Long-Term Adjustment: Perceptions of Paediatric Cancer Survivors

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Abstract

Treatment of paediatric cancer over the past two decades has led to dramatic increases in survival rates. In 1960, only 1 in 1000 children survived beyond one year of treatment, while in 1990 approximately 80% were expected to survive five years following treatment. Our study explored, through grounded theory methodology, how the experience of paediatric cancer influences the life experiences and long-term adjustment of survivors now in adulthood.

Interviews were conducted in two provinces (SK and BC) with 18 survivors. Data were analysed following grounded theory principles and led to the emergence of a theoretical framework. The participants in this study were engaging in a process of moving on from their cancer experience and history. A number of conditions were found to influence the participants' ability to move on including: social support, feelings of powerlessness, fears of recurrence, ability to cope with cancer diagnosis and treatment, ability to accept their history of cancer, and having had cancer when they were young. These conditions influenced their ability to engage in strategies that were used to move on including: maintaining health, seeking information, normalising, and not dwelling on their cancer history. The consequences of these strategies and moving on were an ability to find positive meaning in their cancer experience, to recognise the importance of living life to the fullest, and feelings of empowerment with regards to their cancer history and follow-up.

Overall, this sample of long-term survivors more often looked at the positive aspects of their encounter with cancer, in many instances incorporating these aspects into their lives while recognising the importance of moving on and looking to the future. However, the results from this study indicate that a subset of this population, those with visible late-effects and brain tumour survivors, have more needs and experience difficulty with regards to long-term adjustment.
This study has implications for clinical practice including: continued awareness of the importance and role of social support and normalising strategies during treatment and long-term survivorship, the creation of an informal “get-together” for survivors to facilitate sharing of experiences, as well as advocacy and assistance for those with late-effects from treatment. Implications for further research include: a family systems approach to long-term survivorship, understanding how to facilitate the transitions related to entering adulthood, and a focus on the unique issues and needs of brain tumour survivors and those with late-effects.
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Dedication

This thesis is dedicated to my father, Dr. Patrick Melton, who passed away in 1996, the year I began my graduate program. His life and his dedication as a Paediatrician inspired my research within this area. His constant encouragement and belief in me has been a continuing source of strength. I miss you.
# Table of Contents

**Permission to Use** .................................................. i

**Abstract** ................................................................. ii

**Acknowledgements** ...................................................... iv

**Dedication** ................................................................. v

**Table of Contents** ....................................................... vi

**List of Figures** ........................................................... ix

**List of Tables** ............................................................ ix

1. **Introduction**
   1.1 Introduction ......................................................... 1
   1.2 Statement of the Problem ............................................. 2
   1.3 Objectives and Research Questions ................................. 3
   1.4 Definition of Terms ................................................ 4
      1.4.1 Adjustment .................................................... 4
      1.4.2 Long-term Survivor ....................................... 5

2. **Literature Review**
   2.1 Uses of Literature in Grounded Theory ........................... 6
   2.2 Literature Search Strategy ......................................... 7
   2.3 Paediatric Cancer .................................................. 7
      2.3.1 Incidence and Mortality Rates .............................. 7
      2.3.2 Psychosocial Issues in Paediatric Cancer ................. 8
         Stages of Paediatric Cancer .................................. 8
         Perception of Needs ............................................. 10
         Coping with Cancer ........................................... 10
      2.3.3 Cancer and Childhood/Adolescent Development ........... 11
         Infancy and Early Childhood .................................. 11
         Late Childhood ................................................ 11
         Adolescence .................................................... 12
   2.4 Paediatric Cancer Survivorship ................................ 12
      2.4.1 Survival Rates .............................................. 12
      2.4.2 Biological Late-Effects ................................... 14
      2.4.3 Second Malignant Neoplasms ............................... 16
      2.4.4 Psychosocial Late-Effects ................................. 18
3. Methodology
   3.1 Naturalistic Inquiry ........................................ 31
   3.2 Grounded Theory ........................................... 32
   3.3 Data Collection Strategies ................................. 34
      3.3.1 Participants ........................................ 34
      3.3.2 Recruitment Strategies ............................... 35
      3.3.3 Interview ........................................... 38
   3.4 Ethical Considerations .................................... 39
   3.5 Researcher as Instrument .................................. 40
   3.6 Data Analysis ............................................. 41
      3.6.1 Open Coding ....................................... 42
      3.6.2 Axial Coding ....................................... 43
      3.6.3 Selective Coding ................................. 43
   3.8 Trustworthiness ........................................... 43

4. Results
   4.1 Participants ............................................. 46
   4.2 Cancer Care in British Columbia and Saskatchewan .... 49
   4.3 Model of Adjustment as an Adult Survivor of Childhood Cancer .......................... 50
      4.3.1 Causal Conditions of Phenomenon of Moving On ..................................... 52
      4.3.2 Phenomenon Resulting from Causal Conditions ...................................... 52
      4.3.3 Context of Strategies of Moving On .................................................. 53
      4.3.4 Intervening Conditions Influencing Strategies for Moving On .................... 55
         Social Support ......................................... 55
         Being Young ...................................... 59
         Powerlessness ..................................... 61
         Fears of Recurrence .............................. 63
         Coping with Cancer Diagnosis .................. 65
         Acceptance ....................................... 66
   4.3.5 Action/Interaction Strategies for Moving On ........................................ 67
      Maintaining Health .................................. 68
      Information Seeking ................................. 68
      Normalising ....................................... 69
      “Not Dwelling” on Cancer ......................... 71
List of Figures

3.1 Interrelated Processes of Grounded Theory .............................. 33
3.2 Recruitment Process in Saskatchewan ................................. 37
3.3 Recruitment Process in British Columbia ............................. 38
4.1 Theoretical Framework: Process of Long-Term Adjustment in Paediatric Cancer Survivors.............................................. 51

List of Tables

4.1 Demographic Characteristics of Participants............................ 46
4.2 Disease and Treatment Characteristics.................................. 47
4.3 Medical Status ........................................................................ 48
4.4 Education, Employment and Income Levels ............................ 49
Chapter 1

Introduction

1.1 Introduction

Improvements in the treatment of paediatric cancers over the past two decades have led to dramatic increases in the survival rates for this group of children.\textsuperscript{1,2} In 1960, only 1 in 1000 young children survived beyond one year of treatment, while in 1990 approximately 80% were expected to survive beyond five years following treatment.\textsuperscript{3} It is estimated that by the year 2000, approximately 1 in 1000 individuals between the ages of 20 and 29 will have survived a childhood cancer.\textsuperscript{4,5,6} As the number of paediatric cancer survivors entering adulthood continues to increase, knowledge and understanding of the late-effects of cancer diagnosis and treatment are of increasing importance.

Survivors of childhood cancer who are five or more years beyond the completion of treatment are considered to be cured of their disease.\textsuperscript{7} After this time the risk of relapse is very low, and the status of a child’s cancer is considered as compatible with “long-term disease free survival with minimal chance of recurrence”.\textsuperscript{7} For many patients and parents, the meaning of cure is based on their own definitions, and may not necessarily begin after reaching a chronological watershed of five years.\textsuperscript{8} In addition to biological cure, Van Eys\textsuperscript{9} suggested two types in childhood cancer: psychological cure
and social cure. Psychological cure is the "acceptance of having had cancer as a past event without interference with normal development and schooling", and social cure is the "incorporation of the person cured of cancer into society, without consideration of their past history of cancer and its therapy".\(^9\) There is a need to explore and obtain a greater understanding of how the biological cure of paediatric cancer has met with success in the areas of psychological and social cures of this disease.

1.2 Statement of the Problem

While biological cures of childhood cancer have been remarkably successful, survivors may experience a number of physical, psychosocial and cognitive late-effects. Current literature indicates that paediatric cancer survivors are at increased risk of physical late-effects including fibrotic lung and liver damage, myocardial dysfunction, and sterility.\(^10\) Additional documented late-effects include cognitive impairment and subsequent difficulties with concentration, attention span, memory, and verbal skills. These apply particularly to those treated with central nervous system prophylactic therapy, involving radiation therapy to the brain and/or injection of anti-cancer drugs directly into the cerebrospinal fluid bathing the brain and spinal cord through intrathecal administration.\(^5,10\) While broad measures of psychosocial adjustment have indicated that survivors of childhood cancer are generally well-adjusted,\(^1,11,12\) several studies have documented late-effects including deficits in social competence,\(^13\) behavioural problems,\(^13\) depression,\(^14\) and poor self-esteem.\(^15\)

Much of the research into the late-effects of surviving childhood cancer has involved survivors in late childhood and adolescence, whose cancer was diagnosed at a
young age.\textsuperscript{13,16,17,18} When adult survivors of childhood cancer have participated in late-effects studies, their responses have been combined with those from young persons, telling us very little of how the childhood cancer experience impacts upon their adult lives.\textsuperscript{14,15,19,20} In order to better understand the impact that surviving childhood cancer has, our study obtained responses from childhood cancer survivors who are now adults.

No reported research to date has qualitatively explored the extent to which surviving cancer during childhood affects adult survivors. Therefore, our study investigated, through grounded theory methodology, the perceptions of adult survivors of childhood cancer regarding their experience of this disease and its influence on their lives, as well as their long-term adjustment.

1.3 Objectives and Research Questions

The objectives of the study were threefold:

1) to describe the long-term adjustment of survivors of childhood cancer who are now in adulthood,

2) to generate issues and hypotheses related to the long-term adjustment of this population, and

3) to develop a theoretical framework for further research.

One overall research question guided this study:

What is the process of long-term psychosocial adjustment for survivors of paediatric cancer who are now in adulthood?
More specific research questions that have arisen out of the broader research query include:

1) To what extent do paediatric cancer survivors perceive that their experience has affected choices related to school, vocation, recreation, social interaction, interpersonal relationships, and risk-taking behaviours?

2) How do fears of recurrence affect the emotional, social and lifestyle dimensions of their lives?

3) What are their rehabilitative and psychosocial needs (i.e., physical, cognitive, emotional) in adulthood?

4) What issues do these survivors encounter when they make the transition from follow-up as paediatric patients to follow-up as adults?

1.4 Definition of Terms

1.4.1 Adjustment  For the purposes of our study, the process of adjustment was defined as a sequence of behaviours spurred on by an event, in this case by the diagnosis of cancer. When studying this process, adjustment can be described in terms of either positive adjustment or maladjustment. According to Coan’s definition, a “well-adjusted person is one who experiences a relatively high degree of happiness, contentment, serenity, joy, etc. – a preponderance of positive or pleasurable emotional states of various kinds”. Maladjustment “implies friction with one’s surroundings or with other people, a characteristically high level of need frustration, and a preponderance of negative emotional states – anxiety, depression, rage, etc.”. 
1.4.2 **Long-term Survivor** In our study, a long-term cancer survivor was defined as an individual with cancer between the ages of newborn to 17 years, and who was disease free and off therapy for at least five years.
Chapter 2

Literature Review

2.1 Uses of Literature in Grounded Theory

Grounded theory research involves the discovery of concepts and categories through data analysis. Verification of existing variables or the use of an existing theory as a conceptual framework does not adhere to grounded theory methodology. Proponents of grounded theory suggest that researchers using this methodology limit the literature review prior to initiating a study; rather, exploring the literature in-depth as part of the analysis process. The basis for this stems from concerns that immersion in the literature will result in blinding one’s ability to see the data.

Published literature does, however, serve several purposes in grounded theory. First, the literature is a source of initial research and interview questions. Second, it directs theoretical sampling by providing information on variables used to select initial participants. Third, it serves as a secondary source of data; and fourth, it provides a supplemental means of verification of findings. Lastly, technical literature is used to stimulate theoretical sensitivity. Theoretical sensitivity “is the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn’t”. Thus, the literature provides the background for sensitising the researcher as to what is happening within the data.
2.2 Literature Search Strategy

The purpose of the literature search was to gain an extensive and comprehensive listing of relevant research and information pertaining to the incidence and psychosocial aspects of paediatric cancer, as well as the medical, behavioural and psychosocial aspects of paediatric cancer survival. The literature search began with a detailed search of Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Sociofile and PsycLit databases from 1980 to present. Each of the databases were searched using a combination of the following key words: paediatric, childhood, adolescent, cancer, survival, survivors and survivorship. As well, the University of Saskatchewan Library Database and the World Wide Web were used as additional means of obtaining information relevant to this population.

This process elicited over 100 articles. Those studies and articles, which were deemed to be high quality in terms of design, sample and methodology and provided relevant information, were retained for this study. Approximately 20 articles focused purely on the medical aspects of paediatric cancer survival. They were read but not included in the reference list nor used for data analysis.

2.3 Paediatric Cancer

2.3.1 Incidence and Mortality Rates

In North America, cancer is the second cause of death after accidents in children between the ages of one and nineteen.\(^{24}\) It is currently estimated that 16 of every 100 000 Canadian children will develop cancer.\(^{24}\) In 1998, 1 400 cases are expected to be diagnosed, while 205 children and adolescents are expected to die from the disease.\(^{25}\)
Leukaemia is the most common form of paediatric cancer, comprising approximately one-quarter of all cases.\textsuperscript{24} Based on the average annual rate in Canada from 1985 – 1992, it occurred in 5 of every 100 000 children aged 0 – 19 years.\textsuperscript{24} Both lymphoma and cancer of the central nervous system (CNS) were prevalent in approximately 3 of every 100 000 children.\textsuperscript{24} The two peak age incidences of paediatric cancer are in children between 0 – 4 years of age (23 in 100 000) and in those between the ages of 15 – 19 years (18 in 100 000).\textsuperscript{24} There is a lower incidence between the ages of 5 - 14 years (11 in 100 000).\textsuperscript{24}

Leukaemia and cancers of the CNS are most common in those aged 1 – 4 years.\textsuperscript{24} In contrast, bone sarcomas and Hodgkin’s Lymphoma increase with age, occurring more frequently in those ten years and older.\textsuperscript{24} Infancy is the time with greatest diversity in cancer types with liver cancer, retinoblastoma, kidney cancer and sympathetic nervous system tumours being most common.\textsuperscript{24}

\textbf{2.3.2 Psychosocial Issues in Paediatric Cancer}

Paediatric cancer is a family disease.\textsuperscript{26,27} It affects not only the child but also the child’s environment including family, peer relationships and academic activities.\textsuperscript{28} As well, the outlook in paediatric cancer has changed from a focus on preparation for death to one on cure and long-term survivorship.\textsuperscript{29}

\textit{Stages of Paediatric Cancer} Each of the evolving stages in childhood cancer: diagnosis, treatment, remission, relapse, completion of treatment, survivorship or palliation, brings with it a different set of needs and issues for the patient.\textsuperscript{28} The first year of treatment can be a stressful time for school-aged children. There are new
experiences, often with painful medical procedures and prolonged absences from school, which can lead to isolation from peers and difficulty in maintaining normal academic activities. As well, diagnosis, treatment and relapse disrupt family patterns and cause anxiety for the entire family unit.

In a study of 7 adolescent cancer patients, Rudin et al found, through in-depth interviews, three areas of cancer-related concerns: physical, psychological and social. Physical concerns included fears around treatment, loss of hair, decreased appetite and energy, and permanent disfigurement. Psychological concerns were related to death and feelings of sadness, anger, confusion, frustration and depression. As well, several were concerned about the effect of cancer on their educational and career opportunities. Social concerns centred around peer and family relationships. For some, the cancer experience was positive in strengthening these familial bonds, while for others there was a sense of growing further apart.

Social support, peer and family relationships are central concerns to cancer patients, as highlighted in Rudin et al’s study. These relationships are also of importance to paediatric cancer patients’ sense of well-being. Using the Self-Perception Profile for Children/Adolescents, the Revised Class Play and the Loneliness and Social Dissatisfaction Questionnaire, Noll et al studied the peer relationships of 48 cancer patients and matched classroom controls. Peer report data indicated that cancer patients had a reputation of being socially isolated, although there were no significant differences in the measure of popularity, number of friends, loneliness or sense of self-worth between the two groups.
Remission, completion of cancer treatment and long-term survival are often points in the disease trajectory associated with uncertainty. These are also times in which the child or adolescent is able to renew "normal" patterns of daily living with family and school.\textsuperscript{30} One qualitative study of seven children aged 5 to 18 who were in remission and had completed cancer treatment within the previous year, discovered that realisation of completing therapy was a gradual process. This process involved seeking a new "normal" in their life, modifying relationships through changes with health care providers, seeking normalisation with family members, and moving on.\textsuperscript{34} Completing treatment was characterised by two experiences: one of celebration and hope, and the other of uncertainty and fears of recurrence.\textsuperscript{34}

**Perception of Needs** Paediatric cancer patients strongly desire information concerning all aspects of their disease.\textsuperscript{27,35} Ellis and Leventhal\textsuperscript{35} studied the information needs and decision making preferences in 50 cancer patients between the ages of 8 - 17 years. Fifty-two percent were in treatment, while 46% were off therapy, 18% in relapse, and 2% in palliative care. Results indicated that 76% of the patients wanted to know their chance of cure regardless of any negative prognosis. Ninety-five percent indicated they would want to know if they were terminally ill. While there was a strong interest in information, treatment decisions were felt to be largely the responsibility of the physician. An exception were children and adolescents in palliative care, where 63% of those older than 13 years felt they should have some choice or involvement in decision making with regards to their treatment and care.\textsuperscript{35}

**Coping with Cancer** Van Dongen-Melman and colleagues\textsuperscript{36} developed a model of coping with childhood cancer that illustrates the main issues faced by children and
adolescents with cancer, and the strategies they use to cope. Uncertainty, loss of control, threats to self-esteem and negative feelings are potential stressors paediatric patients face. They use diverse coping strategies such as seeking information, support and comfort; finding meaning in events; trying to change the situation; denial and avoidance; and acceptance.\textsuperscript{36} Additional reports indicate that the use of denial is a common coping strategy for paediatric patients, as well as their parents.\textsuperscript{29} According to Van Dongen-Melman and colleagues,\textsuperscript{37} denial is often more adaptive than maladaptive when coping with the disease.

\textbf{2.3.3 Cancer and Childhood/Adolescent Development}

Childhood and adolescence are times of rapid growth and development. An illness such as cancer can potentially disrupt the normal tasks and stages of development characteristic of these periods.\textsuperscript{29,38,39}

\textit{Infancy and Early Childhood} Infancy and early childhood, typically from birth to the ages of 4 or 5, are times of increased exploration and rapid development of motor and visual skills.\textsuperscript{38,39} As well, they are times when fears of separation and abandonment are common.\textsuperscript{38,39} During treatment for cancer, separation from parents may potentially disrupt the development of trust and attachment, especially during prolonged separation.\textsuperscript{39} Reactions during invasive procedures, common in the presence of parents, include silent withdrawal, sadness, agitation, negative behaviours, temper tantrums and increased panic over medical procedures.\textsuperscript{38,39}

\textit{Late Childhood} At this stage of a child’s life, age 6 through 11 years, there is an increased preoccupation in developing and mastering skills for social acceptance into
the outside world. As well, school becomes a place for competition and facilitates increased involvement with peers. An illness such as cancer often requires hospitalisation that results in separation from such activities and interactions. During both childhood and adolescence, medical treatments such as chemotherapy, that cause hair loss, and surgery, that results in physical disfigurement, can create feelings of doubt relating to one’s acceptability with peers. However, research by Noll et al found that cancer patients did not differ significantly in popularity or number of friends from their matched classroom controls.

Adolescence Adolescence is often referred to as a period of ‘storm and stress’. It is characterised by rapid body changes associated with puberty and a strong desire for autonomy. A struggle for independence from one’s family and a need to belong and “fit in” with one’s peers is commonly observed. Concerns over the future and an increased capability for abstract thinking are also central to this stage of development. Having cancer and receiving treatment for the disease can create a sense of lessened autonomy. Hospital stays, treatment schedules, and side-effects from treatment all increase dependence on adults for care, and limit involvement with peers and school-based activities. Uncertainty over the outcome of the disease also makes it difficult to plan for post-secondary education and careers.

2.4 Paediatric Cancer Survivorship

2.4.1 Survival Rates

Advances in the treatment of paediatric cancer have led to dramatic changes in survival rates. A decrease in death rates was achieved in the late 1950’s, in particular
for those with Wilms’ tumour and Hodgkin’s disease. In 1965, the widespread use of chemotherapy also led to decreased death rates for other solid tumours. In the early 1970’s, the most dramatic change in survival rates occurred because of new therapeutic protocols often involving a combination of three therapeutic methods: surgery, chemotherapy, and radiation therapy. Since 1965, there has been a reduction in death rates by 80% for Hodgkin’s disease, 68% for kidney cancer (primarily Wilms’ tumour), 50% for leukaemia and bone sarcoma, 32% for Non-Hodgkin’s lymphoma and 31% for all other types of paediatric cancers.

It is projected that by the year 2000, 1 in every 900 sixteen to thirty-four year olds will be a survivor of paediatric cancer. With a decrease in mortality rates and an increase in incidence, the number of survivors of paediatric cancer is expected to continue to rise.

The diagnosis of cancer itself appears to impact upon the probability of survival. For example, current survival rates for those diagnosed in Canada between 1985 and 1988 indicate that 92% of acute lymphoblastic leukaemia (ALL) patients survived the first year following diagnosis, with approximately 74% surviving beyond five years. In contrast, of those with acute non-lymphoblastic leukaemia, only 65% survived one year and 39% five years. As well, patients diagnosed with lymphoma experienced differing survival rates, based on the type of lymphoma. Of patients with Hodgkin’s Lymphoma, 99% survived one year and 90% five years. In contrast, 80% of patients with Non-Hodgkin’s Lymphoma survived one year and 68% five years. Those diagnosed with cancer of the central nervous system (CNS) experienced 80% one year survival, while 61% survived for five years. The five year survival rate of those with
soft tissue sarcomas was 69% and bone sarcomas 61%.\textsuperscript{24} In total, 88% of all paediatric cancer patients survived one year, and 71% five or more years.\textsuperscript{24}

The survival rates presented above are based on survival from the date of diagnosis, and therefore include cancer patients who are on treatment or have relapsed. As such, these rates are slightly higher than disease-free survival rates, thus somewhat overestimating overall survival. Disease-free survival rate information have been emerging from cooperative groups; clinical trial data cancer registries often do not include the relevant information required to compute disease-free survival rates. For example, a study of 237 medulloblastoma patients, a cancer of the CNS, found that 59% of those treated with a combination of radiotherapy and chemotherapy experienced five-year disease-free survival.\textsuperscript{43} As well, in Hodgkin’s Lymphoma patients, the five-year disease-free survival rate in those with Stage I or IIA Disease, and treated with 35 – 44 cGy of involved- or extended-field radiation was between 70 and 86%.\textsuperscript{43}

\textbf{2.4.2 Biological Late Effects}

Among those treated for childhood cancer, it has been estimated that approximately 40% will experience some late-effects.\textsuperscript{44} Late-effects are often the result of the cancer itself, its treatment, or a combination of the two.\textsuperscript{45} The severity of late-effects for childhood cancer survivors is dependent on a number of factors including the age and developmental stage of the child, the cancer site and degree of spread at diagnosis, and the type and intensity of treatment received.\textsuperscript{45}

Growth retardation and/or deformity of spinal growth has been reported as a late-effect in patients who have been treated, with radiation therapy alone or in
combination with chemotherapy, during childhood or adolescence. Typically, growth is affected in several ways. Treatment can affect overall nutritional status resulting in decreased height; as well, spinal shortening in those treated for medulloblastoma can occur from irradiation to the entire spine. Radiation treatment to the entire spinal column typically results in decreased truncal height through the inhibition of vertebral growth. Radiation therapy to the flank produces the greatest effect on growth. The production sites of growth promoting hormones can be damaged from irradiation to the head in those with brain, head and neck tumours, and in those receiving preventive CNS therapy for acute leukemia. Scoliosis or kyphosis can result in those with intra-abdominal tumours such as Wilms’ tumour, neuroblastoma, and lymphoma due to unevenly irradiated vertebrae or when radiation is not uniformly absorbed. As well, increased susceptibility to fractures, and growth retardation resulting in short stature, may result following irradiation to the bone. Factors which influence the degree to which radiation therapy affects growth include: the age at which a child is treated, with those younger than six years of age or in puberty most susceptible; the dose of radiation provided, with doses greater than 2000 cGy producing the greatest effect; and the area treated. Those treated with chemotherapy alone usually do not have growth retardation; however certain chemotherapy drugs, such as methotrexate, can result in abnormal calcium metabolism, producing secondary effects of fractures, bone pain and osteoporosis.

Infertility is an additional biological late-effect for paediatric cancer survivors. Some drugs and treatment regimens for paediatric cancers may affect gonadal development. Direct irradiation to the ovaries or testes can result in delayed sexual
maturation due to a decrease or absence of sex hormone production.\textsuperscript{47} Irradiation to the spinal column or ovaries in doses between 1200 and 2000 cGy given to females has been reported to affect hormone production with a resulting delay in menarche. In doses greater than 2400 cGy, approximately one-half of these patients experiencing gonadal failure.\textsuperscript{47} Irradiation to the lower spinal column can result in “scatter” irradiation to the ovaries. Treatment with chemotherapy alone in ALL survivors does not appear to decrease reproductive capacity.\textsuperscript{46,50}

Damage to the cardiovascular system following therapy may also occur. The most commonly observed deleterious effects of cancer treatment to the cardiovascular system include cardiomyopathy, congestive heart failure, and pericarditis.\textsuperscript{48,49} Although all patients treated with one of the anthracycline drugs, such as adriamycin or daunorubicin, are at risk for cardiomyopathy, the overall frequency is less than 10%.\textsuperscript{49} There appears to be a direct dose-response relationship between the development of pericarditis and cardiomyopathy, and the dose of radiation given to the heart.\textsuperscript{46,48,49,50,51} Other organ systems at risk for treatment-induced toxicity include the respiratory, renal, hepatic and gastro-intestinal tract.\textsuperscript{46}

\subsection*{2.4.3 Second Malignant Neoplasms}

For those cured of paediatric cancers, there is risk of developing a second malignant neoplasm (SMN). The true risk of developing a SMN is not currently known because of the limited population that has survived paediatric cancer. However, current estimates indicate a 10- to 15-fold greater risk for paediatric cancer survivors in comparison with the general population.\textsuperscript{52} Other estimates range from 2 – 12% within
twenty-five years following the initial diagnosis, to 17% twenty years from diagnosis. The Late-Effects Study Group, an affiliation of 13 North American institutions currently following a large number of paediatric cancer survivors, estimates the overall probability of developing a SMN at 8.5% within twenty years following initial diagnosis.

Research investigating the cause of death in childhood cancer survivors illustrates a slight decrease in the number of deaths attributable to recurrent tumours. In a study investigating the cause of death in 9,080 childhood cancer survivors five years after their initial diagnosis, 74% of deaths in 793 patients were attributable to recurrent tumours, while 7% were attributable to a second primary tumour. The proportion dying from recurrent tumour decreased from 12% of those diagnosed between 1940 and 1970 to 8% of those diagnosed between 1971 and 1985.

Not all cancer survivors have an equal risk of developing a SMN. Risk factors for the development of a SMN include treatment with specific anti-cancer drugs known to cause a second cancer, combination chemotherapy and/or radiation therapy, and a genetic susceptibility. Children treated initially for retinoblastoma or Hodgkin’s disease develop SMN more often than those treated for other cancers. In a study of 499 survivors of Hodgkin’s disease, 25 had developed a SMN nine years after the completion of treatment, presenting a cumulative risk of 1.5% at five years.

A retrospective cohort study investigated the prevalence of breast masses in 3,436 female cancer patients diagnosed between the ages of 0.4 and 24.4 years (median = 13.8 years). The primary cancer site included a wide range of diagnoses; however, ALL was most common with 33%, followed by CNS tumours (9%), AML (8%),
Hodgkin’s Disease (8%), and neuroblastoma (7%). Other diagnoses included Wilms’
tumour (7%), rhabdomyosarcoma (5%), Non-Hodgkin’s lymphoma (4%), and
osteosarcoma (4%). Sixty-seven were found to have breast abnormalities, of which 26
were malignant. The median age of discovery was 27.7 years, representing a 20 fold
increase over the expected incidence in age-matched controls from the general
population. The most common primary diagnosis of those with breast abnormalities
were Hodgkin’s Disease (23%) and rhabdomyosarcoma (18%). As well, all 26 patients
with malignant masses had received radiation for their primary cancer to a treatment
area inclusive of breast tissue, thereby suggesting the role of treatment in the
development of this SMN.

2.4.4 Psychosocial Late Effects

Long-term Adjustment Research has shown that overall, paediatric cancer
survivors appear to be fairly to well-adjusted. Spirito et al. used the Self-
Perception Profile for Children on a group of 56 paediatric cancer survivors (X = 9.1
years) and 52 classroom controls (X = 8.8 years) to determine whether there were any
significant differences between the two groups in their perceived level of competence.
This measure assesses the child’s view of his/her competence in several areas including
academic competence, social acceptance, athletic competence, physical appearance,
behavioural conduct, and global self-worth. The results from the study did not show
any significant differences in areas of competence between the two groups.
Additionally, in a study of 52 cancer survivors who were two or more years beyond the
completion of treatment, 25% scored excellent global adjustment ratings with 36% good
and 25% average; only 8% scored poorly on this scale. In this study, greater physical impairment was significantly associated with lower adjustment scores.

Survivors of paediatric cancer often report positive benefits of having a history of cancer. In a study of 48 long-term survivors, over one-half felt that they had changed “for the better”, reporting such benefits as an increased appreciation of life and growing up faster. Only five indicated their cancer experience had affected them negatively, reporting increased cynicism, decreased confidence, and more introversion. Chesler and colleagues study similarly found that 76% of 271 survivors felt different from their peers, with many indicating positive aspects of having cancer as increased maturity and a greater understanding of life. Wasserman et al investigated the subjective perception of the experience of cancer and its treatment in 37 Hodgkin’s disease survivors who had completed treatment at least five years prior to the study. Ninety-five percent of the sample indicated that having a history of cancer resulted in some positive benefits. Twenty-six percent experienced an increased appreciation for being alive, 26% an improved outlook on life, 26% increased social involvement, 18% increased religious feelings, 15% greater maturity, 13% increased patience and tolerance, 15% not taking good health for granted and 8% becoming closer to one’s family. They also found that emotional problems associated with Hodgkin’s disease decreased with time. Koocher et al reported similar findings in a study of 116 cancer survivors who had been off treatment for at least one year and were in remission. The further the time from diagnosis, the less likely survivors suffered psychological adjustment problems. Age at diagnosis has been reported to affect adjustment with those diagnosed at a younger age experiencing more difficulty. Sloper et al’s study
involving 31 cancer survivors, five years after their initial diagnosis, found that the diagnosis of a solid tumour versus leukaemia did not appear to affect long-term adjustment.

Although the sample size was small, it was interesting to note that no significant differences were found between the 7 who had experienced a relapse and the remaining 24 who did not.

Recent research has begun to investigate the prevalence of post traumatic stress disorder (PTSD) in the childhood cancer survivor population. Stuber and colleagues undertook an investigation of 64 childhood cancer survivors who were between the ages of 7 and 19, and had completed treatment an average of 6.7 years (SD = 2.8) prior to the study. Twelve and a half percent reported symptoms that were highly correlated with a clinical diagnosis of PTSD. Additionally, more than half reported having bad dreams, feeling afraid or upset when thinking about cancer, feeling "alone inside" and experiencing nervousness. Another study by Stuber and colleagues reported that in 186 cancer survivors, symptoms of PTSD decreased with time and were more prevalent in female subjects. As well, increased stress was correlated with the perception of a higher threat of death during their cancer treatment, higher levels of anxiety, a history of stressful experiences, and a lack of family and social support. While these studies indicate a small group of paediatric cancer survivors do exhibit PTSD symptomatology, a case-control study did not find any significant difference in the prevalence of PTSD symptoms between 130 leukaemia survivors and 155 peer controls.

**Academic Achievement** Disruptions in school performance and achievement related to the diagnosis of cancer during childhood have been reported. Cancer survivors were more likely to have repeated school grades in comparison to their
peers,\textsuperscript{57} and to have dropped out of school for reasons related to their disease.\textsuperscript{12} Of 52 cancer survivors (mean age = 15.9 years), 20\% reported enjoying school more, while 30\% reported enjoying it less.\textsuperscript{1} However, in a case-control study of 108 cancer survivors who had completed treatment 6 months to 5 years prior to assessment, teachers rated survivors as more willing than their peer controls to attend school.\textsuperscript{56}

Different treatment modalities appear to affect the extent of academic difficulties related to the disease, with those who received CNS irradiation tending to have lower academic achievement.\textsuperscript{66,67,68} In a study of 74 cancer survivors, those who had undergone CNS irradiation in addition to standard chemotherapy treatment had lower scores in IQ, written spelling, arithmetic achievement, visual motor integration, memory and fine motor skills in comparison with those who had received chemotherapy alone, and/or no CNS treatment or irradiation to the head or neck region.\textsuperscript{66} Poorer performance on academic, visual motor, spatial memory and fine motor skills was associated with an earlier age at diagnosis, with those diagnosed prior to the age of five more likely to experience cognitive difficulties.\textsuperscript{66} Kelaghan et al\textsuperscript{69} found that in 2 283 cancer survivors compared with 3 270 sibling controls, there was no significant difference in educational achievement in those with non-CNS cancers. However, CNS cancer survivors were significantly less likely to complete eight grades of school, or if completed high school, to carry on to college. Additional research has also confirmed that younger age at diagnosis and doses of irradiation greater than 2 400 cGy are associated with educational difficulties.\textsuperscript{68,69} These include difficulties with concentration, nonverbal memory, sequencing tasks, mathematical and organisational skills, visual perception and integration, and abstract reasoning.\textsuperscript{52}
With the number of studies illustrating the negative effect of CNS irradiation on cognitive functions, research into the additive effect of pre-irradiation methotrexate has been conducted.\textsuperscript{70} In a study of 72 ALL survivors, 27 had received pre-irradiation intrathecal methotrexate and 42 had not, thus serving as controls.\textsuperscript{70} Results indicated that those who had received pre-irradiation methotrexate had comparable IQ scores to the non-irradiated control group, suggesting that this may in fact protect against the damaging effects of CNS irradiation in this population.\textsuperscript{70} However, the small number of those who had received the pre-irradiation intrathecal methotrexate warrants caution in interpreting these findings.

While paediatric cancer survivors were more likely to experience academic difficulties than their peers, research has indicated that the highest level of education obtained was not significantly different.\textsuperscript{66} Of 43 cancer survivors between the ages of 11 and 25, who were in school, 17 experienced learning difficulties (8 learning disabilities and 9 motivational problems).\textsuperscript{58} Of the 18 survivors who had completed high school, 4 were enrolled in college/technical school, 4 were unemployed, 2 attended college but did not graduate, 1 had completed an undergraduate degree, and 11 had no additional training.\textsuperscript{58} In another study of 95 childhood cancer survivors, 77\% indicated that their cancer history had no effect on their educational achievement.\textsuperscript{71} In contrast, a study of 48 cancer survivors and 38 sibling controls found that 22 (67\%) cancer survivors and 4 (10\%) sibling controls believed that their education had suffered as a result of their or their sibling's illness.\textsuperscript{60}

**Peer Relationships** Changes in friendships and personal relationships during cancer treatment are common in cancer survivors.\textsuperscript{12,14,19,56} In a study of 56 paediatric
cancer survivors in comparison to 52 healthy controls who were between the ages of 5 and 12, survivors were more likely to have adults as friends and to spend more time with adults than their peer controls. As well, cancer can result in disruptions in friendships. Lansky et al reported one-half of 39 cancer survivors experienced changes in their peer relationships. Negative experiences with peers included the loss of friends due to beliefs that cancer was contagious, and teasing over baldness or thinness. A study of 28 brain tumour survivors and 28 healthy classroom controls found brain tumour survivors had fewer friendships and were perceived as being more socially isolated than their peers. Many cancer survivors spent more time alone, participating in fewer peer activities, even though they did not wish to do so.

Friendships do appear to play an important role for paediatric cancer survivors. In one study of 115 survivors, those who reported a decrease in their social contacts at diagnosis were less well-adjusted than those who did not.

**Self-Esteem** Research concerning paediatric cancer survivors’ self-esteem indicates that it is affected not by the cancer diagnosis itself, but through the experience of having cancer. Generally, cancer survivors and their peers do not differ on perceived self-image and tend to have good self-esteem. However, significant restrictions in daily activities or severe changes in physical appearance are associated with poorer self-concept scores. Greenberg and colleagues found that in 116 paediatric cancer survivors, those who rated at the extreme high or low levels of self-esteem tended to be poorly adjusted.

**Depression** Research into the frequency of depression in paediatric cancer survivors show conflicting findings. In a study of 450 cancer survivors who had
survived five or more years, and 587 sibling controls, there was no significant
difference in the frequency of depression, nor any difference in reports of attempted
suicide or running away.\textsuperscript{74} Male cancer survivors were more likely to experience at
least one week of "feeling blue" than their male siblings (51 vs. 41%), whereas females
were virtually identical.\textsuperscript{74} Both male and female cancer survivors were more likely to
attribute depression to health concerns.\textsuperscript{74} In contrast, a study of 39 cancer survivors
between the ages of 16 and 33 found a higher rate of treatment for depression,
alcoholism, and attempted suicide than that of the general population.\textsuperscript{14} Zeltzer and
colleagues\textsuperscript{75} found that 580 cancer survivors, in comparison with 396 sibling controls,
had significantly higher scores (p < .01) in depression, anger and confusion as measured
by the 65 item self-response Profile of Mood States.

Among cancer survivors, physical impairment and cosmetic changes were the
leading causes of depression.\textsuperscript{1,16} An older age at diagnosis was associated with
increased frequency of depression; however, differences in treatment and prognostic
factors were not.\textsuperscript{1} As well, female cancer survivors tended to have higher depression
scores than their male counterparts.\textsuperscript{75}

\textbf{Risk-Taking Behaviours} While no studies have investigated the reasons or
beliefs around risk-taking behaviours, prevalence studies have been completed. In a
study of 40 cancer survivors between the ages of 10 and 38 who were five or more
years beyond completion of treatment, one-third reported changes in risk-taking
behaviours during the course of treatment.\textsuperscript{12} Eight reported increases in risk-taking
behaviours during treatment; however, they also reported that this subsided following
its completion. Six became more cautious, while the rest indicated that they did not
change their current behaviours. Three reported excessive alcohol use, while 12 reported use of marijuana, three of whom had done so to alleviate nausea associated with chemotherapy. Meadows, McKee and Kazak\textsuperscript{71} looked at the prevalence of risk behaviours in a group of 95 cancer survivors, and found that while 54% had never smoked, 32% were current smokers. As well, 12.2% had, at one time, used marijuana.\textsuperscript{71} In another study of risk-taking behaviours, 42% of 36 cancer survivors ($X = 16.9$ years) reported taking no health risks.\textsuperscript{10} Fifty-eight percent reported engaging in one or more of four health risk activities - smoking, alcohol use, drug use and pregnancy risk.\textsuperscript{10} Of this group, 27% participated in one risk, 17% two risks, 8% three risks and 6% all four.\textsuperscript{10} Findings from this study indicate a prevalence rate similar to that of the general population suggesting that paediatric cancer survivors are no more or less likely to engage in risk-taking behaviours.\textsuperscript{10} Cancer survivors have been reported to believe that it is more important to protect their own health, compared with most other children and young adults, as a result of their cancer history.\textsuperscript{76}

Tobacco use among childhood cancer survivors is of great concern to health care providers. Those treated for childhood cancer with the chemotherapy drugs, methotrexate and doxorubicin, are at increased risk of decreased pulmonary function and congestive heart failure, respectively. As smoking can potentially magnify these treatment late-effects, in addition to having a known carcinogenic effect, efforts to decrease the prevalence of tobacco use within this population is necessary.\textsuperscript{3,77,78,79} A number of studies have investigated the prevalence of tobacco use in childhood cancer survivors and have found rates similar to that of their siblings and the general population.\textsuperscript{79,80} In a large scale retrospective cohort study, Haupt and colleagues\textsuperscript{79}
found that 1,289 cancer survivors were equally likely (28.6% vs. 30.5%) than 1,930 sibling controls to be smokers. As well, a study of 592 ALL survivors (range = 18.0 – 33.2 years) and 409 sibling controls (range = 18.1 – 41.6 years) found that survivors were significantly less likely to have ever smoked; however, the control group was significantly older, which may have influenced this finding.\textsuperscript{77} Those who used tobacco were older, Caucasian, never attended college and were more likely to be regular smokers.\textsuperscript{77} Similarly, Tyc et al.’s\textsuperscript{78} investigation into the prevalence of smoking in 150 cancer survivors found that of the 40 who were over the age of 18, almost half had tried smoking, with 17.5% being current smokers.

\textit{Employment} Choices related to employment and occupation have been reported by some cancer survivors to have been affected by the disease.\textsuperscript{14,19,81} While having had cancer during childhood or adolescence has led to job opportunities for some,\textsuperscript{81} it has been a source of discrimination for others.\textsuperscript{12,59,74,81,82} Discrimination included several forms such as refusal of employment,\textsuperscript{12,74,81} denial of entry into the armed forces,\textsuperscript{12,74,81,82} loss of promotion,\textsuperscript{81} loss of seniority,\textsuperscript{12} and in one case, transfer from a position of kitchen worker due to concerns over “contamination”.\textsuperscript{12} The incidence of discrimination is low as illustrated in a study of 227 long-term survivors, where 93% indicated that their career advancement had not been limited as a result of their cancer; however, 19% had not disclosed their cancer history to their employer.\textsuperscript{81} Another study of 46 ALL survivors found that 20.5% had experienced some form of employment discrimination.\textsuperscript{82} Cancer survivors who had undergone amputation felt that they had experienced some form of discrimination and were not employed at a level appropriate to their skills and training.\textsuperscript{83} According to Teta et al\textsuperscript{74} rates of employment/
unemployment were found not to significantly differ between cancer survivors and the general population. In contrast, Zeltzer et al.\textsuperscript{75} found that of 580 cancer survivors and 396 sibling controls, cancer survivors were more likely to be unemployed or working less than half time.

**Health and Life Insurance** Difficulty in obtaining health and life insurance is a common problem for paediatric cancer survivors living in the US. In a cross-sectional study of 95 cancer survivors, none had been denied employee benefits because of their cancer history, while 10.6% had been denied life insurance at least once and 2.1% had it cancelled.\textsuperscript{71} Evans and Radford\textsuperscript{60} found that 17% of 48 childhood cancer survivors had been denied health insurance or had to pay higher premiums because of their cancer history. In a study of 450 cancer survivors, 24% of males and 19% of females were denied life insurance, and 14% of males and 9% of females were denied health insurance.\textsuperscript{74} Green and colleagues\textsuperscript{81} examined the prevalence of health and life insurance in 227 long-term survivors of paediatric cancer, and found that 20.7% did not have any form of health insurance. For those currently employed, the company health insurance plan was not offered to 7.5% of those employed full-time and 10% employed part-time.\textsuperscript{81} Cancer survivors who were married were more likely to hold health insurance policies than those who were not.\textsuperscript{81} In this same study, 51% did hold a life insurance policy. In comparison to the general population, cancer survivors were clearly insured at a lower rate.\textsuperscript{79} Forty-three percent of those who did not have life insurance, and 32% of those who did, reported difficulty in obtaining policies.\textsuperscript{81}

**Marriage and Family** In general, marriage rates for paediatric cancer survivors are lower than the general population.\textsuperscript{59,71,81,84,85} In a retrospective cohort study of 2
170 cancer survivors and 3,138 sibling controls, both male and female cancer survivors were less likely than controls to be married. When compared to the rest of the cancer survivor population, male cancer survivors with a diagnosis of cancer of the brain or CNS were less likely to be married. Additionally, this group of male survivors were less likely than controls to have completed the eighth grade, and were earning less than their male siblings. Analysis suggested that these differences contributed to their likelihood of being married. Another study of 263 childhood cancer survivors found that, in comparison with 369 sibling controls, the former group was more likely to report not marrying for reasons related to their health. By contrast, in Meadows and colleagues' study, in a group of 95 cancer survivors, 60% were single at the time of evaluation. While some indicated their cancer history at times affected their ability to meet others, the majority indicated that their cancer history did not affect their desire or opportunities to be married. In the same vein, a study of 45 osteosarcoma and Ewing’s sarcoma survivors showed that in comparison to the general population, their diagnosis did not affect their marital status. Of those who were not married, those with limb amputation were less likely to be married that those who had undergone limb salvage. Other researchers, with much smaller samples, reached similar conclusions in demonstrating that marriage rates do not differ between controls and childhood cancer survivors. Evans and Radford, in their study of 48 cancer survivors and 39 sibling controls, reported both were equally likely to be in a stable relationship. Similarly, Wasserman et al’s study of Hodgkin’s disease survivors reported similar marriage rates amongst survivors and the general population.
Although limited, research to date investigating rates of divorce within this population does not show significant difference between controls and cancer survivors.\textsuperscript{12,84} Research has shown rates of divorce as higher in males diagnosed with CNS cancer below 10 years of age, or in males with a diagnosis of retinoblastoma.\textsuperscript{84}

Decisions around having children are of concern for cancer survivors.\textsuperscript{57,86} In a cross-sectional study of 263 cancer survivors and 369 sibling controls, female cancer survivors were significantly less likely to have been pregnant, although data concerning the reasons behind this difference were not collected.\textsuperscript{86} As well, 11\% had been advised by a physician not to have children as a result of their cancer history. Those most likely to have received this advice had been treated with radiation therapy, or a combination of chemotherapy and radiation therapy. The study did not indicate to which area these patients had received radiation therapy. In a recent study of 405 cancer survivors, 280 pregnancies were reported in 148 patients. Amongst this latter group, there were no cases of childhood cancer diagnosed in their offspring, nor were their offspring at increased risk for congenital anomalies.\textsuperscript{88}

A study of 95 cancer survivors, 50 male and 45 female, found that approximately one-half definitely wanted to have children, while 23\% reported that their cancer history had negatively affected their childbearing decisions.\textsuperscript{71} A smaller study of 48 cancer survivors found no significant difference in the number of children between survivors and their sibling controls.\textsuperscript{60}
2.5 Summary

While research has shown that paediatric cancer survivors are generally well-adjusted, our understanding of this population to date has been limited to cross-sectional and descriptive studies. Thus, while there is a great deal of knowledge concerning the prevalence of behaviours and outcomes of developmental transitions, there is little data that contributes to the understanding of the beliefs and motivations that underlie the choices related to marriage, family, risk-taking behaviours, employment, and education. As well, knowledge of how paediatric cancer survivors perceive the emotional, physical and psychosocial differences found between themselves and the general population affect their lives’ is limited. Additionally, much of the research to date has combined responses from paediatric cancer survivors who are still in childhood with those from adult survivors.

In contrast, this study focuses on understanding the mechanisms whereby the experience of cancer affects the lives of survivors in adulthood. Its purpose is to further our understanding from cancer survivors firsthand, the perceived effects cancer has on their beliefs, behaviours, and motivations.
Chapter 3

Methodology

3.1 Naturalistic Inquiry

Naturalistic inquiry involves the discovery, exploration and seeking understanding of a phenomenon. While the traditional scientific approach views the world as quantifiable, made up of observable and measurable facts, the naturalistic paradigm, in contrast, views the world as complex, consisting of multiple realities that are socially constructed and constantly changing.\(^8^9\)

Naturalistic inquiry is characterised by six principles:

- phenomena are studied in their natural context,
- sampling is based on a strategy where participants are selected purposely to achieve a diverse sample,
- the researcher is the primary instrument by which data are collected,
- data are analysed through an inductive process,
- theory emerges from the data rather than data used to test theory,
- it seeks to understand and illuminate meaning as seen by those under study (emic perspective).\(^9^0\)

In this study, the particular naturalistic approach used is grounded theory. Grounded theory methodology provides an opportunity to explore and develop a theory related to phenomena about which little is known. This is a systematic approach used to
develop an inductively derived theory about a phenomenon that is solely based on the data from which it develops.\textsuperscript{22}

3.2 Grounded Theory

Grounded theory is a qualitative research method developed in the 1960s by two sociologists, Barney Glaser and Anselm Strauss.\textsuperscript{91} The central tenet of grounded theory research is the development of a theory that is grounded in the data from which it emerges.\textsuperscript{22} Strauss and Corbin\textsuperscript{22} offer a concise explanation of this approach:

A grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory stand in a reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge.\textsuperscript{p.23}

Grounded theory is also known as the constant comparative method of analysis. Data analysis begins following the initial data collection for the purpose of discovering concepts and categories that, through constant comparison, serve as the building blocks for theory development.\textsuperscript{22} The analysis serves to generate questions and hypotheses through further data collection in addition to the creation of concepts and categories for theory development.\textsuperscript{22} Data collection is based on theoretical sampling, which is “sampling on the basis of concepts that have proven theoretical relevance to the evolving theory.”\textsuperscript{22,p.177} Theoretical sampling and thus data collection continue until a saturation point is reached - the point at which no new information is being learned.\textsuperscript{22} Using Pandit’s\textsuperscript{92} visual framework (Figure 3.1) of the process of grounded theory helps to illuminate the integrative aspect of the approach.
As the aim of grounded theory is to generate rather than test theory, the use of a conceptual framework is considered inappropriate. However, grounded theory is guided by, and has its roots in, symbolic interactionism. Symbolic interactionism is "both a theory about human behaviour and an approach to inquiring about human conduct and group behaviour." Three premises characterise symbolic interactionism: personal meaning toward things (i.e. persons, objects, situations) determines the action people take toward them; meaning arises out of social interaction; and meanings are modified in an interpretative process through encounters with these things. To study human behaviours is to seek to understand meaning:

The meanings that things have for human beings are central in their own right. To ignore the meaning of things toward which people act is seen as falsifying the behaviour under study."
3.3 Data Collection Strategies

3.3.1 Participants

Data were collected through in-depth interviews over an eight month period with 18 paediatric cancer survivors. Nine participants in both Saskatchewan and British Columbia (n=18) were recruited. While the recruitment process differed in each province, initial selection in both provinces based on four eligibility criteria:

- diagnosed with cancer from 1975 onward,
- age at diagnosis from birth to 17 years,
- five or more years since the completion of treatment,
- currently between the ages of 20 and 35 years.

In addition, participants were identified to represent as diverse a sample as possible, taking into account characteristics such as:

- cancer type, i.e. leukaemia vs. brain tumour
- current age, i.e. early twenties vs. early thirties
  - impact of different life stages
- age at diagnosis, i.e. diagnosis in early childhood vs. diagnosis as a teen
  - impact at different developmental stages
- treatment received, i.e. surgery, chemotherapy, radiation therapy
- gender
- geographic residence, i.e. rural vs. urban
  - impact on availability of health care services
- ethnicity.
Ongoing recruitment was directed by *theoretical sampling* whereby additional participants are selected on variables that have been found to have theoretical relevance in the initial analysis. The underlying purpose of this strategy is to further explore these variables to ensure that the full variation within the explored category exists. Thus sampling is done “to test, elaborate, and refine a category ... for verification or test[ing] the validity of a category”.  

Initial analysis of the first four interviews indicated the theoretical importance of the selection criteria. Variables such as age at diagnosis were not as important as type of treatment and its effect on the experience and late-effects. As well, the first four participants appeared to be very well adjusted, with two having had surgery alone as treatment. Thus, there was a need to explore whether varying treatments affect adjustment. Consequently, sampling was directed towards diagnoses where treatments were more likely to be varied (i.e. ALL, Hodgkin’s disease). An additional six participants were recruited following this strategy. Analysis of these interviews suggested that most were “doing well”; however, those with more severe late-effects appeared to have specific needs. Sampling of the remaining eight participants then centred on those with late-effects to further explore this issue. As well, with a low response rate from males, potential male participants were actively recruited in an attempt to achieve a more balanced distribution in gender.

### 3.3.2 Recruitment Strategies

Participants in Saskatchewan were identified through the Saskatchewan Cancer Registry; in British Columbia participants were identified through the Rehabilitation
Counsellor and the Paediatric Follow-Up Oncologist at the British Columbia Cancer Agency (BCCA). Using differing strategies in BC and Saskatchewan as a means for identifying potential participants enabled the identification of both cancer survivors receiving follow-up in a cancer centre versus those on letter follow-up who no longer received medical follow-up in a cancer centre. In addition, it enabled the identification of those who were likely to be “doing well” and those “not doing well”.

Overall, 49 participants were approached to participate in the study. In Saskatchewan, the family physician or oncologist of 34 potential participants who met the eligibility criteria were contacted (Appendix A and B). Letters and forms were sent by the Saskatchewan Cancer Registry to request permission to contact their patients and to ensure that potential participants were able to speak English and participate in the study. An invitation to participate was sent to 23 potential participants. Eight from the initial sample were no longer seen by the physician listed with the Cancer Registry, 2 were in relapse which deemed them ineligible to participate, and 1 indicated to her physician that she did not wish to be contacted. The invitation package included a description of the study (Appendix C), a consent form (Appendix D), a reply card (Appendix E) and a self-addressed, stamped envelope. Only when potential participants indicated a willingness to participate through returning the reply card did the researcher initiate contact. Eleven replies were received, with 2 indicating that they did not want to participate. One felt she had put her cancer behind her and as such would have little to say, and the other lived too far away to come in for an interview (Figure 3.2).
In British Columbia, 15 individuals were identified by the Rehabilitation Counsellor and the Paediatric Follow-Up Oncologist as potential participants. The invitation package used in Saskatchewan, including a description of the study (Appendix F), a consent form (Appendix G) and a reply card (Appendix E), was handed out by the Rehabilitation Counsellor (n = 9) or was sent through mail to the participant (n = 6). Again, only when the participants indicated willingness to participate through returning the reply form did the researcher initial contact. A total of nine positive replies were received (Figure 3.3).
3.3.3 Interview

Semi-structured interviews were used to elicit in-depth information from childhood cancer survivors in order to understand from their own point of view how surviving cancer affected their lives. An interview guide (Appendix H) with a set of general questions concerning themes of the study provided direction, although the overall goal was to achieve an open-ended flow of dialogue with each participant. The length of interviews varied, from 45 minutes to 1 ½ hours. Interviews were conducted in the home of the participants (n = 8), at the BC Cancer Agency (n = 5), at the Regina Cancer Centre (n=1) and at the University of Saskatchewan (n = 4).

As participants’ medical charts were not reviewed as part of the study, an information sheet (Appendix I) was completed with each participant at the end of the interview to elicit demographic information. Data included interview site and date, age, sex, marital status, ethnicity, employment status, education level, income, living
situation, and gender. Data pertaining to the participants' cancer was also collected through the interview or at the end (i.e., time since treatment was completed, date of relapses, if any, and type of treatment [i.e., chemotherapy, radiation therapy]).

3.4 Ethical Considerations

The Medical Research Council of Canada\textsuperscript{96} states that considering the ethical aspects of research requires a subject-centred perspective. Central to a subject-centred approach are the rights of participants, informed consent, and ensuring the confidentiality of the individual in terms of both the raw data and in publication.\textsuperscript{96}

Ethical approval for this study was sought in both provinces. In Saskatchewan, approval was obtained through the Advisory Committee on Ethics in Behavioural Science Research, University of Saskatchewan (Appendix J). In British Columbia, ethical approval was obtained through the Paediatric Tumour Group, BCCA (Appendix K), Clinical Investigation Committee, BCCA (Appendix L), and through the Behavioural Research Ethics Board, University of British Columbia (Appendix M).

Ensuring informed consent requires three principles to be met. First, the quality of information concerning the study must be clear and sufficient to communicate effectively what is involved in participation, in addition to any known risks and benefits associated with participating. Second, there must be an absence of coercion from those who have a vested interest in the research, enabling the participant to freely choose whether or not to participate. Lastly, there must be the provision of time for the participant to make a decision to participate in the study.\textsuperscript{96}
Within the present study the following measures were taken to ensure informed consent. First, an information sheet was provided along with a consent form to the participants in the recruitment package sent by the Saskatchewan Cancer Registry and the Rehabilitation Counsellor at the BCCA. Doing so ensured that adequate information concerning what was required of the participants and the potential risks and benefits of participation were communicated. Second, a reply form was also sent as a means of obtaining consent to contact the participant. The reply form ensured that only those interested in participating were contacted. Third, the interviewer reviewed the consent form with the participant at the beginning of each interview before the participant signed the form to ensure that he/she adequately understood the information presented.

To ensure confidentiality all transcripts have a code identifier to protect the identity of the participants and all raw data is stored in a locked filing cabinet. The audiotapes will be destroyed following the completion of the study. Names and any additional potentially identifying information were changed to ensure that the participants could not be identified.

3.5 Researcher as Instrument

In qualitative research, the researcher is the primary instrument used in data collection and thus he/she influences both the data collection and analysis. In comparison with quantitative research where the role of the researcher is controlled, qualitative research openly recognises the role of the researcher.
According to Leininger, the researcher “must remain cognizant of emic (local) perspectives and how such data may contrast with etic (external) perspectives, which are often researchers’ views”. As well, Strauss and Corbin maintain that, a qualitative researcher requires theoretical and social sensitivity, the ability to maintain analytical distance while at the same time drawing upon past experience and theoretical knowledge to interpret what is seen, astute powers of observation, and good interactional skills.

A reflective journal was maintained throughout the course of the research to attempt to illuminate the researcher’s personal thoughts and beliefs concerning the research that may be imposed upon the data. Such a journal provided an outlet “in which the researcher can express personal feelings and reflections ... often helpful in sustaining [a] heightened level of awareness”. Throughout the analysis the journal provided a secondary source of data, using reflections from the interviews themselves and from the analysis of transcripts.

3.6 Data Analysis

Analysis in grounded theory occurs with a set of systematic procedures to:

1) build rather than test theory,
2) give the research process the rigor necessary to make the theory “good” science,
3) help the analyst to break through the biases and assumptions brought to, and that can develop during, the research process,
4) provide the grounding, build the density, and develop the sensitivity and integration needed to generate a rich, tightly woven, explanatory theory that closely approximates the reality it represents.

Grounded theory analysis occurred at three levels: open coding, axial coding and selective coding. Basic to all three levels of coding was the constant comparative
method of analysis and the asking of questions. It is these two processes that gave the concepts precision and specificity.\textsuperscript{22} Although the three levels of coding are distinct in nature, movement among the three levels occurred throughout the analytic process.\textsuperscript{22}

All interviews were transcribed verbatim for the purpose of analysis. Ethnograph 4.0 provided the software support in which the data were analysed. Analysis in this study followed the coding procedures as described in Strauss and Corbin's (1990) \textit{Basics of Qualitative Research: Grounded Theory Procedures and Techniques}. The following is a description of the processes involved during each level of coding that was utilised during the analysis process.

\subsection*{3.6.1 Open Coding} The first level of coding involved "breaking down, examining, comparing, conceptualizing, and categorizing data".\textsuperscript{22, p. 61} Initially, each transcript was analysed line by line, sentence by sentence, and labels were given to each discrete phenomenon. Each incident was then compared to the next, with similar incidents being given the same name. Once phenomena were labelled, they were then categorised through grouping concepts that pertained to similar events. Categories were then developed further in terms of their properties and dimensions.\textsuperscript{22} For example, the category of treatment was developed in terms of its properties: type; chemotherapy, surgery, or radiation; and its dimensions: duration; months versus years.

\subsection*{3.6.2 Axial Coding} Following the break down of data that occurred in open coding, data were put back together through axial coding. Axial coding is "a set of procedures whereby data are put back together in new ways ... by making connections between
categories. At this point in the analysis, integration of the data from each transcript occurred with attention focused primarily on the emerging categories and processes rather than the individual stories. The central process in axial coding was the development of the conditions that gave rise to a category. Through the paradigm model, categories were described in terms of their causal conditions, context, action/interactional strategies and consequences. The paradigm model served to increase the density and precision of the developed theory.

3.6.3 Selective Coding In selective coding, the core category, the one in which all other categories are integrated, was developed. Selective coding involved five non-linear steps. First, the story line of how paediatric cancer survivors respond to long-term survivorship was explicated. Two, sub-categories were related to the core category, the central process in which cancer survivors were engaging, through the use of the paradigm model previously mentioned. Three, categories were related at a dimensional level, and fourth these relationships were validated through returning to the raw data and verifying emerging hypotheses. Lastly, “thin” categories were further developed through once again returning to the raw data to increase the conceptual density of the theory.

3.7 Trustworthiness

The fundamental differences between the qualitative and quantitative research paradigms create the necessity for alternative means of addressing the issues of reliability and validity in research. Criteria used to evaluate qualitative research should
be consistent with the philosophical underpinnings of the approach. Lincoln and Guba suggest alternate criteria that are consistent with the qualitative paradigm. These criteria are credibility, transferability, dependability and confirmability.

Credibility is the qualitative term for the quantitative equivalent of internal validity, and is defined “as the ‘truth value’ or ‘believability’ of the findings that have been established by the researcher”. The credibility of a study is enhanced through engaging in several processes throughout the research. First, peer debriefing serves as an external check on the inquiry process in which an individual who is not directly involved in the research process explores with the researcher aspects of the data that may have alternatively been left unexplored or remain implicit in the researcher’s mind. During data analysis, peer debriefing occurred with the researcher’s supervisor, in addition to other clinical and academic professionals. Second, referential adequacy is done through checking hypotheses against the raw data to verify findings. The process of the constant comparative method of analysis in grounded theory ensures referential adequacy is addressed. Third, negative case analysis, a process in which there is constant refinement of the developing hypotheses until all cases are accounted for. Simultaneous data collection and analysis in addition to theoretical sampling aid in this constant refinement. Lastly, member checking involves returning to participants to verify that the analysis fits with what they had said. The last four interviews involved member checking in that emerging hypotheses were presented to participants for feedback. Further member checking involved contacting several other participants by telephone following the analysis. Gender and the participant’s perceived ability to articulate their experiences and to reflect upon them were the guiding criteria for the
selection of participants that were contacted. One participant, a brain tumour survivor, was not contacted as it was felt that she would have difficulty in discussing the findings over the phone due to her short-term memory problems. Asking her to participate through the phone, which was known to be difficult for her, may have served as another reminder of her disability.

Transferability is the qualitative term for external validity. Thick description, the provision of rich contextual information concerning the participants, enables the reader to understand the context in which the research occurred, and thus make their own conclusions as to what is transferable to their own situation, addresses this issue. Dependability, the qualitative equivalent for reliability, and confirmability, the qualitative equivalent for objectivity, are both addressed through the use of an audit trail. An audit trail includes the raw data, the documented process of data reduction and synthesis as well as memos and notes related to analysis and methodology. An independent auditor assesses the process of inquiry as a means for checking dependability. The research supervisor and thesis committee assisted in addressing this issue. To assess confirmability, an auditor examines the data, findings and interpretations. The research team involved in the study periodically performed audit checks. Additionally, confirmability is addressed through keeping a reflective journal throughout the research process. A reflective journal, as mentioned previously, was kept throughout the research process and was referred to throughout the analysis.
Chapter 4

Results

4.1 Participants

Eighteen (13 female and 5 male) paediatric cancer survivors agreed to participate in the study. Data were collected over an eight month period, from January 1998 to August 1998. The participants’ current age ranged from 20 to 33 years ($X = 25$), with the age at diagnosis of cancer ranging from 1 - 17 years ($X = 12$). The majority of the participants were single ($n = 11$), three of whom were currently dating. Four participants were living common-law, and two were married. Two participants were divorced. Four participants had offspring, two of whom had one child each, and another two each had two children (Table 4.1).

Table 4.1: Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>20 – 25 years</td>
<td>11</td>
</tr>
<tr>
<td>26 – 30 years</td>
<td>4</td>
</tr>
<tr>
<td>31 – 35 years</td>
<td>3</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
</tr>
<tr>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>Common-Law$^a$</td>
<td>4</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
</tr>
<tr>
<td>Offspring</td>
<td></td>
</tr>
<tr>
<td>One Child</td>
<td>2</td>
</tr>
<tr>
<td>Two Children</td>
<td>2</td>
</tr>
</tbody>
</table>

$^a$ One who is divorced and is now living common-law.
Diagnoses included a wide range of cancers as listed in Table 4.2. With the diverse cancer types, treatment protocols also varied (Table 4.2).

Table 4.2: Disease and Treatment Characteristics

<table>
<thead>
<tr>
<th>Disease Characteristics</th>
<th>n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Hodgkin’s Lymphoma</td>
<td>4</td>
</tr>
<tr>
<td>Astrocytoma (Brain Tumour)</td>
<td>4</td>
</tr>
<tr>
<td>Acute Lymphoblastic Leukaemia</td>
<td>2</td>
</tr>
<tr>
<td>Ovarian</td>
<td>2</td>
</tr>
<tr>
<td>Osteogenic Sarcoma</td>
<td>1</td>
</tr>
<tr>
<td>Ewing’s Sarcoma</td>
<td>1</td>
</tr>
<tr>
<td>Wilms’ Tumour</td>
<td>1</td>
</tr>
<tr>
<td>Non-Hodgkin’s Lymphoma</td>
<td>1</td>
</tr>
<tr>
<td>Kidney</td>
<td>1</td>
</tr>
<tr>
<td>Teratoma</td>
<td>1</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td></td>
</tr>
<tr>
<td>0 – 5 years</td>
<td>2</td>
</tr>
<tr>
<td>6 – 10 years</td>
<td>1</td>
</tr>
<tr>
<td>11 – 15 years</td>
<td>11</td>
</tr>
<tr>
<td>16 – 17 years</td>
<td>4</td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
</tr>
<tr>
<td>chemotherapy + irradiation</td>
<td>4</td>
</tr>
<tr>
<td>irradiation + surgery</td>
<td>3</td>
</tr>
<tr>
<td>chemotherapy + surgery</td>
<td>2</td>
</tr>
<tr>
<td>chemotherapy + irradiation + surgery</td>
<td>4</td>
</tr>
<tr>
<td>irradiation</td>
<td>2</td>
</tr>
<tr>
<td>surgery</td>
<td>3</td>
</tr>
</tbody>
</table>

The average time from completion of treatment to this study, was 12 years (range = 5 - 19 years). Two participants experienced a relapse. One person experienced a relapse two years after the completion of her initial treatment; she has now been disease free for 18 years. The second relapsed in the past year, between the time from consenting to participate in the study to the time of the interview (Table 4.3).
Table 4.3: Medical Status

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time Since End of Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>5 – 10 years</td>
<td>8</td>
</tr>
<tr>
<td>11 – 15 years</td>
<td>4</td>
</tr>
<tr>
<td>16 – 20 years</td>
<td>6</td>
</tr>
<tr>
<td><strong>Medical Late-Effects$^a$,b</strong></td>
<td></td>
</tr>
<tr>
<td>Physical Impairment</td>
<td>4</td>
</tr>
<tr>
<td>Mental Impairment</td>
<td>3</td>
</tr>
<tr>
<td>Infertility</td>
<td>3</td>
</tr>
<tr>
<td>Scarring$^c$</td>
<td>3</td>
</tr>
<tr>
<td>Short Stature</td>
<td>1</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>1</td>
</tr>
<tr>
<td>Lung Damage</td>
<td>1</td>
</tr>
<tr>
<td>Back Pain</td>
<td>1</td>
</tr>
<tr>
<td><strong>Relapse</strong></td>
<td></td>
</tr>
<tr>
<td>Yes$^d$</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
</tr>
</tbody>
</table>

$^a$ As perceived by the researcher from the interview.

$^b$ Number of late-effects: some participants had multiple late-effects, while 8 had none.

$^c$ Scarring: one participant had visual scars on her abdomen and was currently suffering from gastrointestinal difficulties thought to be related to internal scar tissue from her cancer-related surgery; one participant had scars on her head from surgery in which shunts were placed; one participant had scars to his face resulting from surgery in which facial bones were removed as part of his treatment for Ewing’s sarcoma.

$^d$ One currently experiencing relapse which occurred after consenting to participate.

Fourteen participants had a measure of post-secondary education, with nine completing a period of college or technical training. Five were attending or had attended university. Of these, one was recently accepted into graduate school in Speech Pathology, and another held two degrees in Biochemistry and Computer Science. The remaining four participants had completed a high school diploma.

The current occupation of the participants is presented in Table 4.4. Most participants (14) had incomes of less than $29,999, with nine of these with incomes of less than $10,000. Of these nine, three were full-time students. Only two participants had incomes above $50,000.
Table 4.4: Education, Employment and Income Levels

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>4</td>
</tr>
<tr>
<td>College/Technical School</td>
<td>9</td>
</tr>
<tr>
<td>University</td>
<td>5</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Lab Analyst</td>
<td>1</td>
</tr>
<tr>
<td>Computer Analyst</td>
<td>1</td>
</tr>
<tr>
<td>Store Administrator</td>
<td>1</td>
</tr>
<tr>
<td>Child Care Worker</td>
<td>1</td>
</tr>
<tr>
<td>Hairdresser</td>
<td>2</td>
</tr>
<tr>
<td>Tele-marketer</td>
<td>1</td>
</tr>
<tr>
<td>Restaurant Worker</td>
<td>1</td>
</tr>
<tr>
<td>Full-time Student</td>
<td>3</td>
</tr>
<tr>
<td>Volunteer&lt;sup&gt;a&lt;/sup&gt;</td>
<td>3</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>Less than $10 000&lt;sup&gt;b&lt;/sup&gt;</td>
<td>9</td>
</tr>
<tr>
<td>$10 000 – 29 999</td>
<td>5</td>
</tr>
<tr>
<td>$30 000 – 49 999</td>
<td>2</td>
</tr>
<tr>
<td>More than $50 000</td>
<td>2</td>
</tr>
</tbody>
</table>

<sup>a</sup> Unable to secure paid employment as a results of late-effects.
<sup>b</sup> Three are full-time students and as such have no income.

4.2 Cancer Care in British Columbia and Saskatchewan

In Saskatchewan, paediatric patients with cancer are seen and treated at one of two designated Provincial Cancer Centres and their affiliated hospitals. Follow-up assessments are provided frequently for the first five years following the completion of treatment, and then annually for an indefinite period of time. A social worker is available for those patients in need of counselling. A long-term multi-disciplinary follow-up clinic for survivors is currently being organised.

In British Columbia, paediatric patients with cancer are treated at the British Columbia Children’s Hospital (BCCH). Follow-up care after the completion of
treatment is given at the BCCH yearly until approximately the age of 17. Following this transition, care is provided by the BC Cancer Agency (BCCA), the Provincial Cancer Centre, with follow-up appointments continuing on a yearly basis. While some patients, typically those residing in the Lower Mainland of British Columbia, continue their follow-up at BCCA, others are followed by their family physician in their community. BCCA services, in addition to standard medical care, include counselling with appropriate referrals to neuropsychological centres or vocational rehabilitation.

4.3 Model of Adjustment as an Adult Survivor of Childhood Cancer

The model developed in a grounded theory study typically centres around a core process to which all of the categories that were identified in the data are related. The core process identified in this study was moving on. This process characterises the long-term adjustment for adult survivors of paediatric cancer. The process of moving on was developed through the use of the paradigm model.

The paradigm model relates the process of moving on to causal conditions that led to moving on. As well, the context in which moving on occurred and the intervening conditions that affect moving on are explored. Lastly, the strategies for and consequences of moving on are addressed. The results of this study are presented here following this paradigm model and are presented below. A visual diagram of this model is presented in Figure 4.1.
Figure 4.1 Theoretical Framework: Process of Long-Term Adjustment in Paediatric Cancer Survivors
4.3.1 Causal Conditions of Phenomenon of Moving On

Causal conditions are those "events, incidents or happenings that lead to the occurrence or development of a phenomenon". Moving on was precipitated by three factors: the diagnosis of cancer, societal norms, and being a survivor. The cancer diagnosis resulted in a rapid and often severe change to the child's life, upsetting the ability to engage in normal patterns of activity and behaviour. Treatment protocols and treatment side-effects resulted in changes in appearance and intellectual capabilities, often permanent, that affected the child's ability to be "normal". As they grew older, patients compared themselves to societal norms, resulting in their awareness that they were now different from their peers. Survivorship implies that participants reached a stage where they felt they were able to put their cancer experience behind them. With the awareness they had survived their cancer experience, they began to see the importance of moving on. As such, long-term survivorship provided adult survivors with an opportunity to return to normal, which meant moving on and looking to the future rather than living in the past.

4.3.2 Phenomenon Resulting from Causal Conditions

Moving on was the central process in which participants were engaging in adjusting as an adult survivor of paediatric cancer. Some participants considered their cancer history as part of their past; others considered their cancer history as part of their current identity. Those who felt cancer was part of their current identity tended to have more concerns around recurrence:
“I can’t say it’s really part of my past because it is still here ... it’s not here but the memories and the thoughts and the fears that go with it are still around”.

This same participant, a Non-Hodgkin’s Lymphoma survivor, also indicated her belief that she had moved on even with those concerns around recurrence. In talking about her cancer experience she reflected:

“... I have moved on, definitely. It doesn’t change me that much really”.

Those who were suffering from late-effects of treatment tended to view their cancer history as part of their past while seeing their late-effects as part of their current identity. As Charlie, a Hodgkin’s Lymphoma survivor said when discussing his cancer history:

“It’s part of my past, but I do, I do feel my back problems are part of my current identity, very much so”.

While differing in their perspective of how their cancer diagnosis and treatment had affected their lives and beliefs today, both engaged in processes that were illustrative of moving on from their cancer experience. Moving on was characterised by acceptance, going on with life, putting cancer behind oneself, not dwelling on the past and looking to the future. Feelings of wanting to live life and be happy were part of the driving force behind the desire to move on:

“I believe that it was years ago, it was something that you know it’s in your past, leave it there, go on with life, you’ve got a second chance go out and do something ...”.

4.3.3 Context of Moving On

The phenomenon of moving on is embedded in a context of factors that cannot be changed and are typically beyond the control of the individual. In the case of
paediatric cancer survivorship, the context includes all aspects of the disease and its
treatment. More specifically, it encompasses age at diagnosis, type of cancer
diagnosed, type of treatment received and its duration, perceived severity of illness, and
the presence or absence of medical late-effects.

The participants’ ability to move on appeared to be most affected by the
treatment received, rather than the cancer diagnosis itself. Treatment was the causal
factor in the development of late-effects, which in turn had a considerable impact on
one’s ability to move on, especially when obvious or visible. Cancer treatments varied,
ranging from single modality treatment of chemotherapy, radiation or surgery to a
combination of two, or all three. Treatment also varied in length, from
a single surgical operation to several years of chemotherapy, and was typically
dependent on the diagnosis and the resultant treatment. Perceived severity of the illness
differed as well. Most participants perceived their illness as serious yet non-life
threatening, while at the same time, its potentially lethal outcome was also mentioned.
Only one participant, a kidney cancer survivor, was not concerned about her illness.
Age of diagnosis ranged from infancy to early and middle childhood to teens. Age was
significant because the developmental stage of the individual also played a role in how
one coped and managed with the disease. Developmental stage influenced this through
the participants’ ability to comprehend the seriousness of their disease during treatment,
in addition to the impact it had on their lives and their ability to remember the
experience. The presence or absence of medical late-effects varied from none to
several. Approximately one-half of the participants did not suffer any form of late-
effects, while the other half varied from having one late-effect, such as infertility, back
pain or short-term memory deficits, to having several late-effects such as a combination of memory deficits, an inability to walk, infertility, scoliosis and/or cosmetic scarring. Astrocytoma patients who suffered from memory deficits and those with visible late-effects tended to have more difficulties that affected their daily lives, such as a lack of employment and difficulty with peers.

4.3.4 Intervening Conditions

Intervening conditions are those broader conditions that either facilitate or constrain the action/interaction strategies taken in response to managing the phenomenon. Six intervening conditions influenced strategies that participants used for moving on: social support, being young, feelings of powerlessness, fears of recurrence, one’s ability to cope during the initial cancer diagnosis and treatment, and acceptance.

Social Support Social support played an important role both at present and during the participants’ cancer experience. Strong social support was present for the majority of the participants, while two experienced little or none. Sources of support were family, particularly parents, as well as siblings; friends; health care professionals; teachers; counsellors; cancer camps; and outreach programs offered by neurological centres.

Positive social support enabled participants to cope effectively with having the disease and treatment side-effects. During treatment, positive social support gave strength to cope, and contributed to the normalising strategies used by participants. Typically, parents provided the most support during treatment, being there for procedures and treatments. Parents also acted as information sources concerning
treatment decisions and effects. Information and involvement in dealing with the
disease were important factors in increasing a sense of control, thereby decreasing
powerlessness, over the disease. Katie, an ovarian cancer survivor, mentioned when
discussing the interactions she had with her physician:

“... my mother always came with me and she asked a lot of questions
and stuff and he gave her a lot of answers, which was really good too”.

By encouraging regular involvement in school-based activities, parents, siblings, and
teachers contributed to participants’ motivation to be normal during treatment. Feeling
normal increased their ability to move on through the transition of coming off treatment
and putting their cancer behind them. Many participants did not realise at the time of
treatment the commitment and difficulty that parents had in being with them and
providing such support.

For a few participants, familial support was not as strong. This group often
found it difficult to cope with their cancer, experiencing feelings of loneliness, anger
and frustration with not having someone to talk to about their disease. In two cases,
parental support was limited. Pam, a Hodgkin’s disease survivor, had a stepfather who
did not want to be involved in her life, influencing her mother to also withdraw. Today,
Pam still has feelings of anger and frustration about this lack of support. Matt’s father
was an alcoholic, “hiding in the bottle” during his cancer treatment. As a result, Matt’s
mother relied on him for support, thereby reversing the traditional role of the parent
providing support for their child. Matt, an osteosarcoma survivor, felt that he needed to
be strong for his mother, and as such suppressed his emotions:
“... I’m going to lose my leg, you get that one, you really want to cry and I got one tear out of my eye and then my Mom started to bawl and then I shut [off] my emotions for probably two years”.

Matt feels the lack of expressing and dealing with his emotions during his illness limited his ability to cope effectively with his diagnosis, put the experience behind him and move on.

Other instances of negative social experiences involved peer relationships. During treatment, common experiences with friends included isolation over fears of “contamination”:

“like when my friends found out I had cancer they totally changed, like I was like ... where they can catch it ...”.

As well, an inability of knowing how to act around someone with cancer, particularly when participants had no hair created feelings of uneasiness:

“I am sure it was uncomfortable for them to be around me ... cause I was bald and I had been gaining weight from a lot of the medication ...”.

Peers tended to change their perceptions and behaviours following educational sessions in school. Many participants felt it was a positive experience knowing that their illness had been a learning experience for others. Today, those with late-effects were often acutely aware that their visible impairments contributed to their lack of social relationships. This awareness confronted them frequently, constantly reminding them of their cancer history, and impeding their ability to move on. Participants tended not to share their cancer history with peers for this reason.

For participants who attended cancer camps, peer relationships that developed were important sources of social support. Participants did note, however, that attending cancer camps and meeting others with cancer meant that they were likely to have
friends die from the disease. This experience was often difficult for two reasons: not only losing a friend, but also serving as a reminder of the seriousness of their disease. Cancer camps provided an opportunity to meet new friends and to share their experiences with having cancer. As well, several of the participants currently return each year as camp counsellors, viewing it as an opportunity to stay involved in the camp once they were too old to attend and to learn new skills.

Most participants felt that a support group for paediatric cancer survivors was not necessary, particularly for those who did not have any late effects related to their cancer treatment. However, they liked opportunities to meet and talk about experiences with other survivors. Some felt that support groups would impede their ability to put their cancer experience behind them as they would be more likely to dwell on their experience, while others felt that talking about their experience may facilitate their ability to move on:

“I don’t want to exactly dwell on my experiences but I mean talking about it might help me move on”.

However, several participants mentioned that a support group would have been useful during treatment.

Medical staff served as an additional source of social support. Nurses in particular played a positive role in affecting participants’ feelings during treatment. Nurses made the experience “easier to handle” through their friendly, caring and supportive behaviours. Participants fondly remembered a particular nurse who made a significant impact on their experience with cancer. Thus, nurses played significant roles in care. As Matt noted,
"I had great nurses. Just loved them. My first oncology nurse I still, every time I'm back ... I try to call her up and we go for dinner".

Negative experiences with social support were also prevalent leading often to feelings of frustration, anger and powerlessness. Lack of information, communication, and involvement in decision making were the most common frustrations with medical care. In one instance, Katie, an ovarian cancer survivor was visited by two support workers; one, a nun who spoke only of death and dying, and the other, a counsellor who told her her fears were unsubstantiated and that her disease was not serious. This experience with conflicting information and support was a source of confusion and anger that contributed to her uncertainty around the outcome of her disease. Additionally, missed and subsequent late diagnoses were often a source of anger for participants whose treatment was aggressive as a result.

Social support, when perceived as positive, enabled effective coping with the disease and treatment, contributed to feelings of being "normal" and often provided an information source concerning the participants’ illness. These factors all contributed to the sense of moving on. Negative social support led to anger, frustration and isolation, feelings that were often currently felt, and thus impeded to putting their cancer experience behind them.

**Being Young** Participants were grateful that they had cancer when they were young, believing that it would be much harder to go through should it happen today as an adult. Not having the stressors that an adult typically faces as a cancer patient was mentioned often as a way in which being a paediatric cancer patient was positive. As Nancy, a kidney cancer survivor, stated:
"... younger ones, I believe, survive more because they don't have the stress of an older person. An adult has, you know, maybe a husband or wife, maybe children, you know financial problems to worry about. When you're young ... you don't have stress, so everything you have in your body to fight off your disease, you use it ...".

For young cancer patients the main concern was fighting the disease. Participants often were unaware of the seriousness of their disease. As well, those who were diagnosed in infancy or early childhood had no memory of the disease. Participants perceived this situation as positive.

As well, participants felt that since they were young and still developing both physically and mentally, it would be difficult to determine whether their illness had affected them. As Lucy, an ALL survivor, said:

"... I was only 13 when I was diagnosed so ... I don't know what exactly would have changed. Like I was not necessarily really set in what I believed before ...".

For many, late-effects of cancer treatment had been present for as long as they could remember. These individuals did not have the sense of loss often experienced by those who could refer to who they were before and after treatment. Being able to remember who one was before they had treatment for cancer gave them a sense of how their life had changed and what they had lost as a result of their illness.

Both those who felt cancer was part of their past and those who regarded it as part of their current identity expressed that being a young cancer patient was favourable. Those who felt that cancer was part of their past typically were unable to articulate how having had cancer as child had affected their lives, and as such enabled them to put it behind them. They did feel that if they had cancer today, they would be aware of the consequences of the diagnosis and treatment. This group was not exclusive to those
without late-effects, as many felt that while their cancer was in their past, complications resulting from their cancer treatment were part of their current identity. These survivors tended to be older at diagnosis, and as such were more likely to have stronger memories of the cancer experience, and a greater sense of what their life was like before and after cancer treatment.

**Powerlessness**  Most participants described feelings of powerlessness and a lack of control. Participants believed that having cancer as a child could not have been the consequence of their actions, and as such, was beyond their control. This had implications around fears of recurrence and their perceived ability to decrease the risk of recurrence or the development of second malignant neoplasms. Participants felt that as they did not have any control over the development of their initial cancer, it would be beyond their ability to prevent it from returning. Related to this was the belief that cancer in childhood was the result of bad luck. Katie, an ovarian cancer survivor, in discussing what caused her cancer felt she was not to blame, but rather the development of her illness was beyond her control:

“… sometimes I think cancer is just bad luck … because I mean, 11 years old, what did I do wrong?”.

Luck was a common theme throughout the interviews. Many participants felt they had bad luck in getting cancer but in comparison to other patients in treatment, were lucky to have survived and not have experienced worse. As Sue, a teratoma survivor, put it:

“… there’s always someone worse of than you, you know, so I came out pretty lucky that that’s all I had”.

61
The tendency to attribute survival and experiences with the disease to luck illustrates the perceived lack of control over cancer diagnosis and survivorship.

Feelings of anger were present in those who expressed a greater amount of frustration around their inability to prevent the development of cancer. Participants also expressed anger over having late-effects and their inability to change the situation. Lori, a Wilms’ tumour survivor, who had multiple late-effects tended to feel that her doctors were at fault for her situation and had even looked into a malpractice suit:

“Really mad because I don’t know, like how do I know maybe when it comes to radiation and my ovaries failing … how do I know that they didn’t give me too much radiation?”.

However, while most participants were initially angry following their diagnosis and treatment, they came to realise the need to accept their cancer history and late-effects and move beyond this anger.

For the BC participants, the transition from BC Children’s Hospital to the BC Cancer Agency also contributed to feelings of powerlessness. Participants in BC who had to transfer upon reaching “adulthood”, typically the age of 17, often expressed disappointment in leaving the Children’s Hospital. References to being “kicked” or “booted” out reflected frustration in having to attend a new centre for follow-up care where the atmosphere was perceived as different. William, an ALL survivor, was angry with the way he experienced his transition to Children’s stating:

“… they just leave you out in the cold when you hit a certain age, … you’re not a child anymore, so see you later and look for something on your own”.

62
Those who were given a choice as to when they would prefer to make the transition accepted the need to do so. Those who felt they were forced to make the shift at a time when they were not ready to do so advocated for choice:

“It would be nice to go back just a couple more extra years until you realise, OK, well maybe I shouldn’t be coming here anymore”.

Those who felt involved in decision making around follow-up care or had information concerning their cancer, were further along in the process of moving on in comparison to those who expressed continuing frustration around their inability to change their situation.

**Fears of Recurrence**  Surprisingly, participants had few fears of recurrence. Thoughts of recurrence decreased with time, as the further one was from his/her initial diagnosis, the less likely he/she was to be concerned with relapse. These fears, while typically strong in the first one or two years after completing treatment, tended to decrease with the passage of time:

“… by the time it got to five years I was like, oh I’m considered cured. But I’d say after three years I was kind of more at ease”.

One participant, Alison, who was an astrocytoma survivor, had strong concerns about cancer recurrence. Twenty years had passed since she completed treatment and she had late-effects which seriously affected her life. She continued to believe that decisions concerning her future could not be made as she was unsure if she “would still be here”.

Participants more often were concerned about developing another type of cancer:

“I’m not worried about a recurrence. I’m worried about heart or lung cancer or something which is a little different”.

63
Those who were more concerned with this risk, felt that lifestyle choices could influence this risk, and were more likely to engage in positive lifestyle choices. Additional motivation stemmed from reasons unrelated to their cancer history, such as leading a healthy life as commonly purported in popular media. Others did not engage in any positive lifestyle behaviours to reduce their cancer risk due to perceived lack of control in the development of primary, recurring or secondary cancer. Katie felt her cancer was hereditary and therefore, positive lifestyle choices would not be helpful:

“They say by eating the right foods, like certain foods will limit your chance of getting cancer or whatever and I don’t know if I really believe that because no matter what I ate or whatever, it is hereditary”.

Participants also tended to refer to examples where friends and family despite their positive lifestyle choices developed cancer and then explained why lifestyle choices would not make a difference in their chance of recurrence.

Regardless of concerns about recurrence, all participants were most likely concerned about recurrence at follow-up appointments. Follow-up appointments were a pivotal time in their lives. Often, while temporarily interfering with their ability to move on because of thoughts of recurrence, these clinic check-ups in the long-term contributed to their ability to move on as they typically received positive feedback from test results and visits with their oncologist. This was highlighted in participants thoughts around their follow-up visits:

“... the only time I get really frightened is when I have to come back for a check-up”

“... going to see [the oncologist], it’s a sense of security for me. It makes me feel good. It’s like before, when I go for my check-ups it’s like, ok get that tick and you’re ok”. 
Thoughts of recurrence were stimulated by symptoms, such as headaches, that were similar to those experienced just prior to their initial diagnosis. Pam, whose initial diagnosis of Hodgkin’s disease was found through severe abdominal pains felt:

"...if I have stomach pain or something like that I might think a little bit ... but not too much".

As well, seeing friends or others with cancer or watching/reading media reports on the disease tended to bring up thoughts concerning their cancer risk.

Coping with Cancer A number of participants, particularly those without late-effects, felt they coped well with their cancer. They indicated that while they initially felt angry and experienced some denial, this phase tended to be short lived, moving rather quickly into the acceptance stage and wanting to fight the disease. These individuals tended to put their cancer experience behind them rather quickly upon the completion of treatment, moving on and looking to the future.

Other individuals had more difficulty in coping with their cancer and the effects of treatment. Those who had late-effects that were visible or interfered with their daily lives were more likely to have difficulty coping with the effects of the disease, and experienced feelings of depression and low self-esteem. For Alison, her lack of independence brought about by loss of short-term memory led to severe depression and a suicide attempt. Having to live at home with her parents and being financially dependent left her very unhappy without a sense of purpose in her life:

"My life today is a piece of junk. I have no life. If I do something I have to do it with my parents. I drive my mother’s car, I do everything for my parents".

Patrick, a survivor of Ewing’s sarcoma, had facial surgery and believed that his self-esteem has suffered as a result. He is currently looking into reconstructive surgery
as an option to help increase his sense of self, as he believes his social relationships
have suffered as a direct consequence of his appearance. Lori, who has severe scarring
on her body from treatment for Wilms’ tumour, explored the option of surgery as a
means of improving her self-image. However, she was discouraged by a physician who
felt there was no need for such treatment, resulting in continued anger and frustration
with this long standing complication.

Others used humour and prayer as coping strategies. Matt, who had his leg
removed as a result of osteosarcoma, felt that humour decreased the tension that was
felt at times with his friends:

“I didn’t want my friends to feel like they couldn’t joke with me. I didn’t want
my friends to feel that if they said something I was going to take offence to it.
Why should they suffer for what I’m going through? Why should they feel
uncomfortable? So, I found the more I joked about it, the more happy I was, the
easier it made it for others”.

These participants indicated that these strategies enabled them to find the strength,
particularly those using prayer, to fight their cancer and deal with the effects that its
treatment had left. Faith was a source of strength to fight their disease:

“I used to pray at night, like pray and pray and pray and pray. I had
this whole prayer thing that I had to go through every night before
I went to sleep. I had a lot of faith I guess, even stronger than I had
ever had … and I don’t know where it came from, I guess I just knew
that this was between me and this was my fight and I had to do it”.

Acceptance  Acceptance came with the recognition of one’s inability to change
one’s cancer situation and a need to move on from the cancer experience:

“Well that’s part of me I guess. Just like everything else, I do think
on that. And it’s never going to go away, it’s never going to change.
It’s something that happened. I happened to go to high school, I happened
to have cancer … I took swimming lessons”.

66
In this instance, Lucy’s sense of powerlessness over the cause of her cancer, positively contributed to the acceptance of having their disease. To move on one needed to accept his/her cancer history and/or late-effects. Most participants recognised, and had gone through, a “necessary” process of denial before they were able to accept their cancer diagnosis. Participants accepted their cancer illness and some also accepted late-effects as being the price paid to keep them alive. An ovarian cancer survivor who can no longer have children felt,

“I guess it’s just you learn to accept it. You know, and say this is the way it is and this is due to the fact that you had a fatal, I mean something that could have been fatal when you were a child and they just did what they had to do and that’s it”.

Those who had late-effects found that with the passage of time, their anger and frustrations with impairments decreased and shifted to feelings of acceptance and the need to put it behind them and carry on with life. With increasing lengths of time from diagnosis and completion of treatment, all survivors found that time played a large role in their healing and coping.

4.3.5 Action/Interaction Strategies for Moving On

The action/interaction strategies are those “strategies devised to manage, handle, carry out, [and/or] respond to a phenomenon under a specific set of perceived conditions”. The actions taken are typically goal oriented, and occur in response to or to manage a phenomenon. Participants engaged in four strategies to move on: maintaining health, information seeking, normalising, and not dwelling on their cancer history.
\textit{Maintaining Health} While fears of recurrence were generally low for this group of survivors, when present they appeared to interfere the most in one's ability to \textit{move on}. Therefore, strategies for decreasing fears became important for participants. Despite the feeling that their cancer risk was beyond their control, they did recognize the importance of medical follow-up for monitoring their status and possibly discovering a recurrence early enough to prompt appropriate action. Additionally, dealing with late-effects was an important means of \textit{moving on}, and follow-up care provided an opportunity to learn how to cope with their disabilities.

The majority of the participants attended yearly follow-up in cancer clinics, with a few receiving their care from a family physician in the community. Most participants were happy with their follow-up care, and indicated that medical tests provided the greatest reassurance concerning the risk of recurrence.

Learning to deal with their late-effects was another important part of their follow-up care. Talking with counsellors and attending outreach programs specific to their disability were means of learning effective coping strategies and gaining skills which facilitated \textit{moving on} with their life. An astrocytoma survivor, Marie, who has difficulty with her short-term memory found the services offered by a neurological support centre as extremely valuable in helping for her lead a normal life:

"I’m glad I found them because if I didn’t I don’t know where I’d be … I said I wanted to get some budgeting lessons and do some volunteer work, so they helped me get into some volunteer work. And then maybe later they’ll help train me for a job”.

\textit{Information Seeking} A perceived lack of information for several cancer survivors during cancer diagnosis and treatment led to feelings of confusion, fear and frustration. Participants felt that with increased information concerning their illness
they would be better able to cope with the treatment and possible late-effects, and thus actively sought information concerning all aspects of their disease. Information would enable them to prepare to deal with the negative consequences of treatment, decreasing the potential shock that many experienced when they were faced with treatment side- and late-effects that were not anticipated.

For those diagnosed during their teens, independence was important during their treatment. Having information and being able to participate in their own care helped to maintain their sense of independence. For all participants, information contributed to a greater sense of control.

Seeking information became a strategy for gaining control and a sense of involvement in their cancer care. Through increased control and involvement they felt better able to cope with their disease which contributed to their ability to move on upon the completion of treatment.

**Normalising** Participants’ perception of “normal” was influenced by societal values of what constituted “normal” patterns of behaviours and age-appropriate achievements. Normalising was seen as an important means to moving on, putting their cancer history behind them and fitting in with peers. The majority of participants engaged in some form of normalising, while those with visible late-effects found it more difficult and often felt it was more important to achieve.

Normalising was attained through a number of sub-strategies including achieving age-appropriate goals such as living on one’s own, having a car, engaging in relationships, raising a family and employment. For some participants who had late-effects, employment was difficult to obtain and interfered with their ability to
normalise. Participants with visible late-effects believed they had experienced some form of discrimination and felt their lack of employment was a direct result of their cancer history:

"Take my resume at face value. And on my resume I don’t even have that I’m handicapped. That’s why I get a lot of phone calls or I get, oh come in for an interview. Ok, we’ll call you back. No you won’t. Just tell me you’re not going to call me back, don’t give me false hopes". Feelings of frustration and anger were common as these participants believed they were capable of holding a job but were not given the opportunity to prove themselves.

William, who had failed to grow and needs crutches to walk, felt that if he were to find a job, all of his problems would be solved. He believed it would increase his independence and ability to obtain material goods similar to his peers:

"I still don’t have really enough money so I can buy my own car … because that’s, most people my age now have their own cars and have a job and be able to pay for insurance. And I can’t do that and I want to because I know I can”.

Another normalising sub-strategy used by participants was engaging risk-taking behaviours even though such behaviour may be more harmful to their health than for their peers. The need to fit in led to “partying”, smoking and other risk-taking behaviours that, while recognised as negative, were important for normalising and leading a life like “everyone else does”. When discussing her social life, Lori consistently made remarks that highlighted the need to engage in activities that she felt were “normal” for her age:

"I want to be like every other 25 year old and be out there, you know, partying just like anybody would that’s my age”.

During treatment, maintaining involvement in school activities, both academic and social, enabled one to feel normal and contributed to positive coping with the
disease. Support from teachers and parents played a valuable role in enabling participants to carry on with these activities.

Conditions that influenced normalising included the presence or absence of late-effects, with those with visible late-effects having more difficulty in achieving “normal” status and placing more importance in normalising in their day to day lives. As well, with increasing time from the completion of treatment, normalising became easier. As mentioned above, employment discrimination interfered with participants feeling they were leading and achieving goals similar to their peers. Social support from family, friends, medical staff and teachers also played an important role in keeping a sense of normalcy during treatment and assisting in normalising activities.

“Not Dwelling” on Cancer Not dwelling on one’s past cancer history, late-effects (if present) and concerns around cancer recurrence were important in order to be able to put the cancer experience behind one and move on. William, a twenty year ALL survivor, whose treatment led to a lack of growth and difficulty walking felt:

“I don’t like dwelling on the fact that I had cancer, and I’m dwelling on my disability … I’m feeling sorry for myself, no I don’t like doing that. Just move on”.

Dwelling on one’s cancer history was believed to cause unwarranted stress regarding recurrence, typically because most felt that their cancer risk was beyond their control. As well, one would not be able to enjoy life, constantly worrying about their cancer history, possibly leading to depression:

“… that’s why I say I don’t like to dwell on, on oh I shouldn’t have this ... or this food is bad for me, you know, because you’re not going to be able to enjoy your life if you’ve got that in the back of your head”.
It was an impediment to *moving on*, and participants felt that it was important not to dwell on their past, rather to look to the future.

Various factors influenced participant's abilities not to dwell on their cancer history. Closely related to the conditions around fears of recurrence, seeing others with cancer tended to bring one back to their cancer experience and remind them of the consequences of the disease. As well, attending follow-up was a time in which one was faced with their cancer history making it difficult not to dwell on it during that time. As fears of recurrence tended to be strongest during follow-up appointments, dwelling on the potential for recurrence was common at this time. Feeling sick and having symptoms similar to their cancer diagnosis also made it difficult not to dwell on their history, as did certain smells such as cleaners used in hospitals.

Not dwelling on cancer history was an important step in *moving on*, and tended to be more difficult for those with late-effects from treatment, although most felt they were successfully doing so. Dwelling on their cancer history was felt not to serve any positive purpose in the participants' lives and as such, not dwelling was a means to put it behind them.

### 4.3.5 Consequences of Strategies

Consequences are the “outcomes or results of action and interaction” strategies.\[^{97}\] The consequences presented here are the result of the actions participants took in response to the desire to *move on* from their cancer history. Three consequences of *moving on* became apparent: living life to the fullest, empowerment and finding meaning in the cancer experience.
**Living Life to the Fullest** *Moving on,* and using strategies such as not dwelling cancer history and normalising, enabled survivors to “live life to the fullest”. Living life was important to participants, with many feeling that they had an increased appreciation of life. Many participants felt that they should live day to day, and enjoy life while having fun:

“Nobody in my family likes to hear me say it, or my friends, but I’ve always had a saying that, I’m here for a good time, not a long time. I always say there’s lots of time to sleep when you’re dead … I want to live each day to its fullest”.

Using strategies such as not dwelling and normalising enabled the participants to live life, recognising that their cancer experience gave them a second chance at living:

“Yeah I think I had a second chance at life … so I know it’s special”.

Participants’ recognition of the need to “live life to the fullest” illustrates the impact of cancer on their lives. Expressions of living day to day and living life to the fullest were common throughout the interviews. Such notions illustrate how the experience of having cancer as a child or adolescent had affected their beliefs on living life, and is perhaps reflective of an awareness of the life-threatening aspect of cancer.

**Empowerment** Seeking out information on one’s cancer and late-effects led to a greater sense of control for participants. As participants generally felt a lack of control over their cancer diagnosis, having information and participating in one’s own care were ways by which they could regain a sense of control in their life. Doing so evoked feelings of empowerment. Feeling as though one were part of the decision making process in terms of treatment decisions was important, particularly for those who were in their teens. Alison, diagnosed with astrocytoma at the age of 15, illustrated
her appreciation of being involved in her treatment and having information with the following statement:

“... you knew that the doctors had talked to you and you were going to be ok. I mean certainly I was scared ... but you know what’s going to happen, he even drew diagrams of how we was going to cut around on my head. He even showed me a shunt that was going to be going into my body and where it would be placed and how it would work. It made me feel like a part of it, which helped”.

A greater sense of control was associated with an increased sense of ability to move on and put their cancer history behind them.

**Meaning in the Cancer Experience** Those participants who were able to move on and reflect upon their cancer experience were able to find meaning in their experience:

“I think it definitely makes you take a look at ... your life and make you thankful for what you have”.

“Everyday that you wake up, I don’t care if it’s a bad day or not, be happy you are alive”.

Participants focused on positive aspects of having had the disease. They gained empathy for those with cancer, and found satisfaction in volunteering with other cancer patients, such as attending cancer camps as campers when they were younger and as counsellors later. Participants were inspired by the Terry Fox run to volunteer in it each year. One participant received a Terry Fox Humanitarian Scholarship for overcoming an obstacle, something she felt she would not have received had she not had cancer.

Empathy and being sensitive to others around them was also a benefit. Such feelings led to health care careers for some participants. Two participants were in nursing, one of whom now works in paediatric oncology. As well, two participants mentioned they had intended on entering the health care field, one as a physician and
the other as an x-ray technician. However, while they ended up in other fields, both mentioned that their experiences with cancer would have positively affected the way they interacted with patients.

Other positive aspects of having had cancer included a sense of greater maturity in comparison to peers, particularly while receiving treatment, and increased patience in dealing with daily life. Participants commented that they were less likely “to stress out” if they didn’t meet a deadline, and felt that they were more relaxed than many of their peers.

4.4 Summary

Participants engaged in a process of moving on from their cancer experience and history that began with the onset of treatment. During treatment, their ability to be “normal” and participate in activities with peers had been adversely affected. Thus, they often felt that the opportunities and support that enabled them to continue with their lives during treatment and following its completion, were of great importance.

Several factors influenced moving on: social support, feelings of powerlessness, fears of recurrence, level of coping with cancer and its treatment, acceptance of their history of cancer, and having had cancer when they were young. Participants employed four strategies: maintaining health, seeking information, normalising, and not dwelling on their cancer history. The outcomes of moving on were findings meaning in their cancer experience, recognising the importance of living life to the fullest, and feeling of empowered. Overall, this sample of long-term survivors was coping well as adult survivors of childhood cancer. They more often looked at the positive aspects of their
encounter with cancer, in many instances incorporating these aspects into their lives while recognising the importance of *moving on* and looking to the future.
Chapter 5

Discussion

5.1 Introduction

This study involved in-depth interviews with 18 long-term survivors of paediatric cancer who are now in adulthood. The study sought to examine how the late-effects from treatment, fears of recurrence, and the emotional impact of having a life threatening illness, and surviving, all affect adjustment as they enter adult life. Interviews were analysed following grounded theory methodology, and led to the development of a theoretical model. This model provides a new understanding of how paediatric cancer survivors manage their lives as they reach adulthood as long-term survivors. This framework is unique in that while previous research has provided detailed information concerning transition outcomes, such as employment, marriage and psychological status, the present work sheds light on the factors and processes that contribute to these outcomes. The research questions that provided direction to this study involved collecting information around life choices, the role fears of recurrence play in lifestyle decisions, and the rehabilitation and psychosocial needs of this population. Based upon the framework, and in returning to the research questions, a number of interesting and new issues related to the psychosocial adjustment of this population emerged.
5.2 The Model

Research investigating the long-term adjustment of paediatric cancer survivors has been limited, and thus this framework is unique in that it is the first developed to qualitatively address the processes of adjustment. This model was developed solely on the basis of the interviews with the participants, and thus its purpose was for hypothesis generation to further explore this issue of adjustment. The model attempts to illustrate the many factors involved in adjustment that the survivors themselves identified; however, it presents a linear picture of the adjustment process, and fails to accurately reflect its interrelated aspects in hiding the complexity that exists between the context, intervening conditions, strategies and causal conditions. In continuing to build upon the model in future work, the dynamic and interrelated aspects of long-term adjustment need to be highlighted such that the pictorial view illustrates a more realistic vision of this process. This model is then a preliminary framework that can be expanded through further research.

No models have specifically addressed adjustment in the paediatric cancer survivor population; however, adjustment models have been developed for paediatric patients with a chronic illness. The Disability-Stress-Coping Model developed by Wallander et al\textsuperscript{100} illustrates the factors hypothesised to affect the adjustment of children with chronic physical disorders. Their model highlights the risk and resistance factors that relate to positive adjustment.\textsuperscript{100} While their model does not include strategies or responses to managing adjustment, a number of factors highlighted were also found to be of importance to the participants in the present study. The Disability-Stress-Coping Model presents risk factors related to adjustment difficulty including disease factors
such as handicap severity, medical problems, bowel/bladder control, visibility, cognitive functioning and brain involvement. Psychosocial risk factors include handicap-related problems, major life events and daily hassles. Their model does support some findings in the present study. For example, the disease-related factors are similar to those described as contextual factors in the grounded theory model as both highlight the significant impact on the ability to engage in normalising strategies. As well, the psychosocial factors listed in their model were again reflected in the present grounded theory model, and provide additional support for the model. The resistance factors in the Wallander et al model include intrapersonal factors, social-ecological factors (family environment and social support), and stress processing ability such as coping strategies. Again, their model provides support for the model developed in this study as the participants’ ability to engage in strategies to move on was affected by intervening conditions such as social support, their ability to cope with their cancer and other intrapersonal factors such as feelings of powerlessness. Thus, while the model developed by Wallander et al does not discuss strategies for long-term adjustment, their model identifies factors related to adjustment in those with a paediatric chronic illness similar to those who have survived childhood cancer.

5.3 “It hasn’t affected me that much really . . .”

When asked how the cancer experience had affected their lives or values, many of the participants indicated that it hadn’t or if it had, they would not be able to articulate how it affected them. Although the majority of the participants were between the ages of 11 and 17, and were likely to have memories of their cancer experience,
many felt they could not discern whether the values or beliefs they currently held were related to their cancer experience. It may be that the participants in this study, in attempting to put their cancer experience behind them, have selectively “forgotten” their experience and the affect that it had on their lives. Additionally, late childhood and adolescence are years in which there is rapid change and development. As such, they may not be aware of the larger influences their cancer may have had on their lives since they were already experiencing great change not related to their disease. As a result, paediatric cancer survivors may be less able to relate their cancer experience to their current identity and belief system.

In comparison to adult cancer survivors who have a clear sense of ‘before and after’ a diagnosis of cancer, the assumption that cancer is a life-changing event from an adult perspective may not always hold for the paediatric cancer population. Knowledge of how one is different, and an awareness of the losses resulting from the disease, may act as stimulants to actively search for meaning in the experience and to make life changes as a result.

As shown in previous research, \(^{61,101}\) those who were diagnosed in adolescence were more likely to be aware of how it had affected them, most likely because they remembered their life before cancer. This was heightened by the continuing presence of late-effects from treatment; this aspect has also been documented in the literature.\(^{61}\) While aware that they are different from their “normal” peers, those with late-effects diagnosed and treated at a very young age were often unable to remember and express any impact on their life at present. Many of the survivors indicated that this was a positive aspect of being diagnosed when they were young. Previous research has found
that the younger one is at the time of diagnosis and treatment, the less likely one is to have later adjustment problems. Perhaps the sense of loss often experienced by adults diagnosed with cancer does not occur in most of these paediatric cancer patients, thus contributing to their ability to move on. As well, a lack of memories of the treatment and painful invasive diagnostic and treatment procedures may be a facilitator for positive adjustment later in life.

Another perceived positive factor related to young age was the participants’ belief that higher cure rates in paediatric patients occur because they do not experience similar levels of stress as adult patients. The concept that, unlike adults, paediatric patients do not have “adult” worries, such as children and finances, suggests a belief that stress can affect treatment outcomes.

5.4 The Importance of Normalising

Findings from the present study indicated that participants engaged in normalising as a strategy for moving on. Normalising involved achieving age-appropriate goals and putting their cancer history behind them. The concept of normalising has been previously identified in the cancer survivorship literature. A qualitative study of 7, five through eighteen year olds who were no more than one year post-treatment found that these survivors were engaging in a process of normalisation. While younger than the participants in our study, and much closer to the completion of treatment, these results suggest that the process of normalisation begins early in survivorship and appears to be an important part of positive adjustment. As well, this study found that “the children’s hope was focused, generally, towards a time when their
cancer experiences would no longer be their primary life experience, but rather, only one of their life experiences. The results from our study may be encouraging to paediatric cancer patients on treatment as the goal of the patients previously cited, where cancer is one of life’s experiences, was generally achieved by the long-term survivors in our study.

5.5 Health Beliefs and Risk-Taking Behaviours

Published reports concerning risk-taking or “cancer-causing” behaviours in this population have generally documented prevalence rates similar to that of the general population. The findings from our study illustrate why paediatric cancer survivors often do not see the need for engaging in positive health choices. Feelings of powerlessness over the development of their initial cancer and during treatment were prevalent in our group of long-term survivors. Participants indicated that because of their young age, they were not likely responsible for causing their cancer, and therefore its development was beyond their control. Related to their inability to prevent the initial development of their cancer, was the subsequent inability to prevent it from returning. Thus, their fears around recurrence were, for the most part, quite low. Some study participants felt that while they were unable to prevent a recurrence, they may have some control over the development over a second cancer; others felt that it would be beyond their ability to prevent a recurrence, so positive lifestyle choices would be futile.

As paediatric cancer survivors have been identified as being at increased risk for development of a second malignancy, it is important to encourage positive lifestyle choices within this population. Education around the role of positive lifestyle
choices and avoidance of risk taking behaviours (that could affect their cancer risk) is important for regaining a sense of control over their lives.

The strategy of normalising suggests that as this group was unable to engage in “normal” behaviours during treatment, and for some at present, the ability to engage in behaviours similar to that of their peers, regardless of the potential negative consequences, is important. Thus, encouraging and providing opportunities for other means of normalising within this group may help to deter some from engaging in such risk-taking behaviours.

5.6 Issues of Spirituality

While the participants did not directly discuss aspects related to their spirituality, their references to appreciating life more and finding positive meaning from their cancer experience are reflective of this issue. They mentioned aspects of spirituality more in terms of an outcome of their cancer experience rather than as a coping mechanism during treatment. While not mentioned explicitly, their positive outlook on life was an indicator of the spiritual journey taken in response to their cancer history. However, a few patients did specifically refer to the use of prayer as a coping strategy, finding that these religious practices and faith provided them with strength to deal with their cancer. This is similar to a study of adult cancer survivors found that faith played an important role in their coping and adjusting to a history of cancer.103

It could be hypothesised that these participants did not discuss spirituality as often as one may have expected for two reasons. First, their lack of the perception that in retrospect this experience was a life-changing or life-threatening event may not have
forced these participants to search for their spirituality. Often when one is faced with an event that is perceived as life-changing, there is an examination of one’s own beliefs and spiritual aspects of one’s life. Second, related to this is the fact that children and adolescents are still developing beliefs, and as such may not have not felt a need to dwell on issues such as their spiritual selves.

5.7 Is It A Damocles Syndrome?

In the early 1980s, Gerald Koocher and John O’Malley\textsuperscript{104} conducted one of the first landmark studies investigating the psychosocial adjustment of paediatric cancer survivors. One of their substantial findings was referred to as the \textit{Damocles Syndrome}. These researchers found in a group of 117 cancer survivors who took part in their study that, despite successful treatment, the fear of recurrence or relapse hung over their heads much like the sword of Damocles.\textsuperscript{104}

Much of literature on paediatric cancer survivors continues to refer to the \textit{Damocles Syndrome} in describing the adjustment of this population. However, the findings from this study indicate that for the majority of participants, with the exception of one, the \textit{Damocles Syndrome} does not provide an accurate description of the role the fear of recurrence plays in their lives. In fact, the majority of the participants were not concerned about a recurrence and felt that if their cancer were to return it would be beyond their control to prevent it. As such, to dwell or worry about a recurrence was seen as causing unwarranted stress. Thus, rather than living with a “sword” hanging over their head, this group of cancer survivors \textit{moved on} looking to the future rather
than worrying about the past. Such results give evidence that this group of survivors are able to develop as adults who live essentially normal lives.

Possible explanations for this difference is perhaps related to the time and atmosphere surrounding the success of treatment for paediatric cancer. First, the group of survivors who took part in the Koocher and O'Malley study were treated at a time when cure of childhood cancer was a relatively new phenomenon; whereas those who took part in this study were treated more recently and with treatment protocols that have been more successful. Second, there is a greater awareness today of the environmental and lifestyle factors that are related to the development of cancer. As such, knowledge about the causes of cancer may not have been as mysterious as in the early 1980s when their study took place. Thus, uncertainty as to whether their cancer may return and having less knowledge about cancer may have contributed to the fears of recurrence for their group. Findings of our study show that participants were quite confident about the fact that they could not have caused their cancer and that should it return, it would be beyond their control. While this may seem that it should lead to uncertainty, this knowledge appeared to decrease these feelings for this group.

5.8 Paediatric and Adult Cancer Survivors: The Same or Different?

The findings from this study suggest that paediatric cancer survivors, while at times sharing similar concerns, are different from the adult cancer survivor population. Research into the psychosocial effects of concern for adult cancer investigated similar issues, such as physical changes from treatment, social stigma related to cancer, work place and insurance discrimination, and fears of recurrence. The paediatric cancer
survivors in this study indicated that follow-up appointments and/or the discovery of symptoms similar to those related to their initial cancer diagnosis created anxiety about recurrence. The results from a qualitative study of five long-term survivors of adult cancer found similar findings.\textsuperscript{103} This is suggestive that follow-up appointments are a time where there is an opportunity to receive positive reinforcement for health status, and an opportunity to dispel anxiety created through follow-up attendance.

In relation to lifestyle choices following a diagnosis of cancer, adult cancer survivors appear to be more motivated to make positive lifestyle choices in comparison to the paediatric cancer population. In her study of 31 five-year adult survivors of malignant melanoma, Dirkson\textsuperscript{106} found that this group was highly motivated to take actions that would decrease their risk of recurrence. These actions included healthy eating, exercise and a positive change in attitude and lifestyle.\textsuperscript{106} It is possible that adults, particularly with the amount of information presented in the media concerning the various causes of cancer, are more likely to experience guilt and to feel that their past choices had affected the development of their illness. This guilt and feeling that one may have caused their cancer are likely to be the motivators behind these changes in behaviour. As well, research has found a positive relationship between self-blame and a search for meaning in the cancer experience.\textsuperscript{107} The paediatric cancer survivors in this study did not see the necessity to choose a healthier lifestyle than their peers because the perception of risk did not fit their experiential framework. They did not appear to have any feelings of guilt over the development of their cancer, nor did they feel that they had in fact "caused it". As such, the lack of guilt as a motivator for
positive lifestyle choices could be an explaining factor for the differences between these two groups.

5.9 Researcher’s Reflections

I undertook this study for two reasons. First, my own experiences with the health care system have made me realise the importance of the patients’ voice. Thus, being able to participate in a research project that would contribute to raising the awareness and understanding of patients’ experiences was an opportunity that I felt was both important and interesting. Second, growing up, I spent time on the paediatric ward in the hospital where my father practised as a paediatrician. Meeting (and playing with) children who were suffering from various illnesses left a lasting impression and resulted in my interest in paediatric patients’ experiences. Being able to conduct research in an area that was both of interest to me, and clinically relevant with a potential impact on services, was a great experience.

Throughout the course of the study, I was able to meet individuals who had not only experienced a life-threatening illness, but who also appeared to be doing very well as adults. I felt very fortunate to meet and talk with such fascinating people. I think that perhaps the most outstanding feature of completing this study was learning how my assumptions affected not only the research questions, but also the way in which I spoke with the participants during the first few interviews. Only after completing the first set of interviews did it become clear to me that the assumptions I had regarding the study were different from the responses I had from the cancer survivors. The questions I asked during the interview were reflective of what I thought would create “interesting”
and “deep” dialogue about the participants’ cancer experience and lives today. I believed that participants’ fears of recurrence and understanding how the cancer experience had affected their lives would be the central part of the interview. However, I soon discovered that the questions concerning recurrence and how their cancer history has affected them generated little comments from most of the participants. I had also believed that there would be strong fears of recurrence, and that this would lead to changes in health behaviours.

The discrepancy in what I believed would be the important questions to ask, and what participants felt was important to discuss, highlights the need for qualitative research. This is particularly critical when dealing with an area where there is little knowledge and where the environment is changing. Investigator-driven research may sometimes underestimate or miss what is actually of most value or interest to those being researched. As well, our own biases around certain behaviours and the meaning behind them often are used in interpreting results. In talking to the participants themselves, I discovered that they provided answers that had not previously been considered. For example, the initial assumption that participants would engage in healthy lifestyle choices to decrease their risk of recurrence was not found. Had it been discovered that participants were not engaging in healthy lifestyle choices without talking to them, it may have been hypothesised that they were in denial about the chance of recurrence. Rather, it was a perceived lack of control over their initial diagnosis, and the fact that they were too young for lifestyle choices to affect the development of their cancer that contributed to the lack of concern in making positive lifestyle choices.
I believe such examples highlight the importance and significance of this study. These findings illustrate the discrepancy between some underlying assumptions of the study and what the cancer survivors felt was important. As well, it illustrates how, in talking with those who experience and live with the phenomenon being studied, we can increase our understanding, and subsequently increase our capability to work with them.

5.10 Factors Influencing the Study

The purpose of this grounded theory study was not generalisation but rather the exploration and development of a theory intimately related with the experiences of those participating in the study. It is the researcher who needs to ensure thick description of the data to provide a detailed context of the participants lives in order for the reader to decide which findings are transferable to their own situations. Several aspects of this research limit the potential transferability of these findings.

First, the participation of male cancer survivors in the study was low. As such, there was not an opportunity to discuss and explore all the range of differences with the cancer survivors and therefore limits the full range of the findings about possible gender issues relevant to this population.

Second, during the course of the study it became clear that there was a need to sample cases who were “not doing well” (see theoretical sampling procedure). Participants from Saskatchewan, recruited from the Saskatchewan Cancer Registry, were typically doing quite well and as a result recruitment focused in British Columbia on those likely to be having difficulty. In Saskatchewan, there was no possibility of determining the differences between those who elected to participate and those who did
not in terms of their success of positive adjustment. As a result, the study may have potentially missed survivors with less positive experiences. Whether those who did not decide to participate were doing quite well and had put their cancer experience behind them or were doing poorly and were not interested in participating will remain unknown.

Third, as the adjustment to having had cancer begins the day of diagnosis, there was an inability to document the entire adjustment process into adulthood due to obvious reasons including a lack of time. In order to have a true understanding of the adjustment process one would need to follow a cancer patient from the day of diagnosis into survivorship as an adult. The model presented here relies heavily on the recollection of cancer survivors of their cancer treatment experiences. As well, while information was collected on both their cancer experience and their lives today, for some the time elapsed had been as long as 20 years, and as such a great deal of experiences and events that likely played a role in their adjustment were not collected. However, the time elapsed between the cancer experience and the time of the interview provided an opportunity for participants to reflect upon the meaning of their experiences and reframe it from their present situation.

Fourth, a diagnosis of cancer during childhood and adolescence affects not only the individual with cancer but also the entire family. Exploring the experience of the affected individual in addition to their sibling(s) or parents would likely provide a more holistic picture and contribute to the understanding of the adjustment process.

Fifth, as participants were interviewed only once, it may be that this did not provide sufficient time to establish a relationship between the researcher and the
participant. As such, repeated interviews may have resulted in more in-depth conversation and yielded additional information because both the participant and the researcher might have had more time to reflect on the first interview. As well, they might have enjoyed a more trusting relationship where participants may have felt more comfortable in disclosing the more personal aspects of their experience.

Lastly, the identified late-effects and treatment protocols were based on the participants testimony. Without a medical chart review for each participant, the researcher was unable to verify the information provided during the interview. In retrospect, this process would have provided valuable information in interpreting both the participant’s understanding of their disease and in verifying disease-related relationships that emerged in the analysis.
Chapter 6

Implications and Conclusions

The results from this study provide insight into the cancer diagnosis, treatment and survivorship experiences and beliefs of a group of paediatric cancer survivors. Using the theory developed from the interviews with these survivors, a number of implications for further research and clinical practice during both treatment and long-term follow-up can be drawn. It is important to note that the cancer care practices and professional training have evolved since the time the participants in this study were receiving treatment. As such, the implications drawn from this research highlight not only new information concerning clinical practice, but also highlights the importance for continuing those services that are now in place.

6.1 Implications for Practice

6.1.1 Diagnosis and Treatment

During treatment, a number of factors relating to the participants’ ability to cope with their cancer diagnosis and treatment became apparent. First, the provision of specific information concerning all aspects of the disease continue to be important. Desired information includes knowledge around the potential side-effects from treatment, as well as learning strategies to cope with these side-effects to minimise the impact on patients’ lives. Information can prepare cancer patients for side-effects, and
as such can potentially minimise feelings of fears and confusion. This is also important in terms of the potential late-effects that can occur from treatment. For example, one survivor mentioned that the opportunity to have sperm or eggs frozen to prepare for potential infertility would be a means of preparing for a devastating loss later in life.

**Second,** continued involvement in decision-making, particularly for an adolescent is important. Both the provision of information and involvement in decision-making during both treatment and long-term follow-up contribute to a sense of control, and foster feelings of empowerment. Previous research has found that in children receiving treatment for cancer, the provision of information was very important.\(^{36,108,109}\) As well, research has shown that paediatric patients are often aware of the seriousness of their illness even when such information is not disclosed.\(^{108,109}\) As such, health care professionals should continue to strive to include cancer patients and long-term survivors in the decision-making process.

**Third,** social support during treatment was identified as a positive predictor of psychosocial adjustment. The availability of social support from family, friends, and health care staff can play a significant role in the ability to cope and adjust to having cancer. Social support has also previously been identified in the literature as positively affecting the physical functioning, social adjustment, depression and well-being of individuals with chronic illness.\(^{110}\) In today’s clinical practice, the provision for patient and family support and for a home-like environment is very much emphasised. This study reminds us that health care professionals should continue to play this supportive role as their interactions with patients profoundly affect their sense of self and well-being. As well, it is important that health care providers show empathy and give
practical advise to parents, who likely need support themselves; this in turn will assist parents’ abilities to provide loving care and support for their children.

There are a number of mechanisms by which health care providers can facilitate this process. First, health care providers can continue to act as information sources for parents in order to minimise confusion and fears around the disease. Parents would then be able to focus their attention to their child, rather than on seeking out information they require to understand and cope with their child’s illness. Second, while many parents meet and exchange information during the children’s appointments and in the hospital setting, the creation of a parent support group would give parents an opportunity to hear and learn from other parents experiences. This would provide a formal opportunity to meet other parents in similar situations, and to learn from their experiences. Third, health care providers can be an additional source of support for parents in addition to the patients as an “ear” to listen, or a “shoulder” to lean on. Fourth, nurses in particular are in a unique role to identify parents in need of additional support and to refer them to appropriate services such as social workers, financial advisors and spiritual care personnel. Fifth, adequate support for siblings in the form of a support group would enable siblings to become part of the illness process. Camp Circle of Friends in Saskatchewan and Camp Goodtimes in British Columbia both provide opportunities for sibling involvement. However, these camps are limited in time, and the creation of a network that would last throughout the illness process would likely be beneficial for siblings. Lastly, the development of home support services where patients would be able to receive their treatments in a home setting, particularly for those living in rural areas, could potentially minimise the stress that travel to a large
city for treatment creates on parents. While pilot projects for these services are currently underway in Saskatchewan, parents may feel, in wanting the best possible care for their child, that receiving treatment in a large hospital may outweigh the benefits of receiving treatment at home.

**Fourth**, health care providers, teachers and parents all play a significant role in contributing to the patients’ ability in normalising during treatment. Continued encouragement to remain involved in school-based activities and participate in “normal” age-appropriate behaviours is important. As well as the provision of resources to help them maintain “normal” lives, such as wigs for those with alopecia, will facilitate the normalising strategies used by patients during treatment.

**Fifth**, many of the participants diagnosed in late childhood and adolescence mentioned that during their cancer treatment, a support group would have been useful. The continued availability of support groups either through hospital or cancer treatment centres can provide cancer patients an opportunity to hear how others are coping and gain an additional source of social support. As well, organisations dedicated to the children and families who are affected by cancer, such as Candlelighter’s, the Canadian Cancer Society and the newly developing Rebounder’s, can create social support networks across Canada.

### 6.1.2 Survivorship

The long-term follow-up care of paediatric cancer survivors is important for several reasons. First, monitoring for late-effects or for the development of a recurrence or second malignant neoplasm is vital in ensuring patient health. Second, such medical
follow-up will contribute to the knowledge of the prevalence of these late-effects in the paediatric cancer survivor population. Lastly, follow-up provides continued contact with health care professionals trained in oncology and as such, with a group who is aware of and can assist with the unique needs of this population. A multi-disciplinary long-term follow-up clinic that would focus on the needs specific to this population, and that would achieve the aforementioned reasons would assist in provided adequate follow-up care. A number of recommendations from the research have emerged concerning the follow-up care of long-term survivors.

First, the provision of adequate information concerning one’s medical status and knowledge of specific late-effects as they unfold should continue to be an integral aspect of all follow-up care. As well, patient participation in decision-making is again an important aspect of such care.

Second, as follow-up appointments are a time in which long-term survivors are likely to experience fears and anxiety related to recurrence, health care professionals need to be sensitive to this anxiety. At the time of the appointment itself, health care providers need to be aware of these fears, and show this through their interactions with patients. As well, survivors are likely to be anxiously waiting for test results about their health status, which reiterates the need to ensure that patients are informed within an adequate time period.

Third, while many of the participants indicated that they would not likely attend a support group at present as it was commonly perceived as inhibiting their ability to move on, several did mention that they would like the opportunity to meet with other survivors to hear their stories. While this may sound surprising it may be due to
participants' misconceptions of what occurs in a support group, as many believed it was a time spent discussing the negative aspects of their cancer history. What is critical for health care professionals is to address support needs in a creative way or in a way that encourages them to move on. This may occur through education and recreational activities such as camps for adult survivors. However, an informal “get-together” of paediatric cancer survivors, instead of a formal support group could facilitate this process. Such a gathering could create additional sources of social support and provide an opportunity for information sharing. It is likely that such an event would have a higher participation rate, as survivors may be less likely to perceive it as an experience in which they would dwell on their history and impede their ability to move on. Again, organisations such as Candlelighter’s and Rebounder’s can play a facilitative role in bringing together survivors for social activities. For example, these activities could include family barbecues or informational sessions around issues such as life insurance and employment relevant to survivors.

**Fourth**, continued assistance for those with late-effects is important. Participants who were receiving help in terms of opportunities for re-constructive surgery, assistance with gaining employment skills and with prostheses felt it made a positive contribution in their ability to adjust and live their adult life. Those who needed such assistance and who were not receiving it were more likely to have adjustment problems. Ensuring that those who need assistance are receiving it is an integral part of follow-up care. This requires health care providers who remain in contact with survivors including oncologists in cancer centres and community
physicians to be aware of and make appropriate referrals to services, such as vocational rehabilitation and plastic surgeons, that are specialised in meeting these needs.

**Fifth**, job discrimination in this group of long-term survivors is a reality. More targeted and effective public education concerning employment of those with a cancer history/disability is critical. Involvement of the media in Candlelighter’s and Rebounder’s activities provide opportunities to inform the public. Additionally, telethons that raise money for paediatric illnesses could take this opportunity to educate the public on the recent success of paediatric cancer treatment and on issues such as employment discrimination. As well, the provision of job skill training through referral to vocational rehabilitation services for those with late-effects can assist with employment opportunities.

**Sixth**, continued support for normalising strategies, in particular for those with late-effects is important. Again, support through vocational counselling and assistance with sustained employment play an important role in normalising for this group. As well, opportunities to reduce the visual impact of their cancer, such as through reconstructive/cosmetic surgery should be offered where appropriate.

**Seventh**, for those who live in an area that requires a shift from a Children’s Hospital to an adult treatment centre, it is important to ensure a smooth transition in follow-up care. A smooth transition implies the patient’s acceptance of a need for the transfer, and ensuring that the patient does not “get lost” during the shift. Leaving the transition until a time when the patient feels ready to make the transition can assist in this process. Increased communication between the Children’s Hospital and the adult cancer centre is vital in order to provide the continuity in their follow-up care. The
provision of an appointment date and time for the adult centre at the patient's last appointment at the Children's Hospital can facilitate the process and ensure that patients are not left waiting to hear when their next follow-up care will take place.

6.2 Implications for Research

One of the goals of qualitative research is to generate hypotheses for research and to bring forth issues that may require further examination with a broader sample. From this study, a number of areas and issues suggest directions for additional exploration.

First, paediatric cancer is a family issue. As such, to have a broader understanding of the factors related to the long-term adjustment of paediatric cancer survivors requires an ecological approach. There is a need to understand how the family system reacts to a diagnosis of paediatric cancer and to understand how the family copes and adjusts with long-term survivorship. Research has shown that paediatric cancer survivors' adjustment is related to their family's ability to cope with their cancer. Studies investigating the prevalence of Post Traumatic Stress Disorder (PTSD) in parents of long-term survivors found significantly higher levels of PTSD symptoms than parent controls. As well, another study found parents of long-term survivors suffered persistent psychosocial affects and uncertainty. Such research highlights the importance of understanding not only how the paediatric cancer survivor adjusts, but also the entire family unit. An investigation that would involve the entire family system, including siblings and parents, would provide a more holistic picture of the impact that cancer has not only on the patient but also on the family itself.
As well, research into the effectiveness of family interventions in this population is necessary.

**Second,** a number of transitions occur for paediatric cancer survivors entering adulthood. The disease-related transitions from treatment to off-treatment, from short-term survivorship to long-term survivorship, and from follow-up at a Children’s Hospital to an adult care centre all require further investigation. Understanding the process of how these transitions can be facilitated to encourage positive adjustment is necessary. As well, the developmental transitions that young adults make upon entering adulthood such as leaving home, attending post-secondary education, entering the workforce, and forming a family require better understanding. We do know that survivors, while achieving successful transitions, are at times slower in comparison to the general population.\textsuperscript{14,74,84} However, we lack an appreciation of how the process is slowed and what the positive predictors are for achieving these normal developmental transitions. Such information could provide a better grasp of how health care providers can facilitate these transitions, as well as an awareness of the services that should be in place to prevent negative outcomes.

**Third,** further research into the perceived lack of control that participants felt over their cancer development and subsequent prevention of a recurrence is necessary. With regards to the emergence of their initial cancer, understanding how this affects their feelings of self-blame and the subsequent impact this has on the spiritual and emotional dimensions is important. As well, there is a need for further understanding of the motivating factors behind the risk-taking behaviours, in order for health care
providers to effectively work with survivors and encourage the adoption of healthy lifestyle behaviours.

**Fourth**, the brain tumour survivors who took part in this study appeared to have different needs and issues related to their long-term follow-up in comparison to the rest of the paediatric cancer survivor population. Their treatment often produces late-effects that are unique to this population. The numerous physical assaults that brain tumour patients face through the presence of a tumour in their brain, the surgical removal of brain tissue, and radiation and chemotherapy treatment can create lasting negative effects to the patient. This suggest the need for further research into this population alone as grouping brain tumour survivors along with other paediatric cancer survivor groups may provide misleading information in the outcomes of this group. This is a special population whose late-effects and needs demand their own extra attention because of their greater amount of neuropsychological handicaps in comparison to other long-term survivors.

**Fifth**, research into the potential gender differences is necessary because of the lack of male participation in this study. Their perspective may not have been fully represented and it would be important to devise strategies to elicit their participation in future studies in order to address their specific needs.

**Sixth**, a few of the cancer survivors in this study had difficulties in their shift from follow-up care at the Children’s Hospital to follow-up at an adult cancer centre. Thus, there is a need to identify the follow-up status of this population to ensure that appropriate follow-up care is being achieved. The importance of this stems from the
unique needs of this population that often requires specialised care and in continuing the prevalence of late-effects.

**Seventh**, the results presented here are the perceptions of the experience and late-effects of these paediatric cancer survivors. A study investigating the documented versus perceived late-effects and issues for this population may provide an understanding of the effectiveness of communication of the late-effects and issues presented by health care providers to the patients.

### 6.3 Conclusion

This study explored, in-depth, the process of adjustment into adulthood for 18 long-term survivors of paediatric cancer. Overall, this group of survivors appeared to be well-adjusted and leading productive lives. The theoretical model developed in this study provides a conceptual view of the process of *moving on* that participants were engaging in response to their history of cancer. The strategies used by these participants to *move on* included normalising, information seeking, health maintaining and not dwelling on their cancer. Their ability to use these strategies was affected by a number of intervening conditions including the level of social support during both treatment and survivorship, being young when diagnosed with cancer, feelings of powerlessness, fears of recurrence, ability to cope with cancer diagnosis and history, and acceptance. The consequences of *moving on* and using these strategies included living life to the fullest, positive meaning in their cancer experience and feelings of empowerment.
A number of clinical recommendations emerged. Although information, shared decision-making, and support are part of the standard care for today, this study re-emphasised that they remain critical not only at diagnosis and during active treatment, but also later through long-term follow-up. As well, the provision of social support and resources that would contribute to normalising strategies is important, particularly for those with late-effects. Lastly, the creation of opportunities that would enable cancer survivors to gather and meet in a casual setting.

Further research is recommended in several areas: investigating the processes involved in the developmental transitions for this group, and studies focusing specifically on the brain tumour survivor population. As well, research involving the entire family unit should be carried out in a number of areas. First, to discover how the relationships within the family are affected by the disease; second, how the health care system can better assist them; and third, intervention research for families considered at risk for adjustment difficulties.
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November, 1997

Dear Dr.,

Re: (Patient Data)

Your patient has been selected to participate in a research study entitled "Long-term Adjustment of Pediatric Cancer Survivors". This study is part of a Master's Thesis project of a student in the Department of Community Health and Epidemiology, University of Saskatchewan. It is being coordinated by the Saskatchewan Sociobehavioural Cancer Research Centre. The 10 participants in the Saskatchewan study will be pediatric cancer survivors who are now in adulthood and have been considered disease free for at least five years. Following their consent, they will be asked to participate in a 1 to 1 1/2 hour interview. Ethics approval has been given by the University of Saskatchewan, and all information will be kept confidential.

Patients will be asked to describe how surviving cancer during childhood has affected their lives as adults.

Would you please complete the attached form indicating whether or not we may approach your patient to invite him/her to participate in this study. We would appreciate it if you could return the permission form within two weeks.

Should you have any questions concerning this study, please contact the graduate student involved, Christina Melton at 966-7730 in Saskatoon or her research supervisor, Dr. Anne Leis at 966-7878. Otherwise please feel free to contact myself at 791-2767 in Regina. Thank you very much for your assistance.

Sincerely,

Diane Robson
Director of Data Services
Saskatchewan Cancer Foundation
Appendix B

Long-Term Adjustment of Pediatric Cancer Survivors

PHYSICIAN PERMISSION TO CONTACT

Re: (Patient Data)

The patient may be approached to participate in the study:

Yes ______  Do not approach at this time ________
Reason:


Name

Date

Signature

Please FAX to Diane Robson, Saskatchewan Cancer Clinic at (306) 655-2910
Appendix C

LONG-TERM ADJUSTMENT OF PEDIATRIC CANCER SURVIVORS

You are invited to participate in an interview to explore how having had cancer as a child or teenager has affected your life as an adult. The purpose of this study is to learn from people like you in order to improve health care services for pediatric cancer survivors and patients.

Your name was chosen from the Saskatchewan Cancer Registry. Your doctor has given his/her permission for us to contact you. Participation will involve a 1 to 1 1/2 hour tape-recorded interview to discuss your experiences and an additional follow-up phone call or visit to make sure that the findings reflect what you had said. If you agree to participate, please sign and send in the reply form. We will contact you to set up a time and place for an interview.

The study is being done in Saskatchewan and in British Columbia. The Saskatchewan researchers involved in this study are:

Co-Investigators:
- Dr. Anne Leis, of the Saskatchewan Sociobehavioural Cancer Research Satellite Centre, Department of Community Health & Epidemiology, University of Saskatchewan
- Christina Melton, Graduate Student, Department of Community Health & Epidemiology, University of Saskatchewan

Collaborators:
- Diane Robson, Saskatchewan Cancer Foundation Registry, Regina
- Dr. S. K. Ali, Saskatchewan Cancer Foundation

We hope you will participate. All information provided to us in the study will be kept confidential. You are free to withdraw from the study at any time with no consequences. While you may gain no immediate benefits from participating in this interview, we hope that what we learn from you will help other pediatric cancer survivors and patients. You will have the chance to ask any questions or discuss any concerns you may have at the interview. This study has been approved by the Ethics Committee at the University of Saskatchewan.

If you have any questions or concerns about the study, please feel free to call myself, Diane Robson at 791-2767, Christina Melton at 966-7730, or Dr. Anne Leis at 966-7878.

Remember, please sign the attached reply page and mail it in the stamped return envelope. This page and consent form are for your record and future reference. If you decide not to participate, please take a moment to tell us why on the reply form and mail it in anyway.

Thank you very much.

(Mrs.) D. Robson
Saskatchewan Cancer Foundation
PARTICIPANT CONSENT FORM

Long-Term Adjustment of Pediatric Cancer Survivors

Principal Investigators: Dr. Anne Leis
Christina Melton (M. Sc. Candidate)

The purpose of this study is to explore how having had cancer as a child or teenager has affected your life as an adult. I understand that while I may not receive any immediate benefit by participating, the study is being done to improve services for both pediatric cancer patients and cancer survivors.

I agree to take part in a tape-recorded interview with Christina Melton that will last about 1 to 1 1/2 hours. I understand that this interview will happen at a convenient time and place that is mutually agreed upon.

I understand that any information collected will be kept completely confidential. Only Dr. Leis and Christina Melton will know my name. The interview transcript will instead have a code number. I understand that the tape and transcript will be stored in a locked filing cabinet and will be destroyed at the end of the study. I am aware that Christina Melton will contact me after the interview to check that the results of the analysis reflect what I had said. I may also request a copy of the study findings.

I understand that my involvement is entirely voluntary and that I am free to withdraw from the study at any time with no consequences. I also understand that I may choose not to discuss certain issues during the interview.

I may contact any of the researchers involved, including Christina Melton at (306) 966-7730 or Dr. Anne Leis at (306) 966-7878, if I have any questions or concerns about the study.

I __________________________ have read the above form and agree to participate. I will keep a copy of this form for my own record.

Signature __________________________ Date ________________

Researcher ________________
Appendix E

REPLY FORM

Long-Term Adjustment of Pediatric Cancer Survivors

Your signature below tells us you have read the information and that you voluntarily agree to be contacted to participate in a 1 to 1 1/2 hour tape-recorded interview with Christina Melton at your convenience. You are free to withdraw from the study at any time with no consequences.

I agree to participate: Yes _____ No _____

If NO, would you please take a moment to tell us why and give your name so we do not contact you again. Only the reasons and not your name will be made available to the researchers.

______________________________________________

______________________________________________ Name: ____________________

If YES, please sign and fill out the information below:

Name __________________ Signature __________________ Date ____________

Address

Phone number(s) and suggested days and times when we may reach you.

Phone ___________ Day of Week ___________ Time _________
Phone ___________ Day of Week ___________ Time _________

Please sign this page and mail in the stamped return envelope provided.

Thank you.
Appendix F

BC Cancer Agency

INFORMATION SHEET

Long-Term Adjustment of Pediatric Cancer Survivors

You are invited to participate in an interview to explore how a diagnosis of cancer as a child or teenager has affected your life as an adult. The purpose of this study is to learn from people like you in order to improve health care services for pediatric cancer patients and survivors.

Participation in the study will involve a 1 to 1 1/2 hour tape-recorded interview to discuss your experiences and a brief telephone contact or visit to check to see if the findings reflect what you had said. If you agree to participate, please sign and send in the reply form. Christina Melton, a graduate student conducting the research, will then contact you to set up a time and place for an interview.

We hope you will participate. All information provided to us in the study will be kept confidential. You are free to withdraw from the study at any time with no consequences. If you choose to withdraw during the study, any information you provided to us will be destroyed and not used in the study. While you may gain no immediate benefits from participating in this interview, we hope that what we learn from you will help other pediatric cancer survivors and patients. You will have the chance to ask any questions or discuss any concerns you may have at the interview.

If you have any questions or concerns about the study, please feel free to call Margaret White at (604) 877-6000 Local 2187 or Maureen Parkinson at (604) 877-6000 Local 2189.

Remember, please sign the attached reply page and mail it in the stamped return envelope. This page and consent form are for your record and future reference.

BC Researchers involved in this study: BC Cancer Agency - Richard Dool, Margaret White, Maureen Parkinson, Mary McBride, Christina Parsons; BC Children's Hospital - Angela Presta, Sheila Pritchard; University of BC - Betty Davies; and Christina Melton, University of Saskatchewan graduate student.

The BC Cancer Agency provides comprehensive cancer care including prevention, early detection, diagnosis and treatment, community programs, research and education through provincial programs and regional cancer centres in Vancouver, Victoria, Surrey and Kelowna (1998).
Appendix G

BC Cancer Agency

PARTICIPANT CONSENT FORM
Long-Term Adjustment of Pediatric Cancer Survivors

Co-Investigators:
Anne Leis, University of Saskatchewan
Betty Davies, School of Nursing, UBC
Maureen Parkinson, BC Cancer Agency
Richard Doll, BC Cancer Agency
Margaret White, BC Cancer Agency
Mary McBride, BC Cancer Agency

Graduate Student:
Christina Melton, Dept. of Community Health & Epidemiology, University of Saskatchewan

The purpose of this study is to explore how having had cancer as a child or teenager has affected my life as an adult. I understand that while I may not receive any immediate benefit by participating, the study is being done to improve services for both pediatric cancer patients and cancer survivors.

I agree to take part in a tape-recorded interview that will last about 1 to 1 1/2 hours. I understand that this interview will happen at a convenient time and place that is mutually agreed upon.

This study is being co-ordinated by the Sociobehavioural Cancer Research Network of the National Cancer Institute of Canada. It is also part of a Master's Thesis project by a student from the University of Saskatchewan.

I understand that any information collected will be kept completely confidential. The interview transcript will instead have a code number. I understand that the tape and transcript will be stored in a locked filing cabinet, and the tape will be destroyed at the end of the study. Any information stored on computer will be protected by password.

I am aware that the interviewer will contact me after the interview to check that the results of the analysis reflect what I had said. I may also request a copy of the study findings.

If I have any concerns about my treatment or rights as a research subject I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at (604) 822-8598.

I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time with no consequences. I also understand that I may choose not to discuss certain issues during the interview.

I may contact any of the researchers involved, including Richard Doll at (604) 877-6000 Local 2197, Betty Davies at (604) 822-7456 or Mary McBride at (604) 877-6122, if I have any questions or concerns about the study.

I, __________________ have read the above form and agree to participate. I will keep a copy of this form for my own record.

________________________  ________________________  ________________________
Signature                   Date of Birth                Date

The BC Cancer Agency provides comprehensive cancer care including prevention, early detection, diagnosis and treatment, community programs, research and education through provincial programs and regional cancer centres in Vancouver, Victoria, Surrey and Kelowna (1998).
Appendix H

Interview Guide

Cancer Experience

1. I want to ask you a few questions related to your history of cancer.
   
   - Can you tell me when you were diagnosed, and with what type of cancer?
   
   - Where were you living at the time of your diagnosis? Did you have to leave your home town to receive treatment?  
     Probe: How was that for you?
   
   - Is there anything or any experience that really stands out for you that occurred while you were still receiving treatment?

Survivor Experience

2. Where did you receive the treatment for your cancer? (i.e. Children’s, BCCA, local) Who provides your medical care to you now? Are they aware of your cancer history? How do you feel about the care you are currently receiving?

3. For those treated at Children’s: I would like to hear about your experience when you were no longer seen at Children’s Hospital for follow-up visits. How did you find the transfer? Were there any difficulties? Positive experiences? What types of services, programs, or assistance would have made the adjustment easier?

4. Can you tell me what being a survivor of childhood/teenage cancer means to you?

5. In what ways would you say having had cancer has affected you?  
   Priorities in life?
6. How do you feel having had cancer has influenced the life choices that you have made?

*Probes:* Impacted decisions related to:
- marriage
- children
- career/educational choices

7. Do you have any fears/concerns associated with your history of cancer?

*Probes:* That your cancer may return?

Do you think there are things you can do to reduce the chance of your cancer returning?

Can you tell me a little more about these activities? Have you ever participated in any of these activities (i.e. smoking, exercise, spiritual activities, sun exposure, alcohol, diet) as a way to reduce the risk of cancer?
- Why or why not?

8. Do you consider your cancer history as part of your past or part of your current identity?

9. What else about your experience of surviving cancer do you think has relevance for this study?
   Do you think that there is anything else I should know about?

10. Do you have any questions for me?
Appendix I

DEMOGRAPHIC INFORMATION

Interview Date: __________
Interview Site: __________
Code #: __________

Personal Information:

Age: ______
Gender: ______
Marital Status:
  single
  married
  divorced
  common-law
  widowed
  other

Number of Children: ______
Ethnicity: __________
Educational Level: __________
Employment: __________
Income:
  less than 10,000
  10,000 - 29,999
  30,000 - 49,999
  more than 50,000

Parent Information:

Marital Status at during treatment:
  single
  married
  divorced
  common-law
  widowed
  other

Father Occupation: __________
Mother Occupation: __________

Cancer Information:
Diagnosis: __________________

Age at Diagnosis: _______

Time since treatment ended: ______________________

Relapse: Yes: ______ No: ______
number: _____

Course of Treatment: chemotherapy ______
radiation therapy ______
surgery ______
other ______
Appendix J

UNIVERSITY ADVISORY COMMITTEE
ON ETHICS IN HUMAN EXPERIMENTATION
(Behavioral Sciences)

NAME: Dr. Anne Leis (Christina Melton)
Department of Community Health
and Epidemiology

DATE: October 26, 1997

EC# 97-135

The University Advisory Committee on Ethics in Human Experimentation (Behavioral Sciences) has reviewed the modifications to your study, "Long-Term Adjustment of Pediatric Cancer Survivors: A Grounded Theory Study". (EC #97-135)

1. Your study has been APPROVED.
2. Any significant changes to your protocol should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 3 years.

David Hay, Chair
University Advisory Committee
on Ethics in Human Experimentation
Behavioral Sciences

Please direct all correspondence to:
Bonnie Kortruis, Secretary
UAECBE, Behavioral Science
Office of Research Services
University of Saskatchewan
Room 210 Kirk Hall, 117 Science Place
Saskatoon, SK S7N 5C8
Appendix K

THE UNIVERSITY OF BRITISH COLUMBIA

November 20, 1997

Dr. Christine Parsons
Radiation/Oncologist
BC Cancer Agency
600 West 10th Ave.
Vancouver, BC V5Z 4E6

Dear Dr. White:

Re: "Long Term Adjustment of Pediatric Cancer Survivors"

This is to confirm that BC's Children's Hospital will participate in the above Study. It will involve ten patients. The Post Pediatric Tumor Group approved this Study at their last meeting in Vancouver, BC on October 8th, 1997.

The purpose of the Study is to conduct a survey of long term adjustment of pediatric cancer survivors.

Yours sincerely,

Chris J.H. Fryer, F.R.C.P.(C)
Chair, Post Pediatric Tumor Group
Clinical Professor & Head
Division Hematology/Oncology
UBC and B.C.'s Children's Hospital

CF/th

cc: Dr. Margaret White, BC Cancer Agency

c/data/cfadmin/parsons.n20
Appendix L

CLINICAL INVESTIGATIONS COMMITTEE

FULL APPROVAL
(UBC Approval dated November 27, 1997)

CIC 97-35 LONG TERM ADJUSTMENT OF PAEDIATRIC CANCER SURVIVORS
Principal Investigators: Richard Doll;
Dr. Anne Leis (University of Saskatchewan)
Co-Investigators: Dr. B. Davies (UBC), M. White, M. Parkinson; M. McBride

This protocol and Patient Information and Consent Form have been granted FULL APPROVAL of the Clinical Investigations Committee of the BC Cancer Agency.

When the study has received approval of the UBC Screening Committee, it may be activated. A copy of the written approval from the UBC Screening Committee should be sent to the Chairman and/or Secretary of the CIC when it becomes available.

Please submit any future revisions or amendments of this protocol to the CIC. This will facilitate maintenance of up-to-date records for each study. Changes affecting patient eligibility, treatment toxicity or informed consent must be reported to the CIC.

Unless the Clinical Investigations Committee is informed otherwise, the Committee will assume that the Principal Investigator grants permission to publish the name of this protocol and the name of the Principal Investigator in issues of the Agency Newsletter and the Cancer Research Centre Newsletter.

DR. UMNNE NAKASHIMA
Co-Chair
Clinical Investigations Committee

05-Feb-98
LN/mf

The BC Cancer Agency provides comprehensive cancer care including prevention, early detection, diagnosis and treatment; community programs; research and education through provincial programs and regional cancer centres in Vancouver, Victoria, Surrey and Kelowna (1998).
Certificate of Approval

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<tr>
<th>PRINCIPAL INVESTIGATOR</th>
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The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of:
Dr. I. Franks, Associate Chair
Dr. R. Johnston, Associate Chair
Dr. R. D. Spratley, Director, Research Services

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.