

**CONVERSATIONS ACROSS THE DIVIDE:
JOURNEY OF AN EMERGING HEALTH CARE PROVIDER**

by

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ABSTRACT

This is an account of my personal journey of struggles, reflections and realizations as a care provider for individuals who live with cancer. Using the autoethnography method, I asked the very personally relevant question, “How do I understand my role as an emerging health care provider (HCP) to immigrant and young adults with cancer?” In other words, where do I fit in? How can I be the most effective caregiver possible? This telling of my journey incorporates my own experiences as well as the experiences of those who live and work with cancer. The journey begins almost a decade ago with an unexpected phone call that sends me to the bedside of a family member with cancer, and proceeds to my more recent experiences as a family caregiver, volunteer and counselling student and researcher. Drawing on multiple data sources, I explore the concept of health care provider, the desire to protect others and wear masks, and my own feelings of regret and guilt. Although this thesis presents my own realizations and insights, I hope that readers of these stories find resonance or dissonance with their own experiences, allowing them to make more sense of their own roles and circumstances.

PREFACE

The research described in this thesis was approved by the Behavioural Research Ethics Board at the University of British Columbia, Application ID H09-01073.

TABLE OF CONTENTS

Abstract	ii
Preface	iii
Table of Contents	iv
List of Images	vii
Acknowledgements	viii
Dedication	ix
Chapter 1: Introduction	1
1.1 Journey Beginnings	1
1.2 Thesis Overview	4
1.3 Research Question	8
1.4 Deconstructing Culture and the Self	9
Chapter 2: Methodology	18
2.1 Orienting Worldview	18
2.2 Auto/ethno/graphic Inquiry	19
2.2.1 Rationale for adopting a qualitative ethnographic approach.	22
2.2.2 Rationale for autoethnography.	24
2.2.3 Situating myself	25
2.3 Collecting Data	27
2.3.1 Roles.	27
2.3.2 Methods and sources of data collection.	29
2.4 Data Analysis	32
2.4.1 Questions for reflexive analysis.	34
Chapter 3: Stories	36
3.1 Directions Emerging	36
3.1.1 Arriving	36
3.1.2 Strangers meeting.	37
3.1.3 Adrift	38
3.1.4 Connections	38
3.1.5 Where do I belong?	39

3.1.6	Bearing it.....	40
3.1.7	Deep sleep.....	40
3.1.8	Misunderstandings.....	41
3.1.9	Bear bear.....	42
3.1.10	Auld lang syne.....	43
3.1.11	Evolving questions.....	44
3.1.12	Hope renewed and yet hope lost.....	48
3.1.13	Turning inward.....	53
3.2	Roles, Masks and this Divide Between Us.....	57
3.2.1	Handling others with care.....	60
3.2.2	My critical voice.....	64
3.2.3	Drifting apart.....	65
3.2.4	Struggling to find the balance.....	70
3.2.5	Our cultural context and the divide between us.....	77
3.2.6	Language divides.....	80
3.2.7	Perceptions that divide.....	84
3.2.8	Finding clarity amidst confusion.....	88
3.2.9	Practice dying.....	90
3.2.10	Summary.....	91
3.3	Deconstructing the Health Care Provider.....	92
3.3.1	Who are health care providers?.....	93
3.3.2	Burdens on care providers.....	98
3.3.3	Volunteers as care providers.....	100
3.3.4	A willingness to respond.....	107
3.3.5	The many faces of care providing.....	111
3.3.6	Summary.....	114
3.4	Conversations with Nímāmā.....	115
3.4.1	Juxtaposition of our two realities.....	115
3.4.2	Failing you.....	117
3.4.3	Protecting each other.....	121

3.4.4	Trying something different.	125
3.4.5	Protecting ourselves.....	127
3.4.6	Someone who is simply present.	128
3.4.7	Courage and strength.	135
3.4.8	Your gift of pain.	137
Chapter 4:	Conclusion.....	141
4.1	Implications for My Research Directions.....	142
4.2	Implications for My Practice	145
4.3	Implications for Social Policy.....	148
4.4	Finally.....	150
References	151
Appendices	167
Appendix A.	Initial Research Proposal.....	167
Appendix B.	Literature Review.....	170
Appendix C.	Conceptualizing “Culture” and the Self.....	191
Appendix D.	Culture-Gram.....	196
Appendix E.	Journal Entry: Privilege and Responsibility	197
Appendix F.	Genogram.....	202
Appendix G.	My Life Values	203
Appendix H.	Timeline of Major Life Experiences Related to Cancer and Dying	204
Appendix I.	Data Log	206
Appendix J.	Interview Questions for Patients.....	214
Appendix K.	Interview Questions for Health Care Providers.....	215
Appendix L.	Recruitment Brochure	216
Appendix M.	Recruitment Flyer.....	218
Appendix N.	Initial Contact Letter	219
Appendix O.	Consent Form for Patients.....	220
Appendix P.	Consent Form for Family Members, Friends and Caregivers.....	223
Appendix Q.	Counselling Resources	225
Appendix R.	Journal Entry: Waiting	227

LIST OF IMAGES

Image 1. Personal photo from when I was eight.....	37
Image 2. Personal photo of a bulletin board at the cancer agency.....	51
Image 3. Excerpt from diary of a young woman with cancer.	63
Image 4. Excerpt from diary of a young woman with cancer.	64
Image 5. Excerpt from diary of a young woman with cancer.	67
Image 6. Excerpt from diary of a young woman with cancer.	71
Image 7. <i>Your cancer care team</i>	95
Image 8. Excerpt from diary of a young woman with cancer.	111
Image 9. Personal photo of public art entitled <i>Echoes</i> at Kitsilano Beach in Vancouver, BC....	113
Image 10. Excerpts from diary of a young woman with cancer.	116
Image 11. Excerpt from diary of a young woman with cancer.	121
Image 12. From <i>Volunteer Handbook: A Guide for Volunteers</i>	129

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To Dr. Anusha Kassan, your penetrating questions made me think more deeply in both my research and clinical journey. I have been occupied many an evening in considering your comments.

To the many individuals whose lived experiences have informed this inquiry and helped me gain a better understanding of my place as a health care provider, I am deeply indebted. I feel privileged by your willingness to share your stories. Their impact will continue to be expressed in my work and career long after this document finds itself covered in dust on some library shelf.

To my parents, 妈, 爸, you know. If I had to say anything now and in this form, it would already be too late.

For 二姑姑,
who lives on in my work, my aspirations
and all that is to come.

CHAPTER 1: INTRODUCTION

1.1 Journey Beginnings

This research and personal journey began long before there was ever any consideration to complete a thesis or conduct research or even pursue a career in counselling psychology. My journey began with a single phone call. I remember the day clearly. It was December 2004.

I hastily speed through the corridors of the Tupper Medical Building. Moments ago, I was locked into a classroom filled with other over-stressed, over-caffeinated students, feverishly writing away, fixated on the precious minutes and seconds ticking away on my final exam in Virology. *Tick tock, tick tock*. I reach out my arms towards the door handle to brace for the impact of walking full speed out an exit that I have done so many times before today but this time, it is different. This was my last exam of the term. I walked with an extra bounce in my step from the exhilaration that I was free, free of assignments and due dates, late nights and early mornings. I was free of any and all obligations to the world. ♪♪ *Yeah I'm free, free fallin'*.

It is a brisk, wintery December day in Halifax. There is snow on the ground. Maybe we'll have a white Christmas after all this year, I think. Hopefully, not too much snow though. I don't want to be shovelling the entire holidays. Then again, why does it even matter? I don't have anywhere that I need to go for the next two and a half weeks. Bring on the snow.

As I rush towards my bus stop to meet the ride that will carry me to home sweet home, to warmth and relaxation, I notice my shadow cast onto the ground by the street lights overhead. It's dark already, I remark. I'm embittered. It's hard to believe that I spent that much time in that dungeon of a classroom with that crazy exam. I blink, shaking off the negative thought. Oh well. That's long past me now. Never have to think about it again.

Brain dump?

Enter.

Are you sure?

Most definitely.

But it's dark already. Where has the daylight gone? I lament. It's not even that late, not even supper time yet. Oh supper! I'm excited. Some delicious leftovers waiting for me in the fridge. Just reheat and feast. This time will be different though. No rushing to finish supper just to turn my attention to the very next exam. I am free, absolutely free! I feel a shot of adrenaline course through my body. I take in a deep breath to slow the moment down, to completely cherish this feeling of liberation. The cold air flows into my nostrils and into my lungs. It's refreshing.

I step into my home. The house is quiet, empty. I'm reminded that Mom has gone back to China for the holidays to help Dad. I have the house to myself. My mind swirls with ideas about all the fun I can have with this time off. Laze around and do completely unproductive things like playing some favourite videogames from childhood; plan a holiday gathering with friends next week; attend a Christmas dinner or two; do some running (which I've put off over the last few weeks on account of school craziness). It's been a particularly exhausting term. I've worked so hard to get to this moment, which makes it all the sweeter. This is going to be a great holiday.

With supper alongside the TV out of the way, I plop myself down in front of the computer. It's quiet, peaceful. I sit with the silence as the computer hums to life.

The sudden ringing of the phone breaks my moment of reverie. It's Dad. His voice is sombre. He tells me that 二姑姑 is in the hospital with cancer. Could I go to Washington, D.C. to accompany her?

What? I'm outraged and speechless. Why me? I protest in silence. My words are more subtle, trying to hide my anger. How could you ask me this? I don't even know her that well. There has to be somebody else who is closer to her and more appropriate.

No. He rationally explains that all the extended family members are busy and it would not be easy for them to take time off.

I scream in a voiceless silence. And yet you think that I'm not, that I can take time off just like that! There are so many things that I'm looking forward to these next few weeks here. And now to give it all up! How could you ask me this? I don't say any of these things out loud, though I know my tone probably reflects my bitterness. Part of me wants him to know it.

He senses my reluctance, but instead of addressing it openly, he avoids it as he always does and starts talking about the practical issues. She needs support during this time. It'll just be for these few weeks. You can be back before school starts again.

Calls of familial responsibility and filial piety now swirl in my mind where moments ago there were plans of holiday folly. I begin to feel guilty, the sort that comes about through outside forces or is imposed by someone else's arguments and reasoning. I feel resentful. It's as though I'm being forced to choose amongst one alternative. I bite my tongue and try to turn my attention to some of the practical issues as well. What am I going to be doing? I don't know her all that well. How can I possibly be of any help? Where am I going? When do they need me to go?

He answers each question in turn. Staying with her in the hospital and attending to her needs. It doesn't matter that you don't know her that well. She will appreciate your company regardless. Cousin Charlie can pick you up from the airport and take you there. It would be great if you could go tomorrow.

Tomorrow! I nearly choke. So I won't have any time to enjoy myself. My spirit is deflated at this point. Any will to resist has been overpowered by my sense of duty, my cultural value system. In this moment though, these values feel strangely foreign.

Completely deflated, dejected, disappointed, the conversation ends. It is quiet again, except for the steady hum of the computer fan. I start up the browser and logon to the airline website to buy tickets.

Departure date?

Tomorrow.

Are you sure?

I have no choice.

1.2 Thesis Overview

And so began my journey in providing care to individuals with cancer. My life changed as a result of my experiences that Christmas of 2004 with 二姑姑.¹ I spent two weeks there between the hospital and my Cousin Charlie's apartment. Over that time, I became aware of a number of things that have changed my life. These realizations include the biomedical culture's sometimes tragic disregard of psychological and social dimensions of a patient's life despite providing access to the best that modern medicine has to offer; the inseparable connection between the mind and the body; the false pretences that supported my motivation to pursue a career in medicine. In the years subsequent to this watershed experience, I have developed a lasting interest in the area of psychosocial oncology. This personal interest has spawned the current research inquiry.

The inquiry itself has not unfolded in a neatly linear way however. There was not a single question and methodology that was sequentially executed from beginning to end. My first research proposal was entitled, "Understanding the psychosocial experiences of cancer patients of Chinese ethnicity in the British Columbian cancer care system."² Since then, the inquiry has incorporated a focus on cultural intersections, namely of immigrant young adults with cancer.³ Given the central role of personal culture in shaping one's experiences and worldviews, culture also emerged as an important analytic framework.

¹ 二姑姑 is pronounced *Nimāmā* in the Shanghai dialect of Chinese. It is a colloquial title used by children to address the second oldest aunt in a family. *Nimāmā* is how I have always referred to my Aunt 邱秀瑾 growing up.

² This proposal was submitted nearly four years ago for a scholarship competition. It is included as [Appendix A: Initial Research Proposal](#) to show the changes in my inquiry over time.

³ For a more extensive description of my understanding of the term "culture", refer to [Chapter 1.4](#).

All throughout this inquiry, my focus was outward. I endeavoured to understand the experience of the other, whether that be the cancer patient of Chinese ethnicity or the immigrant young adult. As I spent time collecting data, a number of very personal questions emerged that I found myself preoccupied with. Where do I fit in? How can I be the most effective care provider? That is, “How do I understand my role as an emerging health care provider (HCP) for immigrants and young adults with cancer?” This very self-oriented interest became the main question that guided my inquiry.

At this point, I think it is important to briefly clarify what is actually being studied and therefore the intended implications of this research. Firstly, a few constructs are worth clarifying. In defining cancer as the experience, I do not mean to suggest that what is being researched pertains only to people with cancer. Perhaps more accurately, I am referring to a medical condition that profoundly challenges someone’s very existence, a subjectively life-threatening illness. Similarly, by immigrants and young adults, I allude to populations that are traditionally underserved by and marginalized within society (Arnett, 2000; Bleyer & Barr, 2006).⁴ There exist systemic challenges and gaps for immigrants and young adults in accessing care that may not necessarily be experienced by most others (Cancer Care Ontario, 2006).

With the scope defined as such, my intention is not to draw from my experience some conclusion about some broader population. Indeed, I think that it is imprudent that some research, whether quantitative or qualitative in nature, strive to make brazen claims in the general form of “cancer patients of X diagnosis and Y ethnicity experience more challenges with Z”. Not only would such aims go beyond the intentions of this research, but it would also perpetuate a tradition of over-simplifying and categorizing the complexities of our human experience. This

⁴ For a more extensive review of the relevant literature, refer to [Appendix B](#).

research is necessarily focused on the individual, whether it be my personal experiences or the narratives of the patients, family members and care providers with whom I have interacted. Moreover, I place myself squarely in this thesis to acknowledge the deeply personal (and therefore subjective) nature of this inquiry and the considerations that have directed its ebb and flow. Although my very research question may suggest a certain generalizability of my reflections to all immigrants and young adults with cancer, I will underscore that my experiences are unique and personal.

As such, the aim of my research inquiry is not to quantify or establish causality; nor does this thesis hope to uncover and report on a reductionistic universal truth about what being an immigrant or young adult with cancer entails. There will be no list of prescriptive tips or recommendations at the end of this thesis for the solution-seeking reader. Instead, my research inquiry originated out of my own very practical concern of figuring out my role as a care provider within a system that centers on the individual immigrant or young adult with cancer, extending across people, places and time. My personal aim is to understand how I can effectively support this complex, multicultural system. In turn, this document will try to provide a richly detailed and evocative narrative of my experience in discovering my role as an emerging HCP. Through this account, I hope that you, the reader – whether beginning your journey in health care provision or having served in this role for many years – feel compelled to travel along in this journey and find resonance or dissonance with your own experiences, allowing you to make more sense of your own role and circumstances.

These aspirations are in some ways substantial departures from more traditional academic pursuits that are set in positivistic paradigms, couched in the language of objectivity and neutrality, establishing hypotheses to be disproved and using categorical statements. As such,

this thesis is written in a different format, not structured according to familiar headings like introduction, literature review, methods, results, discussion and conclusion. Instead, this thesis consists primarily of four major sections: 1) an introductory section that situates myself in this research inquiry and defines my understanding of the term culture, 2) a methods section that describes the methodological traditions and process by which I have conducted this inquiry, 3) a narrative account of my realizations about my role as an emerging HCP, and 4) a summative section that discusses my conclusions and implications for my own practice and journey in cancer care provision.

The most substantive portion of this thesis is Chapter 3, entitled “Stories”. It includes four self-reflective dialogues through which I have come to significant realizations about my role as an emerging HCP. Each section weaves together conversations with patients, care providers and colleagues; readings; and personal reflections (not necessarily connected by temporal proximity or chronology). Each section is also meant to be self-contained, allowing you to proceed through sections separately and in whatever order, while still being able to grasp the conclusions drawn. At the same time, I hope that in reading this entire thesis, you may gain a greater appreciation of my experiences and the cultural context which gave rise to them.

The summative section synthesizes my realizations into some ideas about my role as an emerging HCP to immigrant and young adults with cancer. In addition, I will discuss the possible relevance and implications of my personal experiences on the wider cultural context of counselling psychology and cancer care provision.

The notable absence of a formal literature review section is intentional. As is consistent with eminent scholarship using this method of self-oriented inquiry (Ellis, 2004), existing knowledge helps to relate the personal (private) experience to the experience of others or wider

society (public). As such, the relevant literature is referred to throughout the thesis and serves to situate my experiences *a posteriori* rather than justify a research design or direction of inquiry *a priori*.⁵

Overall, this thesis is written in the style of a narrated documentary. My own journey as an emerging HCP will serve as the backbone of the thesis. In order to provide readers with a more real experience, I recount some of the relevant and at times poignant encounters, conversations and self-reflections that I collected while engaged in the research or as part of my day-to-day experience. Oftentimes, I make sense of my experiences through the writing process itself. Therefore you may be able to witness my thought and decision-making process as it unfolds. In the tradition of reflexive qualitative research, this level of transparency is used to reveal my own values, beliefs and biases that lead to my conclusions.

1.3 Research Question

My hope for this thesis is to share with you, the reader, my journey in coming to understand my role as a HCP. That is, “How do I come to understand my role as an emerging HCP for immigrants and young adults with cancer?” In sharing this journey with you, I hope that you may find resonance or dissonance with your own experiences, allowing you to come to a greater understanding about your own role and circumstances.

⁵ A more extensive review of the literature in the area of immigrant, young adult and cancer cultures is included as [Appendix B](#).

1.4 Deconstructing Culture and the Self

This research is at its core an inquiry about people's experiences at the intersection of cultures (Cole, 2009). As such, I will describe in this section my definition of the term *culture* and explain where I see the self as being located within this definition. With this understanding, I will situate myself culturally as well as within this research.

The term *culture* is casually and pluralistically referred to by scholars and laypeople alike. Exchanges between two individuals or groups from different parts of the world are referred to as cross-cultural exchanges. Neighbourhoods or cities can differ in the degree to which they are multicultural. Within popular and academic circles alike, multiculturalism is a desirable social phenomenon that encourages people to consider life from a different perspective and develop empathy for fellow human beings (Fowers & Richardson, 1996). People can be of high or low culture. They can straddle two cultures, go back to or come from their cultures, or even have no culture. Multiculturalism is, to many, "alive and well". Our everyday existence is filled with culture and yet it remains a term that is poorly understood.

Even within cultural-anthropology and -psychology scholarship, there are different conceptualizations of the term culture (Geertz, 1973; Mead, 1971). One prominent definition of culture is as "the system of shared beliefs, values, customs, behaviors, and artifacts that the members of a society use to cope with their world and with one another, and which is transmitted from generation to generation through learning" (Bates & Plog, 1990, p. 7). This definition emphasizes the element of culture as shared meaning or implicit rules that govern behaviour. Other definitions seem to focus on culture's role in differentiating us from them (Hofstede, 2001). Adding to the confusion are contemporary scholars' debates about the similarities and differences between culture and related constructs such as race and ethnicity (American

Psychological Association, 2002; Helms & Talleyrand, 1997; Phinney, 1996). The plurality of definitions as well as some authors' disregard for explicitly defining culture or discussing culture in ways that are inconsistent with their stated definition can cause significant confusions.

Given the centrality of culture within this research inquiry, I believe that it is essential for me to make sense of my own conception of culture. This task entails clarifying where I stand on two ongoing discussions within the scholarship of culture (Chang, 2008). One discussion revolves around the question, "Is culture physical and tangible?" A second and perhaps more fascinating discussion involves whether culture is located inside the person or "out there". The second discussion relates to, though is not entirely synonymous with, the question "Is culture shared or personal?"

Admittedly, like my ebbing and flowing research inquiry, my understanding of culture has evolved over time.⁶ In deconstructing culture for this thesis, I became aware of its central role in all facets of my experience. A number of self-reflection questions that I used in my data analysis⁷ prompted me to recognize how simple processes – from decisions about the research, perceptions in the field and reactions to conversations – are shaped by my cultural location. I am not just a *tabula rasa* or blank slate on which sensory experiences are etched, unaltered.

It quickly became apparent that the debates and analyses about culture are not merely the concerns of theoreticians in the ivory towers of academia. They have significant real world implications also. Take for example the statement, "I come from a culture where..." which I overheard while at a recent multicultural psychology conference. On the one hand, for an individual of African heritage who perceives culture to be an identity that one is born into, he

⁶ Appendix C is an excerpt that describes my understanding of culture two years ago.

⁷ Refer to Chapter 2.4 Data Analysis for a more extensive description.

may enact life in a way that is consistent with cultural stereotypes of stupid, criminal and subordinate (Steele, Spencer & Aronson, 2002). On the other hand, for another person who perceives culture to be a group membership in which one chooses to participate in, then she may feel more freedom to oppose negative cultural stereotypes.

In trying to formulate a definition, I find myself thinking about what culture is not. To me, culture is not a physical object, a group of people or a geographical space. Consequently, I believe that culture can neither be physically pointed nor defined by drawing some boundaries around a set of people or a place. These assertions seem to be intuitively true from the way people colloquially uses the word. It seems somewhat simplistic to refer to a carving or tree as culture itself. It seems more accurate to say that culture includes the artistic techniques used to make the carving or stories about the tree. Similarly, culture seems to be more than just a group of people who share traits or backgrounds. The people themselves are not the culture the way the attendees at a conference or inhabitants of a remote village are not culture. Thus, culture is neither a tangible object nor a group of people that one can point to, but rather the shared collection of knowledge, value and belief systems, practices and traditions that are applied to those objects or by a group of people.

Following on this reasoning, the geographical space in which people occupy is not culture. Nevertheless, the association between geopolitical regions and culture is ubiquitous. For example, consider the ongoing use and abuse of the rather reductionistic binary of Western and Eastern cultures in both popular and scholarly discourse (Chua, 2011; Cohen, 2009). Most audiences would (perhaps incorrectly) assume that a speaker is referring to the practices or beliefs held by people who inhabit that region of the world. Yet, the very use of geographical descriptors (e.g., Western, Asian) seems to suggest something entirely physical. If by Asian, we

actually mean a collection of practices such as eating in ways consistent with *feng shui* principles or values such as Confucian ideals of filial piety, why do we not merely state it as such? In not doing so (i.e. to use cultural contractions such as Asian or Western), I believe that we reduce very complex constructs into simple ones, supporting over-generalizations and cultural stereotypes.

The definition of culture that is emerging at this point seems to be consistent with the mainstream multiculturalism orthodoxy. What remains is perhaps the more interesting consideration of where the self is located within or in relation to culture. In other words, “Is culture inside a person or out there?” Moreover, “Is culture personal or shared?”

In order to grasp these questions, I found myself reflecting on my observations of how certain people tend to fulfill their cultural stereotypes while others shed or ignore them. What appears to be at the heart of these different behaviours is the notion that culture is something one can have membership, in the way I might have memberships to an exercise gym or political organization. I choose to participate in a gym or belong to a political organization. As such, I tacitly endorse the opinions or philosophies of the organization, such as in valuing socialist policies or ecological sustainability.

I find this idea of membership in culture incredibly appealing. It reflects the agency that every individual has in creating their personal cultural identity. As such, individuals may express membership in a culture but not participate actively in it or may display their cultural affiliation in different ways. Consider my cultural identity. Although I consider myself to be of Chinese culture, I did not actively participate in Lunar New Year and do not regularly consume Chinese media. Instead, I experience my identity in my feeling a greater urge to connect with patients who are of Chinese ethnicity or greater sorrow in relating to the struggles of a adolescent

caregiver of Chinese ethnicity. I imagine that if I was situated in a different cultural location, my reactions to these encounters would have been very different.

The notion of having membership in culture also recognizes the power that individuals possess in foreclosing their affiliation in a culture (Berry, Phinney, Sam, & Vedder, 2006), or having membership in multiple cultures (Cole, 2009). As such, one's cultural identity is best viewed as being fluid or temporal rather than born into and permanent. I find this dynamic image quite appealing as it reflects of my own experiences as an active agent in constantly negotiating and defining my multiple cultural identities. As an immigrant, born in China, grown up in Eastern Canada and now living in Vancouver, I have participated in and withdrawn membership from a number of cultures.⁸ At times, I have had to reconcile the conflicting messages that I receive from cultures to which I have membership. In these confusing moments, I find my relationship to these cultures change. I distance myself from one culture while affiliating more closely with another. This often happens with my membership in the graduate student culture. When I walk into a seminar, I affiliate with that culture, ready to learn, take notes and think critically about the material. When I am engaged in my clinical practice, I distance myself from that culture. I behave differently, dress differently and engage in different conversations. This illustrates how my membership in the multiple cultures that forms my cultural identity fluctuates from moment to moment.

Therefore, in response to the question of whether culture is within a person or out there, I believe the most accurate answer is both. My relationship with any of multiple cultures is fluid. It is out there in the sense that I do not participate in certain practices and traditions, or possess

⁸ The creation of a "culture-gram" is suggested by Chang (2008) as an exercise of self-exploration to better locate oneself in an autoethnographic inquiry. My own culture-gram is included as [Appendix D](#).

certain belief and value systems. At any moment though, I may take membership in a culture, in which case, it would be part of me at that moment.

From this, we turn to the question, “Is culture shared or personal?” The likely response of most scholars would be that culture is shared. The established orthodoxy is that culture – the collection of practices, traditions, belief and value systems, etc. – is transmitted from parents to children and within communities that perceive members of that community to share certain commonalities or worldviews. From these assumptions, it would follow that “there is no such thing as culture of one” (Chang, 2008).

From my deconstruction of culture in my life as well as others, I find my views diverging from this established orthodoxy. It seems to me that although we all perceive culture to be shared and even communicate using language that is consistent with this belief, culture is in fact personal and necessarily so. This conclusion follows from my discovery of and resonance with post-modernist thinking, which in essence problematizes the notion that there exists an objective truth. Within this framework, the realities that each of us experiences is necessarily subjective. I receive sensory inputs that are filtered by the lens that I wear; therefore, what I experience as reality is different from what another person experiences.

Moreover, what we may all perceive is a shared culture is no more than a representation of that culture through our individual lens. Taken one step further, our definition of a given culture is subjectively defined. Consider the example of two siblings of indigenous ancestry. Both may self-identify as being members of their indigenous culture and yet perceive very differently what it means to have membership in that culture. One sibling may associate his cultural membership with eating a traditional indigenous diet, while the other may focus more on the endorsement of familial values while not really caring for the traditional diet.

More personally, I find myself often in discussions where the term “Chinese culture” is casually referenced. During these discussions, there exists a tacit assumption and agreement amongst discussants about the meaning of the term Chinese culture. Although we carry on these conversations without any problems, I would imagine that if anyone were to question our understanding of Chinese culture membership, a plethora of (potentially conflicting) viewpoints would emerge. As a first generation Chinese Canadian who grew up in a predominantly Caucasian community in eastern Canada, my understanding of Chinese culture would probably be very different from another first generation Chinese Canadian who grew up on the west coast. The same distinction could be made with two people of the same community or even the same family. If such divergent viewpoints exist within a presumably homogeneous group, I can only imagine the impossibility of arriving at some consensus about what it means to be a member of a given culture. Understood in this way, culture is not some monolithic construct that exists “out there”, independent of people. Rather, cultures exist within every individual, constructed by that individual. In essence, our membership is to an organization of one, and when we withdraw our membership, that organization ceases to be.

In spite of such plural realities, we all continue to collude in maintaining this fallacy of culture as shared. We communicate using language that is consistent with this fallacy. Perhaps, it is our social nature, our desire for a sense of connection and belonging. Perhaps, it is out of a perceived necessity. We act as if we share a semantic framework so that we are able to communicate with each other sensibly.

Whatever our reason for maintaining this collusion, I believe it is important to acknowledge its implications. Having a shared semantic framework does seem to provide a sense of security and order in our communications with another. At the same time, I noticed that

assuming a shared culture can limit my curiosity and humility towards the other; and in turn, lead to misunderstandings. I noticed this in my interactions with people of Chinese ethnicity, as well as between HCPs and their patients.

The assumption of shared culture can therefore be a double edged sword. As such, I find it of practical value to view culture as individualistic. This conclusion compels me to not assume and to remain curious about another. When culture is individualistic, I must acknowledge that the person with whom I am communicating possesses a uniquely different reality, regardless of our use of similar terms.

To summarize this extensive⁹ deconstruction of culture and how the self is located within it, I return to the three questions that began this section.

Is culture tangible?

Is culture located inside the person or out there?

Is culture shared or personal?

In response to the first, my intuitive reasoning based on our colloquial use of the term leads me to understand culture as intangible. It is not the physical objects themselves that is culture but the practices, traditions, beliefs and values symbolically underlie them. In relating to cultures, they can exist either inside the person or out there. Our membership (albeit a membership of one) is fluid, varying with experience and context. Insofar as we define a given culture though, it is like our reality, necessarily personal. Having established in this section a common semantic

⁹ As I reflect on these conclusions, it strikes me how long it has taken both on paper and in my lifetime. I believe that this effort will not be wasted however as this understanding has for me and will for the readers help make sense of this research inquiry.

framework about my own understanding of culture with the reader, I will later situate myself and my cultural identity relative to this research inquiry.¹⁰

In the chapter that follows, I will go more deeply into describing the theoretical and methodological frameworks that structure this research inquiry. I will also describe my interpretation of qualitative autoethnographic inquiry and its appropriateness in shedding light on the present research question.¹¹

¹⁰ Refer to [Chapter 2.2.2 Rationale for autoethnography](#).

¹¹ I must admit that this discussion of methodology will feel like a slight departure from the intimate, narrative voice that this thesis aspires to convey. Given the inevitable pressures that come with being situated in an academic context, I feel obliged to lay out my arguments for the suitability of my methodological decisions using the distantly intellectual voice of established credibility. [Chapter 3 Stories](#) will attempt to return to the more inviting and relatable tone of autoethnography.

CHAPTER 2: METHODOLOGY

This section will discuss the theoretical underpinnings of this research inquiry. I will describe the social constructivist lens with which this research has been conceived and will be interpreted. Subsequently, I will describe the general data collection and analysis methods to be used. A rationale will be provided for the methodological decisions that have been made at the outset of this study. The section will conclude by considering the ethical concerns in engaging in this research project and using this particular methodology.

2.1 Orienting Worldview

My worldview or the lens through which I interpret this research is based on the assumption that knowledge is a social construction; that is, what each person believes to be true is created out of a continual and reciprocal interaction between the person and his or her social context (Geertz, 1973). What is true for one person or group may not be for another. This gives rise to the possibility of multiple, equally valid and coexisting realities (Crick, 1982). This knowledge paradigm contrasts with the positivistic notion of a single universal reality that can be discovered through an objective and value-neutral inquiry. Instead, social constructivism emphasizes subjectivity and agency. Knowledge is thus co-constructed between the individual and society, and is experienced through the subjective lens of the individual.

This self-oriented research inquiry acknowledges the legitimacy of multiple co-existing realities. In this thesis, I report on a single reality, my own, without suggesting that my interpretations are somehow legitimized through being presented in this written document or academic context. Instead, I merely share my journey as an emerging health care provider with the hope of engaging readers in reflection about and becoming more aware of their own reality

and cultural practices. The ultimate goal is in being able to provide more effective, more culturally sensitive health care to immigrants and young adults with cancer.

2.2 Auto/ethno/graphic Inquiry

My inquiry adopted a qualitatively-oriented, autoethnographic approach to data collection. Ethnographic inquiry is a multimodal qualitative research approach that is rooted in sociology and cultural anthropology. Ethnography (from the Greek word “ethnos” meaning other people, group or race) refers to the “first-hand empirical investigation and [...] interpretation of social organization and culture” (Hammersley & Atkinson, 2008). Classical ethnographers would often spend months or years deeply immersed in a foreign geographical milieu. During this extended period of time in the field, the ethnographer would be engaged in the lives of those being studied, documenting and interpreting their distinct way of life, values and belief systems, and underlying worldviews. The ultimate goal would be to construct an “emic” or insider’s account of a culture acknowledging the social, physical and political contexts in which it exists (Pike, 1967).

Ethnography draws its data primarily from the fieldwork experience of the researcher. A multimodal approach to data collection is used, including keeping detailed field notes, conducting interviews, collecting artefacts and writings, engaging in direct and indirect observations, all characterized by prolonged immersion in the environment of study. Ethnography endeavours to gain a better understanding of the common experiences shared by and influences on a culture and to portray them as accurately as possible.¹²

¹² The self-oriented (i.e., autoethnographic) nature of this inquiry will be described in more detail in the following section.

My research focus has evolved over the course of this research journey. My initial interest was in exploring the psychosocial experiences of cancer patients of Chinese ethnicity.¹³ Iterative refinements have included the expansion of the population to immigrants¹⁴ and the inclusion of the young adult culture.¹⁵ My early data collection was driven by the question, “What are the psychosocial experiences of immigrant young adults with cancer?” I began to accumulate data in the form of conversations with patients and care providers, research studies, theoretical papers and policy documents. As I did so, I began to notice that much of my findings simply reaffirmed the conclusions or stereotypes I gained from my prior review of the literature. I became increasingly disinterested in and decreasingly surprised by the data. In spite of my “heightened understanding”, what continued to nag me was a “So what?” sort of question. “Where and how I fit into this care system?” The data was directed at, for the benefit of and could inform someone else. Not me. I was the student, the researcher, the aspiring (but not yet) care professional. I did not have membership with this culture of cancer care.

Over this period, I increasingly reflected on my own experience of this research process. I realized that the question that was important to me was “How do I understand my role as an emerging health care provider for immigrant and young adults with cancer?” In order to answer

¹³ My initial research idea was described in a scholarship application, which is included in the [Appendix](#).

¹⁴ The decision to focus on the experiences of immigrants rather than people of Chinese ethnicity was motivated by my recognition that culture ought to be defined according to experience rather than geographical or geopolitical regions. Refer to [Chapter 1.4](#) for an expanded discussion of *culture*.

¹⁵ [Young adulthood](#) (Arnett, 2001) emerged from my review of the cancer care literature as well as my own experience as a challenging transitional life stage that is often overlooked.

this question, I had to turn the research microscope on myself. In doing so, my ethnographic inquiry became an autoethnographic inquiry.

What constitutes an autoethnography remains unclear and contested. This term is often used synonymously with other forms of self-exploration like autobiographies, memoirs, recollections, personal journals and stories (Charmaz, 2006). At its core, autoethnography is a research inquiry into oneself. Through it, one gains a better understanding of the cultural context in which one's life is situated. Whether such an understanding is meant to represent a wider social culture has been an issue of scholarly contention as well (Hunt & Junco, 2006).

Anderson (2006) considers autoethnography as having five key features: complete member researcher status, analytic reflexivity, narrative visibility of the researcher's self, dialogue with informants beyond the self and commitment to theoretical analysis. Complete member researcher status refers to the requirement for the researcher to be a member of the social world in which she or he is studying; that is, only those who have experienced cancer themselves may engage in an autoethnographic inquiry about the experience of cancer. This allows for a different and arguably more intimate understanding of the experience or cultural context than what could be discovered by a cultural outsider. In this way, the autoethnographer occupies the dual role of the observer and participant in the truest sense.

Some scholars argue that what follows from this insider membership is an obligation to analytic reflexivity (Anderson, 2006; Wolcott, 2004). Analytic reflexivity is the process of inferring from the personal and self-observant experiences to the larger social world in which the researcher belongs. Anderson refers to this as a "[rising] above idiographic particularity to address broader theoretical issues" (p. 379). Scholarly debate continues on this point however. Acknowledging a somewhat more post-modern take, Ellis (2004) contends that the primary goal

of autoethnography ought to be to accurately represent the researcher's emotional experiences, not to generalize. Such a commitment to emotional fidelity would compel readers to journey alongside rather than analyze at a distance. As Clandinin and Connelly (2004) notes that reading others' self-narratives can evoke self-reflection and self-examination. Given my own resonance with post-modern subjectivity, I aligned this thesis more so with the latter evocative autoethnographic approach.

2.2.1 Rationale for adopting a qualitative ethnographic approach.

This research is discovery-oriented. Although many of the premises are drawn from the literature, I tried to remain relatively unconstrained by preconceptions. The aim was not to validate or disprove a particular theory, nor is any one particular theory used as framework to guide data collection or interpret the data collected. The phenomenon of experiencing a life-threatening medical condition while transitioning from one culture to another is very poorly understood. I therefore engaged in this inquiry with an open ear and mind.

Camic and colleagues (2003) perceive the fundamental goal of qualitative researchers as endeavouring to understand the lived experiences and the meanings attributed to those experiences. These experiences are embedded in an individual's circumstances, and can only be understood when considered in the context of the individual's family, community and society. Such understanding cannot be gained through traditional hypothetic-deductive models of knowledge discovery. Rather than creating highly controlled, distally approximate experimental settings (Hammersley, 1990), this research will be grounded in my own world experiences in engaging with people, events and places at the intersection of immigrant, young adult and cancer cultures.

Amongst the various qualitative research methods, the ethnographic approach seems especially well-suited to answer the current research questions. Qualitative research with

vulnerable populations such as IYA with cancer can be challenging, especially when studying illness. Trust for the researcher is an integral component to gaining full cooperation of the IYA in research participation (Broome & Richards, 2003). Without having established a trusting relationship, participants may be reluctant to share their sensitive and private experiences of cultural transition and illness. Ethnographers, by their prolonged immersion in the research context, are afforded the opportunity to develop a trusting relationship with the IYA. Indeed, Camic and colleagues (2003) suggested that, because youth may be suspicious of or unfamiliar with the nature of qualitative research, researchers would do well to meet with participants on many occasions and to employ non-interview based data collection methods.

Ethnographic inquiry's multimodal approach to data collection also substantially reduces the linguistic demands of participants as compared to interview-reliant qualitative research methods. While expressing the subtleties of lived experiences would be difficult for anyone, the difficulty is of particular concern amongst individuals whose first language is not English. Rather than extrapolating from conversations, ethnographers may collectively interpret data gathered through directly observing and participating in the experience being studied to arrive at a more content valid account of the lives of the participants (Mathison, 1988). Moreover, to neglect would be to ignore the complex relationships between peoples' attitudes and behaviours (Hammersley, 1990). Where discrepancies exist, ethnographers are able to follow up to obtain clarification. For these reasons, Suárez-Orozco and Suárez-Orozco (2001) argue that an ethnographic approach is best suited for research with immigrants.

Additionally, ethnographic inquiry engages a participant's whole social context. In order to ensure comprehensiveness and encourage a more reflexive analysis of the data, ethnographers often converse with family members, friends and peers (Kelly, Pearce, & Mulhall, 2004). For

IYAs with cancer, caregivers and health professionals may also contribute valuable contextualizing information. By collecting data using multiple methods and from multiple sources, autoethnographers are able to collectively interpret the data in order to gain a more contextualized understanding of their own experiences.

Rather than being bound by a linear research protocol, ethnographic inquiry employs an emergent research design that is responsive to ever-changing circumstances, and the demands of the study and its participants. Instead of being bound by a particular research topic or set of questions, the ethnographer is able to consider what is currently uncovered and refocus and refine subsequent lines of inquiry. These features provide a means for the research inquiry to be responsive to what is most pertinent to me in considering the research question.

2.2.2 Rationale for autoethnography.

The self-focused, autoethnographic approach to research is especially well-suited to this inquiry for a number of reasons. That said, I will make no effort to pretend that this was a carefully made decision at the outset of my journey. It became well-suited out of necessity, not academic argument. Although a narrative account of how my journey turned inward is outside the scope of this section¹⁶, I want to comment on the value of the autoethnographic approach to research, especially as it relates to my profession of counselling psychology.

Autoethnography is quite unique as an emerging investigative approach in academia and research. In contrast to traditional-positivistic approaches to research that aims to dismiss the researcher's role and influence on the research process, autoethnography puts the researcher front and centre; it acknowledges the researcher as the tool, decision maker and subject of the research process. This thesis does not try to hide the imperfection (or more accurately cultural

¹⁶ Refer to [Chapter 3.1.13 Turning inward](#).

location) in which all research is generated. In laying out every aspect of my research process for you, the reader, I make it available to be examined, and endorsed or rejected for its appropriateness to your own circumstance.

Moreover, as I became increasingly preoccupied and curious about my own place and role as a health care provider (HCP), autoethnography emerged as a valuable methodological framework for examining my experiences. Its emphasis on reflexivity, or the researcher's own influence on the research process, served as a way to make sense of how I perceive my current role of HCP in light of my past experiences. I resonate with the notion of reflexivity in research as it parallels a fundamental commitment in the profession of counselling psychology to self-awareness. A central tenant of counselling is that in order to help others gain insight into their lives, we must first do so for ourselves. Gaining a greater self-awareness becomes almost an ethical obligation as it informs the way my practice. Such knowledge allows me to note how my actions and reactions are influenced by my own experiences over that which exists between the client and me. Like with reflexivity in research, the aim of exposing these influences ought not be to separate it out from the process; rather, an increased insight can greatly inform the process.

2.2.3 Situating myself.

I myself am situated in a social and historical context which has profoundly influenced my experience of the world.¹⁷ The decisions that I make in conceiving this research as well as my interpretation of the data are inevitably filtered by my worldview. As such, I will situate myself in this research process so that readers may more accurately understand why certain decisions or interpretations may have been made.

¹⁷ Refer to [Appendix D: Culture-gram](#) for a pictorial illustration of my multiple cultural identities.

My worldview is significantly influenced by my experiences as a Chinese-born immigrant to Canada. Having immigrated to Canada from China with my parents as a child, I have experienced the challenges of adjusting to a new socio-cultural milieu and integrating different, often conflicting sets of values and worldviews. I have witnessed my parents' socio-cultural and financial struggles having left the safety and support of an extended family, and having given up decent careers for tiring, low-paying jobs that they were overqualified for. Their long hours away from home created an environment where I had to grow up quickly and learn many things on my own. Over the course of growing up in Canada, I have realized many of the benefits and opportunities that this country has to offer. In meeting others who are newly arriving in Canada, I feel both awe and despair in recognizing the struggles that many must face and the untold sacrifices that they have made and continue to make.

As a graduate student and aspiring counselling psychologist, I hope to be able to support and advocate for individuals who struggle in their transition to a new country. Moreover, I hope to be able to help people identify and strengthen the support systems that exist within their families and social networks. Within this ethnographic inquiry, I hope that my research efforts and the obtained findings will sensitize and inform mental health and medical practitioners, as well as informal care providers of the often unspoken struggles of immigrants with cancer.

As a researcher who has experienced or witnessed some of the major life transitions that I endeavour to better understand, I bring to this inquiry my own assumptions about what it has meant for me to be an immigrant, a young adult and a care provider for cancer patients. Rather than denying my own reality, I endeavour to acknowledge it throughout the research process.

2.3 Collecting Data

I employed a multimodal approach to better understand my role as an emerging health care provider to immigrants and young adults with cancer. Over the course of eight months, I adopted a number of different roles related to cancer care and drew on a multitude of different data collection methods.¹⁸ The multiple data sources serve as the basis for triangulating and therefore validating self-reflexive data. Moreover, the eight month period spent in the field gave me a chance to monitor what were some very interesting changes to my understanding of the HCP role and how I fit into it. The following sections describe these roles and methods.

2.3.1 Roles.

I took on a number of different roles through this research inquiry, including as a researcher, a volunteer, a student and a colleague. Together, these roles afforded me a chance to understand what it means to be a HCP and my relationship to it from different vantage points.

Most saliently, I began this journey as a social science researcher. This entailed coalescing my lived experiences and interests into a research question, formulating a research proposal, obtaining ethics board approval, forming partnerships with members of the community and institutional gatekeepers, engaging with participants, applying for funding and more. This intricate and often arduous process began nearly four years ago in beginning my graduate studies and has provided no shortage of moments of reflection.

¹⁸ Refer to [Appendix I: Data Log](#).

I also visited the main cancer care centre on a weekly basis as a volunteer in the chemotherapy and inpatient wards.¹⁹ My time there was spent chiefly offering companionship to patients and family members, liaising with the centre's staff and supporting volunteer events. In order to take on this role, I was required to attend several training workshops. One workshop in particular was very thought provoking as it challenged me to examine my conception of death. Other challenges came in my perpetual struggle to separate my inert volunteer role with the multiple other roles that I adopted. This was reflected on at length in several of my experiences.

I also participated in a four month course on interprofessional psychosocial oncology. My classmates were from a variety of disciplines (including social work, nursing and counselling psychology) were at different stages of their career and lived all across Canada. The course consisted of readings, individual and group assignments and a weekly online discussion on topics in the area of psychosocial oncology. The course facilitator would press us to consider how professionals with different disciplinary expertise could collaboratively provide the most effective care possible to patients and their family.

As an ongoing role, I continue to engage in my clinical training as a Master's student in the counselling psychology program. Throughout the research process, I have been working at two practicum sites that have allowed me a valuable opportunity to make sense of my role as a mental health service provider outside of a cancer care setting. Additionally, my colleagues in the program served as a valuable platform for discussing and making sense of my thought processes over the course of data collection.

¹⁹ Unless specifically asked about, I did not bring up my research project for discussion. I felt that, in my role as a volunteer, this would have inappropriately focused the conversation on me rather than the patient. Although I was mostly able to negotiate these multiple roles during my volunteer time, I did sometimes struggle.

2.3.2 Methods and sources of data collection.

Compounded upon the roles that I adopted, I also collected data in a multitude of different methods. Multiple data sources serve as the basis for triangulating and therefore validating self-reflexive data (Chang, 2008, Mathison, 1988)

The data sources can be divided into two broad categories, outward focused methods (e.g., interviews, observations, reviewing the literature as well as other textual and non-textual artefacts) and inward focused methods (e.g., self-observations and self-analyses through journaling, creating a personal culture gram and reviewing personal memories). Both inward and outward focused methods were used in this research.

Formal hour long interviews were conducted with five health care professionals (including counsellors, social workers and a practice leader), one volunteer coordinator, one immigrant young adult with cancer and one family member. I met with some participants on multiple occasions. All of these formal interviews were both semi-structured, being guided by a defined set of topics and questions – so that discussions can be focused – while allowing participants the flexibility to talk about any topic in depth.²⁰ Hunches and realizations from prior experiences informed the focus of subsequent discussions in a continuously self-refining way.

A review of research in the domain of immigrants, young adults and cancer identified a non-exhaustive list of potential topics for discussion, including relationships with family and friends; home, school and work environments; coping with stressors and transitions as a young adult, immigrant or cancer patient; interpersonal dynamics in medical management (Kim, Sherman, & Taylor, 2008; Liu, Mok, & Wong, 2005; Rich, Lamola, Gordon, & Chalfen, 2000;

²⁰ Refer to [Appendix J](#) and [K](#): Interview Questions

Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006).²¹ As the research focus turned from the experience of patients to my own as an emerging health care provider, a parallel change occurred in the questions that I asked. In interviewing health care professionals, I became more interested in their own struggles, challenges and satisfactions in providing care to immigrants and young adults with cancer. As pointed out by Chang (2008), interviews with others in autoethnography “provide external data that give contextual information to confirm, complement, or reject introspectively generated data” (p.104).

Observations were mostly recorded during weekly visits to the cancer agency as a volunteer. As my autoethnographic inquiry proceeded, it became very apparent that opportunities to examine my role as health care provider was being prompted by all types of circumstances. I soon began to treat each moment of my life as a chance to reframe my experience in the context of my research question. I no longer distinguished when I was in the field and when I left it. As such, I recorded observations during meetings with participants, at conferences, after impactful moments or conversations and in a number of other circumstances. I noted the physical environment, the people present, significant interactions and dialogue. Particular attention was paid to my own sensual experiences and emotional reactions, such as the sights and sounds of an outpatient chemotherapy waiting area or my despair or rage in a particular patient interaction.

During observations, I assumed a participant-observer role. This dual role presupposes that it is impossible to detach oneself as an inconspicuous observer who is able to withhold one’s own biases and worldviews (Davies, 2002). What is more, such disengagement may hinder the researcher-participant rapport and thus prevents the researcher from gaining an emic perspective of the experiences of the participant (Hammersley & Atkinson, 2008). Conversely, it would be

²¹ Refer to [Appendix B: Literature Review](#).

foolish to assume that I may through mere effort blend in seamlessly as a full participant in their lives. It is difficult to be a participant in the same way that it is difficult for a therapist to be a friend. At the end of the day, both the researcher and therapist have fiduciary responsibilities that a participant and friend do not. “Going native” also becomes problematic because it makes more difficult the task of distinguishing personal interests from research interests. Given these considerations, I assumed a participant-observer role, which according to Davies (2002) necessitates a critically reflexive mindset. Reflexivity in this study will involve maintaining detailed records of my fieldwork, taking field notes and creating time while away from the field to reflect on my notes.

A commitment to the participant-observer role was very important to me. Given that note taking is often out of context and would have disrupted the natural interactions of people, it was often necessary for me to first make mental notes. When circumstances allowed (e.g., after an engaging conversation with a patient while volunteering, in securing a seat on a long bus ride), I would find a quiet refuge and make some brief written or verbal notes. Once home, I would transcribe and expand upon these notes into longer narratives. The usage of present tense in these expanded narratives denoted my reliving of each significant moment while engaging in this writing. Each of these note taking steps allowed me to insert into the narrative my meta-commentary (e.g., reactions, hunches, realizations) and in turn progressively deepen my reflexive analysis.

In addition to observations, I collected and reviewed textual and non-textual artefacts. I dug back into my archives and found my graduate school admission Statement of Intention, scholarship applications and numerous self-reflection papers. I amassed a mountain of publications from the cancer agency and training workshops, relevant research papers and radio

broadcasts. I took pictures of scenes that were especially meaningful while volunteering, completing errands, exercising along the beach. Although many of these artefacts have not been created by or about me (as would be the traditional role of artefacts in autoethnographic studies), I found them particularly striking in their content, their location, their intended use as they pertain to cancer care provision. I considered my reactions to these artefacts as reflecting my worldview and cultural location as well as being reflective of how a cancer patient or family member may respond to them.

2.4 Data Analysis

The research question that guided my analysis was “How do I come to understand my role as an emerging HCP for immigrants and young adults with cancer?” In considering the personal nature of the inquiry, I will acknowledge at the outset that my inquiry has been an entirely selfish one. As such, the primary goal of data analysis was to provide a mechanism for my own reflexive analysis.²² Although this process aided me in identifying certain important ideas that I would discuss further in the narratives of Chapter 3: Stories (e.g., the experience of interpersonal divides or a desire for normalcy), I found that the ideas that carried greatest valence for me came from the single conversations with a colleague or encounters at the cancer agency.

In light of this theoretical posturing, I do not aspire (as other inquiries may) to achieve a level of description that enables reproducibility. In fact, reproducibility would have been difficult to achieve for a number of reasons. The greatest challenge I experienced through data analysis was in accommodating the large volume and variety of data collected while in the field and

²² This may be viewed as a divergence from more phenomenological or grounded theory inquiries that endeavour to distil research data down to essentials or universals.

through reflecting and journaling. I tried to lay out a defined protocol for data analysis at the outset, but given the emergent nature of the research inquiry, the protocol was difficult to adhere to. I found myself constantly having to revise the protocol to accommodate a new source of data or feeling paralyzed in not wanting to engage in analysis or further reflection for fear of having to alter the protocol. Very quickly, the task of organizing and analyzing the many diverse sources and forms of data became overwhelming.

In the end, rather than a single systematic plan, a number of evolving plans were implemented for data management and analysis. Some general principles were established. For example, I labelled each piece of data with a title, location and date; used a folder system to organize different sources of data; created regular and separate entries for each significant encounter or conversation; and literally bracketed self-reflections from observations in my field notes.²³ The qualitative data analysis software package *Atlas.ti* was used to centrally store the data, including all field notes, reflections and research articles. Where possible, printed or hardcopy materials such as pamphlets and brochures were digitized. Otherwise, a brief journal entry was used in its place.

Using the coding functionality of *Atlas.ti*, I made at least one complete pass of all the data. In the first pass, I quickly coded each meaningful passages, aiming for maximum coding density. Labels (e.g., “hope”, “burden on caregivers”, “normalcy”) were liberally created in order to begin the process of clustering codes of similar meaning. As I proceeded through the first pass, I periodically reviewed the codes, the labels that the codes were assigned to and the internal

²³ The attempt at bracketing my own reflections from the observations in the field was difficult as the distinction between what is observed and what I contribute to an observation is oftentimes unclear. Even a description as seemingly objective as “he was tired” may be argued to be my own interpretation of an event.

consistency of these labels. This prompted me to constantly decide whether to create a new label, merge similar labels (e.g., “Despair” and “Depression”) or delete redundant labels (e.g., “Compressed time”, “Sense of time”).

This process roughly follows what Glaser and Strauss (1967) describes as the constant comparative method. As interpreted by Hammersley and Atkinson (2008), each passage of data coded in a particular label is examined for similarities with and differences from other passage in that same label. It is possible and likely that the codes that are used to organize and categorize the data in the early stages may become refined or changed in light of new data. Vaguely defined labels may become increasingly precise and descriptively rich. New labels may emerge. This necessitates frequent re-readings of the data to look for new instances of the emerging labels.

A second and third pass of the data served to reduce the coding density, leaving only the most informative passages and labels. Some pieces of data were overlooked in this process given that it was immediately obvious that they did not add any value to my analysis. Given that data collection, management and analysis occurred concomitantly, new data was constantly being added to the analysis. This posed a challenge as it frequently prompted me to re-examine my existing label system, and at times return to and revise already coded passages.

2.4.1 Questions for reflexive analysis.

Not to be lost in this process of coding, I had to repeatedly remind myself that what was important was to engage in reflexive analysis.²⁴ This would allow me to better understand my

²⁴ The constant comparative technique herein described is most commonly often associated with the grounded theory method (GTM; LaRossa, 2005). GTM, originally developed by Glaser and Strauss (1967), aims to construct an explanatory theory of a human phenomenon grounded in the data. As a divergence from the grand ambitions of most studies that employ GTM, I am taking advantage of the constant comparative technique to

role as an emerging HCP as well as connect the cultural factors that situate these realizations. A number of questions were generated to spur this reflexive analysis.

- What from my own experiences, biases, worldviews could be influencing my perception of this research encounter or interpretation of this data?
- What might I not see/understand as a result of my cultural membership?
- What do my own reactions to this situation say about my cultural membership? How would this interaction be different if my cultural membership were different?
- How might the other person's cultural membership be affecting our current encounter or his/her perception of me? How does this person perceive my cultural membership?
- What is the significance of this [observation/interpretation] as it relates to [people/culture/my research question]?
- In what way does my new awareness of my identity help to bring into focus the relationship between the researcher and [others in similar situations]?

These questions serve a number of functions. They provide a framework for creating labels during the coding process (e.g., “culture clash”, “culture shared”, “medical culture”). More importantly, it guides my reflexive journal entries. In reading through an observation or listening to an interview, I regularly referred to these questions to help me reflect on my cultural membership. In coming across a particularly meaningful passage, I would create a new journal entry to reflect on this realization.

construct a coherent personal theory, one that explain how I fit in as a HCP for immigrants and young adults.

Another point of divergence is that this analysis focuses less of an emphasis on the codes, nodes or themes that emerge. The codes more accurately serve as tools for my reflexive analysis.

CHAPTER 3: STORIES

3.1 Directions Emerging

3.1.1 Arriving.

It was evening after I received the phone call from Dad that I touched down in Washington Dulles Airport. My cousin Charlie met me. The drive from the airport was markedly cheerless, contrasting sharply the holiday festivities and cheer that seemed to reach even into the security-screened, border-protected regions of a major US airport. I tried to make small talk but the words seemed effortful.

We don't do a great job staying in contact in my family. It has been more than ten years since we last spoke. We were visiting him and *Nimāmā* during a summer family road trip. I was eight. He was 19. It was a carefree time. How things have changed.

"Do you need anything?" he asks.

Yeah, my holidays back, I think. "No," I answer. I have no idea where we are going. Twenty-four hours after receiving *my orders*, I am still dumbstruck by my circumstances. I have been thrust into this mission and everybody seems to know what I'm doing except me. I wonder why I am here, or perhaps why it is me that is here.

The highway sign overhead said Baltimore. As we approached the city, I saw a large sports stadium. We passed the waterfront. It was humming with activities and lights. There was a large boat completely lit up. My cousin noted that it is permanently docked, serving as a restaurant. I feel a momentary rush of excitement and intrigue. I picture a packed and boisterous stadium, a floating restaurant full of excited tourists. I would explore each of these sites if I were visiting here. But I'm not, reminds a voice inside. My reverence immediately vanishes. No, I'm not here to visit, I say to myself. What am I here for? I wonder. I have no answers to that question.

We pass through the downtown and head straight to the hospital. I feel my heart start to beat faster, the way a performer recognizes that it's coming up on his turn. I begin to prepare. How am I to address her? In English or Mandarin? Am I even going to be able to recognize her? I feel so unprepared. What am I doing here? I wonder again.

My cousin leads me out of the parkade and into the hospital. I can tell it's a prestigious hospital. We pass grand lobbies, stylish décor, glistening floors. Up a flight of stairs, into an elevator. Out the elevator and to the left. I try to remember the route.

3.1.2 Strangers meeting.

The first thing I notice is the hospital cap that covers her head. She is sitting in her bed, pillows propping her up. Even though she is covered by the gown and bed sheets, I can tell that she is weak. Her face is emaciated, but I recognize it as belonging to my Aunt from the brief visit when I was eight, from the black and white photos of her youth. She is wearing a gentle and exhausted smile, the way a parent welcomes a child home in the late hours of the night after an especially long day at school.

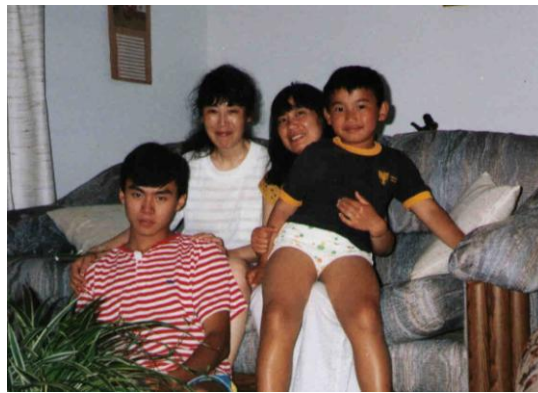


Image 1. Personal photo from when I was eight. It is one of the only memories I had of *Nímāmā*.

“二姑姑你好,” I address her shyly. She feels like a stranger to me. I grew up, alongside many cousins in a flat owned by my grandmother. She, however, had left China to obtain her PhD in the United States before I was born, so the only impressions I have of her are from pictures and from our trip more than ten years ago. She was indeed a stranger, a stranger with whom I was related by blood and would now be getting to know over the next number of weeks.

“Hello,” she gently greets in Mandarin. “Was the flight okay?” Her words are soft, probably due to her exhaustion.

My cousin stays for a while to chat. Our conversation feels unusually distant, even between them. I wonder if it is due to my presence – this stranger who was only a pudgy little boy

with a high pitched voice when they last saw him – or perhaps the distance is between them. Regardless, I continue on in the conversation as best as I can.

He eventually excuses himself to go home, needing to work the next day. I am prepared for this but it still comes as a blow. I'm being thrust into ground zero, alone and without any forewarning or direction. I walk him out, taking a deep gulp of air. Alright, now it's just me. It's time to perform. I try to suppress the anxiety that is growing inside me.

3.1.3 Adrift.

I try to take in the room, this space which will be my base for the next many days. The space is large, almost overly so. There is a single bed in the middle with ample space all around. A curtain hangs overhead to give privacy when needed. There is a bathroom in the back of the room. A computer terminal is set up beside the door, a Lazyboy across the room beside the window. Ah, this will be my refuge for the days ahead. As I become visually acquainted with this space and with *Nimāmā*'s presence, I begin to feel more at ease and yet still just as confused. I feel adrift at sea, directionless, aimless, just bobbing, moving with the currents of the water. My only purpose: to wait it out.

Over the subsequent days, I spend much time sitting in the Lazyboy and wandering the halls of the hospital. It is quiet except for the rhythmic beeps of the hospital equipment. While I sit and star off into space, my mind constantly drifts to the holiday festivities that I am missing in the world outside, the world that is leaving me behind.

3.1.4 Connections.

Nimāmā is a kind woman. I sense a sincerity and authenticity in the way she relates to me. She doesn't treat me like the little boy that she last met or the youngest of the cousins that everyone has to take care of. Maybe it is because we never had the time to establish such a relationship. I am immensely relieved that this is the case. We talk about the progress of my studies, contemplate on what I want to do with my life, reminisce about the past. I feel respected rather than talked down to. I feel an easiness germinating in my body. How have I lived for so long without getting to know this beautiful person in my family? And now, it takes these

circumstances to bring us together. A wave of disappointment hits me, then sadness, then shame. I have not been the good nephew that I should have.

There is no mention of cancer in our conversations aside from her complaints of symptoms – lack of appetite, no energy, pain in her abdomen. Perhaps she doesn't think I would understand. Perhaps she doesn't want to bother me. Perhaps she doesn't think that it would make any difference. Regardless, we relate as though there is no such thing as cancer. We are just two long separated family members, brought together by happenstance, now compelled to get to know each other in this very strange setting.

3.1.5 Where do I belong?

As the days pass, the setting becomes increasingly familiar. The Lazyboy is more comfortable to sleep on than I thought, or maybe I am just getting used to the awkwardness of it. The chair has a lever that releases the leg support so that it easily converts into a makeshift bed. I'm grateful for the setup but can't help but feel impatient by this stagnant existence. There is a pervasive gloom in the room, a heaviness that makes it hard to breathe, hard to think, hard to relax. The ward is practically empty and without stimulation. I feel confined, like an airplane passenger on a flight with no end in sight. Every so often, I would stand up and walk around the room or do some push ups. I have so much nervous energy pent up without an outlet to expend it.

And yet, when I sit back down, my mind often returns to *Nimāmā*. I imagine myself in her shoes; or rather her hospital gown, her bed, her catheter, her feeding tubes. My thoughts juxtapose the despair of the current circumstances against the holiday cheer that I was missing. I imagine feeling impatient with the treatments, feeling angry with the circumstances, feeling left behind by life. My confinement all of a sudden seems so miniscule in comparison to her confinement. How selfish I am. I feel so guilty, so stupid.

Nimāmā seems to notice. She encourages me to head to the cafeteria for food. I try to dismiss her rather accurate interpretation. "That's okay. I can just grab something from the fridge." It is stocked with snacks and juices. The selection is starting to become intolerable and I would much rather something else, and yet I feel uncomfortable, even guilty with the care that I am

receiving. This isn't right, I think. I'm not supposed to be the one being taken care of here. She insists. I give in, though not feeling entirely defeated. At least I made a stand. I let it be known that this focus on me is something that I am uneasy with. It is wrong. I leave the room behind and head off in search for the cafeteria feeling liberated and yet guilty at the same time.

3.1.6 Bearing it.

I have done some exploring since I arrived. I have memorized the route from the parkade to our room, as well as a few detours in between. The way to the cafeteria, the library, chemotherapy ward. Rather than take the elevator, I would opt of the stairs. Sometimes, in reaching the bottom, I would climb all the way back up again, and then down, and then perhaps up again. I have so much energy built up in me that I am desperate to find an outlet for it. I feel frustrated with my confinement.

I have come to discover that the ward itself is pretty humdrum. Aside from us, there seems to be only one other family in this wing over these holidays. They are of Asian heritage as well though we don't interact. Why? I don't know.

My cousin has come by a few times after work. We go out to pick up some groceries during one of his visits. He suggests a few things but I decide on some quick and dirty TV dinners. First time in my life with TV dinners. I scrutinize over the nutrition label of each box. God, I must be losing so much fitness these days. The thought reminds me of my confined predicament. I grind my teeth in resentment. A part of me fiercely tries to suppress this feeling. "This is your duty," the part insists. "It is your duty to bear this discomfort for *Nímāmā*."

The dinners don't taste all that bad.

3.1.7 Deep sleep.

I am half awakened by some activity. My eyelids, glued shut by a welcomed deep sleep, takes great effort to pry open. It is dark except for a light in the distance. I feel a soft padding underneath me, a light sheet covering me. In my dazed and semi-conscious state, I realize that I am not at home. I am lying in my makeshift bed in a hospital room, *Nímāmā* lying close by. Our room door is open. Light from the hallway is streaming in. We have visitors. *Nímāmā* must have

awoken in the night from some pain in her abdomen, some constriction in her breathing. The nurse is probably administering some medication, some intervention to ease her discomfort. It's a familiar routine. I don't make much of it. They've got it handled, I assure myself. With that, I drift back to sleep, eager to find that welcomed deep sleep on this makeshift bed.

3.1.8 Misunderstandings.

It is morning. Sunlight is entering through the window and filling the room with a warm glow. It is a welcome juxtaposition to the sleepless night that *Nimāmā* experienced. Although I had slept comfortably, she was kept awake by abdominal pain that would not go away. She feels nauseous; the food does not appeal to her.

A convoy of doctors enter the room. It must be time for their rounds. One takes the lead, while the others observe the conversation.

"How are you this morning?" asks the senior doctor.

"Fine," she answers dismissively.

The doctor asks for permission to examine her abdomen. She consents by pushing aside the sheets that keep her warm. He leans in to feel around her stomach, perhaps feeling for changes to the masses growing inside her. He stands back, remarks a few things to his colleagues and returns to her. She notes that she doesn't have an appetite. He encourages her to do some walking if she is able to. He turns to me suggesting that I may be able to help her in this. I feel a rush of excitement in being included in the process, in being invited to help.

He also discusses with her the plans ahead, wonders whether she feels up for heading home soon. A brief expression of horror flashes across her face. It occurs so quickly that none of the physicians know. "No, I think I would rather stay here for now, in case something happens," she answers. The doctor tries to ease her worries, mentioning something about home care nurses.

I follow this conversation from my Lazyboy, an uneasiness growing inside me. There seems to have been a misunderstanding here. When she expressed concern about something happening, it wasn't so much in reference to abdominal pain and sleepless nights, but rather

something else. He however has a very different framing of the situation and so concerns that are peripheral to the medical ones don't cross his mind. I want to speak up but I don't know where or even if I belong in this discussion. I wait eager to hear *Nímāmā* clarify for herself. She does not. Perhaps she really does perceive her worries about going home as medical. Who am I to dispute it? I remain silent, watching, not sure what my role is in this.

3.1.9 Bear bear.

Christmas has arrived in our room. One could hardly tell the difference, it being as quiet as always. The only indication was a red and white Christmas gift parcel that was delivered yesterday. In it, there were some beautiful flowers, a teddy bear and a card that was written by a local elementary school student. *Nímāmā* felt uplifted by the kind gesture. She was touched. Seeing her spirit somewhat raised, I feel tremendous gratitude for those who had gone through the trouble and effort of putting this parcel together. We read the card together with the youthful scribbles, appreciating the simplicity of the student's well wishes. I wonder if we should give the bear a name. *Nímāmā* decides on 熊熊 (pronounced *xióng xióng*, translated as Bear Bear). We all agree that it is a fitting name, a playful name. The repeating of the word implies a close and fond relationship with someone that is one's junior. *Nímāmā* holds the stuffed animal up in both of her hands, looks into its eyes. "Xióng Xióng." And with that, she breathed life into the bear, a new companion in our hospital room fellowship.

My cousin came early this morning as well. Although there is none of the hoopla of Christmas trees, lights, music and presents, it feels quite festive in our quiet hospital space. I notice how our conversation seems to flow. It is less restrained, less careful. We even manage a few laughs as we sat around the bed talking about the most frivolous things.

We find a deck of cards and decide to play 争上游, an old game from childhood. We deal four piles, one laid in front of where *Xióng Xióng* sits, peering into the centre of the bed that has now become our makeshift card table. We play intensely, occasionally calling out to *Xióng Xióng*, wondering why (s)he is taking so long to lay down a card. I am struck by the levity of this moment,

how grown adults – and especially *Nímāmā* in her condition – are able to shed our shackles of adultly restraint and participate so playfully, so purely. I yearn for this sentiment to last.

My cousin's cell phone suddenly rings. It stuns us for a moment. He answers it. It is our Aunt, *Nímāmā*'s younger sister. The phone is passed to her. They talk. My cousin and I disperse, roaming around the room to keep ourselves occupied.

The phone call ends. There is an uncomfortably long silence. I feel like a guest who has walked into a party conversation to find everyone remarkably quiet. Where did that sentiment go? Were we all just pretending, just constructing a wishful fantasy that does not exist? Whatever it was, it has now gone, perhaps never to be found again.

3.1.10 Auld lang syne.

It is New Years Eve. *Nímāmā* and I left the hospital shortly after Christmas and moved into my cousin's two bedroom apartment. Although it might otherwise be spacious, it feels quite small with the entirety of *Nímāmā*'s belongs packed into boxes and stacked all around the apartment wherever there is space. My cousin and his partner are in one bedroom. *Nímāmā* has been set up in the other bedroom across the way while I've happily found the couch in the living room which faces one large screen TV with satellite programming. It is tuned to the New Year's programming from Time Square. Although I have never headed out to celebrate the New Year, I have always gotten great delight in following the excitement on TV, seeing the horde of people gathered in Nathan Phillips Square, Times Square and the many other celebration plazas around the world ringing in the New Year. I feel a rush of excitement in connecting with this routine.

I hear my cousin and his partner speaking loudly, perhaps arguing from inside their room. My cousin's partner suddenly storms out of the room. She yells loudly, clearly in the direction of *Nímāmā*'s room. *Nímāmā* yells back from inside her room. I am stunned. My gentle and kind aunt has expressed a rage that I could never have imagined emanating from her weak body. Her fury scares me. The two of them exchange more words across the room. My cousin's partner storms out of the apartment. My aunt, lying in bed in her room, continues to yell after her. She eventually stops. There is silence. I hear my heart pound. *Thump thump, thump thump...*

Where is my cousin? He must still be in his room. I am afraid to go inside to check on him. I'm afraid of the state that I will find him in. *Nimāmā* probably also needs her own space right now, I assure myself. I choose inaction. I choose to stay out in the living room, partly because I can't do anything else. My body is paralyzed.

On the television, the camera is focused on the ball in Times Square. It begins to drift ever downward. The crowd counts down, "...four, three, two, one..." Then cheers, fireworks, confetti everywhere. The New Year song, Auld Lang Syne.

And then, I hear another sound. A sob. No, a weep, coming from *Nimāmā*'s room. Her weeping becomes a shrilling wail. It is deafening to my psyche. I am overcome by it. I begin to shiver. I shiver in despair, a despair that penetrates to my emotional core.

All I can hear now is my aunt *Nimāmā*, her wail from her bedroom. In the background is the sound of the millions of revellers in Times Square singing in unison. I hear them both now.

“♪ Should old acquaintance be forgot, and never brought to mind? Should old acquaintance be forgot, and old lang syne?” (English translation; Burns, 1788).

Happy 2005.

3.1.11 Evolving questions.

These events have been etched permanently in my mind and have left lasting impressions. In those moments of tension, despair and suffering, I felt frustrated with myself because I did not know what I could say or do to relieve my aunt's emotional pain. I was paralyzed, with neither the direction nor wherewithal to make the situation better. I could only watch. I realized how unprepared I was to take on this immense and complex role of care provider. Looking back today, I feel a heavy regret. I often reflect on how it could have been different, how I could have been more useful.

From these preoccupations arose my interest in understanding the experience of minority populations living with cancer. When the time came to proposing a research topic at the beginning of my studies in Counselling Psychology, I felt compelled to formally explore these

interests further. What resulted was a research proposal entitled, “Understanding the psychosocial experiences of cancer patients of Chinese ethnicity in the British Columbian cancer care system”.²⁵ I recognized that often, despite providing the best that modern medical care can offer, health care providers may overlook or be mistaken by what is truly important for the patient. This was the case for *Nimāmā*, whose cultural identity had created a divide between her and her son. The tensions that filled this gap became magnified by the illness to the point that her psychosocial distresses had a larger impact on her overall wellbeing than any medical intervention ever could. I have learned that it is therefore paramount for HCPs to attend to not only the medical but also the psychosocial experiences of their patients and significant others in providing the most effective care possible.

My research question evolved over time in parallel to my own introspection of my cultural identity. Although I am living in a city that surrounded me with people of Chinese ethnicity, I felt in large part different from those around me. I had after all grown up on the east coast of Canada in a small town. I could count on one hand the number of visible minorities in my elementary school. My upbringing was therefore very prominently grounded in an English speaking, European influenced community. Here in a multiethnic city like Vancouver, I encounter people who are often struck by how Anglicized I appear or how accent-free my oral English is.

I quickly became aware that, in spite of my shared ethnic background and skin colour with other people of Chinese ethnicity, my experiences have led to a very different life than others here in Vancouver. Moreover, with increased interaction with people of Chinese ethnicity in Vancouver, I became more appreciative of the tremendous range of people’s background,

²⁵ See [Appendix A: Initial Research Proposal](#).

experiences and in turn cultural identity. The ethnic Chinese population consisted of international students as well as students born in Canada to Chinese parents, newly arrived immigrants as well as those who have lived in Canada for many years or generations. There are also students who are in Canada merely to study and those who hope to stay permanently.

Given the primacy placed in research on defining one's population of study and construct homogeneity, I was challenged to either define more precisely the construct "people of Chinese ethnicity" or abandon it altogether. Abandoning "Chinese ethnicity" became increasingly appealing as I reviewed the literature. My search for relevant literature uncovered cross-cultural studies comparing ethnicities (Ahn *et al.*, 2006) or exploring the experience of Asian breast cancer patients (Ashing, Padilla, Tejero, & Kagawa-Singer, 2003). Study after study used this ethno-racial discourse in such a way that became the norm of the literature. I identify this as originating from our colonial routes where it was always about distinguishing between us and them. I became disenchanted by these studies. In reading through them highlighting points that seemed important, I was often left wondering whether their findings were attributed to this loosely defined "Chinese ethnicity" construct or whether it was just a reflection of our comfort as researchers to categorize and formulate heuristics. Many study findings could have been summarized in the general form of "people of ethnicity X do A, while people of ethnicity Y do B." These considerations again brought me back to my earlier recognition of the diversity amongst members of a given ethnic community. It made increasing sense to abandon an exploration of "cancer patients of Chinese ethnicity".²⁶

²⁶ Admittedly, such an abandonment of an ethnic framework also comes at a cost. As noted, the ethnic framework predominates within academic and research community. My inquiry about immigrants may lose relevance to some members of this community by not using familiar terms such as Chinese and Asian. This is

My attention turned to the experience of immigrants as I asked myself, how are the experiences of Chinese patients any different from Canadian patients? In many ways, the experience of cancer for any two people may be vastly similar. The confrontation with a life-threatening illness and with the possibility of death, the challenges with family and friends, the seeking of support, the coping with the side effects of treatment are themes that exist regardless of ethnic background or cancer type (Carlson *et al.*, 2004; Centers for Disease Control and Prevention, 2004). At the same time, Chinese cancer patients and more specifically immigrants are moving from one social context to another. This transition might entail learning a new language, negotiating foreign social institutions, reconciling different values and beliefs, or adapting to a new political system. These differences underscore a profound cultural transition that is arguably fraught with challenges that are not experienced by Canadian cancer patients. In reflecting on *Nimāmā*'s life, I realized that it was this added transitional experience that I wanted to explore in formulating my initial research inquiry, "Understanding the psychosocial experiences of cancer patients of Chinese ethnicity in the British Columbian cancer care system."

As a result, my evolving research question replaced the reductionistic and falsely quantifiable notion of "ethnicity" with immigrant. Rather than using constructs that are situated in a geopolitical framework, I began to speak about experiences and about culture²⁷. At the end of the day, it is this framework that I feel more comfortable scaffolding my findings onto than constructs such as Chinese ethnicity.

evident in considering the larger number of hits returned on scholarly search engines when using ethnic search terms compared to "immigrant".

²⁷ It should be noted that the construct "culture" in this document is defined very differently than ethnicity. Refer to [Chapter 1.4](#) for a more extensive discussion about my understanding of culture.

In following this line of thought, I became interested in young adulthood as it also represented a transitional experience that can be fraught with challenges. My own confusing and turbulent experiences through my teenage and university years reinforced this view.

In reviewing the psychosocial oncology literature in the area of young adults, I quickly realized that this is a population that is marginalized in cancer care (Adolescent and Young Adult Oncology Progress Review Group, 2006). Young adults seek services in an institution that is geared largely to a patient population that is much older. At the same time, their age and developmental maturity makes paediatric cancer services inappropriate for them. These anecdotes are reflected in the substantial health disparities that exist amongst the young adult cancer population. Since the 1970s, 5-year survival rates have dramatically improved for children and for older adults aged 40 and above, while remaining relatively unchanged for young adults (Bleyer & Barr, 2006). They are referred to by some as the “forgotten generation” (K. Chalifour, personal communication, November 26, 2010).

Interestingly, I believe that at the intersection of my own immigrant and young adult cultures, my experiences were different than if I had been older or born into a non-immigrant family. In the case of *Nímāmā*, there was an implicit and culturally imbued expectation for me to take on the care giving role. More generally, I grew up taking on a number of heavy adultly responsibilities by virtue of being the cultural interpreter and guide in my immigrant family. I have discovered this to be a salient theme amongst other immigrant young adults (Bacallao & Smokowski, 2007).

3.1.12 Hope renewed and yet hope lost.

Three months and a series of embittering struggles after I submitted the first iteration of my ethics application, I received the email from BREB approving my project. Finally! I could

begin with recruitment. It was a boost of adrenaline to my project. I felt momentum again. I was ever hopeful that I could still catch up with the particular timeline that I had set out for myself. Two months for recruitment and participant observations over the summer, a few weeks for data analysis and a few more for writing. If I put in some hard effort, I could graduate in November.

Like my hopes for an efficient ethics review process however, this plan also collapsed. Weeks went by without a single inquiry. It became a test of patience.

I contacted numerous institutional gatekeepers within and outside the cancer agency. My contacts snowballed through colleagues, and then colleagues of colleagues. I presented my study at nurse and counselling team meetings, to local not-for-profit agencies, to organizations in other regions of Canada I discovered on the internet. In spite of these efforts and the many institutional gatekeepers that I managed to gain support in recruitment, only three immigrant young adult with cancer made inquiries of which only one was eligible to and interested in participating. The momentum from a successful ethics application quickly dissipated.

Journal Entry 2011-03-01

Why has this process been so difficult? Was there something that I could have done differently in recruitment? I've been reflecting on these questions with colleagues and HCPs. It seems that many who engage in research with immigrants or ethnic minority groups experience these challenges.²⁸

Maybe, as the volunteer coordinator at the cancer agency speculated, models of volunteerism don't readily exist in some parts of the world. So, the practice of doing work without pay or tangible remuneration would be culturally foreign for some. As a parallel, I wonder to what

²⁸ The challenge of engaging immigrants and visible minority groups came up several times, including in my conversations with a number of researchers at the 2011 National Multicultural Conference and Summit.

degree the concept of research participation is localized to certain portions of our society or socio-economic or educational class.

This prompts me think about how volunteering has served my own life. I volunteered in hospitals and not-for-profit organizations extensively in my adolescence as a way of demonstrating capability or willingness to paying employers and admissions committees. I volunteered in undergraduate psychology courses to gain extra credit. It occurs to me that even though I did not get paid for this time, volunteering was nevertheless commodified in these cases. At this point in my life, I volunteer as a sort of self-righteous social obligation that arises out of my privileged circumstances.²⁹

Now conversely, if I were to ask my parents, they would probably say that they have never volunteered before, and yet they have readily offered to cook lunch for church, help a family member move and arranged a meeting or connection for a friend of a friend. They haven't volunteered as this institutional culture that I belong to might define it – with an organization, guided by a defined role description and at a regular interval – and yet they have supported friends and family without tangible remuneration in times of need.

²⁹ I recently attended a workshop where I explore the concepts of privilege and oppression. I completed a very disarming exercise that gave me an opportunity to examine my own privileges. This exercise and its accompanying reflection are included as [Appendix E: Journal Entry: Privilege and Responsibility](#).



Image 2. Personal photo of a bulletin board at the cancer agency.

I wonder how someone might react to my recruitment flyer if they had not grown up exposed to my commodified model of volunteering. Maybe, it sounds something like, “Look at all these flyers. Why would I ever want to call up these people? I don’t even know them.”

Weeks turned into months. Planned deadlines came and gone without noticeable progress. My research question, “What are the psychosocial experiences of immigrant young adults with cancer?” could not be validly answered with a sample of one. I was desperate for progress. Marla suggested I explore the possibility of adopting an autoethnographic approach, turning the research lens on myself. My first reaction was a sense of uneasiness. I had constructed my entire inquiry around an ethnographic methodology, with an in-depth exploration of the experience of patients and their care providers. What would it mean to just turn the lens on myself because I did not have enough *data*? Was this even legitimate? Even if it was, what would my research question be?

My fears were in large part pragmatic but at the same time, I felt a sense of loss at the thought of this change. In recognizing all the work that came before this point and the prospect of having to start all over again was heartbreaking. I recalled how, in my defended research proposal, I boldly emphasized that the ethnographic approach is an “emergent research design that is responsive to ever-changing circumstances and the demands of the study and its

participants”. Now that I confronted this possibility though, I felt timidly cautious, even paralyzed.

I acknowledged to Marla that I would look into autoethnography more. From what little I knew about the methodology, my outlook was poor. I knew that it essentially is about a researcher writing about herself or himself. I thought back to an early encounter with a professor during the first few weeks of my program.

He taught a different discipline of psychology in a faculty separate from counselling psychology. I was putting together a scholarship application for a national-level competition. I sought out his feedback on my research proposal because he had overlapping research interests. My timidity as a new graduate student suffering all sorts of identity issues was compounded by my discovery of his published textbook on Amazon. I felt diminished in his presence as I handed him my very rough proposal.

He read it over, suggested amongst other things that I mention in my methods section the use of a qualitative data analysis software package. He went on to recount quite disparagingly about how he had once served as an external committee member for a counselling psychology dissertation defence. The student had apparently used an autoethnographic approach, spent some time living with people and just wrote about the experience. During the committee’s deliberation, he had offered some strong dissenting views about the legitimacy of the work but to his great outrage, the student was passed. I remember feeling confused, perhaps equally outraged if my name would have been associated with the project. How could such storytelling pass as legitimate research at an esteemed institution?

I reflected on this early encounter as I walked home from my meeting with Marla, head hanging low, demoralized, without much hope in my thesis ever getting completed.

Journal Entry 2010-10-26

Graduating with an MEd does not sound all that bad.

3.1.13 Turning inward.

My research into autoethnography brought me to the writings of distinguished scholars such as Ruth Behar, Authur Bochner and Carolyn Ellis. At first, I reactively dismissed these works as plain fiction or personal journaling meant to entertain, not scholarly works that inform. The accounts seemed all too intimate, too transparent, too biased. The author was everywhere in the text. As much as I tried to bracket out the author's presence to get at the cleaner, more objective truth, it was impossible to remove them from the account. I constantly referred back to my preconceptions about what research is suppose to look like and found these contaminated writings to be insignificant or invalid.

There came, however, a turning point to these critiques. It came from a book entitled, "Communication as...: Perspectives on Theory", a rather dense compilation of essays on how communication can come in various forms. Bochner and Ellis (2006) authored their essay on *Communication as Autoethnography*. What initially struck me was how it looked nothing like any of the other essays. It looked like the script of a play. In fact, Bochner and Ellis quite cheekily recorded one of their morning dialogues over breakfast and transcribed it into a description on communication theory. I was impressed with how plainly and clearly their piece discussed complex ideas about autoethnography. Their very real dialogue invited readers into their morning discussion at their lakeside cottage over pancakes and blueberries. As I finished this, I looked back to some of the other essays. I was able to get no more than two or three paragraphs into those essays before I got exhausted by the complex language and concepts. I was stunned.

I returned to some of the writings I had previously reviewed (and dismissed) with a fresh lens. Without the taint of my own rigid preconceptions, I found truths of human experience. The

prose were simple and relatable. There was an intimacy conveyed in the narratives that the empirical studies and theoretical discussions I had previously read did not possess.

As I came to recognize the value of these writings in conveying truth about human experience, I began to reflect on the many other forms of communication that have the evocative and deeply intimate elements of autoethnography. Movies, documentaries, literary works of fiction, theatre. Some great works that came to mind immediately were Danny Boyle's movie "127 Hours" (2010), Michael Moore's documentary "Bowling for Columbine" (2002) and Lance Armstrong's account of his cancer journey (Armstrong & Jenkins, 2000). All are to me powerful and therefore effective ways of communicating truth about our human experience.

Journal Entry 2011-01-08

Why autoethnography as a method of research? Watching the movie *127 Hours* last night, I began to reflect on the power of personal narratives to convey a message. In this case, the message is made up of my experiences, the research findings. The movie chronicles the harrowing real life story of a free-willed, I-can-do-it-on-my-own hiker who becomes trapped for 127 hours in a desert canyon with his arm pinned under a large boulder. He experiences desperation, sadness, revelation and peace. He is eventually forced to cut off of his own arm in order to free himself. It struck me how even without ever having been placed in such a circumstance, aspects of the individual's narrative deeply resonated with me. I felt each moment of his desperation, celebration, anger and resolve. One of the most poignant scenes for me was when he shouted for help, at first going through the motions but without a voice and then finding it. It became a transformative moment for the protagonist, going from a person who never sought help and could forever be self-reliant, to someone who needed help and in fact wanted help. He was able to let down his guard. There is some essence of the human spirit that is captured by this story, this very intimate and personal narrative, and despite my very different location life, I have been affected by it, been changed as a result of it. Is that not the purpose of this research

enterprise? To uncover some truth about our human existence and perhaps use it to better govern our future actions or the way we perceive the world?

As I read more about the breadth of autoethnographic topics – living with a life-altering disability (Murphy, 1990), ascending the ranks of academia as a woman (Chang, 2008), being a professional poker player (Hayano, 1982) – I became increasingly aware and discouraged that my own story did not fit my research inquiry. I could not pretend to know what it is like to have cancer. From my limited experience with patients and their care providers, I could not even extrapolate what their psychosocial experiences may be. I did not have what Anderson (2006) refers to as “complete member researcher status”.

For a long time, I ruminated over Anderson’s criterion of complete member researcher status. I was not a member of the culture that I endeavoured to study and therefore did not have the ethnographic immersion or expertise to talk about cancer. I wondered then if I had any expertise at all? I referred to my culture-gram³⁰, desperately trying to find some aspect of my cultural identity that I could link to this inquiry.

Journal Entry 2011-11-25

Here’s a thought. I am a health care provider aren’t I? Well, I’m getting there at least. I’m working on my degree, more than three years in. I’ve worked with a number of different clients, albeit none of them had cancer. But once I graduate, I could see myself working in cancer care. That would be a great job actually. I would get such fulfillment in supporting patients and their loved ones, bringing family members closer during the most precious moments in life. So, I may not be a health care provider now but I will be. So that’s the cultural membership that I have through this journey. I’m a health care provider to be. I’m learning to be one.

³⁰ Refer to [Appendix D: Culture-gram](#).

The realization fills me with a great thrill, a sense of empowerment. Yeah, that's what I'm an expert of. I'm an expert of my own journey as a learner. Wouldn't there be so many people who would be interested in this sort of journey? Sure. I'm sure everybody goes through this experience of wondering about what their role is, where they fit in.

The idea of "my journey learning to be a HCP" ferments inside me for the subsequent weeks as my research inquiry continued evolving.

Email 2010-12-05

This autobiographic account would require revising the research question to fit. Maybe something like "My learning as a care provider for immigrant young adults with cancer." I'll consult with some folks who may be more familiar with the method and constructing such research questions.

Email 2010-12-16

At the moment, my working title is "My journey as an emergent health care provider for immigrants with cancer". [...] As a result of this shift, I've thought about how my inquiry would also have to shift. Rather than presenting the experience of IYA with cancer (which I can't credibly do with the data I have), I've been reflecting more on the personal experience of HCPs in providing care to IYA. This has also shaped my discussions with HCPs, so it's been less about what they think are the experiences of IYA but more about their own experiences in treating them (if that makes sense), which ultimately, I intend to inform my experience as a HCP.

Email 2011-01-11

I formulated a tentative research question to guide data analysis and interpretation: "How do I come to understand my role as an emergent health care provider to immigrants and young adults with cancer?" [...] It still doesn't sound quite right to me as my inquiry also includes a "WHAT is my role" question in addition to HOW.

Both of these questions – "What is my role?" and "How do I come to understand my role?" – seem worth exploring and yet I recognized that they are vastly different. To explore

what my role is appears to be a necessarily personal inquiry. Whatever conclusion I come to about my role would apply to myself only given my unique circumstances and cultural location in life. Others who have different cultural locations – perhaps in speaking different languages, possessing different skill sets – will have different responses. Although I report on my conclusions about the “what” question in this thesis, I would be remiss to suggest that this reality applies to others.

On the other hand, the process-oriented “how” question seems to relate to a rather public experience. As such, this question would seem to yield the answers that will be most valuable to readers. Every individual who aspires to work in the health care field would presumably undertake a journey to figure out where they belong. I would hope then that the process of how I have navigated my own journey will be helpful to readers. I report on the “how” question towards the end of this thesis.

As I became increasingly convinced about the appropriateness of my research inquiry and methodology, the overall picture started coming together. Suddenly the smorgasbord of data that I had collected up to that point – including interviews, textual artefacts, photos, observations and reflections – began to communicate a coherent narrative. That narrative revolved around the discovery of my role as an emerging health care provider. I jumped into the data analysis with a new found clarity and confidence.

3.2 Roles, Masks and this Divide Between Us

Handle With Care? (Gray, 2000)

Scene One (at 19 minutes, 50 seconds)

Woman: I can't believe we're actually going!

Man: A cruise of the Hawaiian Islands!



Woman: I know. Pinch me. It's like I'm dreaming!

Man: You'll wake up with a Visa bill...

Woman: Oh yeah, but until then. Three weeks. Sun, sea, sand, paradise!

Grace: Hi guys.

Woman: Hi!... Grace... (a look of surprise, speechless)

Man: How are you?!

Woman: Grace, I have been thinking so much about you lately!

(with forced sincerity)

Grace: (pauses, uncertain how to respond)

Woman: I've been meaning to call but we've just been really busy.



Grace: (smiles forcefully, shrugs comment off)

Woman: But we've been really busy...

Man: [...]

Woman: (jumps in quickly, speaks over man) ... The usual...

Grace: Anything new?

Woman: (whimsically) This and that.

Grace: Everything's the same? (more as a saddened conclusion than a question)

Woman: Pretty much.

Man: Yeah. Nothing special.

Grace: (turning away, head down)



Scene Two

Woman 1: (miserable, wailing) Oh! My shoulder! I hurt it playing tennis yesterday. I can't do anything anymore. Sleep...

Woman 2: (miserable) Oh, never mind your shoulder. You should have my back. My back is killing me. I guess if I exercised...

Woman 1: Oh back shmack...

Woman 2: I guess if I exercised...

Woman 1: Oh so boring.

Woman 2: Yes, so boring. I know.

Grace: (suddenly entering) Hi girls.

Woman 1 and 2: Oh hi Grace! (surprised)

Woman 2: (cheerfully) Oh I've been meaning to call you but I didn't want to bother you.

Woman 1: (reaching for Grace's hand, patting it) Oh you're looking good Grace. How are you holding up?

Grace: Well, as well as can be expected, but there's some days when I...

Woman 2: (interrupting, extravagantly) Oh Grace. That's what I've always loved about you. You're so positive. (Turning to woman 1, smiling widely) Isn't she positive? She's so positive.

Grace: I haven't seen you girls for a while. How's your back?

Woman 2: (dismissively) Oh, fine. No problem.

Grace: Any pain?

Woman 2: Oh no.

Grace: Oh isn't that wonderful. And how's your tennis game?

Woman 1: (agreeably, smiling forcefully) Great thanks!



Grace: Playing well?

Woman 1: Just terrific!

Grace: Well that's really good (uncertainty in voice).



I came across this theatrical production as part of my Interprofessional Psychosocial Oncology course. Watching Grace desperately want to participate in her friend's joys and frustrations and being shut out was heartrending. I wanted to just reach out to her, to help alleviate the loneliness that she felt. I was angry at her friends for abandoning her, for treating her like a stranger. She is still the same Grace that you knew before her diagnosis. I wanted to scream for her.

Grace is not alone in her experience of loneliness. In fact, this strangeness and distance between people as a result of the experience of cancer is pervasive (Rosenthal, 2009). It takes on many forms and occurs between many people. Through these months of research, I have witnessed this strangeness within many interactions amongst those experiencing cancer. As a mere witness to these interactions, I feel saddened, outraged and helpless. I condemn those who act to isolate, to distant, especially during these moments of greatest vulnerability and need.

As a witness, I want to fault so many and yet, in becoming a participant in these encounters, I discovered my own hypocrisy. As a volunteer and researcher, I found myself paralyzed by fear and uncertainty, which in turn expanded the divide between me and the people I was caring for. These moments were sobering. I also recognized that there are certain contextual factors that make possible this interpersonal divide and in turn cause isolation. In this chapter, I explore these sobering moments as well as attempt to identify the factors that give rise to my role, these masks and the divide between us.

3.2.1 Handling others with care.

“Handle with care.” The phrase brings to mind the image of a delicate museum relic, placed on a cushioned platform for protection and cordoned off from interaction behind glass for fear of breakage. There is a certain beauty to the relic, a mystique, an exoticism that I am

intrigued and allured by. At the same time, I fear it. I fear its strangeness, its other-ness. I recoil from it and choose to observe it at a distance.

I am reminded of the day that I first had this experience of handling patients with care. It was my first volunteer shift at the cancer agency.

Field notes 2010-06-10

Putting on my vest, I notice my heightened anxiety. This is a foreign environment, don't know what to do. The experienced volunteer who is supposed to train me is late. I get excited. Maybe I can leave. It's an avoidance response. I'm so nervous that I just want to avoid this new role. I'm worried I'll mess up. I feel pressure to do well. He arrives. I'm annoyed, partly because of his lateness and partly because I'll no longer have an excuse to go home.

I follow my trainer back to the main lobby, ride up the elevator to the sixth floor. I have so many questions. The ward seems so surreal. There is a large waiting room where patients wait for their attending nurses to call on them. It comfortably seats about 15 people. After getting called, the patient follows their nurse into a go into a room that can have as many as three others and receive chemo. (Life-changing, life-giving and life-killing of tumour cells all at the same time. Funny in a way.)

There's something so unsettling, scary about being here in the chemotherapy ward. Feel so hesitant, apprehensive, reluctant in approaching patients, in entering their rooms for fear of intruding upon their personal space. I feel this way even for something as innocent as peering into a room to see if there are any new arrivals, so I can go in to offer tea and coffee. Even that feels intrusive. I feel disgusted. It's like I'm being a voyeur, an audience in some twisted spectacle. The patients are the performers, sitting in the room for display, to entertain. I feel so awful in what I'm doing, despite the goodness of it on the surface of offering something kind, some conversations, some warm beverages to make them feel comfortable.

I try to make small talk with my volunteer trainer to present a cool, calm and collected image. As I follow him, observing how he approaches and engages the patients, my mind is on overdrive, considering the many possible implications of his every action and response.

He tells me to relax. Don't think too much. (I'm annoyed. Who are you to tell me how to feel? Why is being a bit careful a bad thing? Shouldn't we be aware of how our actions affect patients? My annoyance goes away. I realize that I am being too careful. I am treating these patients so carefully, with such sensitivity and protectiveness that I'm not respecting their ability to take it. To take my entering into their space, to take my looking into their rooms from out in the hallways, to take my happiness or insistence on happy days. That somehow, they are so vulnerable in their circumstances that they can't bear anything. But that's not helpful. If I was a patient, I know that I wouldn't want to feel condemned by my care providers. That would infuriate me, to be dismissed before I was ready to be dismissed. I wonder if that's the case for them. When people are overly kind or overly sensitive, I wonder if patients feel trapped or backed into a corner or condemned to die.)

Later on in the year, when I switched from an outpatient role to an inpatient role, all the same doubts and anxieties re-emerged.

Field Notes 2010-09-16

While eating at lunch, I acknowledge my apprehension about this new role. How do I connect and engage with patients. I feel nakedly unprepared, without any introductions to the staff as the volunteer coordinator had initially mentioned. I feel reluctant to approach the nurses as they are engaged in conversations. I have no idea who is who. Who do I talk to about what?

As I walk along the hallways, nervously peaking into the rooms for people to engage, I notice many patients with their eyes closed. Some are asleep, others, merely resting their eyes. Some have headphones on, some curtains drawn around their bed. I perceive their space closed to me, as if I am a canvasser going door to door, a "Beware of dogs" or "No trespassing" signs mounted on their front lawn.

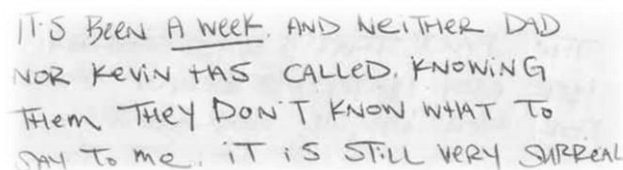
I feel lost, not sure whose room I am permitted to enter. I notice a sign hung on a door to a room at the end of the hall. "Radium Implant Ward," it's labelled. "Visitors please visit nurse station before entering" and "Restricting visits". (I have the vision of a horror movie, an unknown evil residing behind the door to which no-one knows.) [...]

I engage in a conversation with a patient. I am left wondering if he was entertaining me or I him. I feel relief at my presence. Did he really feel relieved as a result of my presence? I feel clumsy at this, incompetent. I feel frustrated with myself and with the lack of clear direction.

I really struggled in trying to establish meaningful connections with patients. In spite of my best intentions, my fears and uncertainties have often gotten in the way. It saddens me to think that if I, as an individual who works on developing meaningful relationships for a living, struggle with such tasks, how many other family members, friends and hospital staff also struggle. We want to connect with our loved one or patient but we fear impacting, hurting them or breaking them; and so we stay away. We withdraw because we care to not hurt. We suspend our own contentment or frustrations for fear of how they may impact our loved ones.

These struggles of ours certainly do not go unnoticed by those we care for. “I don’t know if he is scared about something” said one immigrant young adult with cancer about his father who doesn’t ask about his emotional experiences in cancer. For this young adult, this leaves him feeling distant from his father. He expressed confusion. “I don’t know if he doesn’t want to know... He want to know, but he want to know through my mom. He doesn’t want to know through me.”

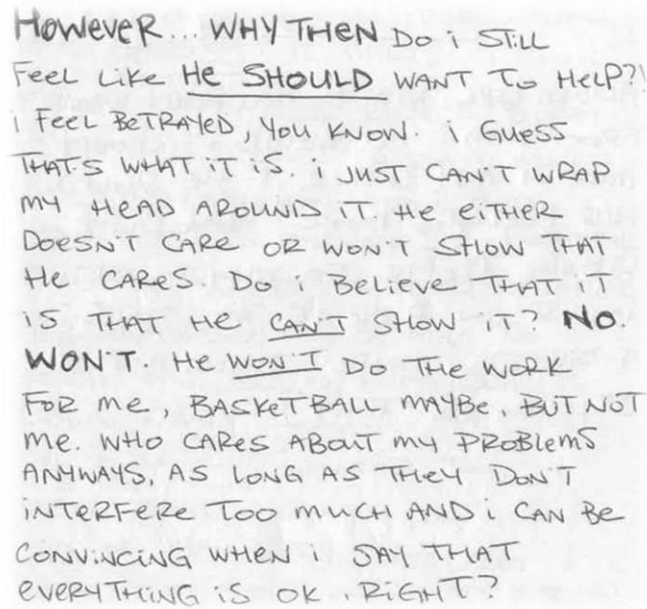
Another young adult expressed similar confusions in her journal about the state of the significant relationships in her life.



IT'S BEEN A WEEK. AND NEITHER DID
NOR KEVIN HAS CALLED. KNOWING
THEM THEY DON'T KNOW WHAT TO
SAY TO ME. IT IS STILL VERY SURREAL

Image 3. Excerpt from diary of a young woman with cancer.

Her confusions cause her to feel uncared for by the significant supporters in her life. She begins to resent them.

A photograph of a handwritten diary entry on lined paper. The text is written in all caps and includes several underlined words. The handwriting is somewhat slanted and expressive. The text reads: "HOWEVER... WHY THEN Do i STILL FEEL LIKE HE SHOULD WANT TO HELP? i FEEL BETRAYED, YOU KNOW. i GUESS THAT'S WHAT IT IS. i JUST CAN'T WRAP MY HEAD AROUND IT. HE EITHER DOESN'T CARE OR WON'T SHOW THAT HE CARES. Do i BELIEVE THAT IT IS THAT HE CAN'T SHOW IT? NO. WON'T. HE WON'T DO THE WORK FOR ME, BASKETBALL MAYBE, BUT NOT ME. WHO CARES ABOUT MY PROBLEMS ANYWAYS, AS LONG AS THEY DON'T INTERFERE TOO MUCH AND i CAN BE CONVINCING WHEN i SAY THAT EVERYTHING IS OK. RIGHT?"

HOWEVER... WHY THEN Do i STILL
FEEL LIKE HE SHOULD WANT TO HELP?
i FEEL BETRAYED, YOU KNOW. i GUESS
THAT'S WHAT IT IS. i JUST CAN'T WRAP
MY HEAD AROUND IT. HE EITHER
DOESN'T CARE OR WON'T SHOW THAT
HE CARES. Do i BELIEVE THAT IT
IS THAT HE CAN'T SHOW IT? NO.
WON'T. HE WON'T DO THE WORK
FOR ME, BASKETBALL MAYBE, BUT NOT
ME. WHO CARES ABOUT MY PROBLEMS
ANYWAYS, AS LONG AS THEY DON'T
INTERFERE TOO MUCH AND i CAN BE
CONVINCING WHEN i SAY THAT
EVERYTHING IS OK. RIGHT?

Image 4. Excerpt from diary of a young woman with cancer.

As we wrestle with our fears and uncertainties, our loved ones or patients will reciprocally have reactions. As the two young adult noted, they felt their loved ones backing away and in turn, they did likewise. The divide between us grows rather than closes, in spite of our best intentions.

3.2.2 My critical voice.

At this moment, I find myself thinking about my own actions in taking care of *Nimāmā*. I think about my concerns with having left a fun and festive Christmas holiday season, my resentment in feeling obliged to do so rather than as my own feeling choice, my frustration in being physically confined to a hospital room. As I reflect on my actions, I am confronted by the painful conclusion that I tried to distance myself from those responsibilities and as a consequence, distanced myself from her. Instead of coming into her life as a family member and support during her moment of greatest need, I turned from her. I betrayed her. I feel like a sleep walker who awakens to find blood on my hands. My heart is beating heavily. I want to scream in

anger, in self-loathing. I have become the very person that I despise the most, the one whose self-centeredness and narcissism clouds all other considerations.

I try to still my thoughts and my body. I take a deep breath. Another. I am being far too critical of myself. *Nímāmā* would not agree. She would have expressed appreciation for my presence, my support.

“And yet she did not know your intentions, your yearning to be elsewhere.”

But this was reactionary. I had left my selfishness behind.

“But you had these selfish desires nonetheless. If you had the choice, you would have been at home, celebrating the holidays with your friends and playing mindless video games.”

Yes I did and I would have, but I did not. My selfishness will always be a part of me, but it is not the only part of me. My cultural identity is composed of many cultures and as such, I choose what value systems I affiliate with at any given moment.

This critical voice. I know it well. It is born out from the cultural value system that I have grown up with; the perpetual dissatisfaction with present circumstances, the unrelenting pursuit of improvement. I almost hear the messages being spoken in my ear. It is the voice of my mother. It is heartening and inspiring. It has pushed me to where I am today, and yet in the same breath, it crushes me, reduces me in stature during moments such as these. I can at times feel diminished, even inadequate, but I must remind myself that this is not the entirety of me.

Another deep breath.

3.2.3 Drifting apart.

As I reflect on some of the significant relationships in the life of individuals with cancer, I imagine the pain of being distant from a mother, a partner or a sibling. I remember a poignant vignette of a young adult with cancer.

Field Notes 2010-10-06

She has been forced to move back home because of her diagnosis. She is sitting in her room, in front of her vanity mirror. The person she sees staring back at her is a stranger, nothing like her. There is a knock on the door. It is her mom checking in on her, telling her that it is time to come down for dinner. She says that she does not feel hungry. Her mother insists that she needs to eat to stay strong. She insists otherwise. A momentary expression of frustration. Having achieved self-sufficiency and moved out on her own, she has now been forced to return to the watchful eyes and control of her mom. She resents her mom for limiting of her independence, her self-determination. Her phone vibrates. It is a text message from her friend. An invitation to a party. She wants to go. It is her way of maintaining some sort of normalcy in this now abnormal life. She calls out to her mom to tell her that she is heading out. A prying response of where and what about dinner. She insists she can pick up something while out. Her mother reminds her that dinner has been especially prepared and that it was decided to be family night tonight. She engulfs a loud and deep breath of exasperation and defeat. She looks back to her mirror, still seeing the stranger staring back at her. In an explosion of anger, she throws her cell phone to the ground and breaks down in tears.

In a journal entry, she also wrote of her experience of the unravelling of her relationship with her boyfriend.

I TOOK HIS HAND AND WE WALKED.
HE WAS TELLING ME ABOUT SOME
NEW VIDEO GAME, VERY BORING,
AND I WAS PRETENDING TO
UNDERSTAND. AND HE KEPT
LETTING GO OF MY HAND TO
EXPLAIN THE GAME. IT WAS PISSING
ME OFF. I KEPT TAKING IT
AGAIN ONCE HIS HAND DROPPED
DOWN TO HIS SIDE AND THEN
HE WOULD LET GO AGAIN, AFTER
A WHILE. IT WAS WEIRD. WE
ALWAYS HOLD HANDS WHEN WE WALK
I WANTED TO ASK HIM IF HE DIDN'T
WANT TO TOUCH ME OR WHAT
BECAUSE IT WAS HARSH. BUT FOR
SOME REASON I JUST COULDN'T
BRING MYSELF TO ASK HIM
WHAT WAS UP. I DON'T KNOW,
IN A WAY, I THINK I'M JUST
SCARED TO FIND OUT.

Image 5. Excerpt from diary of a young woman with cancer.

It saddens me to think about how suddenly such significant relationships can unravel and support systems become coldly distant. We try our best to care for our loved ones or patients and yet in doing so, we are rendered strange, and they, invisible.

Handle With Care? (Gray, 2000)

(Except from 21 minutes, 44 seconds)

Ladies and gentlemen! Step right up and meet Magda the Magician. With a few magic words, I can make things disappear. I can even make myself disappear. Just a simple magic formula. Easier than abracadabra. Well I don't exactly disappear, but after I utter these magic words, a cloud will descend on you, and you will no longer see me. You don't believe me? Wait and see. I've done it before for family and friends. It's sure fire, no fail. And what is this magic

formula you ask? Ready. Here goes... But first, take a good look at me, and remember what I look like.

And now, the five magic words... I have metastatic breast cancer.

So do you still see me, or has the magic cloud done its work. Some of you do? How unusual. The same me you saw before without the usual masks; the mask of the doomed woman, the mask of victim, the mask of indolent, the fighter.

Where's the real me? The one who loves chocolate fudge and Robert Redford movies, the one who wants to play bridge and talk about your son's wedding, and hold my niece's new baby, the one who wants to share your joys and sorrows as much as she ever did. I wish I had a magic formula to bring that woman back from under the cloud and from behind the masks. If any of you know that one, please tell me.

Hearing Magda's words send chills up my spine. I was moved by Magda's resonant description of the many masks that we wear to disguise ourselves and become strangers to each other. It seems crazy that we would inflict such cruelty on each other in the most precious moments of our lives, and yet we do. I do. I did in my relationship with *Nīmāmā*. She wore her mask of togetherness and strength while I, well, I am not quite sure what mask I wore. Nevertheless, I always sensed the insurmountable divide between us. Maybe it was my young age, my younger generation. Maybe in her eyes I was still her eight year old nephew, the youngest of my generation, the one that everyone had to look out for. Maybe even in her weakened state, she still felt compelled to protect me from her pain. I can never know and yet somehow, whether she perceived me as her eight year old nephew or not, I colluded in the role, playing the part perfectly, confused, powerless and helpless. Why? It seems so senseless. Considered in this way, we did not inflict cruelty upon each other as though we had some intentionality in the process. The great tragedy seems to be that, in spite of all of our care and well-meaning, the masks appeared over our faces and we became distant strangers to each other.

Conversely, one counsellor alluded to how young adults she works with often refer to the idea of wearing a mask. The masks serve a valuable function for these individuals with cancer who often feel as though they exist in two different worlds; one containing their life with cancer and the other containing their normal life that they desperately cling onto. In each world, different masks are worn in order to conceal certain fears or pains so as to not stand out in their immediate context. All the while, the cost to them is that they lose themselves and their connection with others. When all that others see is the mask, the person behind the mask simply disappears.

These descriptions eerily hit close to home for me. I am reminded of how similar this is to my own experiences growing up as an ethnic Chinese boy in a predominantly Caucasian community. I recall how my desperation to feel a sense of belonging drove me to wear masks. I have never had cancer. I have never even been seriously sick for an extended period of time, and yet I feel a loose sense of connection, of shared identity with young adults with cancer. I will never know what it is like to walk in their shoes but it feels vaguely comforting to think that, as a HCP, I can identify with them, even if only in the smallest of ways.

I shudder to imagine how our loved ones could just disappear before our eyes. What comes to mind is the image of a great web of life, its fibres representing the connections between people. Cancer eats away at the fibres around supporting people until they are gone, leaving a vertex unsupported, alone and suspended in space. As I think about this image more, I realize how it is the very fibres that make up the vertices. Without the fibres, the vertex does not exist. It disappears from the world. What seems most tragic in this entire cascade of events is the seeming inevitability of it, that it is a natural entailment of the experience of cancer. It is hard to imagine people choosing to isolate themselves from their support systems and yet, it inevitably

occurs. As I think about this, I notice myself exhaling a deep breath filled with frustration, anger, sorrow and anguish. I feel it both for my connection with *Nimāmā* as well as the many other connections that suddenly dissolve.

3.2.4 Struggling to find the balance.

I am therefore saddened to see care providers distancing themselves from their loved ones or patients. As much as I try to avoid this pitfall of handling people with care, I constantly notice myself doing so.

Field Notes 2010-06-17

Prompted by an off-beat remark about his Hawaiian shirt, we start talking at length about past vacations to Hawaii. It's my first substantial conversation. Feeling quite nervous. I am aware of the way I am forcing the conversation, filling the occasional silences with my further questions. At the back of my mind, I recognize the gravity of the circumstances and know full well that this conversation may remind him of how such fun experiences will never be recreated again. Are any topics of conversation safe?

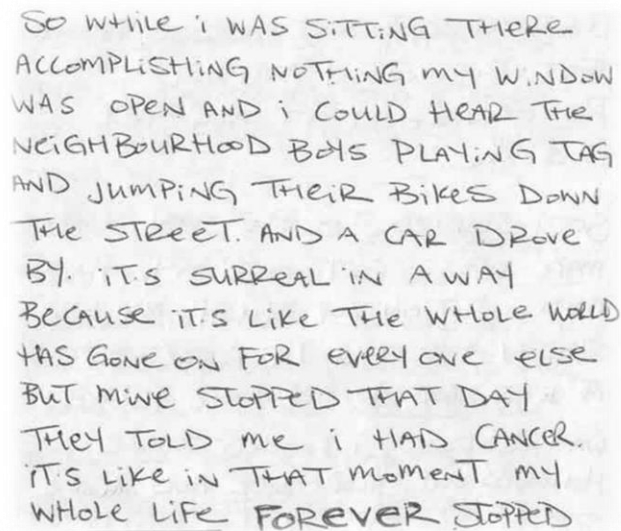
Field Notes 2010-11-04

As I talk with her, I notice the extravagance of my intonation, the effervescence, the emphasis. I know that it often happens in encounters with strangers or older adults. I feel dirty with this dishonesty. What compels me to adopt this mask of happiness? Why am I not my authentic self?

These excerpts describe moments in which I grappled with how best to relate to a patient and tried to find a balance. Be happy. No. Do not show happiness. Well... Maybe be somewhat engaging and exuberant. No, that does not feel right either. Over the weeks and months at the cancer agency, I experienced many of these moments of struggle and confusion.

The first excerpt illustrates my obsession with limiting every little statement that might sound positive or happy. I did not want to disturb the patient, to remind them of more joyful

times in their lives that they may never be able to recreate. As the following journal entry shows, the continuance of life can be a painful reminder of how much life stagnates in the face of a life-threatening illness.

A photograph of a handwritten journal entry on lined paper. The text is written in all caps and describes a surreal experience of watching life continue around the writer while they are immobilized by illness. The final sentence is underlined.

SO WHILE I WAS SITTING THERE
ACCOMPLISHING NOTHING MY WINDOW
WAS OPEN AND I COULD HEAR THE
NEIGHBOURHOOD BOYS PLAYING TAG
AND JUMPING THEIR BIKES DOWN
THE STREET. AND A CAR DROVE
BY. IT'S SURREAL IN A WAY
BECAUSE IT'S LIKE THE WHOLE WORLD
HAS GONE ON FOR EVERYONE ELSE
BUT MINE STOPPED THAT DAY
THEY TOLD ME I HAD CANCER.
IT'S LIKE IN THAT MOMENT MY
WHOLE LIFE FOREVER STOPPED

Image 6. Excerpt from diary of a young woman with cancer.

I was therefore careful to not cause others the same pain. I was restrained in my display of positive emotions. I avoided greetings like “Good morning” and “Nice to see you again” while I was at the agency. I kicked myself for letting slip questions like “How are you today?” I even stopped referring to the outdoors as I would with “Boy, it’s a beautiful day out.” I was constantly walking on egg shells during my time at the cancer agency, always on hyper alert about the words that I used. My intentions were well-meaning. I wanted to take great care to not cause further pain. This however came at the cost of my genuineness and warmth. I became calculated and overly cautious. My good intentions in practice amounted to an obsessive mission to not cause emotional response at all, positive or negative.

Conversely, I postured myself at the other extreme. As the second excerpt shows, I adopted a cheerful and exuberant persona. I wanted to lift people out of their emotional lulls.

Circumstances are depressing enough at the agency that we should all make an effort to cheer people up. Two conversations prompted me to think about where a happy attitude fits into forming connections with people at the cancer agency.

Field Notes 2010-09-02

Three women arrive in the chemo waiting area. I can tell that the one who stands in the middle is the patient. She looks exhausted, fed up with the circumstances she finds herself. The women to either side of her try to engage her. They suggest looking at head coverings. She seems uninterested. They say that there's a box of them. I quickly hurry out of my seat and dig out the box of head coverings made by volunteers. The two supporters dig through the box, occasionally fishing one out and commenting on how its colour or design would go well with this and that. The patient follows along disinterestedly. The two do not seem to find anything satisfactory. "There are more downstairs," I note. The two are heartened. Is there one that is a solid colour, preferably black made of cotton and with a brim, they request on behalf of the patient. I leave to check.

I return to find just the two women. The patient has been called in. I sit down to one side of one and present the head covering that I managed to find. She receives it casually. I'm surprised. Not with the enthusiasm that she'd been expressing while digging through the box. Her tone is also less expressive, more subdued. They're sisters of the patient, both from out of province, she tells me. She's a former oncology nurse. Both feel responsible for constantly reminding their sister to stay positive. It is tough going these days. She sighs. I have no response. What could I possibly say to make the situation better?

I notice the exhaustion in her now, exhaustion that she hid in the presence of her sister. I feel saddened in thinking about the masks that they must pretend to wear. I sit attentively, offering contemplative silence and a quiet place to rest.

Field Notes 2010-12-23

"I'm not ready for Christmas," says the hospital staff member as we sit in the lounge. I think he's worried but he doesn't appear so. He actually perceives it to be a good thing.

“Then, sounds like you are ready for Christmas,” I venture.

“Not in the conventional sense of being ready with all the gifts bought and decorations hung.”

“Oh!”

The commercialization of Christmas, not what it's meant to be, he laments.

“At least here, that is stripped away,” I point out.

“People come here to live, not to die,” he declares. I'm struck by simplicity and yet depth of his statement.

“In working here, I've learned to live each day.”

It's a tough lesson to learn.

“You'll never see me depressed. If you were to walk into a patient room wearing a frown, you'd bring other people down.”

I agree. “So it's part of the job description to wear a smile then?” I wonder.

“You really have to maintain a bright face to work here.”

I recognize the value of maintaining hope and a positive attitude in an environment when death is all around. And yet, I am tempered by the very realistic vignette of Grace and her friends. It was revolting to see Grace's friends cornering her into feeling positive and denying her circumstances. Where does maintaining a positive attitude cross over into self-delusion or denial of an individual's emotional existence? The answer to this question seems somewhat difficult to pin down in thinking about the number of different circumstances that may arise and the different needs or personalities of patients. These considerations add to my confusion around how I could most effectively establish meaningful connections with patients and their care providers.

Regardless of where the balance lies in presenting a positive attitude though, I found myself for the most part trying to be more cheerful than I otherwise felt. My reasoning was that I was after all providing a service to people. I was providing companionship. Who would ever

want a volunteer that seems to have no energy or feelings? I therefore worked hard to come across as a pleasant person, as welcomed company to have around. My existence as a volunteer was validated by the contentment of patients and family members that I served. I was fed by their smiles. I was demoralized by their absence. I found myself feeling dejected in moments when there were fewer patients to serve or when they did not need me.³¹

Field Notes 2010-08-19

I go do my rounds. I serve a few teas and coffees uneventfully.

Field Notes 2010-08-26

I do my 3rd round quickly. No takers. I grab a blanket at a nurse's request but that's it. Quiet. I feel sleepy, unengaged.

Field Notes 2010-09-16

For myself though, I felt relieved that someone actually wanted to engage today.

Field Notes 2010-09-30

I approach the nurses at the desk to ask if they know anyone who might be interested in a visit. "No" says the first nurse. I feel like I get bounced around to a number of nurses but no takers except one. Filled with excitement, I note the name, room and head off to check. Just my luck. ☹ He's sleeping, food tray left untouched on a tray hovering over his chest. I'm disappointed. [...]

I get referred to another nurse on duty. No again. The "lady with the dog" had already come by. (I feel irritated, jealous, foiled again from being helpful, useful. I feel ashamed for trying to compete with the lady who does pet therapy. I don't want to be competing against her. I should be encouraged that there are so many forms of support and interaction here.)

³¹ As I re-write this experience for what must be the fourth time (and as a consequence, reinterpret it for a fourth time), I feel a sense of rightness. The puzzle pieces are finally fitting together properly. This is what my experience was. In each of my previous passes at this experience, I was just forcibly writing a narrative that made sense. Now, this interpretation makes sense to me. Now this narrative is one that I can own.

Field Notes 2010-10-07

I head first to the nurse station. Expectations set low. [...] She names a number of patients. I'm delighted by the lists.

Field Notes 2010-10-21

She accepts my offer to sit with her. I'm hugely surprised and relieved. [...]

She asks if I could look over her request letter. I do so. She thanks me. I leave feeling content that I was able to be useful to someone in need. I wish her well. I notice a warmth inside me.

My cheerful and exuberant tone of voice and these reactions to offering help are all too familiar. They represent my desire to be helpful and therefore to be appreciated by others. There is much more to this desire than just simple helpfulness however. I trace my need for validation back to early childhood experiences of being a different looking kid in my elementary school. Being an outcast, I learned to develop personas that were appreciated by others. I put aside my own identity for those that others preferred. Over time, I became quite skilled in adopting the one that was best received by those around me. The cost of this was considerable as I have come to realize much later on in life. In being what I thought others wanted of me, I lost sight of who I was deep down. In not having presented myself to the significant people in my life, I realized that they really did not know me. In my attempt to satisfy what I thought my friends wanted of me, I lost them.

It is probably for this reason that I react so aversively to when this extravagant, people-pleasing side of me emerges. For me, it represents much more than just being superficial. When I become exuberant and put in more effort into my communication than I feel is honest, I am not only creating a divide between myself and those dearest to me. I am also denying my very existence. I am repulsed when I experience this in myself as well as in others. People who seem overly happy or expressive serve as strong triggers me. I do not trust them. I am unable to get to

know them. Their lack of authenticity keeps others at a distance. I can think of one very aversive encounter at the cancer agency that is imprinted into my memories.

Field Notes 2010-12-24

Another nurse enters the room. My attention is immediately drawn to the tone of her voice. It's bubbly, embellished, increased a few octaves to convey a sense of niceness. It's all that I can hear. She works quickly, adjusting an IV bag, checking a machine. The patient points out to her that he has a visitor. She responds with a cheerful, over the top "Oh, I see!" She makes a few other remarks but I am unable to pay attention to her words because all I can process now is her voice.

Work done, she turns to leave. As she walks by me, she turns her head quickly towards me and with the most incongruent smile, superficial voice, eyes looking past me, she says, "Thank you!" Her overpowering aura hits me like a tidal wave, nearly knocking me over.

The interaction is brief and yet so viscerally off-putting. I recognize how much it is filtered through my own lens of personal experiences. Moreover, I find myself feeling outraged on behalf her patient. Putting myself in the shoes of the patient, I cannot imagine how I could ever relate to or feel comfortable with this HCP. I would feel reluctant to display emotions that were not compatible with hers. Perhaps this is what bothered me the most. I am outraged that someone could act in such a way that robs another human being's very basic ability to express his or her feelings.

My reactions, I admit, are excessively unforgiving. When I remind myself of my own cultural location, I feel compelled to temper my criticisms of this HCP. I come to experience this interaction as someone who practices counselling within the bounded confines of the therapeutic hour.³² Over the course of this hour, I try to create a space in which a client is able to be taken

³² The therapeutic hour refers to the traditional timeframe in which a counselling session is conducted.

through a therapeutic arc of establishing safety, exploring deeply and integrating newfound awareness. Within this model of counselling, “shallowness” would be reflected on and perhaps challenged.

In contrast, most health professionals likely do not operate within this framework. Inpatient nurses play their helper role from the time they start their shift until the time they finish. They might occasionally find reprieve from their patients at the nurse’s desk but that is very different from the physically and temporally distinct spaces that I am able to retreat to outside of the therapeutic hour. As such, the roles that nurses occupy seem to blend together much more. Perhaps in this work environment, they need to wear masks – the mask of the exuberant, positive or optimistic care provider – in order to carry on in their roles (Vahey, Aiken, Sloane, Clarke & Vargas, 2004). Irrespective of the function of masks however, I am disappointed that what results is a deep divide between the care providers and those they care for, an observation that is acknowledged by others (Kuhl, 2005).

3.2.5 Our cultural context and the divide between us.

Up to this point, I have spent a significant amount of time examining how my actions as a HCP and those of the patient may create an interpersonal divide. Taking a step back, I have also noticed how our circumstances, independent of our actions, may also play a significant role.

Field Notes 2010-12-16

As we converse, a pharmacist walks in. I remark how instantly her talk changes from our everyday discussions that are far removed from medical conditions to a pharmacist interviewing her about her ailments and drug reactions. The transition is sudden, abrupt and yet so seamless, as though it is the most natural thing in the world. [...]

Another visitor. Her oncologist. He is older, pleasant in mannerism, dressed in red holiday attire. His tone is respectful, happy but not overly so. (I feel a warmth in his presence. I

feel that I can relate to him.) She engages with him in the same open and forthright way that she has with me. He asks a number of questions. Her responses are short, succinct. The conversation feels rushed to me, her disclosures premeditated; the way a radio interview during a morning news broadcast might be conducted. I get the sense that this is the expectation for how conversations are conducted between doctor and patient in this context. Efficient, to the point, no chit chat, no deviations. His responses are similar to the pharmacist and yet I sense a certain authority in what he says.

He talks about switching her on a few medications. She expresses some concern about side effects. He provides some explanations on why some decisions were made, what alternatives they are considering. It feels collaborative to some degree and yet not so. A decision seems imposed to administer the stronger drugs now to be safe and sure rather than milder drugs with more uncertainty. She asks for permission to leave for home.

(A grown woman asking for permission. Wow. This sounds bizarre and yet normal at the same time. Only in the hospital can such fully capable adults be reduced to the dictums of others. Given the subject matter, knowledge resides with the oncologist. He is in a privileged position and yet this power structure – her need to seek the approval of her doctor – seems so very normal to me. This power differential is so deeply ingrained in the culture that it becomes invisible, or if not invisible, then at the very least accepted. I soberly reflect on my own profession and practice. What is the nature of relationships that my clients and I form?) She has full trust in her doctor, explicitly stating such, which reinforces this relationship. “You are the doctor.”

The above encounter reminded me that the cancer agency represents a distinct cultural context with accompanying practices, traditions and norms of behaviour. It impresses me how each individual in this context is well aware of their roles and engages with each other in ways that are consistent with that role. The immigrant young woman did so seamlessly. One moment, she was talking with me about the holidays and her family and the next, about her medication with her interprofessional care team. The subtext of their conversations also pointed to the power structures that exist between, for example, the patient and her oncologist, with her seeking

permission from him. All of this plays out in a way that seems entirely natural, perhaps speaking to the deep embedding of this institutional-medical culture within our society.

The way each person in this scene communicates with each other is like a graceful and well-coordinated ballet; the institutional-medical culture, a choreographer's directions. Although the patient was born outside of Canada, she spoke very fluent English, conceivably reflecting her familiarity with the choreographer's directions. She was part of the ballet studio, so to speak. Conversely, it is apparent that there are things that would disrupt its graceful flow, things such as the addition of new dancers or dancers who have backgrounds in jazz, for example. Likewise, cultural outsiders who enter the cancer care system, such as newly diagnosed or immigrant patients, their family and even volunteers, will reveal its inflexible norms and practices.

Field Notes 2010-06-17

I walk into one of the chemotherapy rooms. A patient of Asian ethnicity is sitting in one of the chairs, his family of four clustered around him. (It feels lively but cramped, a change from the usual quiet.) My offer of coffee and tea is directed at the entire group. One family member speaks up, questions the nurse whether the patient can have beverages. Sure. The family member-interlocutor turns to the patient and asks in English. (I wonder if they serve as middle people because they feel a need to be of some use. All the while, I can't help but think that the patient sits in a protective bubble. I wonder if it feels anything like being trapped in a prison. I wonder if he feels conflicted, seeing the guards in this prison as his loved ones.)

My wonderings here points to a dilemma that I have often reflected on. To a patient, family members will often serve as an essential crutch in the patient's coping with cancer (Arora, Finney-Rutten, Gustafson, Moser & Hawkins, 2007). At the same time, family members can also make difficult the cancer journey. I think about the tensions that might exist in instances when the viewpoints of family members and patient are at odds (Freedman, 1993). For parents with cancer, complex and unique challenges exist in incorporating them into the cancer journey and

preparing them for the future (Hamilton, 2001). As a volunteer at the agency, I often times perceived a significant interpersonal barrier with the patient when family members are present. I opt to not enter rooms when patients already have company. Granted patients may prefer having their loved ones around over other HCPs – I must temper my own egocentrism – I wonder how medical professionals who experience such distance are impacted in their work. I remember the day in Baltimore when a social worker had come by to check in on *Nimāmā*. In spite of the significant emotional distress that she seemed to be experiencing, her interaction with the social worker was brief and congenial. To this day, I still wonder if my presence caused both *Nimāmā* and the social worker to feel more guarded, more restrained; preventing that interaction from being as valuable as it could have been.

3.2.6 Language divides.

Language gaps also create interpersonal divides between patients and their HCPs. Where family members exist, they often serve as valuable³³ interlocutors in patient-HCP interactions. Where linguistic bridges are lacking, I have found there to be many different sorts of challenges to care provision.

Field Notes 2010-10-21

English is a foreign language for her. She accepts my offer to sit with her. I'm hugely surprised and relieved. I notice how little I expected from this encounter, presuming immigrant

³³ Family members are valuable in helping to bridge language gaps between patients and their HCPs. They are, however, also individuals with vested interests. As such, they will assess and filter words, possibly leading to miscommunication or incomplete information. I was interested to note that the Provincial Health Service Authority has a policy encouraging the use of third party/professional interpreters whenever possible.

patients to be more closed off.³⁴ We talk. I ask questions. [...] I'm having a hard time hearing sometimes, because of her soft voice and throaty articulation. I catch only pieces, but reflect back to show that I'm listening and trying. (I want to honour the story that she's willing to share. I wonder with impatience how long it will take to get a visa for her family member.) I interpret an expression of despair wash over her otherwise inexpressive face.

A few weeks later, I meet her again.

Field Notes 2010-11-11

I enter her room timidly, re-introduce myself gently. She remembers. She just had a friend drop by and is expecting her daughter later in the afternoon. Her speech is soft and throaty, as I'd remembered it. I have a hard time understanding her: There's a family in the adjacent bed speaking loudly. I comment on how difficult it must be to communicate with the staff. She points out that she has no trouble understanding nurses though she has hard time communicating her own thoughts. The woman next door has it worse, she says. Can't even understand.

I felt frustrated with the clumsiness and incompleteness of my conversations with her. As much as the experience of cancer is often expressed in the broad strokes of anger and sadness, it is often in the subtleties of language that meaningful connections are made.³⁵ There was much that I yearned to communicate to her but was unable to. In spite of my frustrations, we were at least able to connect on a number of topics. I felt encouraged that I was even able to look over her visa request letter.

³⁴ This expectation of immigrant patients to be more closed off is admittedly a generalization, though I do not attempt to use it to limit possible connections. I am struck that I have formed this impression in the first place. I wonder how much this deduction has to do with my observations in the field versus my own preconceptions. If the former, does that reflect a discouraged attitude or disparity amongst immigrants in communicating with their HCPs?

³⁵ I have experienced that sometimes, it is also in the silences that connections are made. For a greater discussion of this experience, refer to [Chapter 3.4.6 Someone who is simply present](#).

Her reference to the patient in the adjacent bed who can neither communicate nor understand English was a sobering reminder of the significant challenges that some patients experience. I am reminded of one cheerless visit with a patient.

Field Notes 2010-12-02

A nurse enters to adjust the IV and equipment. She stays only briefly. Her interaction with him is minimal. (I wonder to what degree she feels uncomfortable or inhibited by their language difference. I wonder how much the service received by patients with language barriers suffers due to this barrier, how much patients lose out on the kindness, compassion and humanity that is afforded by language or more specifically, verbal communication.) She leaves. [...]

The nurse returns. He acknowledges her non-verbally in the room. She has to change the IV pouch. (I wonder if he really understands what he is being subjected to.) [...]

A food service staff comes to take an order for lunch. She quickly lists a number of choices which even for me is hard to decipher. He does not understand or does not know how to respond. She clarifies, rephrases her question. Each is struggling to understand the other. "Tuna or egg sandwich?"

He thinks for a moment. "Tuna." (I wonder if he's just guessing. If something as simple as ordering from a lunch menu could be such a struggle, I only wonder how much of his complex treatment plan he participates in deciding. Such a disempowering experience, to be unable to provide someone the vary information that forms his autonomy. I can't imagine a more vulnerable, more helpless position to be in. In counselling, we often talk about empowering the client and the family. I understand now how language can become such a significant barrier to that empowerment.)

In this scene, hospital staff seemed to just come and go in carrying out their duties. It was as if the patient was a mere recipient or subject of the care. As I noted, I am not even sure to what degree he understands what he is being subjected to. Although he carries on with remarkable composure while I am present, I can only imagine how uncertain and disorienting

this process must be for him. I recall one moment where, it was only through ad hoc interpretation support offered by a staff member and me that the health care team discovered the worries and distress of a patient who was nearly in tears.

Then again, even with the greatest of language support services, the subtleties of meaning and feelings are lost in translation.³⁶

Hold Your Breath (Grainger-Monsen, 2005)

Excerpt from 30 minutes, 35 seconds

Mr. Kochi: (in heavy accent, amiably grasps doctor's hand)

See you Dr. Fisher... I like you.

Doctor: I'll see you in a couple of months.

Mr. Kochi: (turns to interpreter, in Arabic) *What about my sore throat? Tell him to give me medication.*

Interpreter: (to doctor) He says what about the...

Doctor: ...the sore throat?

Everyone: (laughing nervously)

Doctor: (places hand on Mr. Kochi's shoulder, with levity)

Take plenty of fluids. (laughs forcefully)

Mr. Kochi: (to interpreter, frustrated) *I need some medicine. This is a hospital.*

Doctor: (with levity) It's what my mother always told me. I'm telling him. Take plenty of fluids. Get some rest.

Interpreter: (translates to Mr. Kochi) ...



³⁶ Sometimes this is intentional, and at other times unintentional (Grainger-Monsen, 2005). Words like cancer become semantically reduced to “masses” and “tumour”. An aversion to carrying a medicine pump is misinterpreted as a refusal to chemotherapy outright. Strong feeling words such as “angry” are moderated to become “mass”.

Mr. Kochi: (to interpreter, insistent) *He needs to give me medicine also.*

Interpreter: (to doctor, smiles forcefully) ...

Mr. Kochi: (to interpreter, adding in broken English) Seven months, not take medicine for me, why?

Doctor: (holding out hand, gesture to end conversation) Okay. So take care and we'll make an appointment for two months but if you have any problems, then come in sooner.



Mr. Kochi: (to interpreter, hold hands near throat)

Interpreter: (nervously) Still want something for you now.

Doctor: How about some Tylenol?

Mr. Kochi: (raises hands in exclamation) Tylenol, oh!

Doctor: (laughing) He doesn't like that. We need something more expensive than Tylenol. (turns to leave) Okay. Anyway, it's nice seeing you again, sir. (shakes hand of interpreter) Bye bye.



Mr. Kochi: (without words, shakes head) ...

As this and earlier stories exemplify, patients who encounter language barriers are often deprived of their very basic human capacity to express their feelings and in turn feel heard. I cannot imagine a greater deprivation in this world than not being heard. In this way, language, or rather the ability to communicate, can be considered a very important mediator of our autonomy.

3.2.7 Perceptions that divide.

Within a particular cultural context, I am also reminded of the many nuanced and subtle ways in which individual perception shapes the interpersonal connections that are possible.

Field Notes 2010-10-07

I introduce myself as a volunteer and ask whether she would like some company. The patient looked me over for a good few seconds. After a pause, she finally declines. (I've failed her assessment, judgement. "Is this the kind of person I would like to allow to enter my space?" I wonder what her criteria are. What are those critical pieces in that first impression? Beauty? Age? Ethnicity? An aura of compassion? Whatever it was, I certainly wasn't exhibiting them.)

Field Notes 2010-12-16

She comments about our age difference, assumes that I have not come to that stage of considering matters such as death. (I find myself feeling mildly amused and mildly irritated at the same time that she is making this assumption. She attributes to me a level of youthful immaturity that I believe I have passed. I wonder if she is discouraged by her belief that I don't get it. I wonder if she feels distant from me as a result. I wonder how her perception of me as an inexperienced, youthful person helps or hinders our relationship. Moreover, if I were her health care provider, how would our work together be impacted? I note that her oncologist – the one she seemed to admire and seek advice from – is much older, maybe in his mid to late fifties.)

These entries make me wonder how I was perceived by the immigrant young adults I engaged with through this study. From my own vantage point, I share with them in some respects my cultural identity as an immigrant young adult. At the same time, I have never been diagnosed with cancer.³⁷ I am in fact a very healthy, able-bodied individual, university educated. I speak English fluently and without any discernable accents. There is also my acknowledged role as a researcher; my objective, to acquire some information, some increased understanding from them.

³⁷ I wrote one journal entry on a recent experience I had in waiting for the bus. It evoked some feelings and thoughts that were perhaps similar in quality but certainly not magnitude to some of the themes I have encountered amongst immigrant young adults with cancer. This was no doubt precipitated by my deep immersion in this inquiry for the past many months. This was an experience that I believe deepened my understanding of my role as a HCP to immigrants and young adults with cancer so I have included it as [Appendix S: Journal Entry: Waiting](#).

In these ways, I perceive myself to be a perpetual outsider who will never truly understand their experiences.

Then again, I recognize that I can never fully understand anyone's experiences because I am not them. I have not grown up in the cultural context that they did or experienced the many things that they have. I do not hold the beliefs or values that they do. Maybe I should just abandon this idea of being or becoming an insider. I should just acknowledge that I am a perpetual outsider and move on. I could even be proud of this fact, accept my position of not knowing and begin to connect with someone then without preconceptions, assumptions or past knowledge to mislead me. This sounds as sensible as it does reckless. Where do I situate the mountain of studies and reviews that have come before me on immigrants and young adults? What would be their usefulness? So many questions but no answers.

I am aware that irrespective of my own identification as insider or outsider, the person with whom I am trying to connect will inevitably have his or her own perception of me (Egharevba, 2001). With some, they may see my dark skin and black hair, and immediately believe that I can understand their experiences, that a connection is possible. With others, as was the case in the previous two encounters, I may be dismissed because I am perceived as an outsider.

It discourages me to think about how little of these interactions is influenced by my own concerns. Then again, this also seems to be quite a liberating thought, that someone declining my offer of company or care may have little to do with me. I chew on that thought for a while. It certainly relieves me during those days in which no one seems to be interested in my company. Of course, this works in the other direction as well. A patient's willingness to engage with me may often have nothing to do with me but much to do with their own circumstances and

openness. I welcome this line of thinking as I have too often sat after a counselling session ruminating over what I did not do effectively and how things could have been better. The strong, critical voice returns. I take ownership of certain outcomes that may not be mine to own. My failure, in turn, paralyzes me. Sometimes, it is the client's responsibility. Sometimes, I need to abandon the self-blame.

I reflect back on my experiences as a volunteer, being driven by a sense of being needed, feeling gratified when someone expresses appreciation for my company and feeling dejected to have my company declined. As a care provider, my very identity is supported by people's need for me. Perhaps this pressure I put on myself is unnecessarily harsh. Part of me wants to accept this conclusion, but another part refuses to. I look back on my time with *Nimāmā*, the brief weeks that we shared in our lives. I feel a tremendous guilt in not having connected in the way that I should have, in not having been a support to her in the way that she needed. I want to acknowledge that much did not have to do with me, but part of me refuses to do so.

I think back to a scene between a patient and his family member. At the time, I found myself being moved so much by their interactions but it was never clear to me why. Now, having had more time to reflect on my own narrative, it seems a little clearer.

Field Notes 2010-09-30

There is a patient and what seems like family member sitting on the couch in front of me facing away. They sit quietly. The family member makes short remarks every now and then in a soft, delicate voice. There is almost no response from the patient. (I even wonder if he's asleep, drifting in and out of consciousness from some extreme fatigue, not even being able to sustain a conversation.) I listen more closely. There are responses – he's not asleep – but they're barely audible and short and minimal. More of an effortful, barely there "mmm" and "un hun". It seems as though both are trying to cling onto a conversation, some sort of verbal connection that they both lack the energy and will to sustain. The family member's occasional remarks therefore seem

awkward, a search for words to fill the emptiness where no words can be found. I feel the uneasiness, the exhaustion, the emotional pain. (I think about my parents, about the prospect of having them only in physical form, but without the emotional connections. The death not of a body but of a relationship. I would be utterly devastated.) I sense in the depth of me a profound longing to make it better for them, but I can't. I feel so helpless, so useless.

Part of my sadness here related to fading connection between these two individuals. I felt sad for them, for their dying relationship. Then again, maybe it was not them that I was sad for. Maybe in this family member, I saw myself, a care provider for someone with cancer. As I did what I could to build a relationship with *Nímāmā*, I felt her slow pushing away from me, her no longer needing me. The more she pushed away, the less needed I felt. I wanted to make it better for her and yet, I could not.

As I consider my own despair in these circumstances, I wonder about the many other family care providers such as the individual above who arrive at a point of feeling not needed. I wonder what their experience must be like, how devastating it must be for them. When we have no role, the divide between us becomes boundless.

3.2.8 Finding clarity amidst confusion.

I began this section wanting to explore the many factors that may contribute to the separation and isolation of people in the experience of cancer. If I can understand how these gaps arise, I may be better prepared to bridge them as a HCP. I realized early on how our disposition to handling people with care produces interpersonal divides. I explored how metaphorical masks become used by patients and others in order to convey positivity, normalcy, while concealing fear and uncertainties. Overlaying these behavioural factors are also contextual factors. This includes cultural norms and practices that direct a certain expectations of all roles involved.

Often times, it is the cultural “outsider”³⁸ who enters this graceful dance that will experience certain missteps or inflexibilities.

As I near the end of this section, I feel compelled to distil for my readers all of these reflections down to some useful lessons learned, a take away message. What do these last many pages really amount to? How do I as a HCP go about establishing meaningful connections with patients or their family? Honestly, I am not quite sure. There are too many factors to consider, too many individual narratives to draw from. I am confused. It is like my reaction to seeing the performance *Handle with Care?* for the first time.

Journal Entry 2010-10-20

I found myself feeling lost. I was unable to keep up with its rapid change of scenes, curt dialogue, plurality of voices and frenetic pace. Even with intermittent pausing and rewinding of the video, I felt dazed like having been put through a spinning amusement park ride that revolved much too fast. I would have to watch it again, and again I did. Instead of providing clarity, however, it remained ever confounding.

For a long time, I was struggling to figure out why I wanted more. I understood the words and the exchanges, the content was clearly articulated, the performers were convincing, and yet the message eluded me.

Then it occurred to me while I was volunteering at our local cancer agency. My goal is to become a competent cancer care provider. I wanted the video to teach me something. I wanted to know how to handle patients with care. And yet, this video was not providing me that neat little handbook. The plurality of voices in the performance contributed to what amounted to a cacophony of differing experiences. There were often divergent views expressed by the breast cancer patients about issues like their desire for information, autonomy or involvement by their

³⁸ By cultural outsiders, I am referring to people who may be unfamiliar with the norms and practices of the medical institution. This might include newly admitted patients, immigrants or previously healthy young adults.

family. As noted in one comment by a doctor, what constituted help “varies a lot” between patients as well as for a given patient at different times.

I realize now that the purpose of the performance was not to provide a handbook or manual for working effectively with metastatic breast cancer patients but rather to confuse and raise doubt. As Kleinman and Benson (2006) point out, [cultural] competency does not entail “a series of do’s and don’t’s that define how we treat a patient of a given [...] background” (p. 1673). It is not about trying to learn to care through guides, textbooks or at arm’s length. Rather, the performance invites us to get to know the patient or family member and their viewpoint, to ask the question “what matters most to them in the experience of illness and treatment” (p. 1676).

That is it. Maybe instead of searching for that illusive path to bridge the divide, I ought to just invite myself to be curious, to ask questions. If anything, I have certainly left myself with that lesson. I am confused, and humbly so.

3.2.9 Practice dying.

I reflect back on the many stories that were shared with me, the many experiences that I witness. If there is one message that serves as a lesson or reminder to me in creating meaningful connections, it would be the disarming encounter I had with one particular young woman with a cancer diagnosis.

Field Notes 2010-11-04

As she shares her experience, it strikes me how healthy she looks, how youthful she looks. I would’ve never guessed she has cancer. She says that she doesn’t let the disease weigh her down, even after five years of cycling through remission and recurrence. Expresses her annoyance with others who adopt the victim identity, “practice dying” as she calls it. (I find the expression cute. It sticks with me.) I put forward the idea of a hospital as a jail for some. She thinks the idea ridiculous. She feels incredible freedom to eat what she wants, to meet with friends at all reasonable hours. (I’m impressed by her vibrancy, her energy, her spunk.) She continues on about her adult children. (I’m startled by her mention of adult children. She looks so

young. It wouldn't be a stretch for me to consider her a peer, someone to go hiking with, or party downtown with.)

We talk about her changing relationship with friends and extended family that happened after she was diagnosed, how some friends became strangers. She puts a real premium on normalcy, on not being treated any differently than when she didn't have cancer. She expresses her disappointment, disgust when people come in and express sympathy or concern for her illness. She greatly values her friends who visit her in hospital and treat her like she was at home, without a disease.

(I'm impressed with the way that she is able to continue on with life, to look ahead to the future, to make plans, to travel. The way she expresses her dissatisfaction with the medication, critically evaluates them, takes only what she needs. With an illness that seems to rob people of control of their body, their life, she has maintained it. She feels secure with herself, her body, her beauty. She has the energy of a fighter.

Maybe that is what we all want. To be treated as a normal human being, not a patient, not a masked stranger, not a fragile object to be handled with care. That message resonates with me.

3.2.10 Summary.

The title of the production that began this discussion, *Handle with Care?* reflected the approach care providers may adopt in interacting with a person with cancer. They are treated like fragile objects, things that can easily break. In turn, we become careful, censored, restrained. We adopt a false, disingenuous optimism. We keep to ourselves our own aches and pains.³⁹ We pretend that our lives are the same, without interesting changes. We do not want to bother you, to sadden you, to make you feeling left behind; and as a result, we do all of this.

³⁹ For an expansive reflection on my experience of protecting others from my pains, refer to [Chapter 3.4.3 Protecting each other.](#)

3.3 Deconstructing the Health Care Provider

Field Notes 2010-12-23

In the lounge, a woman is lying on the couch by the window. A thin blanket is draped over her body. The couch is not entirely long enough and so she lies in a semi-foetal position. Her arms hide her face. I watch her for a period. She remains motionless. She is asleep, I gather. (Not just briefly resting her eyes. She is deeply asleep, and yet, not comfortably so I am guessing. Comfortable would be lying stretched out, arms over her head, airways unobstructed. No, she is sleeping where she can, adapting to the changed and changing circumstances. If life was normal, she'd be sleeping at home, body outstretched, thick warm blanket, sleeping clothes. No, this is not her norm. She has adopted a new norm, perhaps reluctantly, resentfully, maybe even angrily. This is not a culture she wants membership in, this being a family member of a cancer patient but she has been forced to be a part of this. I feel sad for her, as she sleeps uncomfortably, abnormally. This is her momentary respite, respite from her resentment, her anger, her cultural membership.)

This scene of a woman sleeping uncomfortably on a couch in a lounge of the cancer agency was resonant to me. It represented for me the tremendous efforts and sacrifices made by family members who serve as company in the patient's journey of illness. The significant physical and psychological tolls that the cancer experience may have on family members and other loved ones have been thoroughly substantiated (Stajduhar, Barwich, & Fyles, 2008).

In acknowledging the significance of individuals in the lives of patients, I find myself thinking about how I am always fumbling for a term to best describe them. Family members include some people but necessarily exclude others, even if the term was subjectively defined. What about loved ones or significant others? They imply a certain evaluation of the quality of the relationship. That would also exclude certain people who may contribute in meaningful ways to

the patient's journey. I struggle to find the right term to most accurately capture these individuals, and their relationship and responsibility to the patient.

But then, there is the term health care provider (HCP). What do I mean when I refer to someone as a HCP? Who is a HCP anyway? Best to figure this out as I have self-identified as an "emerging HCP" with the accompanying implications of its cultural membership. This need for clarity led me to the current section on deconstructing the HCP. In what follows, I examine how I and others use the term HCP, and the impact of our use of this meaning may either support or hinder cancer care.

3.3.1 Who are health care providers?

I began with my own conception of the HCP. Reflecting on my earlier search for a suitable term for the many supports of a patient, I considered HCP. On first pass however, I intuit that describing a family member as a health care provider seems somehow demeaning or detachedly cold. It is a strange reaction. Perhaps, this is related to my association of HCP with the institutional and medical systems, which are somehow distinct and separate from the family system. The term HCP conjures up images of doctors in lab coats and nurses in patterned uniforms. Health = medical systems > nurses and doctors. That's interesting. I continue to subscribe to the dominant semantic practice of equating health with medicine in spite of my cultural identification as a counselling psychology student and mental health provider who maintains the view that health is a complex construct with multiple dimensions. I find this realization disheartening. It is perhaps reflective of how pervasive this biomedical culture is in


our society and how we may subscribe membership to cultures in spite of our reluctance or misgivings.⁴⁰

So, my own colloquial definition of HCP would include doctors and nurses. No doubt, the list could expand to include a number of other occupational titles. As I sat around the discussion table for my course on Interprofessional Psychosocial Oncology, I thought about the social workers and occupational therapists who were not only my classmates but also possible colleagues in an interprofessional care team. Through our discussions, I became aware of the valuable knowledge and expertise these professionals are able to contribute to improving patients' overall health. These professionals are no doubt HCPs in every sense of the word.

With this new awareness, I was certain that there were more members of this health care team. Looking back over the many cancer agency paraphernalia, I came across few lists that made me feel quite heartened.

⁴⁰ I am taken aback by my association of the biomedical culture with detached coldness. To refer to someone as a health care provider is even a pejorative in my mind. Why do I harbour such disdain for the medical culture? Perhaps it has to do with my experiences in Baltimore with *Nímāmā*, with their detached coldness in their focus to service her medical-physical needs and in the process, overlook her more painful psychological needs as well as the need of her family. As an emerging health care provider and a family member, I would imagine that such an attitude of disdain and distrust would affect my willingness to work collaboratively with others in an interprofessional care team. Moreover, I wonder how much my negative attitude exists in others who share my cultural affiliations to *family member* and *counselling psychology*. What fosters this perception of detached coldness? This would be a worthwhile research inquiry.

Your Cancer Care Team

 [Print this Page](#)

Revised: July 2006

A collaborative team of health-care professionals

Some of your team members will work directly with you to provide high-quality care and support.

- **Oncologists** are doctors who specialize in (drug) therapy.
- **Radiation Oncologists** are specialists who use radiation to treat cancer.
- **Medical Oncologists** are cancer specialists who use drugs to treat cancer.
- **Surgical Oncologists** are surgeons who use surgery to treat cancer.
- **Radiation Therapists (RTs)** are specialists who use radiation to treat cancer.
- **Nurses:** During each visit to the Cancer Centre, you will see the same nurse with the goal that you will see the same nurse. They will explain technical terms or to put you in a more comfortable position.
- **Pharmacists:** The Cancer Centre's pharmacists will provide you with drugs for you to take at home. Drugs not available at the Cancer Centre are available at your local pharmacy. Do not hesitate to ask a question about your prescriptions.
- **Registered Dietitians/ Nutritionists:** They will help you to maintain optimal health during treatment.
- **Counsellors/ Social Workers:** Professionals who will help you discover the strengths you'll need to cope with cancer. You deal with financial stresses and receive emotional support.
- **Psychiatrists** are trained medical specialists who help you through the difficult course of their journey with cancer. They will help you with crisis and rehabilitation issues. They will work with you, your oncologist or Patient and Family Counsellor.
- **Dentists:** Both cancer drugs and radiation therapy can affect your teeth and gums.
- **Librarians:** The Libraries in each Cancer Centre provide you with information and support.
- **Volunteers:** Volunteers at the BC Cancer Centre help you, your family members, friends and other visitors. You will be able to meet them at the Cancer Centre.

Image 7. Your cancer care team. (n.d.). Retrieved March 16, 2011, from <http://www.bccancer.bc.ca/PPI/InfoforNewPatients/YourCancerCareteam.htm>

It is reassuring to think that there is such a diversity of professionals (and accompanying knowledge base) supporting patients and their family. Given that health is a complex and multidimensional construct, no single disciplinary approach would suffice. At the same time, the extensive list of HCPs makes me uneasy. It is falsely reassuring, creating this illusion that because the system is comprehensive, patient care is improved. Unfortunately, interprofessional education and practice is an ideal that often is difficult to implement. In our weekly discussions, many challenges were raised in carrying out interprofessional collaboration, including a lack of time; a lack of awareness of others' disciplinary knowledge or expertise; a disciplinary chauvinism; geographical separation of team members; any of which could derail efforts to maximize the effectiveness and comprehensiveness of patient care. Clearly, better care is not just about having a huge interprofessional team behind a patient.

Moreover, I have often found myself feeling extremely daunted by the complexity of a case study while trying to answer questions like "Which HCP is best suited to address this issue?" and "Who should take the lead?" Diagnosable distress in a patient, significant functional impairment, outstanding tension with family members to the point of estrangement, unresolved grief issues. One HCP expressed anguish while reflecting on a particular case. "Doing short term counselling with someone from another country with cancer, there is so much to explore about their beliefs and attitudes... even process their being in counselling. Where do I even begin?"

It is in these moments of despair that I find myself questioning the value of what I can provide as a HCP. It is in these moments that no well-functioning interprofessional team in the world seems adequate. One particularly poignant interaction comes to mind.

Field Notes 2010-12-02

I enter a room. There are two beds here. In spite of the brightness of the day, it is unusually dark in this room. I notice the blinds drawn, partly blocking some of the light from

coming in. The bed by the window is occupied but the curtains around it are drawn for privacy. The little natural light that is able to enter the room is therefore further prevented from reaching the bed by the door. I find an older woman sitting there. She is quiet, present, seemingly in thought. As I approach, she notices and turns her head towards me. She has a gentle and patient smile.

I introduce myself. "Would you like some company, someone to sit with?"

"Why sure," she responds without second thought. As I pull up a chair next to her bed, I cannot sense any judgment from her, the sizing up that most patients do when I offer my company. I admire her openness to me. I wonder what makes her so willing to accept. I find out that she is here from a tiny community up north. Her tone is soft, patient and friendly. I feel at ease.

Soon into our conversation, another woman arrives. The patient introduces me to her sister, comments that she's been enjoying her conversation with me. I'm delighted that my company is welcomed. At the same time, I want to leave. I feel like I intruded on the family visit and now am standing in the way of them.

I'm surprised that this patient didn't mention anything about her family being here. Patients usually make it known that their family has just stepped out or has just visited, or will be coming soon. It's a polite way to say, "I don't need your company. I'm well supported for now." It occurs to me that in the hierarchy of valued company, I'm pretty far down from the family member.

Recognizing this, I feel compelled to leave. I don't want to be the barrier between these two sisters. Just as I'm about to wish them well, she finds the chair closest to the door and sits herself down there a great distance away. I'm momentarily stunned, confused. She's supposed to stay standing so that I can vacate my seat for her. I'm not sure what to do now. Does she want me to stay? Does she not get along with her sister? She doesn't even try to move her chair closer.

I try to make do, resuming the conversation with the patient, updating her sister as I go. This is new territory for me. I've only ever been company for patients themselves – but both sisters make it feel so easy as though it's perfectly natural for me to be there. We continue on for a while the three of us. The subject of food comes up. I note that there are a few places to get

food. I offer some snacks. They gratefully accept so I head off to get some cookies and juices. I greatly appreciate and admire their unconditional acceptance of me.

As I return to the dimly lit room of the two sisters, I notice the chair by the door empty. She is beside the bed now, closely clutching her sister on the bed as a nurse works on setting up an IV drip to deliver what is probably chemotherapy. Their embrace conjures up the image of two penguins huddling tightly amidst a barren land, the cold winds howling around them. The only support they have is each other, only the warmth of their bodies keeping each other alive.

They don't even notice me. I don't want to be noticed. Approaching the door quietly, I leave the snacks where they can be found and promptly head on my way. I blink to keep the tears from accumulating in my eyes.

“Two penguins huddling.” It is a vivid image. I quiver thinking about it.⁴¹ In spite of their remarkable openness in inviting me, a complete stranger, into their lives, their support for each other represented a care that is irreplaceable. This scene reminds me of the immense importance of family members. Their presence and the care that they provide are irreplaceable. For me, this means that I must always work to include the family members in the care process.

3.3.2 Burdens on care providers.

I also think about how the lives of two penguins separated from their pack would be inseparably co-dependent. In order to survive, both would have to stay alive to provide warmth to the other. If one is to perish, than so will the other. This idea of co-dependency is perhaps best illustrated in the many studies on magnitude of grief experienced by surviving care providers, including parents of children with cancer (Kreicbergs, Lannen, Onelov & Wolfe, 2007).

⁴¹ This display of commitment to family is a value that I resonate with. I am able to identify myself in their narrative. Growing up with my parents as an immigrant family in a community where many had generational ties, I often did feel as though we were the few penguins huddled together, helping each other survive.

Moreover, the cancer care community is just recently coming to acknowledge the heavy toll of the cancer experience on the care providers (Stajduhar *et al.*, 2008) as well as on children and siblings, who are often overlooked amidst the attention on the patient (Hamama, Ronen & Giora, 2008). As reflective of the currency of these considerations, an increased attention to the entire family system was uttered as a rally cry at a recent psychosocial oncology conference I attended. A practitioner working in palliative care challenged the audience to expand our scope beyond the individual patient to the family members, which necessitates a paradigm shift to think of the cancer experience as continuing after the death of the patient.

I am reminded of many instances of the immense pressures endured by family care providers. I think about my cousin, whose tensions with his mother and partner became magnified in the face of his mother's illness. I think about an immigrant young adult I spoke to, whose mother put her life and career on hold, making significant financial sacrifices to leave her homeland to care for her child in a foreign country with different languages and customs. I think about a quick and wordless encounter in the lounge of the cancer agency that called out to me more than any words ever could.

Field Notes 2010-12-23

A man is sitting quietly on the couch in the corner. He speaks softly into his phone, his voice gentle, comforting. I catch only his last words. "You be strong, grandma. You be strong. We'll get through this." The man flips closed his phone, stands up from the couch and proceeds to walk out the lounge. As he walks by, I hear a heavy sigh. To me, it is the most heavy, emotional cry of exhaustion, of anguish. My heart sinks. It's gut-wrenching. I feel a profound despair, a great sympathy. I hear a grown man carrying the great burden that he must bear, while feeling the duty to project a sense of strength. Otherwise, the entire structure collapses.

The depth of this man's sigh, the lethargy with which he got up off the chair, the heaviness with which he walked across the hallway. To me, these were all signs of the heavy tolls that this man bore for his family, for the entire structure that depended on him. I find my heart goes out to him. His linchpin role within the family is a sort of cultural membership that I share with him. Our narratives need not be the same and he might never believe this, but my perception of our shared membership creates in me a compulsion to reach out to him, to support this man who bears it all but cannot, at a risk to his family, reveal his exhaustion.

For me, this is a striking reminder of the significant role that I may serve as a HCP in supporting both the patient as well as their family. Often, within our frantic efforts to ease the pain and suffering of patients, we tend to forget how stressful the process is on people surrounding the patient (practitioner, conference key note). They will be going through their own grieving process. The loss is perhaps of a mother or father, sibling or child; and the subsequent role that their family member had filled in the family or the support that they may have counted on. In considering the man who tries to comfort his grandmother while he is near collapse under the weight of his tremendous responsibility to be strong for his family, supporting the family members will have manifold values. They are valuable members of the HCP team and should be acknowledged as such.

3.3.3 Volunteers as care providers.

Who are HCPs then? So far, they include what I perceived as the medical staff, members of the interprofessional professional team and family members of the patient. This growing list of individuals prompts me to consider whether there exist limits in this search for HCPs. A very lengthy volunteer experience comes to mind. It began in the lounge while I was writing notes to myself.

Field Notes 2011-02-03

A woman abruptly appears in the lounge. She looks familiar but I can't tell for sure if she's a nurse. She asks if I speak Chinese. (The way she asks her question takes me by surprise. There's no pretext, she's to the point.)

I pause for a moment before responding. "Well I speak Mandarin."

As though she doesn't really care or doesn't want to care, she responds in curt terms that there's a patient who speaks Chinese who is trying to communicate something that she doesn't understand. My helping instincts immediately become mobilized. As I confront what is expected of me, I'm uncertain whether I can be of any help, especially if she can only speak Cantonese. I quickly try to explain that to her. I'm also nervous about my Mandarin fluency. What if she speaks Mandarin but her requests are complicated and I screw up? What if I mistake her meaning, relay the wrong message? My body tenses but I force myself onward, wanting to help in whatever way I can. If not me, then who? I stand up rigidly, turning to follow her.

A man sitting on the couch speaks up. He can help.

"So you speak Cantonese?"

Both.

My body instantly relaxes. I offer him my role. He says that he can help if I have any trouble. (So, he's hesitant. I wouldn't blame him. Who knows what this patient needs.)

I continue on out the lounge. We speedily walk down the hallway. She leads the way, not looking back. No dialogue, no further explanation about what she suspects. (I feel slightly irritated that she hasn't even checked in whether I was willing, comfortable or capable of helping. It's as though she's passed the problem onto me and so now she no longer has any responsibility to it. The hand off. Not my problem anymore. I wonder if she knows that I'm a volunteer or if it even matters?)

We enter the room. I arrive at the patient's bedside. "Can you speak Mandarin?" I ask in Mandarin.

"Mandarin," she responds, clearly not comfortably. I ask again in a different way just to make sure. Her response is tentative, broken. Okay, back to the lounge to call for assistance.

“Nope. She speaks Cantonese,” I say to the man who spoke both dialects. (I notice that there’s a sense of urgency in my tone and pace. It’s that I want to bridge this communication gap, to relieve her voiceless-ness as soon as possible. What if she has something incredibly pressing to express? What if she is in pain?) He follows me. I notice that the staff woman is not with me now. (Where did she go? Could she not offer more information?)

I guide him to the room, expressing my appreciation for his help en route. He moves right up next to the patient bedside and bends down to the patient’s level. It not only allows him to hear more accurately but also conveys a sense of respect. (I admire his presence of mind or perhaps his natural instinct to do this. His actions make me reflect on how I had just stopped at the foot of the bed, ever distant, ever impersonal. I wonder how much of this the patient experiences, how significantly it changes the patient’s experience of connecting and relating with another human being, as opposed to merely communicating.)

They speak for a long time, alternating back and forth. I cannot even begin to guess what they are discussing. Every time she speaks, she grimaces. Her eyes squint not so much in bitter frustration but rather in sadness or anguish. Her statements are lengthy and unbroken like the flow of water from a dam that has been restrained for much too long. He responds calmly and softly, without hesitation. (It seems to me as though he knows what to say, how to comfort her.) They continue speaking. I remain at the foot of the bed, completely ignored by them. I’m tempted to leave but it doesn’t seem right. I feel responsible for seeing this interaction through to resolution. Besides, I can’t just abandon this guy who so generously stepped into this role. What if he needs help in some follow up action? What if he needs emotional support or to debrief a troubling conversation? No, I need to stay put. Despite my being forgotten about in their conversation, I still have an important role still.)

As I stand there patiently, I notice the staff woman walking around the room. My thoughts turn to her. She moves busily around the room wiping the floor, cleaning the bathroom. (So she is a caretaking staff, not the nurse. The realization somehow accompanies some degree of forgiveness, as though it is expected for a caretaking staff to be so curt and that more should be

expected of a nursing staff. I catch myself using this classist stereotype. It's reprehensible. I'm ashamed to find myself thinking this way.)

(I wonder what her matter-of-fact behaviour is due to. It could just be her personality, as in a disposition to act in a particular way and she did not notice the irritation I felt because of it. Then again, it could be a function of the cultural context that we're in. "Never look for a psychological explanation unless every effort to find a cultural one has been exhausted" as anthropologist Margaret Mead (Mead, 1959 p. 16). Perhaps this is the prevalent culture amongst health care providers who work in a cancer care setting. We step in where we can despite our distinct job titles or professional training. Perhaps in this aspirational interprofessional care context, our responsibilities ought to remain intentionally fluid, not rigid. These interpretation tasks get being filled by those who are able to in the moment. Then again, could this fluidity be reflective of a system that does not have clear guidelines, protocols to follow? This Cantonese speaking patient seems to have experienced a communication breakdown over an extended period of time, not just in this instance. Is my fluidity reflective of a gap in the system? Moreover, what about this handing off of responsibility that I've experienced.)

My attention returns to the conversation. Her statements are now shorter, his longer. (Something seems to have changed in their relationship. He seems to no longer be in the role of listener but is instead providing information or advice or something. I begin to feel uneasy, concerned whether this may be what the patient needs right now. Maybe so. Who am I to judge, not understanding a word.)

He is still talking.

He pauses. I look to her reaction. Her expression seems to be of despair; cheeks clenched upward, eyes squinting, jaw tense. She seems to be exerting a great effort to hold back whatever she's feeling inside, to not break down in tears and yet her cheeks and jaw begin to quiver. (I still don't know what is going on. I feel a profound sadness, however. A sadness that words can't describe.) He offers a few words, perhaps to console her, try to instil hope in her. (I wonder what he's feeling right now. Discomfort? I wonder how much if his words of console are

for her and how much for himself.) He steps backwards. Nods. Reaches out to touch her, the first time in this interaction as well as the last. He walks away. I follow this time.

I thank him for all his help. Apologize that this probably wasn't what he had signed up for.

"No problem. I'm a health care provider too." (Ah, I see. That's why he seemed to have so much to say to the woman. Judging by his clothes, he must be social worker or something.) Medical geneticist. "I don't get to talk to patients very much. (Surprised. Interesting that he considers himself as part of the team as well.) He asks me about what I do. "Volunteer." He rephrases his inquiry to get at what he means. "What do you study?"

I hesitate, seeing where this is going. "Counselling Psychology," I disclose rather reservedly.

"Ah!" he remarks. "So you should have been the one in there."

"Well it's the language thing," I admit trying to make a joke out of it but feeling shameful on the inside. It's a forced admission. Secret let out again. My feeling of self-worth takes another clubbing at the hand of myself.

Feeling responsible, I outline that I'll take what I've learned and pass it to the nurse. Can't just let this conversation go unheard. I clarify what he has learned from the conversation. Frustration with not being able to clearly communicate with hospital staff, anxiety with not knowing road ahead, regret that even when her son is around, many conversations go over him, suggestion for an interpreter. It strikes me how familiar and basic her sentiments are. People just need to be listened to, to have someone present. My gut wrenches. I wish I could have been that for her.⁴²

⁴² The accumulation of encounters such as this one, although unsettling and confronting of my shortcomings, has helped me acknowledge the privileged position that I occupy as a bi-ethnic individual. I could, with some effort to improve my Mandarin fluency, support this population that seems so very underserved even in a health care community as diverse as we have here. Refer to [Appendix E: Journal Entry: Privileges and Responsibilities](#) for a more in depth discussion about how I have found ways to apply myself as a result of this inquiry.

“If not me, then who?” Amongst other themes, this question of responsibility was central to this encounter with a patient whose English proficiency served as a barrier in care. As members of the ethnic Chinese culture, this HCP and I felt compelled to help this woman in her time of distress. This was not part of any job description but we stepped in because we could. I myself felt compelled to stay in the room even though I had no skills to contribute. I wanted to support this individual and complete the follow up.

As I questioned at the time, it was not clear who was there to support the client. Such is the risk when many people are involved in the care of the patient. In my interprofessional psychosocial oncology class, this diffusion of responsibility or lack of clarity was considered a major contributor to the ball being dropped in care. Who is responsible for helping this individual?

I feel infuriated just now in hearing myself even ask this question. Who is *responsible*? When someone just needs to be accompanied and understood, why is it even about a responsibility as though it appears on our job descriptions. The question shouldn't be “Who is responsible?” but “Who is willing to respond?” At times, it is up to those who are capable and available to maintain an openness, a desire to take responsibility.

Any person can make a difference.

I can identify why taking responsibility is such an important point for me. It goes back to one very emotional exchange in Baltimore.

It is Friday afternoon. I only know this because I overheard one of the hospital staff rejoice about it as I was walking about the hallways earlier. Otherwise, I would not know. The days are all the same within these hospital walls. Each day blends into the other, each meal infringes upon the next.

I am now cozying up on this my makeshift bed of a Lazyboy. Reading a novel that I found in the library. Usually I fall asleep while reading but these days, I'm well rested, overly rested, getting all the sleep that I need. It has been a rather quiet afternoon. On the encouragement of her doctor, *Nímāmā* and I tried for a brief walk around the ward. We didn't get too far until we had to come back. Exhausted.

I hear a quiet murmur. My attention turns away from the story of conspiracies and murders. I hear it again. Not a murmur though. A moan. It's *Nímāmā*. She's in pain. I get up from my bed and approach her.

"How is everything?" No response. Her eyes are shut, her body hunched over, her face grimacing in a sign of great pain. I tremble seeing her this way. I feel some remnants of her pain. "I'm going to get the nurse," I try to assure her, not even sure if she can hear me behind the veil of her pain.

My pace is fast, as fast as the institution would allow. Approaching the nurse station, I identify *Nímāmā*'s nurse. She seems relaxed, engaged with her peers, probably about their Christmas festivities. "She is in pain. Could you come quick."

"It is about time for her morphine. Let me page the doctor to check if it's okay to give it to her." Her words seem frustratingly unhurried. A rhythmic southern drawl. There's nothing more to say. I head back to the room.

Her state is unchanged. "They're going to check with the doctor whether it's time to administer your morphine," I relay to her. Too anxious to sit, I pace around the tiny room. *Nímāmā* continues to moan.

I glance at the clock. Fifteen minutes pass. My anxiety and discomfort and irritation continue to build. Thirty minutes. Forty. The pressure within me is reaching a breaking point. I rush out the room and back to the station.

She and her peers are just as they were before. I try to restrain my voice, try to remain cordial. "She is still in pain." I'm not sure what else to say to not irritate them.

"Oh." She smiles back. "I checked with the doctor and your aunt isn't due for her morphine for another two hours."

My teeth clench. I draw in a deep breath, chest raised, readying to explode. “Abort! Abort! It’s not going to help,” a voice screams in my head. I heed it. I’m speechless, shocked by her seeming indifference to *Nímāmā*’s pain, to the gravity of the situation. Why wouldn’t you just come and tell us then?! Then at least we’d know to expect it! I want to scream all this at the top of my lungs. I want to teach her a lesson with my fury. I want her to hear me, but she doesn’t. I restrain myself. It won’t help. I just swallow my fury, turn around and go back to *Nímāmā*.

I felt completely powerless in this interaction. What could I do? Protest in outrage? No. As my voice of reason warned, it was not going to help. As a family member, I felt my voice silenced in light of the circumstances. Our nurse had occupied a position of control over the care we receive. She may choose to be more open and communicative, or to leave us in the dark. My protest would have if anything aggravated her. We would have been deemed the “difficult family”. Our care would have suffered as a result.

3.3.4 A willingness to respond.

Taking responsibility has since been quite important in our relationship. Too often, such as in that interaction, I have experienced being passed off to another without support and follow-up that I felt compelled to stay with that Cantonese speaking woman and hospital staff until the resolution of that situation.⁴³ I was just a volunteer, but even in this role with neither knowledge nor control of care, I felt more empowered than the patient. The patient was completely powerless. Her language barrier robbed her of the one source of her power, her voice. With openness and a willingness to adopt responsibilities not listed in our job descriptions, we were

⁴³ As I recall this situation, I am confronted with the painful fact that even with my most fervent effort to help that woman, I failed her. I failed to return to her after speaking with her nurse to assure her that her voice was being heard. I have done no better than the nurse who responded to *Nímāmā*’s cry for morphine that day. As a HCP, am I (are we) doomed to let down my patient?

able to give her voice. One language-challenged volunteer and a medical geneticist on his lunch break.

Such stories are to me heartening reminders that any individual has the power to affect significant impact on the care of a patient, whether it is by offering some bridge between languages or in simply being willing to listen. As an example of the latter, I recall one memorable encounter with whose life journey was eerily similar to my own.

Field Notes 2010-08-19

I return to the waiting room, feeling lethargic. I notice that the teenage son of the patient who had just gone in is sitting on the couch. I ask if I can join him. He accepts with minimal acknowledgement. I sit down. Just a moment passes and suddenly, he starts talking to me. I'm told of his upcoming year, his needing to work hard for the first half of his high school grad year with all the applications. I listen, recognizing my role as the listener, feeling in a way confident that I can do this competently. I empathically reflect. The conversation takes a turn.

He tells me about being here for his mom, their strained relationship, her worries about everything these days, his frustrations/resentment, wanting to get out of the house, hopes for his mother to go back to China where she would be supported and connected with family, his burdens/responsibilities going into Grade 12 and needing to get good grades, his university considerations given his mom's wishes and his own, his feelings of being stretched by his own interests and that of his mother's, the support of friends on his illness, the two-faced existence that he lives. "Everybody thinks I'm fine."

(As we talk, I'm struck by his maturity, his mature articulation, his knowledge of the family's circumstances, his consideration of different points of view. I weigh the various responsibilities I have in my volunteer role and reassure myself that I have to be here for this person now.) We speak for what seems like half an hour. There are contemplative silences which don't feel uncomfortable. I comfortably allow the space, knowing that he yearns to fill it. He seems to be thinking. When he begins speaking again, his pace is regular, as though he's not rushing to fill an uncomfortable silence. This is honest and raw, not scripted. I stay with him. (I'm startled on

the inside. We didn't even bother with names. I'm now feeling uneasy, wondering whether I've stepped over my boundaries as a volunteer. I'm concerned about him, his circumstances, his telling me all these things. Do we need to find a private room to talk? Will he say something private that he'll regret not being able to take back later?)

The conversation reaches a natural pause. He needs to go check on his mom. I say that I'll be here. (It doesn't feel like abandonment, just a break to recharge.) We finally introduce ourselves, shake hands. I go for a walk, quickly trying to decompress. Something heavy has been put out, unexpectedly.

I feel such tremendous sympathy for this teenager, this young man. We share so many cultural memberships. He is his family's cultural linchpin, serving as an interpreter, an advocate, a peacemaker, a mediator and now a care provider for his mother. He has been thrust into circumstances, forced to take on heavy responsibilities way beyond his years. There are so many parallels between my own narrative and his. Perhaps that is why I felt so moved and so compelled to reach out to him. I did not have to sit down beside him. I could have easily opted to give him his space, seeing how troubled he felt. But I did choose to sit next to him.

Conversely, he did choose to accept my sitting next to him and to share his story with me. What caused him feel such a degree of comfort and safety that he could reveal himself in such a way? Maybe he had, as I did, recognized our shared cultural memberships and felt assured that I would understand, that we would speak the same "language". Then again, maybe it was just simply my young age. One way or another, he felt compelled to reach out and I in turn expressed my willingness to receive him.

Since that encounter, I have also reflected on the significance of the green volunteer vest that I wore that day. It is by no means an insignificant aspect of the way that I was perceived by this young man. Like the head covering for a patient, the lab coat for a doctor, the patterned uniform for a nurse, the hair net for food service staff, the white uniforms of porters, the blue

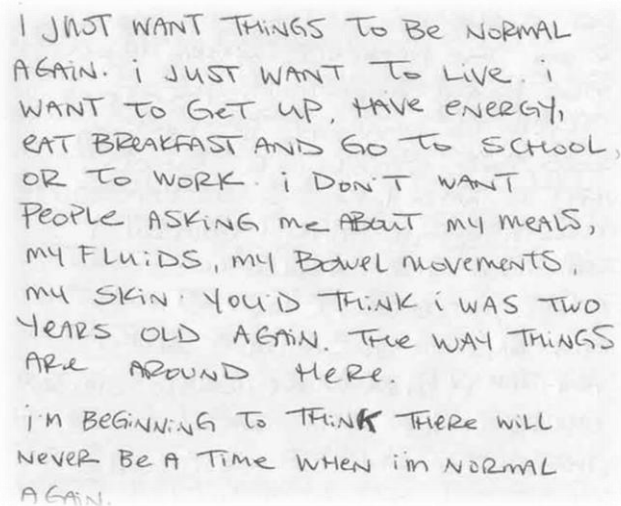
jumpers of maintenance staff; my vest served as a visible identifier within the cancer agency⁴⁴ and to him. Moreover, they serve to facilitate communication. Thinking back to when I first began at the agency, I had struggled greatly to locate myself, to find the right person to talk to. As I learned about these identifiers and countless other more subtle cultural behaviours and practices, I felt more oriented, more empowered. For a patient or family member who does not understand this language, I can only imagine how disorienting their experience must be.

What if this young man felt compelled to share his story for no reason other than the fact that I was a volunteer? This seems to make sense. In this convoluted hospital setting of health professionals and staff of various flavours, with their respective responsibilities and agendas, volunteers occupy a significant and unique role. I was prompted to think about this in an inspiring conversation with the volunteer coordinator at the agency.

It's not about [paying volunteers] because the minute I pay you, it changes the balance of the relationship from what you are able to have right now with the patients and caregivers in the building... and it's one thing that I hear from patients and caregivers all the time when I chat with them or when I see the comment cards that they write... how much they've appreciated talking to

⁴⁴ I have experienced a number of encounters at the agency where, in having been identified as a volunteer, I was addressed as such. There have been a whole host of reactions to this recognition of my position. In some instances, hospital staff had expressed appreciation for my efforts and welcomed my inquiries. In other instances, I was quite abruptly dismissed a person perhaps for taking up her time. I suspect that my apparent youthfulness also contributes to my being dismissed in some cases and that if I were wearing a white lab coat, things would be quite different. This entire train of thought makes me wonder if this inadvertent discrimination is also experienced by patients, that the way that they dress or appear may either advantage or disadvantage their care. I have certainly heard many young adults with cancer express anger in being dismissed by their medical care providers as not being sick, often leading to delayed and misdiagnoses.

someone who is “just like me. Just a normal person who is not here to poke me, prod me or document everything I say.” That’s a real comfort to people that can’t be done by anyone else.⁴⁵



I JUST WANT THINGS TO BE NORMAL AGAIN. I JUST WANT TO LIVE. I WANT TO GET UP, HAVE ENERGY, EAT BREAKFAST AND GO TO SCHOOL, OR TO WORK. I DON'T WANT PEOPLE ASKING ME ABOUT MY MEALS, MY FLUIDS, MY BOWEL MOVEMENTS, MY SKIN. YOU'D THINK I WAS TWO YEARS OLD AGAIN. THE WAY THINGS ARE AROUND HERE. I'M BEGINNING TO THINK THERE WILL NEVER BE A TIME WHEN I'M NORMAL AGAIN.

Image 8. Excerpt from diary of a young woman with cancer.

This is a startling reminder of the privileged position occupied by unpaid HCPs who may offer support not because it is in their job description or that they have to, but that they want to. Such optics make a world of a difference to patients and their caregivers.

3.3.5 The many faces of care providing.

So, who are HCPs? As suggested by the preceding stories and comments, perhaps anyone can be a HCP. Anyone can provide some care or support or willing ear to a patient or family member that will provide them comfort, relieve their anxiety, reduce pain and suffering. Anyone can be a HCP. Volunteers and family members may in many ways provide a quality of support

⁴⁵ Similar sentiments of appreciation were expressed for peers in support groups. At these gatherings, they found support, willing listeners and normalizing experiences, all free from the loaded relationships and expectations of their “real life”.

and comfort to the patient that no paid staff member ever could. For me, this point was powerfully reaffirmed on a sunny morning volunteering in the Chemotherapy waiting room.

Field Notes 2010-07-15

A patient asks me about head coverings. She seems of South Asian ethnicity. They're free to take, I respond. Having dug through supply, she's disappointed by lack of cotton coverings with a rim. They're mostly knitted. Either too warm for summer or lacks a rim. I tell her I'll look around. She thanks me for my kindness. (It feels sincere. I'm struck by how nonchalant she notes she is going to lose her hair. I guess there's a time when they go through realization which happens before we meet. I wonder what that moment of realization is like.)

When I come back from search, I find her with another woman engrossed in a conversation about head coverings like they are the dearest of friends. (How odd. I think about how a waiting room is usually like most other public space in this city. People keep to themselves. Here, people usually come with friends or family, leaving only the volunteers and nurses as the only outside people they connect with. I wonder what's caused these two women to connect. Maybe it has to do with some part of their chemo/cancer experience like losing their hair. Commonalities, perceived shared culture bring people together. I wonder how distant patients feel from the rest of us.)

What strikes me about this scene is not just that this woman had connected with another patient in the waiting room but that she spoke so plainly about losing her hair. As studies have uncovered, hair loss for cancer patients is often intimately tied to one's body image and self-esteem (Bello & McIntire, 1995). Some patients experience it as a loss of their gender identity, a very distressing moment in their treatment. As this woman spoke of her impending hair loss with such normality, I try to imagine that significant moment in her life when she did have to confront her hair loss, cancer diagnosis or any other devastating change due to the illness. And then, it suddenly occurred to me. I was not there. I was not present in her moments of greatest despair. I am only part of her life for this one fractional moment. How could I ever expect to understand

her experiences or to help her in her moments of despair? I try to imagine myself not as a volunteer, but as a paid HCP like a counsellor or nurse. The conclusion remains the same. My encounter with her, this service that I provide is such a small part of the overall support that she receives.

The thought is humbling. As a practicing counsellor, it reframes my perception of the value of my service or of me in relation to my client. It challenges me to look outside of me as the sole source of support for the client. This thought is as humbling as it is liberating, for in looking beyond our dyadic relationship, I discover a whole host of resources and support systems and HCPs.



Image 9. Personal photo of public art entitled *Echoes* at Kitsilano Beach in Vancouver, BC.

Journal Entry 2011-01-23

The simplicity of the art was what struck me initially, it's straightforwardness, it's upright arrangement, nothing more than a bunch of chairs. No angle, no variety, no people to occupy them. My imagination began to fill the chairs with people, interactions and conversations. I began

to realize that each chair arrangement would reflect a very different way of relating to another. The side-by-side forward facing chairs suggest a very different relationship than the face-to-face chairs. The angled arrangement reminded me of an engaged but not confrontational relationship like in counselling, while the three chair arrangement feels very egalitarian and collaborative. It struck me how these interactions are reflective of the many different ways in which we may relate to each other.

For me this art is about acknowledging and accepting such diversity. I think about how health care provision should be similarly perceived. We may position ourselves in relation to others we care about in a number of different ways. It is not to say that one is more valuable than another but that each serves a different function.

3.3.6 Summary.

Anyone can be a HCP. To me, the magnitude of this statement is not to be lost in the triviality of its kumbayah-like tone. This statement challenges my own notion of health care provision as an exclusive task or responsibility or skill of the salaried, job titled, licensed or trained. Instead, it is done by all. This statement legitimizes the impact of those who are not recognized, their work in merely being present or offering support, not only those providing treatment or distributing medication or diagnoses. In fact, the majority of the healing seems to come outside the institutional walls of funded, educated, structured cancer care. I for one had this attitude of viewing care provision as an exclusive task but that merely undermines and denies the value and impact of care provided by so many HCPs. It places a burden of responsibility on the professional or causes the professional to not look beyond his/her own surroundings for ways to relieve pain and suffering. A further consequence of this attitude was in denying my own contribution to relieving the suffering and isolation of cancer patients, as a researcher-listener to their story, as a volunteer supporter of their family members, as an advocate of their

underrepresentation and being overlooked. No longer will I wait for the day that I have a salary position or job title that “graduates or permits” me to be a cancer care provider.

Whether we are the volunteers who help navigate a patient to their meeting during their first contact with the agency or the interpreter who bridges a language divide that robs individuals of their voices or the volunteer who provides information on driving services or the researcher who is unconditionally curious about the experiences of their participant or the oncologists who formulate treatment options, we are all HCPs.

Everyone is a HCP. This statement is not merely about making everyone feel good. Rather, it is about liberating, empowering and giving responsibility to the masses. Despite our social inclination to legitimize the institutions, the funded, the professional, the titled, it is worthwhile to fight back and to acknowledge the value of the countless others. Otherwise, it is doing a disservice to those we strive to care for.

3.4 Conversations with *Nimāmā*

3.4.1 Juxtaposition of our two realities.

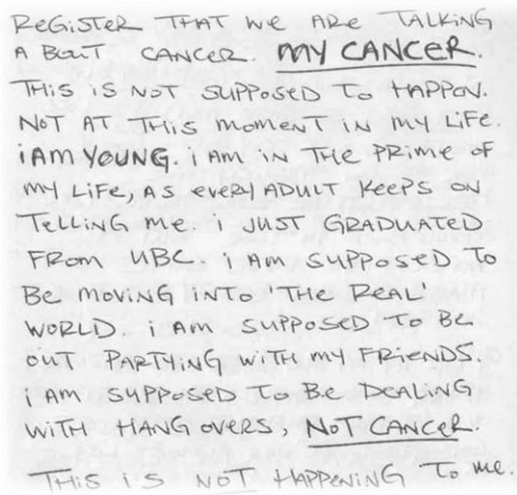
Field Notes 2010-10-07

I’m sitting in the lounge. It feels more busy than usual. A family with two young children sit quietly in one area. The girl gets up, tries to do what she can to entertain herself in the small space. She charges for a few steps and tries to slide as far as she can across the floor. She tries again, trying to get farther. And again, and again. She delights in trying, not so much in succeeding. (I can’t help but laugh watching. It lightens an otherwise sombre atmosphere. I find it to be a strange juxtaposition, that amidst people fighting and on the brink of death that there exists the sound of a young, innocent little girl, giggling with playfulness.)

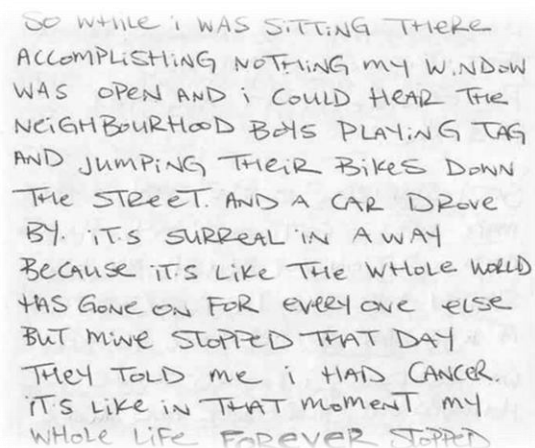
Nimāmā, isn’t it so very strange, so very incomprehensible how these two realities can co-exist. This weird or even twisted juxtaposition of health and sickness, of life and death, of

innocence and a loss thereof confuses me. How is it fair? How is it fair that you must bear pain and suffering while I carry on in freedom and health? Whereas you confront death, I will live on. In spite of circumstances that have brought us together in the final months of your life, life, you continued to care for those around you, while I remained ever self-focused and reflective of my own needs. How is this fair?

In these moments of sober reflection, I recall the stories of the young adults with cancer that I have met, their recounts of life interrupted, of normalcy lost, of potential unrealized, of plans shelved, of life's natural order disrupted, of being left behind by the world.



REGISTER THAT WE ARE TALKING
ABOUT CANCER. MY CANCER.
THIS IS NOT SUPPOSED TO HAPPEN.
NOT AT THIS MOMENT IN MY LIFE.
I AM YOUNG. I AM IN THE PRIME OF
MY LIFE, AS EVERY ADULT KEEPS ON
TELLING ME. I JUST GRADUATED
FROM UBC. I AM SUPPOSED TO
BE MOVING INTO 'THE REAL'
WORLD. I AM SUPPOSED TO BE
OUT PARTYING WITH MY FRIENDS.
I AM SUPPOSED TO BE DEALING
WITH HANG OVERS, NOT CANCER.
THIS IS NOT HAPPENING TO ME.



SO WHILE I WAS SITTING THERE
ACCOMPLISHING NOTHING MY WINDOW
WAS OPEN AND I COULD HEAR THE
NEIGHBOURHOOD BOYS PLAYING TAG
AND JUMPING THEIR BIKES DOWN
THE STREET. AND A CAR DROVE
BY. IT'S SURREAL IN A WAY
BECAUSE IT'S LIKE THE WHOLE WORLD
HAS GONE ON FOR EVERYONE ELSE
BUT MINE STOPPED THAT DAY.
THEY TOLD ME I HAD CANCER.
IT'S LIKE IN THAT MOMENT MY
WHOLE LIFE FOREVER STOPPED

Image 10. Excerpts from diary of a young woman with cancer.

A diagnosis of cancer can be life transforming. Some also continue to persevere in the face of their illness, to refuse to succumb to “practice dying”, to retain some sense of normalcy as though “it’s all good” (Salsman, Garcia, Victorson, Brockstein, & Cella, 2011).

Field Notes 2010-07-15

As I wait for the elevator door to close on the ground floor, a tall and slender young woman slips in. She's dressed in a t-shirt and running shorts with a hydration pack strapped around her waist. She is wearing a hat which covers from sun. (I wonder what department she

works in. Maybe one of those health-conscious, athletic nurses who doubles up exercise and getting to work. I then notice the scarcity of hair underneath her hat. She's a patient! Oh... Just coming in like any other person, doing whatever she needs to do now and then going on with rest of her day. It strikes me how cancer can be all encompassing, and yet for some, they persist in their day-to-day normal lives. I find that remarkable, admirable. I'd like to think that that is what I would do if I ever had cancer. My god. That could very well be me, and yet, it's not me. I feel a sudden connection with this person. From one runner to another, I'm saddened to think about the chronic injury that she has to run through. No amount of rest or remedies could ever remediate.)

Nimāmā, how is this fair? I have struggled with this question much since our weeks together. How cruel life can be to inflict such suffering upon you and upon others – others like me who have left their home countries and find themselves in a foreign context, or others like me at my transitional stage in life – like the young woman of these journal entries or the runner with cancer. And yet, not me. Not me.

Nimāmā, as much as our paths intersected during our life journeys, we were travelling in two completely different directions. I do not live in physical and emotional pain, restricted to certain rooms or certain activities. I am allowed to go free. Like a visitor to this eternal prison that you have to occupy, I moved on when my time was up. I returned to my humdrum life and studies, while you continued to fight, losing, weakening.

3.4.2 Failing you.

I am not sure if you remember the day when we watched a movie or rather, you watched a movie. I will always remember it as the one moment that I failed you so utterly. It was the first day we left the hospital and moved into Charlie's apartment. I remembered it was a warm and sunny day. It felt good to be leaving the coldness and sterility of the hospital, to be going home. I remember you took up the spare bedroom beside the kitchen. Your bed and a big flat screen TV

were unpacked from your move from Michigan but the rest of your worldly belongings remained in boxes, stacked up in the living room wherever there was room.

There was optimism in the air, or at least there was for me. Your big sister, my *Dàmāmā* was coming to support you in a few days. I felt relieved. You'd finally have someone close to you, be with you in a way that I never could. We were strangers after all, connected only by blood and not by experiences or memories. I was your little eight year old nephew when we last met, when we first met really. Maybe this is how you would always see me. I am not resentful of that because I understand how I may always be the little boy to you. Our cultural location was just too separated. Young versus older, generational gap, gender gap, cultural expectations of aunt and nephew roles. I am, however, frustrated that I could not have been a support to you as an equal. Had I approached my responsibilities whole-heartedly and with the awareness that I have today, I would still have encountered a divide between us that I would not be able to bridge. I felt too different from you. I wonder if you felt that way about me.

In spite of my own optimism and *Dàmāmā*'s arrival, I know that it was probably quite unsettling for you to move into the same household as Charlie's partner, the one with whom you have developed such tensions and felt such vitriolic anger towards. I can only imagine how much it scared you to have her so close to you, how much it hurts to be reminded of her presence in your son's life. I imagine that that is why you resisted leaving the hospitals when the staff asked. They even urged you but you resisted. It strikes me now how unsafe that environment must have felt for you, whereas at the time, I felt an oblivious and blissful optimism. The twisted juxtaposition of your fear and my optimism. The cruelty of this divide between us.

In spite of your lack of safety that day, you continued to project strength. You wore your mask of contentment so effectively that I forgot to take care of you. I forgot how much you

needed an ally, a companion and a connection to the world. Having been confined to a hospital ward and room for nearly two weeks, I had such pent-up and anxious energy: When I discovered the stationary bicycle out in the living room, I was determined to use it. At the same time, I felt uneasy for abandoning my mission to stay with you and keep you entertained. My solution was the large collection of DVDs. I could set up a movie for you and then go work off some energy on the stationary bike.

I suggested watching a DVD. You agreed, smiling. I read through the familiar Hollywood titles. I had seen some of them but not others. I was even interested in watching a few of them, and yet I maintained my stubborn commitment to get on the stationary bike, to release my pent-up energy, to exercise. I had decided that I would not watch the movie with you. I presented a number of interesting titles that you might like. We deliberated on each one, reviewing plots, discussing our interest in movies, past movies that we'd seen. We agreed on *Gone in Sixty Seconds*, a car heist thriller with Nicholas Cage. Light-hearted, action-packed. A good escapist movie for the circumstances. You seemed pleased with the selection. Just set it up and back away slowly, make my unnoticed exodus. I remember that day, how you sat in your bed surrounded by a mound of blankets, the brilliant sunlight flooding through your windows. I thought that were comfortable and enjoying the movie. My conscience was eased as I sat out in the living room, expelling energy on the stationary bike.

Then a phone call from *Dàmāmā* or another family member disrupted the movie. You talked on the phone, I came in to pause the movie, believing that you had wanted to but did not know how. The phone call ended, but you never restarted the movie. You could have. You could have restart the movie if you were really interested, but then you really were not interested in the

movie were you? Maybe you were never really interested. You were just pretending to entertain me entertaining you. Who was helping who? I was not sure what to make of it.

The more I thought about it, the more miserable I felt. I had come all this way to support you, to take care of you; and all this time, you were actually taking care of me. In your weakened state, you continued to take care of me and my feelings, watching a movie that you were not even interested in just so that I could allow myself to do what I wanted to do. My guilt magnified. I was so conflicted. I wanted to be angry with you for tricking me like this, for not letting me help you; at the same time, I wanted to have admiration for your altruism. How could I have maintained anger towards you when your intentions were so good?

Underneath this internal conflict, all I can think about is how I abandoned you in your moment of greatest need. When you felt most unsafe, I left you to attend to my own vanity. I regret leaving you for the stupid stationary bike. I feel guilty for being with you but resenting it, for not having committed myself wholeheartedly. I feel guilty for not being your companion, to help you maintain a connection to this world in your last moments of life. I feel guilty for surviving while you died.

These days, my guilt sometimes moves me to tears. I even feel disgusted sometimes. I begin to loathe the person that I discover myself to be. As much as I want to think of myself as a good person, I am confronted by these instances of selfishness and am left wondering whether my self-conception is accurate or just a grand delusion. In providing care to another, will I choose to care wholeheartedly or just step back, distance myself and be driven by my own needs? I am afraid of what my answer might be, afraid that I may not be who I thought I was.

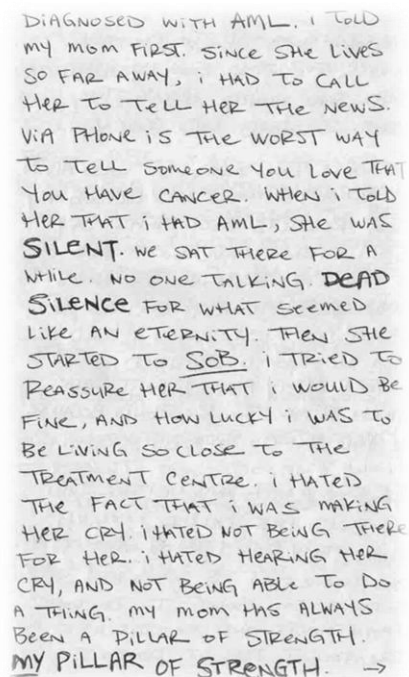
Nīmāmā, I know that you would tell me to not be so tough on myself; that you valued my presence regardless of what I thought I did wrong; that you appreciated me coming all the way to

Baltimore; that without me there, you would have had no one but yourself and that would have been infinitely more difficult. I know that you would say that to comfort me. That is the selfless individual that you are, someone with an extreme loyalty to your family and instinct to protect. You would try to protect me from my feelings of self-loathing and disgust.

3.4.3 Protecting each other.

I have been increasingly thinking about this idea of protecting others, about how we are all so predisposed to protecting those that we love from worries, disappointment, sadness or pain. As you seem to have done for me, you protected me from your own fears of uncertainty. If you had known about my self-loathing, you would try to dispel that too. Even though you were near a breaking point yourself, you took on my burdens along with your own. You wore your mask of contentment to convey a strong image, all the while hiding the tremendous pressures and fears you must have been experiencing. Why did you have to be this way?

This tendency to protect others has cropped up in a number of narratives.



DIAGNOSED WITH AML. I TOLD MY MOM FIRST. SINCE SHE LIVES SO FAR AWAY, I HAD TO CALL HER TO TELL HER THE NEWS. VIA PHONE IS THE WORST WAY TO TELL SOMEONE YOU LOVE THAT YOU HAVE CANCER. WHEN I TOLD HER THAT I HAD AML, SHE WAS SILENT. WE SAT THERE FOR A WHILE. NO ONE TALKING. DEAD SILENCE FOR WHAT SEEMED LIKE AN ETERNITY. THEN SHE STARTED TO SOB. I TRIED TO REASSURE HER THAT I WOULD BE FINE, AND HOW LUCKY I WAS TO BE LIVING SO CLOSE TO THE TREATMENT CENTRE. I HATED THE FACT THAT I WAS MAKING HER CRY. I HATED NOT BEING THERE FOR HER. I HATED HEARING HER CRY, AND NOT BEING ABLE TO DO A THING. MY MOM HAS ALWAYS BEEN A PILLAR OF STRENGTH. MY PILLAR OF STRENGTH. →

Image 11. Excerpt from diary of a young woman with cancer.

For cancer patients and their loved ones alike, this may be experienced as a very confusing reversal of roles. “What am I supposed to do? How am I to act around this person?” This young woman’s journal entry could have easily been your words, *Nimāmā*. In seeing your family grieve for you and your suffering, your instinctual reaction was to comfort us, to stop the source of that discomfort. The source of our discomfort was in seeing you weak and distressed, and so for us, you protected us from yourself. You concealed that vulnerable part of you and put on your mask of strength. We also backed away from you to avoid further burdening you with our concerns and worries. We engaged in this dance of repulsion in spite of our best efforts to conceal our fears from each other and the so divide between us grew ever greater. To others, we remain ever together, and yet we cry in silence on the inside.

I am reminded of a conversation I had with a young man about not crying after receiving news of his diagnosis.

IYA: Yeah! I was sad... but not crying about it. I don't cry a lot. And actually, I have problems crying. I wish I could cry more because then I think that would alleviate me, make all these feelings going away. But I don't.

David: You try to not allow yourself to feel sad.

IYA: Yeah (tentative) I think, I don't want to because I know that if I feel sad, I know that [my partner] will cry more. He's always crying, so I try to protect him, not crying in front of him. But at the same time, we had a conversation a while ago that I want to cry more [...] I told him, if I start crying, you don't need to come and help me. Let it come out first, and then after, you can help me because if you make me stop, it will be worse. Then I will stop, and then the tears won't come anymore.

David: So you mean if he tried to help you or if he cried himself, then it would be even worse for you?

IYA: Yeah, yeah. I think, I think so cause then I would stop. If I see him crying, I would stop crying and try to... make it easier for him. And if he comes and just tries to support me without crying, I think that would make me stop crying because he's trying to stop me, and the feelings won't come out all the way, would stop half way through. So I think it's better to let me cry and let all these feelings cause I won't cry forever. One day it'll stop right? Maybe half an hour of crying will be enough for me and then it will stop and then, and then he will come and help me, and then it will be fine. I think that that way will work better for me.

David: Just to let you have your moment.

IYA: Yeah (laugh nervously), but it hasn't happened yet.

He goes on to identify the “weirdest” and rare moments when he does find himself being moved to tears. Each of these moments, such as in watching a documentary about his career passion or hearing a support group member’s story⁴⁶, were moments of sadness for others. It is as if grieving for others is safe while grieving for oneself is not. The latter can only cause hurt to self and others, whether that may be in reinforcing one’s own discouraging circumstances or in making others worry about us. *Vicarious catharsis*, for lack of a better term.

⁴⁶ The value of peer support groups was commented on by many in the young adult cancer community, from patients to health care providers. This seems to make sense I considering that young adulthood are transitioning from a life stage that places immense priority on social relationships and a sense of belonging. Several young adults with cancer commented on how these forums allowed them to share openly with peers, a rarity given that they experience themselves as a significant minority in a cancer care system that is largely geared to serving an older demographic. Two HCPs observed the immense relief that young adults seem to experience in stepping out from behind the mask that they put on to exist in their day-to-day life. It can reduce pressures in their day-to-day social spheres. Young adults find significant common ground in their shared experience of cancer despite differences in language, experience and cultural identifications. For immigrants in particular, support groups may serve as a community that they are lacking.

I was struck by the clarity with which he sees his circumstances, the openness of his conversations with his partner about crying. In spite of these pieces being in place, his moment of alleviation remained ever elusive to him. There is sombreness and pessimism in the story going forward. "... but it hasn't happened yet." Will he find his moment of relief soon? Will he find it ever?

Nimāmā, if he was unable to reach that point of emotional honesty and relief with the level of awareness and openness in his relationship, I am humbled to think about the insurmountable barrier that we faced. I was your eight year old nephew and you were my aunt, the second oldest of my dad's siblings. Consistent with Confucian traditions⁴⁷, we were cast into our social roles, you as the perpetual care giver and me as the child in need of protection.

In the end, this divide between us comes about through our instinctual desire to protect our loved ones. I find myself falling into this trap. After my recent bicycle accident, where I crashed into the back of a truck at high speeds, lost consciousness and was carted to the hospital in an ambulance, I refrained from telling my parents until I was asymptomatic and fully recovered from the event. I did not tell them because I did not want to worry them. They are so far away that there was nothing that they could have done anyway. Given that we only connect now via Skype, I know that telling them what happened would have just filled their days with worries and a sense of helplessness. The analogy may be drawn for many, especially for immigrants with cancer whose loved ones may be far away. Our tendency to protect others resurfaces, in this case from their feelings of worry and helplessness. It was a simple decision for me at the time, the most course of action that would yield the greatest benefit and least cost.

⁴⁷ Confucianism is considered to be a system of teachings that reinforces existing social hierarchies (Dawson, 1981). Its influences are noted in both ancient and modern day China.

I shared all this with a colleague recently. He was surprised to realize how well I had kept this serious accident hidden from him. I had put him in a similar position as my parents, not letting him know until long after the incident had lost its potency to cause worries. He wondered out loud how I might react had I been in my parents' position, perhaps if my dad was in a serious accident and I was not made aware until long afterwards. I found myself stunned by the thought. I would surely want to know, even if it caused me great distress.

I imagined the reactions I would have. I would probably be outraged and resentful in being left in the dark. Why wouldn't they just tell me? Underneath my anger would be a fear perhaps in being reminded about the mortality of someone I care deeply about. If they hid things from me, I would begin to feel uncertain about our relationship, about whether it was as honest and open as I thought. It would have chipped away at my security in the state of my relationship with my parents. I began to imagine a divide appearing in my relationship with them. I imagined myself becoming distant from them. All of this fell out of their well-intentioned desire to protect me. It was a simple conclusion and yet one that was hidden behind my good intentions, my hypocrisy.

3.4.4 Trying something different.

As I had expected, when I eventually did tell my parents about my accident, my mom expressed some restrained frustration and ongoing worry about my well-being. I reassured them that everything was all right and we moved on. I was relieved that more was not made of the incident and that my decision to wait to tell them worked well. In hindsight, I wonder how much this delayed disclosure also caused them the anger, fears and insecurities that I had experienced in my imagined scenario. I am disappointed that even now, I may have caused them pain even in these moments.

A few days later, something surprising happened. My parents called. They expressed a desire to purchase disability insurance for me. I felt uneasy. They provided arguments of its worth which I heard but had a hard time taking in. Preparing for my own mortality was something that I had rarely if ever confronted. Nobody wants to think about life and disability insurance. The thought of preparing for our own end seemed perversely self-condemning.

These thoughts rattled in my mind as my parents continued their many rational arguments. “Insurance is about buying peace of mind.” “You would have income to live on just in case anything was to happen to you.” “It doesn’t cost that much.”

Then something different. “In case anything happens to us, we’ll know that we’ll always be taking care of you no matter what happens.” Her words hit me like a tidal wave. “...we’ll always be taking care of you.” I had no words. My body began to shiver. I fought back tears over Skype’s faceless interface. For a long moment, there was silence and yet, a whole lifetime of communication was taking place.

Something important occurred to me that day. Had I chosen to never share my bike accident with my parents in order to protect them from their worries, my life would never have amounted to that day. That day, I was awakened to the depth of their care for me. I was reminded of how much their presence is important in my life. It brought our relationship closer together. I examine other relationships in my life, like the illusive and distant relationship I have with my dad. The way we have related to each other for much of our lives revolved around maintaining harmony and protecting each other's feelings. From this, we have remained emotionally distant. Then there was our relationship, *Nīmāmā*, the way we kept away from each other. You were locked in your care giving role as my aunt, and I was ever fearful, handling you with care.

Whereas our instinct to protect others creates a great divide between us, our “gifts of pain” bring us closer together.

3.4.5 Protecting ourselves.

What keeps us from realizing this gift? Maybe we are protecting each other. Maybe we also protecting ourselves. From what? From the care of others, from their rush to action. I am reminded that I often keep things from others because I do not want to be blamed, criticized or nagged. In the case of my bike accident, I had predicted that had I told my parents about the incident, I would have been verbally bombarded with a host of advice, suggestions and warnings. Have you ever experienced this, *Nimāmā*. Knowing our family, you probably have. I imagined that you might be as averse to people’s misplaced and inappropriate advice as I am.

Maybe not though. I acknowledge that as an immigrant young adult who has come to greatly value my self-sufficiency, I react quite strongly to my parents’ even well-meaning support. I perceive it as an attack on my very identity as a young adult.⁴⁸ I resent them for holding me back from becoming successful in life. My frustration and resentment becomes directed at them. Indeed, resentment and anger towards my parents were themes that dominated much of my late adolescence and early adulthood. Their advice often came across as imposing and restrictive, rather than supportive to my growth. What is more, I dismiss their advice because it does not fit my circumstances. I think in my mind, yes, that would work for you but

⁴⁸ I wonder how pervasively this is also experienced by young adults with cancer whose illness forces them to receive support and care from their family. I would imagine that it is a conflicting experience to accept support that they very much need and yet feel as though they are giving up their identity as a strong and self-determined young adult. Maybe some will also, like me, develop resentment towards their well-meaning loved ones who seem to be the source of their regression in life development.

not for me. Given their strong identification with their parental roles and resulting fears and yearning to help, they would quickly jump to problem solving mode. I would in turn be left feeling let down by them, wondering if they had even heard how much the experience had affected me. This is often all that I truly want from them, to be heard. Is that not what everyone wants? I am quite capable of reflecting on the past and taking prudent actions for the future. All I want is to share with them my life, be heard and understood.

Given my past disappointments in sharing my experiences and not feeling heard, I became cautious and even avoided sharing as I did about my bike accident. It is a simple process of behavioural conditioning (Skinner, 1990). Behaviours that are followed by adverse consequences are extinguished over time. Subtly, the divide between us widens.

Recognizing the value of sharing in bridging interpersonal divides and forming strong relationships, how then could I have done things differently for you, *Nimāmā*? For my future, how can I as an emerging HCP encourage sharing and connecting amongst those I care for? What I want for myself, I will try to provide others. A willingness to listen, without judgement, without conditions, without a compulsion to respond.

3.4.6 Someone who is simply present.

In my role as a volunteer, I have learned much about how to be comfortable just being present.⁴⁹ The disposition to simply be present with patients and family members seems to be embedded into the cultural norm of the volunteer role.

⁴⁹ The commitment to simply be present remained a challenging one despite my four years of clinical training in counselling psychology. I was quite surprised by this given my discipline's commitment to the theoretical orientation of humanistic psychologist, Carl Rogers, whose principles of genuineness, empathy and unconditional positive regard in essence describes the commitment to be present and bear witness (1957). Perhaps this speaks to

Journal Entry 2010-04-15

As part of my cancer agency training to be an inpatient volunteer, I have been attending an extensive four day workshop offered by Vancouver Hospice Society. One of today's topics was on being present with someone. One handout read, "In this work, it simply comes down sooner or later to how comfortable we are with ourselves, with others, and with the whole idea of dying, because often working with the dying involves more 'being' than doing."

Acknowledging that those we care for may not always be able to respond, the facilitator guided us through an exercise in approaching and being with someone who is asleep. Go in, speak to the person as though they can listen, announce that I'd like to sit with them for a while and then just sit there, being fully present, feeling their existence. At the end of five minutes, we'd get up softly announce our exit and leave. The experience felt awkward, almost embarrassingly mystical. There was even some discussion afterwards about spirit, energy and connection. I am usually quite open-minded about these things but the idea of sitting with someone who may not even be aware that I am there sounds somewhat futile.

- **Disclose accurate and appropriate information. You may be asked questions that you cannot answer. Rather than avoiding the question or providing an untrue answer, you should acknowledge the importance of the question and direct the patient to a person who can address the concerns. For example, if a person asks you a question about their cancer treatment, you could respond by saying, "It sounds like you are very concerned about your treatment. Your doctor or nurse may be able to answer your medical questions."**

Image 12. From "Volunteer Handbook: A Guide for Volunteers," by Volunteer Services, 2009, p. 21. Copyright 2009 by Volunteer Services. Reprinted with permission.

the cultural norms of the counselling profession where an aim for growth and healing creates pressures for observable change within the boundaries of the therapeutic encounter. Being a volunteer has taught me how to simply be present with someone that I was unable to experience in my professional training.

At first, I found these norms overly restrictive and disempowering. I believed that volunteers were capable of doing so much more than this. It seemed as if we were just divesting responsibility and liability in a way that lacked compassion for those we cared for. What I am able to better appreciate now is how the most compassionate act may be in just being present.

Field Notes 2010-12-02

I head for the room belonging to the Chinese patient that the nurse suggested. It is a single room. The room is dark with the window blinds closed. The privacy curtain is drawn around the bed so that those in the hallways cannot see directly into the bed. I have to fully enter into the room before I am able to see him. He is hidden behind the curtain. He is sleeping, his blankets tightly bound around him. It is as though he is in a cocoon, enveloped, protected, body undergoing some process of metamorphosis though unlike for the emergent butterfly, this being is undergoing a process of degeneration. We are trying to slow it but can't. I notice his position, turned away from the hospital and towards the window as though he is saying, "I don't want visitors." I look around and see no sign of visitors. I feel saddened.

Still asleep. I leave, disappointed and burdened that I was not able to bring company to his isolation, comfort to his life this day. [...]

I go back a second time, committed to connecting with him. He still looks asleep, but I'm persistent this time. I make some noise with my shoes. It works. His eyes open. He notices me. I smile hoping I didn't freak him out. I offer my invitation. He makes no response but looks at me curiously. Ah, there may be a language barrier between us. I rephrase my invitation, then a second time. I am persistent, maintaining a smiling, gentle expression. I want to convey compassion, care, hoping that he will accept my offer. He nods his head. I'm unsure whether it is in consent or in affirmation, the way someone does naturally as a gesture of politeness. I check again to making sure, worried that I may impose myself at his discomfort. "Can I sit in this chair with you?" He nods his head. I hesitate, still unsure, but I sit down.

I take a deep breath, a breath of accomplishment, a breath of relief in having reached a new stage. I sit with my back to the window, looking back into the room, towards the bed,

perpendicular to it. I do not stare at him, just at the bed, the covers. I feel no compulsion to immediately start talking. His expression doesn't seem to give an invitation to want to talk. He can initiate if or when he feels comfortable. I will just be with him today.

I take a moment to reflect on my surrounding, regulating my breathing to adjust to this new position. I peer out of the corner of my eyes at him, his eyes are open, staring off into space. We sit there in silence. I hear the sounds of nurses engaged in discussions out in the hallways, the movement of the caretaking staff preparing the bedroom next door for a new patient. Beyond that there is silence. I wait. I somehow feel patient, at piece today. I feel no compulsion to leave at the earliest opportunity. (This is a strange experience. Why is this so? No need to leave till much later on so I have time for once. It feels good to have time, for the patient and for myself. I also feel especially committed given the life history that I've projected onto this individual, the background that I imagine we share.)

"You speak Chinese?" he asks suddenly and in tentative, court English.

"I do," I answer, eager for contact and for this commonality. I switch over to Mandarin repeating that I can. (The broken Mandarin that I have been left with after years of growing up in an English context. I lament my fading language skills, what could have been. These encounters remind me about what I have lost. I am filled with sadness in having lost such a big piece of my childhood.) He doesn't respond immediately.

He asks me in English if I speak Cantonese.

"I don't," in Mandarin. (I'm disappointed by the missed opportunity to connect on this front.) "Do you understand Mandarin?" I ask in Mandarin.

Yes, he responds in tentative Mandarin. From this, I sense that this is as far as he may comfortably proceed in Mandarin.

In English, he asks me what I do.

I tell him that I am a student at UBC. He nods his head in understanding, but more so in approval or admiration, the way our overlapping value systems put education in high regard.

"Ah, so you must be very smart." I immediately and politely laugh it off. I tell him that I am from the East Coast. Our conversation turns to weather, coldness, how nice it is in Vancouver.

He coughs suddenly, not heavily but enough to cause his body to convulse. I remark his cough and that it must bother him a little. "No," but rather than continuing on, he pauses for a moment (seemingly thinking about his coughing or sore throat) and an expression of annoyance or disgust emerges on his face. He corrects me. "Not a little, a lot cough." I check whether he needs water. He doesn't. He is okay. I resume my position in the chair.

He asks more questions. I openly answer, careful to my use of words. After a few exchanges, the conversation reaches a natural lull. I have answered his questions. He has no more for me. There is silence. (I feel at peace with the silence. My mind is not racing to fill it with my own questions. I am aware of my reluctance to burden him, to barrage him with questions as though I'm an interviewer or interrogator. I recognize that because of his challenge with English, my questions would cause more discomfort than anything. I am therefore comfortable with the natural lull that we have arrived at. My goal is not to make conversation but to communicate an unconditional acceptance of him and willingness to be here. I believe that he understands. I don't know why I believe so.) And so we sit, I comfortably. (I am not sure whether he shares my comfort with the silence, whether he is relieved to not have the burden of language to deal with another's presence. I sense that this is the case, that he too is comfortable with the silence as he does not hastily try to fill the silence with more questions.) I stare across the bed to the wall at the other side. Occasionally, I sneak a peek at him. His eyes just stare off towards the ceiling, towards something. (I wonder what it is that his mind's eye is staring at.) He seems calm, not anxious. His mind does not appear to be racing in thought.

In the silence, I hear laughter. Two staff are joking about an upcoming event. The levity of that mood is juxtaposed against the peace. Yes, it is peace that exists here. I feel irritated, that our peace is being disturbed, violated, infringed upon by their levity.

I stare out the corner of my eyes. His eyes are still open, still starring upward, towards something. (I wish I knew what.) I check periodically. At one point his eyes close. He is asleep, not just resting his eyelids. I remain in my seat, feeling no compulsion to use this as an excuse to leave. I feel no compulsion to leave. Rather, I feel that it is just right, right for me, to remain present while this person sleeps. This is my task for today, I acknowledge to myself. This is my

contribution to this man's life. In this moment, I feel proud to have this task. I feel uniquely suited to do so.

I feel the ambiance of the room. I sense a connection with him, perhaps not in spite of the silence but due to the silence.

After some minutes, my attention begins to focus outward. I go from being the participant to the observer. I note the colour of the walls, the scribbles on the board, the nurse's name, emergency contact number, his shoes neatly placed on the floor against the wall so that it does not get in people's way. I become aware of how bare the room looks. (No one seems to live here or call it home. I wonder if he feels at home here or if this is a foreign environment to him. It strikes me how there exists a tension living in this space for the patient. Should I set roots down in this space, try to feel comfortable, at home, in spite of the circumstances. Feeling at home in this space almost seems self-condemning. The alternative would be to remain detached from the space, to allow it to maintain its bareness, its lack of a personal quality. Both alternative are undesirable. How uncomfortable of an existence this must be.) My mind returns to him. I wonder if he perceives himself merely as a visitor here, a sojourner.

I return to my completely present state, staring at the wall across the bed. Minutes pass. My eyelids become heavy. I fight to keep them open. Frantically, I refuse to give into my tiredness, to make it possible for him to open his eyes and find mine closed, uncaringly closed. I do not want him to feel uncared for. I want to demonstrate my full attention, my unconditional acceptance of him. I do not want him to believe that I am bored or want to be somewhere else. My eyelids become increasingly heavy. I notice myself drifting in and out of consciousness. [...]

I awaken, startled to the sound of a nurse in the room. Luckily, I regain my senses before he does. [...] The nurse leaves. The silence returns. I sit, not wanting to initiate the discussion, not wanting to burden him with my questions, my demand for language.

I am now becoming aware of the passing of time. I glance at the clock every minute or two, realizing that now I need to go. I have a research interview. I try to sit patiently, but now I am no longer able to. I contemplate in my mind how I can leave without disrespecting this individual. I

consider just leaving. No. I decide to make some noise again to get his attention and tell him that I am going to go and come back.

“Go,” he says quickly. (I wonder if I have offended him, that I gave him the impression that I was plotting to abandon him all along. But I don’t, I want to reassure him, yet I say nothing. I wonder if he has understood anything of what I have thought. Perhaps not. I leave, feeling uneasy, uncertain.)

In this encounter, I was deeply committed to just being present with him. As I reaffirmed to myself on several occasions, I simply wanted to communicate my unconditional acceptance of him and willingness to be there. In a somewhat ironic way, the language barrier between us seemed to free me from the obligation to fill in the silences with idle conversation.

On several occasions, however, I fought back the urge to pull out a notebook to capture my experiences in the moment. In the end, I became distracted by my limited time and other obligations. Even with the freedoms from responsibility afforded me as a volunteer, my other roles as a researcher and as a student permeated into this peaceful space and challenged my ability to just be present. This is a sobering thought. I wonder how many other HCPs hurry about with their tasks, not attending to their patients’ fundamental need for human presence, to be heard and understood? Perhaps, like me, they have a commitment to this and yet the expectations imposed upon them by their job, their system, their institution derail even the most fervent commitment to just be available for someone.

Then again, I imagine that others may simply not share my acknowledgement of the immense value of bearing witness to someone’s joys and sufferings. It is perhaps easier to make such a claim when amongst a group of counsellors, whose forefathers of Freud and Rogers modeled a comfort in just being present. Amongst other professions, where success is framed in

terms of reduced physical discomfort, hospital utilization, and survival and mortality rates, such an acceptance of a patient's anger or misery would seem quite absurd or superfluous.

Whatever our professional aims may be, being present for another is a gift that is often undervalued. Both volunteers and peer support group members seem to be valued within cancer care for their very unique role in simply being with someone. As noted by the volunteer coordinator, patients and family members express appreciation for having a volunteer just be present for them, to hear and understand their experiences. Often, volunteers provide this form of comfort in moments or places where no one else could or would, such as in a lounge or while waiting for an appointment with a medical staff. Likewise, young adult cancer patients have identified groups as being a valuable part of their support network. As many group practitioners have pointed out (Westwood & Wilensky, 2005; Yalom, 1998), one of the primary therapeutic functions of groups for group members is often in being witnessed in ones journey of struggle and growth. Through group norms of non-judgmental listening and a disposition to shy away from giving suggestions, group members are able to simply witness, hear and understand.

3.4.7 Courage and strength.

As I think about the value of just being, it occurs to me that it takes tremendous courage and strength for care providers to adopt such a position. In relationships that I value, such as with my parents, I have a hard time resisting my temptation to solve problem. Admittedly, I often find myself providing unsolicited and inappropriate solutions rather than simply listening and understanding. I feel compelled to respond in some way because I care, and yet all the while, I disempower them. I dismiss their capacity to come up with their own solution that fits for them. Like handling someone with care, I care so much that I rob them of their ability to handle it.

Therefore, it seems to me that it takes tremendous strength to bear someone's pain without moving to rescue them or relieve them of their suffering. Often, such inaction goes against my deepest instincts to love and care, and yet it may be the most compassionate act of all. My parents had struggled to find the strength to just accept my bike accident. It was only when they stopped imposing solutions and spoke to their own experiences and fears that I felt a connection with them that brought our relationship closer together. This, in turn, gave me a sense of reassurance that I could share with them in the future. As such, being present seems to create an environment where interpersonal divides are bridged rather than widened, and relationships are strengthened.

Nimāmā, as much as I can convince myself through these arguments, how could I ever feel at peace having simply been present with you. I am still haunted by the sound of your crying in the middle of the night. You were alone in your bedroom while I remained awake outside, in the living room. Yes, I witnessed your pain in those moments, but not out of courage. I did so because I did not know what else to do. I was not sure what else to do. I had left you in your room to watch the movie all alone because I did not know how to be in sitting with you. The nervous energy that I was so eager to expel was perhaps from being witness to your pain and yet feeling paralyzed, not knowing what to do to ease your suffering. During those days in the hospital, I just wanted to look away and leave that hospital setting. I wanted to leave that world where cancer, pain and suffering existed. I was scared and did not know what to say. I was afraid to get close, to touch, to drop, to break you so I put on my mask. I was not strong enough and unable to bear witness to your pain. I ran away from you in the same way I ran away from one individual at the cancer agency.

Field Notes 2010-10-07

Noises, cries, painful grunting from within. I notice the sign on the door. "Restricted Access." (It creates the impression of a movie scene. Some untold danger beyond. I cautiously peer in. A single bed deep inside the room. It seems so far from the doorway. A man occupies it, turned away from me, face not visible. His body is hunched, lurching, contorting, clearly in pain. In solitary, last room at the end of a hallway, far away from the nurse station, other patients and any compassionate ears, I find it difficult, heart-wrenching standing here in my serene comfort, witnessing his pain and suffering. It's like watching a war prisoner being gruesomely tortured to tell some secret. I'm filled with despair and pity for him. Part of me wants so much for him to tell his secret, to give up to the torturers, but he refuses to. As if he is able to. If only he was able to.

Help! Help! I want to cry. I look back down the hallway. The world is still the same. No alarms, no screams. No one is rushing towards us. The normalcy makes me accept this torture, accept that people are suppose to suffer. I move on, refusing (By doing nothing, have I become an accomplice in this man's torture and perhaps death.) to be a spectator in this man's torture.

I have been haunted by the image of this man's screams and contorting body. "be a spectator in this man's torture." A striking choice of words. Why torturer? Why implicate myself in his suffering? Now, I recognize that that person in the room was you and I did see myself as your torturer. I was too cowardly and weak to just stand there, to bear witness to your pain, and so I ran away. I abandoned you and so I hold myself culpable. Even now. I regret that I did not stay. I regret that I did not share my fears with you. I regret that I did not tell you that I was there, that I had witnessed your pain and suffering.

3.4.8 Your gift of pain.

Journal Entry 2011-03-13

Nimāmā, today I thought I heard your voice. I thought I heard you speaking to me. I was working on this thesis. Music was playing in the background. The familiar and lulling melody of

Michael Jackson's *You Are Not Alone* came on. As the song progressed to the chorus, I was startled by the sound of your voice. You were speaking to me.

Chorus from Michael Jackson's *You Are Not Alone*

♪♪ That you are not alone

I am here with you

Though you're far away

I am here to stay

But you are not alone

I am here with you

Though we're far apart

You're always in my heart

This song has always had special meaning for me. It is a dialogue between two voices: one represented by the verses, sad and lamenting; the other represented by the chorus, reassuring and comforting. I always thought of myself as the comforter, the care provider who reassures that you, *Nīmāmā*, are not alone. Today, as I listened to this song, I heard your voice in this chorus, not mine. You were the reassurance, the comforter. I was the lonely one. And with that shift in frame, the song felt so very right.

As I reflected on the words with newfound clarity, I noticed a void within me that I'd never noticed before. "♪♪You never said goodbye, someone tell me why." I was overcome with sadness. My body convulsed like some coldness had filled the room. But it wasn't coldness. It was warmth. "♪♪Though we're far apart, you're always in my heart." I felt your presence and your voice comforting and reassuring. You were telling me to forgive myself. You were asking me to let go of the critical voice that resides in me.

So I cried for you today, *Nīmāmā*. I cried in sadness for your pain, the worries that filled your sleepless nights, your isolation from those around you; your life unlived, your potential

unrealized. But then, I also cried for myself today. Crying for the regret I feel about all that I did, all that I was too scared to do and the guilt that I have carried for so long.

Today, I have come to a sense of acceptance of my role in your life. I acknowledge the value that I may have had in just sitting with you during those weeks together. For a long time, I regretted not having done anything for you. Then again, maybe that was the most compassionate act of all, to simply be present for you, to hear and understand you. I want you to know that I did, that while I had left you in your room to watch the movie, my thoughts were still with you. Even though I was too weak to handle my own fears and to remain close to you, I tried the best I could. I wish I had told you this, but maybe you already know. I hope you knew.

As much as I was frustrated by the divide that was between us, I'm trying to accept that these were the circumstances that were laid out for us, the cultural locations that we occupied. We began as strangers to each other, connected by blood only. I was your nephew, you my aunt. I wanted to be your protector, your care provider and when I felt myself being unable to do that I became frustrated and blamed myself for my failure.

“♪♪Your burdens I will bear, but first I need your hand.”

I was resistant and resentful of your protection. It made me guilty to think that on top of the burdens that you bore, you also had to bear mine. But then, that was my mistake because you were also my protector, my care provider. You modeled someone who is ethnically Chinese, and yet much more. You gave me permission to feel comfortable and not ashamed with my own Chinese-ness. You have given me a gift, the gift of pain.⁵⁰ I have come to understand how the sharing of pain although scary can bridge interpersonal divides and bring people closer together. Over this journey of being a researcher and care provider, I feel much more connected to you as a result of the pain that we have shared.

So I guess I cried for the both of us today, but rather than a cry of sadness or pain, maybe it was more so in remembrance of the past and in marking a new beginning.

⁵⁰ I was drawn to this idea that pain can be a gift. It was the theme of a documentary I came across entitled *The Gifts of Grief* (Sobonya, 2005).

Poem 40 (Rumi, 1974)

I saw grief drinking a cup

of sorrow and called out,

"It tastes sweet, does it not?"

"You've caught me," grief answered,

"and you've ruined my business.

How can I sell sorrow,

when you know it's a blessing?"

CHAPTER 4: CONCLUSION

Through the ebb and flow of this research journey, the question that emerged as being most relevant to me was “How do I understand my role as an emerging HCP for immigrants and young adults with cancer?” My journey has brought me to speaking with individuals living with cancer and their care providers, to examining my cultural location and that of the other, to reviewing the scholarly literature and other textual materials related to cancer care, to being immersed in the cultural context of the cancer agency, and to reflecting on my own experience as a care provider for my Aunt *Nimāmā*.

At this point in the thesis, I feel greatly tempted (or perhaps obligated) to draw broad conclusions, or make bold claims and premature recommendations about the implication of this research. Admittedly, in this institutional context, doing so may somehow legitimize this research inquiry. I am, however, rather reluctant to prescribe or impose any of my own insights gained over the course of this research journey upon you, the reader. It might be inappropriate or even arrogant to suggest that my insights ought to become your lessons; that somehow, I am a voice of authority on being a health care provider (HCP). I hope that I have been able to create a seat for you on this journey and did not leave you behind. I hope that these stories have engaged you to reflect on your own role or circumstances as a HCP. As such, I am reluctant to determine the “implications of this research” (i.e., what I have discovered through my own self-reflections) for you. If there are implications at all, I hope that you have come upon them through your own reflections.

Recognizing my obligations in having membership to and participating in this institutional culture, however, I will attempt to summarize my own insights from this four year

research journey and their implications on my own research directions, clinical practice and future.

4.1 Implications for My Research Directions

The qualitative ethnographic approach I employed in this inquiry my self-analysis and clinical experience. As an immigrant of Chinese ethnicity who grew up in a predominantly Caucasian society, I have never perceived myself to be a typical person of culture X or Y. As considered in my understanding of the term culture⁵¹, my cultural identity remains fluid. This has informed my view that that we are all multicultural beings and as such we do not fit neatly into the ethnic or racial framework used within and implied by the research community. Questions such as “What are the attitudes and beliefs toward mammography among African American women?” (Champion *et al.*, 2008) or “What are the breast cancer experience of Asian American women?” (Ashing *et al.*, 2003) presume a certain homogeneity in the cultural constructs being investigated. Given that constructs such as African American or Asian are often anything but homogeneous if not semantically ambiguous, such inquiries and their associated findings seem problematic. The aim of such research seems often to be reductionistic in drawing some simplified conclusions about a vast and diverse population.

Out of these realizations, what struck me as infinitely more informative to my own clinical practice are inquiries that seeks to understand how individuals experience their lives at the intersection of their cultural identities. In other words, what part of a person’s identity is affecting his/her experiences? Many scholars argue that this “intersectionality” research is what will ultimately inform and advancing our clinical practice (Cole, 2009). Moreover, Brown (2011)

⁵¹ For a more extensive discussion about my understanding of the term culture, refer to [Chapter 1.4](#).

likens such research efforts to the continuous n=1 research and data collection that clinicians engage in on a daily basis.

Through this current study on the intersectionality of my own cultural identities, I have come to recognize the immense value of such inquiries aimed at revealing complexities rather than simplification and heuristics. Research that aims to simply and formulate heuristics is not as valuable to me given the nuanced richness of our human experiences and the stereotyping that such research has encouraged in me. At the same time, I find the confusion and sense of not knowing that I have experienced in this inquiry helps me remain grounded to a position of humility, curiosity and interest. In my clinical practice, it is when I lose this attitude that my work becomes less effective. Likewise, as someone who provided support to patients and their loved ones, I was able to establish a compassionate connection when I remain humble.

Over the course of this research, I have also come to appreciate Ruth Behar's argument that "research that doesn't break your heart isn't worth doing" (1997). On first pass, Behar's argument seemed intentionally exaggerated. Then again, when I think about the studies that have left the greatest impression on me, they are ones that are able to communicate their findings in a way that reveals the raw and emotional experiences of individuals.⁵² I find these accounts to reveal more about the truth of individual human experiences than the horde of aggregative and comparative findings that dominate the literature. Moreover, I have become aware of how stable

⁵² For me, examples of such works include Gray's (2000) *Handle with Care?*, a theatrical production that portrays the experience of metastatic breast cancer patients; and Bryant's (2010) *Wrong Way to Hope*, a documentary about young adults who live on in spite of their cancer.

my worldviews can sometimes in the face of new and conflicting information.⁵³ In consuming research, I tend to overlook or rationalize away findings that are not consistent with my existing understanding. As a result, I simply dismiss or forget about many well-designed and carried out inquiries.

My initial uneasiness and dismissal of the autoethnographic research approach was surprising and revealing of my cultural location and the beliefs that I hold about what constitutes research. In a brief moment of forgetting these lessons, I became awakened to the power of the self-narrative inquiry to uncover and communicate truth about human experience. I felt as though I was being invited along on their journey of self-discovery, rather than taught or sold to. When autoethnographers spoke from their own experiences in a way that profoundly evoked or revealed their emotional experience, I in turn felt intimately moved. Given the transparency with which authors made clear their own position, I found myself participating in a discussion with them about how my own narrative was similar or dissimilar. As a result of the author's self-exploration, I was able to learn about my own.

Given my own experiences with the evocative self-narratives of Ellis (Ellis, 2004) and Hayano (1982), I became inspired to adopt this exciting but foreign and intimidating approach. What made autoethnography a particularly valuable analytic framework was its fitness with the personal question that emerged as being most important and relevant to me. Moreover, the emphasis on reflexivity parallels counselling psychology's tradition of increasing self-awareness.

⁵³ This reflects a widespread phenomenon known as a confirmation bias. It is the natural tendency for people to favour information that confirms their existing worldview, while dismissing that which is inconsistent (Abreu, 2001). In essence, our attentiveness to new information or recall of existing information is selective and biased.

As I was preparing myself to work in the field of cancer care, the opportunity to examine my own position and biases has prepared me to be more comfortable in my role as a provider of cancer care.

All of these factors have given me a newfound appreciation for this method of inquiry. In considering the question of how (or the process by which) I have come to understand my role as a HCP, I have recognized the significant role of the individual narratives in informing me. As I find myself less and less informed by the aggregative findings of traditional research, I found the narratives that came from my conversations with participants or through reading autoethnographic writings, to be much more compelling. Rather than categorize and simplify as in the case of most research I read, people's narratives made things more muddy and confusing, a position that helps me maintain my humility and curiosity. As I go forward, I feel much more at ease with seeking out narrative and autoethnographic works as a source of knowledge about human beings.

4.2 Implications for My Practice

In [Chapter 3.3](#), I asked the question, "Who is a HCP?" In reflecting on the many forms and sources of helping that I observed and personally experienced along my journey, I realized that providing health care is not some task or responsibility that is exclusive to those who possess official job titles, or expensive education and training. I found myself empowered by this realization as a volunteer who, together with a laboratory staff, was able to quickly step in to engage with and support a Cantonese speaking woman under significant distress.

Anyone can be a HCP. In this way, I faced the sobering and yet comforting realization that much of our suffering, healing and support takes place outside the institutional walls of funded, licensed, structured cancer care. People's engagement with the cancer care system is

infinitesimally brief. Some may even try their best to minimize their interaction with the system. It was sobering to realize that a patient who seemed so pleasantly cheerful and warm when I met her had one day been confronted with some earth-shaking experience like losing her hair, her sense of womanhood or self, or her family. The encounter made me wonder where I was when these experiences took place. Where will I be in my role as the trained, paid, well-intentioned HCP in her life when she next experiences moments of intense pain and suffering? The fact that I will never know and will likely not be there in her “moments of greatest need” was quite humbling.

It is a romantic notion, this idea of being the knight in shining armour that my client or patient is waiting for, that *Nimāmā* needed. Of course, like most romances, it collapses under the weight of its own expectations. I realize that having this view does a disservice to those who I am trying to support. It is an egocentric, self-aggrandizing position, to put myself in the centre of the individual’s universe as though I as the counsellor or volunteer am the only show in town. As I have experienced with *Nimāmā* and with clients in my clinical practice, it also places immense pressure on those brief moments that we share. Therefore, recognizing that you have a life and support system beyond my dyadic relationship with you is relieving and empowering of you. I shift from a role of providing to one of facilitating and bridging.

Anyone can be a HCP. My time with *Nimāmā* and as a volunteer helped me appreciate that often times, the greatest gift I can provide another is my presence, and my willingness to hear and understand. As much as I expect to provide some observable relief or concrete solution, my simple company may be what invites people out from behind their masks and closes the interpersonal divides that the experience of cancer so often creates. And yet, the greatest gift I could have provided her was my presence, my courage to stay. I do not think that she wanted or

needed me to take her physical pain away or to resolve the interpersonal conflicts that had existed in her life. From me, she simply wanted someone that could accept her unconditionally and not have advice or expectations for her.

Someone that could sit with her and watch a lousy escapist movie with her.

Someone that could play cards with her.

Someone that could share with her stories, learning and hopes for the future.

Someone that could help her stay grounded in this world at a time when she was losing grip.

At the very least, I provided these gifts to her.

And although anyone can fulfill this role for someone, I have realized that it takes tremendous courage and strength to be able to bear witness to their pain. So often our natural response may be to be moved to action, advice or solution, and despite my good-intentions and care, my help becomes often misplaced and unwanted.

“Anyone can be a HCP” also means that those who are cared for, may also provide care themselves. I did not realize this in the time that I shared with *Nimāmā*. Instead, I desperately tried to impose myself as the HCP, which condemned her to a position of illness, weakness and need. It denied her the opportunity to express her strength, her self-sufficiency, her deep devotion to her family, qualities that remained with her even while she had to bear a disease that was shutting down her body.

I did not need to be her care provider, but she was mine. She provided the gift of pain, the lesson that through sharing her suffering then and through crying for her now, we become closer. We were no more than strangers before, connected only by heredity. Now, my pain, my grief and

even my guilt is what connects me, and all my future work and aspirations in this profession to her.

4.3 Implications for Social Policy

Such considerations prompt the question, “What holds currency?”, and in follow-up, “Who determines what holds currency?” To the first, I was reminded of a recent and thematically familiar news report. A local weekly, drop-in recreation group therapy program for seniors was closing due to provincial funding cutbacks. Several group members expressed sorrow and anger as the program was “a lifeline” that gave them “motivation to get up”. I was disappointed in hearing about this news, not only for its implications on the well-being of group members but also for what it suggests about those engaged in policy making. Is it a reflection of their attitude about what sort of care holds currency and thus is deserving of funding? For those who see no motivation to get up or looking forward to the next day beyond the sense of community and contact which they may experience, is the mere being present not the most invaluable care that we could provide them?

What discourages me more than the views of certain policy makers is to think that similar attitudes may be pervasive within society at large. Indeed, I recognize even my own tendency to give value to that which is observable and immediate, and to those who are trained, positioned or salaried. How many others also dismiss the tremendous value of the volunteers, family members and random strangers who offer their skills and contributions in moments of need?

I struggle with these seemingly conflicting aims, to either be present for someone or to provide solutions, interventions and treatments for them. We will always have broken bones that require casts, infections that can be treated with medication and tumours that warrant surgical removal. In these cases, distress on the body affects the mind as much as much as the inverse is

the case. And yet, does our society's dominant focus on our bodily distresses come at the cost of our capacity to exist in our body. My greatest worry is that it may.

Recently, I was surprised to find myself deeply engaged in a conversation with a colleague about this research. I was very heartened to discover that many of my realizations held resonance for her. More significantly however, I was amazed and impressed with how cogently I was able to communicate my ideas to her. It is especially remarkable given that I have never been good at presenting messages impromptu and always need time to assemble my thoughts and rehearse. Where has this ability come from? As I reflected on this question, I began to identify the many conversations I have had about this research over the course of this four year journey. I have engaged with scholarship adjudication committees, colleagues, professors, research ethics boards, conference attendees, community and family members, and even perfect strangers. Each of these experiences has helped in honing my ability to communicate complex ideas to a broad audience and in a variety of contexts.

Having arrived at this point, I cannot help but feel a certain pride and excitement at my growth as a HCP, researcher and communicator. While I have always had an interest in working at a social justice and policy level, I had never thought of myself as someone with the skills to do so. My recent conversation with a colleague challenged me to believe that I can. From here, I could arrange to conduct more formal presentations or write manuscripts. Irrespective of the direction that I take with this inquiry though, I have a sense that I will be able to do so and that is a very gratifying feeling.

4.4 Finally

If this inquiry has taught me anything at all, it would be that in order to care for others, I must first start by caring for myself. It is like the familiar analogy of being in an airplane cabin that has depressurized. If the oxygen masks appear, we are instructed to always secure our own masks before assisting others; otherwise, we will lose consciousness before we may be of any support to our loved ones. No one wins.

My culturally ingrained value to uncover new knowledge creates a certain disposition for me to look outside of me for data. Through this autoethnographic inquiry that endeavoured in the beginning to better understand how to more effectively support immigrants and young adults with cancer, I realized that my major barrier was to study myself. There are no hidden tricks, no expert skills in being a HCP. At its most foundational level, being a HCP for me involves simply being present for another, being there to bear witness to both their moments of joy and sorrow.

When all else seems disrupted, put on hold or lost, it is our sense of connection that will sustain us. When our faces seem strange or masked, it is our willingness to be genuine that will reveal us. In being present to you, the divide between us closes.

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APPENDICES

Appendix A

Initial Research Proposal

Understanding the psychosocial experiences of cancer patients of Chinese ethnicity (CPCE)
in the British Columbian cancer care system

Context. In Canada, it is estimated that nearly 160,000 new cases of cancer will be diagnosed this year (Marrett *et al.*, 2007). Of these, approximately 15% will be from an ethnic minority. Unfortunately, there is growing evidence to suggest that individuals from ethnic minorities are receiving lower quality health care in Canada than the general population, leading to poorer health outcomes (Lin *et al.*, 2002). This is especially the case for cancer patients of Chinese ethnicity (CPCE, defined here as either Chinese-born or of Chinese descent), whose cultural differences (e.g., in language, beliefs and attitudes) produce challenges for health service providers.

Because of language difficulties, Chinese patients are often reluctant to seek medical attention, sometimes ignoring symptoms until they become severe (Gany, *et al.*, 2006). Research also shows that CPCE are less aware of services such as home-based palliative care or hospices and, as a result, access them less frequently than Caucasians (Feser & Bon Bernard, 2003). Patient compliance is also a problem and when physicians are not understood, Chinese patients are reluctant to seek clarification (Green *et al.*, 2005). As a group, they are also more likely to rely on complementary or alternative medicines (Xu *et al.*, 2006), which may reduce their compliance with conventional treatment programs. Some CPCE are reluctant to discuss their illness for fear of burdening their loved ones (Tong, 1994). This, as well as the belief that cancer

is contagious may lead certain Chinese cancer patients to feelings of social isolation (Gany *et al.*, 2006).

Where culture is a focal determinant in our perception of illness and suffering, increased cross-cultural understanding becomes a necessary component of providing the best quality health care possible (Kagawa-Singer & Blackhall, 2001). Unfortunately, there is little guidance for service providers working with CPCE within the literature, especially in the context of the Canadian Health Care System. Past studies have examined the views of both cancer care professionals working in Asian communities and cancer survivors; however, very little is known about the quality of care received from the perspective of the minority patient. Further research directly examining the experiences of CPCE is needed to help guide service providers in delivering culturally competent care.

Research Framework. The broader research program will aim to develop a theory to explain the overall experience of CPCE in the British Columbian cancer care system over the course of their illness. The proposed study will more specifically focus on the psychosocial dimension of the patient's experience. I will employ a qualitative approach based on Glaser and Strauss's (1967) grounded theory. In contrast to deductive research where an existing theory is either supported or rejected by testing its predictions, the grounded theory approach is characterized by research in which a theory is developed from (i.e. becomes grounded in) a series of observations. This approach is suited to examining the experience of CPCE where there is still an insufficient theoretical basis to draw from.

In working closely with Mr. Richard Doll at the British Columbia Cancer Agency, thirty CPCE will be recruited at the beginning of their treatment. This will include participants of varied age, education level, English proficiency, length of time living in Canada and ethnic status

(immigrant or generational Canadian). The setting is a major Canadian city that is home to a large Chinese population (30%) of varying age and degrees of acculturation. An equal number of men and women as well as a varied selection of cancer types will be recruited in order to minimize the possibility of obtaining gender- or cancer-specific information.

Over the course of one year, I will conduct a series of semi-structured interviews with each participant. A review of the literature has identified a number of possible areas for discussion including cultural beliefs, family and peer support, communication difficulties and mental health (Liu, 2005). The patient's condition (either recently diagnosed, recently treated with promising results, recently treated with uncertain results or palliative) will be noted at the time of each interview. Interviews will be recorded, transcribed and coded. Themes that emerge from an ongoing examination of the data (using the *Nvivo* qualitative data analysis software) will direct the focus of subsequent interviews. This corrective feedback will continue until a general theory emerges.

Significance and Future Directions. There is a paucity of literature to inform cancer care professionals about the unique psychosocial experience of CPCE. The proposed study is situated within a broader research program, which will attempt to develop a theory to explain the overall experience of CPCE in the British Columbian Cancer Care System. In later doctoral research, I hope to build on the current study by exploring other dimensions of the patient's experience including the physical and spiritual components. In developing this theory, it is hoped that new insight will be provided for health professionals and policy makers working to improve the quality of care for CPCE. The theory may also be used to generate additional research to explore the experiences of other minority groups in cancer care or more general health care settings.

Appendix B

Literature Review

In this appendix, I will provide a review of the relevant literature to inform my inquiry into the cultural experiences of IYAs with cancer. This research is at its core an inquiry about cultures. As such, this chapter will begin by conceptualizing culture and in turn locating the self within this concept.

The cultural experiences of IYAs with cancer are complex and diverse. No single body of literature could wholly capture their experiences. I have therefore constructed this review, and thus my inquiry, around three domains of cultural knowledge: the experience of immigrants, individuals transitioning from adolescence to adulthood, and the culture of cancer. To my knowledge, no previous research has specifically focused on the overlap of these three knowledge domains. A knowledge gap will be identified over the course of this literature review. It is the aim of the current study to address this gap.

This collection of knowledge will serve neither to limit the current research inquiry, nor to generate testable hypotheses *a priori*; rather, this base of knowledge will help to sensitize me to the range of possible experiences of IYA with cancer. Although I am not immune to my own biases and worldviews, a broadened awareness of past scholarships will prepare me to receive fieldwork conversations and interactions with a more open mind. This open-minded attitude will be central to this inquiry, a point to be described in more detail in Chapter 3.

B.1 The Experience of Immigrants

In order to make sense of the present experiences of IYAs with cancer, it is necessary to understand their cultural past. I therefore begin this section by describing some of the

circumstances that may motivate immigration. Following this overview, I consider some of the significant dimensions of many immigrants' experience of transitioning from their community of origin to their new community, including challenges to the family integrity and the integral role of language. Although no single narrative can capture the lives of all immigrants, I believe an appreciation of the research described below allows me to better contextualize each individual's unique narrative.

B.1.1 Pathways of immigration.

Every year, an increasing number of newcomers from more than 180 regions of the world arrive in the province of BC seeking education, employment, safety, refuge or the promise of a better future. At present, BC's population is made up of 1.1 million individuals who were born outside of Canada. The most frequently reported non-English mother tongues include Punjabi, Mandarin, Cantonese, German and Tagalog, with over 100,000 individuals who speak neither English nor French (Scott, Harmsen, Pricor, Sowden, & Watt, 2003; Statistics Canada, 2006).

Although often colloquially referred to as "immigrants", newcomers may be broadly distinguished into two different groups. Refugees or asylum seekers as referred to by some scholars account for roughly 6% of newcomers to Canada (Statistics Canada, 2008). In their homeland, they often resided in conditions of political or economic insecurity. Their decision to emigrate is often sudden or forced. The journey of refugees is often fraught with fears and uncertainties. Many refugees sustain deep physical or psychological wounds in their homelands that remain long after their escape (Liebkind & Jasinskaja-Lahti, 2000). Historically, events such as the Vietnam War and Cold War as well as civil unrest in Haiti and the Middle East have resulted in mass displacement of individuals to various countries of the world (Vernez, 1991).

Unlike refugees, immigrants are largely motivated to immigrate by pull factors such as educational opportunities, and social and economic prosperity in the new country (Chen, Gee, Spencer, Danziger, & Takeuchi, 2009). The decision to leave the home country can be a life-changing one and is often only arrived at after having carefully weighed all of the possible gains and losses. Consequently, immigrants are often psychologically more prepared to transition to a new sociocultural context than refugees. Of these two groups of newcomers whose experiences may be vastly different, the present inquiry will solely examine the experience of immigrants.

Many economic and social forces are at work as immigrant families decide to leave their home country for a new country. A comprehensive survey of newcomers to Canada found that the most common reasons for immigration included reuniting with family and friends, improving the future for one's family, and seeking better work and educational opportunities (Statistics Canada, 2005).

Once immigrants arrive in their new sociocultural milieu, their lives may unfold in vastly different ways. The 2005 report of the Longitudinal Survey of Immigrants to Canada Study (2005), six months after arrival 26% unemployed and about one-third reported not having enough money to meet their basic needs. Immigrants may also experience challenges as a result of language barriers, a lack of recognition of previous training and education, or a loss of social supports.

Despite the challenges of settlement and integration during the initial period post-immigration, most immigrant families are sustained by hope for a better future (Statistics Canada, 2005). They have a positive social attitude that can take them on an upward social trajectory. A vast majority of immigrant children and their parents perceive school and education as pathways to success in their new cultural milieu (Krahn & Taylor, 2005). When asked to complete the

statement, “In life the most important thing is...” many immigrant youth will respond with some reference to their school (Suárez-Orozco & Suárez-Orozco, 2001).

Although some immigrants engage in upward social mobility over the course of their residency in a new country, a large number of immigrants increasingly struggle over time. A number of studies have observed that although immigrants arrive with above average health, more positive social attitudes, and higher academic performance and aspirations – potentially an artefact attributed to the selection bias fostered by Canadian immigration policies (see Li, 2002) – these advantages decline over time (Beiser, Hou, Hyman, & Tousignant, 2002; Blake, Ledsky, Goodenow, & O'Donnell, 2001; Krahn & Taylor, 2005). For example, research has found lower rates of depression and alcohol dependence amongst newly arrived immigrants as compared to both long-term immigrants and a Canadian-born sample (Ali, 2002). Moreover, the chances of reporting chronic health conditions increased with increased length of residence in Canada (Alegria, Sribney, Woo, Torres, & Guarnaccia, 2007; Pérez, 2002).

B.1.2 Family dynamics.

The process of immigration has the potential to destabilize family life, creating complex patterns of fragmentation and reunification (Suárez-Orozco, Todorova, & Louie, 2002).

Traditional immigrant narratives often describe a family member, often the father, acting as the “migration pioneer” in leaving his home for foreign, uncharted lands. His hope is to find a new world that will bring social and economic prosperity to his family. In these circumstances, the child is left at home in the care of the remaining parent or relatives while the pioneer attempts to settle and establish him or herself in the new world. Once settled, parents may send for children, allowing them to be reunited after a lengthy period apart. Conversely, a child may be sent to a

new country to learn English and get an education while their family remains in the native country. The child may live with relatives or host families.

In both scenarios, complex attachment patterns may develop. Often grandparents or other relatives may become the source of safety and security for a child that is left by the parents. In some collectivistic cultures where a child is raised by a community of individuals, this may be perceived as normal (Suárez-Orozco *et al.*, 2002). The extended separation due to immigration may be experienced quite similarly to a parent going off to work. For other immigrant youth, being separated from the parents may be experienced as abandonment (Brown & Whiteside, 2008). The child may come to believe that his parents do not want him, leaving him feeling unloved or inadequate. In light of these circumstances, reunification of the family may be quite disorienting for the youth. Early attachments formed with non-parent caregivers may become broken through immigration. At the same time, the immigrant youth may be required to reacquaint himself with his parents, people who may seem entirely foreign to him.

Children who are transposed from one family context to another during their formative years may struggle later in life in developing healthy attachments (Bayer, Sanson, & Hemphill, 2006; Suárez-Orozco *et al.*, 2002). According to Bowlby's (1969; 1973; 1980) attachment theory, unpredictable care-giving patterns may foster confusion, hopelessness and fear in children (Ainsworth, 1979). They may try to deal with stress in very incoherent and ineffective ways. Moreover, parents who struggle themselves with the economic and social difficulties of moving to a new country may find less time to spend with their children. As a result, immigrant youth may experience their parents as being physically or psychologically unavailable to them.

Another often observed phenomenon amongst immigrant families is the inversion of power hierarchies (Bacallao & Smokowski, 2007). While many practitioners would describe a

desirable family structure as one involving the parents taking charge, setting rules and making decisions; the children often find themselves assuming adult-like responsibilities within the immigrant household. This often occurs in situations where parents depend on their children to serve as linguistic or socio-cultural interlocutors in the family (Lee, 2004).

This family structure, although not inherently harmful, has the potential to create challenging family dynamics (Minuchin, 1974). While neither cognitively nor socio-emotionally prepared for their adult-like responsibilities, immigrant children may feel overwhelmed by the pressures to uphold their family (Tseng, 2004). Furthermore, practitioners have observed how this accelerated maturational process can lead to significant and enduring distress for the children long into their adulthood (Westwood & Wilensky, 2005).

At the same time, an absence of proper parental authority may lead to children growing up unconstrained, unguided and unsupported. Children who grow up in unstructured environments may experience anxiety due to a perceived absence of safety (Bowlby, 1973). Their worldview becomes one where they may depend only on themselves because they have learned that no one will help them in their time of need. Such experiences, although not inexorably etched into the pathway of immigration, are nevertheless important considerations in the understanding of immigrant family dynamics.

Crosscutting these patterns of family dynamics is a divergence in value and belief systems between immigrant parents and their children. Portes (1997) coined the term "dissonant acculturation". It refers to the phenomenon whereby immigrant adults adapt to Western culture at a slower rate than those who arrive as children or who are born in the West.

Dissonant acculturation has been attributed to a number of factors (Phinney, Ong, & Madden, 2000). From the outset of immigration, older immigrants have accumulated more years

of experience and cultural influences in their country of origin than younger immigrants. Their years of socialization in a different cultural context have created a more deeply-rooted culture that is not as easily amenable to change. Children and younger immigrants are often more adept at learning and adopting new lifestyles, attitudes and social practices.

Moreover, the contact and exposure children have with the new society – in the form of schools, peer groups, popular media – is often more pronounced and enduring than that of adults (Suárez-Orozco & Suárez-Orozco, 2001). Due to continuous and regular contact with social institutions such as school and the mass media, immigrant youth are able to quickly develop competencies suitable to survive in their new society. Immigrant parents, on the other hand, have fewer opportunities to do so. During the early years of resettlement, many will find employment in culturally segregated workplaces and interact mostly with their own cultural communities. These factors create a generational divergence between immigrant adults and youth. This dissonant acculturation increases with time in a new country.

B.1.3 Language as a significant factor in immigration.

A further factor that fosters this dissonant acculturation is the different rate of language acquisition amongst immigrants, particularly between younger and older immigrants. A combination of age at arrival in Canada, length of time in Canada and educational attainment significantly predict an immigrant's English proficiency (Rumbaut, 2009). The younger non-English speaking immigrants are at the time of migration, the more likely they will possess a high level of English proficiency. This is rooted in a biological predisposition for language acquisition that, over time, diminishes as the neuroplastic properties of the brain decreases (Birdsong, 2006).

Where language serves as a fundamental tool for gaining access to valuable social and institutional resources (Statistics Canada, 2005), language barriers can often act as mechanisms for creating social disparities (Carrasquillo, Orav, Brennan, & Burstin, 1999). Because a large proportion of immigrants come from non-English speaking backgrounds, it is not surprising that researchers have found lower rates of health care access amongst immigrant groups as compared to the overall population (Centers for Disease Control and Prevention, 2004; Chen, 2005).

Thus, many social forces exist that pressure non-English speaking immigrants to learn to communicate in the majority language. At the same time, researchers have observed that, over time, people's commitment to their ancestral language becomes fleeting at best (Rumbaut, 2009). A multiethnic study of young adults in Los Angeles found that 97.4% of first generation immigrants grew up speaking a language other than English and 17% preferred to only speak English at home (Rumbaut *et al.*, 2004). Amongst third generation immigrants, there was a striking reversal of preferences. Several studies have found similar dramatic declines in retention of ancestral languages and acquisition of English across multiple immigrant generations (Pew Hispanic Center, 2004) and within a given generation over time (Rumbaut, 2009). Although some languages survive longer when situated within highly concentrated ethnic communities, even the most deeply-rooted languages will die out over the course of two or three generations (Rumbaut, 2009).

Rumbaut (2009) notes that “[i]n the United States, a country lacking centuries-old traditions and receiving simultaneously millions of foreigners from the most diverse lands, language homogeneity came to be seen as the bedrock of national identity. Immigrants were not only expected to speak English, but to speak only English as a prerequisite for social acceptance and integration” (p. 36).

In spite of the prevalence of statistics and studies that describe the precipitants of language acquisition, what remains unexamined are the experiences of immigrants as they transition linguistically and socially into a new community. What external or internal acculturative pressures do IYA experience in learning to speak a different language? How do they cope with these pressures?

B.2 Young Adult Culture

Little scholarly work has been done to theoretically frame the study of the developmental period of life immediately following adolescence (Nelson *et al.*, 2007). This is a significant time in the life of an individual, often characterized by transitions, distress and conflict. While experientially considered by many to be a distinctly different developmental period, research often subsumes these individuals under either the adolescent or adult categories (Adolescent and Young Adult Oncology Progress Review Group, 2006; Arnett, 2000). The result is a dangerous overgeneralization in which practitioners and researchers construct their knowledge base of “young adults” from studies using adult samples, a demographic category that may include individuals as old as 64. This section highlights and distinguishes the period of life immediately following adolescence and before adulthood, one that some scholars have referred to as “emerging adulthood”.

B.2.1 Conceptualizing emerging adulthood.

It has only been recently that the concept of emerging adulthood has surfaced within the scholarship of western industrialized societies. Emerging adulthood is considered a unique period of development in the life course. Arnett (2000; 2001) proposes five conceptual features that set it apart from adolescence and adulthood, including: 1) exploring identity especially in the

areas of work, love and world views; 2) experiencing change and instability; 3) a heightened focus on the self with few obligations to others; 4) feeling in-between, being neither an adolescent nor an adult; and 5) perceiving potential to steer life in any number of desired directions.

Survey studies with samples of individuals aged 19 to 30 have further defined the concept of emerging adulthood to emphasize subjective experiences like relational maturity (i.e., accepting responsibility for the consequences of actions, establishing a relationship with parents as equals) and family capacities (i.e., running a household, financially supporting the family) over specific life events like marriage, completion of education and starting a career (Nelson & Barry, 2005). Little importance was ascribed to biologically- and age-defined transitions such as reaching a certain legal age or height, being legally allowed to drink or having sex.

B.2.2 Between and within groups differences.

Although the construct of emerging adulthood has been well defined and validated in western, industrialized settings, some have questioned its generalizability to other ethnic groups (Fazio & Micocci, 2003; Nelson, Badger, & Wu, 2004). The very notion of developmental periods or stages of life is a very western notion structured by a legal age of majority and the timing of education. Even amongst western industrialized societies, the conferring of adult responsibilities adhere to different timelines are dependent on regional, if not familial factors. Indeed, the cultural construction of emerging adulthood becomes evident upon examining different ethnic groups. For example, a survey study of university students in China revealed that the majority felt they had reached adult status in their early twenties, had different criteria for adulthood, and behave differently and have different belief systems as adults (Nelson *et al.*, 2004). A study of Argentinean adults also found different endorsement patterns of criteria for

adulthood (Facio & Micocci, 2003). Amongst adults of Aboriginal Canadian heritage, a greater emphasis was placed on interdependence and the maintenance of harmony, as well as the role of children and family (Cheah & Nelson, 2004). Thus, the timing and construction of emerging adulthood is not universal but rather specific to ones cultural upbringing.

Despite differences between ethnic groups, comparative studies have indicated that immigration may have a marginal effect in shifting conceptions. For example, Chinese and Latino university students studying in the United States had more similar views of emerging adulthood when compared to White American students, than their counterparts in China and Latin America (Badger, Nelson, & Barry, 2006; Facio & Micocci, 2003). These findings suggest that individuals who immigrate to a new ethno-cultural setting may to some degree adopt local constructions of emerging adulthood.

There is also indication that the perspective of emerging adulthood differs between children and their parents. One study compared criteria for adulthood as espoused by parents and their emerging adult children (Nelson *et al.*, 2007). Although many items were similarly rated as being important and unimportant, children consider some processes to be significantly more important for adulthood than their parents. This included accepting responsibility for personal actions, achieving relationship with parents as equals, being financially independent from parents and deciding on beliefs/values independently of other's influences.

B.2.3 Summary of a young adult culture.

Overall, the construct of emerging adulthood is at its core a transitional period during which individuals are largely ambivalent about their status as adults. Individuals in this developmental period have passed adolescence but have yet to self-identify as adults with all the relational and familial capacities that characterize adulthood. Although now conceptually well-

defined, the research community continues to ignore the lived experiences of these emerging adults. Missing from the plethora of survey studies with researcher-defined items and closed-ended response scales are the actual voices of young adults who experience the uncertainties and instabilities of this period of life. Similarly, although one survey study has examined how the construction of emerging adulthood differs between children and their parents (Nelson *et al.*, 2007), little is known about how such differing viewpoints impact their relationship.

Thus a significant knowledge gap exists in understanding the experience of young and emerging adults. This direction of research inquiry is of particular importance amongst immigrant and cross-cultural scholarships. As past studies have indicated, the experience of emerging adulthood is not universal but rather specific to one's cultural upbringing. How, then, might the transition to adulthood look different for those also experiencing immigration and adapting to a new social context? A discovery-oriented, individual-centered research approach is desperately needed to explore the cultural experiences of young adults and specifically IYA. Such research would serve to inform mental health professionals about how to better support IYAs during their many transitions in life.

B.3 The Culture of Cancer

The term “cancer” has many meanings. As a biomedical term, it refers to a diagnostically diverse category of disease states where normal cells of the body lose their ability to self-regulate and begin reproducing uncontrollably (Canadian Cancer Society, 2009). This cellular process can manifest itself in a plethora of different ways, many of which lead to pain and suffering for both the individual patient and those around him or her. The symptoms can be acute and pressing,

or acute and intense. The course of treatment for this disease state can also take on many forms from surgery to radiation therapy to chemotherapy to gene therapy.

As such, the personal narrative of each cancer patient is wholly unique. This section reviews only some of the possible experiences of individuals with cancer found in research. I will begin by reviewing research that suggests young adults may be a marginalized and thus particularly vulnerable population in cancer care. This will lead to a discussion of the important role of social support during illness and the influence of culture in support seeking behaviours. From this review, a case will be built for an increased need for research into the experience of young adults and immigrants with cancer using an approach that not only honours their voices but also recognizes the cultural influences that have shaped their lives.

B.3.1 Young adults with cancer.

Rowland's (1990) developmental model of adaptation to illness suggests that, although there are common experiences associated with the diagnosis and treatment of cancer, the specific needs of patients may vary significantly across different ages or developmental periods of life. The experience of young adults with cancer is of particular concern. Since the early 1970's, cancer incidence among young adults aged 15 to 29 years has been rising faster on an annual basis than that of cancer diagnosed in both younger children and older adults (Bleyer & Albritton, 2003). Today, more than 25,000 young adults are diagnosed with cancer in Canada and the United States each year (Bleyer & Barr, 2006; Canadian Cancer Society's Steering Committee, 2009). Despite these staggering figures, young adults with cancer are marginalized by both our cancer care system as well as the research community (Adolescent and Young Adult Oncology Progress Review Group, 2006). Young adults are in a transitional period in their lives, no longer

an adolescent and yet not quite an adult (Arnett, 2000). As a result, they have significant psychosocial needs that are often quite different from either children or older adult patients.

For example, research has found that young adults may experience cancer as much more distressing and debilitating than either older adults or children. Compared to cancer patients aged 65 and over, younger adults were found to be more profoundly impacted by their disease (Williamson & Schulz, 1995). Researchers accounted for this in a number of ways. Young adults usually have had fewer experiences with illness and disability. They also have a high expectation about their level of functioning. Young adults are often looking to the future. At a time when many are assuming significant responsibilities, planning out their careers and forming intimate relationships, a cancer diagnosis can be especially devastating and life-changing for young adults.

The experience of cancer often leads to concerns about body image and self-esteem particularly amongst young adults (Evan, Kaufman, Cook, & Zeltzer, 2006). Disfigurement of the body due to the disease progression and treatment (e.g., hair and weight loss), reduced energy levels, missed social opportunities or classroom time because of visits to the hospital all contribute difficulties in developing a healthy self-image. Young adults, who would otherwise be in the best health of their life, may disengage from their supportive social relationships. Many become reluctant to commit to intimate relationships for fear of an uncertain future (Evan *et al.*, 2006). Alternatively, young adults may feel resolved to being self-reliant and would feel ashamed to seek help (Taylor *et al.*, 2004). These experiences form a vicious cycle where poor self-esteem fosters increasing disengagement from life and vice versa. Young adults with cancer may withdraw themselves from their social resources at a time when they may need it the most (DiMatteo, 2004).

Thus, for young adults with cancer, their life is a lonely struggle and their future looks bleak. Due to advances in cancer treatment, however, more young adults than ever before have overcome their cancer ordeal. From 1991 to 2001, 5-year survival rates amongst young adults with cancer have increased from 67 to 77 percent (Bleyer & Barr, 2006). Conditions that were once fatal have become more chronic and treatable. It is now estimated that 1 in every 640 young adults is a long-term survivor of childhood cancer (National Cancer Policy Board, 2003). Moreover, for many young adults who are survivors of cancer, an end to treatment, returning to school or work, leaving home, dating, starting a family or career are all significant milestones in their transition into adulthood (Adolescent and Young Adult Oncology Progress Review Group, 2006).

In this changing landscape, cancer care providers must broaden their attention to supporting not only the immediate medical needs of young adults, but their long-term psychosocial needs as well (Soliman & Agresta, 2008; Stuber, Shemesh, & Saxe, 2003).

B.3.2 Social support during illness.

The importance of social support in the life of young adults with cancer cannot be understated. Studies have repeatedly found that support can provide significant and lasting benefits during times of illness. Social support serves as a buffer to stress (Tyson, 2008), increases a patients' adherence to treatment (DiMatteo, 2004) and leading to lower rates of mortality (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Given its significant role in the cancer patient's recovery process, an increased understanding of social support would aide my interpretation of this current research. This section provides a framework for understanding the construct of social support and its potential sources.

Taylor and colleagues (2004) define social support as “the perception or experience that one is loved and cared for, esteemed and valued, and part of a social network of mutual assistance and obligations” (p. 355). This definition highlights how support may be either real or perceived. House and Kahn (House & Kahn, 1985) further subdivide the construct into three types: informational, instrumental and emotional support. Informational support refers to helping another to understand a stressful event better or to ascertain what resources and coping strategies may be needed to deal with it. Instrumental support includes tangible assistance such as services, financial assistance, and other specific aid or goods. Emotional support refers to providing warmth and nurturance to another individual and reassuring the person that he or she is a valuable person who is cared about.

Research has found that as we grow up, our sources of social support may change, a process that varies by culture. Amongst Euro-Americans, for example, the predominant sources of social support prior to grade four are parents or significant care providers (Wentzel, 2002). Up to grade 10, same-sex peers slowly take the place of parents as sources of support and connection. During young adulthood, romantic partners, friends and other adults are identified as sources of support (Connolly, Furman, & Konarski, 2000; Laible, Carlo, & Raffaelli, 2000).

Zebrack and colleagues (2006) found that the social support networks of young adults with cancer seem to be consistent with the above findings. What is notable in this study, however, is that medical professionals misunderstand the relative importance of particular aspects of a young adult cancer patient’s life. Medical professionals perceived the biomedical, psychosocial and informational needs of young adults to be higher than what young adults rated. Furthermore, more young adults ranked the relative importance of opportunities to meet other young people with cancer as greater than the importance of support from family and friends.

These findings highlight the need for medical professionals to be more informed about the needs of their young adult patients. When misunderstandings occur, patients' needs will inevitably become neglected. This disconnect may serve as a hindrance to providing the most person-centered and thus effective care possible.

B.3.3 Ethno-cultural influences on support seeking.

Consideration of the psychosocial needs of young adults is overlaid by complex ethno-cultural factors (Kim *et al.*, 2008). For example, one's cultural upbringing may influence the type or source of social support that one considers to be most valuable. Likewise, individuals may vary significantly in the way they express a desire for support. This culturally-informed perspective is vital for medical and mental health professionals to provide the most effective and holistic cancer care possible.

Regrettably, there have been few studies that have contextualized social support within a cultural framework. Many of the exceptions adopt a largely positivistic, quantitative paradigm that silences the voices of individual participants. Take, for example, Moilanen and Raffaelli's (2009) multiethnic survey study that compared European-, Asian-, Cuban-, Latin-, and Mexican Americans college students on their support seeking behaviours. Participants were asked to rate a series of questions on their degree of connectedness with various individuals, like parents and friends. Their findings were reported as mean levels of support sought and received aggregated by ethnic group and gender. A similar study of Asian American college students found that they were significantly less likely to draw on familial support than their Euro-American counterparts (Taylor *et al.*, 2004).

Social psychologists have also attempted to shed light on the nature of social support amongst different ethnic groups. In one experiment, Asian and Euro-American participants were

asked to give their appraisal of a woman who, upon being exposed to a stressful event, either sought out support or bore the stressor (Chu, Kim, & Sherman, 2008). It was found that Asian American participants evaluated the woman more negatively if she sought support. Conversely, Euro-American participants saw the woman more positively after watching the same video. Thus, it was concluded that not only are Asian Americans less likely to seek out support, but they would also perceive others more negatively. In another study, when students of Asian ethnicity underwent a priming task that made them reflect upon their relationships, they were not only less likely to seek support, but also expected that any support would be less useful (Kim, Sherman, Ko, & Taylor, 2006). These findings, if collectively interpreted, support the widely held belief that individuals of Asian ethnicity are less likely to seek out social support than their Caucasian counterparts in times of stress. This conclusion is consistent with qualitative and quantitative studies amongst Asian American cancer patients (Ashing *et al.*, 2003; M. S. J. Chen, 2005; Gany, Herrera, Avallone, & Changrani, 2006).

A number of explanations exist to account for this. Bolger, Zuckerman, and Kessler (2000) found that people who draw on their support networks during times of stress may find it further distressing because it is an admission of weakness and reduced one's self-esteem. Moreover, people, especially those of collectivist cultures who place high value in group harmony, may be reluctant to seek the support of family members because it was perceived as taxing of others' (Ashing *et al.*, 2003). In fact, older cancer patients of Asian ethnicity are sometimes unwilling to seek their children's support for fear of being a burden.

In order to make sense of a reluctance to seek support based on the perceived impact on others requires a worldview that is premised on the interconnectedness of people. This is

juxtaposed against an individualistic worldview that would conceptualize social support as a specific and explicit transaction (Kim *et al.*, 2006).

Thus, in reviewing the social support literature, Kim *et al.* (2008) conclude that there may be differences in how people seek and receive social support. Moreover, what constitutes effective social support may differ by culture. With this knowledge, health care professionals must in turn provide support in culturally sensitive ways such that the support is welcomed rather than shunned as a perceived burden to the supporter. For example, it has been proposed that social support resources that do risk disrupting relationships and do not explicitly discuss the problem may be most readily sought out by individuals of collectivistic values (Kim *et al.*, 2008). These findings have resulted in Taylor *et al.* (2008) constructing the binary explicit and implicit social support, the latter referring to “the emotional comfort one can obtain from social networks without disclosing or discussing one’s problems vis-a-vis specific stressful events” (p. 832).

In large part, these studies and explanations reinforce the East-West, individualistic-collectivistic binaries that many scholars have come to rely. What remains lost in this massive body of research are the voices of individuals who struggle in their lives and either embrace or turn away from their social resources. In spite of what we know about the relative tendencies of large ethnic populations, our understanding of the complex experiences of the individual remains unexplored. What discourages an individual from seeking support? How does someone’s perception of social support change when experiencing a life-threatening illness or the transition of immigrating to a new country? What forms of support are most meaningful? Clearly, more research is needed to unravel these complex inquiries.

Beyond these inquiries, however, exist a more fundamental concern arising from studies that attempt to make generalizations based on comparison groups that are arbitrarily constructed.

What is an Asian American? I find myself wondering. What are the common traits or experiences that supposedly characterize this group? I suspect that there may be no easy answer to these questions. Even if such questions are overlooked, one is left to wonder about the clinical utility of knowing that, on average, people of Asian ethnicity are more reluctant to seek out social support. How would an Asian American cancer patient that I am supporting be similar to the Asian Americans and different from the Euro-Americans that are represented in these studies? In order to better understand people's experience of cancer, research efforts need to adopt a more person-centered, exploratory approach that acknowledges the profound impact of our individual cultures.

B.3.4 Summary of the culture of cancer.

The literature suggests that young adults may face significant struggles during their cancer ordeal, and given their transitional stage in life, these struggles may be uniquely difficult. In providing service to young adults with cancer, the challenge, then, for medical and mental health professionals is in understanding the experiences of this age group. Moreover, a substantial body of literature has underscored the importance of social support and its cultural contextualization. Where mobilizing the social resources of cancer patients becomes an integral component of holistic cancer care, medical and mental health professionals must be aware of the complex role of culture in support seeking.

B.4 Summary of Literature Review

In all, the world of an IYA with cancer may be filled with turbulence and uncertainty. Presently, there exists no literature to guide our understanding of the experiences of this population. Scholars and practitioners may only piece together a rough understanding using

associated literature. Often these research efforts overlook the experience of young adults and immigrants. An increased understanding of the experiences of IYA with cancer from a person-centered and culturally-sensitive lens becomes a necessary component of providing them the most appropriate, effective care possible (Kagawa-Singer & Blackhall, 2001).

The current research is situated at the interface of three major transitions in an individual's life; settling in a new country, becoming an adult and experiencing a life-threatening illness like cancer. Adjusting to these transitions is often difficult and fraught with pressures and conflict. Mental health practitioners and caregivers who seek to effectively support individuals during these trying times must be well informed about the experience of individuals engaged in these transitions. Regrettably, to date, research attention has focused primarily on adolescents and adults with relative neglect for the transitional period referred to as emerging adulthood. What is more, research has largely been of a positivistic-quantitative paradigm that sorts them into arbitrarily constructed ethnic categories and in the process, leaves out the voices of the individual.

Appendix C

Conceptualizing “Culture” and the Self

Our increasingly mobile and electronically interconnected world has afforded people from different backgrounds unprecedented opportunities to interface. Within this world, the term “culture” is casually and pluralistically referred to. Exchanges between two individuals or groups from different parts of the world are referred to as *cross-cultural* exchanges. Neighbourhoods or cities can differ in the degree to which they are *multicultural*. Within popular and academic circles alike, multiculturalism is a desirable social phenomenon that encourages people to consider life from a different perspective and develop empathy for a fellow human being (Fowers & Richardson, 1996). People can be of *high* or *low culture*. They can be straddling *two cultures*, go back to their cultures or even *have no culture*. Multiculturalism is, in fact, “alive and well”. Our everyday existence is filled with “culture” and yet it remains a term that is poorly understood.

Even within cultural-anthropology and -psychology scholarship, there exists different conceptualizations of the term culture (Geertz, 1973; Mead, 1971). Contemporary scholars have also debated the similarities and differences between culture and related constructs such as race and ethnicity (American Psychological Association, 2002; Helms & Talleyrand, 1997; Phinney, 1996). This pervasive neglect in explicitly defining culture can spawn significant confusions about what exactly a writer, reporter or casual discussant is claiming. Given the centrality of culture within the proposed research inquiry, I believe that it would be useful for audiences of this research to understand my own concept of culture. In the section that follows, I wish to present my interactions with the term as a social construction and then contextualize these experiences within past scholarships.

In order to personally define culture, I find myself thinking about all that culture is not. For me, culture is not a collection of people of similar traits or backgrounds; nor is it a descriptor applied to an individual or group. I believe that one ought not be able to physically point to a culture or construct one by delineating ephemeral boundaries around a set of people or a place. It seems inappropriate and illusory to describe people as “belonging to culture X”, “marginalized by culture Y” or “having their feet in two cultures”. Such statements are perhaps most problematic when considering the difficulty of the semantic enterprise of defining with any degree of precision a cultural label like “Asian” or “collectivistic” or “masculine”. Given the plurality and fluidity of our personal identity, it would be difficult to identify someone as belonging to one or more of these categories (Christopher & Bickhard, 2007).

Considering these difficulties, I find that I am only able to speak sensibly of culture in the past tense similar to the way I speak of memories, heritage or ancestry. Thus, in my mind, a culture is a related collection of antecedents that dynamically influence and shape our present personhood. We may have more than one and perhaps an infinite number of cultures. To say that “I am of Chinese culture” is to subjectively refer to a collection of antecedents – such as memories of living in China, teachings from my parents, Confucian belief systems, familial values, cooking and eating practices – that influence my current actions and reactions. I may also be of a graduate student culture, which refers to another collection of antecedents. Thus, the referential framework for this conceptualization of culture is defined by past common experiences, not socio-political or geographical boundaries.

Geertz’s (1973) view of culture is perhaps most closely aligned with my own. He wrote that culture “denotes a historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which men

communicate, perpetuate, and develop their knowledge about and attitudes toward life” (p. 89). It may be argued that this description neither makes an allusion to nor entails the notion of culture as a “shared” experience as many scholars describe (Fowers & Richardson, 1996; Kwak & Berry, 2001; Phinney *et al.*, 2000). In my mind, culture is not shared: We do not “belong to a culture” in the same way as we might have membership in an organization. Instead, culture is shared by two people in so far as they report antecedents that have similarly shaped their lives. For example, my experiences growing up in Nova Scotia have instilled in me an appreciation and openness to strangers that I might share with others of East Coast culture.

Juxtaposed against culture is the term, ethnicity. Whereas I understand culture to be personally-defined and situated in past experiences, I consider ethnicity to be more socially constructed. Ethnicity is something that can be physically pointed to, often with geopolitical boundaries as a frame of reference. For example, I am of Nova Scotian, Canadian and Asian ethnicities. It would therefore be appropriate to use ethnicity as a label or description of an individual. That is, to self-identify as being of Chinese ethnicity is equivalent to describing myself as having been born and raised in China. In referring to a group of people as being of Asian ethnicity is an objective claim that is not entirely informative in understanding the influences that have shaped a person to be what he or she is today.

Thus, it is the endeavour of this proposed project to understand the contextualized culture of IYAs with cancer. Despite the incredible uniqueness of each individual’s experience of cancer, this study is premised on the belief that there exists a culture – some collection of antecedents – that underlies the experiences of individuals with cancer: To mention cancer is to conjure up feelings of pain, uncertainty and fear. To refer to someone as a cancer survivor is to recognize the struggles an individual has endured and to sympathize and admire their courage.

A number of conceptualizations of culture seem to be consistent with my own. Gramsci (1971) describes understanding oneself as necessitating a recognition of the self “as a product of the historical process to date, which has deposited in [the self] an infinity of traces, without leaving an inventory” (p. 324). Gramsci’s image is both rich and heuristic. It suggests that the process of self-understanding involves “compiling an inventory” of these “infinite traces” or cultures that become imprinted in the self.

Thus, the self has been imprinted on by past experience. This being said, I believe that it is inaccurate to view the self as a mere computer that executes actions based on programs. Rather than being a passive recipient of our cultural experiences, I believe that we possess an incredible amount of agency. Our culture is dynamic: The antecedent experiences operate with different salience at different times depending on the context. As Frank (2001) vividly describes, we are like mapmakers.

Culture is not simply a cognitive map that people acquire, in whole or in part, more or less accurately, and then learn to read. People are not just map-readers: they are map makers. People are cast out into imperfectly charted, continually shifting seas of everyday life. Mapping them out is a constant process resulting not in an individual cognitive map, but in a whole chart case of rough, improvised, continually revised sketch maps. Culture does not provide a cognitive map, but rather a set of principles for map making and navigation. Different cultures are like different schools of navigation designed to cope with different terrains and seas. (p. 44-5)

As such, we not only choose the maps that we read, we create the maps that we chose. Culture is thus a dynamic concept and the self is an active agent in its construction.

In summary, I perceive a person’s culture to be a related collection of antecedents or past experiences that have shaped (or imprinted) ones current personhood. The process of self-understanding involves taking an inventory of these antecedents. This conceptualization of

culture informs the current research inquiry. In order to understand the current experiences of IYA with cancer, the experiences will need to be contextualized within the participant's personal cultures. By consequence, a central task of this research will be to provide participants the space to engage in their inventorying process.

Appendix E

Journal Entry: Privilege and Responsibility

Location: Hotel

2011/01/27 3:30 PM

Attended experiential workshop entitled “Standing Target and Shifting Privileges: Exploring Our Power, Privilege and Access to Resources”, facilitated by two members of an anti-oppression community advocacy group in California. I was attracted to the title given my recent self-reflections catalyzed by the culture-gram exercise. This workshop gave me a chance to further explore this notion of privilege and how it relates to my personal identity.

The facilitators defined the terms oppression and privilege (which involves the distribution of power, access, opportunity, resources, etc.), and identified the “four pillars of oppression” (i.e., how oppression is maintained). I was aroused to the idea that privilege maintains oppression, that there is both a progenitor and target of oppression and that there is a system that maintains oppression. It was quite thought provoking to consider that both the privileged and targeted group collude to maintain this power relationship. The target-oppressed group may for example approximate the privileged group in order to access power and privilege. “It takes two to tango”, as the saying going.

Then, it was onto the exercise. The facilitators prefaced it by saying that we may easily identify the areas in our lives where we have experienced oppression, but that we often don’t reflect on our privileges. They in turn invited us to identify the privileges that I have been advantaged by over the course of my life that have led me to where I am today. What a paradigm shifting exercise this was! My eyes opened to the many privileges that are part of my life that have allowed me to get to where I am today. Privileges of being financially stable, well-educated,

Fabric of Oppression

	Racism	Sexism	Genderism	Classism	Heterosexism	Ageism	Ableism	Sizism	Religious Oppression	Etc.
Privilege Group	White	Male	Cisgendered, boys/men, girls/women	Wealthy, owning class, middle class	Heterosexual/straight	Adults	People without disabilities	Culturally valued height and body weight	Christians	Education, Family nucleus, Citizenship/residency
	Privilege	Power	Access	Opportunity	Resources	etc.				
Target Group	People of colour	Female	Transgendered persons/ Gender queer	Poor, working class	Lesbian, gay, bi, queer	Youth, seniors	People with disabilities (physical, mental or emotional)	Culturally rejected height and body weight	Jews, Muslims, Atheists, Buddhist, Wiccan, etc.	

Timeline of Privilege

Childhood

- Extended family that was involved in communal child rearing so that my parents could work
- Parents commitment to immigrate to Canada
- Lack of criminal record allowing freedom to travel/immigrate to Canada
- Ability to attend free public school without worries about school conflicts, gangs
- Having grown up in two countries in espousing a valuably critical cultural identity

Adolescence

- English as the lingua franca of the world which means that others must conform to my language of preference
- English educational upbringing which allows me to access much of the world's knowledge
- No major barriers to education
- Education that emphasizes critical thinking
- Intact family nucleus that allows me to focus on personal growth
- Physical and mental health to be able to participate in athletic and social activities
- Living in a society where religious beliefs (or lack thereof) do not cause interpersonal conflicts

Young Adulthood

- Financial stability which allows me to access higher education
- Visible minority status in attaining scholarships, employment
- Male in predominant female profession which, with all else being equal, makes me stand out
- Higher education that allows me to access knowledge, conversations that others cannot
- English proficiency/acclturation so that I may navigate complex social institutions
- Financial freedom to not worry

male, heterosexual, cisgendered, an adult with good health, a stable family nucleus and living in a democratic and free society. A wave of gratitude overcame me that caused my body to shiver. How wonderful my life has been, I reflected. How privileged I have been. I imagined how different my life would have been had I been female, or questioned my sexuality, or less financially stable or had a medical condition that prevented me from enjoying the many physical activities that I do.

My gratitude was quickly displaced by an outwardly sympathy for those who do not enjoy these privileges and suffer the incapacitating forces of oppression. I thought about those many immigrants who have recently come to this country, do not have high linguistic proficiencies or do not have the knowledge to effectively navigate social institutions in Canada; and the immense difficulties that they face.

The reflections that group members subsequently shared was equally profound. One individual noted the interplay between her oppressed and privileged identities, and her conflicting emotions towards confronting her own privileges. These experiences resonated with me. In recognizing my privileges, and therefore feeling gratitude and sympathy, and therefore guilt, I struggle with how I am to proceed. I cannot disown the privileges that I own; they are a part of me whether I wish to be associated with them or not. The alternative then would be to embrace these privileges, and yet such an action may risk further oppression of others, given the intimate bidirectionality of the privilege-oppression relationship. I feel paralyzed. How do I proceed?

Amidst this paralysis, I thought about that adage, “With great power comes great responsibility.” The idea of taking responsibility, of taking action, of being an agent for change has been increasingly at the forefront of my mind. I do feel a sense of responsibility to help those

who confront social and institutional challenges by virtue of their minority status and marginalization. I am educated, skilled as a professional, can communicate in English with a certain fluency. I am therefore well positioned to enact change. This line of thinking brings me out of a position of paralysis and guilt, and into a position of empowerment.

Other group members remarked that privileges can be both as a result of perception (e.g., female beauty) or earned through hard work (e.g., financial security). Moreover, it seemed that it is our perceived privileges that result in our sense of guilt. This also resonates with me. I reflect on my relationship with my parents, my indebtedness to their sacrifices and experienced hardships, all to set up these opportunities that I have. I am reminded of D.W. Sue's poignant baseball metaphor depiction of privilege. "George W. Bush thought he had hit a triple, but in fact, he was born on third base."

Although I have not hit a homerun, I am already on base, and for that I feel indebted and responsible to my parents.

The Confucian virtue of filial piety or respect for one's parents and ancestors, seems to capture motivations. Then again, I experience a certain disconnect with Confucian's teaching or perhaps preaching of filial piety. It is done out of simple duty, because someone deems it important, whereas for me it is an internal drive. The Confucian teaching lacks an effect on me; in fact, I would go so far as to reject it as the very act of following it robs me of my own genuine desire to carry it out. How do I respect my parents though merely adhering a social tradition or following a teaching? I cannot. I would be demonstrating respect in action but lacking respect in emotion.

One group member referred to these "unearned" privileges as having been "stolen". The word "stolen" jars me out of my introspective state. It sounds harsh, even criminal. The word

implies a relational action, a thief stealing from a victim. In a way, this might be true for I am indeed realizing resources, power and opportunities at the expense of another. The others are the countless others who continue to be oppressed, to be marginalized. And yet, how do I steal from someone who has never had resources, power and opportunities in the first place. No, I am not stealing from the oppressed.

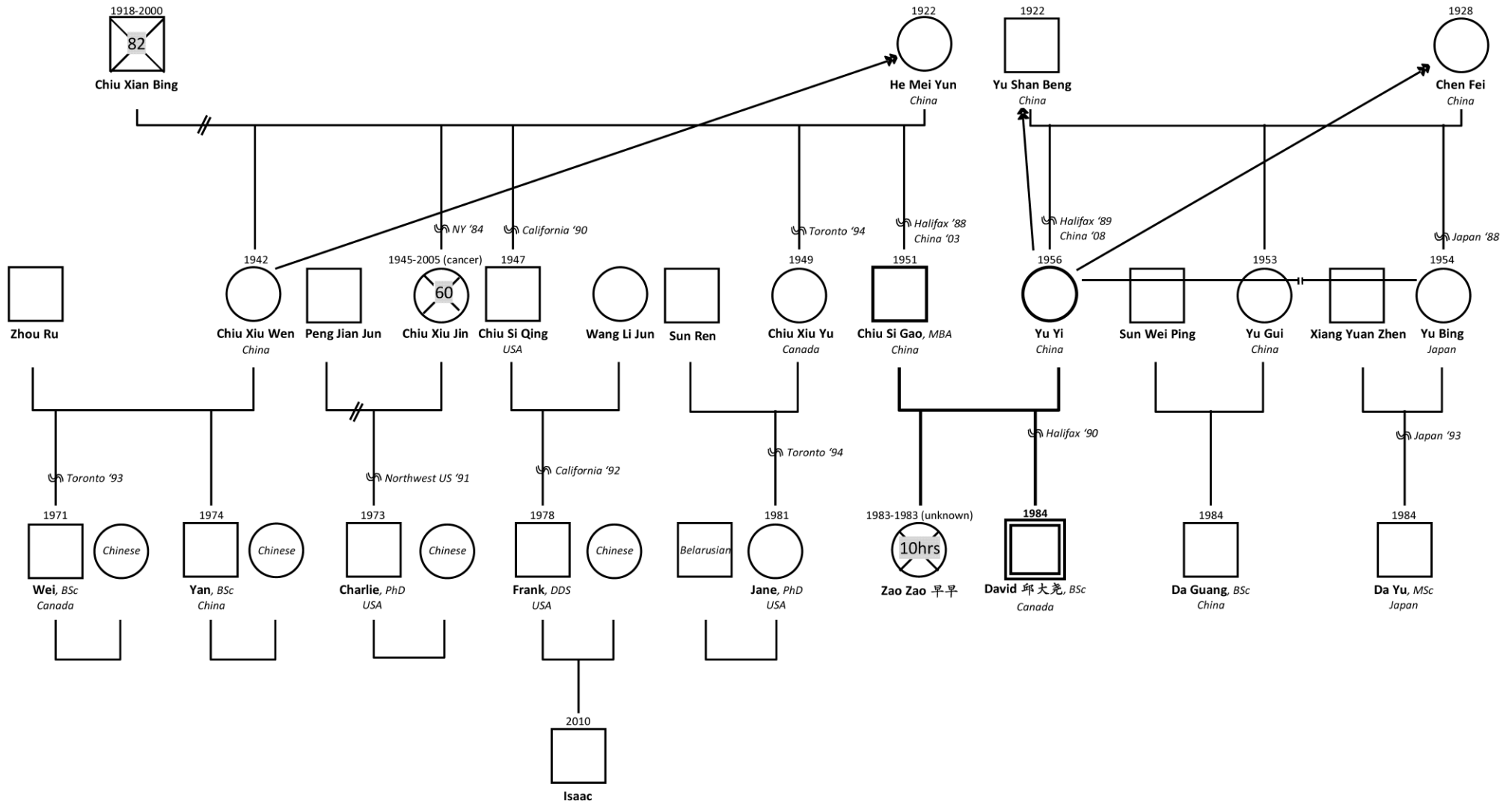
What about stealing from the privileged group? Am I stealing from a dominant majority their privileges? How could that be? It is not as though the privileged are somehow entitled to their privileges, that the resources, power and opportunities are theirs to own. They merely play out their lives based on the cards that they are dealt. No, I am not stealing from the privileged either. For me, I am using playing with the cards that I have been dealt.

In doing so, I am cautious of not bestowing a heavenly mandate upon myself. I do not want to be the person who will fix things or make things better. I am cautious to not assume on this self-righteous attitude, for who am I really to do so. In lessons learned from a deconstruction of colonial practices (Said, 1979), I recognize the dangers of meaning well and doing research.

In the end, I am still unsure what my role is as a health care provider to immigrants and young adults with cancer. I recognize what I don't want to do and what I can't do but I am confused as I have remaining the void of what I can and should do.

Appendix F

Genogram



Appendix G

My Life Values

Definition:

- “A principle, standard, or quality considered worthwhile or desirable” (The American Heritage Dictionary of the English Language, 2000).
- “Cultural values are what you are encouraged to strive for and are encoded in moral standards by which your behaviors and thoughts are publically and privately sanctioned” (Chang, 2008, p.98).

Autonomy: the right of each individual to self-determination, to live as one so chooses – regardless of how they may be perceived by others – so long as one’s actions do not harm others

Generativity: the responsibility of each individual to contribute to improving rather than destroying his/her social, physical and ecological surroundings

Authenticity: the importance of representing ones true self in the world and to other people, and the parallel exploring of oneself to understand ones true self

Industriousness/Diligence: the importance of working hard, planning ahead, being self-driven to realize long-term goals as opposed to fleeting, immediate desires

Humility: the importance of neither looking up nor down to any individual, regardless of education level, social class, financial situation or institutional position

Appendix H

Timeline of Major Life Experiences Related to Cancer and Dying

I select physical and symbolic border –crossing experiences in my life because they challenged my presuppositions and perspectives at the time they happened, have sometimes derailed me from my comfort zone, have broadened the horizon of my life, and have shaped me as a multicultural educator. Each entry identifies a border-crossing experience, then in parentheses briefly describes its effect on me.

- 1990/08 Moved to Halifax, Nova Scotia, Canada from Shanghai, China (being supplanted into an entirely foreign cultural context, disconnected from significant cultural ties except for my parents)
- 1990-2007 Growing up in Nova Scotia (growing up as an outsider, bearing the responsibility of having to negotiate a new cultural surrounding on my own)
- 1995/07 Travel back to China for the first time after moving to Canada and returning regularly thereafter (realization that I had become a stranger in the land that was born in, the cultural context that I had left felt more foreign than familiar)
- 2001/09/11 Terrorist attacks in the United States (realizing that my life does not exist in an idyllic vacuum and can be profoundly transformed in an instant)
- 2002-2007 Served as property manager for family's rental property (maturing quickly and assuming responsibility for things normally relegated to adults)
- 2000/01 High school peer dies in a boating accident (increasing salience of the finitude of life, experience of a public grieving process)
- 2000/07/10 My grandfather dies of old age (my first experience with death in the family)

- 2004/12 Accompanied *Nímāmā* during her cancer treatment at Johns Hopkins (first personal experience with cancer in my family)
- 2005/04/18 *Nímāmā* passes away of cancer (my first experience with death where I felt a strong connection with the person)
- 2004-2006 Work in a cancer research lab during my undergraduate degree (learn about the biological mechanism of cancer and that my interests existed elsewhere)
- 2006/08 My mother tells me that I had an older sister who died at birth (I become aware of the special place I occupy in my family and in the eyes of my parents)
- 2006/12 Write statement of intention for admission application to the Counselling Psychology program (acknowledging to myself that my career transition has been in large part motivated by my experience in caring for *Nímāmā* with cancer)
- 2007/08 Move to Vancouver (first experience living in a multiethnic society, first time living on my own, apart from my family)
- 2007/09 Begin graduate studies in Counselling Psychology (undertaking a major career and life transition, opportunity for self-reflection)
- 2007/10 Submit national scholarship application (first public admission of intentionality to engaging in career/research activities in cancer care)
- 2007/11 Discuss suicide assessment in class (being awakened to the possibility of supporting people who may be contemplating death)
- 2010/04 Attend training workshop for BCCA/Hospice care volunteers (being introduced to the idea that through confronting death, we learn how to live)
- 2010/09/18 Cycling accident (became frighteningly awakened to my own physical vulnerability and mortality, and the possibility of a physically disabled life)

Appendix I

Data Log

ID	Date	Time	Location	Activity/Item Type	Participants	Code
001	01/12/09	10:57 AM	Online	Email communication	David	Data collection
002	20/01/10	4:09 PM	Online	Email communication	David	Planning
003	01/02/10	12:47 PM	Online	Email communication	FC	Planning
004	01/02/10	2:45 PM	Online	Email communication	David	Planning
005	02/02/10	10:52 PM	Online	Email communication	David	Planning
006	02/02/10	10:56 PM	Online	Email communication	FC	Planning
007	03/02/10	10:36 AM	Online	Email communication	HR	Planning
008	04/02/10	8:22 AM	Online	Email communication	David	Planning
009	04/02/10	10:42 AM	Online	Email communication	JD	Planning
010	04/02/10	11:42 AM	Online	Email communication	HR	Planning
011	04/02/10	12:44 PM	Online	Email communication	David	Planning
012	04/02/10	1:37 PM	Online	Email communication	RD	Planning
013	07/02/10	9:26 AM	Online	Email communication	David	Planning
014	08/02/10	9:14 AM	Online	Email communication	HR	Planning
015	09/02/10	4:07 PM	Online	Email communication	RD	Planning
016	11/02/10	8:49 AM	Online	Email communication	David	Planning
017	11/02/10	9:16 AM	Online	Email communication	HR	Planning
018	01/03/10	8:34 AM	Online	Email communication	David	Planning
019	02/03/10	10:03 AM	Online	Email communication	RD	Planning
020	05/03/10		Waterfront	Journal entry	David	Reflection
021	09/03/10	9:58 AM	Online	Email communication	David	Planning
022	09/03/10	12:23 PM	Online	Email communication	RD	Planning
023	25/03/10	2:32 PM	Online	Email communication	David	Planning
024	25/03/10	2:47 PM	Online	Ethics application	Marla, David	Planning
025	26/03/10	7:02 AM	Online	Ethics application	Bill Borgen	Planning
026	26/03/10	8:33 AM	Online	Email communication	RD	Planning
027	31/03/10	1:36 PM	Online	Email communication	JM	Planning
028	06/04/10	2:41 PM	Online	Email communication	JM	Planning
029	07/04/10	8:21 AM	Online	Email communication	David	Planning
030	13/04/10	6:00 PM	Meeting room	Volunteer training	Volunteers	Data collection
031	13/04/10			Textual artefact		Data collection
032	13/04/10			Textual artefact		Data collection
033	13/04/10			Textual artefact		Data collection
034	13/04/10			Textual artefact		Data collection
035	13/04/10			Textual artefact		Data collection
036	13/04/10			Textual artefact		Data collection
037	13/04/10			Textual artefact		Data collection
038	13/04/10			Textual artefact		Data collection
039	13/04/10			Textual artefact		Data collection
040	15/04/10	11:00 AM	Office	Meeting	Amanda, David	Planning
041	15/04/10	2:21 PM	Online	Email communication	David	Planning
042	15/04/10	6:00 PM	Meeting room	Volunteer training	Volunteers	Data collection
043	16/04/10	5:53 AM	Online	Email communication	David	Planning
044	16/04/10	10:49 AM	Online	Ethics application	BREB	Planning
045	16/04/10	1:25 PM	Online	Email communication	Marla	Planning
046	17/04/10	7:24 AM	Online	Email communication	David	Planning
047	17/04/10	9:00 AM	Meeting room	Volunteer training	Volunteers	Data collection
048	19/04/10	9:48 AM	Online	Email communication	LK	Planning
049	19/04/10	9:59 AM	Online	Email communication	David	Planning

ID	Date	Time	Location	Activity/Item Type	Participants	Code
050	19/04/10	1:16 PM	Online	Email communication	David	Planning
051	19/04/10	3:50 PM	Online	Email communication	Amanda	Planning
052	19/04/10	8:56 PM	Online	Email communication	Marla	Planning
053	20/04/10	8:29 AM	Online	Email communication	Amanda	Planning
054	20/04/10	1:03 PM	Online	Email communication	LK	Planning
055	20/04/10	6:00 PM	Meeting room	Volunteer training	Volunteers	Data collection
056	21/04/10	7:15 AM	Online	Email communication	David	Planning
057	21/04/10	2:11 PM	Online	Email communication	Amanda	Planning
058	22/04/10	6:00 PM	Meeting room	Volunteer training	Volunteers	Data collection
059	24/04/10	9:00 AM	Meeting room	Volunteer training	Volunteers	Data collection
060	26/04/10	10:33 AM	Online	Email communication	David	Planning
061	26/04/10	11:00 AM	Online	Email communication	David	Planning
062	26/04/10	5:26 PM	Online	Ethics application	Marla, David	Planning
063	27/04/10	3:33 PM	Online	Email communication	Amanda	Planning
064	28/04/10	9:30 AM	Online	Email communication	Marla	Planning
065	29/04/10	11:38 AM	Online	Email communication	David	Planning
066	29/04/10	12:01 PM	Online	Email communication	David	Planning
067	29/04/10	2:57 PM	Online	Email communication	Amanda	Planning
068	30/04/10	9:32 AM	Online	Email communication	David	Planning
069	30/04/10	9:55 AM	Online	Email communication	David	Planning
070	30/04/10	10:01 AM	Online	Email communication	Amanda	Planning
071	04/05/10	3:17 PM	Online	Email communication	LK	Planning
072	04/05/10	4:46 PM	Online	Email communication	David	Planning
073	04/05/10	8:45 PM	Online	Email communication	David	Planning
074	05/05/10	8:55 AM	Online	Email communication	David	Planning
075	05/05/10	9:16 AM	Online	Email communication	MF	Planning
076	06/05/10	11:18 AM	Online	Email communication	David	Planning
077	07/05/10	10:55 AM	Online	Email communication	David	Planning
078	07/05/10	11:16 AM	Online	Email communication	David	Planning
079	07/05/10	2:50 PM	Online	Email communication	MP	Planning
080	10/05/10	12:55 PM	Online	Email communication	David	Planning
081	10/05/10	4:44 PM	Online	Email communication	MP	Planning
082	11/05/10	7:46 AM	Online	Email communication	David	Planning
083	11/05/10	9:13 AM	Online	Email communication	LK	Planning
084	12/05/10	10:22 PM	Online	Email communication	MP	Planning
085	13/05/10	8:20 PM	Online	Email communication	David	Planning
086	17/05/10	8:52 AM	Online	Email communication	CN	Planning
087	17/05/10	4:10 PM	Online	Ethics application	BREB	Planning
088	18/05/10	11:18 AM	Online	Ethics application	David	Planning
089	19/05/10	8:30 AM	BCCA	Volunteer training	BCCA volunteers, David	Data collection
090	31/05/10	9:34 AM	Online	Email communication	David	Planning
091	31/05/10	10:48 AM	Online	Ethics application	BREB	Planning
092	01/06/10	7:51 AM	Online	Email communication	David	Planning
093	02/06/10	7:58 AM	Online	Email communication	LK	Planning
094	02/06/10	10:01 AM	Online	Email communication	Amanda	Planning
095	02/06/10	11:01 AM	Online	Email communication	David	Planning
096	02/06/10	11:36 AM	Online	Email communication	LK	Planning
097	02/06/10	11:41 AM	Online	Email communication	David	Planning
098	03/06/10	9:30 AM	Online	Email communication	CNPS Program	Planning
099	03/06/10	8:52 PM	Online	Email communication	Marla	Planning
100	09/06/10	7:03 AM	Online	Email communication	David	Planning
101	10/06/10	9:15 AM	BCCA	Volunteering	David	Data collection
102	10/06/10	9:15 AM	BCCA	Volunteering	David	Data collection

ID	Date	Time	Location	Activity/Item Type	Participants	Code
103	10/06/10	9:20 AM	Online	Email communication	Amanda	Planning
104	10/06/10	11:13 PM	Online	Email communication	David	Planning
105	10/06/10		BCCA	Field notes	David	Reflection
106	10/06/10		BCCA	Field notes	David	Reflection
107	11/06/10	10:12 AM	Online	Email communication	JM	Planning
108	11/06/10	11:06 AM	Online	Ethics application	David	Planning
109	11/06/10	12:54 PM	Online	Ethics application	BREB	Planning
110	11/06/10	2:27 PM	Online	Ethics application	David	Planning
111	13/06/10	8:19 PM	Online	Email communication	David	Planning
112	14/06/10	1:30 PM	BCCA	Meeting	GM, Amanda, David	Planning
113	15/06/10	8:51 AM	Online	Ethics application	BREB	Planning
114	15/06/10	1:48 PM	Online	Email communication	David	Planning
115	17/06/10	10:32 AM	BCCA	Volunteering	David	Data collection
116	17/06/10		BCCA	Field notes	David	Reflection
117	15/07/10	9:30 AM	BCCA	Volunteering	David	Data collection
118	15/07/10		BCCA	Field notes	David	Reflection
119	20/07/10	9:15 AM	BCCA	Meeting	PFC staff, David	Planning
120	19/08/10	9:15 AM	BCCA	Volunteering	David	Data collection
121	19/08/10		BCCA	Field notes	David	Reflection
122	26/08/10	9:15 AM	BCCA	Volunteering	David	Data collection
123	26/08/10		BCCA	Field notes	David	Reflection
124	31/08/10	2:32 PM	Online	Email communication	David	Planning
125	31/08/10	4:35 PM	Online	Email communication	GM	Planning
126	31/08/10		Online	Email communication	David	Planning
127	01/09/10	9:47 AM	Online	Email communication	David	Planning
128	01/09/10	9:51 AM	Online	Email communication	David	Planning
129	01/09/10	9:52 AM	Online	Email communication	GM	Planning
130	01/09/10	11:55 AM	Online	Email communication	BG	Planning
131	02/09/10	7:20 AM	Online	Email communication	David	Planning
132	02/09/10	7:31 AM	Online	Email communication	David	Planning
133	02/09/10	9:25 AM	BCCA	Volunteering	David	Data collection
134	02/09/10	9:34 AM	Online	Email communication	BG	Planning
135	02/09/10		BCCA	Field notes	David	Reflection
136	03/09/10	11:03 AM	Online	Email communication	GM	Planning
137	03/09/10	3:41 PM	Online	Email communication	JB	Planning
138	03/09/10	4:09 PM	Online	Email communication	CN	Planning
139	05/09/10	4:39 AM	Online	Email communication	David	Planning
140	07/09/10	6:01 AM	Online	Email communication	NB	Planning
141	07/09/10	9:12 AM	Online	Email communication	KJ	Planning
142	07/09/10	9:43 AM	Online	Email communication	DR	Planning
143	07/09/10	11:09 AM	Online	Email communication	Amanda	Planning
144	07/09/10	11:36 AM	Online	Email communication	David	Planning
145	07/09/10	11:48 AM	Online	Email communication	David	Planning
146	07/09/10	12:08 PM	Online	Email communication	David	Planning
147	07/09/10	3:30 PM	Online	Email communication	BB	Planning
148	07/09/10	5:51 PM	Online	Email communication	David	Planning
149	08/09/10	8:26 AM	Online	Email communication	David	Planning
150	08/09/10	8:28 AM	Online	Email communication	David	Planning
151	08/09/10	9:01 AM	Online	Email communication	KJ	Planning
152	08/09/10	9:06 AM	Online	Email communication	David	Planning
153	08/09/10	4:05 PM	Online	Email communication	Amanda	Planning
154	09/09/10	10:30 AM	BCCA	Volunteering	David	Data collection
155	09/09/10		BCCA	Field notes	David	Reflection

ID	Date	Time	Location	Activity/Item Type	Participants	Code
156	10/09/10	10:31 AM	Online	Email communication	CN	Planning
157	10/09/10	3:36 PM	Online	Email communication	CN	Planning
158	13/09/10	7:32 AM	Online	Email communication	David	Planning
159	14/09/10	8:02 AM	Online	Email communication	BB	Planning
160	14/09/10	3:00 PM	Coffee shop	Interview	CN, David	Data collection
161	14/09/10	7:15 PM	Online	Email communication	David	Planning
162	15/09/10	11:36 AM	Online	Email communication	CN	Planning
163	15/09/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
164	16/09/10	7:54 AM	Online	Email communication	David	Planning
165	16/09/10	8:43 AM	Online	Email communication	David	Planning
166	16/09/10	10:16 AM	Online	Email communication	David	Planning
167	16/09/10	10:45 AM	BCCA	Volunteering	David	Data collection
168	16/09/10	11:44 AM	Online	Email communication	KC	Planning
169	16/09/10	11:52 AM	Online	Email communication	David	Planning
170	16/09/10	12:00 PM	BCCA	Meeting	Nurses, David	Planning
171	16/09/10	10:12 PM	Online	Email communication	David	Planning
172	16/09/10		BCCA	Field notes	David	Reflection
173	17/09/10	7:30 AM	Phone	Meeting	KC, David	Data collection
174	17/09/10	12:19 PM	Online	Email communication	David	Planning
175	17/09/10		Online	Email communication	KC	Planning
176	19/09/10	7:59 AM	Online	Email communication	David	Planning
177	19/09/10	2:22 PM	Online	Email communication	David	Planning
178	20/09/10	7:00 PM	Phone	Phone communication	CN, David	Planning
179	21/09/10	8:34 AM	Online	Email communication	David	Planning
180	21/09/10		Home	Journal entry	David	Reflection
181	22/09/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
182	22/09/10			Article		Data collection
183	23/09/10	2:35 PM	Online	Email communication	David	Planning
184	23/09/10	5:28 PM	Online	Email communication	CN	Planning
185	25/09/10	11:00 AM	Park	Interview	CN, David	Data collection
186	25/09/10		Park	Field notes	David	Reflection
187	28/09/10	1:26 PM	Online	Email communication	ES	Planning
188	29/09/10	6:43 AM	Online	Email communication	David	Planning
189	29/09/10	8:12 AM	Online	Email communication	ES	Planning
190	29/09/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
191	29/09/10			Video		Data collection
192	30/09/10	11:30 AM	BCCA	Volunteering	David	Data collection
193	30/09/10		BCCA	Field notes	David	Reflection
194	05/10/10	8:44 AM	Online	Email communication	David	Planning
195	06/10/10	3:58 PM	Online	Email communication	Amanda	Planning
196	06/10/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
197	06/10/10	8:03 PM	Online	Email communication	David	Planning
198	07/10/10	7:20 AM	Online	Email communication	KC	Planning
199	10/10/10	2:28 PM	Online	Email communication	CN	Planning
200	11/10/10	10:49 AM	Online	Email communication	David	Planning
201	11/10/10	11:03 AM	Online	Email communication	CN	Planning
202	11/10/10	11:21 AM	Online	Email communication	David	Planning
203	11/10/10	11:35 AM	Online	Email communication	CN	Planning
204	12/10/10	9:54 AM	Online	Email communication	David	Planning
205	12/10/10	10:30 AM	Online	Email communication	David	Planning
206	12/10/10	11:22 AM	Online	Email communication	CN	Planning
207	12/10/10	12:17 PM	Online	Email communication	LC	Planning
208	12/10/10	1:52 PM	Online	Email communication	JM	Planning

ID	Date	Time	Location	Activity/Item Type	Participants	Code
209	12/10/10	8:45 PM	Online	Email communication	David	Planning
210	13/10/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
211	13/10/10	7:00 PM	Library	Interview	CN, partner, David	Data collection
212	14/10/10	9:24 AM	Online	Email communication	David	Planning
213	14/10/10	11:46 AM	Online	Email communication	LC	Planning
214	19/10/10		Home	Journal entry	David	Reflection
215	20/10/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
216	20/10/10		Home	Journal entry	David	Reflection
217	21/10/10	9:15 AM	BCCA	Volunteering	David	Data collection
218	21/10/10		BCCA	Field notes	David	Reflection
219	25/10/10	9:47 AM	Online	Email communication	BB	Planning
220	25/10/10	3:04 PM	Online	Email communication	David	Planning
221	27/10/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
222	29/10/10	9:00 AM	UBC	Meeting	Amanda, Marla, David	Planning
223	31/10/10	10:29 AM	Online	Email communication	BB	Planning
224	02/11/10	8:30 AM	Online	Email communication	David	Planning
225	02/11/10	8:37 AM	Online	Email communication	Amanda	Planning
226	02/11/10	8:43 AM	Online	Email communication	David	Planning
227	02/11/10	9:00 AM	Online	Email communication	JM	Planning
228	02/11/10	9:14 AM	Online	Email communication	David	Planning
229	02/11/10	9:23 AM	Online	Email communication	David	Planning
230	02/11/10	9:52 AM	Online	Email communication	Amanda	Planning
231	02/11/10	1:06 PM	Online	Email communication	GM	Planning
232	02/11/10	3:47 PM	Online	Email communication	BB	Planning
233	02/11/10	3:58 PM	Online	Email communication	Amanda	Planning
234	02/11/10	8:41 PM	Online	Email communication	David	Planning
235	03/11/10	3:05 PM	Online	Email communication	BB	Planning
236	03/11/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
237	03/11/10	6:47 PM	Online	Email communication	David	Planning
238	04/11/10	2:00 PM	BCCA	Volunteering	David	Data collection
239	04/11/10		BCCA	Field notes	David	Reflection
240	04/11/10	9:53 AM	Online	Email communication	David	Planning
241	04/11/10	10:25 AM	Online	Ethics application	Marla, David	Planning
242	04/11/10	10:31 AM	Online	Email communication	PN1	Planning
243	04/11/10	11:59 AM	Online	Email communication	David	Planning
244	04/11/10	12:18 PM	Online	Email communication	David	Planning
245	04/11/10	12:19 PM	Online	Email communication	HR	Planning
246	04/11/10	12:28 PM	Online	Email communication	David	Planning
247	04/11/10	12:37 PM	Online	Email communication	David	Planning
248	04/11/10	12:59 PM	Online	Email communication	David	Planning
249	04/11/10	1:12 PM	Online	Email communication	David	Planning
250	05/11/10	2:16 AM	Online	Email communication	David	Planning
251	05/11/10	9:30 AM	Online	Email communication	DS	Planning
252	05/11/10	12:36 PM	Online	Email communication	PN1	Planning
253	05/11/10	2:34 PM	Online	Email communication	Amanda	Planning
254	05/11/10	2:56 PM	Online	Email communication	DS	Planning
255	05/11/10	3:38 PM	Online	Email communication	David	Planning
256	05/11/10	3:42 PM	Online	Email communication	Amanda	Planning
257	05/11/10	3:57 PM	Online	Email communication	GM	Planning
258	06/11/10	3:14 PM	Online	Email communication	David	Planning
259	09/11/10	9:46 AM	Online	Ethics application	BREB	Planning
260	09/11/10	10:21 AM	Online	Email communication	David	Planning
261	09/11/10	10:27 AM	Online	Email communication	David	Planning

ID	Date	Time	Location	Activity/Item Type	Participants	Code
262	09/11/10	11:58 AM	Online	Email communication	Marla	Planning
263	09/11/10	6:57 PM	Online	Email communication	Marla	Planning
264	10/11/10	2:59 PM	Online	Email communication	Amanda	Planning
265	10/11/10	4:00 PM	Online	Course meeting	Social work, nursing students	Planning
266	11/11/10	8:05 AM	Online	Email communication	David	Planning
267	11/11/10	11:09 AM	BCCA	Photograph		Data collection
268	11/11/10	11:15 AM	BCCA	Volunteering	David	Data collection
269	11/11/10		BCCA	Field notes	David	Reflection
270	15/11/10	8:54 AM	Online	Email communication	KC	Planning
271	15/11/10	11:42 AM	Online	Email communication	David	Planning
272	15/11/10	2:50 PM	Online	Email communication	GM	Planning
273	15/11/10	4:27 PM	Online	Email communication	GM	Planning
274	15/11/10	9:36 PM	Online	Email communication	David	Planning
275	15/11/10	9:53 PM	Online	Email communication	David	Planning
276	15/11/10	10:09 PM	Online	Email communication	David	Planning
277	16/11/10	7:50 AM	Online	Email communication	SK	Planning
278	16/11/10	8:35 AM	Online	Email communication	GM	Planning
279	16/11/10	9:31 AM	Online	Email communication	PN1	Planning
280	16/11/10	9:53 AM	Online	Email communication	KC	Planning
281	16/11/10	1:05 PM	Online	Email communication	Marla	Planning
282	16/11/10	5:46 PM	Online	Email communication	HL	Planning
283	17/11/10	8:53 AM	Online	Email communication	David	Planning
284	17/11/10	8:59 AM	Online	Email communication	David	Planning
285	17/11/10	9:05 AM	Online	Email communication	Marla	Planning
286	17/11/10	9:23 AM	Online	Email communication	David	Planning
287	17/11/10	9:30 AM	Online	Email communication	David	Planning
288	17/11/10	9:51 AM	Online	Email communication	David	Planning
289	17/11/10	10:37 AM	Online	Email communication	LC	Planning
290	17/11/10	2:13 PM	Online	Email communication	David	Planning
291	17/11/10	2:18 PM	Online	Email communication	SK	Planning
292	17/11/10	4:00 PM	Online	Course meeting	Social work, nursing students	Reflection
293	18/11/10	8:18 AM	Online	Email communication	David	Planning
294	18/11/10	11:57 AM	Online	Email communication	RW	Planning
295	19/11/10	11:33 AM	Online	Email communication	KC	Planning
296	19/11/10	9:00 PM	Online	Email communication	David	Planning
297	22/11/10	5:24 AM	Online	Email communication	KC	Planning
298	22/11/10	9:41 PM	Online	Email communication	SB	Planning
299	23/11/10	7:45 AM	BCCA	Interview	SK, David	Data collection
300	23/11/10	3:12 PM	Online	Email communication	SK	Planning
301	24/11/10	8:25 AM	Online	Email communication	David	Planning
302	24/11/10	8:31 AM	Online	Email communication	David	Planning
303	24/11/10	9:03 AM	Online	Email communication	PN1	Planning
304	24/11/10	11:13 AM	Online	Email communication	PN1	Planning
305	24/11/10	2:35 PM	Online	Email communication	David	Planning
306	24/11/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
307	24/11/10	9:03 PM	Online	Email communication	David	Planning
308	25/11/10	3:30 PM	House room	Meeting	DS, David	Data collection
309	25/11/10	5:25 PM	Online	Email communication	PN1	Planning
310	26/11/10	9:30 AM	Phone	Interview	KC, David	Data collection
311	29/11/10	8:54 PM	Online	Email communication	David	Planning
312	30/11/10	9:31 AM	Online	Email communication	Amanda	Planning
313	30/11/10	12:08 PM	Online	Email communication	Marla	Planning
314	30/11/10	9:25 PM	Online	Email communication	David	Planning

ID	Date	Time	Location	Activity/Item Type	Participants	Code
315	01/12/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
316	02/12/10	10:15 AM	BCCA	Volunteering	David	Data collection
317	02/12/10		BCCA	Field notes	David	Reflection
318	02/12/10	9:00 AM	BCCA	Meeting	Amanda, David	Planning
319	02/12/10	11:30 AM	BCCA	Interview	PN1, David	Data collection
320	02/12/10	3:04 PM	Online	Email communication	Amanda	Planning
321	03/12/10	3:27 PM	Online	Email communication	SK	Planning
322	03/12/10	4:14 PM	Online	Email communication	PN2	Planning
323	03/12/10	6:04 PM	Online	Email communication	David	Planning
324	03/12/10	6:18 PM	Online	Email communication	David	Planning
325	03/12/10	8:31 PM	Online	Email communication	PN2	Planning
326	04/12/10	9:30 AM	BCCA	Volunteering	Other BCCA volunteers	Data collection
327	05/12/10	8:40 AM	Online	Email communication	David	Planning
328	06/12/10	7:27 AM	Online	Email communication	David	Planning
329	06/12/10	9:20 AM	Online	Email communication	PN1	Planning
330	06/12/10	9:23 AM	Online	Email communication	GM	Planning
331	06/12/10	11:32 AM	Online	Email communication	David	Planning
332	06/12/10	11:43 AM	Online	Email communication	David	Planning
333	06/12/10	12:18 PM	Online	Email communication	GM	Planning
334	06/12/10	6:12 PM	Online	Email communication	David	Planning
335	06/12/10	7:09 PM	Online	Email communication	PN2	Planning
336	07/12/10	8:28 AM	Online	Email communication	David	Planning
337	07/12/10	1:19 PM	Online	Email communication	David	Planning
338	07/12/10	3:15 PM	Online	Email communication	PN2	Planning
339	07/12/10	6:30 PM	Online	Email communication	David	Planning
340	08/12/10	10:09 AM	Online	Email communication	CC	Planning
341	08/12/10	4:00 PM	Online	Course meeting	Social work, nursing students	Data collection
342	15/12/10	8:28 AM	Online	Email communication	David	Planning
343	15/12/10	10:00 AM	Online	Email communication	Amanda	Planning
344	15/12/10	4:07 PM	Online	Email communication	LK	Planning
345	15/12/10	8:42 PM	Online	Email communication	David	Planning
346	16/12/10	9:27 AM	Online	Email communication	David	Planning
347	16/12/10	9:30 AM	BCCA	Volunteering	David	Data collection
348	16/12/10	10:15 AM	Online	Email communication	Amanda	Planning
349	16/12/10	10:28 AM	Online	Email communication	Amanda	Planning
350	16/12/10	10:30 AM	Online	Email communication	Marla	Planning
351	16/12/10	10:31 AM	Online	Email communication	Marla	Planning
352	16/12/10	12:03 PM	Online	Email communication	AB	Planning
353	16/12/10	9:45 PM	Online	Email communication	David	Planning
354	16/12/10		BCCA	Field notes	David	Reflection
355	17/12/10	1:04 PM	Online	Email communication	David	Planning
356	23/12/10	9:30 AM	BCCA	Volunteering	David	Data collection
357	23/12/10		BCCA	Field notes	David	Reflection
358	24/12/10	3:00 PM	BCCA	Volunteering	David	Data collection
359	24/12/10		BCCA	Field notes	David	Reflection
360	04/01/11	10:00 AM	BCCA	Interview	GM, David	Data collection
361	05/01/11	2:00 PM	UBC	Meeting	Marla, David	Planning
362	08/01/11		Online	Article	Wall Street Journal	Data collection
363	08/01/11		Online	Article	Wall Street Journal	Data collection
364	10/01/11	8:56 AM	Online	Email communication	David	Planning
365	10/01/11	8:57 AM	Online	Email communication	David	Planning
366	10/01/11	9:42 AM	Online	Email communication	JM	Planning
367	10/01/11		Online	Podcast	CBC Radio The Next Chapter	Data collection

ID	Date	Time	Location	Activity/Item Type	Participants	Code
368	10/01/11	9:41 AM	Online	Email communication	JM	Scheduling
369	10/01/11	8:57 AM	Online	Email communication	David	Scheduling
370	10/01/11	8:56 AM	Online	Email communication	David	Research planning
371	11/01/11	8:34 AM	Online	Email communication	David	Planning
372	11/01/11	3:04 PM	Online	Email communication	David	Planning
373	11/01/11		Home	Journal entry	David	Reflection
374	11/01/11	5:05 PM	Online	Email communication	David	Planning
375	11/01/11	3:04 PM	Online	Email communication	David	Planning
376	11/01/11	4:28 PM	Online	Email communication	Marla	Planning
377	11/01/11	2:35 PM	Online	Email communication	Marla	Planning
378	12/01/11	3:14 PM	Online	Email communication	David	Planning
379	13/01/11		Radio	News	CBC Radio Early Edition	Data collection
380	13/01/11	7:20 AM	Home	Journal entry	David	Reflection
381	14/01/11	8:00 AM	Online	Email communication	David	Planning
382	14/01/11	9:28 AM	Online	Email communication	David	Reflection
383	14/01/11	10:27 AM	Home	Letter	David	Reflection
384	14/01/11		Radio	News	CBC Radio Early Edition	Data collection
385	14/01/11		Online	Article	Wall Street Journal	Data collection
386	14/01/11	8:01 AM	Online	Email communication	David	Research planning
387	15/01/11	12:15 PM	Home	Journal entry	David	Reflection
388	16/01/11		Online	Article	Wall Street Journal	Data collection
389	17/01/11		Home	Journal entry	David	Reflection
390	18/01/11	10:20 AM	Online	Email communication	David	Planning
391	18/01/11		Home	Journal entry	David	Reflection
392	18/01/11		Home	Journal entry	David	Reflection
393	19/01/11	8:16 PM	Online	Email communication	David	Planning
394	20/01/11	6:32 PM	Online	Email communication	David	Planning
395	20/01/11	10:50 AM	BCCA	Interview	LK, David	Data collection
396	20/01/11	9:35 AM	Bus stop	Journal entry	David	Reflection
397	21/01/11	11:30 AM	UBC	Conversation	LP, David	Data collection
398	21/01/11		Home	Journal entry	David	Reflection
399	23/01/11	11:02 AM	Beach	Photograph		Data collection
400	23/01/11	1:36 PM	Home	Journal entry	David	Reflection
401	23/01/11	2:10 PM	Home	Journal entry	David	Reflection
402	24/01/11	8:02 AM	Online	Email communication	David	Planning
403	25/01/11			Grant application	Marla, David	Planning
404	25/01/11	2:30 PM	UBC	Meeting	Amanda, Marla, David	Planning
405	25/01/11	10:11 AM	Online	Email communication	David	Planning
406	27/01/11		Seattle	Conversation	Attendees, David	Data collection
407	27/01/11		Seattle	Journal entry	David	Reflection
408	27/01/11	3:30 PM	Seattle	Journal entry	David	Reflection
409	30/01/11	11:30 AM	Home	Journal entry	David	Reflection
410	30/01/11	8:35 PM	Online	Email communication	David	Planning
411	30/01/11	9:46 PM	Online	Email communication	David	Planning
412	31/01/11	11:31 PM	Online	Email communication	AK	Planning
413	01/02/11	7:18 AM	Online	Email communication	David	Planning
414	01/02/11	8:23 AM	Online	Email communication	David	Planning
415	01/02/11	1:23 PM	Online	Email communication	RG	Planning

Appendix J

Interview Questions for Patients

Establishing Rapport:

- How did you hear about this study?
- When did you come to Canada? What was it like?
- What are you studying at school?
- What do you like/dislike most about being in Vancouver?
- Can you tell me a little about your typical day now and what it used to be like?

Values:

- What part of your life do you value most?
- Which people in your life are most important to you?
- What are the parts of your life that are most neglected/ignored?

Coping:

- What things causes you stress?
- How do you deal with stress?
- Where do you find support or go for help?
- Is there anything that's keeping you up at night?

Cultural Experiences:

- How did/do you normally spend your day? What was/is a typical day for you like?
- How has your life changed as a result of being an immigrant, becoming a young adult or getting cancer?
- What past experiences have had the biggest affect on who you are today?
- How does being an immigrant, cancer patient or young adult affect your everyday experience?

Appendix K

Interview Questions for Health Care Providers

- What is your current role and responsibilities as it relates to immigrant young adults (IYA) with cancer?
- Could you tell me about your experience in working with this population?
- What have you observed to be challenges or unmet needs experienced by IYA with cancer and their family members ?
- What are some challenges that you have experienced in working with this population?
- How do you perceive being an immigrant or young adult to differentially affect the experiences of this population?
- To your knowledge, what resources are available (specifically) for young adults and immigrants with cancer?

Appendix L

Recruitment Brochure

Study team members



Dr. Maria Buchanan
(Principle Investigator)
Professor, Counselling Psychology
University of British Columbia



Dr. Amanda Ward
BCCA Investigator
Research Scientist, Cancer Rehabilitation,
Sociobehavioural Research Centre, BC Cancer Agency



David Chiu
MA Student, Counselling Psychology
University of British Columbia


David is a Master's student in the Counselling Psychology program at UBC. He is conducting this study as part of his thesis research. After graduating, he hopes to work to support people during times of major life transitions.

For more information, feel
free to call or email David.



The Experiences of Immigrant Young Adults with Cancer

A UBC-BCCA research study to
understand how best to
support young adults during
major life transitions.

 THE UNIVERSITY OF BRITISH COLUMBIA
Faculty of Education

 BC Cancer Agency
CARE | RESEARCH

Purpose of the study

The purpose of this study is to learn about young adults' experiences during major transitions in life.



Life as an immigrant young adult with cancer can be complicated and tough. What you're going through and what is most important to you are often misunderstood by those who try to support you, including your doctor, family members and friends.

Our goal is to:

- learn from your unique experiences in life.
- understand how your life has been affected by having cancer, by being an immigrant, by being a young adult.
- educate health care professionals and other caregivers about how best to support people with similar experiences as yours.

Who can take part in the study?

- (1) Young adults aged 19-29.
- (2) English is not your first language.
- (3) Live in the Lower Mainland.
- (4) Is diagnosed with cancer.

Sounds interesting!

How do I get more info or sign up?

Feel free to call or email David.

Why should I participate?

As a participant who has experienced so much in life, you will be helping to inform health care professionals about how best to support people with similar experiences as yours.

For yourself, you may find that the chance to talk about your experiences may help you gain a better understanding of yourself, your needs and values. You may even find it easier to express those needs to other people in your life.

Also, some people also say that just sharing with another person what's going on inside of you can be a stress release.

What will I be asked to do?

Talk with David about your current experience as an immigrant young adult with cancer. You could talk about your relationship with family and friends, school, adjusting to life in Canada, your cancer. Basically, whatever is most significant in your life right now. David will arrange to meet with you at your home, school, the hospital or wherever life happens for you.

We'll cover the cost of bus fare or gas if you need to travel to participate in this study.

How long will the study take?



Beyond the one hour initial meeting, you decide how much/little you participate. It depends on what you're comfortable with. The more time you're willing to spend with David, the better he will understand your experiences. This is something you can decide with David at the start and as you go along.

Are there any risks?

Sometimes, sharing and exploring personal experiences can bring up uncomfortable feelings. If you have any concerns about how you're feeling, we will provide all study participants with a list of educational resources.

Who will see my information?

All personal information will be kept strictly confidential. No one except the study team members will have access to the notes we make. No real names will be used. When discussing specific research findings, we'll always eliminate details that might identify you.



Can I find out my "results"?

Yes, in a way. You're the expert of your life after all, and so what you share with us are the "results". We do want to make sure that we're getting it right though, so David will check with you regularly to see how his interpretations match up with your experiences.

Do you pay participants?

No, but your name will be put into a draw for one of two \$50 gift certificates.

What if I change my mind and no longer want to participate.

You're free to withdraw at any time, for any reason. If there is anything you're not comfortable talking about, your free to just pass. The quality of medical care you receive won't be affected in any way.

Appendix M
Recruitment Flyer



The Experiences of Immigrant Young Adults with Cancer

BC Cancer Agency
CARE - RESEARCH
UBC
UNIVERSITY OF BRITISH COLUMBIA
Faculty of Education
Research Study

**Help us understand.
Share your experiences.**

- WHO:** Immigrant young adults (19-29) diagnosed with cancer and English is not your first language.
- WHAT:** Help us understand your experience of going through the many major transitions in your life. What are your days like? What has changed? How have you adjusted? What parts of your life are most important?
- WHY:** To understand how best to support other young immigrant adults going through similar experiences.
- WHEN:** Arranged at a time and place that is convenient for you.

FOR MORE INFO:
David, UBC MA Student

Immigrant Young Adult Study

Immigrant Young Adult Study

Immigrant Young Adult Study

Immigrant Young Adult Study

Immigrant Young Adult Study

Immigrant Young Adult Study

Principle Investigator: Dr. Marta Buchanen, PhD
BCCA Investigator: Dr. Amanda Ward, PhD
REB: HD9-01073
Version 1.4 Recruitment Flyer (2010-06-15)

Appendix N

Initial Contact Letter



Department of Educational and Counselling Psychology,
and Special Education
2125 Main Mall
Vancouver, B.C., Canada V6T 1Z4
<http://www.ecps.educ.ubc.ca/>

Dear Potential Research Participant:

I am a researcher and counselling psychologist at the University of British Columbia (UBC). Together with David Chiu, a counselling psychology student, we would like to invite you to participate in a UBC study titled **"Exploring the Cultural Experiences of Immigrant Young Adults with Cancer"**.

You have been identified by [health care professional's name] as someone whose life experiences could valuably inform this study. Rest assured that your contact information has not been shared with anyone. Your right to privacy is legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected.

The purpose of this study is to learn about individuals' experience during major transitions in life. The lives of immigrant young adults with cancer are unique and often misunderstood by those who try to support them, including doctors and other health professionals. Each individual has different values, life circumstances and backgrounds. We want to better understand the lives of immigrant young adult with cancer. We think that your participation in this study can help inform health care providers about how to better support people with similar experiences as yours.

In order to get a complete picture, we will gather information through a number of different ways. We would like to talk with you and the significant members of your lives. We would also like to join you during your day-to-day activities. Your participation in any and all parts of the study is voluntary. Where, when and how information is gathered will be determined with you. You may choose to pass on a particular part or question, or to withdraw at any time without consequences. Your doctors will continue to provide the best available medical care.

If you are interested in participating in this study or have any questions, please contact David




Dr. Marla Buchanan
Principle Investigator
Professor
Department of Educational and Counselling
Psychology and Special Education
Faculty of Education
University of British Columbia

David Chiu
Co-Investigator
Master's Student
Department of Educational and Counselling
Psychology and Special Education
Faculty of Education
University of British Columbia


Appendix O

Exploring the Cultural Experiences of Immigrant Young Adults with Cancer

Consent Form

Principal Investigator: Marla Buchanan, PhD
Associate Professor, Counselling Psychology
Faculty of Education, University of British Columbia


Co-Investigators: Amanda Ward, PhD
Research Scientist
Cancer Rehabilitation, Sociobehavioural Research Centre, BC Cancer Agency


David Chiu, BSc
Master's Student, Counselling Psychology
Faculty of Education, University of British Columbia


Purpose:

You are invited to participate in a UBC research study to learn about the diverse experiences of immigrant young adults with cancer. By taking part in this study, you will provide valuable information for learning about the experiences of individuals in times of major life transitions. What is learned from this study may help inform health care providers about how to better support people with similar experiences as yours. This study is part of David Chiu's Master's thesis project.

Research Method:

In order to gain a comprehensive understanding of your experience, this study will use an open-ended research method called ethnography. Ethnographic research involves studying human behaviour in the natural settings in which they occur. The primary goal is to learn how members of a community (immigrant young adults with cancer) make sense of their own community and its relationships with other people, communities, and institutions.

A number of ways are used to collect information in ethnographic research. These include but are not limited to unobtrusive direct observation, participant observation, structured and unstructured interviewing, focused discussions with individuals and community members, analysis of texts, and audio-visual records.

Research Participation:

You will be asked to meet with David to share your experience as an immigrant young adult with cancer. Discussion topics might include important areas of your life, relationship with your family and friends, changes that have taken place and how you are managing them. This conversation with David will take approximately one hour. After this initial meeting, your level of participation will be up to you to decide. Where, when and how David gains a better understanding of your experiences will be determined with you as the research proceeds. For example:

- You may be asked to continue your discussion with David again to follow up on particularly interesting points.
- David may ask if he may accompany you during your day-to-day activities (in the hospital, at school, at home, etc.)
- In order to get another perspective on your experiences, David may ask if he may talk with particular important people in your life (like your family, friends or health care provider).

There are no rigid procedures to follow. The research will take the direction that you are comfortable with. David will always check with you before deciding on the direction.

Voluntary Nature of Participation:

Your participation in any part of this research is completely voluntary. You have the right to participate, decline or discontinue at any time without any effect on the quality of medical care you receive. That means if you agree to participate, you are still free to pass on any questions David asks or refuse to go ahead with some part of the research while continuing with others.

Anonymity and Confidentiality:

Every effort will be made not to reveal personally identifiable information about you in publications based on this research. To accomplish this, no records will be created or retained that could link you to personally identifiable descriptions, paraphrases, or quotations. What you share will be presented without specific reference to you either by using pseudonyms or combining anonymously with the actions and words of other participants.

The only people who will have access to the information you share are David and Dr. Buchanan, the principle investigator. All documents and notes will be collected in an unlabelled notebook that is kept in a secure, locked location in the office of the co-investigator. Interview recordings, transcripts and other computer files will be secured on a single password protected laptop.

Risks of Participation:

Sometimes, the sharing and exploring of personal experiences can bring up uncomfortable emotions like sadness, distress or anger. A list of counselling resources will be provided to you that can be taken advantage of. Also, remember that you have the right to stop or refuse to participate at any point in the study without consequence. Rest assured that David will not be offended by this.

There is also a risk that despite our best efforts to not reveal personally identifiable information in publications of this research, your participation in this study might still be recognized by people you know. This is because the goal of this study is to create detailed descriptions of participants' experiences. Your involvement will be sought in reviewing our research findings and publications. We would welcome your feedback on how we may present the research differently and where our interpretation does not quite align with your experiences.

Potential Benefits of Participation:

Although we cannot promise that you will receive any benefits from participating in this study, the research will make you reflect about your personal values and priorities. You might find that, as a result, you may gain a better understanding of yourself as a person. For some people, this increased self-awareness is very rewarding.

Some people find that talking about their experiences with another person can be a stress release. This might be the case particularly for people who keep a lot of their thoughts bottled up inside.

You might also find that talking about what is going on for you inside might help others in your life understand and support you better.

Payments:

Your expenses in taking part in the research will be reimbursed, includes any bus fare, gas and parking expenses. Regardless of whether you decide to continue with the research or not, you will be entered into a draw for one of two \$50 gift certificates.

Contact Information:

If you have any concerns or questions about this research, please feel free to contact the principle investigator, Dr. Marla Buchanan, at [REDACTED]

If at any time there are any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

I, _____, have read and understand the description of this research project,
PARTICIPANT'S NAME
and consent to participating. I understand that I will collaboratively determine with the researcher when, where and how information about my life experiences will be collected. I also understand that I have the right to refuse to participate in parts of the project or discontinue at any time.

Signature: _____ Date: _____

Appendix P

Exploring the Cultural Experiences of Immigrant Young Adults with Cancer

Consent Form for Family Members, Friends and Caregivers

Principal Investigator: Marla Buchanan, PhD
Associate Professor, Counselling Psychology
Faculty of Education, University of British Columbia
[REDACTED]

Co-Investigators: Amanda Ward, PhD
Research Scientist
Cancer Rehabilitation, Sociobehavioural Research Centre, BC Cancer Agency
[REDACTED]

David Chiu, BSc
Master's Student, Counselling Psychology
Faculty of Education, University of British Columbia
[REDACTED]

Purpose:

You are invited to participate in a UBC research study to learn about the diverse experiences of immigrant young adults with cancer. By taking part in this study, you will provide valuable information for learning about the experiences of individuals in times of major life transitions. What is learned from this study may help inform health care providers about how to better support people with similar experiences as yours. This study is part of David Chiu's Master's thesis project.

Research Method:

In order to gain a comprehensive understanding of the life of the immigrant young adult with cancer, this study will use an open-ended research method called ethnography. Ethnographic research involves studying human behaviour in the natural settings in which they occur. The primary goal is to learn how immigrant young adults with cancer experience their lives and the people in it.

Research Participation:

You will be asked to meet with David to share your insight as a significant person in the life of an immigrant young adult with cancer. Discussion topics might include your relationship with the patient, your experience as a caregiver and your observations of their experiences.

Voluntary Nature of Participation:

Your participation is completely voluntary. You have the right to participate, decline or discontinue at any time without any effect on the quality of medical care the patient receives.

Anonymity and Confidentiality:

Every effort will be made not to reveal personally identifiable information about you in publications based on this research. To accomplish this, no records will be created or retained that could link you to personally identifiable descriptions, paraphrases, or quotations. What you share will be presented without specific reference to you either by using pseudonyms or combining anonymously with the actions and words of other participants.

The only people who will have access to the information you share are David and Dr. Buchanan, the principle investigator. All documents and notes will be collected in an unlabelled notebook that is kept in a secure, locked location in the office of the co-investigator. Interview recordings, transcripts and other computer files will be secured on a single password protected laptop.

Risks of Participation:

Sometimes, the sharing and exploring of personal experiences can bring up uncomfortable emotions like sadness, distress or anger. A list of counselling resources will be provided to you that can be taken advantage of. Also, remember that you have the right to stop or refuse to participate at any point in the study without consequence. Rest assured that David will not be offended by this.

Potential Benefits of Participation:

Although we cannot promise that you will receive any benefits from participating in this study, the research will make you reflect about your experiences with the patient. You might find that, as a result, you may gain a better understanding or stronger relationship with him/her.

Contact Information:

If you have any concerns or questions about this research, please feel free to contact the principle investigator, Dr. Marla Buchanan, at [REDACTED]

If at any time there are any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

I, _____, have read and understand the description of this research project,
PARTICIPANT'S NAME
and consent to participating. I understand that that I have the right to refuse to discontinue at any time.

I would like to receive by mail a summary of the research findings at the end of the project.

Signature: _____ Date: _____

Appendix Q

Counselling Resources

We all need support in our lives to remain healthy. The amount of connections to others we need is different for each of us. Support programs provide social support, information, resources and a great way to learn new skills. Family, friends and caregivers benefit from using support programs as well.

There are programs that address coping, aftercare issues, grief and loss and stress management techniques. There are programs you can meet with for a time limited period, drop in as you need, in person or on the web. One size does not fit all.

- 1) **BC Cancer Agency Patient and Family Counselling**
600 West 10th Avenue
Vancouver, BC
604-877-6000 (ext. 2194) or 1-800-663-3333 (ext. 2194)
<http://www.bccancer.bc.ca/RS/VancouverCentre/CancerCareTeamandServices/TreatmentServices/pfc/default.htm>

Patient and Family Counselling Services offers a number of support programs and services to patients and their families.

- 2) **Canadian Cancer Society, BC and Yukon Division**
565 West 10th Avenue
1-888-939-3333
www.cancer.ca

Offers support to cancer patients and their families. Provides information, public education, financial aid, health advocacy, prevention initiatives, accommodation and camps. Also offers Cancer Connection, an individual peer support program. Non-profit society.

Programs

- [Canadian Cancer Society Cancer Information Service \(CIS\)](#)
- [Canadian Cancer Society Child and Family Camps](#)
- [Hair Donations](#)
- [Jean C Barber Lodge](#)
- [Volunteer Drivers](#)

- 3) **Burnaby Hospital Regional Cancer Centre**
3935 Kincaid Street
Burnaby, BC
604-412-6116 or 604-412-6367

Multidisciplinary team including physician, pharmacist, nurse, social worker, and dietitian assess and plan care to help cancer patients cope emotionally and physically with their illness. Referral required from family physician. Also offers various support groups for patients, family members, and support persons, including a relaxation/visualization group, Up Front for women breast cancer survivors or patients, a support group for women with recurrent breast cancer, and a prostate cancer support and awareness group. Offers breast self-examination instruction, and breast prosthesis instruction and consultation. Also offers therapeutic touch appointments. Clinic hours are 9:30 am to 4:30 pm Monday to Friday.

- 4) **Delta Hospice Society**
115-1077 56th Street
Delta, BC
604-948-0660
www.deltahospice.org

Staff and volunteers provide support to individuals and families coping with a life-threatening diagnosis, advanced illness, death, or bereavement. Programs are available for all ages at no cost, and include one-to-one support, counselling, relaxation circles, cancer support circle, respite, vigils, life review, activity groups, and loans of pressure relief materials (mattress overlays and cushions). Office hours are 9 am to 4 pm Monday to Friday.

- 5) **Vancouver Friends For Life Society**
1459 Barclay Street
Vancouver, BC
604-682-5992
www.friendsforlife.ca

Friends For Life is a non-profit organization that offers complementary and alternative health and support services for people confronting the challenges of HIV/ AIDS, cancer and other life-threatening illnesses. Services range from clinics in massage, naturopathy and Traditional Chinese Medicine, to Reiki, shiatsu, tai chi, and yoga, to music therapy, art therapy, meditation, group support work and individual counselling.

- 6) **Living with Cancer Support Group**
301-9808 King George Highway
Surrey, BC
604-583-2228

Self-help group for cancer patients, their families, and friends. Offers support, information sharing, and discussion. Meets 7 pm to 9 pm on the second and fourth Wednesday of each month at the Surrey Unit Office of the Canadian Cancer Society (301-9808 King George Highway).

- 7) **Other organizations that offer support groups:**
- Young Adults with Cancer www.realtimecancer.org
 - Canadian Breast Cancer Foundation www.cbcbf.org
 - Lung Cancer Canada www.lungcancer canada.ca
 - Ovarian Cancer Canada www.ovariancanada.org/
 - Canadian Prostate Cancer Network www.cpcn.org
 - Brain Tumour Support Foundation www.braintumour.ca
 - Leukemia/BMT Program of B.C. www.vch.ca/bmt
 - Lymphoma Foundation Canada www.lymphoma.ca
 - Willow Breast Cancer Support www.willow.org
 - Chinese Living with Cancer Support Group (604-253-8470)

Appendix R

Journal Entry: Waiting

Location: Bus stop

2011/01/20 9:35 AM

It is a snowy day. Cold but not bitterly so. The snow is coming down at a steady pace. As I head for the bus stop, I notice my feet slide with every step. Even with my hiking boots, every step is a struggle against inertia. I have to slow down. I have to lower my expectations for how fast I can go. That's okay. I have some time today. I am heading to the cancer agency to volunteer and to interview a participant. The latter is scheduled but not for a while yet. I have time.

I see a few buses drive by on the main drag as I walk towards the stop. Whereas on other days, I'd feel anxious or disheartened that it might have been my bus, today I feel okay. I patiently approach the stop. Another bus is approaching in the distance. My senses become alert, ready to fish out my bus pass from my pocket. The sign gets bigger as it approaches. It is not my bus. I relax, stand down. Next one.

Another two buses approach. The first one is an accordion bus, too big to be mine. The one after is out of service. The next is a 41. Wasn't the very first one that passed 41? I become suspicious. This is strange. The 41's can't be running twice as frequently as 33 at this time of day. A few more buses approach. None of them is my bus.

The snow continues to fall.

41 pass seems like every 3 minutes, twice two in a row. With every passing bus that is marked "Out of Service" or is not mine, I feel more and more disappointed and frustrated. It seems that every second one is out of service. "Sorry" and "Out of Service" the sign would

alternate. “Sorry”. “Sorry, sorry.” Stop your apologizing, I want to lash out in anger. Just do something to change it.

Early on, each coming bus brings with it a wave of hope. With each passing bus, the hope diminishes, becoming more and more jaded to it. I try to endure, to remain hopeful, to keep my spirits high. But one can only maintain hope for so long.

A number of people arrive at the bus stop and board, heading on their way. I feel demoralized, distressed that I am being left behind, that they are leaving me behind, that life is leaving me behind. I am tempted to hop onto the next bus, any bus, just to get somewhere. I feel uneasy, impatient with this stagnation in my life.

A sudden thought occurs to me. What if I don’t ever get on a bus?! I begin to panic. My heart beats faster, louder. I feel it inside my chest, my rib cages hardly able to contain its panic. What if I don’t ever get on a bus... There must be a mistake, I try to assure myself. The 33 bus driver forgot to switch their sign. A number of other scenarios enter my mind. An accident along the route. A cancellation of the service. Something, anything to explain these circumstances as being about somebody else; not about me, that I did something wrong, that Fate was upset with me.

The snow continues to fall, more heavily it seems. Either that or my feelings are getting the better of me, accentuating the experience of reality. Weather accentuated by my feelings or not, it’s getting colder. That’s real for sure. Just from standing out here for so long, anybody would get colder. What were snowflakes have turned into drops of water on my jacket. Ice into water, solid into liquid, a process that requires energy. “In any isolated system, the total energy remains the same.” First law of thermodynamics. Energy, my energy. My god, the snow is stealing my energy! Anger, resentment. I despise the snow.

I try to calm down, to find some peace, some acceptance in these crazy circumstances. I jam my head a little closer towards the ceiling of the umbrella canvas to protect myself from the snow, as much protection as this pathetic little umbrella can afford me. I need more than an umbrella. I need warmth, a house, a fireplace, a hot cup of water to warm my hands. As I wait in silence, my senses attune to the constant crackle of snowflakes as they land on the canvas next to my ears. It's like I'm inside a drum, trapped, with nothing but the reverberations of each strike of the surface to occupy me. With nothing else, I focus on the sounds. There is an occasional thuds as a particularly large clump strikes the canvas. I'm stunned by the loudness. I reflect on how snow is supposed to be silent and yet in this state of existence, I perceive their fall. In this state of trapped-ness, the crackles and thuds is relieving. It feels calming, peaceful.

“You're just distracting yourself,” says a little voice inside. “Nothing has changed.”

“Yeah, but I like it,” another responds with gentle reverence. “I just want to stay distracted for a while.”

I notice a twinkle in my right hand. It's clutching the umbrella handle, exposed to the elements. I wish I could shelter it as well but it's what's keeping the rest of me protected, or at least as much as my measly little umbrella is able. Beginning to feel the biting pain of the cold, my hand being at that transitional state after the point of comfort but before losing all sensation. It's that transitional state that is figuratively and literally the most painful to exist in. Strikes me, such parallels with the experience of cancer.

My spirit weakens under the weight of each passing bus.

Consider leaving to pick up the 99 at the main loop several times but afraid that it may come just as I leave, being left more disappointed by my own doing. So I remain there, foreclosing on any decision-making, even though that is a decision in itself.

After 45 minutes, my bus finally appears. I stare down the flashing lights, unwilling to believe it at first. To believe it is to be set up for disappointment. But this time it is, for sure. A relief like no other I have ever experienced spreads through my entire body. I turn towards the stop to indicate my desire to board it, to seek its refuge, to continue on my journey. But something strange happens. The engine continues to roar, no indication of slowing down. It is only meters away. It has to stop now or else it won't be able to, its momentum too great. A shock of terror rush through me, they are going to drive right by, my lifeline slipping through my desolate fingertips. I stick both arms out desperately to get attention. In fact it speeds up. I see my hope driving away. Ignoring my silent cries. I cry out in rage, then in anguish, then in destitute. No one responds.

I feel like I want to cry out in frustration, in anguish. Actually, I just want to cry.

I've arrived at the 99. There are others waiting, some silently, others, talking with the people next to them. There is an occasional laugh. I revile such levity. I feel outraged that the world doesn't appreciate this abomination, this injustice. Life continues on, completely unaware of the injustice that has been done to me.