

**WHEN A PARENT HAS CANCER: AN EXAMINATION OF  
THE LIVED EXPERIENCE OF ADULT CHILDREN  
LIVING AT HOME**

by

Carmen Cecilia Almarza  
B. A. Simon Fraser University 2003

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

In the  
Faculty of Education

© Carmen Cecilia Almarza 2008

SIMON FRASER UNIVERSITY

Spring 2008

All rights reserved. This work may not be  
reproduced in whole or in part, by photocopy  
or other means, without permission of the author.

# APPROVAL

**Name:** Carmen Cecilia Almarza  
**Degree:** Master of Arts  
**Title of Thesis:** When a Parent has Cancer: An Examination of the Lived Experience of Adult Children Living at Home

**Examining Committee:**

**Chair:** David Paterson, Senior Lecturer

---

**Stephen Smith, Associate Professor**  
Senior Supervisor

---

**David Cox, Associate Professor, Department of Psychology**  
Committee Member

---

**Ann Chinnery, Assistant Professor, Faculty of Education**  
External Examiner

**Date Defended/Approved:** Feb 19 2008



SIMON FRASER UNIVERSITY  
LIBRARY

## Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the "Institutional Repository" link of the SFU Library website <[www.lib.sfu.ca](http://www.lib.sfu.ca)> at: <<http://ir.lib.sfu.ca/handle/1892/112>>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author's written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library  
Burnaby, BC, Canada



**SIMON FRASER UNIVERSITY**  
THINKING OF THE WORLD

## **STATEMENT OF ETHICS APPROVAL**

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

(a) Human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

(b) Advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

(c) as a co-investigator, in a research project approved in advance,

or

(d) as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Bennett Library  
Simon Fraser University  
Burnaby, BC, Canada

## ABSTRACT

The present qualitative study explores the lived experience of adult children living at home whose parent has been diagnosed with, and treated for, cancer. Little is known about how these adult children experience their parents' illness. Yet, how adult children navigate the cancer journey may ultimately influence the patient's recovery. Using van Manen's (1990) interpretive phenomenological approach, four major themes emerged from the participants' stories: *confronting death, experiencing the impact of treatment; the need for emotional support; and the cancer legacy*. Results showed that adult children experienced intense and distressful emotions such as fear, anger, shock, and helplessness. Treatment was described as a 'turbulent time,' of multiple demands and of heightened emotional distress. Yet, despite the suffering, these study participants also drew constructive meaning from their experiences. Participants highlighted the crucial need to have someone to talk to, and to be there for them. Implications for counselling are discussed.

*In loving memory of my husband:*

My anchor,

My refuge,

My solace

## ACKNOWLEDGEMENTS

I am forever grateful to my senior supervisor Dr. Stephen Smith, who encouraged me, gave me confidence in my work, and inspired me to think in ways I would not have thought possible. Your mentorship allowed me to inscribe into text an experience that is very dear to me. I am indebted to Dr. David Cox for his support throughout my many years at SFU, and for his valued advice and comments. I thank Dr. David Paterson, for his guidance and constant kindness, which allowed me to continue on an arduous journey. To Dr. Ann Chinnery, I thank you for sharing your expertise and your time as the external examiner. Many thanks go to Penny Simpson for her valued technical expertise, and always for her humour.

I am deeply grateful to my husband for being an integral part of this journey: you sustained me throughout seven years of unending work and multiple trips to campus, and always with a smile on your face. I am extremely grateful to my daughter, Alex: you pushed me to conquer my fears and encouraged me to continue when all seemed lost. You were always there to listen. To my son Andrew: you kept my humour up when I needed it most. I would also like to thank my father and mother, whose unconditional love gave me the courage to follow my dreams.

Lastly, and above all, I would like to extend my deepest gratitude to John, Amy, and Sarah, the three participants in this thesis, for sharing their courageous and inspirational stories.

## TABLE OF CONTENTS

<b>Approval</b> .....	<b>ii</b>
<b>Abstract</b> .....	<b>iii</b>
<b>Dedication</b> .....	<b>iv</b>
<b>Acknowledgements</b> .....	<b>v</b>
<b>Table of Contents</b> .....	<b>vi</b>
<b>CHAPTER I. INTRODUCTION</b> .....	<b>1</b>
Statement of the problem.....	8
Choice of methodology .....	11
Literature review: introduction .....	12
Cancer .....	13
Impact of cancer in the family.....	14
Spouses .....	17
Parental cancer: adult children as caregivers .....	19
Parental cancer and adult children.....	22
Summary .....	26
<b>CHAPTER II. METHODOLOGY</b> .....	<b>30</b>
Method.....	34
Interview procedures .....	35
The interview .....	36
Questions.....	37
Data analysis and interpretation .....	37
Criteria to evaluate qualitative research .....	41
Reflexivity .....	42
Resonance: “lived throughness” and “evocation”.....	43
Openness/transparency.....	45
The researcher.....	47
<b>CHAPTER III. RESULTS</b> .....	<b>50</b>
Participants .....	51
Themes .....	58
<b>CHAPTER IV. GETTING THE DIAGNOSIS: CONFRONTING DEATH</b> .....	<b>59</b>
The intense emotional reaction to diagnosis .....	59
Agency: pulling together.....	85
<b>CHAPTER V. EXPERIENCING THE IMPACT OF TREATMENT</b> .....	<b>92</b>
Treatment begins: the darkest days.....	96
Measuring life in day-by-day doses .....	104
Cancer lingers on.....	110



<b>CHAPTER VI. THE NEED FOR SOCIAL SUPPORT.....</b>	<b>117</b>
<b>CHAPTER VII. THE CANCER LEGACY.....</b>	<b>136</b>
<b>CHAPTER VII. CONCLUSION.....</b>	<b>159</b>
Summary of the present inquiry .....	160
Summary of the findings.....	161
Limitations: methodology .....	166
Limitations of findings and implications for future research.....	168
Implications for counselling.....	169
<b>EPILOGUE: REMEMBERING THE DEAD.....</b>	<b>173</b>
<b>Reference List .....</b>	<b>176</b>
<b>Appendix: Interview Questions .....</b>	<b>185</b>

## CHAPTER I. INTRODUCTION

In 1998 my husband was diagnosed with testicular cancer just as I began work on my Bachelor of Arts studies. It was the first time that my children and I would confront the big “C”. After eight years of cancer free results, on January 26, 2006, we encountered a new challenge: my husband was diagnosed with a far more aggressive cancer, Acute Myeloid Leukemia (AML). The beginning of 2006 was not what I had expected it to be. The previous year (2005) had been both an exciting and frustrating year for me. Exciting, because I had had the opportunity to work with clients in an exceptional practicum opportunity at a counselling centre. Yet, I was frustrated and felt uninspired with the thesis I had been working on at the time, and its progress. I decided to take a “reflective leave of absence” upon completion of the counselling practicum. It was now a new year, and little could I know how our lives were going to change. I had no idea what was about to happen.

Following a routine blood test, my husband was immediately diagnosed with Acute Leukemia (“blood Cancer”). How could this be? He was always a healthy, strong, and fit individual. At the time he was preparing to go on a six-week vacation, a time to spend relaxing with his family. How could Leukemia figure into this? What did our family doctor mean by Acute Leukemia? This was not something that was supposed to be happening to us again. Though my children were now adults (living at home), nothing had prepared us for this new challenge. As a family, we were thrown into an illness over which we had no control. I entered a world of fear: fear of cancer, of its treatment, of the unknown, and an all-engulfing fear of the outcome. I entered a world of sadness, grief and, above all, a world

of pervasive uncertainty and vulnerability. Paradoxically, throughout this experience, I would also encounter a world of hope.

The diagnostic time was terrifying, I was numb and in total shock. I can recall the diagnosis in vivid moments. As we drove to the physician's office, I felt unsettled and scared. We had been called in for an "urgent" meeting. The word "urgent" kept resonating in my head. I wondered about the previous day's blood test. As we drove silently toward our family physician's office, I felt my body tense and my mind wondering. I just could not stop the frightening thoughts that the meeting was "urgent." And then, there was that paleness that I had been noticing, and the "flu" that just did not go away. As we entered the office, I noticed the seriousness of the environment, an indescribable sense of being "frozen," as if a bitter cold air was engulfing the room and me... I felt an even deeper tension. Yet nothing could have prepared us for the news: Acute Leukemia.

We embraced, cried, and supported each other, yet we held back our feelings in order to be able to function in the time of crisis. As a family, we were thrown into this illness and we needed to press on with what this illness demanded. Life and newly encountered medical obligations had to continue despite our emotional pain. On the following day, my husband, my children, and I attended the first meeting with the oncologist. Strenuous medical treatment protocols and the medical information hit me hard. As a family, we learned that the treatment would be "harsh"; that things would become "dark" and that, for now, the outcome would at best be unpredictable. We learned of words such as "induction," "consolidation" and "salvage" treatments (when things do not work). Information about blood and platelets transfusions, immune suppression, and potential bone marrow/allogeneic stem cell transplantation followed. We learned that each treatment carried high toxicity, "morbidity" and potentially deadly risks. We learned that without

treatment he would certainly die. We sat and listened to the medical facts, we could only hope for the best. Yet, despite all the “frightening” information, we could not wait for the “chemo” to start.

While our experience of my husband’s testicular cancer had also been sudden and unexpected, retrospectively, we had not perceived it as life threatening. One might say, testicular cancer was after all, a “good cancer” to have. This time it became apparent that scenario would be an altogether different experience. For my adult children, my husband, and myself, this would be a long and treacherous journey. It would be nothing less than the fight of our lives. Although we are not a religious family, we did turn to God, Prayer, and spiritual guidance.

The word “Chemo” became an immediate reality. It was only the next day after diagnosis, and treatment had already begun. We found ourselves walking into the “Cancer” hospital to pick up the first chemotherapy drugs. We were told that the “induction” phase of treatment of invasive chemotherapy would start within the next couple of days; 29 days of hospitalization were expected to lie ahead of us – this was the minimum expected. Three days later, on a sunny winter morning, we entered and were fully consumed into the hospital world. As we exited the elevator, we encountered a new existence where sterile isolation was the norm: On the topmost floor we were greeted with hermetically closed doors and a telephone to identify one’s entrance into this world. Here, I learned that I would have to give up control and totally surrender myself to the medical experts. To give up control or the illusion of it and develop absolute trust in the health professionals was challenging for me. Yet I realized that acceptance and giving up control, were part of my own journey.

Leukemia has a standardized medical treatment protocol and patients are under the care of a specialized haematologist medical team. Being a goal oriented, information seeking and, high achieving person, the complete “takeover” by the medical team of my husband’s illness was not easy to bear. I needed to organize, carry this fight, and search for information. I submerged myself into information seeking on the net and on medical journals. Yet, I felt nothing I learned would influence or help in my husband’s care. Initially I felt I had to negotiate with our doctor for even the most basic of information regarding my husband’s health. Logically, I understood the doctor’s need to respect privacy laws but I could not help feeling that the medical professionals would not allow me to share in the responsibility of my husband’s care.

The hospital world taught me that there was nothing more I could do than to be there with my loved one, to hold his hand, talk to him. I learned to step aside with much frustration and anxiety. As a family, we witnessed in silence the experiences of invasive procedures as they unfolded. Waiting, hoping, and trusting those with the medical knowledge became the new reality. Despite the medicalization of our experience, doctors, nurses, and the “hospital,” were also our sense of comfort and security.

Throughout this journey, I wondered how my adult children were coping. Following the diagnosis we only ever heard of “odds” or percentages of survival. We have now come to know that Myeloid Leukemia has different streams, a few carrying a better prognosis, while others worse ones. Nonetheless, no prognosis could be speculated until the cytogenesis work and first phase of treatment were complete. As the journey began, we confronted new emotional, financial, physical, and instrumental responsibilities and challenges. Paper work and forms waited to be filled, medical and drug treatment protocols

to be administrated. There was no time to grieve. The “induction” phase of chemo came much faster than we had anticipated and was also emotionally more difficult than expected.

For ten days, my husband lay unresponsive in his bed, with a catheter feeding pre-meds, blood and blood products, massive amounts of antibiotics and of course, six straight days of chemotherapy. For two weeks, we witnessed life-threatening reactions. Soon after, the “cancer” identity began to emerge: all body hair, including eyebrows and moustache began to fall out. Nausea, loss of appetite, throwing up, weakness, pain, and intense fatigue, among others, conquered his body. Despite our fears, we stood determined against the disease; he would not succumb.

Even when the initial hospitalization came to an end, the medical protocol would still require everyday hospital trips and long hours of appointments. Fighting Leukemia is a full-time job, seven-days a week, with no day-off, and no holiday. Even small tasks such as hospital parking became financially demanding and bothersome. Yet, it was the psychological work that was most difficult to endure. Psychologically, our journey was one of worries, apprehension, and anxious waits for test results that never arrived soon enough to quell our fears. We nervously waited for the second bone marrow biopsy to see whether the first chemo had worked and again we anxiously waited for the first lumbar puncture to know if leukemia had travelled to the brain. We waited for blood test results that would hopefully indicate that we had a matching donor for a bone marrow transplant. We waited and watched for the immune system to be killed so that the leukemia would also be killed. We waited and watched for blood counts to go so dangerously low that any trivial infection or bleeding could be life-threatening. And while we waited for results, in this new hospital world, we learned that life could as easily be given as taken away.

As we waited in the same room with other families, separated from them only by a thin curtain that kept our faces unseen, diagnoses and prognoses floated and hovered within our hearing space. In an instant, with the utterance of one word, a life could change forever. “Treatment has failed,” a doctor says. His voice reverberates against the silence that permeates the room. For that patient, that family, a peaceful death is all the medical staff can offer. Nearness of death was a daily reality: life and death were not abstract phenomena in this world.

Throughout these waits, and because of my background in counselling psychology, I observed with surprise at the little or nonexistent support of counselling services. I wondered about my children’s own emotional roller coaster. What were their thoughts and feelings? What was this experience like for them? Was there something that would help them at this difficult time? I deeply sensed that, for them, sadness and fear were engulfing; the prospect of losing their father had become an overwhelming reality. Were anger and sadness deeply intertwined as they confronted potential death? I observed that they stopped talking about their fear, sadness, and vulnerability. I sensed they were trying to protect me from further grief.

Over the duration of four months, my husband endured two weeks of total hospitalization, four rounds of chemo (24 chemo treatments), pain, sleepless nights, serious and potentially fatal infections, frightening fevers, multiple blood and platelet transfusions, excruciating headaches that morphine did not help, and painful bone marrow biopsies and lumbar punctures to deliver chemotherapy to his brain and body. For the last four months the leukemia experience was one of an “emotional roller coaster,” with exhausting physical demands and rigorous drug treatments. Throughout all this experience, I saw my children’s world transformed into one of devoted caregivers – a world of new roles and multiple

responsibilities. I observed them navigate through heightened anxiety, worries, fatigue, struggles, vulnerability, and an all-pervading sense of uncertainty and threat. Yet, in this world we also shared hope and life celebrations. In this journey I experienced an increased awareness to accept and be grateful of the opportunities that are brought to us, including those which bring us suffering. Without cancer, I would not have felt the power of support, empathy and, above all, of courage.

Throughout this journey I came to know other patients and their families. I have had the privilege of hearing their experiences, also becoming a participant of their courageous life stories. Cancer is indeed a family illness. I saw the patient, the spouse and their adult children, despite the odds, determined to fight this disease. I have been blessed to be a witness of others' and of my own family's strength and determination. I had witnessed the story of others in B4 (Bone Marrow Transplant/Leukemia Clinic) whose experiences are the inspiration for this thesis.

The above description unveils moments of my cancer journey. I have included my story to illuminate how an experience is lived from the perspective of the writer, the one who is living it. As van Manen affirms, this kind of experience "is pre-reflective," it is "lived," "is already there," and belongs to the "world of immediate experience" (van Manen, 1990, p. 182). I lived this experience as a wife and as a mother, without imposing a theoretical background or explanation. It is the expression of layers of memories captured in one particular instant: that moment in which I inscribe into text the thoughts imprinted in my mind. The story is never complete, it continues to be written. Cancer lingers in my reality. Cancer dwells and is incarnated as I write; it inhabits time and duration. Death and losses, writes van Manen (2002), are events in which the past "becomes a living present" (p.



167). In that sense, my experience is not one that is lived in the past, but rather involves a living experience.

I offer my story not simply to inform the reader of my pre-existing knowledge about the lived cancer experience, but also to invite the reader to enter my living space to explore jointly the adult child's experience of parental cancer. I am hoping that the above text, my story, as van Manen (1990) affirms, "speaks" to the reader, and in doing so, provides the background as to why I have chosen cancer as the subject of my inquiry and why I chose to explore the lived experience of adult children living at home whose parent has been diagnosed with cancer.

### **Statement of the problem**

My interest in exploring the lived experience of adult children also stems from my own response as a counsellor and researcher to what appears to be a lack of knowledge in the lived experience of adult children living at home whose parent has cancer. While the medical literature on cancer is plentiful, much has focused on the biomedical and clinical aspects of cancer, as it must. Yet recently, a growing body of research that examines psychosocial dimensions of the impact of cancer has emerged. Using a quantitative methodology the overwhelming majority of these studies have focused on the patient and their spousal caregivers (e.g., quality of life, psychological distress, coping) (Harden, 2005; Northouse, Mood, Templin, Mellon, & George, 2000; Peleg-Oren & Sherer, 2001). Yet, despite the recognition that cancer affects the entire family unit, the experience of adult children living at home continues to receive minimal attention in psychosocial research (Mosher & Danoff-Burg, 2005).

One may argue that they are the forgotten participants in the cancer journey. It is worth noting that in the English Language there is no specific word to denote the status of an adult child. Rather, the word child is generally used to indicate the dependent nature of the offspring; that is, “child” generally evokes the image of a youngster in need of parental care. How then does the adult child who cares for the parent fit within this framework of “child”? Thus, as a counsellor and parent, I wondered about the adult child’s experience of having a parent diagnosed and treated for cancer. I wondered in particular about the adult children, like my own, who were young adults living at home, rather than adult children who were older, married, or not living at home. In searching the available literature, I realized that there was scant research in this area; moreover, I discovered that in contemporary Canadian society, a new trend has begun to emerge: an increased number of adult children, 20 to 35, are now remaining in the parental home or returning to live with their parents, a phenomenon that is now being highlighted by the media.

In the 1996 census, Statistics Canada reported that 47 % of women aged 20 to 34 lived with their parents (Statistics Canada, 2006). Furthermore, this trend is now even more prominent in urban areas, with the highest number (41%) of adult children living at home found in Vancouver, British Columbia (Statistics Canada, 2006).

In reviewing the available psychosocial literature and psycho-oncology research that has looked at the impact of parental cancer on adult children, I was surprised to find the literature review was limited and patchy, providing a very fragmented understanding of the phenomenon. For example, of the studies that examined adult children, many have excluded young adult children living at home, a living situation where adult children may have unique and different responsibilities than those adult children who have left the familial home. It is worth noting that younger adult children are the most ignored in the literature

on parental cancer. For example, Given, Wyatt, Given, Sherwood, Gift, DeVoss, et al. (2004) who examined depression and caregiver burden among family caregivers (spouses, daughters or son, sister or brother, granddaughter or grandson, niece or nephew, other) of terminally ill cancer patients, noticed that only 1 participant out of 152, was in the age category of 25 to 34.

More recently, a small number of studies have begun to study the experience of adult children, however these investigations have been concerned only with daughters of breast cancer patients. These participants were mainly women of middle age or older, and most did not live at home. As well, these studies all exclusively used a quantitative methodology. Whereas quantitative psychosocial cancer research is important, it does not sufficiently capture the in-depth experience of living with a parent who has been diagnosed with, and undergone, cancer treatment. What is it like for the adult child to hear this diagnosis? How does the adult child experience the parent's illness? How is the experience felt and lived? Are the stories of these adult children similar to what I have experienced and observed? Thus, the purpose of this study is to describe the experience of parental cancer diagnosis and treatment from the perspective of adult children who are living at home.

While the diagnosis of a life threatening illness such as cancer poses a major threat to the family unit, it is also the case that exposure to such a traumatic event may bring positive or transformational outcomes, a phenomenon that Power and Dell Orto (2004) call the "perspective of affirmation" (p. 14). Thus, while at times, I was surrounded by death, I was also surrounded by laughter, solace, friendship, support, and hope. Would the experience of parental cancer, despite its difficulties and uncertainty, also bring something of value to these young adult children? Is there anything positive that they might also have experienced? Van Manen (1990) suggests that lived experiences will alter a person's life and worldview. Is

there such a transformation in these adult children's worldview as the result of their parents' life-threatening illness? Thus far, most of the literature available has taken the approach of viewing the experience of cancer exclusively as one of distress, loss, and vulnerability, and ignoring the idea that it is possible that individuals, through their pain, suffering, and struggles, can construct meaning that involves positive changes, such as personal growth and enhanced family relations (Tedeschi & Calhoun, 1995).

### **Choice of methodology**

Gall, Gall and Borg (2003) suggest that qualitative research may be suitable when the topic is of personal relevance and significance to the researcher. As these authors propose, I am "intimately connected with the phenomena being studied" (p. 481). Polkinghorne (2005) argues that the research question should determine the method to be used. In examining adult children's experiences of having a parent diagnosed with, and treated for cancer, I deemed that a qualitative methodology, and more specifically, hermeneutic phenomenology, was the more appropriate to use. Several reasons have guided me to this conclusion. My interest in this area of research lies within the human science and lived experience. I was not attempting to draw empirical generalizations, seek causal conclusions, solve problems, or to classify the human experience (van Manen, 1990). My concern lies in the attempt to deeply understand the accounts of adult children living at home whose parent has been diagnosed with, and treated for, cancer. This study involves the interpretations of these young adults' unique stories. It is worth noting that hermeneutic phenomenology recognizes that the researcher comes to the inquiry with pre-existing beliefs, assumptions, prior knowledge, and experiences. Rather than assuming a value-free and detached stance, the researcher makes explicit such knowledge (de Witt & Ploeg, 2006).

My approach is one that is rooted in the work of scholars such as van Manen (1990) and in the phenomenological method that he proposes: one that is experiential and interpretive in nature. I chose this approach because I am interested in uncovering adult children's lived world: the everyday immediate experience, "pre-reflective" and "pre-theoretical" (p. 7), that is, the living experience as it is lived. What are these adult children's thoughts as they sit by their parent's hospital bed? What is their experience of awakening each day to prepare for the daily outpatient routine? What is it like to drive to the hospital ward? What is it like to inhabit the house where the ill parent can no longer live? As van Manen proposes, these are experiences that are lived and understood without imposing a theoretical framework. Thus, I chose van Manen's hermeneutic phenomenology approach because as van Manen would say, I was interested in explicating the meanings of these adult children's experiences as "they live them in their everyday existence" (van Manen, p. 11). Ultimately, my choice of methodology is one that seeks to gain a deep understanding "of what it means to be in the world" (p. 12) for an adult child living at home when a parent is diagnosed with, and treated for, cancer.

In the section below I present the reader with current findings of the extant body of research available. I also identify current gaps and biases of the literature available.

### **Literature review: introduction**

The present thesis seeks to explore a human experience that has been for the most part ignored in the extant body of knowledge. A thorough literature review shows that, to date, little is known about the experience of adult children living at home who have a parent diagnosed and treated for cancer (Mosher & Danoff-Burg, 2005). Thus, the unique issues and challenges that these adult children may face as a result of their parents' cancer diagnosis

and treatment remain unknown. The purpose of this broad literature review is to inform the reader of the state of current research to identify gaps, limitations, and biases, as a context for undertaking the present thesis. I first provide a brief review of psychosocial research on the impact of cancer on the family in general. I follow by introducing studies that have looked at adult children and parental cancer.

## **Cancer**

Cancer is the second leading cause of death in North America and, according to Statistics Canada (2007), the second cause of death in Canada. What is more, the Canadian Statistics Agency recently reported that in a very near future, cancer may surpass the death rate of the current leading cause of death, cardiovascular disease. In fact, while cardiovascular deaths have been decreasing since 1979, cancer deaths have been steadily on the rise. According to Statistics Canada (2007), 324,486 Canadians died from cancer between the year 2000 and 2004. In 2007, it is expected that 159,900 Canadians will be diagnosed with cancer (and that excludes 69,000 cases of non-melanoma skin cancer), while 72,700 will die from the illness (Canadian Cancer Society, 2007).

Cancer, as an illness, has been conceptualized as one that brings instant feelings and thoughts of pain, suffering, and death (Gordon, 1990). Yet, most of the literature in cancer has focused on conceptualizing cancer as a disease: there are diagnosis, treatment protocols, and a prognosis, all of which are cast in technical and scientific terms: the language of medical science (Hayne, 2002). According to van Manen (2002, cited in Hayne, 2002), in a search for a cure, biomedical experts have searched for scientific knowledge, and in doing so they have come to define healing in terms of logical and “rationalistic factors” (p. 184) that classify, explain, and cure pathology. Cancer ushers forth a new life experience: we enter

into the world of biomedical knowledge, one that focuses on the physical and biomedical processes of the disease, in what van Manen (2002) calls the “scientized” (p. 179) illness experience. Such a new world is shaped, informed, and defined, by objective scientific facts and discoveries that comprise the biomedical knowledge. Yet, Hayne argues that such an approach ignores a different but very important knowledge: how human beings experience illness in their everyday lives.

There is a vast body of knowledge that has shown that a diagnosis and treatment of cancer brings to the forefront a host of difficulties that threaten the physical, psychological, and emotional well being of the cancer patient. For example, pain, financial burden, anxiety, sleep disturbances, fatigue, nausea, appetite disturbances, hair loss, depression, and fear, among others are well-documented findings in the empirical literature on the impact of cancer on the patient (Chochinov, 2001; Graci, 2005; Herrstedt, 2002; Kayl & Meyers, 2006; Kvale & Shuster, 2006; Richardson, 1995; Rosman, 2004; Visser & Smets, 1998; Wright, Kiely, Lynch, Cull & Selby, 2002).

While empirical sources are valuable, they may not address many of the cancer patients’ experiences. As Hayne (2002) and van Manen (2002) suggest, one may wonder, for example, how does it feel to see one’s hair falling out? How does the body experience nausea? What is it like to live with pain? How does one make sense of one’s illness?

### **Impact of cancer in the family**

Increasingly the family is becoming the major provider of informal care for cancer patients (Mosher & Danoff-Burg, 2005; Thomas & Morris, 2002). Moreover, there is an increased recognition that the diagnosis and treatment of cancer not only causes significant distress for patients but also for their families. Some researchers have begun to view family

members as the “co-sufferers” in the cancer journey (Matthews, Baker, & Spillers, 2003).

While there is an extensive body of research that has examined the impact of other chronic illnesses such as Alzheimer/dementia on family members, less is known about how cancer can affect the family (Matthews et al., 2003; Thomas & Morris, 2002).

More recently, studies have begun to explore the impact of cancer on family members. These few investigations have focused predominantly on the impact of cancer on parents whose offspring have cancer (Goldbeck, 2001; McGrath & Chesler, 2004), the impact of parental cancer on children and adolescents (Harris & Zakowsky, 2003; Lewis, Hammond, & Woods, 1992; Osborn, 2007), and overwhelmingly on spouses of cancer patients (Case, 2004; Colgrove, Kim, & Thompson, 2007; Chen, Chu, & Chen, 2004; Fang, Manne, & Pape, 2001; Harden, 2005; Passik & Kirsh, 2005; Pitceathly & Maguire, 2003; Teel & Press, 1999; Wagner, Bigatti, & Storniolo, 2006).

For example, Welch, Wadsworth, and Compass (1996) examined the impact of a parental cancer diagnosis on children and adolescents. The authors found that while parents did not perceive any distress in their children (6 to 10 year olds) and adolescents (11-18 year olds) following the diagnosis, adolescents and children scored high in anxiety/depression and aggression measures. Adolescents reported higher anxiety and depression symptoms than children, and female adolescents whose mothers were ill scored the highest in psychological distress. In this study, internalizing (i.e., depression) and externalizing problems (i.e., aggression) were assessed through standardized measures such as the Youth Self Report (YSR) and the Child Behavior Check List (CBCL). Welch et al. acknowledge that there was great variability on participant scores. It is important to note that in a recent study, no differences were found in anxious-depressive symptoms among children whose parent had cancer and those whose parent was healthy (Harris & Zakowsky, 2003). In fact,



adolescents whose parent had cancer had lower symptoms of post-traumatic stress disorder (PTSD) than adolescents whose parents were healthy (Harris & Zakowsky, 2003).

Osborn (2007) who conducted a recent literature review on the impact of a parent's cancer diagnosis on children and adolescents (4 databases were searched) found, however, that children (between 3-8 years) and adolescents (ages varying from 16-18 years old) who had a parent diagnosed with cancer were at a greater risk of internalizing problems (i.e., depression), with adolescent daughters having the highest risk. Osborn highlighted that all these studies were quantitative using standardized inventories such as the Youth Self Report (YSR), the Child Depression Inventory (CDI), and the State Trait Anxiety Inventory (STAI) that are designed to tap into symptoms of psychopathology. As well, the majority of participants in the above studies were overwhelmingly female accounting for 89 % to 100% of the sample.

Although quantitative studies contribute to our knowledge, it is also the case that they can only provide a partial understanding of the phenomenon. Quantitative research does not and is not designed to describe the rich details of everyday experience of parental cancer as it is lived by the children/adolescents, nor does such research inform us as to how these children and adolescents understand their experience. Thus, such research presents only a partial picture of what it is like to have a parent diagnosed with cancer, viewed through a child/adolescent lens. Moreover, these studies are biased as they only use measures of psychopathology, taking a vulnerability/deficient perspective to illness (Mosher & Danoff-Burg, 2005; Power & del Orto, 2004). One may wonder how one can discover transformation and growth through the experience of cancer, if participants are only presented with measures that tap into pathologies?

## Spouses

Studies have been concerned with the impact of cancer on spouses of cancer patients (Mosher & Danoff-Burg, 2005; Pitceathly & Maguire, 2003). Empirical findings have indicated that many spouses of cancer patients experience considerable social (i.e., isolation) and psychological distress (i.e., anxiety, worry, stress, depression) that are equal to (Fang, Manne, & Pape, 2001, Pitceathly & Maguire, 2003; Wagner, Bigatti, & Storniolo, 2006) or surpass that of the patient (Harden, 2005). Furthermore, emotional distress may continue long after the cancer treatment has concluded (Northouse et al., 2000; Harden 2005; Pitceathly & Maguire, 2003). Psychosocial distress may be explained by Peleg-Oren and Sherer's (2001) findings that a diagnosis of cancer often creates a crisis for spouses' caregivers. Spouses not only need to cope with increased social isolation, diminished income, and new responsibilities brought by the cancer diagnosis, but they also need to provide emotional support to the family without being able to express their own distress. Such findings are supported by Harden (2005) who indicates that a consistent finding in the literature is that spouses not only need to hide their own feelings of distress, but also must instil hope in others by projecting an image of being "strong and positive" and to carry on with the daily routines in order to maintain a sense of normality for the family. For Harden (2005), spouses' depictions of being strong and hopeful at a time of crisis, while at the same time repressing their own fears and worries, may explain why they identify their role as providers of emotional support as their most stressful job, despite the increased instrumental responsibility that they face due to their spouses' illnesses.

It is worth noting that the increasing instrumental/physical responsibilities that a cancer diagnosis places on the family may also lead to fatigue, lower energy, and significant sleep disturbances among cancer patients' spouses, independent of the carers' gender (Passik

& Kirsh, 2005; Teel & Press, 1999). Increasing instrumental responsibilities and higher physical demands related to patients' physical care may explain Colgrove, Kim, and Thompson's (2007) findings. According to Colgrove et al., spouses of cancer patients have poorer physical health than the population at large. In turn, poor physical functioning is related to higher caregiving stress and diminished quality of life among spouse caregivers (Colgrove et al., 2007). Increased physical demands brought on by the cancer treatment leaves many spouse caregivers to experience decreased sleep, which may then impact adversely their psychological health (Teel & Press, 1999).

As with the research in children and adolescents, the large majority of studies examining the impact of cancer on spouses have also used a quantitative methodology that has been biased in examining only the negative impact of the illness (Mosher & Danoff-Burg, 2005; Thomas & Morris, 2002). In fact, Thomas and Morris (2002), who conducted a review of the research on family carers of cancer patients, call attention to investigating this area of research from a human science perspective. These authors argue that most of the research in cancer family carers has for the most part solely focused on the experience of wives from a "positivistic" (p. 179) perspective and, consequently, relies exclusively on psychometric measures to produce what the authors call the "hard evidence" (p. 179). Furthermore, Thomas and Morris affirm that by focusing only on spouses as carers and, in particular, carers of palliative patients, the experiences of other family members, such as adult offspring, continue to be ignored. These authors call for "interpretive" and "qualitative" approaches (p. 181) in order to gain understanding of the complexity of the participants' parental cancer experience. In doing so, Thomas and Morris argue this area of research may also uncover the potential for individuals to construct meaningful growth or positive personal change as a result of the cancer illness rather than focusing exclusively on

what the authors call the current “burden” and “distress” (p. 181) perspective. Bellizzi (2004) echoes such concerns, suggesting that in order to uncover meaning as a result of a traumatic event such as a cancer diagnosis and treatment, researchers must abandon the quantification of the inquiry in favour of a qualitative paradigm. For Bellizzi, quantitative studies reduce findings to numbers and statistics and only tap the very surface of a complex phenomenon such as personal growth in the face of trauma.

### **Parental cancer: adult children as caregivers**

While the above studies have examined the impact of cancer on family members in general, a small number of studies have begun to include some adult children as participants. For instance, Lowenstein and Gilbar (2000) examined perception of caregiving burden among caregivers of elderly cancer patients. Though most participants were spouses, the researchers also included adult children; spouses were defined as the primary caregivers, and adult children were operationalized as secondary caregivers. Caregiving burden was assessed via the Caregiver Burden Scale that taps into measures of psychological well being, financial distress, and caregiver health. Participants also completed the Instrumental Activities of Daily Living Scale. The authors found that spouses and offspring of cancer patients reported equal emotional distress but higher distress than the patient. Elderly spouses reported higher burden, however, and higher financial and physical distress than the offspring. It is worth noting that in this quantitative investigation none of the adult children whose ages ranged between 25 to 56 years old were living at home.

Matthews, Baker, and Spillers (2003) examined the impact of cancer among spouses, middle-aged adult children, and other family members (i.e. mothers, fathers, siblings, etc.). The sample also included friends of the patient. Data were collected through a series of

Likert type questionnaires such as the Quality of Life-Family Tool (i.e., subjective burden, anxiety, worry and other negative affect), The Life Orientation Test (to assess pessimistic expectations), and the Caregiver Strain Scale (i.e., to assess relational isolation, relational loss, health behaviours such as smoking, alcohol use, etc.). An important contribution of this quantitative study is that caregivers scored higher in all measures of physical and emotional distress (i.e., uncertainty about the future, fear of recurrence) than the patients themselves. In addition, caregivers' mean scores in pessimistic expectations were also significantly higher than those of the patients. It is important to know that in this study the large majority of caregivers were spouses or partners (83%). In fact, only 7 % of the sample was classified as adult children. Moreover, the authors did not provide any information as to the age of these adult children (though it was stated that the majority were middle-aged) and whether or not the adult children were living at home at the time of their parents' cancer.

Although Matthew et al.'s (2003) study reveals some information as to what the impact of cancer may be like on family caregivers, it is also the case that its contribution in understanding the experience of parental cancer on adult children living at home is limited. For example, given the comparative nature of Matthew et al.'s research, results showed only that as a group, family caregivers experienced higher distress and higher strain than patients, but did not reveal how adult children perceive their experience. Neither does the study provide the rich details necessary to understand the full extent of the distress that adult children experience as a result of their parents' cancer diagnoses and treatment. Moreover, these researchers do not distinguish between the impact of caring for a cancer patient on a spouse from the impact of parental cancer on an adult child, as results are collapsed into two groups "patients" and "caregivers." Lastly, and more importantly, whereas this study informs us that as a group, family caregivers experienced higher distress than patients, group

mean differences cannot elucidate the meaning of the experience or what the experience of having a parent diagnosed with cancer for an adult child is like. As Polkinghorne (2005) notes, quantitative research is designed to collect numerical data, typically by using Likert type questionnaires/scales. Yet, these instruments can only “gather surface information” (p. 138) rather than illuminating the fullness of the experience as it is lived and felt. Thus, Matthews et al.’s study is limited in its contribution to furthering our understanding of the phenomenon of interest: the lived experience of parental cancer for the adult child living at home, from the participants’ accounts.

Matthews et al.’s findings are in line with those recently reported by Bowman, Rose, and Deimling (2006) who found that family members of cancer patients, either the spouses or adult children, appraised the cancer experience as more stressful than the patients themselves during diagnosis, treatment, and remission, and such an appraisal prevailed even years after the cancer treatment had concluded. In this quantitative study no information was provided in terms of whether adult children of cancer patients were living at home and it is not possible to distinguish specific ages for each group (spouses and adult children). Family members were described as one group, inclusive of spouses and adult children, with ages ranging between 29 to 86 years old, despite the fact that adult children and spouses may have different carers’ responsibilities, obligations, and needs (Bakas, Lewis, & Parsons, 2001).

It is important to note that all the above studies (Bowman, Rose, & Deimling, 2006; Lowenstein & Gilbar, 2000; Matthews, Baker, & Spillers, 2003) are quantitative and are therefore not designed to explore the illness experience as it is lived by the participants. Quantitative research does not delve into or explore the rich contextual details that may influence how an experience is lived, or capture the complex meanings that participants may

draw from their experience (Maxwell, 1996). For example, the above quantitative studies inform us that as a group there are differences among the participants or correlations among the variables under study, but do not provide insight into the unique experience of the individual adult children who participated. As van Manen (1990) explains, mechanistic and statistical explanations of causation and correlates cannot account for how the experience is lived and felt.

### **Parental cancer and adult children**

Mosher and Danoff-Burg (2005) highlight the need to examine the experience of adult children apart from the experiences of the spouse. Moreover, they note that currently there is scant research that has examined the impact of parental cancer on young adult children. For these authors, research for the most part has been concerned with investigating cancer from the spouses' or patients' perspectives while ignoring the social context in which the illness emerges. For Mosher and Danoff-Burg, the focus on the individual spouse-dyad may reflect the individualistic values of Western/North-American culture. Yet, one may rightly argue that adult children living at home are very much an important part of that social/familial context in which the illness unfolds.

For Hodges, Humphris, and Macfarlane (2005), cancer unfolds within the landscape of a familial context. Hodges et al., who conducted a meta-analysis examining psychological distress on family members of cancer patients, noted that, in most of the studies, adult children are heavily underrepresented. Of the 21 studies in Hodges et al.'s (2005) meta-analysis, in 17 of them participants were exclusively spouses. In the remaining four studies, the overwhelming majority of participants were still spouses, with adult children (and other family carers such as mothers, sisters, brothers, nephews, etc) accounting for less than 5 %

of the sample. In fact, given the low representation of adult children, Hodges et al. report only on the spouse-patient dyad, in discussing the findings. It is important to add that in the studies that have included adult children, it is impossible to distinguish their ages, as spouses and adult children's ages are collapsed into a single group. Hodges et al. concluded that it is crucial that future research examine the experience of the impact of cancer on the family beyond the spouse-patient dyad.

Recently a small number of researchers have begun to examine the experience of adult children. Yet these studies have focused chiefly on the experience of middle-aged daughters (not living at home) of breast cancer patients (Mosher, Danoff-Burg, & Brunker, 2005; Cohen & Pollack, 2005). Mosher and Danoff-Burg (2005) also note that, like the studies involving children, these studies have taken a quantitative approach and used psychometric measures assessing pathology, thus underscoring a deficit/distress approach to illness. For example, one study using a series of standardized instruments that tap into depressive symptoms, mood, and posttraumatic stress disorder (PTSD) found that among daughters of breast cancer patients (mean age 50), one fifth of them could be diagnosed as having some form of PTSD and close to half of the daughters had symptoms of clinical depression (Mosher, Danoff-Burg, & Brunker, 2005), and these results were independent of whether daughters were involved in caregiving.

In a similar line of research, Boyer, Bubel, Jacobs, Knolls, Harwell, and Goscicka et al. (2002) explored distress and posttraumatic stress symptoms among daughters (aged 15 to 71) of breast cancer patients and their mothers (aged 40-95). In this study, daughters, who were mostly middle-aged and married, reported seeing their mother once a week, and close to 40 % reported little or no involvement in their mothers' care. Participants responded to a series of tests assessing posttraumatic stress (the PTSD-RI scale), the degree of contact with



the ill mother (Family Exposure to Cancer Rating, FECR), and caregiving involvement. The authors found that the large majority of daughters (92 %) thought of the diagnosis as a “trauma,” that had been “very stressful,” and 13 % of daughters had symptoms consistent with PTSD. It is important to add that in Boyer et al.’s study close to 20 % of the daughters had a cancer diagnosis of their own. It is possible that such an experience may also play a role in the daughters’ distress.

Cohen and Pollack (2005) extended the above study by examining whether emotional distress of mothers with breast cancer impacted daughters’ psychological distress, daughters’ perceived feelings of stress, and daughters’ immune system functioning. Daughters (aged 24 to 40 and mostly married) responded to various standardized inventories such as the Symptoms Checklist Revised (SCL) which tap into measures of emotional distress, a scale tapping into subjective caregiving burden, among others. Blood (i.e., cortisol plasma), urine tests, and hormonal tests were also taken. Daughters also responded to how frequently they met with the mother and how frequently they provided some assistance to their mother. It is important to add that only 41 % of the target daughters participated in the study.

Results of the study revealed that daughters, whose mothers scored high in measures of distress, also reported higher distress themselves, and also had a more impaired immune system. Daughters’ distress was also associated with their perception of caregiving burden. Moreover, daughters that met more frequently with their mothers (once in two weeks or once a week) reported higher psychological distress and higher subjective caregiving burden than those daughters who met less frequently (less than once in two weeks), though the amount of care that daughters gave did not differ. Thus Cohen and Pollack’s findings, as well as those of Boyer et al., highlight that a breast cancer diagnosis impacts the

psychological and physical health of daughters, despite the fact that, on average, daughters met once a week with their mother. One may wonder then about the experience of adult children who live on a day-to-day basis with their parents at the time of their parents' diagnosis and treatment. What are the consequences for these adult children?

Whereas in Cohen and Pollack's study daughters are in close age range to the age inclusion of the present thesis, there are also methodological differences that distinguish my research from that of Cohen and Pollack. First, I am interested in uncovering the experiences of adult children who were living at home at the time of their parents' diagnosis and treatment. In Cohen and Pollack's study, participants on average met with their mothers once a week (or less). Second, I am seeking to explore such an experience for both sons and daughters, regardless of the type of cancer. In contrast, Cohen and Pollack's research is concerned only with daughters whose mothers have breast cancer. Third, the current thesis is not concerned with using a standardized battery of psychometric measures such as inventory and scales that tap into indices of psychopathology, as is the case with Cohen and Pollack' study. The present thesis gathers personal and individual data through in-depth interviews in the hope of gaining access to the meaning of the lived experience from the point of view of the participants. Lastly, and more importantly, the present thesis, in contrast to the research of Cohen and Pollack, is rooted in differing and competing epistemological assumptions. Like the above-mentioned studies on adult children and parental cancer, Cohen and Pollack's research is quantitative in nature, relying on psychometric measures and statistical analysis (i.e., inferential statistics, multivariate analysis of variance) that tap into differences among groups, relations among variables, or general characteristics of the sample being studied (Polkinghorne, 2000). The present thesis is one that is grounded in a qualitative paradigm, and more specifically, in one that is rooted in an

interpretive phenomenological approach as proposed by van Manen (1990). As such the present thesis does not seek to capture, through the use of instruments and scale, a detached objective reality. This thesis seeks to uncover essential themes from the participants' rich narratives. Knowledge is constructed through the interaction of the speaker and the listener and through the interpretations of what is said.

Polkinghorne (2000) argues that the psychological inquiry has relied on quantitative methods that can be followed "step by step" (p. 453). According to Polkinghorne, such a methodology assures "valid and reliable" (p. 453) findings and the discovery of the "truth" (p. 459). Yet, Polkinghorne affirms that "true knowledge" of everyday experience cannot be "methodologically generated" (p. 456). For Polkinghorne, it becomes essential that the inquiry of our everyday experience must be from a human science perspective. According to Polkinghorne, human science addresses people's experiences, and how people understand and actively make meaning of those experiences. It is in this way, Polkinghorne argues, that knowledge is advanced. Although there is a growing body of research that has now begun to qualitatively explore the experience of cancer patients, it is also the case that such an effort has not been extended to understand the unique experience of adult children living at home when a parent has cancer.

## Summary

The body of research reviewed highlights that a diagnosis and treatment of cancer brings considerable distress to family members of cancer patients that may compromise their ability to cope with their parents' illness. Among middle-aged adult children, the literature shows they are at a higher risk of experiencing emotional distress as well as symptoms related to depression, anxiety, and post-traumatic stress. Middle-aged adult children, who

are involved in their parents' care, are more likely to report diminished quality of life, fear, uncertainty, and higher burden from the caregiving tasks.

The studies reviewed provide, however, a limited understanding of the parental cancer experience from the point of adult children living at home. Several limitations have been identified in the extant body of research. Most studies on the impact of cancer on family members have overwhelmingly focused on spouses of cancer patients. Of the few studies that have incorporated adult children in addition to the spouses, findings are reported under the umbrella term of "caregivers," and thus it is not possible to distinguish either the age of the adult children as results are collapsed into a single group. Moreover, within studies that have included adult children, ages are quite disparate with the majority being middle-age adult children. The cancer experience of a 21 to 35 year old adult children living at home may present unique challenges to those from offspring who are much older, not living at home, who already have a family of their own, and whose parents may be elderly, in what is referred to as the "sandwich generation" or "women in the middle" (see Brody, 1990, for a review). Lastly, in most or all the studies examining the impact of cancer on adult children, participants were adult children not living at home.

The vast majority of studies on the impact of cancer on family members, including adult children, have used quantitative methodology. While quantitative studies contribute to the body of knowledge in important ways, it is also the case that their contribution is limited, allowing access to groups or individuals differences, but providing an incomplete understanding of how the illness is lived by each individual. Polkinghorne (2005) indicates that quantitative research may not be suitable to the in-depth exploration of the fullness of the participant's unique life experience. Quantitative studies do not answer the question of what the experience of having a parent diagnosed with cancer when one lives at home is like.

Quantitative studies cannot illuminate the meaning of that experience nor do they provide in-depth insight into the individual's unique story: that is, the rich details that comprise the human experience remain hidden.

Much of the literature available is based on a conceptualization of the parental cancer experience as one of distress, loss, and burden, and thus the idea is perpetuated that individuals, in the face of adversity, are unlikely to assign some positive meaning to their experience; instead, the human experience is reduce to one that stresses psychopathology. Current research focusing on quantitative measures of psychopathology (i.e., depression, anxiety) entrenches the notion that individuals are unable to experience growth in the face of a life threatening illness and, in this way, continues to reinforce the “stress-vulnerability” perspective on illness (Power & Dell Orto, 2004, pp. 5-6).

People are unique and they construct unique meanings from their experiences. While a diagnosis of a life threatening illness such as cancer may bring losses, it is also the case that such a diagnosis may have the potential for transformation. As Power and Dell Orto (2004) note, illness may be redefined not just as an experience of loss and distress but also as an opportunity to rise above the very challenges that the illness has brought. Such positive findings in the face of adversity have now been recognized in the empirical literature as the phenomenon of posttraumatic growth (PTG) (Tedeschi & Calhoun, 1995; Tedeschi, Park, & Calhoun, 1998).

In the chapters that follow, we will delve deeper into the lived experience of adult children drawing from an additional body of literature. I will first complement the literature review by presenting an in-depth description of the qualitative methodological procedures that I have followed to gain insight and a deeper understanding into these participants'

stories and thus to uncover the significance of these adult children's experience of parental cancer.

## CHAPTER II. METHODOLOGY

The purpose of this study is to describe and explore the lived experiences of adult children living at home whose parent has been diagnosed with, and has undergone, cancer treatment. The present exploratory study is rooted in hermeneutic phenomenology as proposed by scholars such as van Manen (1990). Guba and Lincoln (1994) define a methodological approach as “the basic beliefs system or worldview that guides the investigator” (p. 105). It follows then that hermeneutic phenomenology has informed all aspects of this study, including the research method, rationale for the study, and the research question. Hermeneutic phenomenology combines features of both Husserl’s descriptive phenomenology (for a review see Wertz, 2005) and interpretive phenomenology (for a review see McLeod, 2001; Polkinghorne, 2000; van Manen, 1990).

Phenomenology is the study of “lived experience,” writes van Manen (1990, p. 9), and it can be seen as “a science of meaning” (Purcell, 2006, p. 14). Phenomenology is concerned with the experiential life of human beings and aims to understand the “lifeworld of immediate experience” (van Manen, 1990, p. 182). Phenomenological research does not seek to provide “scientific” explanations; rather it is concerned with methodically describing and understanding the essence of the phenomenon as it is lived by participants (Purcell, 2006; van Manen, 1990). According to Husserl, to gain access and to reflect on the “lifeworld” of others, the phenomenological researcher must engage in a dialogue in which he or she empathically listens to the participants’ voices without assumptions, pre-conceived ideas, theories, judgements, and values: a process described as *the epoché* or *bracketing-off* of any

preconceived knowledge (van Manen, 1990; Wertz, 2005). It is only by bracketing our assumptions that the phenomenon under study, the “thing” itself as Husserl states, can emerge and be understood free of bias (Burston & Frie, 2006; Gadamer, 1989). It is by “bracketing off” our assumptions, a process known as the phenomenological reduction, that the very essence of the phenomenon can become known (Wertz, 2005).

Martin Heidegger, with the publication of his seminal work Being and Time (1962, English translation) brought about a major shift in phenomenology. Heidegger proposed a hermeneutic phenomenology, that is, a phenomenology that is interpretive rather than descriptive (Gadamer, 1989). Hermeneutics was traditionally defined as the interpretation of text, and in its earliest years it underscored the interpretation of religious and sacred texts (Polkinghorne, 2000; Gadamer, 1989). Later, and with Heidegger, it came to be the interpretation of human beings. Central to Heidegger’s hermeneutic phenomenology is the concept of *Dasein* or examination of humans, “Sein”, as “Being-in-the-world” (Burston & Frie, 2006). For Heidegger (1962), being human is to exist always in relation with others; thus, understanding cannot occur in isolation. Rather, it is always contextually situated. According to Heidegger, in the search for objectivity the inquirer has attempted to lift his or her experiences, suppositions and beliefs, yet our interpretations are “never a presuppositionless apprehending of something presented to us” (Heidegger, 1962, pp. 191-192). We encounter the world through the prism of our perspective and through the knowledge we already have (Burston & Frie, 2006). Thus, contrary to Husserl’s proposition that the researcher is able to transcend his or her biases, for Heidegger, to “bracket out” or to suspend our presuppositions, past knowledge, values, beliefs and previous experiences is futile; the inquiry does not occur in a vacuum. Knowledge is filtered and interpreted through the would-be-knower milieu. As soon as the inquirer asks a question about the



lived world of experiences, notes Heidegger, the inquirer's words reflect his or her assumptions and interpretation about that experience (McLeod, 2001).

Humans are intrinsically connected to time, others, and their socio-culture world, notes Heidegger (Herda, 1999), and this relatedness is always linguistic (Llewelyn, 2002; Herda, 1999). For Heidegger, "Being in the world is Being in dialogue" (Llewelyn, 2002, p. 123). "Discourse," writes Heidegger, may be at the very core of the essence of what it means to be human (Herda, 1999) while Gadamer (1989) asserts that language and dialogue lie at the very crux of hermeneutic phenomenology. For Gadamer, understanding unfolds through a dialogue between two parties: the researcher and the streams of words to be interpreted. Through this dialogue, the researcher uncovers the meaning "spoken" by the text. Yet the researcher does not come to the linguistic encounter devoid of assumptions and beliefs. For Gadamer, interpretation does not involve "neutrality nor the extinction of one's self" (1989, p. 238) and as Heidegger (1962) earlier stated, becoming aware through a process of reflection on one's biases, prejudices, and suppositions is critical to the process.

Like Gadamer, Levinas also underscores the dynamic dialogue between the text and its interpreter (Davis, 1996). As Davis states, for Levinas "every aspect of language is potentially interpretable" (p. 117). Just as Heidegger (1962) and Gadamer (1989) had suggested, Levinas sees language and interpretation at the very core of our experience as humans (Critchley, 2002). According to Levinas, writes Critchley (2002), phenomenology seeks to uncover through a process of reflection and interpretation the meaning of our common and unreflective experiences as we historically live in the social world. Whereas Heidegger had stressed the subjectivity of a solitary *Dasein* as a "being that interprets itself" (Llewelyn, 2002, p. 121), for Levinas "intersubjectivity" is the very essence of our being-in-the world (Davis, 1996). "Concrete life implicates others," affirms Levinas (Purcell, 2006, p.

23) and thus we embody an “intersubjective” world. Language is not only an instrument of *Dasein*, of our own understanding, as proposed by Heidegger, but is the very event in the *face-to-face* encounter with the other (Cohen, 1986). “The face-to-face relation with the other is not a relation of perception or vision, but is always linguistic. The face is not something that I see, but something I speak to,” affirms Levinas (Critchley, 2002, p. 12). As Llewelyn (2002) explains, for Levinas language is fundamentally “a possession by others” (p. 122) with whom we inhabit our social milieu. Language is ultimately an “ethical relation” (Cohen, 1986, p. 190): it is the ethical responsibility for responding to the other (Levinas, 1987).

Echoing Gadamer and Heidegger, van Manen (1990) notes the importance of language in phenomenological inquiry. For van Manen (2000), “language is the way of accessing and understanding experience” (p. 316). He proposes a method that is grounded in hermeneutics, phenomenology and language, a method that is both descriptive and interpretive, and therefore encompasses the traditions of both Husserl and Heidegger (van Manen, 1990). Thus, van Manen’s method is one that emphasizes the importance of turning to the “thing itself,” to the lifeworld of the other, yet at the same time highlights the essence of humans as interpretive beings.

Phenomenology, writes van Manen, requires an attitude that demands attentiveness and openness: to be attentive to those slight details that make us wonder, and which inform us about the lifeworld or the lived experience of those with whom we engage in dialogue, and to be open to the myriad possibilities that our search for meaning might uncover. It is this natural attitude that allows the researcher to enter “a relationship of dialogical openness” (Kleiman, 2004, p. 13) in which the researcher is open to the experienced world of others, sensitively and empathically sharing, listening, and discovering the feelings and thoughts embedded in our stories and the stories of others (Wertz, 2005).

The hermeneutic, phenomenological method as proposed by van Manen (1990) offers a unique qualitative methodology. It allows the researcher and participants to become immersed in what van Manen calls the “conversational interview.” It is through dialectical engagement that the very essence of the lived experience is understood. For van Manen, “to do research is always to question the way we experience the world” (1990, p. 5). While van Manen’s method is one that is geared to educational research, his interpretive phenomenology is one that has become particularly relevant for those interested in studying lived experience in the realm of counselling (McLeod, 2001) and is becoming widely used in researching lived experiences among those afflicted by illness (Breaden, 1997; Gasquoine, 2005; Giles, 2003; Hall, 2005; Lane, 2005; Locsin, 2002; Murray, 1998).

## **Method**

A purposeful sampling design was used to select respondents for this study. To be included in the study, participants needed to meet the following criteria: be a male or female adult child, living at home at the time of their parent’s cancer diagnosis and treatment, be between 21 to 35 years old at the time of the diagnosis, be 21 to 35 years old at the time of the interview, and their parent must be in remission or currently attending outpatient treatment at the time of the interview. The decision to include participants ranging from 21 to 35 years old was made after reviewing Canadian family statistics. According to Statistics Canada (2006), in 2001 the largest group-age of adult children still living at home is within adults aged 21 to 35 years of age. In contrast to less than 40 % of young adults aged 19 or older living at home with their parents in 1980, nearly 57 % of adult children lived with their parents in 2001. It is worth noting that among young adults of ethnic descent and those living in urban areas, over 60 % of adult children may still live at the family home. Given

that this type of living arrangement has increased, in order to have a better understanding of how cancer affects the entire family unit, it is important to also investigate the experience of young adults (daughters and sons) when dealing with parental cancer. Absent in the current research literature are the voices of adult children living at home when a parent is treated and diagnosed with cancer. Consistent with Statistics Canada, the name “adult children” in this thesis encompasses young adults living at home within an age of 21 to 35 years. According to Statistics Canada (2006), children who are in the category of 20 years or younger and still living at home “are in a different life cycle or life situation” (p. 3) than those aged 21 to 34 years old.

To invite participants for the present study I placed posters at a university, a college, at a major hospital specializing in the treatment of haematological cancers, and through advertisements placed in various community/local newspapers. Participants were also drawn from personal contact.

### **Interview procedures**

The researcher conducted all interviews, each in a location and time chosen by the participant. Interviews were audiotaped and then transcribed verbatim. Interviews lasted one and half to three hours and questions were open-ended. Participants were not required to provide their names and pseudonyms were used to protect their identities. The initial contact was made by telephone or email. Before the open-ended interview began, participants were given or sent by email a written document stating the purpose of the study, what their participation involved, and potential risks. In our first meeting participants were again asked to read the informed consent document and were encouraged to ask any questions that they might have about their participation. Participants signed the consent

form before engaging in a conversational dialogue. The Ethics Board of the Simon Fraser University approved this study.

### **The interview**

Interviewing as a way of knowing was chosen because I was interested in gaining access to the complexity of the adult children's lifeworld. In-depth interviews allow participants to discuss their daily life experiences, thoughts, feelings and the events most significant to them in their own words and voices. As individuals recount their stories, they tap into lived experiences: vivid and meaningful moments, images, and instants imprinted in their "consciousness," writes Seidman (2006, p. 7). Interviewing allows a dialogue between researcher and participants and thus becomes a tool in gaining a deeper understanding of the rich experience of others through their stories (Seidman, 2006).

As we began our interview, I encouraged participants to recount the time, from just before the diagnosis until the present experience, in as much detail as he/she felt comfortable, including their thoughts, feelings, beliefs, and the significant events they experienced. Consistent with phenomenological research's aim to describe human experience as it is lived by the person (Wertz, 2005), I kept my verbal responses to a very minimum. I used paraphrasing, reflective listening, and asked open-ended questions. Drawing from my clinical experience in the counselling field, I incorporated the use of prompts, minimum encouragers, active listening, and above all, empathic understanding to facilitate the unfolding of the participant's story. My clinical experience as well as my personal experience with cancer were important in building trust and most importantly in facilitating empathy with the participants, which is critical in qualitative interviews (Stiles, 1993). Wertz (2005) notes that building rapport with participants is an essential task for the

researcher if meaningful data is to be generated. Trust may in turn lead participants to feel comfortable and thus openly disclose and share their experiences (Wertz, 2005).

## Questions

The question that this study seeks to answer is: What is it like for adult children living at home to have a parent diagnosed with, and treated for, cancer? While I encouraged the participants to relate their stories freely, I also prepared guiding questions, followed by prompts, to focus the interview and to facilitate the unfolding of the participants' stories. Specifically, while five main questions guided the interviews, they were left open with questions asked only if they were not covered spontaneously by the participants. Examples of guiding questions are: What was it like for you to discover that your parent had cancer? What was it like for you when your parent went through cancer treatment? (See examples of questions and prompts listed in the appendix).

## Data analysis and interpretation

This study required immersing myself in the data so as to draw interpretations of the participant's accounts. In his book, Researching Lived Experience, van Manen (1990) proposes the following framework to study the lived experiences: "First, one must discover and turn fully to the phenomenon of study. Second, one must investigate the experience as we live it, in all its aspects, rather than conceptualize it. Third, it is necessary to reflect on the essential themes that characterize the phenomenon, that is, thoughtfully asking oneself: what makes this experience significant? What is essential to this person's experience of having a parent undergo invasive cancer treatment? Fourth, one describes the phenomenon through writing and rewriting: it is about a rich and deep interpretation of evocative descriptions. Lastly, it is to consider the parts as well as the whole" (1990, p. 31-32).

In the present study, two of Van Manen's approaches were used to analyze the data: *the wholistic reading* approach and *the selective reading* approach (p. 93). In the first approach, the inquirer must attend to the text as a whole, while searching for phrases that may capture the fundamental meaning of the co-researchers' story as a whole. He or she then attempts to express the very nature or fundamental meaning of the experience in a phrase. In the later approach, the inquirer must listen and/or read the narrative time and time again. Once this is completed, the inquirer must ask: "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" (p. 93). The inquirer then proceeds to make those phrases salient by circling or highlighting the identified text.

"The preferred method for human science involves description, interpretation, and self-reflective or critical analysis," writes van Manen (1990, p. 4). Several authors have asserted the need and importance of developing guidelines to handle qualitative data, as well as providing detailed descriptions of them (Seidman, 2006; Wertz, 2005). Based on van Manen's framework of thematic analysis, I have used the following protocol to conduct an in-depth exploration of the interview and transcripts. First, I listened to the tape a number of times to get a general sense of the whole of the experience. Then I transcribed the entire audiotape verbatim. I immersed myself in the data, that is, I listened to the tape first after finishing the interview and various times after that in order to get a sense of the dialogue as a whole. While listening to the audiotape, I also paid close attention to the speech intonation, affective intensity, short pauses, repetitive language, and long silences. I then read the entire description numerous times, by itself or against the background of the audiotape to get a general sense of the experience as a whole. As I read and listened to the participants' words, I asked myself: what does this narrative tell me as a whole about this adult child's lived

experience of parental cancer diagnosis and treatment? I also wrote about my own experiences with cancer in order to keep in check any pre-conceived ideas and prior understandings that might influence my understanding of the complete story. I then wrote a first impression of the general characteristic of the experience (van Manen, 1990).

Once having written my sense of the participants' stories, I turned to identifying the essential themes and sub-themes embedded in what was said. To accomplish this, I went back to the paper transcripts, and re-read the text, this time with the specific goal of capturing words, phrases, or passages that stood out and that seemed to describe compelling aspects of the experience. I then highlighted those passages and wrote tentative names on the side of the page. In analysing and reducing the data I asked myself: What is powerful here? What is the meaning embedded in those words? What is my empathic understanding of these passages? This process was repeated several times, checking if the phrases or passages selected connected to other passages in the text. I then clustered related themes, labelled them, when possible, using words from the participant's narratives.

*"Languaging* encompasses speaking, gesturing, moving, and being silent," writes Northrup (2002, p. 320). I gave particular attention to every word said, as well as to silences, intensity, intonations, and field notes of my observations written after I had conversed with each informant. For example, I noticed that as participants began to recall their experiences, they were clearly emotional at some moments, at times pausing for long silences when describing them. While nervous, they were also determined to continue their compelling narratives. I also attended to my own speech in the audiotape.

As preliminary themes and sub-themes began to emerge, I wrote down my initial interpretations. Northrup (2002) suggests that it is also important for the researcher to write



alternative interpretations of the described phenomenon. Thus, I again read the text to confirm, modify or drop the emerging themes. Van Manen (1990) argues “hermeneutic phenomenology is fundamentally a writing activity” (p. 7). Accordingly, this later process was repeated several times and the text was written and re-written. Seidman (2006) proposes that in interpreting the data, researchers must reflect on what has been learned from the participant’s lived experience. These are the questions that must highlight interpretation, writes Seidman (2006): “What connecting threads are there among the experiences of the participants? How have the interviews been consistent with the literature? How inconsistent? How have they gone beyond?” (pp. 128-129). I kept such questions in mind as I engaged in re-writing. Having been a participant observer from the beginning of this study, I revisited memos and field notes that I had made and self-reflection annotations I have kept since the very early conception of the study. I also went back to my notes of my talks with my thesis supervisor, revisited the thoughts, ideas, and records that I had made from the literature review so as to illuminate the process of re-writing. My purpose was to allow the participants’ voices to come to the fore in a language that captures the essence of these adult children’s daily lives.

While the above protocol gives the reader an understanding of how I carried on the thematic analysis, it is also important that the reader become familiar with some empirically established criteria by which qualitative research is evaluated. In the section below, I provide a brief summary of current research looking at important guidelines to evaluate qualitative studies, and how I met these criteria in my study.

## Criteria to evaluate qualitative research

Increasingly, researchers have highlighted the inadequacy of evaluating the quality of qualitative research through standards (i.e., validity, reliability) designed to establish credibility in quantitative research, especially in light of the fact that these two methodologies are grounded in opposite philosophical assumptions (Davies & Dodd, 2002; Fisher, 2006; Meyrick, 2006; Morrow, 2005; Rolfe, 2006; de Witt & Ploeg, 2006). Such practices become even more troublesome when they are applied to hermeneutic phenomenological research (Morrow, 2005; Rolfe, 2006; de Witt & Ploeg, 2006). For example, Meyrick (2006) proposes that a common way to evaluate the strength of qualitative research is to ask participants to re-check themes, transcripts, or interpretations, yet Meyrick argues such a practice removes the researcher from the research process — interpretations may no longer express the voice of the researcher. Interpretation is the essence and goal of hermeneutic phenomenology, with the researcher going beyond the realm of the participant's words (Rolfe, 2006; van Manen, 1990). In hermeneutic phenomenology, the researcher seeks to uncover what lies behind the words, with words that are more profound than what has been said, yet always remaining faithful to the intent of the participants' words (Smith, 2007, Personal Communication). In Levinas' words, the researcher must be mindful and respectful of the face of the "other" that speaks. Yet, while the researcher remains faithful to the participant's voice, it is also the case that the text is now embellished with the researcher's interpretation of the event (Smith, 2007, Personal Communication).

Below are presented standards to evaluate hermeneutic phenomenological studies. These standards are by no way exhaustive, but rather reflect the work of scholars such as Meyrick (2006), Van Manen (1990, 1997), Rolfe (2006), and de Witt and Ploeg (2006).

## Reflexivity

Phenomenology underscores the importance of the researcher engaging in self-reflection (Stiles, 1993). Reflexivity may be a crucial tenet in judging or establishing quality in qualitative research (Davies & Dodd, 2002; Meyrick, 2006; Rolfe, 2006). Bradbury-Jones (2001) defines reflexivity as “the process of reflecting critically on oneself as a researcher” (p. 292). As a researcher, counsellor, and a family member of a cancer patient, I have come to the research process with intuitions, knowledge, and assumptions. In disclosing my stance to the reader in the introductory chapter I attempt to make these clear, in what Morrow (2005) calls disclosing the “horizon of understanding” (p. 250). Engagement in a reflexive process has been a focus of my responsibility as a researcher from the very conception of the thesis and throughout the entire research process. For example, I critically pondered what qualitative approach would be most appropriate to answer the research question. I also contemplated how my own experience and prior knowledge could affect the inquiry. For instance, an assumption on my part was that considering the age of the participants, that information seeking through the Internet would play a large role in how participants responded or cope with their parent illness, however my assumptions were not borne out, as this did not arise as a major theme. Another of my pre-conceptions that was not substantiated in the participants’ accounts was the struggle on surrendering control to the medical establishment.

Reflexivity is something that I feel quite familiar with. I have engaged in self-reflection throughout my counselling training and through my work as counsellor. I kept notes before and after the interviews reflecting on my thoughts, feelings, and the interview. I also kept notes of thoughts emerging from my meetings with my supervisor, discussions that took place from the start of the study, and throughout the study, including the

interpretive process and the gathering of data. These notes were of key value in aiding me in the interpretive process. I revisited these memos as I listened to the audiotaped conversations, while I read and re-read the transcripts, and through the entire data analysis process, again paying close attention and monitoring my thoughts. Reflection led me to further immerse myself in the data and again reflected deeply on what participants have said. This also helped me to be mindful of non-verbal behaviour, to be attuned to the impact of my questions, and to fully attend to the participant in the here and now, while also paying attention to my own process. This is the self-reflected stance that strengthens the credibility of the present's thesis findings.

### **Resonance: “lived throughness” and “evocation”**

An important criterion to evaluate hermeneutic phenomenology is the concept of resonance (de Witt & Ploeg, 2006). Interpretative phenomenology does not impose theory nor is there a step-by-step method or guaranteed technique that aims at producing “scientific” results, affirms van Manen (1997). A hermeneutic phenomenological text is one that inspires understanding of our everyday realities (van Manen, 1997). The power of interpretive phenomenological texts, writes van Manen, lies in the “resonance that the word can effect” (p. 345). That is, resonance is “the experiential or felt effect” that the text exerts on the reader (de Witt & Ploeg, 2006, p. 226). For van Manen resonance may include “evocation,” and “lived throughness”, what de Witt and Ploeg (2006) refers to as “concreteness” (p. 225). For van Manen, an evocative text is one that describes the experience in as vivid detail as possible so that the text instils clear and intense images that allows the experience to be brought into the readers’ presence; concreteness requires a text

in which the experience is described in a concrete manner so that it is “sensed” and “felt” by the reader: it becomes recognizable and familiar.

At the very core of this study are concreteness and evocative interpretations and descriptions. The goal was to produce a text that could “speak” to and “resonate” with the reader. My goal was to provide readers a text that allowed them to “suddenly see” (van Manen, 1997, p. 345) the meaning of one life experience: that of adult children living at home whose parent has been diagnosed with, and treated for, cancer. In this thesis, I attempt to engage the reader in a written-text that is suggestive, thoughtful, alive, and one that makes the reader wonder (van Manen, 1997). I strive to re-instate moments and images, feelings and thoughts, embedded in the participants’ narratives. To do that I provide experiential and detailed descriptions in the form of participants’ excerpts, in the hope that readers “sense,” “feel,” and bring into “presence” (van Manen, 1997, p. 353) the experience of these adult children. I went beyond the realm of what is said. I integrated emotional and vivid descriptions articulated in the participants’ voices, woven with existential philosophical thoughts and my own reflection of my cancer experience, to offer thoughtful and potential interpretations, in the hope that the text will uncover for the reader the hidden meaning of these adult children’s experiences. Thus, the reader will come to gain an understanding of *Being-in-the-world* when a parent has cancer. As van Manen affirms, through a text that resonates with the reader, participants’ voices and my voice become alive. This is the “feelingly understanding” (van Manen, 1997, p. 360) that helps the reader to judge the value of this thesis and lend support to the study’s findings.

### **Openness/transparency**

The strength and quality of the inquiry rests with the readers (Rolfe, 2006; Stiles, 1993). It is the reader who ultimately evaluates and judges the quality, cohesion, and credibility of the text (Morrow, 2005; de Witt & Ploeg, 2006). A stance of openness throughout the research process and a balanced integration of the researcher's interpretation and the participants' descriptions are important for the credibility of the studies (de Witt & Ploeg, 2006; Meyrick, 2006; Stiles, 1993). Openness demands that the researcher make explicit to the reader the choices and decisions undertaken throughout the study (Meyrick, 2006; de Witt & Ploeg, 2006). Throughout the study I have attempted to do so: I have tried to describe the research process and what was involved, from how the idea came about, the research question, aim of the study, methods to gather participants' accounts (in-depth interviewing), participants' inclusion criteria, detailed information about the participants, type of questions, and data analysis. In addition, and as Stiles suggests, I have offered to the reader my own narrative, making explicit my prior personal and professional knowledge. I have informed the reader that my stance as a researcher is one that is grounded in hermeneutic phenomenology.

Hermeneutic phenomenology is essentially an interpretive inquiry, yet detailed and rich descriptions are vital so that the reader can assess the quality of the text (Fisher, 2006). It follows that the researcher must strike a balance between the excerpt from the participants' narratives, the researchers' interpretations, and philosophical thoughts (Fisher, 2006). To elicit rich accounts I suggested to participants that they describe their experience in as much detail as they felt comfortable. Interviews were comprehensive and questions were open-ended. I asked few, rather than numerous, open-ended questions. I also followed the questions with probes inviting the participants to provide concrete examples of

the experience being shared. I made sure to seek clarification and/or confirmation as to whether or not I had understood the experiences (Stiles, 1993). Using my skills as a counsellor, I reflected back what the participant had said to make sure that I had understood. All the above helped in grounding descriptions that are detailed and rich.

Through a process of reflexivity, listening and re-listening to the audiotapes, reading and re-reading transcripts and memos, writing and re-writing, re-reading interpretations and re-visiting understanding as I re-immersed myself in the data, I let the text “speak to me” (van Manen, 1997, p. 359). As I interpreted the text, and throughout the research process, I engaged in thoughtful discussions with an expert scholar in the field of hermeneutic phenomenology as well as in van Manen’s (1990) approach. I also supported the findings by using existing philosophical writings from seminal hermeneutic phenomenological thinkers, such as Heidegger (1962) and Levinas (1981, 1987), allowing me to balance descriptions with thoughtful, empathic, and evocative interpretations. I also explored the complexities of the lived experience in light of the existing psychological and social science body of knowledge. Making the research process transparent helps the reader to evaluate the credibility of the present study’s findings (de Witt & Ploeg, 2006).

“In qualitative studies, the researcher is the instrument of the research,” writes Maxwell (1996, p. 66). In fact, van Manen (1990) argues that the lived experience that constitutes the focus of the phenomenological inquiry must have been lived by the researcher. Thus, in the section below I present my background as the “research instrument of the study.”

## **The researcher**

A researcher's background and experience are central to the qualitative research process. One may argue that the researcher becomes the instrument by which data is collected, analyzed, and interpreted. For example, interpretation of the data aims to identify units of meaning or themes in a manner that genuinely reflects the participant's lived experience. For such a task, the researcher's personal experiences are brought to the interpretative field. Thus, the meanings that are discovered, as well as the questions to be answered, may be influenced by the researcher's past experience. That is to say, my own personal experiences with cancer play a significant role in the research process, influencing the interview process and the lenses through which I, as a researcher, see, interpret, and find meaning in the phenomenon being studied.

For van Manen (1990), "the problem of phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much" (p. 46). What we "already know" cannot be suspended. Rather, our beliefs, biases, acquired knowledge, and the suppositions that we make must be put forth. Consequently, it became apparent that my own background must be made explicit to the reader, as it is this background that influences the topic and the research methodology that I have selected for this study.

Van Manen (1990) also argues that a phenomenological question must have been "lived by the researcher" (p. 44). This author also indicates that the investigator must state the stance that influences an interest in the phenomenon being examined. Throughout this research process, I have oriented myself as a parent, a counsellor, and a researcher. I am a Master of Arts student in the Counselling Psychology program at Simon Fraser University. My interest in cancer has been sparked by my own experience with this illness. I am a



mother of two adult children, and my decision to focus on adult children's lived experiences of having a parent diagnosed with cancer is guided by my own experience, as a mother of two adult children coping with this disease. To my knowledge, there is scant psychosocial research that has sought to enter the lives of these adults to attempt to deeply understand the significance of their experience when a parent is diagnosed with cancer.

Phenomenological research, observes van Manen (1990), begins with personal experience and then seeks to see whether it expands to the experiences of others. "We learn from the other," writes Levinas (Waldenfels, 2002, p. 68). Throughout the cancer journey, as a mother and as a counsellor, I often wondered what it must be like for other adult children to have a parent diagnosed with cancer. As I sat each day in the hospital room, I observed other adult children accompanying what appeared to be their fathers or mothers. I noticed myself wondering and asking myself about what it was like for these adult children to have a parent diagnosed and treated for cancer. I wondered what were their feelings after hearing the diagnosis. What were their thoughts as they sat by their parents' bed each day in the cancer ward? What events were vivid to them? Did they find meaning in their lives after going through this experience? Were my own adult children's experiences similar to the experiences of others, as van Manen had suggested? Can their lived experiences teach us anything, as suggested by Levinas? What could we learn from hearing their voices? Given my own academic training in the area of counselling psychology and my personal background in the area of cancer experience, the decision and choice to use hermeneutic phenomenology for this thesis arose organically from the situation: hermeneutic phenomenology is concerned with exploring, understanding, and interpreting the complexity of people's subjectively lived-world through the stories that they tell. In the next chapters I

introduce to the reader the participants' narratives woven in with my reflections and interpretations.

## CHAPTER III. RESULTS

The purpose of this phenomenological study is to understand the lived experience of having a parent diagnosed with and treated for cancer, from the perspectives of adult children living at home. What does this event/illness mean to these adult children? Despite the recognition that cancer affects the entire family unit, the experience of adult children living at home receives minimal attention in psychosocial research. Little is known about how these adult children experience their parent's illness. The present study focuses on uncovering the meaning of these experiences from the initial diagnosis through treatment, with special attention paid to suffering and healing through transformation. My goal is to help uncover the phenomenon and present it to the reader with the hope that the narratives illustrated here might make the immensity of the parental cancer experience known to others. It is hoped that the information gained from this study may serve as an important resource in identifying emotional and psychosocial needs of adult children whose parents have been diagnosed with cancer.

In the results chapter I begin by introducing, through vignettes, John, Amy, and Sarah, the adult children who shared their story with the interviewer. While information such as age, ethnic background, educational level, and marital status, is accurate, the names and some background details have been changed to preserve the respondents' anonymity. I then continue with chapters IV, V, VI, and VII where I present to the reader the emerging essential themes and sub-themes uncovered from the textual analysis. These emerging

themes and sub-themes are interwoven with my personal reflections, my own experience with cancer, philosophical thoughts, and findings from the empirical literature.

The essential themes and sub-themes were derived through a process of reflection and evocative writing as I tried to ask myself and answer: What is revealed here that is essential to this person's experience of having their parent undergo invasive cancer treatment? According to van Manen (1990), phenomenology seeks to come as close as possible to the essence of the teller's lived experience. To gain access to the essential themes embedded in the interviewee's lived experience van Manen proposes asking two fundamental questions: "Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?" (p. 107). These were the questions that guided my thematic analysis.

## **Participants**

Three participants volunteered to take part in the study. Given the depth and detail of the data, and consistent with the literature in phenomenology, three participants were considered sufficient (Wertz, 2005). Participants were drawn either through word of mouth in a local hospital or through acquaintances. John was the first of the participants I interviewed. John knew about my project and had expressed interest in taking part. John and I talked about the thesis that I was developing and he volunteered to participate if I were to pursue the topic. John related that sharing his story was an important step in his cancer journey. Once I received ethical approval to proceed with the thesis, I informed John. We then discussed criteria for participation in the study and agreed on tentative dates for the interview after deciding that John fulfilled the selection criteria. Prior to the interview John

read the study information document and then signed the consent form. John chose to be interviewed at the home of the researcher.

At the time of my conversation with John, approximately seven months had elapsed since John's father, Robert, an accountant, was diagnosed and treated for Leukemia, a haematological (blood) cancer. At the time of his father's diagnosis and treatment, John, 23 years old, was living with his family in the Greater Vancouver area. John was single and he identified himself as being Canadian, from a mostly white background. Up to that time he had been enjoying a leisurely and comfortable middle class lifestyle, working part-time hours and participating in various social activities and sports. Though he was attending college he "was not as focused as he wanted to be." John described himself as outgoing, and prior to the diagnosis, living in a world with "no real worries" or major stressors. John portrayed his life as centred on work, social relationships, sports, school, and just enjoying life. "Before, it was wake up, go to work, come home, either workout, if not, hang out with friends or my girlfriend, just socializing or staying at home and watching a movie. No real worries," he reminisced. Things were quite "positive," with just the ordinary worries of everyday living, he recalled. "I was more or less a happy person, more or less positive with my friends, my girlfriend, and my family. So I was a happy person," John said with a nervous laugh.

Robert, John's father, was diagnosed with Acute Myeloid Leukemia (AML), a life threatening disease. AML is a rare haematological cancer of the blood that demands invasive, arduous, and lengthy treatment protocols including high doses of chemotherapy and other drugs to prevent infection. The treatment also demands lengthy hospitalization, isolation, and at least four months of daily ambulatory hospital treatment. His father's diagnosis was sudden and unexpected as Robert was considered to be in good health. "My father had been working a lot, so things were more routine. For me it was going to school

and working, just like any other year. My day was going to school, going to work and then coming home, and then the same things the next day, seeing my girlfriend here and there. I was getting back into the thick of things after the holidays. Things were good, same old, same old, things were pretty good," John recalled with nostalgia.

John described being actively involved in the care of his father during both the time of hospitalization and the months of daily ambulatory chemotherapy treatment. Treatment included two weeks of hospitalization followed by several months of outpatient chemotherapy, spinal/brain chemotherapy, blood and platelet transfusions, and intensive pharmacology treatment for immune suppression support. John stated that his father was in remission at the time of our conversation.

Amy was the second participant to be interviewed. I met Amy through numerous encounters while our family members attended cancer treatments at a Greater Vancouver Hospital. Amy knew that I was enrolled in the Master in Counselling program and I was pondering the possibility of a project related to adult children living at home whose parent has been diagnosed and treated for cancer. Amy expressed interest in taking part in the study and gave me her phone number and email should the project ever come to life. In a sense Amy was one of the inspirations of the thesis. We exchanged phone numbers and emails. I contacted Amy late in 2006. I emailed Amy and let her know that I had been given ethical approval to conduct the study and I asked whether she would still be interested in participating. I also emailed a document explaining what the study was about, what her participation involved and potential risks of participation, among others. Amy responded that she would like to participate and we agreed on tentative days for the interview. Our second contact was by phone where we reviewed the participant selection criteria and agreed that she fulfilled all the requirements. We then set up a date for the interview.

Amy chose to be interviewed in a small quiet coffee place with which she was familiar. Our conversation lasted a bit over three hours. In our first meeting Amy read and signed the study consent form. At the time of the interview with Amy, approximately over ten months had passed since her father was diagnosed with Acute Myeloid Leukemia, a haematological cancer, and approximately five months had passed since her father had successfully concluded his treatment. At the time of her father's diagnosis, Amy, the middle daughter of three female siblings, was 24 years old, living with her father, mother, and siblings in the Greater Vancouver area. She continued to live at home throughout her father's cancer treatment and at least up to the interview. She identified her ethnicity as Asian. At the time of her father's diagnosis, Amy had finished her post-secondary education at a Greater Vancouver college and she was fully devoted to establishing her career. Amy was single and portrayed her life prior to her father's diagnosis as centred on work, social relationships, and her boyfriend. She had been working two jobs, seven days a week, and had an active social life. "I came from a very busy, busy life," Amy emphasized. "I was seldom at home," she added. Amy described herself as quiet, calm, and the one sibling with the closest bond to her father.

Like John's father, Amy's father Mike, was diagnosed with Acute Myeloid Leukemia (AML), a life threatening disease. As with John's experience, Amy's father required invasive and lengthy treatment protocols including high doses of chemotherapy, blood transfusions, and immune suppression support to prevent and fight infections. The initial induction treatment required six weeks of hospitalization. "He was there for a little bit more than a month, six weeks, ...and then readmitted for a week or two as he had the fever that didn't go away," Amy said. "My dad was readmitted three times to the hospital with all the

complications, until the end of June, then he was declared in remission and then he got to go home,” Amy recalled.

Amy’s father’s diagnosis was sudden and unexpected, as her father was considered to be in good health. Amy noted that her father “had been more tired,” yet he “seldom went to the doctor.” “My mother had been trying to tell him to get a blood test for years, every time she got him an appointment he didn’t go. And he continued to be tired,” Amy stated in recalling the time previous to the diagnosis. “Yeah, my mother had gotten him another appointment. And this day he called his friend as usual to go for coffee. For some reason that day, his friend said, I can’t, I am busy, and I am helping my son fix the house. So my father said: oh, what do I do? I might as well get this done since I have nothing to do. So he got his blood test done and that afternoon we got the call,” Amy said. “There was no time to think. With other illnesses usually you have a year before this person gets sick, and think about it, and cry about it. But here, with leukemia, its not like you have that chance,” Amy said.

Amy described being actively involved in the care of her father during both the time of hospitalization and the months of daily ambulatory chemotherapy treatment. In fact, Amy recalled that she felt responsible for her father’s care. “In a sense I was there 24 hours,” Amy said in referring to her father’s treatment. Amy stated how her mother’s health was also “not very good.” Amy explained, “She had really low haemoglobin to the point that it was dangerous.” “Treatment [for her father] was really hard. Every day was hard,” Amy recalled. Treatment included six weeks of initial hospitalization followed by several instances of readmission to the hospital and total isolation. “It was even scarier when he had to be readmitted from the bone marrow transplant unit to the hospital to stay in a regular ward...and the staff there had no idea about leukemia,” explained Amy. Months of



outpatient care followed, consisting of further chemotherapy, spinal taps, and pharmacology treatments for immune suppression support. At the time of our conversation, Amy said her father had been in remission for the last six months.

Sarah was the third participant. I met Sarah through a family member. Sarah knew that I was completing my thesis in the realm of cancer and adult children experiences. Sarah also was aware that my husband had recently completed his cancer treatment. Sarah contacted me by phone and we discussed the purpose of the study, participation selection criteria, and what her potential participation would entail. Later, we met in person and I gave her the letter of invitation and related that I was happy to provide any additional information she might be requiring before making her decision. Sarah said she would like to share her story but she would prefer to do it after her father had completed some of the scheduled chemotherapy treatments. Sarah confirmed her participation and we made arrangements for a later date that was convenient to her. Sarah chose to be interviewed at my home. Previous to the interview, Sarah and I reviewed the informed consent document. The interview took place in the living room when my children and husband were not in the home. The interview lasted approximately two hours.

At the time of her father's diagnosis, Sarah was living with her father, mother, and a younger sister, at her parents' home located in the Greater Vancouver area. Sarah continued to live at home throughout her father's treatment. Sarah related that she also had an older brother. Sarah stated that she was 24 years old and single. Though she had already obtained a Bachelor degree, at the time of her father's diagnosis Sarah was taking courses at a local university with the intention to continue into graduate studies. Sarah portrayed her life prior to her father's diagnosis as busy with friends, social relations, school, part-time work, and active involvement in volunteer work. Sarah described herself as quiet, happy, and fully

committed to her educational goals. She enjoyed languages, traveling and outdoor activities such as horse riding. Like Amy, Sarah also observed that she was the closest to her father. "I am the closest to my dad in general and he is so sick," Sarah whispered in a tearful voice.

Like the other two adult children that I interviewed, Sarah's father's diagnosis was "totally unexpected." Sarah said that her dad was in good health though he was having some type of urinary problem. "He had been going to the doctor to check for that problem, not cancer," Sarah said with a sombre voice. Sarah described being actively involved, along with her mother, in providing emotional and instrumental care to her father, from the initial diagnosis and throughout treatment. "You need to share the journey. You need to depend on each other," Sarah said.

At the time of the interview with Sarah, approximately six months had passed since her father was diagnosed. Sarah's father was now attending a major cancer center located within the greater Vancouver area where her father was receiving his second chemotherapy treatment. "It is hard," Sarah observed. She stated that her father's treatment involves chemotherapy (six months), as well as a month of radiation treatment. Her father's initial cancer treatment involved total hospitalization for a major surgery, followed by eight weeks of recovery before receiving chemotherapy. "That part was good because he was getting better and stronger. He was eating and you can see he was healthier everyday. But in the back of your head you knew January was coming and that means he was going to start chemotherapy [silence] and you have no idea how he was going to be," Sarah recalled. "It was nerve wracking," she lamented.

It is important to note that two other potential participants answered the community paper ads. The first person participant did not meet the selection criteria due to age (older

than 35) and cancer outcome (death). Then, another potential participant who had learned of the study through university posters, contacted me; unfortunately she contacted me after I had concluded the study.

## Themes

Four essential themes emerged from the stories of John, Amy, and Sarah: 1) *Getting the diagnosis: confronting death*, 2) *Experiencing the impact of treatment*, 3) *The need for emotional support*, and lastly 4) *The cancer legacy*. Each of these four main themes consists of associated sub-themes. These broader themes are grounded in the structure of lived time or temporality. Thus, the cancer experience may be regarded as a journey moving from intense shock and suffering, to agency and responsibility, and lastly to enduring physical and psychological demands. Yet, it was also one of personal growth and transformation.

In the chapters that follow I present to the reader the themes and sub-themes in detail. I have named the first main theme of chapter IV, *Getting the diagnosis: Confronting death*, as it provides a compelling narrative of what is it like for these adult children to have a parent diagnosed with cancer, that is, the diagnosis experience as it was lived by the participants. Chapter V presents the second essential theme that unfolded: *Experiencing the impact of treatment*. Theme two in chapter V exposes the reader to the emotional and personal costs to these adult children of having a parent treated for cancer. Chapter VI provides us with Theme three that arose from the participants' stories as they embarked on their cancer journey: *The need for emotional support*. Theme four, the last essential theme from the participants lived experience, *The cancer legacy*, is presented to the reader in chapter VII. Lastly, in chapter VIII, intertwined with my final reflections of my lived experience, I turn to the conclusion and implications of this thesis.

## CHAPTER IV. GETTING THE DIAGNOSIS: CONFRONTING DEATH

*“Then I got referred to a rheumatoid specialist. And he said, ‘maybe cancer of the bone.’ He stated right out, ‘cancer of the bone,’ which shocked me. I just freaked out. I never heard anything else he said after that.”*  
(Hayne, 2002, p.190).

The first major theme that emerged from John’s, Amy’s, and Sarah’s interviews is: *Getting the diagnosis: confronting death*. It captures the first time that John, Sarah and Amy confront the real possibility of their fathers’ deaths. This theme is consistent with literature on cancer that underscores the belief that cancer, unlike other illnesses, is a family illness (Lewis, 1993), a disease that brings to the fore an existential crisis not only for the patient but also for the family (Becvar, 2005). It involves two sub-themes: the *Intense Emotional Reaction to the Diagnosis*; and *Agency: Pulling together*. John, Amy, and Sarah spoke of how the diagnosis brought a juxtaposition of feelings of shock, disbelief, uncertainty, injustice, and a pervasive fear of the potential loss of their father. *Agency: Pulling together* also emerged as a later theme of *Getting the Diagnosis: Confronting Death*. *Agency: Pulling Together* involves gathering emotional resources, such as sharing emotions and suffering so as to take on whatever responsibilities and actions are needed to restore the loved one’s health.

### **The intense emotional reaction to diagnosis**

Thomas and Morris (2002) note there are few diseases whose diagnosis brings such strong intense emotional reactions as cancer, not only for the person diagnosed with cancer, but also for the family members sharing the news. “Cancer is not a disease of just one

person,” writes Lewis (1993, p. 127). Rather, it affects the family as well as the patient (Case, 2004; Mosher & Danoff-Burg, 2005). Certainly, the cancer diagnosis marks a pivotal event in John’s life. In our interview, John told me that he experienced a large range of intense emotional responses to his father’s cancer diagnosis. John stated that he was shocked upon hearing the word “leukemia” and that he was overwhelmed by feelings of anger, uncertainty, vulnerability, disbelief, anxiety, injustice, and an intense sense of fear.

Without exception, however, the chief feeling that dominated John’s, Sarah’s, and Amy’s emotional reactions during our interviews was fear. Each of the participants provided a thoughtful and touching narrative about how cancer made real the possibility of losing a father. When I asked John what was the first thought that came to him upon hearing the diagnosis, he replied simply “fear,” an intense feeling of fear. Taking long silences he reiterated twice: the “fear of losing my dad.”

I guess, the very first one, was probably fear. Being scared for my dad and then [long silence] after that [long pause] it was the need for all of us to be comfortable with each other, to be comfortable with the kind of disease my dad has. For me, it was the fear of losing my dad [pause]. For me it was, the fear of losing my dad [twice, and long silence].

John’s fears and concerns of death are clear. In John’s words, the type of disease that his father has is one that is associated with the possibility of death. He continued:

I had all these fears in the back of my mind, and if the treatment doesn’t work then obviously it’s just the fear of losing your father. Now it’s a different type but at that point it was because we never knew what was going on. We never knew if the chemo was going to work, we never knew if he was in the group that would react to the chemo, so there was a fear of the unknown. I think you’re always going to have this fear.

John talked about “the fear of the unknown,” a feeling that is rooted in the unpredictability and uncertainty of the future – an intense worry of whether the treatment would spare his dad’s life. John’s fear appears as one of “a future without a future” (Hayne,

2002, p. 189) with his dad. Hayne writes about the uncertainty experienced in diagnosis: “But now, a different awareness may prevail, an awareness coloured by prognostic expectations. An ordinary tomorrow is not assured” (p. 189). John’s narrative highlights that his perceptions of immortality and longevity have been shaken by cancer. Previously, John had perceived death as an event that might occur in a distant future, with old age, when you are “old and grey, the time that you are supposed to die.” Now, he is fearful about his “future without a future” (p. 189) with his father. For John, the cancer diagnosis cements the idea that death can occur suddenly and at a premature age. As Heidegger (1962) noted, for John the word cancer suddenly brings the possibility that his father will *no- longer- be- able- to- be* (Keenan, 1999).

Like John, Amy’s fears also centred on the possibility of her father’s death. Amy uses the word “scared” in response to her father’s cancer diagnosis, a word that she repeated numerous times throughout the interview. According to the Merriam-Webster’s Collegiate Dictionary (1993, p. 1042), “scare” is first defined as “a sudden fright” and secondly as “a widespread state of alarm” whereas “scared” is to be “thrown into or being in a state of fear, fright, or panic”. For Amy, the cancer diagnosis brings the sudden awareness of a new reality: a father, who has never been ill, now faces a potential death. The cancer diagnosis defies Amy’s beliefs that death *stands before* those who are not frail.

It was scary knowing that your dad is sick, knowing that your dad is never sick. Yeah, he was never sick. I was scared. I couldn’t show it but I was really scared. I was scared but a lot of me was just like: Ok, God, you have to take care of the family now. It’s scary. It was really, really fast. It was more like you worry but you can’t worry because you’re not supposed to...I was telling myself: I can’t, I shouldn’t. But I was scared. And you can’t really show that you are scared because that will make everybody else scared. Yeah, No I couldn’t. But I was really scared. [Interviewer: scared of?] The fact that he might not be here for a long time.

Amy, like John, also talked about the fear of the unknown. As the word cancer emerges into existence, death and an uncertain future loom on Amy's horizon. Amy now contemplates the possibility of her father dying, while fears and worries make themselves present in her mind. One word changed her lived present. "Leukemia changes everything," said Amy, a statement signifying that the certainty of her previous daily reality, of a strong and healthy father, was no more. "He was never ill," Amy recalled. "He was the healthiest in the family."

So when they said it is CANCER, and that he may be dying, it is obviously very upsetting when you think that. Everything changes. Leukemia changes everything. I guess [long silence] it was: what is going to happen?

Sarah also used the word "scared" in referring to her first thought upon hearing of her father's cancer. When asked what feelings came upon hearing the diagnosis, Sarah reiterated twice "I was really scared, I was really scared." Like the other adult children, Sarah's deepest fear is linked to the potential of her father's death. For Sarah, cancer brought a new reality, one she feels she, along with her family and father, may not have the strength to respond to. She said:

I was really, really scared. I was scared and I just didn't think that our family could go through it. Because we never had anything like that in our family so... Yeah, I was really scared. I just didn't know what to do. And I didn't feel like I could talk to him [father] about it because he was scared and I was scared so it would just upset him.

[*Scared of*] I was scared that he might give up [silence] and that he will die [long silence].

I was really scared that he wouldn't be able to handle it. I was really scared that he wouldn't want to go for the treatment. And I didn't know and I thought that if that happens [silence] then: what was going to happen?

It is interesting to note that both Sarah and Amy use the phrase “what was going to happen,” highlighting how the cancer diagnosis swiftly projects an uncertain future. She continued:

I think there is always this about how the future is going to be. Always when you hear the diagnosis you think of the future. How is this going to end? Probably the easiest way to put it is you always wonder how the end is going to be.

As Gordon (1990) affirms, for John, Sarah, and Amy the word cancer conveys a sudden potential: their fathers' deaths. Becvar (2005) notes that a fundamental characteristic of western society is a profound fear of death. According to Becvar, rather than accepting the finitude of life and our mortality as something natural, westerners attempt to deny it and take steps to avoid confronting what cannot be altered, with the ultimate result being an intense feeling of anxiety over death. For Handley (1991), death and the fear it inspires may be conceptualized as a source of “universal anxiety” (p. 250).

In his seminal work, *Being and Time*, Heidegger (1962) describes fear, anxiety, and dread as fundamental moods of connecting and being in the world. Central to human existence is “dread, anxiety, forlornness, and death” (Stewart & Mickunas, 1990, p. 69). “Death is something that stands before us—something impending,” (p. 294), that is, death is something that we will experience, something from which we cannot escape. “As soon as man comes to life, he is at once old enough to die” (Heidegger (1962, p. 289). Thus, to be human, an authentic being, is to acknowledge the possibility of finitude. Yet, Heidegger argues, we are inevitably “fleeing in the face of death” (p. 298). To face the possibility that we may no longer be here brings on us a compelling desire to escape that very possibility, “a looking away from the end of Being-in-the-world” (Heidegger, p. 543). It is in this way that we suppress the “reality of death” (Handley, 1991, p. 251). Yet, for John, Amy, and Sarah, it



seems that the “looking away from finitude” is no longer possible. In the aftermath of the cancer diagnosis, death can no longer be ignored. Fear derives not from confronting one’s own death, but the death of the “Other,” the other person, writes Levinas (Chanter, 2001; Hand, 1989). John, Amy, and Sarah now contemplate that their father may not survive the illness, and this reality cannot be suppressed. The possibility of death, as Heidegger (1962) notes, “stands before” John, Sarah, and Amy. This is the fear that permeates their experience of diagnosis.

It is important to add that Amy’s, Sarah’s, and John’s feelings of fear, dread, and anxiety over the possibility of their fathers’ deaths were described as the chief feelings dominating the entire cancer experience. John and Amy articulated fear of losing their fathers to cancer as being present during diagnosis, treatment, and after treatment had been completed. When the treatment had ended, John said he still felt fearful about the illness coming back. “Now that he is in remission it’s a different type of fear.”

Amy described the initial phase of treatment as a time of feeling very scared. “I would panic then. I still have nightmares. It was scary.” Similarly, in describing the end of treatment, Amy said:

It was a big relief the last day at the BMT. And the happiest day is when they removed the Hickman Line, because it symbolized, “I’m sick, I need help”. So when you get it removed it is like: OK, he no longer needs that. So it was a big, big relief, [silence] and it was nice. OK you are good [laughs] you don’t need more chemo and medication. But there is still that fear when I think, what if it comes back? [Silence] Because part of you knows that cancer tries to come back.

Fear is a temporal structure because it is fundamentally tied to the uncertainty of the future. Thus, in the cancer experience the present is fused to the past and to the future that is perceived and foreseen as uncertain (Levinas, 1987). Lived time does not follow the

objective line marked by quantified hours, minute and seconds. In the cancer experience, fear does not follow a linear and chronological sequence of mathematical measurements of seconds and minutes. In illness, fear is lived and re-lived in the past of the diagnosis and the treatment; fear intrudes and informs the present through the past and through a menacing future invading the present (Levinas, 1987).

When we are well, we are embodied in our plans for the future: we make plans as if tomorrow belongs to us, as we, to tomorrow. So our future is as familiar to us as our past and present. When disease strikes, however, we no longer belong in this structure of achievement and expectations...We are emptied of all that is familiar (Olson, 1993, p. 112).

In the midst of the crisis, participants tell me how important it was for them to control an ever-present fear of death. John understands that fear cannot be let go and of his need and struggles to accept fear as a part of the cancer experience. You have to have “hope and faith” he said, and “talk as a family.” It became apparent that John sees himself grasping for “hope,” along with family support, so as to control the fear of the outcome that has permeated his experience. While John cannot change the situation, he attempts to control the anxiety and fear of an unpredictable outcome. Talking about his determination to overcome the dread that the cancer diagnosis has brought, John said:

I think in the long run the reason why it was so important for us as a family to talk about it, was that we are going to have these fears no matter what. But [pause] you always have to have hope and faith that everything, although it may not be perfectly fine from the beginning to the end, if the end result is my dad being OK, my dad responding to the treatment, then it will be OK.

You’re always going to have this fear but if you as a family talk about it, then you understand that fear [silence]. You know it is [death-fear] there but you don’t have to believe that that is going to happen.

Sarah also stressed how she struggled to keep a positive view and hold tight to the belief that treatment will work in order to control the ever-present fear of death that she was

feeling. Sarah used the phrase “it will overcome you” in referring to the fear she feels. Like John, Sarah also identified talking and sharing her feelings with her family as an important coping resource. Sarah stated:

And definitely, mentality is the most important thing. You have to always believe that it is going to be OK because otherwise you will get really scared and it will overcome you. And you know you’ll become very sad. But if you keep on thinking that it is going to be OK. And make sure that you talk. And family is very important. I prayed. I am religious but I don’t practice all the time, but I prayed.

She continued by echoing John’s thoughts of how cancer brings “fear” and “worries” that are hard to defeat: while she hopes for a future where her father is cancer free, the shadow of cancer will be lived and re-lived in the uncertainty of the yearly check up. “As long as he is good, then it is good,” Sarah said.

You are so worried when you find out at the very beginning, when you hear it is cancer. And you are always going to be scared and nervous and worried. And you will worry until the end when you hear he is OK, when he finishes everything and they tell you he is OK. That there is no more cancer and that it was the last treatment and all that you will need to be concerned about is the yearly check up. And then, as long as he is good, then it is good.

Tedeschi and Calhoun (1995) indicate a well-documented finding in the empirical literature that fear is among the most common emotional reactions when individuals confront an illness that implicitly carries a threat to life. Escaping the fear of death is not possible for John and Sarah. The above comments seem to indicate that John and Sarah need to control their emotional reactions despite the profound fear and uncertainty they are experiencing. It appears that the framework John uses in coping with the potentially feared outcome of his father’s illness is one that is both cognitive and behavioural in nature (Grulke, Bailer, Hertenstein, Kachele, Arnold, Tschuschke, et al., 2005). The former involves changing the way that we think about the event and the latter includes seeking

emotional support from a loved one. As we can see in John and Sarah's narrative, talking with family is very important as they struggle to re-evaluate their ever-present fear of death. Within their families, John, as well as Sarah, needed to come to terms with unavoidable fear while holding onto a belief that all would be well. Though the outcome is unpredictable and threatening, it must not be seen as one that is either certain or final. For John and Sarah, as long as the unthinkable does not materialize, they are prepared to endure the struggles that lie ahead. This is the hope and faith that John and Sarah grasp in order to carry on.

Amy also expressed how she needed to control her sense of dread. "I have a lot in my throat," Amy said a couple of times, perhaps signifying the terror she attempts to withhold. "You need to go behind what you are feeling," Amy said. Amy uses the word "hell" in describing the treatment that is fast approaching. Yet, "hell" is the only alternative if her father is to survive cancer; there is nothing else available for them. There is no ambivalence in Amy's mind: "hell," while scary, must be borne out, or her father will perish. Like John, in the midst of the cancer crisis Amy searches for faith and trust, and finds that the medical team becomes the anchor that contains her fears of death. She recalled:

And they [doctors] also told you that in the grand schema of things that the hell you are going to go through is better than nothing. So you balance it out. And just knowing that it is really bad, but it is the best that you can do, with what you have, right? And you need to go behind what you are feeling. It is hard. Yeah, I couldn't show it. But I was really scared. But at the same time I had a lot of trust in the medical staff. I knew they were the best in town. So I had a lot of faith. Knowing that they were very professional made me feel safe, and knowing that, I was a bit less scared.

In contrast to John and Sarah who expressed a need to talk openly about the real fears of their fathers' illness, Amy spoke about her need to hide such fears. For Amy, concealing her fears may have brought a sense of reassurance to her family. "If I show that I was scared then they will be scared too. So I was the stronger one," Amy elaborated. "Like

you have more knowledge, therefore you need to be the stronger one. Yeah, I know more about these things than anyone else in the family.” Being the one who brings solace and calm to her family allows Amy to gain control over the very fear that assails her. “You sort of have the obligation to be the strong one,” Amy said. One may speculate that such an obligation also gave her a strategy to protect her father from his own angst and fears, which she feared could lead to him giving up on life.

He knew he was sick and he didn't want to say that there was the possibility that he might die. That is what could happen because you got sick, and what are you going to do? You have got to be brave and focus on other things before it happens.

I sometimes have to accept the fact that my father could just easily give up, that he may not have wanted to continue to live. I always believed if he wanted to give up no matter what kind of treatment, then [death] will happen. The biggest part is having the faith to want to live on.

Likewise, all participants in this study acknowledged that the approaching treatment would encompass a hard journey. John talked about an experience that may not be “fine” from diagnosis to the end, while Amy refers to the “hell” that she is told she must endure. For Sarah, this is a journey that she feels she may not have the strength to bear. Yet, for these adult children, there is no alternative to the treatment that invades their day-to-day realities: there is no escape from it. The trials and struggles of the treatment must be faced while at the same time they need to keep their fears in check. Fear is lived and re-lived.

It is worth noting that, for all participants, re-gaining control of the fear of death was a hard battle. The struggle between hope and dread is readily apparent in Sarah's, John's and Amy's narratives. Perhaps, naming the word “death” is a critical challenge for these adult children. For example, in the above excerpt, John used the phrase “you know it is there but you don't have to believe that it will happen,” alluding to the very thought of death that he is

attempting to suppress. What potentially “is there” is his father’s death. Yet John talks of “what is there” without explicitly saying the word “death,” perhaps in an effort to escape the power of the word (Gordon, 1990). In recounting her struggles between fear and hope, Amy also struggled to name the word “death.” On the one hand, Amy clings to the doctors’ expertise for solace. “Knowing that they knew what they were doing made me feel better,” she said. On the other hand, she feels the divide between her hope for survival and the shadow of death:

You say the word... but you don’t really feel it. I don’t know what it is. Maybe it is that I am in denial. I feel I might be in denial but the way I feel is that I think that they are just not around. They are just not around [twice]. And I think that might be the whole reason why I am in denial. I feel it deep down in my gut, but I am thinking NO! I don’t know if it is denial or just I might be thinking that he won’t [pause]. Like deep down inside me I don’t think he will... I’m thinking that he won’t [silence]. Just even to think it is scary. But deep down inside I am thinking that he would survive. I don’t know.

One may speculate, as Gordon (1990) does, that naming the word “death” might ultimately remove the “hope” to which John, Sarah, and Amy clutch. “Naming closes the door to hope, while not naming leaves it open...the only real hope is for death not to come at all,” writes Gordon (p. 289). Phenomenologically, Gordon notes the immediate association of cancer and death leads to living the “disease as disembodied” (p. 276). That is, to say, cancer is “kept at a distance mentally by not knowing its name” (p. 276). For these adult children, the word “death” may also be lived as “disembodied,” as Gordon has suggested. Not naming the word may serve the purpose of keeping the fear of death at bay. Death, even a whisper of such a word, may interrupt and shatter the hope and faith that John and Amy are very much trying to seize. This is the power of “naming,” writes Gordon (p. 276). This is the divided world of cancer, a battle between “good” and bad” (Gordon, p.

276). For Amy, Sarah, and John, cancer is a battle between “trust” and “fear,” “hope” and “death.”

In our conversation, John explained how, besides fear, the first reaction that he experienced upon hearing the diagnosis was one of anger. John said that the diagnosis brought intense feelings of anger at the injustice of having it happen to someone who is “a good person,” and at the real potential of having his father taken away from him in the most final of ways. John recalls directing his anger at God, due to what he saw as the unfairness of the situation. “I think I was probably angry at first. Angry at God that it has to happen to my dad,” John said in a strong voice. Part of his anger stemmed from the unpredictability he observed in his father’s diagnosis: that the diagnosis happened at all to someone who should otherwise not have faced their mortality until they were “old and grey,” in John’s words. John sees his father as being robbed of his life. “I think the way you want to end your life is on your terms. You don’t want to have your life taken from you,” he said. Along with the unpredictability he perceived, it became apparent that John’s anger might also have been in reaction to the loss of control that he ultimately felt in confronting a new reality.

John speaks about his anger:

So, I got angry [in a strong voice] because my dad has done so much for me. Everyone wants to die old and grey, and have enjoyed their life and not have your life was not taken away by disease or an accident. I felt angry about the diagnosis and the fact that it had to happen to my dad...I was mad mainly in a spiritual sense and at God. It’s hard to understand why such a good person has to have something like this happen to him.

Sarah also confided how she felt angry as she heard in disbelief that her own father had cancer. Sarah told me how she could not comprehend the word that she was hearing: cancer. Whereas John had expressed anger toward God, Sarah felt angry toward life. Sarah wondered why this illness was happening to her family. She said:

It was: how is that? NO! How is that possible? I guess I didn't understand...like: why? And I was angry. I felt angry. I don't know at what or whom I was angry [silence]. I guess I was angry at life. I don't know that I was angry with anyone in particular, just angry. I was angry, I just angry that this has to happen. [Interviewer: why your dad?] Yeah. Why us? Yeah, why does this have to happen to us?

In her seminal work, Loss and Grief, Kubler-Ross (1969) indicates that anger is a common feeling among those experiencing the loss of a loved one. In the face of crisis and suffering, Kubler-Ross and Kessler (2005) posit that anger may be followed by the question "why?" and in particular by "why me/us?" These questions, in turn, may be rooted in a pervasive sense of injustice – that one is undeserving of a life-threatening illness such as cancer. In attempting to make sense of what is perceived as a senseless and unjustified occurrence, the individual may question and challenge his or her spiritual beliefs (Kubler-Ross & Kessler, 2005). Taylor (1999), inspired by his own experience of dealing with his wife's cancer, writes in his Poems of Grief and Healing: "Hopelessness makes me lash out. And God is the most convenient target... for a while. Why, oh God? Why? Why? Why? Why?" (pp. 6-7). I noticed that John related his anger in a strong voice, yet when he spoke of his fears he did so in a soft, emotional and, at times, broken tone.

It is important to add that Lewis (1993) argues that the "Why us? Why now?" (p. 127) question that is brought up among family members when a loved one has been diagnosed with cancer may in fact be an important psychosocial transition or moment for the family. John's and Sarah's narratives are consistent with research that has pointed out that anger is a common emotional reaction in response to a traumatic event, particularly when the event is sudden and unexpected, as in the diagnosis of a potentially fatal disease like cancer (Worden, 1991). For example, Power and Dell Orto (2004) indicate that strong feelings of anger are a common response among patients and their loved ones, in particular



if the illness is perceived as life-threatening, that it may reoccur or it is “terminal’ (p. 56). Clarke (2002) who writes specifically about the anger experience as a reaction to a loved one’s illness reminds us that etymologically, “Anger shares the roots of grief” (p. 151). “Anger is rooted in *angere*, which is *anguish*, *anguisse* is narrowness, *agkbein* to strangle” writes Clarke. “I am anguished and I become anger,” notes Clarke (2002, p. 151). For Clarke, anger may derive from a profound sense of powerlessness and helplessness to confront suffering.

“The emotional response to frustration is anger,” write Power and Dell Orto (2004, p. 59). John said he felt angry toward God. Amy described her experience using words such as “frustration” and “resentment” directed to “everyone and everything.” “People take their frustration out on others when they are going through a hard time,” Amy confided. Like John, Amy also uses a strong tone when she spoke of her “frustrations.” Similarly, when talking about the kind of disease her father has, one that is “very serious,” she continued talking softly followed by a long silence, perhaps implicitly conveying the vulnerability that the illness has brought to her life.

I was frustrated with everything and everyone, and my family. I resented them. I lashed out quite a bit at my family because of frustration [strong voice]. It is hitting you that it is a serious, serious illness [Amy continues softly followed by a long silence]. And now I feel guilty for that [long pause].

In describing the family response to a life-threatening illness diagnosis, Power and Dell Orto (2004) indicate that feelings of powerlessness may lead to feelings of frustration. As the awareness of the loss becomes concrete, anger can also be “projected onto other family members and friends by unnecessary arguing, continued sarcasm, and constant criticism” (p. 58). It is worth noting that Amy uses words such as “lashed out” and “resentment” in describing her experience, the former meaning a “verbal or physical attack”

(Oxford dictionary of current English, 2001, p. 510), the latter, a synonym of anger meaning: “bitterness or anger about something one thinks is unfair” (Oxford dictionary of current English, 2001, p. 768). Perhaps, like John who had expressed a sense of injustice of why a “good “person gets cancer, Amy’s” resentment may also signify a sense of unfairness at her father’s diagnosis. “He was never sick. He’s not a smoker, he is hardworking, and that was all he did,” Amy lamented.

John, Amy, and Sarah also told me how the initial reaction to the diagnosis was one of intense feelings of shock and disbelief. For example, when I asked John how he found out about his father’s illness, he took a few minutes to reply: “It was out of the blue, from the other side.” “Others may have had a hint,” he added, yet he was hit with the diagnosis without any warning, “I had no idea that this was coming,” John said.

My mom called me. No, I called home from work because I knew my father had some kind of blood test and I was just eager to find out [higher pitch intonation]. I can’t remember who, maybe [“J”], or my mom said that they had the feeling that it could be something like this [silence] but I had no idea, but for me, when I heard, when I found out [long pause], it was out of the blue [pause] from the other side.

They didn’t tell me [on the phone]. I could tell my mom was upset so then I knew I had to come home because I knew it was something big. I didn’t know specifically it was cancer... Because my mom was crying and my mom doesn’t cry that often. Then I knew I had to come home. I felt it. It was a sense of urgency.

John’s words bring us back to Levinas (as cited in Keenan, 1999) and what he describes as the “Other” or knowledge of the “Other,” the other person. From John’s account, it is a sense of disconnection of watching a scene unfold in which one has no idea of becoming a main character. In describing his experience, John uses a powerful phrase “from the other side.” It is important to note that the phrase “other side” in the Oxford Dictionary (1990) means: “what is invisible,” “what is unknown.” The Roget’s International

Thesaurus (1992) lists the phrase as the “other face” and “the enemy.” This harks back to the thoughts of Emmanuel Levinas. Death “approaches as other,” writes Levinas (Chanter, 2001, p. 202). The core of the power that death exerts over us is the unknown quality of its arrival. For Levinas, observes Chanter (2001), “death is other” in the sense that it is unknowable” (p. 202). Perhaps this is about “the other side” of what was invisible and unknown to John. His mother may have intuitively known, but he is on the “other side,” unaware that things might have been changing in his father’s health. What his mother might have noticed had remained invisible to him. Now, death, which was an unknown word, may be approaching. “Life was good, one of no worries, school, work, and socializing,” John had said earlier. He had been accustomed to follow his own routine and life. It seems as though, up to the cancer diagnosis, John had not experienced the face of the “Other” – the one who is suffering (Levinas, 1987). Levinas notes how it is then the “other” person who interrupts one’s enjoyment:

Enjoyment is self-sufficiency. It comes into play as a withdrawal into oneself, an involution or coiling movement of a spiral...It is this self-sufficiency that is then interrupted by the other (cited in Keenan, 1999, p. 42).

John had not seen the face of the “Other,” the one that calls you to respond when in suffering. In that phone call there is the urgency of something that cannot be delayed. His mother who does not cry is crying now, and in that phone call John feels the “Other” voice and the “responsibility” to “respond” (Levinas, 1987). John felt that something “big” was coming, and John felt compelled to return home. It is not until the word cancer enters his life that John is no longer able to withdraw into his comfortable life where he experienced few worries.

Sarah also has a vivid recollection of how the word cancer entered her life. As with the other participants, a phone call brought a sense of urgency and an unwelcome present. Sarah, in the midst of the morning, still not awake, hears her sister desperately inquiring for her father's work number, and Sarah then senses her sister's distress. As she rushes to her mom, Sarah hears the word: cancer. Sarah recalled:

It was early in the morning I was still sleep. My sister came into my room and she woke me up and she was upset. My dad was at work. And she said: Do you have dad's phone? And I said: No. Why? And she just couldn't tell me because she was too upset. So I woke up and I ran to talk to my mom and I said: WHAT'S WRONG? And she said: we got a call from the doctor. It looks like it was cancer [silence].

Sarah related her sense of desperation to reach her father and the urgent need to go to her family physician. As she hears from her doctor, the word 'malignant' makes itself present:

And then I was trying desperately to get a hold of my dad, and he wouldn't answer his cell and we couldn't reach it at work, at his company phone. And finally my sister found a general switchboard number. And she called. And she said: I am looking for my dad. So she gave them the name and the department. And then he called home. And we said: You have to go to the doctor RIGHT NOW. So we met him at the doctor. And then the doctor told us: Yes, it is malignant.

Sarah also noted how her father had gone for a simple urine test; that a test could bring devastation to her world could not have been further from her mind.

And he was having urine problems but there was nothing like that. Because the two systems are not connected, so we never thought of [cancer]. So it was a total surprise. I was in shock.

Amy also expressed her reaction to the diagnosis as one of shock. "Life finally got him. He did the regular check up that he hadn't done in 20 years. With my dad never being sick my mother has been trying to tell him to get a blood test for years," Amy said. Yet,

Amy related how her father would not go to any of the appointments that her mom booked for him. Amy related how her father finally decided to get the blood test when his friend could not meet up for their regular coffee. Suddenly, a phone called intruded into Amy's reality. In describing her reaction to the diagnosis, Amy said:

At the beginning it was sort of like shock, because my dad, never had any symptoms. He barely went to the doctor. He barely went to the doctor [twice in a whisper]. It was quite a shock. It was quite a shock.

She continued:

And then we got the call. And he [the doctor] talked to my younger sister and said, "Is your dad OK?" And she said: yeah. And he said: does he feel sick, dizzy or anything? And my sister said: I think he is fine. And now she is scared, so she phoned me and she said: "This doctor guy said make sure that your father is OK, that if he faints or anything like that you need to take him to emergency right away." She called me right away. And she is panicking with this phone call [whispering], so we had no idea.

And instead of waiting for the specialist, my family Doctor got through to Dr. X [oncologist] and he told him about the case and Dr. X said get him into the outpatient and get a biopsy right away. And my mom called me right away.

Just as John expressed earlier, Amy also received a "phone call." And when Amy heard her mother calling her at work she felt a sense of urgency; her mother telling her to take her father to a hospital, right at that moment. In that phone call, in that instant, Amy knows she cannot "withdraw" into the routine of her daily life. Her life is about to change completely. Before the diagnosis "I was barely home," Amy recalled. A busy work and social life left little time at home. "I was very busy with my work. Before, that was all I would do, my work. My life was very busy," Amy said with nostalgia. But in that phone call, Amy recognizes the voice of the other. Just like John, her self-fulfilment, her job, is interrupted by the other. Amy knows that, despite the distress of leaving her work, she needs to do it right away. Amy recounted:

And my mom told me: dad needs to be at the hospital right away. So she called my dad to get me. And he picked me up at my work. I had to quit my job right there and that was really upsetting. I was running the store at that time. So it was really, really upsetting and quite a shock.

It is like a weird feeling, like this can't be happening, but I knew that it was. And I called my manager and I said: I need to leave right now, so if you could come right now. So I left.

The “other” is taking her hostage (Levinas, 1987). She needs to attend to her father's health. John's and Amy's narratives bring us back to Levinas (as cited in Keenan, 1999) and what he describes as the “Other” or knowledge of the “Other” person. This is the moment in which John and Amy transcend the selfish self (Levinas, 1987) as they hear their mothers' voices on the phone. For Amy, Sarah, and John there is a sudden sense that one needs to be prepared to respond. But is anyone ever prepared to confront an illness that brings the possibility of death?

As John describes his memories of the diagnosis, the impact of the word “cancer” in his world becomes clear:

I remember that I came home and our cousin was downstairs and I went upstairs. As I came up my sister's eyes were red, she had been crying. And when I came into my room my mom and my dad were on my bed. They looked calm when they told me. I think because I still didn't understand exactly what leukemia was. Then I was just shocked.

Then when I really understood that it is cancer, that's when it really hit me, and I CRIED [emphasis and long silence] in that moment in front, in front of everyone. Yeah, in front of my parents and my sister [long pause].

The impact of cancer on Amy is clearly seen in the excerpt below:

It was quite a shock. First, when we got the call I thought: “No, it's not really happening”. Maybe he is just not eating properly, or something like that. And like him never being sick to “OH you got Cancer.” I think, as with all other people, when they think of the word cancer they think that you will die. Part of me was “OH NO, this can't be happening.” It was like STOP [strong voice]. Stop my life. Stop everything.

“Diagnosis is an example of where knowledge alone can profoundly change people’s lives...Cancer – can instantly shatter a world,” writes Hayne (2002, p. 181). It is important to note that John clearly emphasized the fact that his shock was so intense that when he understood that it was cancer, he broke down in front of others. When I said back to John: “I get the feeling that you don’t cry that often,” he responded affirmatively. Like John, for Amy, clearly the impact of cancer is one that “shatters” her world: death is inescapable. And her world needs to stop.

For Sarah, the word cancer brought shock, anger, and guilt. In describing her experience, Sarah said:

Yeah. First I was shocked, shocked and just angry. And he was already thinking like something bad – something bad. He was already down. But I kept on saying: don’t think like that. Don’t think like that because if you think like that you’re going to find something bad. It was like don’t worry about it.

And then this happens. So it was something bad [long silence] really bad. It was really, really bad. So my dad was right. And that part, I kind of felt a bit guilty because I was telling my dad not to think anything is serious. Don’t be so negative. I kept on telling him: Don’t be so negative, don’t be so negative and then he would say: what if it is something really bad? And then I said: NO, NO, it is not, no, no. But then it ended up being something really bad. So, I guess I felt guilty for saying that it is nothing, that nothing was bad, because I gave him false hope.

A significant contributor to shock was the lack of forewarning. John speaks about his disbelief in that a person could look healthy yet have a body that is very ill. John remembered how his father, who looked healthy, acquired a new identity with just one word: “cancer.” John explained how cancer came in the midst of family gatherings and celebrations. Nothing then, says John “could have hinted at what was to come.” As John continued, his voice became sombre, his tone and speech slower. At times, closing his eyes and lowering his head, he described the experience vividly, as if time had been suspended, as

though past moments were now encoded in his mind. When asked to describe what he did when he heard, John replied:

Yeah, I came home and it was ‘what’s happening?’ I knew it was something big regarding my dad. I was just trying to prepare myself for whatever was going to happen. So when you go in there, you go preparing yourself emotionally. What is going to happen, bracing myself for something, and that’s why probably, at first, I was shocked.

Yeah, when I realized it was cancer I cried. But I was still shocked that just last week, at that time, we had gone for dinner to celebrate my dad’s birthday. My dad still looked perfectly fine but then when you hear cancer obviously you know. Sure he looks fine but something is really wrong with his body. There is no warning.

I guess that for me when I asked the question ‘what is going to go on?’ or something like that, either my sister, my dad, or my mom, they referred to it as “cancer.” And so when you hear CANCER, it is obviously stronger words. When I realized it was Cancer then I think I cried [sad voice, pause]. You understand as an adult what kind of disease this is.

Amy also talks about how the diagnosis came without any concrete warning, perhaps shaking her beliefs that illness is something that shows itself in an unhealthy body. For Amy, shock also derived from the sudden reality that her father, who she said “does not look sick,” who is the “healthiest” in the family, and who seldom saw a physician, is now related to the word “Leukemia.” Amy’s image of a healthy father defies the very word she is being told: “Leukemia.” How could this diagnosis be real? Amy asked herself. In recounting her reactions to the diagnosis, Amy describes how shock gives way to uncertainty and fear.

Then we got the call from Dr. X [oncologist], and he called me and told me “OK I don’t want to alarm you but I think it is very likely that your father has Leukemia and he was talking about that [very soft voice].

And everyone went into shock. Because you don’t look sick, and he probably was the healthiest. It was a reality check for everyone. They all got scared because he, of all people, never gets sick. Yeah, he was never sick. Maybe he will occasionally have hay fever, and that’s it. He barely went to



the doctor. He barely went to the doctor [twice]. It was really scary for all of us. There was no warning. We were shocked. There was no warning at all.

It is worth noting that Sarah also used the phrase “no warning” in describing her father’s diagnosis, even though she confided that her father was having some health problems. “He was going just for a urine test,” Sarah said. Like the other adult children, Sarah also expressed a pervasive fear of death. In fact, Sarah’s description demonstrates how the word cancer embodies the idea of death as readily present. She said:

Because the last thing that you expect is to hear that someone you know has cancer. Yeah, and I was shocked. There is no warning. He was going to the doctor to have a test because of his urine problem. My dad had some health problems before but I didn’t know that this was going to happen.

You know what the word cancer is kind of associated with it. There are so many cancer related deaths so I think it is almost natural when someone has cancer to think that they might die.

Hayne (2002) talks about the impact of the word cancer. “This one word can change one’s life... Just hearing it can change everything. Like a curse it stains my existence,” writes Hayne (p. 184). Fear begins to show itself as the word “cancer” registers with John’s, Sarah’s, and Amy’s existence. When you hear of cancer, “it is natural” to think of “death” Sarah said in the excerpt above. While John does not mention the word “death,” when describing his father’s cancer diagnosis, he mentioned the need, several times, to understand the “kind of disease his father has”: the kind of disease that implicitly carries the meaning of “suffering, hopelessness, and death” (Gordon, 1990, p. 281). Gordon argues that in hearing a cancer diagnosis, individuals are likely to “fuse diagnosis with prognosis” (p. 288), and lastly to a prognosis that highlights the death-cancer connection. It is a time in which the future is lost, and one’s present vanishes. The present that had assured many more years together is no longer guaranteed (Gordon, 1990). Before the diagnosis, John, Sarah, and

Amy had perceived and judged their fathers' bodies as healthy. Now the word cancer has changed the landscape of their past, present, and future (van Manen, 1990). This is the power of the cancer diagnosis, Gordon says: "it essentially spells the end, as if the announcement itself brings on the very end it anticipates" (p. 289).

John also explained how he tried to make sense of what was happening without having a clear understanding of the medical terminology that he was being told. The unfamiliarity with "technical/medical" language may have intensified that sense of shock. "When I heard leukemia just by itself, I didn't understand," John stated a number of times. Van Manen (2002) writes how in modern life we now confront an interesting paradox. In one way, van Manen notes, we are confronted with a medical terminology that ultimately conveys little or no meaning for our day-to-day life. Yet, at the same time, van Manen adds that medical discourse has "so permeated our everyday living that our human existence, our experience of the world, and our selves has become scientized (p. 179). While John has little understanding of what "leukemia means," he neither required, nor demanded an explanation for the word "cancer." When someone refers to "leukemia" as "cancer," John no longer needs to know more. With such a word, "cancer," Amy, Sarah, and John know the "type" of disease their fathers will confront.

The word "cancer" brings an immediate reality: the very possibility that in cancer death is inescapable. As Heidegger (1962) noted, death is "impending," (p. 294) fleeing is no longer possible. When Amy and her family hear the word cancer, Amy refers to cancer as "not something that you can go through and not die:"

The doctor said leukemia. And my mom said WHAT IS THAT? And the doctor said, and he is quite honest: I can't guarantee 100% but it is very likely that it is blood cancer, cancer of the blood. We don't know, but you have to be prepared that it is very likely. I can't tell you 100% until we have all the

test results, but it is very likely. And my parents went “BLOOD CANCER?” But he doesn’t smoke. He doesn’t do anything.

And you put two and two together. The word cancer was “OH MY GOD, this is serious. I know my mom’s first thought was: he is going to die. I am sure that was her first thought, because you know cancer. It is not something that you can go through and not die.

For Sarah the word cancer is so alien that it is not until she says it out loud that she realizes what is happening: uncertainty, fear, and the potential of death begin to make themselves present:

I think when I first found out at home I don’t think that I actually understood. All I was trying to do was to get a hold of my dad. I couldn’t even think about anything because I just wanted to get my dad. It didn’t hit me then. Then we went to the doctor and we heard it from the doctor. And at that time it started sinking in and I was trying to grasp what was happening. Then when I got home, when I finally said it out loud, CANCER, to someone, when I said it out loud, that was when it sunk in, and then, it hit me.

And that was when it got to me because my dad had lost his friend, from the same cancer, just the year before. His best friend so [long silence] knowing that probably is like the worst part because it was exactly the same cancer [long silence]. His best friend since he was in elementary school. And, yeah I was scared of the same. And I try not to think about it but you can’t help it. You can’t stop thinking on that. What is going to happen?

No doubt the word cancer begins to shape Amy’s, Sarah’s, and John’s experiences of the world (van Manen, 2002). As a researcher, a counsellor, and a mother, who has also been touched by the cancer experience, I cannot stop my own reflections as I write this thesis. In my experience, I remembered sitting at the hospital, listening to a diagnosis, and the medical facts and terminology. I remember later submerging myself in information seeking on the net and in medical journals. I could hopefully understand and make meaning of the medical discourse: “induction,” “cytogenesis,” “immune-suppression,” “irradiated platelets,” “catheters,” “pre-feeding lines,” “Hickman lines,” “salvage treatment,”

“haematopoietic cell transplant,” among others. Yet, it was the word cancer that frightened me the most.

John also explained that while he had heard the word “leukemia,” it was also the case that “leukemia” was something distant, something that happened to “others”: the “hockey players,” John said.

And I didn't really understand what Leukemia was. I have heard of hockey players getting leukemia and lymphoma and that there were several types and I didn't know the extent, but for me when I think of Cancer, I associate it with something [long silence] that is very serious [intonation stress]. You hear from the news and even from TV that it is always a very serious disease. From what I think and from what I see, it isn't always resolved in a very positive ending.

Heidegger (1962) noted that to protect ourselves from the angst of “death” we trick ourselves into believing that death happens to the “others,” the “they,” who are not us. “Someone or other ‘dies’, be he neighbour or stranger. People who are not acquaintances of ours are ‘dying’ daily and hourly,” writes Heidegger (pp. 296-297). It is the “Other,” the one who is not related to us, Heidegger theorizes. “One of these days one will die too, in the end; but right now it has nothing to do with us,” observes Heidegger (p. 297).

Echoing John, for Sarah cancer was also an illness that affected “others.” Other families got cancer. Sarah confided how the diagnosis time came in the midst of friends and acquaintances being diagnosed with cancer. Yet, despite the closeness of the illness, she related that such a threat was totally foreign to her family: cancer could not happen to her family. Now Sarah lamented her disbelief when she heard that the illness of others was also striking her family. She said:

I think my first thought was like [silence] it was after a whole bunch of... Like that year a lot of people that we knew got cancer. Cancer was hitting a lot of people, a lot were getting cancer. And I thought: that was the last thing that

could ever happen to our family. Because it is so weird all these people that we knew, that I knew, there was someone in their family who was being hit with cancer. But then we find out that it was my dad too.

For Amy cancer does not happen to those who look healthy. “Oh God, this can’t be happening,” she had said before. “Cancer? But he does not smoke or drink heavily as others do,” Amy recalled. Yet, now Amy said she is “no longer invincible”: now the disease “of the other” is happening to you.

Yeah, he was never sick. And partly this scares me too because I am barely sick. I am like my father in that we don’t get sick often, our immune system is very high. We never go to the doctor [long pause]. So at that point it is really scary too because even if we are not feeling sick . . . Because I am thinking you are not invincible anything can happen. That happens to your father, right? And your father is never SICK, and you have this idea that everything is good and that they will never get sick. Now it could be me. It could be anyone. You never know who can get cancer.

It is this angst that highlights the cancer diagnosis (Gordon, 1990). According to Gordon (1990) cancer is an illness still strongly associated with death and suffering, and it is ultimately this powerful cancer - death relation that brings us to keep “death, decay, and suffering in the other” (p. 276). Yet, in diagnosis, one enters “the world of the other” (Gordon, 1990, p. 290). Thus, the cancer diagnosis, Gordon writes, shifts cancer as an “illness of others” (p. 278) to an illness that is now happening to us. Lewis (1993) writes about the family adjusting to cancer:

The diagnosis of cancer challenges the assumption that everyone is invincible; that things are always good; and that what is good in life goes on forever. The cancer experience puts these beliefs up for grabs. Givens are no longer certainties; life is no longer infinite; health is no longer assumed. Death is not for someone else but is for everyone (pp. 127-128).

John, Sarah, and Amy confront the face of the “Other”: these adult children are now confronting mortality through the ‘face’ of their fathers. Levinas, in his work on death, writes, “Death threatens me from beyond. This unknown that frightens me, the silence of

the infinite spaces that terrify, comes from the other..." (Levinas, 1969, cited in Keenan, 1999, p. 67). For John, Sarah, and Amy, the desire to make sense of these efforts is to little avail. In cancer one experiences anger, vulnerability, disbelief, and helplessness in the face of confronting an enemy whose face remains unseen (Levinas, 1987). Shock and disbelief give rise to anger, frustration, injustice, and fear, whether or not expressed immediately. But life goes on and the reality of treatment comes all too soon.

### **Agency: pulling together**

*Agency: Pulling together* is also an important sub-theme of *Experiencing the diagnosis: Confronting death*. It can be described as one of re-assessing what is happening and of the unfolding need for action to restore health despite the emotional turmoil that cancer brings. This theme is about confronting the challenges that the cancer diagnosis brings. It can be seen as an intentional strategy that individuals engage in so as to face the struggles of their current situation. As I talked to John it became evident that diagnosis and treatment brought about a drastic change in his life routines. But despite the intense emotional reactions that a diagnosis of cancer brings about, there is also a sense of surrender to the drastic life changes as well as the unfolding of a sense of urgency and agency in bringing about whatever needs to be done to survive. For John, *pulling together* involves sharing the suffering, responsibility, and felt emotions that the diagnosis brought, in order to fight for life. John spoke of the need to make sure that what needs to be done gets done. "Making sure we are all on the same page for dad," John said. John is increasingly aware of the dramatic changes to his life. The 'potential' changes become concrete. There is an explicit consciousness of time. Events keep changing, yet it is always about priorities, about preparing for how life will change "right the next day." Time does not move at a normal

pace, rather it exists always as a state of urgency. Of entering the hospital experience and of facing the changes he had begun to anticipate, John states after a long silence:

I think that day for me was “OK what do we have to do then.” I remember after that week I wanted to get the whole airplane ticket cancelled. I knew from that day things were going to change. And they pretty much did because we had to go to the hospital right the next day, and I think two days after that he got admitted. So it was this drastic change.

OK we’re going to be at the hospital. I guess this is going to be our new home, but that part didn’t bother me at all because I knew I had to do it. There was no other way around it. You can’t say you are not going to go to the hospital.

Pulling together also brings a sense of agency. In effect, togetherness and pulling resources may be seen as a strategy to contain the anger at the powerlessness of an illness that has been allotted to him. In confronting a situation that he feels powerless to change, John knows that all he may be able to control are his thoughts. At the crux of his experience is his need for his father not to succumb to the illness. For that to happen, he must push his feelings aside so he can immerse himself in whatever needs to be done. There is no time to grieve, only a need for action. Yet, he cannot do it alone. John said in the following excerpt:

I think that you have to take a decision on how you are going to look at things...and I could be angry but that wouldn’t lead to anything that would contribute in a positive way. As I said earlier, I was mad mainly in a spiritual sense at God. I think after a couple of days I wasn’t angry anymore. The reason that I stopped being angry after a couple of days is because I realized that it wasn’t God who chose my dad [pause] to have cancer, it was the way that things are, and this was something that not only my dad, but all of us will have to go through as a family.

I wasn’t perfectly fine, but understanding the circumstances, I wasn’t angry anymore. Because I figured that, as a family, this is what we have to do. So you know, once we got to VGH [hospital] and my dad was admitted to it, that was pretty much it: whatever everyone has to do to help my dad.

As we can see from John's description, the idea of death, God, feelings of anger and then acceptance lead toward an idea of how to make it through, and how to survive. John had said earlier that he felt angry as he questioned why such an illness happened to his father. Lewis (1993) argues that "the why" question may be an important psychosocial transition in the family's adjustment to cancer. For Lewis (1993), psychosocial transitions involve "personal reflections that are deeply contemplative" (p. 127) in which issues are revisited and analyzed. As a result, new conclusions and a deeper understanding emerge. After a couple of days, John realized that it "wasn't God who chose my dad." "Maybe in the long run it was good for me to be angry because it was just one part of the stuff you go through," John added. From John's words, we can also note that John takes an active agency, a thought of taking decisions when a situation is far out of control. In a place and time of no control, he chooses to control the only thing that he might control – his feelings. Controlling one's emotions, write, Grulke et al. (2005) may be seen as an intentional strategy that individuals engage in order to face the struggles of their current situation.

In a time of trauma the development of agency is not unheard of. Bentovim (1992, as cited in Kaslow, 2004), explains how the family pondering the diagnosis organized themselves differently than before the diagnosis had been heard. This author argues that when confronting a life threatening illness some are likely to shift to a crisis mode. They first assess what needs to be done, and then act on it. John states that his family would do "whatever everyone has to do to help my dad." This appears to be a key statement towards the sub-theme of pulling together.

Importantly, in order to survive the experience of his father's illness, John needs to depend on others. At the heart of the experience is the need of the family to share the grief. His father is facing the physical pain; for John and his family there is the emotional pain. It



was crucial for John that the family stay emotionally together. There must not be any emotional distance among family members. They need to be emotionally connected if they are going to survive his father's cancer journey. John said: "I always felt that all of us as a family had to be on the same page." Sharing with his family, feeling that connectedness, John senses his agency in facing the unthinkable. Surviving the experience is a "shared project."

I always felt that for us to be able to go through this, obviously it's my dad who is actually physically going through this, but I always felt that all of us as a family we have to be on the same page. And what I mean by that is that we all will have to be talking to each other. I think what made it easier is that we all talk about it, we all cried, and [pause] you know all that stuff the very first day.

Sarah's account conveys a similar experience: she also comes to realize that the only important thing is her father's cancer. "And I felt that nothing else was important anymore, and that cancer will be all that we have to do for the next while. So I didn't care about work, I didn't care about school," Sarah lamented. Like John, Sarah also spoke about the need to regain agency over the fear and worries that paralysed her. "I was just scared that I wasn't able to do it," Sarah said before. Yet, for Sarah, it became critical to overcome her fears as the treatment was fast approaching.

"I didn't feel like I could talk to him [father] about it because he was scared and I was scared," Sarah lamented. As Sarah senses her father's terror, she worries that he might give up. And in that instant, Sarah knows that she must move beyond the dread she is feeling.

For the first day [silence] I really didn't do much. I knew if I talked to my parents and my dad that I would get upset and then he would get upset and I just didn't want that. So I think for the first day I stayed to myself. And after, probably the next day I told my dad, I said: You have to have the surgery and you have to have the chemo or whatever else they will tell you to

do. You have to do it all. And I told him he had to keep on no matter what. Whatever it is, he had to keep going, no matter what. You can't give up [whispering].

She elaborated on how instilling hope is a joint effort:

My mom, too, kept saying you have to do this [silence]. He just kind of nodded his head and he was very scared. You could see [whispering] he was very scared [silence] of dying.

Sarah also explained how the cancer journey is one that must be shared if the suffering is to be survived. In adversity family becomes central to her life. "Yeah, and you need to know that you have to share your journey," Sarah confided. And while Sarah revealed that they usually did not talk among her family, cancer is an illness that has brought the family together.

And talking was a good thing. It is important that everyone knows how everyone is doing. Cancer brings your family closer together even if in your family you are not very affectionate.

Amy, like John, also talked about how treatment comes so soon. As her father's hospitalization begins, Amy also shares her need to control her feelings if she is to help her dad. The idea is that, like John, she is sad, but how is this going to help? She needs to push aside her emotional reactions and concentrate on what needs to be done. Amy uses words such as "it is useless" and "no time to cry." Like John she also sees the need to accept the illness.

I don't know. It is weird. I kind of accept it. Afterward, kind of halfway through the treatment, I was thinking: What I am feeling. Should I cry? Why don't I cry? Maybe I am a little bit insensitive or something like that. But no, I just accepted the fact that sickness happens and that it is unfortunate that it happens [silence]. But it is so hard. I was so sad. And I didn't have time to be sad.

This is the sense of agency: you do whatever is needed to help your dad and the family. There are only two choices, sit and cry or do something. Amy chooses the latter; there is no time to cry.

I figure I have to take care of them, so I have to focus on what it is that we all need, so that my dad is OK. I will not allow myself to sit back and cry, to feel pessimistic. You don't have time to sit and worry and cry, or any of that. Because at that moment in time you feel: IT is USELESS [strong intonation]. You can sit there and cry or you can do something and try to make the best of what you have.

I can't think of the "what if." I only have time to think: this is what's happening and this is what you need to do. You don't have time to think of anything else, but this is what you need to do for your family. This is what you need to do to help your dad, and this is what you need to do for yourself to get through this. And you DO IT [strong voice]. Yeah, sometimes I felt like it was useless, it is useless to cry about it. It is OK to cry about it but at the same time you could do something else. And you have to get things done.

In contrast to John and Sarah who stressed the need of "pulling together" among family members in order to survive the new and grim reality of cancer, Amy's above account is one that may be viewed as a "pulling together" within herself. Giving herself the responsibility to be the strong one may in fact allow Amy to overcome the engulfing fear that embodies her new reality. Amy said:

You sort of have that obligation to be the stronger one. Like you have more knowledge, therefore you need to be the stronger one. You can't really show that you are scared because that will make everybody else scared.

That's how I cope. But I wouldn't say this is the best way. But it was the best thing for me [repeated twice]. The best thing for me was to just educate myself on what this is, and what you need to know. And I think when you have more knowledge, when you educate yourself, what this [cancer] is, and what you are dealing with, then you are not as scared anymore.

Thus surrender becomes the form of acceptance that is left to these adult children.

There is not acceptance of the diagnosis, rather, they are presented with a choice that is not a

choice, and are left to yield to the oncoming events that will fill the newfound realities that await. Treatment fast approaches.

## CHAPTER V. EXPERIENCING THE IMPACT OF TREATMENT

*What is Real? Anything? Nothing? "I think: This is not Real, It's not really happening; This is a dream, And tomorrow I'll awake"*  
(Taylor, 1999, p. 13).

A second theme to emerge is the impact of treatment upon the adult child.

Treatment has the potential to save or end the life of a loved one. It is a time of drastic change and of physical, psychological, and emotional demands for all involved. John, Sarah, and Amy bore the intense emotional, psychological, and physical demands throughout the course of treatment. John described his father's entire treatment experience, from onset through remission, to the end of treatment, as "a very turbulent time." Leukemia requires an initial induction phase and consolidation stage, each necessitating invasive chemotherapy and immune suppression support therapy, taking place entirely in a hospital setting for periods upwards of four months. For Sarah, whose father was in treatment at the time of the interview, treatment would also be lengthy, extending for a period of over 8 months, comprising 6 months of chemotherapy, radiation, and invasive surgery. John and Amy recalled the experience of treatment as having left a vivid impression on each of them. When asked if there was a particular thing/event that stood out in treatment, John replied, "All of it is a big stand out." Participants described the entire treatment as something happening outside one's reality, as though one had been living in a dream.

Cancer treatment is described as a "surreal" experience, an otherworldly state where changes to one's daily life and routine are drastic and occur suddenly, essentially forced upon

the person. In contrast to his life after the cancer diagnosis, John described his life prior to Leukemia as one of relative ease. John's carefree existence changed abruptly to one ruled by a highly regimented hospital routine. The "normal" reality he had enjoyed a few days prior, one with few "real worries," ended swiftly with John removed wholly from any security he had once known. In the new "abnormal" routine of the treatment, the only certainties are uncertainty and worry. Life, no longer recognizable to John, jolts him again and, as in a dream, he wakes up to find the treatment ending. The familiarity of the hospital fades and with the flip of a switch he becomes separated from the "abnormal" events of recent memory, thrown back into the "normal" life he lived before diagnosis. In summing up this experience, John says:

It changes you. It changes in the fact that you go from the 'normal,' or what they call the 'normal' life before the diagnosis, which was going to school for me, mom was at work, dad was at work, my sister at school, to being at a hospital every day. I think it's funny, well not funny, but ironic that you go from a state of the diagnosis to not knowing what's going on, and then as of today, you switch from being at the hospital back to a "normal" life [long silence]. It is almost surreal because of all the worries you had about your dad. Because you had to worry before if his skin was too dry, or if his temperature was too high, and then going back to recovery to how it was before. So it is like a switch.

Thus, for John it becomes apparent that the experience of his father's treatment is of something unreal: an altered reality. Tishelman and Sachs (1998) argue that in the cancer diagnosis and treatment a new paradigm of "normality" and "non-normality" emerges, one that is derived from the health care sector and dictated and controlled by the biomedical model. For these researchers, this biomedical perspective ultimately comes to define one's "normality," as well as the "entry and exit criteria for the categories of health and unhealth" (p. 55). As such, these authors indicate that those afflicted by sickness must then constantly negotiate between "two different worlds" (Tishelman & Sachs, 1998, p. 57): the "normal"

world of “health” prior to the illness, and the hospital, which is wholly alien. John shifts from his social reality of “few worries” and established routines to the medical world where treatment takes place: a realm of worry, insecurity, vigilance, and suffering. As his father’s health returns, John is placed back into the social context he lived prior to the illness. Yet, with the same swiftness with which he was placed in the “dream,” he is abruptly taken out of the “dream” once treatment ends. Perhaps this is the surreal experience of treatment.

One may speculate that with so little control over the events, the experience may be perceived as something foreign to the adult child, as something that is not happening at all. Such disembodiment from the treatment experience may help to make sense and maintain order so as to “avoid chaos” (Tishelman & Sachs, 1998, p. 57). As Charmaz (1999) has noted, in suffering there is “a sudden disjuncture between past and present... Images of past and present appear in sharp contrast” (p. 365). This is the lived time of the “dreamlike” experience of treatment.

Like John, Amy also described the cancer treatment as both the most salient experience in her mind and at the same time as an altered dreamscape, as though the experience had not happened at all. It is important to keep in mind that where John described his experience as “surreal,” in the excerpt below Amy describes her changing reality as “sort of a dream.” Both use the word “normal” to contrast their realities before and after treatment:

I don’t know. It feels closer to a dream. It happens so fast. And now it feels normal again because he is fine. And I forget sometimes he was sick. It was sort of a dream. I really don’t know how to explain it. It is weird. I still don’t remember too much. I think my biggest memory is probably just being in the hospital and going through all the treatment.

Regarding the treatment Amy says she doesn't "remember too much," yet paradoxically she describes this same time frame as her "biggest memory." One may speculate that treatment comes so abruptly and unexpectedly that this may lead to a sensation that the event is not actually happening at all.

Amy related how the treatment started the day after diagnosis. She said: "It is sort of like a weird feeling like this can't be happening, but I knew that it was." From there she relates how everything began to move in a time dimension that felt unreal:

So from there it was a really fast pace. We went home and waited for a phone call and the next morning we went to get the biopsy and while we were waiting for the results they admitted us in the hospital. And the next day he had his Hickman line so it was really fast happening. So, Oh my God, there was no time to think and it was the next day after that he got his first chemotherapy treatment. It was FAST [silence].

While Sarah did not construct the idea of her father's treatment experience as a dreamlike state or as an altered reality, it is worth noting that Sarah's father is currently undergoing a combination of drastic cancer therapy. Thus, Sarah has not returned yet to the world of her school, work, and friends. For Sarah, "cancer" does not lie in the landscape of her past, it is the very reality that she inhabits. The daily hospital routines are the only reality that Sarah lives.

The theme of "The Impact of Treatment" is composed of three distinct sub-themes: the early treatment named "*Treatment begins: the darkest days,*" the impact of continuous daily outpatient treatment called "*Measuring life in day-by-day doses,*" and the end of the end of treatment entitled "*Cancer lingers on.*"



## Treatment begins: the darkest days

*Treatment begins: The darkest days* refers to the early treatment experience where total hospitalization is required for the patient. John described it as facing new and uncharted territory: confrontation with the unknown. A new reality emerges, one of powerlessness and total uncertainty for what the future holds. John recounted:

I think at this point it's still in the back of your head. "What is going on? What will go on? You just don't know."

As with diagnosis, the initial treatment is also a time of intensely felt emotions: fear, apprehension, anxiety, loss, sadness, and an intense helplessness. One may hypothesize that it is the intensity of such emotions that permeate and distort the perceptions, thus rendering their "reality" into a surreal or dreamlike state. As the narrative below demonstrates, intense feelings of uncertainty and sorrow arose as John, Sarah, and Amy became witnesses to the invasive chemotherapy treatments in the hospital ward. Seeing their loved one lying in a narrow bed, in the middle of a hospital room, tubes and needles connected to an "unresponsive body," the participants silently observed the unfolding of a new paternal identity: from strong to fragile. John, Amy, and Sarah spoke about what they felt at seeing their father endure pain. For the adult child, cancer was simultaneously robbing them of a future with their loved one, while also fundamentally altering the image they'd held of their father as they witnessed the deterioration that comes with disease. Amy said:

It was hard. I don't know how I felt at that moment but I didn't like the feeling. You realize how fragile he is. With all the side effects, he would lie flat there. And I know at one point – he couldn't control his bladder even to make it to the bathroom – and I think at that point in time I really saw [long silence] how fragile he was.

Cause you grow up thinking that your father is the bravest one, and the strongest one, and that he can handle everything. And now you see what is happening and he is so vulnerable. You grew up with this image, and then

the father becomes the vulnerable person because he is the one that is sick. I guess in almost every child's eye your dad is the strongest person in your life. And your father is never SICK and you have this idea that everything is good and that he will never get sick.

For Sarah, the initial treatment was also one in which she saw her father's image change. As a result of cancer, her father is no longer the strong figure. In the hospital bed, she sees a father whose body is frail. Sarah wrestles with trying to make sense of what is happening: fathers are the ones who take care of their children, yet her father cannot. Sarah continued by relating her devastation at seeing her father's strong image shatter in front of her eyes. For Sarah, total hospitalization is the very "worst" experience. She said:

That was the hardest thing. Because there you see him in the bed and he is SO small and he is so weak. And he is in so much pain. And he doesn't want to be there. That was really hard [whispering, long silence]. Yeah, that was the worst part when he was in the hospital. And he hated to be alone. And it is hard to leave at night and he hated it when we had to leave. That was hard. Yeah, and he is all-alone there [long silence].

It is the worst experience [long silence]. It is worst because you think he is your dad and he is the strong one. He is the one to whom nothing bad will happen. He is the one who is supposed to take care of you. He is supposed to always be there for you, and now we have to take care of him [whispering and silence]. It is hard to see such a strong figure in your family be [whispering long silence]...the weakest. It is so hard [almost inaudible].

John also told me how his father's identity changed from the "strong" father he had known all his life, to one who is "weak" and despondent. John said:

But for me, the hardest was probably seeing my dad at the point where he was having induced sleep. So he was out of it, and he was obviously through a lot of this medication and receiving the chemo...I think that was hard. It was hard because it was the first point of this experience, and because it is your dad, and you see your dad. And you have this image of him, who always provided for you and doing whatever he can, and see him having to go through that, it is hard.

You don't want this for anybody that you care about it. I think that was probably the hardest thing. I think because you see them so weak, my dad

wasn't eating, my dad was just throwing up when he had food, and when you know my dad normally doesn't stop eating, so when you know that he can't eat, that he is throwing up, obviously you know he is not feeling well at all.

It is telling that in John's excerpt above, in describing his father's pain and suffering, he uses the word "care." In exploring the meaning of the word "care," van Manen (2002), indicates that etymologically, the earliest meaning of "care" was associated with "sorrow and anxiety" (p. 266). According to van Manen (2002) this meaning is echoed in the earliest version of the Oxford Dictionary in which the equivalent of care is also anxiety and worry. He continues by writing in its expanded version the same dictionary lists "care" synonyms first as one meaning "mental suffering, sorrow, grief, trouble" (p. 266) and secondly as signifying a "burdened state of mind arising from fear, doubt, or concern" (p. 266). This is the parent experience of care: "caring-worrying," van Manen (2002, p. 265) notes.

Van Manen (2002) posits how "caring" is intrinsically related to the worry that parents feel deeply for their children's welfare. The parent cares for the child, and at each instant the parental existence is one of concern, comfort, apprehension, and vigilance for his or her child. The parent suffers when he or she sees and feels the child's pain. They worry for their children's struggles and they wish they could take away their distress. The child's sorrow becomes the parent's grief. "The parent feels powerless in the deep desire to help the child who suffers," writes Clarke (2002, p. 151). "This is the parental experience of "care": worry, responsibility, and suffering, notes van Manen. Yet, van Manen does not account for the "caring-worrying" (p. 265) experience of the adult child. Sarah had alluded to the "normal" order of caregiving: parents are to care for their children. Yet cancer shatters such an assumption, suddenly taking away the order of life. Cancer invades their father's corporeal body, and adult children embody their father's pain. "The image of the sick child waiting for the parent becomes like an icon imprinted in visual memory," notes

Clarke (p. 150). For the adult children, the image of their father's ill body, lying in the hospital bed, is now "imprinted" in their minds. The adult child now silently waits, worries, and suffers: in cancer, the moral responsibility of care has been reversed.

This is John's experience when he sees his father fading away in his presence. John understands that his father must endure the treatment yet he is anguished at his inability to alleviate his father's pain. "He has to go through it," John said. There is no escape from it if his father is going to survive. Amy and John describe watching by their fathers' bed, witnesses to the continuous rounds of toxic chemotherapy that shrink their fathers' bodies and blind their eyes. Worse still is the implacable knowledge that there is nothing that can take away the suffering. As the treatment unfolds, there is no relief for his father's physical pain, and John tells me how there is also no escape for him: he cannot flee from his feelings of helplessness and sadness at his father's suffering. John recounted in the excerpt below:

And it is hard because you know he has to go through that in order for him to feel better, but it's so hard nonetheless, to see that one of your parents has to go through that. And that was the worst part, seeing my dad with all the medications, seeing my dad at some time not being able to see, with the eye-drops, blind. Seeing that he couldn't even open his eyes, he was in so much pain. Because he has to go through this, it was hard in that sense, probably when I said hard, I probably mean just sad, because it was just nothing that you can do, and nothing that the doctor could do, because, he [my father] has to do it. But that doesn't change the fact that it is sad to see your dad like that.

Amy also observes her helplessness.

At that time I had a lot in my throat and I think that was when it really hit me, my dad ... because his eyes were gone, he really didn't even answer. Everything was bad. That was very scary because there was nothing that anyone can do to help and with all this pain and needles, and there is nothing that you can do.

I just felt that I want to help. I want it to make it better and the only way I knew how, was to be there. I sat awake by his bed almost every night, just waiting to see if he needed to go to the bathroom, or if he needed anything,

anything, so I can get up right away [broken voice]. I didn't really sleep. The only thing was to make sure that you are there if he needs you. So it was really, really sad for me [long silence, broken voice]. So just being there. Yeah, but I couldn't help [whispering]. It wasn't much that I could do. But at the same time you are there and you try to do as much as you can, and I tried to help as much as I could. But it was hard, because you tried [to help], but you just can't.

Sarah also spoke about her fear, helplessness, and anguish as she witnessed her father's pain. "Yeah. Yeah. Helpless and it was the hardest and the scariest," she said in referring to the initial hospitalization. While Amy's narrative highlights how suffering brings the need to be vigilant by her father's side, for Sarah vigilance is not enough: she wishes to embody her father's illness. In expressing her grief and helplessness, she said:

Seeing him so weak [tears] was really hard. Seeing him like that, he couldn't move and he was in so much pain. He was in a lot of pain and that part was really hard [long silence]. And he is so sick [Whispering/tearful].

It was really hard. And I was scared you know... you wish it didn't happen to him. Because I kept on thinking it would have been so much easier [silence] if it were me. Because I am not the head of the family, if it was me he would take care of me [silence] he was supposed to take care of me.

Gantt (2000) discusses how suffering does not take place in isolation. Rather, it is a social encounter requiring the presence of at least two people: the one who is directly experiencing the physical pain of the suffering, and the one who is asked to respond to the suffering. This brings us back to the work of the French philosopher Levinas and his work in human suffering and the fundamental ethical responsibility in what he called "*suffering-with* and *suffering-for* the other person" (Gantt, 2000, p. 21). Levinas writes about the experience of suffering:

...Physical suffering in all this degree entails the impossibility of detaching oneself from the instant of existence. The content of suffering merges with the impossibility of detaching oneself from suffering... In suffering there is the absence of all refuge. It is the fact of being directly exposed to being. It

is made up of the impossibility of freeing or retreating. The whole acuity of suffering lies in the impossibility of retreat. (Levinas, 1987, p. 69).

This is John's, Sarah's, and Amy's experience of helplessness: they cannot detach themselves from seeing the face of the other's pain in the daily lived routine of the hospital ward. John, Sarah, and Amy cannot flee or retreat from the experience. Clarke writes that "being there" is to "respond to the sonar call of distress as if the very words were screamed inside our sleeping brain" (2002, p. 152). In the face of the "Other's" suffering, John, Sarah, and Amy see and hear the "call for aid" (Cohen, 2001, p. 274): it is their fathers' faces. Their fathers are calling them to respond yet they are helpless and powerless to help. Only the father's body can endure the pain, and this is John's, Sarah's, and Amy's experience of suffering.

Feelings of sorrow during the early hospitalization were also accompanied by feelings of uncertainty, a pervasive fear of the unknown, and ultimately of death. Despite the rigorous and myriad procedures to combat the leukemia, the outcome always remained unknown. "What then could come next?" John recalled asking himself. Behind the uncertainty of the unknown lay the fear of the treatment being unsuccessful and thus of potential death. He described the experience of early hospitalization as one in which fears of death are always with him. He is never without them and these fears are compounded by the ambiguity of the future. This is a time of uncertainty as John reported:

It was sad [silence] I wasn't angry or anything, it was just sad, cause at that point you still didn't know with him even receiving all this [treatment], you still don't know what is going to happen. So not knowing was hard.

Despite all the grief and pain that the treatment brings, for John there is no assurance of a positive outcome. Cohen, in his book Ethics, Exegesis, and Philosophy (2001), writes that for Levinas "Pain, is the most extreme intensification imaginable of our

bodily being. But maybe it is even more, that is: death” (Cohen, 2001, p. 275). Cohen argues that responding to the call of the “other” is Levinas’ fundamental premise. Yet Cohen argues, “what if the other’s call is silenced?” (p. 275). One may speculate that at the very core of John’s sadness, helplessness, and fear is the uncertain outcome. Could his father’s call be silenced? Could death come? John said:

I think what helped control the feeling of not knowing, [long silence] was just, having all these fears in the back of my mind but there was no point in me acting on those fears when you don’t know anything yet. For example, if the medication or chemo didn’t work, then it goes into maybe a bone marrow transplant, and if that doesn’t work then obviously it’s just the fear of losing your father.

Fear and uncertainty of the outcome are also readily apparent in Sarah’s narrative. Would her father survive cancer? “The hospital is definitely the hardest part emotionally. When I was in there that was the most tiring emotionally, because probably that was when I was the most scared,” Sarah said in recalling her father’s hospitalization. In describing her experience, she said:

And not knowing was really hard because you want to know, but you can’t. You have to wait to see the doctor. I felt the whole time we were not sure of anything. And the whole time I was scared and even now I am scared because it still is not over. Even after the surgery we still didn’t know if they had gotten everything. We didn’t know if they had taken it all out, whether all the cancer was out. Yeah, I might have been more scared at the hospital than the diagnosis. And the scary part was that he could die [long silence].

Amy also talked about her deepest fear: the possibility of her father’s death. In recounting the hospital experience she said:

And it is really hard because for you, your father never dies, and to be there, at the hospital, and see that your father could die. It was “Ok it is really bad but not bad enough to die from.” But part of me was: will he die? And that was really hard [long silence]. But I might have been in denial because I kept telling him “NO” you are not going to die and everything is going to be ok. [Interviewer: Did that thought cross your mind?] Yes, it did [long silence].

Levinas (1987) remind us that “death” is never knowable, but rather “it comes” (p. 73). As Levinas proposes for these adult children, sorrow, pain and suffering from their father’s uncertain treatment outcome brings near the “proximity of death” (p. 69). For Levinas the “very relationship with the other is the future” (p. 77), yet for John, Amy, and Sarah, a relationship with a father is not assured: cancer may not spare their fathers’ lives. This is the fear that permeates John’s, Amy’s, and Sarah’s experience in the hospital ward.

Participants have similar recollections that the early hospitalization was also physically and mentally exhausting. They also shared how their reality was one of living day-by-day, John states:

Yeah, it was living day by day. At that point, obviously at that point we were all tired, mentally and physically as a family. From going from work to the hospital and you are trying to help your dad feel the best he can, so whether its trying to bring him food or spending time with him, you’re just trying to make sure that he is comfortable.

Sarah, without hesitation, described the initial hospitalization as the “hardest part of the treatment.” Of her daily routine Sarah notes: “I guess when you’re at the hospital you just did it. You go there and you come home and you go there and you come home. You go and come home,” she said. Yet, for Sarah, vigilance never ends even at the moment when she attempts to fall sleep. When asked if it was a physical or psychological type of tiredness, Sarah replied “both.” She explained:

Physically, because you have to go in the morning to the hospital, and then you come back at night and you sleep. And then you go back early in the morning but you don’t sleep well because you are worrying about your dad. So, you are tired physically but also tired emotionally because you are scared, because you are so nervous. The hospital is definitely the hardest part emotionally.

Amy also observed this day-by-day existence in detail:



I was there every day and the treatment was really hard. He was there [hospital] a bit over a month. And I was there every day, day and night. It was tiring but at the same time it felt good to know that whenever he needed me, I was there. Yeah it was a long treatment. I was living there because there was this English barrier, because my dad doesn't speak English. I was there everyday. I will go home an hour a day and take a shower. And when my sister gets off work she comes to the hospital; and I would go home and shower and then come back.

For Amy, vigilance is complete. She is day and night by her father's side, she continued:

So I was living there, so that threw me a little bit crazy. I had weekends, like Friday night and Saturday night, because my sister didn't need to work the next day. She will get there [hospital] and I will go home to get a good night sleep. But even then I still felt that I needed to be there [hospital], so I will go home and sleep but as soon as I was awake I will return to the hospital. Yeah, in a sense I didn't have days off.

### **Measuring life in day-by-day doses**

*Measuring life in day-by-day doses:* this sub-theme relates to the day-to-day living experience of the daily outpatient care. The impact of physical demands unfolded as chemotherapy, radiation, and other treatments continue.

For John, his daily routine drastically changed: lived time is experienced as never ending, with multiple chores and responsibilities that he must assume. His day begins early to drive his dad to the daily hospital outpatient care, and finishes late as he spends the day alongside his father. Outside the visits to the outpatient care there is always "something" else to do. Social relations, partners, and school are left behind: cancer requires all his time and concentration. "There is always something to do" he said, describing time as one of "no day off." John said:

I think that part was more tiring physically because you have to get up so early and then work in the evening, etc., then pick up the dog. There were always extra things, but you know it's fine, because you're trying not to complain so much, [long pause]. So doing all those things and being so

tiring, I always justified it as still nothing compared to that which my dad has to go through.

Sure I was tired, sure I can't go out; yes things did change. I wouldn't go out with my friends as much, and I took time off school, I wasn't able to see my girlfriend as much. But when I thought of what my dad has to go through, then you know it's fine... It was more like a schedule. They even give you a daily schedule to go to the hospital, and that's what you follow.

My sister and my mom will ask me how I was doing, and I will say "fine." I said: I'm just tired. And I think it became tiring, I was tired. I remember one time I had so many days off work and I spent all those days in the hospital [BMT/hospital outpatient], so it was tiring because you don't have any days off. Yeah, I have no day off.

Sarah also talked of how her father's current outpatient treatment is one of day-by-day demands. "And now it is more like a routine," Sarah said. Sarah relates her day-by-day existence, of multiple responsibilities that need to be borne. As John stated before, Sarah refers to the initial hospitalization as one that is "emotionally exhausting" while the outpatient chemotherapy treatment is "physically tiring." And although tired, Sarah needs to continue day-by-day and fulfill her duties: "You just do it," she noted.

Going to the hospital now every day is more tiring physically. But now my life is getting more regular, more routine. He is at the hospital Monday to Friday, but he goes there and then he comes back. And now this is his second round so you kind of know what happens, you know what to expect, so it is not as stressful. I just go and I do what I have to do. I totally live day-by-day. I know what I have to do. In the morning when I wake up I know what I have to do and deal with it. And I don't think: I just do it. And you go through it day-by-day and that is the most you can hope for. And you continue to go through day-by-day and then at the end you will reach the end.

I really didn't go out at all from the beginning of course. You really don't want to, and that part isn't important, to go out anymore. Having a social life isn't really important. Yeah, I don't go out at all, and stuff like that, but that is OK. It isn't a problem. It doesn't bother me.

Sarah continued by relating how her father, already having gone through outpatient treatment, brings some mental respite from the uncertainty that she has been experiencing in the hospital ward during the initial treatment. There is a sense of stability of what happens as her father continues his treatment, yet uncertainty never leaves:

You know what to expect now, though you don't know what to expect for the future. But because you already have done one cycle and you already know what that was like, then we know what to expect to at least until the end of treatment.

Amy, in describing how the experience impacted her own quality of life, also relates how her daily routines, and essentially all aspects of her life before leukemia, changed abruptly and “completely”:

I had to quit my work, stop working full-time. My life completely changed. I didn't see my friends. I didn't have time to see my boyfriend. But I appreciated my friends because they knew what was going on. My boyfriend came all the time and I have his support. And it was hard because I came from a very busy, busy life, where I worked 2 jobs, my career job with the designer and the other part-time.

So I worked 7 days a week, and I worked 60-70 hours a week and I had a really, really busy life. You have your friends, boyfriend and all that completely stops. Yeah, I was barely home [twice] and all that completely stops. My life went from having 4-5 appointments a day to just being there at the [BMT/hospital], just sitting there. Doing nothing, I felt a bit useless but at the same time I felt that it was something that I needed to do. But it was funny because you have no time off. This made me realize that the stress that I had before was nothing. Yeah, it wasn't even that stressful compared to this stress of taking care of your family and [silence] the fact that your father is very sick [soft voice].

The outpatient hospital stage also brings new and unwelcome responsibilities. For Amy the task of driving brought about additional and tangible fears. Amy explains that she must take on the task of driving though she feels inadequate to the task, for which she feels real fear and stress. Amy recounts her struggles:

I felt that there was even more pressure for me just because I don't drive. You want me to drive? And part of me is like I don't drive, I don't enjoy it, and now I don't trust myself to pay attention. I know that I could be a good driver but at the same time I felt like, why are you putting yourself at risk? And part of me was: 'you don't understand, I have so much stress that if I am driving not only do I put my own life at risk, but also my father's life, which we are trying to save.' And I didn't explain it like that because I think they wouldn't understand. In their eyes it is like, "well that means you don't have confidence in yourself." And it is not like you don't have confidence. I wouldn't pay attention to the road. So if I know that then why would I put myself in danger? Why put others at risk? And I felt so forced that eventually I said: fine I will drive.

One must go ahead and do the task; there is no other option. Moreover, this will be a task she must endure, not once or twice, but every day for four months, or the entire length of her father's outpatient hospital treatment. In Amy's excerpt below she refers to the "everyday" nature of her duties. With the addition of new and challenging responsibilities this phase of outpatient treatment becomes more daunting and more stressful than the initial hospitalization:

I haven't driven since I was 16 and the fact is my dad can't drive because he is sick, and now I need a ride everyday everywhere. So I had a lot of pressure. And I think I felt more stress during the BMT [outpatient ward] than when we were at the hospital, just because I already have taken on so much responsibility. And now I have to drive.

Along with the physical demands of daily trips to the hospital, the emotional toll continued throughout the later outpatient treatment, including unforeseeable tasks such as protecting their fathers from associating the illness and death around them with their own prognosis. Despite John's own fears of death and uncertainty with which he is struggling, he realizes that he must now protect his father from those same fears. John details:

I always wanted to make sure that I talked to my dad, or play chess, or just spend time with him, because obviously on the other side of the room there is a patient who is not doing so well and I think my mom thought that too. We didn't want my father to think that was going to be him, or that was his

fate. I wanted to make sure that he never made the association that it was going to be him.

The future is always coming to the present, writes Levinas (1987). The adult child sees the potential fates in the faces of the patients around them, that is, the uncertain future that may await their loved ones, and attempts to keep it from intruding on the present.

For Amy the need to protect her father is also clear, though manifested differently. She is the main carrier of information since her father does not speak English. This presents a heavy responsibility because she must act as both translator and judge between what she feels she can or should disclose and what she must hold only to herself. To protect her father from the medical information that she is receiving daily, she holds tightly to what she is feeling and hearing. Perhaps this is best illustrated by Amy's statement "I have a lot in my throat," as shown in the excerpt below:

I am translating and I am also giving the bad news to him. So I have a lot in my throat. And what was playing on my mind was: Do I tell everything? Or Do I filter certain things. It was really hard, and my mind had to work very fast because translating English into Chinese it's very, very hard. And at certain times I felt like I should filter out certain information to protect him.

She continues detailing the struggle she faced in confronting the dual images of her father as a patient whom she must protect, and withholding information from the man who is still an authority figure who is owed respect:

Or do I respect and I let them [parents] know all the information, and they get to know everything they are supposed to know. Do they need to know everything? That was really hard. In hindsight I might not have told them some information. I am pretty sure I filtered quite a bit of stuff. In my mind it was: "I can't tell them that." Yeah it was a hard position for me in the sense that I am the carrier of the information. And at the same time I am supposed to be the daughter that is telling a father that he is sick, not the other way around. But I am the translator and I am the one taking care of my family. So it is a baggage of responsibility. All this responsibility is left in my face.

The experience in the outpatient clinic continued to present other worries for Amy, as intense as what she faced in the hospital. In the hospital she said she felt safer as the environment of doctors and nurses provided a sense of security that if something were to happen, someone with knowledge would respond. In the eventuality of an emergency she said there were “professionals that know exactly what to do.” Not so at home where she must take on that responsibility in the caring, a responsibility for which she felt ill prepared and helpless to respond.

But I got more stress in the outpatient ward than in the hospital, I think I got less scared at the hospital less worry, and I think that I would prefer being in the hospital. Everything is taken care of, than in the outpatient with all the problems. The insecurity came with worrying that dad had a fever and you are an outpatient. The scariest thing for me was that he gets this fever and what can you do for him if you are at home, what can you offer? Cause everything is OK and when he got that fever, I don't know, and I feel uncomfortable. I don't how to take care of him and you are home, so I panicked and I felt helpless. If you are at the hospital, if anything is going to happen you know you have them [doctors] there, and at the outpatient, you are there but then they close, and then what do you do?

Echoing Amy, Sarah also expressed how as her father recovered from the initial surgery, worries and helplessness emerged when he was discharged from the hospital. “Coming home was a good day. He was happy, so we were all happy,” Sarah recalled. Yet, paradoxically, it is an event that brings much worry and doubts. The hospital, while scary, is also a needed sanctuary. In Sarah's words:

But leaving the hospital was kind of scary because he was at the hospital and he was in pain. And we knew all the doctors and nurses are there. But when he came home, we are not doctors, and we are not experts. We don't have the equipment so he was really nervous coming home. And that made me nervous about him coming home because even the day he left the hospital he was in pain. And I was worried that he wouldn't be able to stand the pain. And even though the hospital was tiring and it was hard to see him at the hospital, I felt safer there. The doctors are there. Like if something goes wrong that is when they can help him. At home, we would have to go to

emergency, and drive there, whatever. In the hospital, he is there, and help is there.

So I was HAPPY [emphasis] that he was coming home. It was nice to have him home instead of sleeping by himself at the hospital. But it is still a bit nerve wracking because you always worry what if something happens, then what are we going to do?

As treatment continues in the outpatient hospital care, treatment and prognosis also come in day-by-day doses. Each patient is given daily their blood counts detailing the levels of white blood cells, haemoglobin, platelets, and other indicators that track the level of progress or the lack of it. That is, the counts act as a daily monitor of whether treatment is succeeding or has failed. Thus these counts pervade and inform one's reality with the uncertainty of the future. Good counts bring hope and relief, while bad counts frighten and carry unwanted possibilities. John recounts one such scare:

And you go from meeting to meeting, the next one and so on. I knew I would have to wait before I jumped to any conclusion. I'd have to wait for the doctors to tell us something. So until the next meeting you would feel like that, and then the next meeting, and one after that, and so on.

One time early on, when we were in outpatient, I think it was during the weekend when we got the numbers back, one of the nurses thought it could be that the chemotherapy hasn't worked or not worked completely. Obviously it was "what is going to happen now"? It was then, more fear coming back [long silence].

### **Cancer lingers on**

A new theme emerges from John's account of the end of treatment: that beyond the physical ending of treatment, fear and psychological uncertainty remain fixed in the adult child's perception of their new world. The dread of cancer never completely leaves. Instead, a new fear emerges: the threat of recurrence. John stated that, despite his father's remission, deep down he could hear in the back of his head how "Cancer lingers on."

I think the fear you will have it, no matter what, whether from the beginning or the end, because even now that my father is technically in remission the first year is where we all have to watch out because that is the year the percentage of leukemia coming back is at its highest. So you still think in the back of your mind: fear.

When I asked John if it was a fear of recurrence he responded:

Yeah, like fear of recurrence. Yeah, fear that it could just come back... [silence]. I think from here to the end, five years down the road, when they actually tell you and your family that your dad is cancer free, because until that point still, you have that thought that it could come back. Obviously, the thought is not so much as before [silence] but the word Cancer lingers on [long pause].

Etymologically the word “linger” derives from the Middle English “*lengeren*” meaning to dwell and from the Old English “*lengan*” meaning to prolong (Merriam-Webster dictionary, 1993). The Oxford advanced learner’s dictionary of current English (1989, p. 727) notes that, to “linger” is to “stay for a long time...to remain in existence.” To “dwell” said Heidegger (1977, cited in Clarke 2002), is a way by which “mortals are on earth” (p. 146). The centrality of the lived time is readily apparent during the remission time. John’s way of being in the world is one in which his present is fused to the past as well as to a future that is obscured. Levinas (1987) notes that the past cannot be left behind; the past intrudes into the present and informs the future. There is a time before the diagnosis and one after the loss of health, and while the parent may be in remission and declared healthy in the present time, the past of the diagnosis cannot be stopped from intruding in the present and the future. At the very moment that there is news, a check up, something said about the illness, or a doctor’s appointment, the past emerges. “In the back of your mind is fear,” John says. The past endures in the ambiguity of the future that now constitutes John’s present. Each blood work laboratory evokes his “calling home and noticing his mom



crying”; a doctor’s phone call brings back “his sister’s red eyes.” As testimony to the awareness of death, news brings the sense of “urgency” that he once felt.

For Levinas (1987), “the present is the future making itself present” (p. 122). The “helplessness” John felt in seeing his parent “blind” and “weakened by treatment” returns as John waits for “five years” to pass. Duration time, writes Levinas (1987), is “an interpretation of instants, a time where each instant is “heavy” with its entire past and “big” with its entire future, where nothing, consequently, is ever definitive” (p. 130). This is the experience of “lingering on.” “Past, future, and present, are tied together in time” (Levinas, 1987, p. 119), and this is the lived time of the cancer experience.

Cancer “lingering on” is also conveyed in Amy’s narratives. Cancer becomes timeless, never interrupted, its presence having no end. It is a circular presence where no time exists that it does not occupy. Cancer is never gone, it remains latent, only in remission. Amy uses the phrase “there is no forever” to strongly signify that cancer does not leave her. Time remains still, even as the cancer recedes from her father’s body. Amy said:

Just because he is in remission does not mean that it won’t come back. So there is no forever. You can’t say OK it is over and done. There is no forever, and you really need to know the reality. The thought that it MAY COME BACK [strong voice] is scary, and I don’t want that to happen. And you think that it may come back, because it is true, and you need to accept it [soft voice/whispering]. The idea of leukemia gone forever, well, there is no forever. The idea of this thing [leukemia] gone forever and being one hundred percent better, well there is no one hundred percent. The idea that it is one hundred percent gone, no, there is no one hundred percent. Yeah, yeah, there is no one hundred percent.

Lived time is also evident in the experience of how these adult children handle the threat of recurrence. Fear is a feeling that is readily present, from which there is little escape. John described how he attempts to control his fear by focusing on his father’s now healthy

appearance. He again uses the words “lingers” in reference to fear, perhaps signifying the new vigilance with which he has learned to live.

I think of it only as a fear. I don't think of it as the truth, that it will come back, only that it could. The fear lingers but it is not in my mind all the time...Especially now, just because you may see my dad looks quite happy... and when we see him feeling fine, you don't really have to think about it [long silence].

Amy's lived time appears also as one of vigilance. Rather than focusing on the present, she confided how she prepares herself for the very eventuality that what she fears may become a reality:

Because part of you knows that this thing [cancer] tries to come back. Yeah, that is exactly what it is you need to know [long silence.] You need to prepare yourself for the worst. And if you are able to prepare yourself for the worst, then if the worst [broken voice] happens, maybe you are able to handle it better, and you will be less scared. And if it is not as scary, then you will be stronger when you deal with it, and then you are able to fight back. If you prepare yourself for the worst then you are able to defend yourself and defend other people. And I think that is important. And it is less scary and then you go: I am OK; we will be ok. I don't want to be in denial ever again.

And I can be more prepared than I was before. And I know that has happened to others that they said: “everything is good” and it has come back and it has hit them even harder than before.

Thus, for John and Amy, the possibility of cancer is not just a future that has not yet come, it is a future that is “making itself present” (Levinas, 1987). Amy and John are aware that cancer may come again; they are vulnerable. As much as they seek to move beyond cancer, the presence of it remains inexorably tied to their identities as a frightening reality that may suddenly re-surge again. Cancer lives time and again. The naiveté of their lives before diagnosis, where the belief that parents are “strong” and “invincible,” that illness and death come at an old age, is gone and may not be regained.

It is important to add that though Sarah's father treatment has not ended, she already expresses the fear of cancer coming back. For Sarah, the future is one of worries, cancer is lived and re-lived everyday in the hospital room and in the thoughts that cancer may never be left behind. And Sarah worries. John has talked about this experience using the word "linger" while Amy has reminded us earlier that "there is no forever" without cancer. In referring to the enduring presence of cancer, Sarah uses words such as "re-occur" and phrases such as cancer is something that "you can't get rid of it," something that "you can't forget it." For Sarah cancer is indeed inescapable. Sarah said:

And you don't want ever to come back. And that nobody gets cancer whether is my dad, or my mom, or anyone. And you hope that it never happens again. Oh yeah, because probably it is in the back of your head that cancer is not a thing you lose. It can re-occur. And it is so common now and you went through it twice, so you think really it can happen over and over again. Yeah, the day he is cancer free and always will be cancer free, and that is what you are hoping for. But it is always possible that it may come back. So this is always going to be something that you worry about. And I know that every time my dad goes to the doctor after he is cancer free, I am going to make sure that nothing is wrong. But you can't get rid of it [the fear]. You can't forget about cancer. You can't escape it.

While John stated that his father looking "good" and "happy" helped him to evade the ever-present fear of cancer, Sarah also confided how focusing only on the present time with her father now responding well to the treatment, allows her to escape the fear and vigilance that is holding her hostage. Sarah explained:

Before, at the beginning you are just scared because you know how cancer is such a fearful thing. Even right now we don't really know because he is getting his treatment and we are hoping that it is working and after he finishes he will be OK. But we still don't know. But right now I am thinking that if he is doing OK right now, and he is doing OK right now, then he is going to be OK. And then I can go on with my life.

And I try not to think in the negative. Something that I don't want to focus on, I just want to focus on the very end, when treatment ends.

Perhaps adult children's inability to withdraw from the vigilance of cancer may be best exemplified by Levinas' experience of "the existing without existents", *the il y a*, (Levinas, 1987, p. 50). Levinas' concept of "passive vigilance" (Toumayan, 2004, p. 151) can explain the experience of cancer *lingering*, of never ceasing to withdraw. Levinas brings the concept of the *il y a*, the existing that occurs without a subject, without us. For Levinas, writes Toumayan (2004), the *there is*, "the *il y a* represents the intrusive presence of something" (p. 147), an "anonymous" that threatens you, and from which escape is not possible (Toumayan, 2004). There is no "refuge nor recourse, one can neither counter this threat nor withdraw from it" (p. 151). "Vigilance without refuge," says Levinas (1987, p. 49). The experience of cancer lingering on is also about vulnerability from which one cannot seek refuge. According to Levinas, at the core of our vulnerability is our filial responsibility toward the other. It is important to keep in mind that, as Cohen (2001) reminds us, Levinas refers to vulnerability as "proximity, non-indifference, insomnia, substitution, hostage" (p. 23). In describing this experience, Levinas turns to the night, using the word "insomnia:"

Insomnia is constituted by the consciousness that it will never finish – that is, that there is no longer any way of withdrawing from the vigilance to which one is held. Vigilance without end. From the moment that one is riveted there, one loses all notion of a starting or finishing point. The present is welded to the past, is entirely the heritage of the past: it renews nothing. It is always the same present and past that endures... Here, time begins nowhere, nothing moves away or shades off. (Levinas, 1987, p. 48).

John, Amy, and Sarah must bear the idea that cancer might not "shade off." Cancer is not exiting from their lives. Rather, lived time for Amy, Sarah, and John is constituted by a vigilance from which they cannot withdraw. "Lingering," "no forever," "no escape," gives a sense of how cancer takes them hostage. Just as Levinas would have reminded us, for these adult children, cancer stands as a shadow of one's reality (Toumayan, 2004). This is the experience of cancer lingering on: there is no forever that exists without cancer.

Toumayan (2004), in his work on Levinas, notes that Levinas uses the metaphor of the image and the shadow, something less than grasping, to signify the encounter with the *il y a*. One may suggest that cancer “lingers on” through the images of the unresponsive father lying in a hospital bed, of needles and pain that cannot be eased. Despite the call to alleviate the suffering, John, Sarah, and Amy cannot, they can only sit by their father’s bed. Cancer invades them as an obscure invasion from the “other side,” as John had said previously. Cancer lingers as it “strips the self of its initiative and power, retaining only its passive vigilance” (Levinas, as cited in Toumayan, 2004, p. 151).

## CHAPTER VI. THE NEED FOR SOCIAL SUPPORT

The third theme that emerged from the participants' narratives is the need for social, and in particular, emotional support. For example, John spoke of the importance of clear communication and expression of emotions in working through the multiple responsibilities and physical and emotional demands suddenly placed on him by his father's cancer diagnosis. Knowing that the demands of the cancer experience would be shared, and not shouldered by him alone, eased John's cancer journey. Support came from the implicit understanding among family members that his father would not be alone throughout the treatment – it was reassuring to know that each family member had clear responsibilities that would be carried out without complaint. "That's all I really needed," he reflected. Perhaps this is the meaning of John's phrase "being on the same page," in describing what was helpful for him. To survive the experience everyone needed to have one priority, namely his father's well being. When I asked what was helpful, John replied:

My family and I always made sure that someone was there with dad. Someone has to pick up dad, someone has to be there with my dad, and someone has to come back quickly to pick up the dog and walk him - and there wasn't anyone arguing or anything when it came to do stuff, like waking up early to go to the hospital. We all understood what was wanted. I always felt that if we were to pull through this then we all had to be on the same page. We understood that we had to understand each other. Because I felt I had that, it was all I really needed.

Sarah's narrative is one that also speaks to the need of family connectedness.

Closeness with significant others facilitates how Sarah navigates the cancer journey.

Connectedness with loved ones allows Sarah to find strength and cope with the cancer

reality she is now living with. “I guess my mom was there a lot with me too. So being with my mom, helped me cope,” Sarah said. John reflected on how family members “must understand” each other. For Sarah, the family must count on each other. She continued:

Definitely depend on your family, depend on each other. It is not that you can’t do it for yourself but depend on them to be there for you. They have to be there for you and you have to be there for them.

In contrast, Amy’s experience was marked by an inability to connect with others in her family in terms of asking for, and receiving, support:

I wanted them to tell me: “we will do the little things, we will take care of the small things we know that you are dealing with all that.” Like helping in another part, but I was assuming that they should know. So I got frustrated in terms of their support. Like you have to help me if I am taking on all this burden. Maybe they should have helped me with the little things.

Amy added that in retrospect she now understands it was ultimately her own decision not to accept the help being offered. “I know in a sense that it was me who didn’t allow it,” she confided. It is important to add that Amy stressed throughout the interview her firm decision to take on the sole responsibility for her father’s care.

But in hindsight I was the one who took on all the responsibility. It wasn’t their fault because I took on all the responsibility myself. Yeah, because at the moment you would say why is all this on me, why couldn’t you offer to help and things like that, but in hindsight afterward I realized that it wasn’t that they didn’t offer.

This decision seems to be spurred on by Amy’s perception of her relationship/role. Amy stated she was the one “with the most knowledge,” “the strongest,” “most calm,” and lastly, “the one closest to her dad.”

I didn’t take their offer. I didn’t want them to have to deal with this because I knew what I was doing and they didn’t. SO let me handle it, I said. I knew what I was doing and I felt safer because of the fact that I knew what I was doing at that time. In hindsight it wasn’t really their fault and now I feel guilty for feeling that way.

Where John sought reassurance from his family's aid, Amy's role as sole provider for her father's care brought a sense of safety, a mechanism of relief from the state of vigilance in which she lived. "I was there 24 hours," Amy said. She related how her sister and mother would offer her more time to herself. Yet, Amy added, she didn't feel comfortable leaving her father's side. "I needed to be there. It is like, as much as I want you to be helping, I don't trust anybody else except myself."

Despite seeking the role of sole caregiver Amy acknowledged that others did provide help. Ultimately it was her uncle who provided the daily rides to the hospital outpatient care. "My uncle gave us the rides. My uncle drove. I was lucky," she said during the interview. "And my sister's boss offered my sister to come during her break." Amy also described how her sister would go to work and offer her respite from the daily care. "My sister got off work and then she would come to the hospital," Amy noted.

The importance of social support cannot be overstated, and emotional support may be its most important component. As Grulke, Bailer, Hertenstein, Kachele, Arnold, Tschuschke, et al. (2005) state, emotional support is the "crucial active ingredient" (p. 343). To express "one's own feelings and sorrows and looking for emotional support from others" (p. 343) is an important part of coping. This is consistent with research in cancer that has indicated that those who are providing informal care to cancer patients are likely to be subject to "demanding emotion work" (Thomas & Morris, 2002, p. 180). For Thomas and Morris (2002), the diagnosis and treatment of cancer brings considerable burden, anxiety, and fear not only to the cancer patient but also to those close family members providing informal care. Yet, at the same time, the cancer patient's loved ones must engage in maintaining a positive attitude and instilling hope, despite their own fears. Consequently,



Thomas and Morris suggest that emotional support may be crucial for those who are closely caring for someone being treated for cancer.

Emotional support may come from different arenas, such as family members, friends and intimate loved ones. When I asked John what was there to support him, he responded, “My family, my friends, and my girlfriend all understood, they all listened.” John also described how his family constantly checked on him throughout the cancer experience to see how he was managing the demands he was facing. In John’s case, he specifically noted his need for openness between himself, his mother, and his sibling about what they were feeling. This desire for openness was immediate from the initial moment of diagnosis and throughout treatment. John recalled:

I think it was just important to make sure that we all talk, and we really didn’t need to explicitly say that as a family – because just from what I remember when I came home, we were all there and we all talked and we continued to talk.

Such emotional support allowed John to process his emotional experience, in particular his feelings of fear, uncertainty, anger, and shock. He underscored the need not to “bottle up feelings.” He said: “I always had someone to talk to. As a family we were very close and very tight when it was something regarding my dad.”

Crying, talking, sharing, and feeling understood eased the adjustment to the illness and facilitated adjustment in the face of uncertainty. “You really don’t know what is going to happen so you try to say everything that is on your mind, especially when you are handed such a disease,” John said. Talking functioned as a coping mechanism allowing John to work out the myriad stressors that he faced daily. It was also a mechanism of security, a safeguard against the fear and chaos of the hospital existence.

Yeah. Because you can have fear about everything but sometimes those are just fears and if you put that aside as being a fear you can focus more on doing well. We talked about it. We talked about it and I expressed my fears.

I knew in the end it was good for me to cry because I let all that out. And I let that out in front of other people, in front of my family. My family saw my fear, and when I saw my mom crying I thought she was letting out her fears. That is an example of what I mean when I said we let everything out – we all talked about it, and showed our emotions in front of each other.

John also perceived talking as a way to keep the family together; the openness John sought from his family functioned to control any bickering or strife that can and often does occur from the heightened stresses with which such families struggle. A family not fighting and directed toward one purpose together is a unit without unnecessary “turbulence.”

I think if we hadn’t really talked we might have held more things back and have let our fears dictate our actions. So there would be more infighting between the family. That’s just an example. I felt that could happen, and because we did talk and acted as a family, nothing like that happened, we never really fought. No, I don’t think we did.

When asked what he would talk about with his family, John responded:

Oh just, you know, as a family we talked about how dad will get through this. Even when the bishop came over my dad was telling me that we would get through this.

You have to make sure that everybody is talking about how they are feeling. It was talking about whatever, whether it’s jokingly, or just trying to be at ease, [long silence] because it really is a very turbulent time [soft voice].

Sarah also stressed the importance of talking, sharing feelings and the suffering.

Sarah spoke of the need for family to rely upon each other if they are to survive the experience. Talking allows them to “depend” and “be for each other.” For Sarah, cancer is indeed a shared journey:

Normally we don’t talk like that, but here we DID [What would you talk about?] Oh, my mom will tell me what she was scared about and I will tell her if I was scared about something.

And even just making the schedule together you know. Like this day, I will take him to the hospital, pick him up, and see how it is all going to work. And being together is important, even just watching television together.

Yeah, you need to know that you have to share your journey. Don't take it for yourself. Don't. Share everything with your family. So everyone knows how everyone else is feeling. And talk about it with them because they are the ones that are going through it and it is important that they know how everyone is doing.

Like John and Sarah, Amy also spoke of a yearning to feel understood. While Amy lamented feeling alone and unsupported by her family, she also noted that it was she who did not permit the very support for which she longed. Amy said:

And what was frustrating to me was that I wished my mom and my sisters knew what I was going through, and that was all that I needed. I also wanted their support in the sense that they understand what I was doing and the stress that I had. But I know in a sense it was me who didn't accept their support. I felt like I didn't have support from my family, but in hindsight I did have their support. I really didn't allow it.

Amy related that her upbringing might have played an important influence in being unable to openly share her thoughts and emotions. She said:

Growing up in my family, you don't really talk. My father and I, we are probably the very closest. We always hang out, and we do things but we don't really talk. You just do things. So we do things: like go stereo shopping, shop at the home depot, or things like that. We'll go and look at things but you don't talk. And I grew up like that.

Amy noted how expressing emotions is regulated heavily by her Chinese cultural background.

We weren't brought up to be emotional. I think it is very much a Chinese thing that you don't really voice your emotions. We never say: 'We love you' or anything like that. It is not something that you do or say how you feel. And you just know that.

Such cultural influences also seemed to pull Amy back from connecting to her father and offering the emotional support that he might have needed. It becomes readily apparent

how torn Amy might have felt sitting by her father's bed and remaining silent without being able to utter comforting words to her father. Amy, by her father's side day and night, found no respite from feelings of guilt as she pondered the little time she might have left with her father. There appears to be a sense of desperation in wanting to be emotionally connected with her dad, yet this is a bridge she cannot cross. She does not know the words to express how or what she feels, to her dad, to her family, or even to herself. "I did not know how," she repeated a number of times.

You have all these people telling you: "talk to your dad" "talk to him more." But I didn't know how. And having my dad so sick and people telling you: "talk to your dad." "You should make him feel better, and tell him that everything is going to be ok." This was so hard for me because I didn't know how. So we never really talked. We would be at the hospital everyday but we barely talked. I just sat there but we didn't talk.

And part of me feels guilty thinking, what if I haven't much time left with my dad and I haven't talked to him? But I didn't know how.

John highlighted his need not to "bottle up feelings." For Amy this was not possible: "I didn't cry but I wanted to. I think I hold in my emotions a lot because I am just thinking I can't express them. I am not allowed." When I asked Amy what emotions she suppressed, she answered:

Obviously I wanted to cry. The few times that I cried it was in the shower [laughs nervously]. I will have all these emotions going on and you tell yourself: OK go ahead let everything out, because here, in the shower, you can. Yeah, I couldn't really cry. Yeah, I couldn't cry cause you can't do that.

Like John, Amy also spoke of the crucial need for emotional support. Amy lamented how she could not share or unveil her emotions at home, despite the intense feelings that she felt. Neither could she provide emotional support to her family:

And I realize that my younger sister needed a lot of emotional support but I wasn't able to provide it, and my other family members were not able to provide it because we are not emotional people.

When I asked who was there to support her, she replied: "My boyfriend." Similarly, Amy also had the belief that her close group of friends would be there whenever she needed them. Thus, her boyfriend and her friends offered her the much needed refuge to escape her emotional solitude:

My friends listen and if you need to cry, then you cry. They said: "If you need to talk, just call us. Just let it out." And I did not have that in the house. "Cry if you need to," my friends said. And I said "I don't feel that I need to cry," but it was nice to know that people understood what I was going through. I needed mental support. I didn't need to talk about it. I didn't need them [friends] to ask me, but just knowing that they were there. Just that offer: I was grateful that someone was there. Even with my boyfriend he would say: "cry if you need" but I didn't need to cry, just to know that he's there.

Sarah, whose father is currently attending outpatient treatment, also identified friends as a crucial source of emotional support. Like Amy's statement above, Sarah also uses the phrase of "having someone that is there" in alluding to her friends' help: someone who is there to talk with and to listen. She added:

Friends help. Not a lot of my close friends have cancer in the immediate family. But they all know that it is very scary. And they are there for me. They always say: "If you want to talk about it or if you don't want to talk about it, we are here." And they know when I don't want to talk about it.

So what is helpful is having someone to talk to about it when you want to and having someone that is there. They don't push me to talk, but I know they are there.

From their narratives, adult children named emotional support and a sense of being understood as being unquestionably essential. This theme has clear implications for counselling for both the adult child and the patient. "Just being there," writes Klass (2001,

p. 85), may be a common expression among those experiencing trauma when summarizing what helps in times of crisis and adversity. For Klass, “being there” conveys both a sense of acknowledgement of the challenges and struggles inherent to the trauma and, at the same time, some sense of security in very uncertain and dreadful times. John, Sarah, and Amy attest to the importance of having someone to talk to.

It is important to note that a sense of being understood and validated is also described as a key component of coping with cancer (Murray, 1998; Tarzian, Iwata, & Cohen, 1999). Sharing with others who have had a similar experience was seen as an important component of emotional support. John and Amy both shared a feeling that others who have gone through the cancer experience would be able to genuinely understand their fears, doubts, vulnerabilities, despair, and crushed expectations – more so than those who have not gone through such an event. John’s and Amy’s narratives below clearly show a sense of shared connection in suffering (Klass, 2001). For example, the emotional support derived from shared experience provided a sense of validation for John’s feelings of what the experience can be like. He recalled:

One girl at work, her father died of leukemia...No, her father died of lung cancer and her uncle had leukemia [pause, silence], so she knows. So obviously when you talk to someone who knows, with someone who has had it (cancer), it is different. Because others can’t understand what you’re going through or the way you want them to understand what you are going through.

Just like my other friend, his mom had cancer, but it came back. So he is going through this as well. So we talk “what’s going on”? Or just saying, “I’m tired” becomes: I know what you are going through. I know from the beginning, when you are being told about the diagnosis, and what it is like going through the treatment. And we talk about that because you know that they know what you are going through.

When asked whether there was a feeling of being understood, John immediately replied in the affirmative. The statement “Because others, they just can’t understand” has implications for counselling in terms of fostering contact among adult children, in the form of support groups. It is only those in the “cancer ward” who can understand. It is the knowledge that they “know” because they are living it as well. Those outside the cancer treatment experience cannot “know,” because cancer is something that happens to “other” people. They can sympathize and empathize, but cannot intimately understand John’s reality: It is alien to those outside the cancer circle, but there is fraternity within and between the shared space of those who experience it. Only those who have undergone a similar experience, those referred to as having “been there,” (Klass, 2001, p. 85), can know John’s grief. Emotional support derived from shared understanding provides a sense of validation for John’s feelings and what the experience can be like. Sarah also added how just knowing that others have gone through the experience brings a sense of hope. Sarah, who knew about my husband’s cancer said, “Your story helps because you beat it and your family gives me hope. It happens twice and you beat it twice,” Sarah noted.

Tarzian, Iwata, and Cohen (1999), in their study of cancer patients receiving bone marrow transplantation, found that patients were likely to report the value of talking to someone who has “been there.” Talking to others who had gone through the procedures not only instilled a sense of hope, above all it also provided a validation of the competing feelings and emotional struggles the patient was facing. More recently, McGrath and Chesler (2004) paralleled Tarzian’s et al. finding: in exploring the experience of fathers confronting childhood cancer; those fathers reported that talking to other fathers whose children had been diagnosed with cancer, regardless of the type of cancer, “was seen as particularly helpful” (p. 49), providing a strong sense of mutual emotional support and understanding.

Similarly, Murray (1998) who interviewed the healthy siblings of childhood cancer reported that siblings attending meetings with other siblings facilitated the voicing of “burning feelings” (p. 223), feelings that were rarely shared with “outsiders” (p. 224).

Just like John, Amy also affirmed the importance and the invaluable source of emotional support of others who have gone through the same experience. Sharing a common experience appears to offer a genuine and heartfelt understanding. “Others just can’t understand.” Amy reported a similar experience:

I needed the support where I knew that someone was able to relate...to understand this. That was all I needed. It is sort of nice knowing that there are people that understand, and knowing that others are going through exactly the same thing that you are going through. Because others just can’t understand.

In the midst of deep feelings of fear, worries, and uncertainty, Amy spoke how those foreign to the cancer experience would say: “Everything is going to be okay.” Yet she wondered, would it? Will it be okay? Could those words offer comfort and solace? Could those words speak of the enduring fear, dread, and vulnerability that Amy experienced at that instant?

Others will say: “don’t worry.” For me those are just words. I almost feel like everybody is trained to say that. So it doesn’t feel heartfelt. You are trained to say when someone dies: “how are you today?” but you don’t really mean it [laughs nervously]. Maybe it is not like you don’t mean it, but it is just something that you are trained to say. Like something bad happens and you are trained to say: don’t worry about it, think positive [soft voice]. And I just shrugged them off, and I said ok.

But I felt like saying [strong voice]: WHAT DO YOU KNOW? [twice]  
WHAT DO YOU CARE [strong voice] I sort of shrugged them off [voice very soft].

Klass (2001) and Olson (1993) wrote about how those who are experiencing loss commonly report that others who have not shared such an experience may offer comments



which might convey, unintentionally, an opposite meaning of what they had intended to say. “It’s all for the best” was often said, yet in the face of sorrow such a statement may “sound callous, though not ill meant” writes Olson (p. 154). Ultimately, such comments, notes Klass (2001), carry the inherent message that the grieving event “doesn’t hurt as bad as it does” (p. 81).

Thus, for Amy and John, the “others”, those who have gone through the parental cancer experience, can be there *for* them in suffering (Levinas, 1987). Perhaps having shared the same experience brings a sense of “identity” of “belonging together” (Toumayan, 2004, p. 14). It is important to note that Toumayan observes how for Heidegger the concept of “identity implies a relation” (p. 13). This relation of “together,” writes Toumayan, is “the necessary connection of the one with the other” (p. 15).

From the excerpts above one can see that for John, Sarah, and Amy understanding is derived from someone having “been there” – the assurance that someone is able to comprehend the totality of their emotional experience and express it in a way that is understood by both. This is then a sense of relief and is a crucial source of emotional support and connection. It is interesting to note that both John and Amy explicitly or implicitly address the notion of others “being there” and “sharing the pain” (Klass, 2001, p. 85). Klass writes how in his long years of working in the area of loss and grief, he has observed that “just being there” (p. 85) is a common expression among parents to describe helpful support at times of suffering.

According to Klass, “being there” symbolizes the acknowledgement of one’s loss and the distress, despair, and suffering associated with it. Yet, at the same time, Klass argues the same phrase may also signify that only others who have lived the same experience can

understand the devastation, uncertainty, and turmoil that the traumatic event brings to one's life. For Klass, "being there" ultimately represents, as Heidegger (1962) observed, "a stance, a way of being in the world" (p. 86). Such a stance ultimately helps in making meaning of the traumatic event (Klass, 2001). Perhaps it is beyond "walking in someone's shoes" (Rogers, 1962), rather, as Levinas affirms, it is to wrap oneself in the skin of another, to walk as they walk, feel what they feel, and see the experience from within (Hand, 1989). To be there is to ease the dis-ease of illness," writes Olson (1993, p. 149); that is, to be *for* the other when the sufferer's life has been taken fully by the complexities demanded by the illness (Olson, 1993). It is this "being there" that fosters a "mutual endeavour, a mutual accomplishment," (p. 149) in which we stand together in facing despair, pain, and tribulations (Olson, 1993). Perhaps the sense of being emotionally and implicitly understood by friends can be best exemplified by Olson's writing about her mother's experience in dealing with her daughter's illness. Her mother said: "We share grief with a devoted friend: this expression of grief in words and tears, gives release to the pain and anguish dwelling in the depths of our beings" (p. 154).

"In suffering there is an absence of all refuge. It is made up of the impossibility of fleeing and retreating," writes Levinas (1987, p. 69). In writing about the Event and the Other, Levinas observes "...only a being whose solitude has reached a crispation through suffering, and in relation with death, takes its place on a ground where the relationship with the other becomes possible" (p. 76). Perhaps this is John's, Sarah's, and Amy's experience of being understood in suffering. Others whose parents have gone through the cancer experience can grasp the immensity of their experience, and thus offer true understanding. For John, Sarah, and Amy, it is perhaps comforting to know that there are others to whom they can relate. There are others, who just like Amy, Sarah, and John, have seen death,

sorrow, anguish in their parents' face. They have seen death approaching in their parents' pain (Levinas, 1987). When John shares his experiences with his friend, whose mother's cancer has come back, John instantly knows the meaning when he is asked: "what is going on?"

John said, "Just saying 'tired' becomes 'I know what you are going through.' In that instant, John feels the comforting notion that his tiredness, the daily early mornings to accompany his father to the treatments, the never ending chores, the rigid hospital schedules that he must follow, and his weeks with no respite, with "no day-off," is understood. The "others" who have walked this path can recognize Amy's vigilance day and night, by her father's bed side. "I was there 24 hours," she said. "I remain awake until 6 am, next to the puzzles at the hospital, each morning, just in case he needed something," Amy recalled. The "other" the one that is there for her, can understand Amy's vigil, and the tears that she withholds. In that instant, she feels the voice of the other, the other sees her; her pain has become visible. The other recognizes and acknowledges her trials in this uncontrollable experience: "cry if you need to," "just let it out," she hears in the voice of the others. Just for that, she is grateful. For Sarah, having heard the stories of others who have survived the illness instils hope. Those are the instants in which John, Sarah, and Amy recognize the physical and emotional presence of the *other*. This is the transcendent space (Levinas, 1987) they together inhabit.

It is interesting to note that the Colour Oxford thesaurus (2002) lists the English synonyms of "to know" as "to be aware of... to be conscious of ... [to] sense, [and to] recognize." According to the same thesaurus, to know is to "have known tragedy... [to] experience, to be acquainted with... [and to] fraternize" (p. 344). In the Oxford English Dictionary (1989), to know is to "have personal experience of (something) as affecting

oneself; to have experienced, met with, felt, or undergone.” Perhaps this is Amy’s, Sarah’s, and John’s lived relation with those who *have been there* and those others who are perceived as *being there* for you: it is the call to be understood and to become known. It is worth noting that Levinas uses the word “recognize” in writing about recognizing the face of the *other* who calls you in suffering.

Perhaps this is about the face of the *other* (Levinas, 1987, 1981). Others, who have been there, recognized my face, as Levinas said, they have seen my face, my face in suffering and they have heard my call to respond. This is the ethical responsibility that Levinas reveals. Just as these adult children have seen the face of the other in their father’s face, others have seen Amy’s, Sarah’s and John’s faces. That is the sense of connectedness in understanding. The appeal to those who have already “been there” and those who are “just being there” for you, writes Klass (2001) is to accept and understand the feelings of the sufferer (pp. 85-86). Adult children seek to connect with others and themselves, and in doing so they cope with their sufferings. In a sense, sharing the suffering is a way for John to be together with his family and his friends. When he talks about his sorrow and the cancer experience, John connects with his mother, his father, the bishop, his friends whose parents also have cancer, and to his own feelings. Sarah feels her family and friends standing by her side, and she feels less alone. She recognizes the stories of other cancer survivors as passing on a sense of hope that she is now grasping. Similarly, Amy feels the solace that someone will be there for her: her boyfriend, her friends, and counsellors, and she feels that she is not alone.

This is the lived experience of time in relations with the *other*, writes Levinas (1987). “Time is not the achievement of an isolated and lone subject, but that it is the very relationship of the subject with the Other,” observes Levinas (1987, p. 39). Lived time also

changes in the presence of the others who accompanied John, Sarah, and Amy in the cancer experience. In the instant that John talks to another adult child whose parent is being treated for cancer, he feels understood. When he sees his mother crying, in that moment, he sees his mother “letting out her fears,” which are also his own. Bearing all the responsibility for her father’s care, Amy, in her solitude, hears the voice of the other who is responding to her; it is the voice of her friends, perhaps her boyfriend, telling her that they are just one phone call away from her pain, only minutes away from comforting her. The other becomes present. In that moment in time, Amy feels her emotional burden less heavy, her intimate friends embrace her, and she is able to regain strength and carry on.

As she witnesses the deterioration of her father’s body in the hospital room, Sarah knows she is not alone: she sees her mother standing by her side. She feels the presence of her mother as they share and plan the daily routines of her father’s care. Like the other adult children, Sarah observed her friends silently and devoutly standing by her. This is the strength that sustains and carries Sarah through her current journey. Such are the fragile instants in which the *other* approaches John, Sarah, and Amy, and allows these adult children to escape the harsh emotional burden of their experience.

When Amy, Sarah, and John speak about their friends, they “call their presence into being as it were,” writes van Manen (2002, p. 239), and this is the stance of “being there” (Heidegger, 1962). For Sarah, Amy, and John, these isolated times need to be no more: Others, who are “there for you,” and those who have “been there” through this dreadful illness, can offer solace in facing an uncertain and fearful present. The *other* offers comfort to John’s, Sarah’s, and Amy’s intangible and unknown futures. Thus, there is a sense of an immediate togetherness that these adult children share with those who “have been there” and those who offer to “be there.” This is to be together in suffering, to sense belonging.

As Levinas would say, in the cancer experience we are made visible in time and relations; in suffering, we become visible to ourselves, and visible to others. The lived time of the cancer experience is one of time and relations.

The “movement” of time understood as a transcendence toward the Infinity of the “wholly other” does not temporalize in a linear way, does not resemble the straightforwardness of the intentional ray, . . . makes a detour by entering into the ethical adventure of the relationship to the other person (Levinas, 1987, p. 33).

Health professionals in the hospital setting are also seen as a valuable emotional support. Counsellors and health personnel understand and normalize the participants’ emotional reactions. Ultimately, just knowing that someone is able to understand the tumultuous feelings that the participants experience appears to bring security and comfort. At the core of understanding is the felt sense that others are able to acknowledge the emotional impact of cancer. Amy spoke of how counsellors give a sense of normalcy to one’s life when one is living a reality that is outside ordinary existence. Amy said:

The counsellors were really good, they understood. They said “I know that you must be really confused and you must be very scared at the moment. If you have questions, we have answers for you.” I didn’t go for counselling. The social worker came and said “whatever is going through your mind, is OKAY. It happens, everyone goes through that.” And they said, if you have questions, ask. That was nice. Just to know they are there. . . and the fact that they say: it is OKAY to feel the way you feel and everybody goes through this, that you are sad, and you are confused and you are scared, and everything, and have all these feelings at once.

John’s narrative was also one that highlighted how allied health personnel helped in making sense of the emotional reactions that he was experiencing. John recalled:

I remember when we were at the BMT [hospital outpatient], and at VGH, and they came and gave me that binder telling you about your feelings. And then I read through it, and it said “you may feel angry” and you may feel this, and you may feel that. I remember reading it and saying to myself: oh that’s the way you may feel. And that’s the way I feel.

Thus, for John and Amy, reassurance that what one is feeling is “normal” is seen as an important emotional support. From the narratives above, it is apparent that health professionals such as counsellors can help adult children make sense of their experiences from the multitude of unfamiliar and competing emotions they may be confronting for the first time.

There is no escape from their feelings. When Amy hears the voice of the social worker she feels reassured that she is not alone: someone is there who can understand her experience and what she is feeling. “Knowing that there were counsellors and services definitely was enough,” Amy said. For John, reading the text handed to him by the treatment centre helped to make sense of the disarray of emotions he was experiencing. “Oh that is what people feel,” he recalled upon seeing his feelings stated in the text. He could now acknowledge them. His tension, stress, and confusion had an outlet that recognized and validated what he could not himself recognize as being normal.

Sarah also expressed how knowing that counsellors were there to talk to brought a sense of comfort and re-assurance that help is readily available.

They do have counsellors and they offer counselling for all family members. I knew that the service was there but I didn't go, but they offer it, and that was good. They offer a lot of help. But they offer counselling only at the cancer centre. They are good there. They say if you want to talk they have a counselling schedule of services that you can use. It was helpful.

Sarah also makes clear that such services were only offered at the cancer agency, but only after the time of the diagnosis and first round of in-hospital treatment. During the time that she referred to as the “hardest,” emotionally nothing was available: Speaking of the availability of counselling she said,

But that was at the cancer centre that they were really good. But not before you were sent to the cancer centre, not during the surgery, not when you get to know the diagnosis, and when you are still waiting for results. And that is the hardest time.

Knowing that others can be called to talk or to share feelings without judgement may be seen as an important support needed among carers (Stoltz, Willman, & Uden, 2006).

Emotional support from friends, family members, and in particular by health professionals, write Stoltz, Willman, and Uden (2006), may be referred to as “Experiencing togetherness with others in caring” (p. 600). In their study of carers of seniors in home palliative care, Stoltz et al. found that family carers reported that perceived emotional support brought a sense of understanding and recognition for the carers “feelings, or struggles” (p. 601). In contrast, note Stoltz et al., a lack of support or inadequate support led informal carers to feel a strong sense of “insecurity and aloneness” (p. 601).

From the narratives above it becomes evident that adult children’s lived relations are paramount for coping. Yet, despite the well-documented findings of the significance and positive impact of social support in the cancer experience, paradoxically, writes Becvar (2005), a researcher, university professor, grief therapist, and cancer survivor, for most families the cancer experience continues to be one of pervasive isolation.



## CHAPTER VII. THE CANCER LEGACY

*“There are two Lance Armstrongs, pre-cancer, and post. The truth is that Cancer was the best thing that happened to me.”  
(Armstrong, 2000, p. 5).*

The final theme that emerged is that of the cancer legacy – a legacy characterized by a reconciliation of suffering and despair with personal growth and transformation. This theme is about ascribing meaning to life events that seem incomprehensible and beyond one’s control. As the adult children begin to glimpse and comprehend their loved ones’ mortality, hope fades (Davis, 2001). Despite their anguish and fears, however, they struggle to seek meaning and make sense of their experience.

Etymologically the word legacy derives from the Latin *“legare,”* meaning to be given something from the past, something bequeathed to another. That is, a legacy is bestowed upon one, without having asked for it. The Oxford Dictionary of Current English (2001) lists legacy as “something handed down by a predecessor or from the past” (p. 516). Such a legacy could be something material as well as immaterial. What could be the lasting gift of cancer? Could this illness bring something other than misery, fear, and despair? What could cancer have handed down to these adult children that endures beyond suffering? Despite its unwelcome presence, cancer may also bestow a long lasting gift. Anderson and Martin (2003) who explore illness experience as stories of self change, write that “facing the possibility of death associated with a critical illness produces an emotional life-changing experience for those affected by its anguish” (p. 133). It is possible that cancer lingers not

only through the fear of recurrence, but also through a legacy embodied by changes in the perception of the 'lived world' as reported by participants after the cancer experience.

Davis (2001) in The Tormented and the Transformed writes "Loss and trauma events often represent severe threats to how people perceive themselves and how they perceive the world. These events can shatter hopes, destroy confidence, and cast people into despair to last a life-time" (p. 137). Yet, Davis continues, for some individuals the traumatic experience may be "a turning point in their lives, a watershed after which their sense of identity or purpose was transformed" (p. 138). Perhaps this is best illustrated when Sarah shared the impact of cancer: "Cancer, you can't forget about it," she said. Yet cancer also changes you "forever" she added. In Sarah's words:

I think when you hear that someone in your family whom you love has cancer, makes you change forever. Before you are happy and you don't think that anything wrong can happen, anything bad, nothing really serious. Little things, are bad here and there, but not serious. And then something like this happens. And you see a new part of something that you never saw before. Something very serious.

Consistent with Davis' view, it is worth noting that in the interviews these adult children viewed cancer as something that brought positive changes to themselves, yet, paradoxically it was also unanimously referred to as the worst experience of their lives. Thus, a traumatic event such as a diagnosis of cancer has the potential to bring both distress and personal growth (Tedeschi & Calhoun, 1995; Tedeschi, Park, & Calhoun, 1998; Sears, Stanton, & Danoff-Burg, 2003), a phenomenon that Tedeschi and Calhoun (1995) have called Posttraumatic Growth (PTG). For Tedeschi and Calhoun, Posttraumatic Growth (PTG) represents the positive changes reported by individuals who have experienced loss or a traumatic life event as a result of the struggles they faced. According to Tedeschi and colleagues (Tedeschi & Calhoun, 1995; Tedeschi, Park, & Calhoun, 1998), in confronting a

traumatic or extremely stressful event, individuals witness the shattering of long held assumptions and beliefs. In attempting to cope and make sense of the events, individuals come to re-examine such assumptions and ultimately re-define their long-standing worldviews. Positive changes in the face of trauma may be more likely to be observed in three ways: “perceptions of the self” such as personal strength; “changes in interpersonal relationships” including better kinship relations; and a new “philosophy of life” (pp. 30-37).

These changes are readily apparent in the narratives of the adult children I interviewed. John’s, Sarah’s, and Amy’s narratives denote a defining moment in which cancer changed the manner in which they understood life, themselves, and others. Feelings of transformation and gratitude are at the heart of the theme – life and others must not be taken for granted. Adult children described the meaning of the illness using words and phrases such as: “appreciation,” “gratefulness for loved ones,” “life is short.” They also expressed a sense of purpose: “I want to finish school,” John said, while Amy stated, “I want to help others.” There is a newly transformed self. “Everything is possible,” Amy confided. “Before I thought we could not go through this,” Sarah remembers saying, yet “we are doing it now, and we will keep on doing it.” This theme may be described as one that encompasses an intense personal awareness of the finitude of life, gratitude, empathy, and connectedness to others. In the excerpts below, participants relate the legacy of the cancer journey as one that has brought new values, self-understanding, strength, and a strong awareness of the sensitivities and plights of others who inhabit their social reality.

The cancer journey is one of discovering the fragility of life and the importance of loved ones. The finitude of life cannot be ignored. A time without a future becomes possible – John and Sarah appreciate the significance of communicating their feelings of love

to their loved ones. John is mindful of communicating his feelings to his parents in the here and now.

Oh Yeah! I think that with my parents, letting them know that they are appreciated – a lot more. I guess I’m the type of person that doesn’t tell my parents “I love you”, but I think they know it. I hope they know it.

Sarah echoes John’s need for expression – her father must know how she feels in the here and now. Sarah talks about how, as she grew older, she stopped expressing her affection to her father. Sarah may feel reassured that her father understands her feelings, however she nonetheless feels compelled to voice her affection. Sarah stated:

And you said “I love you” when you were a kid but I guess because you are with them it fades. You forget when you are older and you don’t say it anymore. But now I want him to know, so I say “I love you.” It is important that he knows. I just want him to know.

Obviously it is something that even though he KNOWS [strong intonation] that I love him when I say it, it is nice to hear it from someone that you love.

For these adult children the “Other” is no longer taken for granted. For John, the nearness of death and the uncertainty of an unknown outcome created an awareness of the importance of his parent’s place in his life. His busy social life, and his plans to move out were left behind. John said:

Now I’m spending more time with them. For example, before I wanted to move out of the house, whether for school, but just outside the house, because of the independence. Now I’d rather just stay at home and be with my parents [long silence]. I guess it just made me revolve around my family [silence].

The need to be with family was also evident in Sarah’s comments. In fact, Sarah reported that the most salient change that cancer brought was a strong awareness of the importance of her family in her life. “That is the big thing, togetherness and closeness,” she

said. Sarah continued by elaborating how she felt close to her family before the illness struck, yet she had been sharing little time with them. Sarah said:

Spending time with your family, something that I didn't do enough before, because you probably don't think. You don't want to stay home with your family. You don't talk to them really unless you have to talk about something. You don't go and sit and talk to them casually. But now you want to. Now I want to spend more time with them. I want to be with them more.

It is important to note that the above comments are supported by the literature on traumatic growth. For example, Tedeschi, Park, and Calhoun (1998) underscore that confronting a traumatic illness, one that carries the threat of death, may enhance appreciation for loved ones, and in particular, the desire to spend more time with significant others. Prior to the diagnosis John had thought of moving away. Now, as Hayne (2002) notes, a potential "future without a future" (p. 189) with their fathers sparks within these adult children the desire to spend the present with them. For John and Sarah, the discovery of the fragility of life and the uncertainty of the future, brings the desire to fully experience life in the present moment. Sarah said:

Even though I was close to my dad growing up, when I got older I stopped kissing him and hugging him and saying "I love you" and all that stuff. Yeah, and this thing happens [long silence, tears]. And now I started telling him again and, hugging him again. You show your affection now. I do that with my dad and, the same with my mom.

The diagnosis and treatment now behind him, John still perceives the future as uncertain. There is a sense of immediacy to time – the only time he has to act is the now.

I guess it's making sure, wanting to do as much I can for them and just appreciating them because unfortunately we don't know what is going to happen. I didn't know that my father was going to get Leukemia [long silence]. Although before I never told my dad how much I loved him, I do now because when I think something like this happens to you, I guess with leukemia you really don't know, you take things day by day.

The nearness of death brings to the fore the importance of giving back to his parents. At each instant there is a sense of preparedness for the uncertainty of the future and in each instant the present is informed by the past. Like John, Amy also used words such as “appreciation,” echoing John’s new awareness of the finality of life. With that comes the realization that friends and family must be valued in the here and now.

I am probably more grateful and appreciative of the people in my life, the friends that I have and the family I have. I think it makes you stop and just focus your attention on doing something nice. Before it was: I’ll do my work, whatever. Now, life is short and your main focus in life is different.

The cancer legacy brings into view the “temporal horizon of being” (Bloechl, 2005, p. 78). When life is short, one must seek the “Other” at that very instant, a tomorrow is not assured. For Amy, her job was at the centre of her existence prior to her father’s diagnosis. She admitted that prior to the diagnosis she had been working non-stop: “I worked 60 to 70 hours a week.” Now she stops. Life is “moving toward death” as Heidegger (1962) indicates, and Amy thinks of the “Other.” It is important to add that a common finding among individuals who attempt to make sense of their losses is a new sense of gratitude for loved ones, friends, relationships and, in particular, life (Tedeschi & Calhoun, 1995; Tedeschi, Park, & Calhoun, 1998). For example, Bellizzi (2004) who examined potential psychological changes among adult cancer survivors found that a majority of patients (64 %) reported an increased realization of the “fragility of life” and the importance of loved ones in their lives as the most significant positive change in the aftermath of cancer. Bellizzi suggests that a cancer treatment makes death salient and real, and such an undeniable possibility in turn may be the very catalyst for gaining an increased appreciation of life and of loved ones.

That sense of gratitude is mirrored in John's resolution to obtain his university degree. This goal is now concrete and has acquired a new meaning. After the cancer experience, the face of the "Other" makes itself known in all aspects of his life – the "Other" cannot be put aside. He reaches for goals to transcend the selfish self. John wants to finish school and obtain his degree, not for his own gratification, rather as a medium that ensures his capacity to take care of those who have taken care of him. John's goals are tied to the future welfare and sense of security of his parents. When I asked John if he felt anything positive this experience might have brought, he pointed out:

It reinforces and reiterates the goals that I want to achieve, especially now. Like school, I want to finish not only because I can fulfil my own thoughts and dreams for my career but to be able to take care of my family as they did for me...As they get older I want to take care of them, whether getting a good job, financially, all the stress that they might have had about money, they wouldn't have anymore. This incident with my daddy having cancer reinforces that, though not because I have to provide for them later, but because I want to, because they have done enough for me all my life.

This is the responsibility of care (van Manen, 2000) – John's sense of preparedness for the eventualities that the future might bring. Before the diagnosis John was not in a hurry to finish school. "I was not thinking of finishing soon," he said early in the interview. Now he needs to be prepared so he can take "care" of those who have taken care of him, the best way he can. Just as his father cared for him when he was young and vulnerable, John now sees himself as the provider of future care. The past is projected towards a future that is not here yet, but one that will come nonetheless. Now, as a result of the cancer experience, John sees the other: his father is no longer strong and he is aging. Now, John wants to care for him. John sees himself taking what Hamilton (1994, cited in de la Cuesta, 2005) calls "the role of the other" (p. 889). John, who is young and strong, recognizes that he has begun to switch roles with his parents. This is John's experience of "caring as a

responsibility” (van Manen, 2000, p. 269). It is in this sense that adult children’s “identities are transformed” (de la Cuesta, 2005, p. 889); they are now “the parent of their parents” (p. 889).

The responsibility for the “others” care is also readily apparent in Amy’s account. Like John, Amy’s account demonstrates a new sense of responsibility for her father’s care. Amy perceives her father as vulnerable. She in turn is young and strong. She noted:

And I will be wondering sometimes: what is going to happen when they get older [deep voice]. And even now that he is not sick, I still feel like the adult here. Every time they go out it’s like ‘where are you going? What time will you be home?’ Like ‘don’t stay out too late’ and I will sit there waiting. And I worry now. It is not as bad anymore, because now I have picked up my life. But it is still there. Like when they go out I say – you shouldn’t be going out – and things like that. I am no longer the child: the child is my father.

For Sarah, her worries reside in the present: cancer is embodied in the current outpatient treatment of her father. “We don’t know anything yet,” she confided. “I just want to focus on the end of treatment,” she added. Sarah’s narratives reflect a father who is still undergoing treatment. In describing her life prior to the illness, she talks about the competing needs of balancing her goals and multiple demands. As cancer abruptly enters Sarah’s life its effects become engulfing. She says:

Before you have to balance school and work and volunteering and you have to think about your future. Then all of a sudden cancer comes along and none of these things are important anymore. Cancer is all you think and feel. And it takes over everything and leaves everything else out. You only have to worry about the cancer.

One can hypothesize that, for the participants, the unexpected nature of the cancer diagnosis and being witness to the effects of cancer treatment make their parents’ mortality, fragility, and vulnerability concrete. Amy earlier stated how she believes that in life everything happens for a reason and everything is a learning experience. For Amy, Sarah,



and John, the cancer experience brings a new learning experience: the responsibility for the other who suffers (Levinas, 1987). It is worthwhile to note that John uses the word care in describing his experience, while both Amy and Sarah used the word “worry.” Van Manen (2002) writes about the experience of “care-as-worry” (p. 276), a vigilant responsibility felt by parents. The parent cannot fall asleep, worrying for the child; if the child is weak the parents feel compelled to be vigilant over his or her well-being. As Levinas would propose, it is a call that they wish not to escape (Hand, 1989). Amy’s, Sarah’s and John’s lives, prior to the illness, were centred on themselves. Now the presence of the other is felt, and thus, John, Sarah, and Amy worry for the other (van Manen, 2002). In writing about the ethical responsibility for the other, Levinas asks: “Why does the other concern me?...Am I my brother’s keeper” (Hand, 1989, p. 107). This is the gift of the illness: caring for the other. John’s, Amy’s, and Sarah’s identities have been transformed, as Levinas would have said: they are now “their father’s keepers.”

“The artisanship of caregiving is about crafting new family relations and therefore identities,” writes de la Cuesta (2005, p. 892). These adult children are not free from the past of the diagnosis, nor of the experience of treatment, and the uncertainty of the future is a constant link to this chain of memories. There is a new sense of responsibility in wanting to protect and “care” for the other. “The most basic mode of Dasein is care (*Sorge*)...care about the others,” writes Heidegger (Stewart & Mickunas, 1990, p. 70). For Heidegger (1962), “Being-in- the-world is essentially care” (p. 237). Care, notes Heidegger, never occurs as care for the self, rather it is intrinsically tied to others. For John, Sarah, and Amy, “care” as “solicitude” as “concern” (Heidegger, 1962, p. 237) is key to their parents’ welfare. This is the care that the adult children I interviewed feel “responsible” to respond to: their fathers are calling (van Manen, 2002). “Care-as-worry” (van Manen, 2002, p. 276) is

manifested in John's desire to be capable of providing for his father's needs. Similarly, in Amy's need to keep an "eye on him," and for Sarah also, anything unrelated to cancer is now unimportant.

A growing number of studies have lent support for Tedeschi and Calhoun's (1995) proposition that facing a traumatic event can often make evident what is important in life (Bellizzi, 2004; Sears, Stanton, & Danoff-Burg, 2003). All the adult children said how relationships had acquired new meanings. John explained how family ties became stronger in the nearness of death. "When you have gone through something like cancer, disputes or quarrels with others are not really worth it." John desires to be united and live in harmony with significant others: "because when you come so close to death, you became closer and united," John said. When I asked what has changed, John responded:

I think that things are better as a family. Well, my sister and I don't fight as much [laughs]. I think it is better because we appreciate each other more [silence]. I don't know how exactly, but if this thing didn't happen uh... For example, things that we might have fought about before we no longer fight about. Or, between my parents, for example, things that they may have fought about before, they may not now because now it's not really worth it.

After you go through something like cancer it is not worth it to get angry because you have gone through something that is more stressful as partners. The cancer experience was very stressful, but because you go through it, like I said, it is like my mom jokes is "the family united."

Similarly, Sarah also noted that prior to the cancer diagnosis and treatment hers had been a close family. "Before I could talk to my mom and dad," Sarah said. However, now as a result of the cancer diagnosis, and the treatment given at an outpatient treatment, she feels that as a family they have become much closer. "It is a different type of closeness," Sarah added. She echoed John's sentiments that cancer not only had a positive impact on

her relationship with her parents, but also among the parents themselves, and her siblings,

Sarah confided:

One good thing is that it brought our family closer together, during the surgery, all the stuff, and now through all the treatment, and that is really good. We were always close. When you go through something like this you spend all your time together: when you are scared together, when you worry together, and you plan together, you grow closer together.

And then you can even see this between my parents. They are closer. My dad depends on my mom now. And she knows she has to step up and take care of him. They are closer in their own little way. That is a good part. And my sister and I can talk about it too. She was very upset when she found out and I would talk to her and she will feel better.

Amy also spoke about the impact of cancer on family relations. As a result of the cancer diagnosis and treatment she now feels more mature and more understanding of what others might be going through. “I definitely feel like I am older,” she said. And while she is not grateful that cancer has come to her life, nonetheless she sees herself as having grown as a result of the experience. In fact, Amy uses the word “transformation” and “change” in describing her experience. Like John, Amy also talked about how it is no longer worthwhile to become upset about mundane things. No stressor could be compared to the fears and tribulations that she once felt in the hospital wards. Despite all the fears, cancer has spared her father’s life: yet, she cannot be the Amy she once was. As a result she has a new perspective on her relationships with her family and others:

Definitely with family, definitely with family [twice] because with everyone in the family, there is always drama [laughs]. There was definitely a sense of transformation for me. I have changed. Oh yeah. In a sense [long silence] I will no longer be making a big deal when things go bad. And before I got really upset when something went bad, or something didn’t go right or even for little things. But now nothing. You go: it is ok in the grand schema of things, no matter what happens; in the grand schema of things you are lucky. So it is ok. It is OK. It is not that I am glad that it happened [cancer], but that I am able to know myself more after going through this. And it makes

me sort of proud of myself, proud of my parents, of how they handled things and how they went through it. And you appreciate things.

Aldwin, Levenson, and Spiro (1994) indicated that confronting a traumatic event may inoculate individuals against future stressors. “In comparison to the trauma” daily stressors are no longer bothersome, and may be viewed as “insignificants” (p. 42).

According to Aldwin et. al., for some individuals, surviving a traumatic event may lead to a sense of enhanced capabilities to cope with current daily stressors. Moreover, Aldwin et al. speculate that, despite the suffering, traumatic events may have a “maturational effect” by broadening individuals’ perspectives on how they come to see others, and how they come to view themselves.

The cancer experience not only changed the way Amy dealt with her family and stressful events but also how she viewed people in general. “I think I have changed my view of how I see people. I used to get upset at how rude people are.” Yet now, Amy tells me she has developed a more empathic, sensitive, and more tolerant view of others, regardless of their actions. The ability to see others and to transcend judgement is at the very core of her experience, as we see in the narrative below:

After the experience [leukemia] you just go maybe they are going through a bad time or something like that. Or like you get a stupid driver and I used to get very, very upset. Maybe you are more sensitive toward other people. Maybe something bad is happening for them. You are able to see people for what they are rather than for what they are doing. You think more positively because I used to get really upset. Now it is like: “it is ok, they have to be going through something bad.”

The cancer experience not only led to a kinder view of others but also of herself. As Aldwin, Levenson, and Spiro (1994) suggested, in the narrative below we see a changed paradigm in terms of Amy’s view of herself. There is a shift in who she now wants to be around. Amy says she has become more selective of those she allows in her life.

I find myself more selective. Maybe because I was younger then too, I came from high school and I had to please everyone, and you wanted everyone in your life to like you.

As a result of the challenges she faced through her father's illness, she no longer feels it necessary to "accept others" simply from the desire to be liked. There is a new sense of self-integrity in the relationships that form her life.

Amy's transformed self also includes an enhanced self-confidence. She notes she is able now to leave out of her life those individuals who may diminish her sense of self-worth, those who might not accept her for who she is, and she is able to make her boundaries known. Lived time is valued and deemed short: there is a realization of the finitude of life. Amy used the phrase "life is short" several times. Time must be lived fully in the present moment: one does the best with what one has. Thus, for Amy, there is now a pressing call for living her time surrounded by people who bring optimism, respect, and self-worth to her life. In describing her personal changes, Amy offers the following account:

I am more selective of the friends that I have. Before I would befriend even people that are not very nice, and now I am more selective. I will say to myself 'why do you have them in your life?' You only have a certain time of life and you should be able to choose for yourself and treat yourself better. And surround yourself with positive people and if certain people are not that nice to you then why would you put yourself through it? You deserve more than that. Now I am able to say: "I like you but I don't want you in my life because I want to surround myself with happy, positive people and happy things." I don't want to feel bad about myself because now you know life is so short. So why make yourself miserable with the SHORT TIME that you have [strong voice] when you can be happy with all the other people in your life.

Perhaps Amy's new selectiveness is indicative of the very encounter with herself: when life is short, when one is *moving toward death*, the self becomes visible. Amy had described how prior to her father's cancer she would render the "self" to conform to the expectations of others. "I had to please everyone...and you wanted everyone to like you,"

she said in the earlier excerpt above. Yet, the illness makes real for Amy that “life is short.” To live authentically, Amy removes her mask; she no longer needs to silence her inner voice. She feels the voice: “life is so short...do the most with it.” And now Amy hears her voice, a voice that is firm and resonates: she now selects whom to allow into her life. She, too, is strong now.

For John the threat to life also brought a new view. This is highlighted in his priorities in life through his evaluation of what is important. The materialistic world with an emphasis on goods, money, and assets that he once strived to possess begins to seem unimportant. In the aftermath of cancer, family relationships acquire a new meaning in terms of humanity and caring. In describing what has changed for him, John stated:

For me, before I joke about it. I always said to myself, all the things that I could buy, all the nice things, all the nice electronic things, but now it's kind of, Oh well, they are not important. For example, my DVD player broke down and now, well, I don't really need it. So you do realize what is important; these are just materialistic things. You want nice things. I like to have nice things, but you don't really need them. I think money-wise you don't really need them. I think the only stress was from money, because my dad is not working, it was a burden on my mom, but I was always felt that if we [John and John's sister] have to work more, if I have to work more to give them money, it would be OK.

He continued:

What is important is my family. To make sure they are OK. It is not like we always have to be nice to each other. We still argue here and there. And I'm sure my sister and I will still be arguing in the future, too, but I think now we have become closer, now my sister and I, we are much more comfortable with each other. When you came so close to death, you become closer and united through the treatment.

Priorities have changed from a life that was centred on the self to one that now reaches out and touches the others. John's life priorities are no longer self-satisfaction and self-fulfillment; rather fulfillment can only come when those whom he loves are well taken

care of. This is the experience of transcendence in John's life. Empathic understanding of his family's needs becomes paramount. This is a change that is also apparent in Sarah's narratives. She also elaborated on how, prior to the cancer diagnosis, she focused on her needs and goals. Sarah uses the word "self-absorbed" to describe her previous lived time:

Before, you worried about your school and your future and then you become self-absorbed. Because you are so busy. You have to go here and you have to go there, and after you finish school and you finish work and volunteering, you want to go out and have fun.

Yet in the uncertainty of a future and the sudden prospect of losing a loved one, Sarah cannot ignore the presence of those she loves. She said:

But you really see how your family is so important when you don't want to lose them. When you come close with something like cancer and you think about the possibility of something happening and that you can lose someone in your life, you really realize how much you love them, and how important they are, and how much you need to spend time with them now, because you don't know what is going to happen.

This is consistent with Fromm, Andrykowski, and Hunt (1996) who indicate that being less selfish, enhanced family relations, and a greater appreciation for what is important in life, were common among adults who have experienced a bone marrow transplant. A bone marrow transplant carries high probabilities of death, and ultimately it is that risk that leads to these patients overcoming selfishness and treasuring loved ones. It is interesting to note that adult children recounted such changes through the landscape of "death." Amy talked about her realization "that life is so short," John spoke about coming "so close to death," while Sarah refers to facing the real possibility "of losing" a love one. Heidegger notes that authentic existence is the legacy of the illness – death has been faced. Now John, Sarah and Amy no longer cling to the idea that death is for the "others." The gift of the illness is the new authentic stance of "being-in-the-world" (Heidegger, 1962).

Each adult child that I interviewed also communicated the idea that, despite cancer being the worst nightmare a person could face, it was also the case that it is through this same struggle and despair that they also found a sense of strength they did not know they possessed. Amy talks about feeling strong and discovering a new sense of confidence. Now, she said, she may be able to face new challenges: whatever needs to be faced, she knows she is up to the challenge.

Oh yeah. I feel that I could now undergo any challenge. After that [leukemia] you feel pretty much you can take on anything. You feel stronger in that no matter what could happen, I can handle things with so much strength. You already feel like: What is the worst that can happen? You know you have already gone through it.

A newfound strength as a result of confronting a parent's diagnosis and treatment also emerged in Sarah's narrative. Sarah told me how currently, with her father in the middle stage of treatment, she feels a strong inspiration as she and her family carry on the fight against cancer: a battle that initially she did not feel was possible to bear. Sarah's viewpoint is one that underscores strength and bravery as a family accomplishment. Sarah explained that it is not about personal strength. "I don't see it as a personal strength," she said. Rather, it is a collective strength, togetherness in anguish, as we see in her thoughtful excerpt below:

And definitely I feel we can survive. I definitely feel that now that we have gone through the first round and we have gone through the surgery and we can keep on going. And now we know we are going to keep on going. So now you know. You don't feel like, "I don't know if we can do it," because you ARE DOING IT. So you know you can do it. We can't say 'I don't know if we could go through it' because we are DOING IT! [Emphasis]

I guess I probably didn't give my family, what is the word, . . .uh, enough benefit of the doubt. [Interviewer: credit?]. Yeah, credit. Yeah I didn't give them enough credit. I didn't have enough faith in our family and now I DO [strong intonation]. NOW WE CAN DO IT [strong voice]. Now we CAN



do ANYTHING that comes. Like that was one good thing that happened and for that I am happy. But it is the worst thing that I have gone through.

John also talks about strength in unity, his family having become one that is strong in suffering. John's experience may be characterized as one of togetherness in transcending the sense of vulnerability that he once felt, to discover a heightened awareness of his strengths. John mentions the word "very strong" twice, perhaps signifying how his strengths and that those of his family, have become visible for him. John reflected on his experience:

The way I see it from the beginning to the end of this experience is that when you have a group of people, all wanting one thing, then they become very strong, they act as one, so they go through everything, whatever they have to face, they face it. It is like one large group, just as one. And that is why, I think, we were all able to go through it... As my mom said, "through all, we are very united, and we are all very strong."

Heidegger (1962) notes that being unable to escape in the face of death, and having to face the unimaginable, carries the idea that one is able to face whatever life brings. Sarah had said previously how cancer changes your world "forever," from a reality that was experienced as predictable, to seeing something that one has never viewed before cancer. There is no more need to flee the anxiety of death (Heidegger, 1962). What Sarah signifies is that through cancer these adult children have seen the face of death and now they no longer run from it.

The participants' narratives highlighting a newfound strength as an outcome of facing serious threat and struggles is one of the most common findings reported in the literature in Posttraumatic Growth (Tedeschi, Park & Calhoun 1998). For example, Elder and Clipp (1989) found that among war soldiers a sense of courage and learning to cope with adversity were among the positive effects that a war-related trauma may have brought. Aldwin, Levenson, and Spiro (1994) also support these findings. These authors, in their

study of exposure to traumatic events during war, found that individuals were likely to report that they felt stronger and that they would be able to handle everything. More recently, Manne, Ostroff, Winkel, Goldstein, Fox, and Grana (2004) suggest that a new-found sense of personal strength is among the most named positive changes reported by breast cancer patients, despite the insidious treatment side effects and the pervasive fear of relapse. Moreover, Manne et al. indicate that these changes are readily apparent shortly after receiving the cancer diagnosis. For Tedeschi, Park and Calhoun (1998), paradoxically, it is the very sense of vulnerability, suffering, and pain that individuals confront when they are exposed to a traumatic illness, such as cancer, that leads to discovering a strength they may not have known they possessed.

Tedeschi, Park, and Calhoun (1998) indicate that a traumatic event not only uncovers the individual's hidden psychological strength but also a new empathic understanding of others. It is the very uncertainty and the heightened awareness of one's own vulnerability when facing a traumatic event that brings about strong feelings of compassion and desire to help others. These authors write that confronting a traumatic event may very well be "a kind of empathy training" (p. 13). Such "empathic training" can be clearly seen in Amy's narrative below. Though her upbringing has been one where emotions are not expressed, she knows the very essence of the pain, and helplessness, and she uses this to help others.

Amy reports:

Something happened to a really close friend of mine. Her really close younger sister was found dead, and it was suicide. Right now it is like I have my dad, but her sister is gone. Even though I don't know what she is going through, how she really feels, I know the point when you feel everything is hopeless, and you're upset and sad, and you feel like your world has gone downwards. So I felt at least I was able to help other people because I was able to empathize with how she felt.

I felt that I was able to help. Because others who have not gone through this wouldn't understand and they'll say things like "Oh don't worry about it," "everything will be better" and "don't think too much," "don't worry too much." But I was able to tell her: "No, it is Ok to be sad. It did happen."

Amy's narratives also made evident that empathy and increased understanding of others' feelings extend to strangers:

Even working downtown, the junkies are there, and now you have more empathy towards those people. And there are people that say: "Oh my God, you have to see those people' [soft voice] And I go: NO! THEY ARE JUST PEOPLE [strong voice] with an addiction.

Empathy toward others is also shown in Amy's narrative below. It is clear that Amy feels a strong commitment to help others by sharing her experience. Amy expressed in the excerpt below how important is for her to educate herself so she can help others that might go through the same sickness in hopes that they might know what is it like to be an adult child caring for a parent.

Going through this, I am educating myself in any way. So I would be able to help people in any way I can. You have this thing happen to you and you learn.

It is like right now with the project that you are writing about, because in a sense you are helping other people to see and educating them on what this experience is like. And I am grateful to be able to be a part of it because I haven't really talked about it. And it is a great feeling to talk if it helps other people going through it. It is important to know that maybe everybody goes through things differently, that there are different faces, but in the end it is the same.

One may speculate that transcendence from a self-centred existence to an empathic existence may be the lasting legacy of the illness as illustrated in John's narrative below. In conversation with John I asked if there was anything that I had not asked that was very meaningful for him and that he would like to add. John was silent a moment, and then summed up the experience with the phrase: "I wouldn't want to wish this upon anyone."

The fact that my dad is doing well is great, fantastic, but it is not like that for everyone [Long silence and then deep, quiet voice]. My parents got to know a couple of people and they passed away [deep voice, long silence]. They knew them because they were in the same room with them, so obviously it is unfortunate [long silence, tearful, deep voice] and that's why I said I don't wish this on anybody because not everyone will have a good or positive resolution to it [long silence].

Perhaps this is the very gift that the experience bestows: it is the gift of stepping outside oneself to see the face of the others. In his analysis of ethics and responsibility for the Other, Levinas attends to the *face* or *visage* (Waldenfels, 2002). The “human face is not simply what it seems to be, it is much more than that” (Waldenfels, 2002, p. 64). The French word *visage* (*face*) means “seeing and being seen” (p. 64) and in Greek the word *prosôpon* refers to the face as well as the act of “looking at” (p. 64). For Levinas, notes Waldenfels, the face may have two distinct meanings: the narrow common meaning of face as a “frontal view...the central zone of the body” (p. 64) and an “empathic” meaning that embodies the moment when one encounters the others’ face in suffering and is summoned to respond (Levinas, 1981). This is the empathic meaning of the face: empathy through incarnation, of “having-the-other-in-one’s skin” (p. 115). That is, the “other is immediately present and self-present” (Waldenfels, p. 73). This is John’s and Amy’s cancer legacy. Amy’s experience is the gift of the illness – to be able to wrap herself in her friend’s skin (Levinas, 1981) when she hears her friend’s loss of a loved one.

The legacy of cancer came through in John’s last thought in the interview. His father survived the illness, and in that instant John sought the faces of those who did not survive. In that moment John cannot override the others’ corporeal self-presence (p. 65) – those with whom he and his mother had shared a room at the Leukemia ward, and those who have now passed away. Prior to the diagnosis John had not encountered the face of the “other.” He had not sought out others who are suffering. Lived time was one of enjoyment and self-

preoccupation, or as Levinas would have called it, a life of “dwelling at home with itself” (Davis, 1996, p. 44).

Davis notes how, for Levinas, before the encounter with the other, one inhabits the world as if others were devoid of existence, as if one “was alone in this world” (p. 44). There is lived time and space, in which one withdraws to privacy and can “accept or refuse to act as host to alien presences” (Davis, 1996, p. 44).

In enjoyment I am absolutely for myself. Egoist without a reference to the Other, I am alone without solitude, innocently egoist and alone. Not against the others, not ‘as for me...’ – but entirely deaf to the other, outside of all communication and all refusal to communicate – without ears like a hungry stomach (Levinas, as cited in Davis, 1996, p. 44).

But John cannot withdraw after his father’s illness. He cannot be deaf to the other’s plea. He is no longer for himself, but for others. This is the gift of the illness. Cancer, as Davis explains, is the *visage* or *face to face* encounter (Davis, 1996); it is the very event that brings meaning to John’s life as it makes the *other* visible (Davis, 1996). For Levinas, without the encounter with the *other*, freedom is meaningless, “without a purpose or foundation” (Davis, 1996, p. 49). There is no ethical choice between responsibility for the other and egotistical self-fulfilment (Davis, 1996). Ethics “derives from the original ethical moment when the self is challenged by the presence of the other” (Davis, 1996, p. 49). In cancer, John has been challenged by the presence of the *other* and all others. And now John cannot stop thinking of those who had succumbed and will succumb to the illness. “My father is doing well, it is fantastic” John said. Yet, it is a bitter-sweet victory. John’s empathy for the Other’s death can be best exemplified by Levinas’s words:

The death of the Other affects me in my very identity as a responsible I... made up of unspeakable responsibility. This is how I am affected by the death of the Other, this is my relation to his death. It is, in my relation, my

deference toward someone who no longer responds, already guilt of the survivor (Levinas, as cited in Derrida, 2001, p. 205).

This is the cancer legacy: a gift that takes one out of self-centeredness to be *with* and *for* others (Levinas, 1987). The cancer legacy is the ethical responsibility of the other. To be *with* and *for* the other, one recognizes the face in despair, hopelessness and suffering (Gantt, 2000). The cancer experience makes visible the face of the ‘Other’, the one that previously was invisible to John. For Levinas, we live in solitude, absorbed in our own self-centred world. Yet “death breaks this solitude by establishing the possibility of an encounter with something outside the self” (Davis, 1996, p. 31). The *other* reveals that “my power and freedom are limited” (p. 49). John is no longer free to attend only to his welfare and that of his family: the other has made itself present. “I wouldn’t want to wish this upon anyone,” John had said. Yet he is powerless: others will die, and he will mourn. “I am responsible for the death of the other to the extent of including myself in that death,” writes Levinas (cited in Derrida, 1995, p. 46). Levinas reminds us that responsibility is the very legacy of death.

This is John’s and Amy’s cancer legacy. Amy, having described herself as “someone quiet that keeps to herself,” has never talked about her despair and suffering. Yet now she thinks of the others. As she thinks about the other adult children whose parents will be diagnosed and treated for cancer, she now wishes her story to be known. “Faces are different,” she said. Yet, they are joined in suffering.

Although his father is in remission, John’s last thought takes him to the others. John cannot ignore those who have not or may not survive the illness. “The completely other, dead, living on me,” writes Derrida (2001, p. 11). The other “appears only as the one who has disappeared or passed away, as the one who, having passed away, leaves “in us” only images” (Derrida, 2001, p. 159). As the interview concludes, for John the images of those in

B4 – the leukemia ward – who have now passed away, remain vivid. Through cancer, John's, Sarah's, and Amy's lives have been forever changed: through cancer John, Sarah, and Amy have come to know themselves, the meaning of death, and have to come to know the others.

The cancer experience bestows on these adult children transformation and transcendence. The cancer legacy, the gift of the illness, is a movement that alters how adult children come to view themselves, others, and the finitude of life. This theme refers fundamentally, as Levinas (1981) would have suggested, to the very visibility of the others. The legacy of the illness is finding meaning in the very realization that, while their parents' lives have been spared, others are mourning. The gift of the illness is about invoking the faces of all others, "in their infinite alterity" (Derrida, 2001, p. 11) for whom escaping despair and suffering is not possible. It is the ability to see the face of the 'Other' that is the cancer legacy.

## CHAPTER VII. CONCLUSION

The present study examined the lived experiences of adult children living at home whose parent has been diagnosed with, and treated for cancer. In seeking to explore the meanings of this experience I grounded this thesis in a hermeneutic phenomenological approach as proposed by van Manen (1990, 1997). Phenomenology is concerned with the study of the lived experience, and hermeneutics is concerned with the interpretation of the narrative to illuminate the meaning of those experiences. The question that this study sought to address was: What is it like to have a parent diagnosed with and treated for cancer for an adult child living at home? Such a question has been ignored by the empirical literature in cancer and psycho-oncology research, despite the fact that there is a growing recognition that cancer is a family illness (Hodges, Humphris, & Macfarlane, 2005; Lewis, 1993; Mosher & Danoff-Burg, 2005; Thomas & Morris, 2002).

The conclusion is organized in four sections. In the first section I provide a summary of the present phenomenological inquiry. In the second section, I briefly discuss the main findings of this study. I examine these findings in view of the existing, yet limited, body of research available on the experience of family members of cancer patients. Empirical research in this area has been mostly concerned with the experience of spouses of cancer patients, and has mostly used a positivistic and quantitative approach of knowing (Thomas & Morris, 2002). Limitations of the present hermeneutic-phenomenological study, its methodology, and implications for future research are presented in the third section.



Potential implications for counselling practices are the focus of the fourth section. The epilogue to this thesis offers the reader a concluding personal reflection.

## **Summary of the present inquiry**

The present hermeneutic-phenomenological inquiry involved thematic analysis of verbatim transcriptions of open-ended and tape-recorded interviews that I conducted with three adult children, John, Amy, and Sarah, who were living at home at the time of their fathers' diagnoses and cancer treatments. Interviews lasted between one and a half and three hours and a purposive sample was sought; my aim was to attain rich and in-depth accounts. I was not concerned with empirical generalizations, but rather with exploring and gaining understanding of the lived experience of adult children living at home whose parents have been diagnosed with, and treated for cancer, in the hope of uncovering the meaning that these adult children give to their experience.

Thematic analysis allowed me to identify core themes and sub-themes that encompassed the lived experience of parental cancer as it was lived by the participants. I fully and carefully informed participants of the study and all interviews were conducted in a place chosen by them. I immersed myself in the data, listening and re-listening to the tape, reading and re-reading the transcripts, writing and "re-writing (re-thinking, re-flecting, re-cognizing)" (van Manen, 1990, p. 131), and re-visiting new insights while suspending previous knowledge that stemmed from my own experience with cancer, so as to produce an evocative phenomenological text (van Manen, 1997). "Evocation means that experience is brought vividly into presence so that we can phenomenologically reflect on it," writes van Manen (1997, p. 353).

For van Manen (1997), it is through evocation that the text “speaks” through “images and sensibilities that are so crisp and real” (p. 354). Enriched and in-depth texts invite the reader to actively reflect and ultimately engage in a dialectical dialogue with the text, a way of knowing that van Manen calls “pathic” (p. 21). For van Manen this dialectical interaction produces new knowledge, “action sensitive knowledge” (p. 21): knowledge that is experiential: “it is lived, felt, undergone, made sense of, and accomplished by human beings” (Schwandt, 2001, p. 84, as cited in Polkinghorne, 2005, p. 138). This was the approach that guided me throughout the present inquiry and through which I tried to create a text that speaks strongly to the participants’ experiences.

### **Summary of the findings**

The stories of these adult children living at home reveal that a parental cancer diagnosis and its treatment, regardless of the type of cancer and differences in treatment, poses a major threat to the adult child’s lifeworld. The lived experience is one of emotional devastation upon hearing the diagnosis and of overwhelming physical, instrumental, and emotional demands as the treatment unfolds and sets in. These adult children’s stories reveal that the parental cancer experience is one that is complex and embedded in their social environment. Adult children experience a myriad of feelings from the first time they hear the cancer diagnosis and through the different stages of treatment.

Throughout the cancer journey their father’s illnesses engulf these young adult children lives. Cancer inhabits their thoughts, feelings, and actions. Cancer becomes their lifeworld: A lived present time that was perceived as certain gives rise to an uncertain future as the word cancer makes itself present. Cancer then becomes ever-present in these adult children’s lives. It lingers through the fear of recurrence, even when the adult child hears the

word remission. Cancer lingers in time and space and inhabits these adult children's lifeworld; cancer is lived and is re-lived. Yet, cancer can also remain in the form of legacy: the gift of the illness.

The adult children's stories in this thesis reveal that a cancer diagnosis involves intense distressful emotions, particularly feelings of anger, shock, uncertainty, disbelief, frustration, apprehension, and above all intense dread: an intense fear that stems from facing the prospect of a father's early death. In sharing their fathers' diagnosis stories, the adult children I interviewed used similar feeling words and exact phrases to express both the astonishment and incomprehension that cancer might dwell inside a body which for these adult children is neither "frail" nor "old" as well as to express the uncertainty that the diagnosis brings. For instance, all the adult children asked the question: "what is going to happen"? This question may reveal the demarcation of, and the defining moment at which the map lines of old lives disappear and where the new lines of an uncertain terrain await. The "unknown" looms ahead; the new map of existence does not promise or assure their parents' "being-in-the world," and cancer, a disease that once intruded into others horizons, is now fused to their own landscapes: cancer is now happening to them.

Thus, as Heidegger (1962) has suggested, and parallel to Gordon's (1990) findings, the dreadful hopelessness and death-fear that the word cancer brings leads most people to conceptualise cancer as an illness of "others," a finding that is supported by Bury (1982) who asserts that the illness that may be linked to a deadly outcome is likely to be seen as belonging to the "plight of others" (p. 169). Hilton (1993) who wrote about the experience of family members of cancer patients argues that uncertainty may be highest at diagnosis as family members struggle with not knowing "whether the patient would live or die" (p. 91). It is worth noting that Mosher and Danoff-Burg (2005), in their literature review of the

impact of parental cancer in adulthood, argue that existential concerns brought by parental cancer have rarely been explored. The narratives of these adult children clearly address such shortcomings and thus extend the literature on the impact of parental cancer.

It is important to add that intense distressful emotions as a response to a cancer diagnosis have now been documented in the empirical literature insofar as the experience of spouses of cancer patients are concerned (Harden, 2005). Peleg-Oren and Sherer (2001) and Hodges, Humphris, and Macfarlane (2005) argue that the intense emotional reactions of family carers and, more specifically, spouses of cancer patients, are likely to be equally intense or even surpass that of the patient. Such responses may be spurred on by the fact that cancer is still seen as having “a cultural connotation of a death sentence” (Thomas & Morris, 2002, p. 179). It is interesting to add that researchers have indicated that while female emotions have been examined, the emotional experience of “sons” remains unknown (Mosher & Danoff-Burg, 2005). The present study tapped into the felt emotions of daughters and a son and thus it extends the current body of knowledge.

These adult children’s accounts also reveal that in the midst of shock, anxiety, worry, and an engulfing dread, they also grasped for hope, faith, and trust, perhaps as coping strategies to re-gain control of their tumultuous emotional inner worlds, thereby allowing them to re-claim a sense of agency to carry-on with the crucial business of seeking health. The reality of a fast approaching treatment demands urgent action. In their yearning to preserve life, these adult children, despite their all-encompassing fears, cope by *pulling together* within themselves or *pulling together* with others for the needed resources to deal with their new, frightening, and uncertain reality. That is, the adult children in this thesis sought to control their emotions so as to reclaim the agency to “do whatever” was needed to avoid a father’s death. This is consistent with literature that shows that individuals may attempt to

regain agency as a cognitive coping strategy to control the losses and threat that the illness brings about (Paterson, Thorne, Crawford, & Tarko, 1999).

All participants admitted that treatment was the most difficult phase in the journey: “a very turbulent time,” “an altered reality,” where instrumental caregiving and emotional work was demanding. These adult children’s stories highlight that although they are the forgotten members in the empirical literature on cancer, in the practical realities of the home and the hospital, they responsibly, willingly, and faithfully endured the caregiving work. While two of the three adult children stated that the caring of parents was a shared experience among all immediate family members dwelling in the house, one adult child solely assumed such a role.

In this thesis, adult children confided how their reality was completely altered: school, friends, work, socializing, pleasure, self-enjoyment, were left behind. The story of these adult children revealed that treatment is experienced as a time of multiple and unending demands. There is no day-off from the treatment protocols, no escape from the taxing emotions that adult children living at home experience: hopelessness, helplessness, misery, anguish, uncertainty, and death fear. As treatment unfolds, an altered reality emerges when a strong father figure lies down fragile, despondent and weak on a hospital bed. Parental cancer is lived and re-lived as a “disrupted biography” (Bury, 1991, p. 460) “where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982, p. 169). Cancer, as a “disrupted biography,” is at the very core of adult children witnessing toxic treatment and the emergence of a new paternal identity. As Bury (1982) and Hilton (1993) suggest, the father’s new identity defies the adult children’s knowledge: the very image that they have upheld of their father – “the strongest,” “the provider,” “the bravest,” the “one that takes care of you, the “invincible” – is to be no

more. It is, a “turbulent time” witnessing their father’s suffering. As treatment further advances to the outpatient clinic, with little or no time to spare from the daily responsibility of their father’s treatment, life is lived “day-by-day.” Thus, the stories of these adult children extend the current body of available research showing that adult children living at home, regardless of gender, are fully involved as physical and emotional carers throughout their entire parents’ treatment. Silently, attentively, and vigilantly these adult children live by their parents’ bedside. They have become their parents’ keepers (Hand, 1989).

Each of the adult children I interviewed also conveyed that, despite cancer bringing intense distressful emotions and overwhelming instrumental and emotional demands, they also experienced personal growth and transformation, or what Tedeschi and Calhoun (1995) call posttraumatic growth. While the literature on the impact of cancer in family members has for the most part taken a distress/vulnerability approach to illness (Mosher & Danoff-Burg, 2005; Power & Dell Orto, 2004), the present study shows that adult children assign some form of positive meaning to their experiences. As a result of the very struggles that they faced, the adult children’s stories revealed that they experienced enhanced self-confidence, gratitude, stronger family ties, greater mental strength, empathy, and appreciation for what is important in life, as well as fuller appreciation of life itself. Above all, these adult children’s narratives unveiled the ability to transcend the self and respond: “Here I am”, as Levinas (1981) suggests, when they hear the others’ call, the one that is suffering. Through cancer, John, Sarah, and Amy have come to know themselves and have come to know the face of the *other*. Their narratives highlight *being with* and *for the other* in suffering, and thus their stories are embedded in the ethical responsibility for the *other* (Purcell, 2006).

**Limitations: methodology**

Phenomenology seeks to uncover the hidden meaning of everyday phenomena: that which is passed over, in our daily lives (Purcell, 2006). It is not concerned with scientific/empirical generalizations, theoretical explanations, solving problems, predictions, or drawing causal explanations (van Manen, 1990). No theory guided my inquiry and no hypothesis or hunches were proposed. In this study I was concerned with describing, as accurately as possible, the lived experience of having a parent diagnosed with, and treated for cancer as lived by three adult children. Yet, qualitative accounts, writes Polkinghorne (2005), “are not identical to the experience that they are describing” (p. 138) nor are the participants’ recollections a “mirrored image of” (p. 143) his or her experience. The story, affirms Polkinghorne, is always a “joint production” (p. 143) of both “participant and researcher” (p. 138).

Bracketing is never complete, observes Wertz (2005), and interpretations are always subjective. The hermeneutic-phenomenological inquiry assumes “an active, intentional construction of a social world and its meaning by reflexive humans beings” (McLeod, 2001, p. 57). As I stated in the introductory chapter, from the beginning of this thesis I have not been a detached observer of the cancer experience or of others’ cancer realities. My choice of thesis has been actively and intentionally shaped by my own experience with cancer. Sharing the cancer experience allowed me to create strong rapport and trust with the participants and thus helped me to ‘unpack’ their stories. Yet, it is possible that, despite keeping my pre-assumptions, biases, and prior knowledge of the extant literature in check, my own experiences with cancer, my background as a counsellor, and my experience as a parent, might have influenced, for example, the organization or interpretation of the text. Though I used clear methodological guidelines, those proposed by van Manen (1990),

almost invariably and indisputably, it is ultimately the researcher who decides, for example, what words and phrases are most meaningful, and which are to be highlighted.

Van Manen reminds us that phenomenology is “discovery oriented” (p. 29), yet our discoveries are always incomplete. Interpretations and descriptions can never be absolute: “full or final descriptions are unattainable,” writes van Manen (1990, p. 18).

To do hermeneutic phenomenology is to attempt the impossible: to construct a full interpretive description of some aspects of the lifeworld, and yet to remain aware that lived life is always more complex than any explanation can reveal (van Manen, 1990, p. 18)

Context, historical events, and time influence and transform the stories that people tell. “Human experience is difficult to study. It is multilayered and complex; it is an ongoing flow (Polkinghorne, 2005, p. 138). Stories are never static and thus meaning unfolds through a temporal horizon of a lived past, a living present, and through the background of a “yet-to-be-determined future,” writes Wertz (2005, p. 169). The descriptions of these adult children’s accounts are complex and reflect a particular time in which the stories were told. At the time of the interview, two participants’ fathers had ended treatment and had achieved remission with good prognosis; the father of a third participant was attending treatment. An examination of these adult children’s stories must be framed within that temporal horizon (McLeod, 2001). Might the lived experience be the same if an outcome of achieving remission had changed throughout the treatment? Could a cancer legacy still emerge if the very fear of relapse materializes and brings death to the foreground of these children’s lives? How would these adult children feel, sense, and act, under a different temporal horizon? Thus, the present study’s findings are limited to the lives of the three adult children in a particular temporal horizon and to a limited interview-time of ninety minutes to three hours with the researcher.



### **Limitations of findings and implications for future research**

In addition to the inherent limitations of phenomenological research, it is worth mentioning that all participants came from a relatively homogeneous group in terms of socio-economic status (SES). All participants have some post-secondary education, and were from a middle class background. Given such an homogeneous background, one may wonder how this experience might be lived by adult children, who in addition to facing a parental life-threatening illness also confront financial stressors. For example, Caplan and Schooler (2007) found that coping with stressful events was more difficult among young adults from low socio-economic status. Such young adults were more likely to perceive less control over the stressor and thus experience higher psychological distress. Williams, Williams, Graff, Hanson, Stanton, Hafeman, et al. (2002) in turn found that the absence of a sufficiently disposable income in the face of mounting stress may seriously impact family relations. Cancer may place financial demands that may further handicap families whose financial resources are already compromised before the onset of the illness (Laizner, Shegda, Barg, & McCorkie, 1993). Thus, it would be worthwhile to speak to adult children from a more mixed SES and to those who might also be experiencing financial burden at the time of their parents' diagnoses.

In terms of family relations, all participants reported having strong family bonds prior to the diagnosis. In fact, Sarah and Amy identified themselves as being the closest to their father. Future research might explore the experience of parental cancer diagnosis and treatment among adult children whose relationships may be estranged or disrupted before the diagnosis.

While the thematic analysis used in this study follows van Manen's approach, it is also the case that such an approach is only one way of generating meaning. Analysis could

also have been guided through the prism of immersing myself in the life-world of these adult children. For example, for future studies, exploring lived time, lived space, lived relations, and lived body, as proposed by van Manen can be a powerful existential approach. How was lived time experienced? All participants confided that diagnosis was experienced as moving faster than normal time: “there was no time to think,” said Amy. Perhaps lived time is one in which memories of the past, of a healthy parent, intrude and now seem unreal in the face of an uncertain present, and a future that appears unpredictable at best. One may wonder how space is experienced? How does the house, the dwelling that John has inhabited with his father for 23 years, feel as John returns from the hospital ward? How does Amy, who lived in the hospital 24 hours a day, inhabit the hospital room? Do these adult children live-space as “bodies without a home” as Giles suggests? (2003, p. 37). Amy confided how upon hearing the diagnosis her life stopped. One may wonder how the body registers the cancer experience. How do these adult children embody their parents’ illness?

Despite the limitations inherent with qualitative research and those specific to the study, through the compass of richly intense interviews, the present thesis contributes to the extant body of knowledge by beginning to uncover the uniqueness of such adult children’s experiences and serves as an important step in understanding and elucidating the meaning that adult children living at home, whose parent has been diagnosed with, and treated for cancer, give to their experiences.

### **Implications for counselling**

Some of the implications for counselling may be derived from the very methodology used in this study, that is, from hermeneutic phenomenology. Wertz (2005) notes that phenomenology and counselling share a number of basic existential tenets: just as the

researcher must hold prior bias, pre-suppositions, and beliefs in order to get to the essence of the lived experience or the participants' lifeworld, counsellors must also suspend pre-conceived ideas and judgement about their clients and the stories they tell. Both phenomenology and counselling share the core beliefs that people are unique and that they actively create meaning in their everyday lives experiences. Phenomenological researchers engage in interpretation of the lived experience told from the participants' points of view. Interpretive phenomenological researchers use language to create a thoughtful, compelling, and evocative text that elucidates the essence of the experience. As such, narrative may be an invaluable therapeutic tool to uncover the essence of a client's experience and to possibly make sense of it. Counsellors, through narrative, may play an important role in helping adult children engage in a meaning-making process, that is, a search for a potential meaning to make sense of the event. This in turn may help to facilitate adult children's adjustments to traumatic experiences such as cancer. Whereas counsellors should be attentive to the emergence of transformational language in adult children's speech, they should also be aware that not all adult children will derive perceptions of growth and transformation from their traumatic experiences (Sears, Stanton, & Danoff-Burg, 2003).

Empathic listening and empathic understanding are at the very heart of both counselling practices and the phenomenological way of knowing. Phenomenological researchers strive to immerse themselves in the data, that is, in the participants' experiential realities; counsellors need also to be immersed in the client's stories or experiential realities as they are being told from the client's perspectives. Such empathic understanding may help counsellors to gain a deeper understanding of, for example, the diversity of coping strategies that people use in the face of mounting and indescribable stress. Although there may be similarities, each story is unique and complex, thus, coping strategies in responses to

traumatic events, such as a diagnosis of cancer, are also diverse. Accordingly, counselling practices must take into account the richness and diversity of the lived human experience, and the context in which the experiences unfold. Our experiences emerge against the background of a complex social web, and cultural influences are in the very foreground of our lives. For example, culture influences how people display and regulate their emotional expression, as clearly seen in Amy's narratives, thus clinicians should be sensitive to cultural differences among their clientele.

Clinicians need to pay attention to the intense emotional turmoil that these adult children experience as they confront, without warning, the onset of an illness and treatment that poses a major threat to life. Counsellors must be sensitive in helping adult children to process the myriad and, at times, conflicting emotions that unfold as a result of their parents' cancers. For example, all the adult children in this study, as Thomas, Morris and Harman (2002) suggest, were involved in demanding emotional work: they needed to instil hope in others and in themselves, despite the pervasive fear and hopelessness that they experienced.

Moreover, experiencing the sudden onset of an illness such as cancer, which is still seen as a death sentence, may call into question beliefs, assumptions, and expectations about the world. For instance, all the participants' accounts revealed that the unfolding of a new paternal identity that is weak and vulnerable, defied the belief that a father is "invincible." Likewise, cancer crashed the assumptions that parents are supposed to "take care of the child," rather than the other way around. For all participants, cancer made real the possibility that someone who is "strong," "young," and "good" can also die. Thus, counsellors may help adult children search for answers to potential existential concerns that might arise.

The adult children in this thesis expressed that without a doubt, the key to their perceived emotional support was the validation of their lived emotional experience. For these adult children, validation of their emotions was the crux of feeling understood. All the participants conveyed the need for instrumental and emotional support, and more importantly, the need to have someone “be there” to listen and talk, as well as to share with others who had also “been there”, that is, persons who had experienced, or were experiencing the same journey. Sharing with those who had walked the cancer journey has important implications for clinicians in terms of fostering, when possible, some form of contact, such as support groups, for this particular age.

Above all, counsellors, and in particular counsellors/social workers working in hospital settings, need to be aware that support and/or interventions must include all members of the family, not only the spousal caregiver, as typically has been the current focus of counselling practices (Thastum, Munch-Hansen, Wiell, & Romer, 2006). Despite the need for emotional support, the accounts of these adult children showed that, for the most part, their journey was one of isolation. Increased understanding and heightened awareness about adult children’s full participation in the cancer journey may help counsellors assist adult children by “being there” *with them and for them* in suffering (Gantt, 2000). Just as adult children recognize their parent’s call in suffering, counsellors also need to “incarnate” the lived experiences of adult children living at home whose parent has been diagnosed with and treated for cancer, so as to grasp and understand the immense impact of parental cancer on their lives. Counsellors must also recognize the face-to-face encounter, in which they are called to be responsible *to and for the other*: the adult child who is suffering.

## EPILOGUE: REMEMBERING THE DEAD

*“The house stands empty for us. There is no one watching at the window, no one waiting at the door. No rush of greetings and silence and sudden laughter... All that remain are silent photographs on the mantel (Olson, 1993, p. 155).*

The present study is dedicated to those who have been diagnosed with cancer, treated for cancer, and to the memory of those who have died from the illness.

February 28, 2007: it is a dark winter evening, and the telephone rings. I have been expecting this call, yet it is a call I do not want to have. I hear the quiet and sombre voice of the doctor on the other side. He tells me the news that I do not want to hear: cancer has come back.

Once more cancer returned to our lives. As I write this conclusion, such familiar words still resonate in my head, memories imprinted onto my self. As my husband, my daughter, and I walked into the hospital the next day, I wondered about our future. I sat stoically, learning that only one thing was left to us: to try to “fight the illness.” “A Bone Marrow Transplant,” the doctor said. I held tight to those words. The whisper of those words allowed me to cling to life in the very face of death. “It is a risky procedure,” the doctor told us. “It could save his life, or end it very quickly.” I did not listen to the last part. I grasped the chair, hoped that we would find our place in the survivors’ camp. Our family could not – would not – be left behind.

The doctor was optimistic: the chances of dying were not great, quite slim in fact. My husband looked “quite healthy” and no one on seeing him would suspect that a critical

illness was growing in his body. I felt assured, empowered, and hopeful. Just the words that we needed to hear.

“You need to buy a plane ticket for the donor that can be postponed or returned,” the doctor continued.

Returned? I heard myself asking.

The “conditioning” phase of chemotherapy would start soon. If the chemo did not work the transplant would be postponed, and plan B or “salvage” as he called it, would begin. A new medical language began to emerge, and through this language I re-entered the world I had left behind only a few months before.

“How long then if plan B doesn’t work,” I asked.

“Six months to a year,” he answered, “but most likely six.”

I heard a silent yet strong murmur in my head: it has to work. My fingers clenched my palm. “It has to work,” I whispered over and over to myself. At home I reached once more for Lance Armstrong’s book: despite all the frightening odds, he had beaten cancer. He won the battle. I needed to start my own preparations for battle: coordinating the donor’s trip, and a multitude of unending tasks. Fear of death could not enter my mind. Despite the training of the previous year, the months spent in the outpatient clinic, I never once imagined the journey that awaited us.

A new metaphor seems to dominate western culture, a view of cancer as a disease of survivors (Gordon, 1990), where the hero always beats cancer and the heroine never succumbs. We live in a culture of battles to be won and conquered (Bahar, 2003; Gordon, 1990). Bahar (2003) notes how this new metaphor has come to dominate the cancer experience. Cancer is now an illness of “survivors” (p. 1028). Cancer is no longer seen as

“chaotic” and patients as “victims”; rather, cancer is an illness to be mastered by “personal heroism,” affirms Bahar (p.1027). This is the discourse of the “Race” against cancer, writes Bahar. Health campaigns and prevention programs are now cancer “wars” (p. 1027). In these wars there are “brave soldiers involved in courageous battle” (p. 1027), and ultimately the battle is won and the “brave soldiers” survive.

The problem with this new metaphor, argues Bahar, is that it not only places the responsibility of fighting and surviving the illness on the patient, it also creates an image of a patient who is “triumphant” (p. 1029) and an image of an “optimistic” outcome: survival. In North America, writes Gordon (1990), cancer is now viewed as a “challenge” that can be beaten, with what the author calls a “fighting spirit” (p. 277) (for a review of the “fighting spirit” metaphor see Greer, 1991). Yet these new optimistic discourses, argues Bahar, ignore the ongoing suffering, pain, hardship, and intense emotional distress that cancer brings to patients and their families. More importantly, argues Bahar, this optimistic discourse ignores an undeniable reality: the “prevalence of cancer death” (p. 1030). The reality is that cancer continues to kill: many who are diagnosed and treated for cancer will not survive. They will succumb to the illness, despite all the latest scientific discoveries and technological and medical advances to fight this war (Bahar, 2003).

On July 21, 2007, my husband’s “battle” came to an end. The longed for place in the survivor’s camp was not to be. In its place my family and I now begin a different journey, an unknown passage ahead of us. It marks the unseen path travelled by all who have watched a loved one fight the cancer battle, win, and yet, still die.



## Reference List

- Aldwin, C. M., Levenson, M. R., & Spiro, M. (1994). Vulnerability and resilience to combat exposure: Can stress have long life effects. *Psychology and Aging, 9*, 34-44.
- Anderson, J. O., & Martin, P. G. (2003). Narrative and healing: Exploring one family's stories of cancer survivorship. *Health Communication, 15*, 133-143.
- Armstrong, L. (2000). *It's not about the bike: My journey back to life*. New York: Berkley Books.
- Bahar, S. (2003). "If I'm one of the victims, who survives?": Marilyn Hacker's breast cancer texts. *Journal of Women in Culture and Society, 28*, 1025-1052.
- Bakas, T., Lewis, R. R., & Parsons, J. E. (2001). Caregiving tasks among family caregivers of patients with lung cancer. *Oncology Nursing Forum, 28*, 847-854.
- Becvar, D. S. (2005). Cancer in context: A commentary. *Family Systems, and Health, 23*, 148-154.
- Bellizzi, K. M. (2004). Expressions of generativity and posttraumatic growth in adult cancer survivors. *International Journal of Aging and Human Development, 58*, 267-287.
- Bloechl, J. (2005). The difficulty of being: A partial reading of E. Levinas, De l'existence à l'existent. *European Journal of Psychotherapy, Counselling and Health, 7*, 77-87.
- Bowman, K. F., Rose, J. H., & Deimling, G. T. (2006). Appraisal of the cancer experience by family members and survivors in long-term survivorship. *Psycho-Oncology, 15*, 834-845.
- Boyer, B. A., Bubel, D., Jacobs, S. R., Knolls, M. L., Harwell, V. D., & Goscicka, M., et al. (2002). Posttraumatic stress in women with breast cancer and their daughters. *The American Journal of Family Therapy, 30*, 323-338.
- Bradbury-Jones, C. (2001). Enhancing rigour in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing, 59*, 290-298.
- Breaden, K. (1997). Cancer and beyond: the question of survivorship. *Journal of Advanced Nursing, 26*, 978-984.
- Brody, E. M. (1990). *Women in the middle: Their parent-care years*. New York: Springer.
- Burston, D., & Frie, R. (2006). *Psychotherapy as a human science*. Pittsburgh, PA: Duquesne University Press.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*, 167-182.

- Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health & Illness*, 13, 451-468.
- Canadian Cancer Society. (2007). Canadian Cancer Statistics 2007. Retrieve July 16 2007 from [www.cancer.ca/vgn/images/portal/cit\\_8675111436/181625\\_cw\\_2007\\_en.pdf](http://www.cancer.ca/vgn/images/portal/cit_8675111436/181625_cw_2007_en.pdf)
- Caplan, L. J., Schooler, C. (2007). Socioeconomic status and financial coping strategies: The mediating role of perceived control. *Social Psychology Quarterly*, 70, 43-58.
- Case, P. (2004). Surviving cancer and family costs: Examining the needs of spouses. *Illness Crisis & Loss*, 12, 126-138.
- Chanter, T. (2001). *Time, death, and the feminine: Levinas with Heidegger*. Stanford, CA: Stanford University Press.
- Chapman, R. L. (Ed.). (1992). *Roget's International Thesaurus* (5<sup>th</sup> ed.). New York, NY: HarperCollins Publishers.
- Charmaz, K. (1999). Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research*, 9, 362-382.
- Chen, M., Chu, L., & Chen, H. (2004). Impact of cancer patients' quality of life on that of spouse caregivers [Electronic version]. *Support Care Cancer*, 12, 469- 475.
- Chochinov, H. M. (2001). Depression in cancer patients. *Lancet Oncology* 2, 8, 499- 505.
- Clarke, M. (2002). Memories of breathing. In M. van Manen (Ed.), *Writing in the dark: Phenomenology studies in interpretive inquiry* (pp.138-153). London, ON: The Althouse Press.
- Cohen, M., & Pollack, S. (2005). Mothers with breast cancer and their adult daughters: The relationship between mothers' reaction to breast cancer and their daughters' emotional and neuroimmune status. *Psychosomatic Medicine*, 67, 64-71.
- Cohen, R. A. (2001). *Ethics, Exegesis, and Philosophy: Interpretations after Levinas*. Cambridge, UK: Cambridge University Press.
- Cohen, R. (1986). *Face to Face with Levinas*. New York, NY: State University of New York Press.
- Colgrove, L. A., Kim, Y., & Thompson, (2007). The effect of spirituality and gender on the quality of life of spousal caregivers of cancer survivors. *Annals Behavioral Medicine*, 33, 90-98.
- Cowie, A. P. (1989). *Oxford advanced learner's dictionary of current English*. Oxford: Oxford University Press.
- Critchley, S. (2002). Introduction. In S. Critchley, S., & R. Bernasconi (Eds.), *The Cambridge companion of Levinas* (pp. 1-32). Cambridge, UK: Cambridge University Press.
- Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health Research*, 12, 279-289.

- Davis, C. (1996). *Levinas: An introduction*. Cambridge, UK: Polity Press.
- Davis, C. G. (2001). The tormented and the transformed: Understanding responses to loss and trauma. In R. A. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss* (pp. 137-155). Washington, DC: American Psychological Association.
- Derrida, J. (1995). *The gift of death*. (D. Wills, Trans.). Chicago: The University of Chicago Press.
- Derrida, J. (2001). *The work of mourning*. Pascale-Anne Brault and Michael Naas Ed. (s). Chicago: The University of Chicago Press.
- de la Cuesta, C. (2005). The craft of care: Family care of relatives with advanced dementia. *Qualitative Health Research, 15*, 881-896.
- de Witt, L., & Ploeg, J. (2006). Clinical appraisal of rigour in interpretive phenomenology nursing research. *Journal of Advanced Nursing, 55*, 215-229.
- Elder, G. H., & Clipp, E. C. (1989). Combat experience and emotional health: Impairment and resilience in later life. *Journal of Personality, 57*, 311, 341.
- Fang, C. Y. Manne, S.L., & Pape, S. J. (2001). Functional impairment, marital quality, and patient psychological distress as predictors of psychological distress among cancer patients' spouses. *Health Psychology, 20*, 452-457.
- Fisher, C. T. (2006). Qualitative psychological research and individualized/collaborative psychological assessment: Implications of their similarities for promoting a life-world orientation. *The Humanistic Psychologist, 34*, 347-356.
- Fromm, K., Andrykowski, M. A., & Hunt, J. (1996). Positive and negative psychosocial sequelae of bone marrow transplantation: Implications for quality of life. *Journal of Behavioral Medicine, 19*, 221-240.
- Gadamer, H. (1989). *Truth and Method*. New York, NY: Crossroad
- Gall, M.D., Gall, J. P., & Borg, W. R. (2003). *Educational Research: An introduction* (7<sup>TH</sup> eds.). Boston: Pearson Education.
- Gantt, E.E. (2000). Levinas, psychotherapy, and the ethics of suffering. *Journal of Humanistic Psychology, 40*, 9-28.
- Gasquoine, S. E. (2005). Mothering a hospitalized child: It's the 'little things' that matter. *Journal of Child Health Care, 9*, 186-195.
- Giles, S. (2003). Transformations: A phenomenological investigation into the life-world of home haemodialysis. *Social Work in Health Care, 38*, 29-50.
- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., & DeVoss, D., et al. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum, 31*, 1105-1117.
- Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology, 10*, 325-335.

- Gordon, D. H. (1990). Embodying illness, embodying cancer. *Culture, Medicine and Psychiatry*, 14, 275-297.
- Graci, G. (2005). Pathogenesis and management of cancer-related insomnia. *Journal of Supportive Oncology*, 3, 349-359.
- Greer, S. (1991). Psychological response to cancer and survival. *Psychological Medicine*, 21, 43-51.
- Grulke, N., Bailer, H., Hertenstein, B., Kachele, H., Arnold, R., Tschuschke, V, et al. (2005). Coping and survival in patients with leukemia undergoing allogeneic bone marrow transplantation-long term follow-up of a prospective study. *Journal of Psychosomatic Research*, 59, 337-346.
- Guba, E.G., & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N. K. Dezin, E. G. Guba, & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (pp. 105-117). Thousands Oaks, CA: Sage Publications.
- Hall, E. O.C. (2005). Being in an alien world: Danish parents' lived experiences when a newborn or small child is critically ill. *Scandinavian Journal of Caring Science*, 19, 179-185.
- Hand, S. (Ed.). (1989). *The Levinas reader*. Malden, MA: Blackwell Publishing.
- Handley, N. (1991). Death awareness and personal change. *Death, dying, and society. Changes: An International Journal of Psychology and Psychotherapy*, 249-261.
- Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: A review of the literature. *Cancer Nursing*, 28, 85-98.
- Harris, C. A., & Zakowsky, S. (2003). Comparisons of distress in adolescents of cancer patients and controls. *Psycho-Oncology*, 12, 173-182.
- Hayne, Y. (2002). Experiencing diagnosis. In Max van Manen (Ed.), *Writing in the dark: Phenomenology studies in interpretive inquiry* (pp.179-195). London, ON: The Althouse Press.
- Heidegger, M. (1962). *Being and Time*. (J. Macquarrie & E. Robinson, Trans.). New York: Harper & Row, Publishers. (Original work published 1927).
- Herda, E. A. (1999). *Research conversations and narrative: A critical hermeneutic orientation in participatory inquiry*. Westport: Praeger.
- Herrstedt, J. (2002). Nausea and emesis: Still an unresolved problem in cancer patients? *Support Care Cancer*, 10, 85-87
- Hilton, A. (1993). Issues, problems, and challenges for families coping with breast cancer. *Seminars in Oncology Research*, 9, 88-100.
- Hodges, L. J., Humphris, G.M., & Macfarlane, G. (2005). A meta-analytical investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine*, 60, 1-12.

- Kaslow, F. W. (2004). Death of one's partner: The anticipation and the reality. *Professional Psychology: Research and Practice*, 35, 227-233.
- Kayl, A. E., & Meyers, C. A. (2006). Side-effects of chemotherapy and quality of life in ovarian and breast cancer patients. *Current Opinion In Obstetrics & Gynecology*, 18, 24-28.
- Keenan, D. K. (1999). *Death and Responsibility: The "work" of Levinas*. New York, NY: State University of New York Press.
- Klass, D. (2001). The inner representation of the dead child in the psychic and social narratives of bereaved parents. In R. A. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss* (pp.77-94). Washington, DC: American Psychological Association.
- Kleiman, S. (2004). Phenomenology: to wonder and search for meanings. *Nurse Researcher*, 11, 7-19.
- Kubler-Ross, E. (1969). *On death and dying*. New York: McMillan.
- Kubler-Ross, E. & Kessler, D. (2005). *Life lessons: two experts on death and dying teach us about the mysteries of life and living*. New York: Scribner.
- Kvale, E. A., & Shuster, J.L. (2006). Sleep disturbance in supportive care of cancer: a review. *Journal Of Palliative Medicine*, 9, 437-450.
- Laizner, A. M., Shegda, L.M., Barg, F. K., & McCorkie, R. (1993). Needs of family caregivers of persons with cancer: a review. *Seminars in Oncology Research*, 9,114-120.
- Lane, M. R. (2005). Spirit Body Healing-A hermeneutic, phenomenological study examining the lived experience of art and healing. *Cancer Nursing*, 28, 285-291. Retrieved July 05, 2006, from [http:// gateway.ut.ovid.com.proxy.lib.sfu.ca/gw2/ovidweb.cgi](http://gateway.ut.ovid.com.proxy.lib.sfu.ca/gw2/ovidweb.cgi).
- Levinas, E. (1981). *Otherwise than being or beyond essence* (A. Lingis, Trans.). The Hague: Martinus Nijhoff Publishers.
- Levinas, E. (1987). *Emmanuel Levinas: Time and the other* (R. A. Cohen, Trans.). Pittsburgh: Duquesne University Press.
- Lewis, F. M. (1993). Psychosocial transitions and the family's work in adjusting to cancer. *Seminars in Oncology Nursing*, 9, 127-129.
- Lewis, F. M., Hammond, M.A., & Woods, N. F. (1992). The family's functioning with newly diagnosed breast cancer in the mother: The development of an explanatory model. *Journal of Behavioral Medicine*, 16, 351-370.
- Lindberg, C.A. (Ed.). (1999). *The Oxford American Thesaurus of current English*. New York, NY: Oxford University Press.
- Llewelyn, J. (1995). *Emmanuel Levinas: The genealogy of ethics*. London, UK: Routledge.
- Llewelyn, J. (2002). Levinas and language. In S. Critchley, S., & R. Bernascony (Eds.), *The Cambridge companion of Levinas* (pp. 119-138). Cambridge, UK: Cambridge University Press.

- Locsin, R. C. (2002). Ebola at Mbarara, Uganda: Aesthetic expressions of the lived worlds of people waiting to know. *Nursing Science Quarterly*, 15, 123-130.
- Lowenstein, A., & Gilbar, O. (2000). The perception of caregiving burden on the part of elderly cancer patients, spouses, and adult children. *Families, System, and Health*, 18, 337-346. Retrieved April 18, 2006 from <http://web116.epnet.com.proxy.lib.sfu.ca/citation.asp>
- Manne, S., Ostroff, J., Winkel, G., Goldstein, L., Fox, K., & Grana, G. (2004). Posttraumatic growth after breast cancer: Patient, partner, and couple perspectives. *Psychosomatic Medicine*, 66, 442-454.
- Matthews, B. A., Baker, F. & Spillers, R. L. (2003). Family caregivers and indicators of cancer-related distress. *Psychology, Health, & Medicine*, 8, 45-56.
- Maxwell, J. A. (1996). *Qualitative research design: An integrative approach*. Thousands Oaks, CA: Sage Publications.
- McGrath, P., & Chesler, M. (2004). Father's perspective on the treatment for paediatric haematology: Extending the findings. *Issues in Comprehensive Paediatric Nursing*, 2, 39-61.
- Merriam-Webster Inc. (1993) *Merriam-Webster's Collegiate Dictionary* (10<sup>th</sup> ed.). Springfield, MA: Merriam-Webster.
- Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology*, 11, 799-808.
- McLeod, J. (2001). *Qualitative research in counselling and psychotherapy*. London: Sage Publications.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counselling psychology. *Journal of Counseling Psychology*, 57, 250-260
- Mosher, C. E., & Danoff-Burg, S. (2005). Psychosocial impact of parental cancer in adulthood: A conceptual; and empirical review. *Clinical Psychological Review*, 25, 365-382.
- Mosher, C.E., Danoff-Burg, S., & Brunker, B. (2005). Women's posttraumatic stress responses to maternal breast cancer. *Cancer Nursing*, 28, 399- 405.
- Murray, J. (1998). The lived experience of childhood cancer: one sibling's perspective. *Comprehensive Pediatric Nursing*, 21, 217-227.
- Nixon, M., Coventry, L. (Eds.). (2002). *The colour Oxford thesaurus* (2<sup>nd</sup> ed.). Oxford: Oxford University Press.
- Northouse, L. L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science & Medicine*, 50, 271-284.
- Northrup, D. T. (2002). Time Passing: A Parse research method study. *Nursing Science Quarterly*, 15, 318-326.

- Olson, C. T. (1993). *The life of illness: One woman's journey*. New York: State University of New York Press.
- Osborn, T. (2007). The psychosocial impact of parental cancer on children and adolescents: A systematic review. *Psycho-Oncology*, *16*, 101-126.
- Passik, S. D., & Kirsh, K.L. (2005). A pilot examination of the impact of cancer patients' fatigue on their spousal caregivers. *Palliative and Supportive Care*, *3*, 273-279.
- Paterson, B., Thorne, S., Crawford, J., & Tarko, M. (1999). Living with diabetes as a transformational experience. *Qualitative Health Research*, *9*, 786-802.
- Peleg-Oren, N., & Sherer, M. (2001). Cancer patients and their spouses: Gender and its effect on psychological and social adjustment. *Journal of Health Psychology*, *6*, 329-338.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer*, *39* (11), 1517-1524.
- Polkinghorne, D. E. (2000). Psychology inquiry and the pragmatic and the hermeneutic traditions. *Theory & Psychology*, *10*, 453-479.
- Polkinghorne, D. E. (2005). Language and Meaning: Data collection in qualitative research. *Journal of Counseling Psychology*, *52*, 137-145.
- Power, W. E., & Dell Orto, A. E. (2004). *Families living with chronic illness and disability: Interventions, challenges, and opportunities*. New York, NY: Springer.
- Purcell, M. (2006). *Levinas and Theology*. Cambridge, UK: Cambridge University Press.
- Richardson, A. (1995). Fatigue in cancer patients: a review of the literature, *European Journal of Cancer Care* *4*, 20-32.
- Rolfe, G. (2006). Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing*, *52*, 304-310.
- Rosman, S. (2004). Review. Cancer and stigma: Experience of patients with chemotherapy-induced alopecia. *Patient Education and Counseling*, *52*, 333-339.
- Sears, S.R., Stanton, A. L., & Danoff-Burg, S. (2003). The yellow brick road and the emerald city: Benefit findings, positive reappraisal coping, and posttraumatic growth in women with early stage breast cancer. *Health Psychology*, *22*, 487- 497.
- Seidman, I. (2006). *Interviewing as qualitative research: a guide for researchers in education and the social sciences*. New York: Teachers College Press.
- Soanes, C. (Ed.). (2001). *The Oxford dictionary of current English* (3<sup>rd</sup> ed.). Oxford: Oxford University Press.
- Statistics Canada (2007). The Daily: Friday, April 27, 2007. Mortality, summary of list of causes. Retrieved June 30, 2007 from <http://www.statcan.ca/Daily/English/070427/d0704275.htm>
- Statistics Canada (2006). *Parents with adult children living at home*. Catalogue No. 11-008.

- Stewart, D., & Mickunas, A. (1990). *Exploring Phenomenology: A guide to the field and its literature*. (2<sup>nd</sup> ed.). Athens: Ohio University Press.
- Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review*, 13, 593-618.
- Stoltz, P., Willman, A., & Uden, G. (2006). The meaning of support as narrated by family carers who care for a senior relative at home. *Qualitative Health Research*, 16, 594-610.
- Tarzian, A. J., Iwata, P. A., & Cohen, M. Z. (1999). Autologous bone marrow transplantation: The patient's perspective of information needs. *Cancer Nursing*, 22, 103-110. Retrieved July 05, 2006 from <http://gateway.ut.ovid.com.proxy.lib.sfu.ca/gw2/ovidweb.cgi>.
- Taylor, B. (1999). *They that mourn: Poems of grief and healing*. Edmonton, AB: Brightest Pebble Publishing.
- Tedeschi, R. G., & Calhoun, L.G. (1995). *Trauma & transformation: Growing in the aftermath of suffering*. London: Sage publications.
- Tedeschi, R. G., Park, C. L., & Calhoun, L.G. (1998). Posttraumatic growth: Conceptual issues. In R.G. Tedeschi, C. L. Park, & L.G. Calhoun (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 1-22). London: Lawrence Erlbaum.
- Teel, C.S., & Press, A. N. (1999). Fatigue among elders in caregiving and noncaregiving roles. *Western Journal of Nursing Research*, 21, 498-520.
- Thastum, M., Munch-Hansen, A., Wiell, A., & Romer, G. (2006). Evaluation of a focused short-term preventive counselling project for families with a parent with cancer. *Clinical Child Psychology and Psychiatry*, 11, 529-542.
- Thomas, C., & Morris, S. M. (2002). Informal carers in contexts. *European Journal of Cancer Care*, 11, 178-182.
- Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through cancer: the care given by informal carers in cancer contexts. *Social Science & Medicine*, 54, 529-544.
- Tishelman, C., & Sachs, L. (1998). The diagnostic process and the boundaries of normality. *Qualitative Health Research*, 8, 48-60.
- Toumayan, A. P. (2004). *Encountering the other: The artwork and the problem of difference in Blanchot and Levinas*. Pittsburgh: Duquesne University Press.
- van Manen, M. (1990). *Researching lived experiences: Human science for an action sensitive pedagogy*. London, ON: State University of New York Press.
- van Manen, M. (1997). From meaning to method. *Qualitative Health Research*, 7, 345- 369.
- van Manen, M. (2000). Moral language and pedagogical experience. *Journal of Curriculum Studies*, 32, 315-327.
- van Manen, M. (2002). *Writing in the dark: Phenomenology studies in interpretive inquiry*. London, ON: The Althouse Press.



- van Manen, M. (2002). Care- as-Worry, or “don’t worry, be happy”. *Qualitative Health Research, 12*, 262-278.
- Visser, M. R., & Smets, E.M. (1998). Fatigue, depression and quality of life in cancer patients: how are they related? *Supportive Care in Cancer, 6*, 101–108.
- Wagner, C.D., Bigatti, S. M., & Storniolo, A. M. (2006). Quality of life of husbands of women with breast cancer. *Psycho-Oncology, 15*, 109-120.
- Waldenfels, B. (2002). Levinas and the face of the other. In S. Critchley, S., & R. Bernascony (Eds.), *The Cambridge companion of Levinas* (pp. 63-81). Cambridge, UK: Cambridge University Press.
- Welch, A. S., Wadsworth, M. E., & Compas, B.E. (1996). Adjustment of children and parental Cancer: Parents’ and children’s perspective. *Cancer, 77*, 1409-1418.
- Wertz, F. J. (2005). Phenomenological research methods for counselling psychology. *Journal of Counseling Psychology, 52*, 167-177.
- Williams, P.D., Williams, A. R., Graff, J.C., Hanson, C., Stanton, A., & Hafeman, C., et al. (2002). Interrelationships among variables affecting well siblings and mothers in families of children with a chronic illness or disability. *Journal of Behavioral Medicine, 5*, 411-424.
- Worden, J. W. (1991). *Grief counseling & grief therapy: A handbook for the mental health practitioner*. New York: Springer Publishing Company.
- Wright, E.P., Kiely, M.A., Lynch, P., Cull, A., & Selby, P.J. (2002). Social problems in oncology. *British Journal of Cancer, 87*, 1099-1104.

## Appendix: Interview Questions

### Guiding Questions

1. What was it like for you to discover that your parent had Cancer?

*Prompts:* if participants do not cover these areas.

- a. How did you find out?
- b. Who told you? What was said?
- c. What were you doing when you learned?
- d. What did you do upon hearing your father/mother had cancer?
- e. What did you feel? What feelings did you experience?
- f. What thoughts came for you upon hearing the diagnosis?
- g. What did you do when you heard?
- h. What stands out for you of the diagnosis experience?
- i. What did this experience mean for you?

2. What was it like for you when your parent went through cancer treatment?

*Prompts:*

- a. What were your thoughts?
- b. What was the hardest time for you? Can you describe what was happening at that time?
- c. What feelings were you experiencing during treatment?
- d. What was a bad day like? Were there any good days?
- e. What significant feature or event stands out for you of treatment? What did this experience mean to you?

3. Some people say that the treatment experience affected their daily lives. Was this your experience, and if so, in what way?

- a. What areas?
- b. Social Relationships?
- c. Work? School?

4. Some people have said that despite the struggles and challenges, cancer also brought something of value, change and growth. Is there anything positive or valuable that has come about as a result of this experience? How so?

*Prompts:*

- a. Are there any ways in which you are different now as a result of this experience? What things are different?
- b. What has remained the same?

- c. What have you learned from this experience that you did not know before?  
Explain
5. During your parent's cancer diagnosis and treatment, what support was available to you?  
*Prompts:*
  - a. Who/What was helpful? In what ways? What was unhelpful?
  - b. Were there any emotional services that you would have liked to receive that were not readily available or accessible?
  - c. Were there any services that were available that were helpful to you during this experience?
  - d. Having gone through this experience, what service do you think might be helpful for other adult children?
6. Is there anything that I have not asked you but you would like to share?