unit of Dalhousie University for linkage to defined administrative data sets.
3. Access to SEU staff for input and feedback into the data analysis process and results.
4. Identification of subjects for the qualitative component of the study.
5. Management of contact process for the study subjects in the qualitative section.

The SEU is looking forward to this project that explores second cancer risk since it is an area that has not been explored in Nova Scotia. The opportunity to increase analytic capacity through support of PhD level research also fits the mandate of CCNS. If I can be of any further assistance, please let me know.

Yours truly,
Maureen MacIntyre, B.ScN, MHSA
Director, Surveillance and Epidemiology Unit
Cancer Care Nova Scotia

APPENDIX K: APPROVAL LETTER FROM MANITOBA HEALTH

Health Information Privacy Committee
4045 – 300 Carlton Street
Winnipeg, MB R3B 3M9
Phone: (204) 786-7204
Fax: (204) 944-1911

February 20, 2008

Ms. Krista Wilkins
IWK Health Centre
5850/5980 University Avenue
PO Box 9700
Halifax, NS B3K 6R8

File No. 2007/2008 - 54

Dear Ms. Wilkins:

Re: Magnitude and Risk Factors of Second Cancers and Second Cancer Deaths Among Cancer Survivors in Manitoba and Nova Scotia

Upon review of your original application (dated December 14th, 2007), as well as the additional information provided in your letter received February 5th, 2008, the Health Information Privacy Committee (HIPC) has considered and *approved* your request for access to data for the purposes of this project.

It is the understanding of the HIPC however, that the Manitoba Health Registry data will be accessed directly from CancerCare Manitoba, linked to the Cancer Registry data, and only the de-identified and anonymized line-level data will be sent to you and secured in the manner you described in your letter of February 5th, 2008.

Please note also that any significant changes to the proposed study design should be reported to the Chair for consideration in advance of their implementation. Also, please be reminded that *all manuscripts and presentation materials (including a student thesis) resulting from this data request must be submitted for review at least 30 days prior to being submitted for publication or presentation.*

If you have any questions or concerns, please do not hesitate to contact Dr. Patricia Caetano, Committee Coordinator at 786-7204.

Yours truly,
Dr. R. Walker
Chair

Please quote the file number on all correspondence

c. L. Barre
D. Turner

**APPENDIX L: APPROVAL LETTER FROM CANCERCARE MANITOBA'S
RESEARCH RESOURCE IMPACT COMMITTEE**



CancerCare
MANITOBA
Action Cancer Manitoba

675 McDermot Avenue
Winnipeg, Manitoba
Canada R3E 0V9

409 Taché Avenue
Winnipeg, Manitoba
Canada R2H 2A6

www.cancercare.mb.ca

January 24, 2008

Ms Krista Wilkins
IWK Health Centre
4th Floor Goldbloom Pavilion
5850/5980 University Avenue
Halifax, Nova Scotia
B3K 6R8

Dr. Roberta Woodgate
465 Helen Glass Centre
Faculty of Nursing
University of Manitoba
Fort Gary Campus
Winnipeg, Manitoba

Dear Ms Wilkins and Dr. Woodgate,

**Re: RRIC 04-2008 Approval for the following study:
A Mixed Method Study of Second Cancer Risk Among Cancer
Survivors Phase 2: Magnitude and Risk Factors of Second Cancers
and Second Cancer Deaths Among Cancer Survivors in Manitoba
and Nova Scotia**

The above study was reviewed by the CancerCare Manitoba RRIC on January 23, 2008. I wish to advise that your study was approved.

Any significant changes in this research should be reported to the Chair for consideration in advance of implementation of such changes. The RRIC should be notified regarding discontinuation or study closure.

The approval is for the RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,

Rochelle Yanofsky, MD, FRCPC
Chair, Resource Impact Committee

APPENDIX M: RECRUITMENT PACKAGE FOR PARTICIPANTS
RECRUITED THROUGH THE NOVA SCOTIA CANCER REGISTRY

Cover Letter from the Nova Scotia Cancer Registry

<Address>

<Date>

Dear <Cancer Survivor's name>,

On behalf of *Cancer Care Nova Scotia* (CCNS), I am writing to invite you to participate in a cancer research study. CCNS is a program of the Nova Scotia Department of Health involved in standard setting, monitoring services and research related to cancer.

Your name was identified from the Nova Scotia Cancer Registry at CCNS. The Registry is a data system that contains information on persons diagnosed with cancer in this province and has been in place since 1964. It operates by authority of the Provincial Health Act and under the direction of the Nova Scotia Department of Health. CCNS is responsible for the day-to-day operation of the Registry and ensuring the confidentiality of all the information it contains. Registry information is used to study and monitor cancer in Nova Scotia, and to produce statistics about the types of cancer seen here.

From time to time, we are contacted by researchers who want to talk with Nova Scotians about their cancer experience. The Registry is not allowed to give your name to any researcher, so we are contacting you on their behalf to request your help with this study. This study has been considered in detail by CCNS and has been approved by the Research Ethics Boards from each involved organization.

The researcher's name is Krista Wilkins, a nurse based at the University of New Brunswick. Ms. Wilkins is doing a research study titled "Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer". She is completing this work as part of doctoral studies at the University of Manitoba, and in partnership with CCNS and the IWK Health Centre. The study involves interviewing people living in Nova Scotia who have had cancer about what they think and feel are their potential risks for developing another cancer. This study is being done because although there has been research that explores the general public's views about their cancer risk, we know very little about what cancer survivors think about this topic. Please review the materials sent with this letter, which describe the study in detail and explain how to contact Ms. Wilkins if you are interested in participating.

If you have any questions for the cancer registry or Cancer Care Nova Scotia, please contact the Registry Director, Maureen MacIntyre at (902) 473-6084 or 1-866-599-2267. If you wish to contact the researcher directly to participate in the study or need more information, please contact Krista Wilkins at 1-877-361-7070 or by e-mail at

kwilkins@unb.ca. You may also contact Krista Wilkins' supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11 a.m. and 3 p.m. or Roberta_woodgate@umanitoba.ca.

Thank you for considering this request.

Sincerely,

Maureen MacIntyre, BScN, MHSA
Director, Surveillance and Epidemiology Unit
Cancer Care Nova Scotia

Reminder Cover Letter from the Nova Scotia Cancer Registry

<Address>

<Date>

Dear <Cancer Survivor's name>,

On behalf of *Cancer Care Nova Scotia* (CCNS), I am writing to invite you to participate in a cancer research study. CCNS is a program of the Nova Scotia Department of Health (NSDOH) involved in standard setting, monitoring services and research related to cancer.

A few weeks ago you received a letter about a research study titled "Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer" in which you may be interested in participating. If you have already responded, we thank you. If you have not had time to respond or your letter about the study has been misplaced, this letter is to remind you about the study. If you are not interested in the study, no further contact will be made.

Your name was identified from the Nova Scotia Cancer Registry at CCNS. The Registry is a data system that contains information on persons diagnosed with cancer in this province and has been in place since 1964. It operates by authority of the Provincial Health Act and under the direction of the NSDOH. CCNS is responsible for the day-to-day operation of the Registry and ensuring the confidentiality of all the information it contains. Registry information is used to study and monitor cancer in Nova Scotia, and to produce statistics about the types of cancer seen here.

From time to time, we are contacted by researchers who want to talk with Nova Scotians about their cancer experience. The Registry is not allowed to give your name to any researcher, so we are contacting you on their behalf to request your help with this study. This study has been considered in detail by CCNS and has been approved by the Research Ethics Boards from each involved organization.

The researcher's name is Krista Wilkins, a nurse based at the University of New Brunswick. Ms. Wilkins is doing a research study titled "Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer". She is completing this work as part of doctoral studies at the University of Manitoba, and in partnership with CCNS and the IWK Health Centre. The study involves interviewing people living in Nova Scotia who have had cancer about what they think and feel are their potential risks for developing another cancer. This study is being done because although there has been research that explores the general public's views about their cancer risk, we know very little about what cancer survivors think about this topic. Please review the materials sent with this letter, which describe the study in detail and explain how to contact Ms. Wilkins if you are interested in participating.

If you have any questions for the cancer registry or Cancer Care Nova Scotia, please

contact the Registry Director, Maureen MacIntyre at (902) 473-6084 or 1-866-599-2267. If you wish to contact the researcher directly to participate in the study or need more information, please contact Krista Wilkins at 1-877-361-7070 or by e-mail at kwilkins@unb.ca. You may also contact Krista Wilkins' supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11 a.m. and 3 p.m. or Roberta_woodgate@umanitoba.ca.

Thank you for considering this request.

Sincerely,

Maureen MacIntyre, BScN, MHSA
Director, Surveillance and Epidemiology Unit
Cancer Care Nova Scotia

Invitation Letter from Researchers

<Date>

Dear Cancer Survivor,

My name is Krista Wilkins. I am a nurse currently working in the Faculty of Nursing at the University of New Brunswick (Fredericton campus). This letter is being sent to you on my behalf by the Nova Scotia Cancer Registry. I do not know your name or have any information about you.

I am writing to cancer survivors living in Nova Scotia to invite them to participate in a study titled "Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer". I am doing this study as part of the doctoral studies that I am doing through the University of Manitoba. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. L. Parker, Dr. L. Degner and Dr. D. Turner are the other three members of my thesis committee. This study has been approved by the University of New Brunswick Research Ethics Board, Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board. The study is funded by an IWK Health Centre Category A Grant.

The purpose of my study is to learn from cancer survivors what they think and feel are their potential risks for developing another cancer. I am doing this study because although there has been research that explores the general public's views about their risks to cancer, we know very little about what cancer survivors think about on this topic. I am inviting you to participate in this study because the information obtained may be used to inform future cancer prevention programs.

This study will not provide you with any information about your personal risk for developing a second cancer or instruct you on what you can do to manage that potential risk. You can, however, talk to your oncologist or family doctor about your potential second cancer risk. If you do not have a family doctor, you can find a family doctor currently accepting new patients by calling the Physician Information Line at 902-424-3047 or visiting the Nova Scotia Department of Health's website at www.gov.ns.ca/health/physicians/physicians.asp.

Study participation will involve participating in one to two interviews. Each interview will take about one to two hours of your time. Although two interviews are planned, you may decline to do the second interview. All interviews will be completed in Nova Scotia. You may decide where and when to be interviewed. The interviews will be audio-taped, so I do not miss any important information.

The information I obtain from the interviews will be written up for my doctoral thesis, but there will be no names in the report and no one will be able to identify any individual study member in any way. I also plan to publish the study in a professional journal and

present it at a health conference. In all instances, your identity will not be shared with anyone. Only grouped data will be reported.

You shall receive a movie or bookstore gift card for taking part in the study. If you choose to have the interview conducted outside of your home, you will be reimbursed for parking. A summary of the study will be mailed to you if you would like one.

If you agree to be interviewed, you may change your mind and drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you decide not to take part in this study, you can say no without any problem.

Please complete the enclosed reply card about your interest in my study and return it in the postage-paid envelope. If you are interested in my study, I will contact you by telephone to provide more information about the study, and to set up a time and location for the interview that is convenient for you. If you are not interested in my study, no further contact will be made.

If you have any questions, concerns or need additional information, please contact me at 1-877-361-7070 or by e-mail at kwilkins@unb.ca. You may also contact my supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

Sincerely,

Krista Wilkins, RN, MN
Lecturer, Faculty of Nursing, University of New Brunswick
Doctoral Student, Faculty of Nursing, University of Manitoba

Reply Card

Please complete and return this form whether or not you are interested in participating in the study **Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer**.

Are you interested in participating?

YES, I have read this letter and would like further information about the study.

Name: _____

Phone number: _____

Email: _____

The best time to contact me is: _____

NO, I do **NOT** want to participate in this study.

Please return this sheet to let us know that you do not want to participate and no further contact will be made.

**APPENDIX N: RECRUITMENT PACKAGE FOR PARTICIPANTS
RECRUITED THROUGH THE IWK PEDIATRIC ONCOLOGY
DEPARTMENT**

Cover Letter from IWK Pediatric Oncology Department

<Address>

<Date>

Dear <Cancer Survivor's name>,

I am writing to tell you about a research study in which you may be interested in participating. Krista Wilkins, a New Brunswick nurse, is doing a research study titled "Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer". Krista is doing this study for her doctoral studies through the University of Manitoba. The study involves interviewing people who have had cancer about what they think and feel are their potential risks for developing another cancer. This study is being done because although there has been research that explores the general public's views about their risks to cancer, we know very little about what cancer survivors think about on this topic. This study has been considered in detail by the Nova Scotia Cancer Registry, and has been approved by the University of New Brunswick Research Ethics Board, Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board.

Please read the enclosed letter from the researcher to learn more about the study. If you would like to participate in the study or need more information, please contact Krista Wilkins at 1-877-361-7070 or by e-mail at kwilkins@unb.ca. You may also contact Krista Wilkins' supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11 a.m. and 3 p.m. or Roberta_woodgate@umanitoba.ca.

Thank you for considering this request.

Sincerely,

Dr. Peggy Yhap

Reminder Cover Letter from IWK Pediatric Oncology Department

<Address>

<Date>

Dear <Cancer Survivor's name>,

A few weeks ago you received a letter about a research study titled “Cancer Survivors’ Perceptions of their Potential Risk for Developing a Second Cancer” in which you may be interested in participating. If you have already responded, we thank you. If you have not had time to respond or your letter about the study has been misplaced, this letter is to remind you about the study. If you are not interested in the study, no further contact will be made.

Krista Wilkins, a New Brunswick nurse, is doing a research study for her doctoral studies through the University of Manitoba. This study involves interviewing people who have had cancer about what they think and feel are their potential risks for developing another cancer. This study is being done because although there has been research that explores the general public’s views about their risks to cancer, we know very little about what cancer survivors think about on this topic. This study has been considered in detail by the Nova Scotia Cancer Registry, and has been approved by the University of New Brunswick Research Ethics Board, Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board.

Please read the enclosed letter from the researcher to learn more about the study. If would like to participate in the study or need more information, please contact Krista Wilkins at 1-877-361-7070 or by e-mail at kwilkins@unb.ca. You may also contact Krista Wilkins’ supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11 a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

Thank you for considering this request.

Sincerely,

Dr. Peggy Yhap

Invitation Letter from Researchers

<Date>

Dear Cancer Survivor,

My name is Krista Wilkins. I am a nurse currently working in the Faculty of Nursing at the University of New Brunswick (Fredericton campus). This letter is being sent to you on my behalf by the pediatric oncology long-term follow-up clinic at the IWK Health Centre. I do not know your name or have any information about you.

I am writing to cancer survivors living in Nova Scotia to invite them to participate in a study titled "Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer". I am doing this study as part of the doctoral studies that I am doing through the University of Manitoba. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. L. Parker, Dr. L. Degner and Dr. D. Turner are the other three members of my thesis committee. This study has been approved by the University of New Brunswick Research Ethics Board, Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board. The study is funded by an IWK Health Centre Category A Grant.

The purpose of my study is to learn from cancer survivors what they think and feel are their potential risks for developing another cancer. I am doing this study because although there has been research that explores the general public's views about their risks to cancer, we know very little about what cancer survivors think about on this topic. I am inviting you to participate in this study because the information obtained may be used to inform future cancer prevention programs.

This study will not provide you with any information about your personal risk for developing a second cancer or instruct you on what you can do to manage that potential risk. You can, however, talk to your oncologist or family doctor about your potential second cancer risk. If you do not have a family doctor, you can find a family doctor currently accepting new patients by calling the Physician Information Line at 902-424-3047 or visiting the Nova Scotia Department of Health's website at www.gov.ns.ca/health/physicians/physicians.asp.

Study participation will involve participating in one to two interviews. Each interview will take about one to two hours of your time. Although two interviews are planned, you may decline to do the second interview. All interviews will be completed in Nova Scotia. You may decide where and when to be interviewed. The interviews will be audio-taped, so I do not miss any important information.

The information I obtain from the interviews will be written up for my doctoral thesis, but there will be no names in the report and no one will be able to identify any individual

study member in any way. I also plan to publish the study in a professional journal and present it at a health conference. In all instances, your identity will not be shared with anyone. Only grouped data will be reported.

You shall receive a movie or bookstore gift card for taking part in the study. If you choose to have the interview conducted outside of your home, you will be reimbursed for parking. A summary of the study will be mailed to you if you would like one.

If you agree to be interviewed, you may change your mind and drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you decide not to take part in this study, you can say no without any problem.

Please complete the enclosed reply card about your interest in my study and return it in the postage-paid envelope. If you are interested in my study, I will contact you by telephone to provide more information about the study, and to set up a time and location for the interview that is convenient for you. If you are not interested in my study, no further contact will be made.

If you have any questions, concerns or need additional information, please contact me at 1-877-361-7070 or by e-mail at kwilkins@unb.ca. You may also contact my supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

Sincerely,

Krista Wilkins, RN, MN
Lecturer, Faculty of Nursing, University of New Brunswick
Doctoral Student, Faculty of Nursing, University of Manitoba

Reply Card

Please complete and return this form whether or not you are interested in participating in the study **Cancer Survivors' Perceptions of their Potential Risk for Developing a Second Cancer**.

Are you interested in participating?

YES, I have read this letter and would like further information about the study.

Name: _____

Phone number: _____

Email: _____

The best time to contact me is: _____

NO, I do NOT want to participate in this study.

Please return this sheet to let us know that you do not want to participate and no further contact will be made.

APPENDIX O: TELEPHONE SCRIPT FOR INTERVIEW RECRUITMENT

My name is Krista Wilkins. I am a nurse currently working in New Brunswick, and a doctoral student at the University of Manitoba in Winnipeg, Manitoba. I understand that you have received some information about a study titled “Cancer Survivors’ Perceptions of their Potential Risk for Developing a Second Cancer” that I am doing as part of my doctoral studies. As you know, you have been invited to participate in this study because you had have cancer.

For potential participants recruited through the Nova Scotia Cancer Registry:
Before I begin discussing the study, I would like to ask whether or not you are currently receiving cancer treatment.

If person responds “yes”:

Thank you for your interest in my study. However, for this study, we are only interviewing people who have completed cancer treatment.

If person responds “no” or has been recruited through the IWK pediatric oncology department:

The purpose of my study is to learn from cancer survivors what they think and feel are their potential risks for developing another cancer. I am doing this study because although there has been research that explores the general public’s views about their risks to cancer, we know very little about what cancer survivors think about this topic. I am inviting you because what you tell me may be used to inform future cancer prevention programs.

This study will not provide you with any information about your personal risk for developing a second cancer or instruct you on what you can do to manage that potential risk. You can, however, talk to your oncologist or family doctor about your potential second cancer risk. If you do not have a family doctor, you can find a family doctor currently accepting new patients by calling the Physician Information Line at 902-424-3047 or visiting the Nova Scotia Department of Health’s website at www.gov.ns.ca/health/physicians/physicians.asp.

Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. L. Parker, Dr. L. Degner and Dr. D. Turner are the other three members of my thesis committee. This study has been approved by the University of New Brunswick Research Ethics Board, Education/Nursing Research Ethics Board at the University of Manitoba, Capital District Health Authority Research Ethics Board, and IWK Health Centre Research Ethics Board. The study is funded by a Canadian Institutes of Health Research studentship.

Study participation will involve participating in one to two interviews that will each take about one to two hours of your time. Although two interviews are planned, you may decline to do the second interview. You may decide where and when to be interviewed.

The interviews will be audio-taped, so I do not miss any important information.

The information I obtain from the interviews will be written up in my doctoral thesis, but there will be no names in the report and no one will be able to identify any individual study member in any way. I also plan to publish the study in a professional journal and present it at a health conference. In all instances, your identity will not be shared with anyone.

You shall receive a movie or bookstore gift card for taking part in the study. If you choose to have the interview conducted outside of your home, you will be reimbursed for parking. A summary of the study will be mailed to you if you would like to have one.

If you agree to be interviewed, you can change your mind and drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you decide not to take part in this study, you can say no without any problem.

Are there any questions you would like to ask about the study?

Do you think you would like to take part in this study?

If person responds “no”:
Thank you very much for your time.

If person responds “I would like to think about it”:
I would certainly appreciate you doing that. When should I call you back to get your decision? <Date> and <Time> for return phone call.

If person responds “yes”:
Thank you for your interest. When would be a good time for the first interview?

Would you like to do it at your home?
If person responds “no”:
Where would you like to do it?

Thank you for your time. I will look forward to meeting you on <Date> at <Time> at <Location>.

APPENDIX P: DEMOGRAPHIC FORM

Information gathered in this form will help us get to know you better. All information will be kept confidential.

1. What is your age (in years)? _____

2. Who lives in your household? (check all that apply)
 - Yourself
 - Roommate
 - Spouse or partner
 - Children
 - Grandchildren
 - Parent(s) and or step-parent(s)
 - Grandparent(s)
 - Brother(s) or sister(s)
 - Other (please specify): _____

3. Which of the following describes the area where you live?
 - Rural
 - Urban
 - Suburban

4. What is your highest level of education?
 - 1-8 years (grade school)
 - 9-12 years (high school), but did not graduate
 - High school diploma
 - University/college degree
 - Trade certificate or diploma
 - Other (please specify): _____

5. Are you currently working?
 - Working full-time
 - Working part-time
 - Unemployed
 - Retired
 - Other (please specify): _____

6. Which of the following best describes your racial/cultural background?
 - White (Caucasian)
 - Black
 - Aboriginal (First Nations, Metis, Inuit)
 - Chinese
 - Korean
 - Japanese
 - Arab

- Filipino
- Latin American
- Other (please specify): _____

Health Questions

As you know, you are taking part in this study because you have had cancer. The following questions are related to your original cancer and its treatment.

1. Please write the name of the cancer you had.

2. When were you diagnosed with this cancer? _____ (year)
3. How old were you when you were diagnosed with this cancer? _____ (in years)
4. What cancer treatments did you receive for this cancer? (check all that apply)
 - Chemotherapy (i.e., drugs by mouth, injection or intravenous)
 - Radiation therapy
 - Surgery
 - Stem cell/bone marrow transplant
 - Other (please specify): _____
5. Have you ever had a relapse of your cancer?
 - Yes
 - No
 - Don't know

If yes, please answer the following questions:

- a. When did you have the relapse? _____ (year)
- b. How old were you when you relapsed? _____ (in years)
- c. What cancer treatments did you receive for the relapse? (check all that apply)
 - Chemotherapy (i.e., drugs by mouth, injection or intravenous)
 - Radiation therapy
 - Surgery
 - Stem cell/bone marrow transplant
 - Other (please specify): _____

APPENDIX Q: INTERVIEW GUIDE

Note: Probes will only be asked as necessary. They are meant to stimulate discussion.

Introduction to the interview: I would like to learn more about your thoughts and feelings about your potential risk for developing a second cancer. To help you share your thoughts and feelings, I am going to first ask you to talk about your personal cancer experience.

1. Tell me about your experience with cancer.
 Probes: Ask questions related to cancer history (e.g., type of cancer, when diagnosed, treatments etc.)
 How did things change for you because of being diagnosed with cancer?
 What was most difficult about having cancer?
 Was there anything good about having cancer? Please explain.
 Can you share with me some of the good days and bad days during the time when you had cancer?
 What do you remember most of having cancer?
2. What has life been like for you since being treated for cancer?
3. How has your health been over the last (time since treatment has ended)?
 Probes: Do you have any health concerns/worries? Please explain.
 How likely do you think it is that your health concerns are related to your previous cancer treatment and/or having cancer?

If a participant discloses he/she has had a second cancer diagnosis, the interview will be stopped and the participant will be thanked for his/her time.

4. What risks in general are you concerned about for your health?
 Probes: What do you attribute these risks to?
 Are risks something different from concerns? Please explain.

I now want to talk more about your thoughts about your risks to a second cancer.

5. For cancer survivors who don't mention second cancer risk: Some cancer survivors think they can develop a second cancer several years after their cancer treatment has been completed, while others do not think will ever develop a second cancer. What is your understanding of your risk of developing a second cancer?

or

For cancer survivors who mention second cancer risk: You mentioned previously that you felt you were at risk for a second cancer. Could you please tell me more about this?

Probes: What does being at high risk/low risk mean to you?

Compared to other people your age, how would you describe your risk of developing cancer this year? In 5 years? In 10 years? Please explain.
 Compared to other cancer survivors your age, how would you describe your risk of developing a second cancer this year? In 5 years? In 10 years? Please explain.
 On a scale of 1-10 how would you rate your risk to cancer?

6. In the previous question you said your risk of getting cancer was <repeat response person gave>. Can you tell me why you think you are high risk/low risk? (e. g., Having had cancer, cancer treatment, genetics, lifestyle choices, aging process, gender, age at cancer diagnosis)

Probes: What things did you think about that led you to your answer?
 Discuss a recent situation that makes you think about your risk of developing cancer (e.g., reading a newspaper or magazine article about cancer, family member or friend was diagnosed with cancer, genetic counseling)

7. Is there anything you do in your life that you feel may possibly help to reduce your risk of developing a second cancer?

Probes: What do you do to reduce your risk of developing a second cancer? (e.g., Routine check-up, cancer screening, exercise, diet)
 What motivates you to reduce your risk of developing a second cancer?
 What makes it difficult for you to reduce risk of developing a second cancer? (e.g., time, cost, transportation)
 What can others do to help you reduce your risk of developing cancer?

8. Who or where would you turn to for information about your risk of developing a second cancer?

Probes: What information have you received about your risk of developing a second cancer that you find has been helpful/not helpful?
 What would keep you from finding cancer risk information?
 What would be helpful for healthcare professionals to know about communicating cancer risk information?

9. Cancer prevention messages are all around us. Do you think they meet the needs of people who have already had cancer? Please explain.

10. What advice would you give health professionals about cancer survivors' risk of developing a second cancer, and how they can manage that risk?

Probe: How might health professionals tailor cancer prevention messages to meet the needs of cancer survivors?

11. What advice would you give key health care decision-makers and policy-makers about cancer survivors' risk of developing a second cancer, and how they can manage that risk?

Probes: What type of policies do you feel need to be developed?
What types of policies are needed to be tailor cancer prevention messages to meet the needs of cancer survivors?

12. Is there anything further that you would like to share or you think would be helpful for me to know?

At the end of the interview, please note that the interviewer will ensure that participant is feeling alright. The interviewer will also call participants within 24-48 hours to ensure all is well.

**APPENDIX R: CONSENT FORM FOR PARTICIPANTS RECRUITED
THROUGH THE NOVA SCOTIA CANCER REGISTRY**

CANCER SURVIVOR STUDY

Faculty of Nursing
University of New Brunswick
PO Box 4400
Fredericton, New Brunswick E3B 5A3

**CONSENT TO TAKE PART IN A RESEARCH STUDY
Participant Information**

STUDY TITLE: CANCER SURVIVORS' PERCEPTIONS OF THEIR
POTENTIAL RISK FOR DEVELOPING A SECOND
CANCER

**PRINCIPAL OR
QUALIFIED
INVESTIGATOR:** Krista Wilkins, RN, MN
Faculty of Nursing
University of New Brunswick
PO Box 4400
Fredericton, New Brunswick E3B 5A3
Telephone: 1-877-361-7070

**ASSOCIATE
INVESTIGATORS:** Dr. Roberta Woodgate (Supervisor)
Faculty of Nursing, University of Manitoba
Winnipeg, Manitoba, R3T 2N2
Telephone: (204) 474-8338

Dr. Lousie Parker
Rm 455, 6050 University Avenue
Dalhousie University
Halifax, Nova Scotia, B3H 1W5
Telephone: (902) 494-3566

STUDY SPONSOR: IWK Health Centre Category A Grant

**PART A.
RESEARCH STUDIES – GENERAL INFORMATION**

1. INTRODUCTION

You have been invited to take part in a research study. The study is being offered by the University of New Brunswick, University of Manitoba, Capital Health and IWK

Health Centre. This study is being done as part of Ms. Wilkins' doctoral studies through the University of Manitoba. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

We do not know if taking part in this study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. We will always give you the best possible care no matter what happens. If you decide not to take part or if you leave the study early, your usual health care will not be affected.

PART B. EXPLAINING THIS STUDY

2. WHY IS THIS STUDY BEING DONE?

Although there has been research that explores the general public's views about their risks to cancer, we know very little about what cancer survivors think about this topic. With this study, we hope to gain information that will inform future cancer prevention programs.

3. WHY AM I BEING ASKED TO JOIN THE STUDY?

You are being asked to join the study because you were identified by the Nova Scotia Cancer Registry as having had cancer and expressed interest when told about the study.

4. HOW LONG WILL I BE IN THE STUDY?

The study involves participating in one to two (1-2) interviews. Each interview will take approximately one (1) hour to two (2) hours of your time.

5. HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

This study is taking place throughout Nova Scotia. The number of participants in this study will be thirty-two (32).

6. HOW IS THE STUDY BEING DONE?

You will be asked to participate in one to two (1-2) interviews. Taking part in the interviews means that you will be asked questions about your personal cancer experience, your potential risk for developing a second cancer, and how you manage that risk. The interviews will be audio-taped. The interviews will take place at a time and place that is convenient for you. You will also be asked to complete a Demographic Form for background information about yourself, including your cancer history. This form will take about 5 minutes to complete.

7. WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you want to be in this study and sign this consent form, you will be asked to participate in one to two (1-2) interviews. You will also be asked to complete a Demographic Form. In total, each interview will take one (1) hour to two (2) hours to complete. You may choose to leave the study at any time, ask to stop the interview at any point, or do not have to answer any questions. Although two interviews are planned, you may decline to do the second interview. If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed.

8. ARE THERE RISKS TO THE STUDY?

There are risks with this, or any study. To give you the most complete information available, we have listed many *possible* risks, which may appear alarming. We do not want to alarm you but we do want to make sure that if you decide to try the study, you have had a chance to think about the risks carefully. Please be aware that there may be risks that we don't yet know about.

You may find the interviews you participant in during the course of the study upsetting or distressing. You may not like all of the questions that you will be asked. You do not have to answer those questions you find too distressing. This study will not provide you with any information about your personal risk for developing a second cancer or instruct you on what you can do to manage that potential risk. An information sheet on reducing second cancer risk will be given to you. This information sheet is for information purposes only. You should seek the advice your oncologist or family doctor about any questions you have about your potential second cancer risk and what you can do about that risk. If you do not

have a family doctor, you can find one by calling the Physician Information Line at 902-424-3047 or visiting the Nova Scotia Department of Health's website at www.gov.ns.ca/health/physicians/physicians.asp.

9. WHAT HAPPENS AT THE END OF THE STUDY?

You may ask the researchers to see and receive a copy of your interview transcript and demographic form. You may also ask the Principal Investigator to correct any study related information about you that is wrong. A summary of the study results is available to you, if you want one.

Would you like to receive a copy of your interview transcript? Yes ___
No ___

Would you like to receive a copy of the study results?
Yes ___ No ___

Please provide your mailing address:

10. WHAT ARE MY RESPONSIBILITIES?

As a study participant, you will be expected to follow the directions of the Principal Investigator.

11. CAN I BE TAKEN OUT OF THE STUDY WITHOUT MY CONSENT?

Yes. You may be taken out of the study at any time, if:

- There is new information that shows that being in this study is not in your best interests.
- University of New Brunswick Research Ethics Board, Education/Nursing Research Ethics Board at the University of Manitoba, Capital Health Research District Authority Ethics Board, IWK Health Centre Research Ethics Board, or the Principal Investigator decides to stop the study.

You will be told about the reasons why you might need to be taken out of the study.

12. WHAT ABOUT NEW INFORMATION?

It is possible (but unlikely) that new information may become available while you are in

the study that might affect your health, welfare, or willingness to stay in the study. If this happens, you will be informed in a timely manner and will be asked whether you wish to continue taking part in the study or not.

13. WILL IT COST ME ANYTHING?

Compensation

If you choose to have the interview conducted outside of your home, you will be reimbursed for parking. You will also receive a gift card to reimburse your time and effort for participation, even if you withdraw prior to the conclusion of the study.

Research Related Injury

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the Principal Investigator, the research staff, the study sponsor or involved institutions from their legal and professional responsibilities.

14. WHAT ABOUT MY RIGHT TO PRIVACY?

Protecting your privacy is an important part of this study. When you sign this consent form you give us permission to:

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

Investigator will see study records that identify you by name.

Other people may need to check or see your study records to make sure all of the information is correct. These include:

- The University of New Brunswick Research Ethics Board (UNB REB), which is responsible for the protection of people in research by faculty members
- The CDHA Research Ethics Board (CHREB), which is responsible for the protection of people in research with the Nova Scotia Cancer Registry
- The Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba, which is responsible for the protection of people in research by students of the University of Manitoba

- The IWK Health Centre Research Ethics Board (IWK REB), which is responsible for the protection of people in research associated with the IWK Health Centre
- Quality assurance staff including the auditors for the UNB REB, CHREB, ENREB and IWK REB, who ensure that the study is being conducted properly

Use of records

The research team will collect and use only the information they need to complete the study. This information will only be used for the purposes of this study. This information will include: age, household, place of residence, education, occupational status, ethnic/cultural background, cancer diagnosis and treatment, and information from study interviews.

Your name and contact information will be kept secure by the research team at the Principle Investigator's office at the Faculty of Nursing, University of New Brunswick (Fredericton campus). It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will kept at the University of New Brunswick for 7 years. The Principal Investigator is the person responsible for keeping it secure.

You may also be contacted personally by Research Auditors for quality assurance purposes.

Your access to records

You may ask the Principal Investigator to see and receive a copy of your interview transcript and demographic form. You may also ask the Principal Investigator to correct any study related information about you that is wrong.

15. WHAT IF I WANT TO QUIT THE STUDY?

If you chose to participate and later change your mind, you can say no and stop the research at any time. If you wish to withdraw your consent, please inform the Principal Investigator. All data collected up to the date you withdraw your consent will remain in the study records, to be included in study related analyses.

16. DECLARATION OF FINANCIAL INTEREST

The sponsor is paying the Principal Investigator and/or the Principal Investigator's institution to conduct this study. The amount of this payment is sufficient to cover the costs of conducting the study. The Principal Investigator has no financial interests in conducting this research study.

17. WHAT ABOUT QUESTIONS OR PROBLEMS?

For further information about the study call **Ms. Krista Wilkins**. Ms. Wilkins is in charge of this study. Ms. Wilkins' telephone number is 1-877-361-7070.

The Principal Investigator is **Ms. Krista Wilkins**.
Telephone 1-877-361-7070.

18. FUTURE CONTACT/FUTURE RESEARCH

Would you be interested in participating in subsequent research projects on cancer survivorship?

Yes___ No___

Please provide your mailing address:

19. WHAT ARE MY RIGHTS?

After you have signed this consent form you will be given a copy. If you have any questions about your rights as a research participant, contact the **Patient Representative** at **(902) 473-2133**.

In the next part you will be asked if you agree (consent) to join this study. If the answer is "yes", you will need to sign the form.

PART C.

19. CONSENT FORM AND SIGNATURES

I have reviewed all of the information in this consent form related to the study called:

**CANCER SURVIVORS' PERCEPTIONS OF THEIR POTENTIAL RISK FOR
DEVELOPING A SECOND CANCER**

I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction.

I agree to allow the people described in this consent form to have access to my health records.

This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time.

Signature of Participant _____
Name (Printed) _____ / _____ / _____
Year Month Day*

Witness to Participant's
Signature _____
Name (Printed) _____ / _____ / _____
Year Month Day*

Signature of Investigator _____
Name (Printed) _____ / _____ / _____
Year Month Day*

**Note: Please fill in the dates personally*

I WILL BE GIVEN A SIGNED COPY OF THIS CONSENT FORM.

Thank you for your time and patience!

**APPENDIX S: CONSENT FORM FOR PARTICIPANTS RECRUITED
THROUGH THE IWK PEDIATRIC ONCOLOGY DEPARTMENT**

Research Title

Cancer Survivors' Perceptions of Their Potential Risk for Developing a Second Cancer

Researcher(s)

Krista Wilkins, RN, MN (Doctoral Student)
Faculty of Nursing, University of New Brunswick

Dr. Roberta Woodgate, RN, PhD (Chair of Dissertation Committee)
Faculty of Nursing, University of Manitoba

Dr. Louise Parker, PhD (Dissertation Committee Member)
Department of Pediatrics, IWK Health Centre

Dr. Lesley Degner (Dissertation Committee Member)
Faculty of Nursing, University of Manitoba

Dr. Donna Turner (Dissertation Committee Member)
CancerCare Manitoba

Funding

This study is sponsored by an IWK Health Centre Category A Grant.

Introduction

You are being invited to take part in the research study named above. This form provides information about the study. Before you decide if you want to take part, it is important that you understand the purpose of the study, the risks and benefits and what you will be asked to do. You do not have to take part in this study. Taking part is entirely voluntary (your choice). Informed consent starts with the initial contact about the study and continues until the end of the study. A member of the research team will be available to answer any questions you have. You may decide not to take part or you may withdraw from the study at any time. This will not affect the care you or your family members will receive from the IWK Health Centre or any other health center in any way. This study is being done as part of Ms. Wilkins' doctoral studies through the University of Manitoba.

Why are the researchers doing the study?

The purpose of this study is to better understand how people who have had cancer think and feel are the potential risks for developing another cancer and what they do to manage those risks.

How will the researchers do the study?

This is an interview study that is being done in Nova Scotia. Thirty-two adults who have

had cancer will be enrolled in the study.

What will I be asked to do?

You will be asked to participate in one to two interviews. Each interview will last from 1 to 2 hours. Taking part in the interviews means that you will be asked questions about your personal cancer experience, your potential risk for developing a second cancer and how you manage that risk. The interviews will be audio-taped. Although two interviews are planned, you may decline to do the second interview. The interviews will take place at a time and place that is convenient for you. You will also be asked to complete a Demographic Form for background information about yourself, including your cancer history. This form will take about 5 minutes to complete.

What are the burdens, harms, and potential harms?

There are no known risks for taking part in the study. However, having the opportunity to talk about your experiences may make you more aware of your feelings. This study will not provide you with any information about your personal risk for developing a second cancer or instruct you on what you can do to manage that potential risk. An information sheet on reducing second cancer risk will be given to you. This information sheet is for information purposes only. You should seek the advice your oncologist or family doctor about any questions you have about your potential second cancer risk and what you can do about that risk. If you do not have a family doctor, you can find a family doctor currently accepting new patients by calling the Physician Information Line at 902-424-3047 or visiting the Nova Scotia Department of Health's website at www.gov.ns.ca/health/physicians/physicians.asp.

What are the possible benefits?

This study may not benefit you personally. However, information learned may help cancer survivors and healthcare professionals better monitor the long-term health of cancer survivors.

What alternatives to participation do I have?

Not participating will not affect the care you or your family members will receive from the IWK Health Centre in any way.

Can I withdraw from the study?

Your participation in this study is entirely voluntary. You may choose to leave the study at any time, ask to stop the interview at any point, or do not have to answer any questions. If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. Withdrawing from the study at any time will not affect the care you or your family members will receive from the IWK Health Centre.

Will the study cost me anything and, if so, how will I be reimbursed?

If you choose to have the interview conducted outside of your home, you will be reimbursed for parking. You will receive a \$20 movie or bookstore gift card to reimburse your time and effort for participation, even if you withdraw prior to the conclusion of the

study.

Are there any conflicts of interest?

There are no conflicts of interest.

What about possible profit from commercialization of the study results?

There is no potential profit from commercialization of the results of this study.

How will I be informed of study results?

You may ask the researchers to see and receive a copy of your interview transcript and demographic form. You may also ask the Principal Investigator to correct any study related information about you that is wrong. A summary of the study results is available to you, if you want one.

Would you like to receive a copy of your interview transcript? Yes___ No___

Would you like to receive a copy of the study results? Yes___
No___

Please provide your mailing address:

How will my privacy be protected?

Your name will not be shared with anyone. Your name will be replaced with a code number. Only Krista Wilkins and Dr. Roberta Woodgate will read the interviews. All data including the audiotapes, interview transcripts, and demographic information will be stored in a locked filing cabinet at Krista Wilkins' office at the Faculty of Nursing, University of New Brunswick (Fredericton campus), and computer protected by a password known only to Krista Wilkins. All data will be destroyed seven years following completion of the study. In any publications or presentations of the study findings, no one will be able to identify any individual study member in any way. Your doctor will not be notified of your participation in the study.

Some other people or groups may need to check or see your study records to make sure all of the information is correct. All of these people have a professional responsibility to protect your privacy. These groups and people are:

- The University of New Brunswick Research Ethics Board (UNB REB), which is responsible for the protection of people in research by faculty members
- The Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba, which is responsible for the protection of people in research by students of the University of Manitoba
- The Capital District Health Authority Research Ethics Board (CHREB) which is responsible for the protection of people in research with the Nova Scotia Cancer Registry

- The IWK Health Centre Research Ethics Board (IWK REB), which is responsible for the protection of people in research associated with the IWK Health Centre
- Quality assurance staff including the auditors for the UNB REB, ENREB, CHREB and IWK REB, who ensure that the study is being conducted properly

The information they check may include questionnaire and interview results. You may also be contacted personally by the research auditors for quality assurance purposes.

What if I have study questions or problems?

You may contact Krista Wilkins at 1-877-361-7070, Monday to Friday between 9a.m. and 5p.m. or kwilkins@unb.ca if you have any concerns, questions, or need additional information. You may also contact Krista Wilkins' supervisor, Dr. Roberta Woodgate, at (204) 474-8338 Monday to Friday between 11a.m. and 3p.m. or Roberta_woodgate@umanitoba.ca.

What are my Research Rights?

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator, the research doctor, the study sponsor or involved institutions from their legal and professional responsibilities.

If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Centre at (902) 470-8765, Monday to Friday between 9a.m. and 5p.m.

Future contact/future research/other use

Would you be interested in participating in subsequent research projects on cancer survivorship?

Yes ___ No ___

Please provide your mailing address:

Signature Page

Study title: Cancer Survivors' Perceptions of Their Potential Risk for Developing a Second Cancer

Participant ID: _____
Participant INITIALS: _____

Participant Consent

I have read or had read to me this information and consent form and have had the chance to ask questions which have been answered to my satisfaction before signing my name. I understand the nature of the study and I understand the potential risks. I understand that I have the right to withdraw from the study at any time without affecting my care in any way. I have received a copy of the Information and Consent Form for future reference. I freely agree to participate in this research study.

Name of Participant (Print): _____
Participant Signature: _____
Date: _____ Time: _____

STATEMENT BY PERSON OBTAINING CONSENT

I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw at any time from participating.

Name (Print): _____
Signature: _____
Position: _____
Date: _____ Time: _____

APPENDIX T: INFORMATION SHEET ON SECOND CANCER RISK

Risk of Second Cancers in Cancer Survivors

This information is meant to be a general introduction to this topic. Please seek the advice of a qualified healthcare provider with any questions you may have about your second cancer risk and how you can reduce that risk.

What is a second cancer?

A second cancer is a different type of cancer from your original cancer diagnosis. Several studies have shown that cancer survivors in general have a slightly higher risk of developing cancer compared to people of the same age in the general population.

Whether or not you will have a second cancer depends on many different things. The development of a second cancer is thought to be a result of cancer treatment, age at cancer treatment, genetic and family history of cancer, and lifestyle.

A second cancer may appear at any time after treatment. Research shows that second cancers usually develop around 5 to 9 years after treatment. However, because the exact causes of second cancers are not known, it is difficult to predict when they might appear.

How do I know what my risk is for developing a second cancer?

You can find out your risk of developing a second cancer by discussing your cancer treatment and family history with your family doctor or oncologist. It is important to know that every cancer survivor is different, so even if you find you are at a higher risk for a second cancer, it does not mean that you will have one.

What can I do to reduce my risk of developing a second cancer?

It is important to talk with your healthcare provider about what you can do to reduce your risk of developing a second cancer.

Some examples of things you can do are:

- Know the details of your cancer diagnosis and cancer treatment
- Get all screening tests that are recommended for you
- Have a yearly comprehensive health check-up
- Maintain a healthy body weight
- Avoid exposure to tobacco smoke whenever possible
- Protect your skin from sun exposure
- Eat low-fat, high fiber, vitamin-rich foods
- Drink alcohol only in moderation
- Know if your family has a history of cancer
- Perform regular breast or testicular self-exams and skin examinations each month so that you know what is normal for you
- Report any new or persistent symptoms to your family doctor or oncologist promptly

What symptoms should I look for?

Sometimes you cannot prevent second cancers from happening. Knowing the general symptoms of cancer will help you detect a second cancer early. The earlier a second cancer is diagnosed, the more likely it can be successfully treated.

Some symptoms of cancer are:

- ❑ Changes in bowel or bladder habits
- ❑ Sores that do not heal
- ❑ Unusual bleeding or discharge
- ❑ Lumps
- ❑ Difficulty swallowing
- ❑ Changes in moles
- ❑ Persistent cough or hoarseness
- ❑ Excessive fatigue
- ❑ Changes in vision
- ❑ Easy bruising or bleeding

The symptoms above are just a short list. Just because you experience these symptoms does not always mean that you have cancer.

Other Resources:

The resources listed below provide more detailed information and support services to help you with second cancers.

- ❑ Canadian Cancer Society. www.cancer.ca
- ❑ Children's Oncology Group. www-survivorshipguidelines.org
- ❑ LIVESTRONG SurvivorCare Program. www.livestrong.org/survivorcare
- ❑ National Cancer Institute. www.cancer.gov