Living with HIV and Navigating the Work of Food Security in Kelowna, Canada: An Institutional Ethnography

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

in

THE COLLEGE OF GRADUATE STUDIES
(Interdisciplinary Studies)

The University of British Columbia

(Okanagan)

April 2014

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Abstract

Using institutional ethnographic methodology, this dissertation explores how 12 people living with HIV/AIDS (PLWHA) go about maintaining food security in Kelowna, a small urban centre in southern British Columbia. Food acts as a lens through which a variety of issues are experienced; these include low income, poor health, and lack of mobility and social support. The paper is organized according to the “work” of being food secure, which encompasses obtaining food (by grocery shopping, visiting the food bank, or growing produce), affording food (by being employed or having income from a government program), being well enough to shop, prepare food and eat, and navigating institutional discourses around HIV and food security. Gregory Bateson’s notion of the double bind provides analytical grounding, as participants frequently encounter situations in which they are bound—physically, financially, socially, or discursively—by competing injunctions that hamper their overall health and food security. One of the main binds, which was experienced by most participants and found in nearly every act of the work of food security, existed in the dichotomy of affluence and invisibility. Kelowna is a very affluent city in which poverty and disease exist but are largely unseen. PLWHA are marginalized in this locale but simultaneously expected to look and act in ways that complement and contribute to the neoliberal capitalist marketplace. Findings build on the scant research on HIV and food security in the global north, and can be extrapolated to similar urban centres in North America, Europe, and Australia.
Preface

This research required, and was granted approval, from the University of British Columbia (Okanagan) Behavioural Research Ethics Board. The certificate number of the Ethics Certificate was H11-01096.
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>BCCDC</td>
<td>BC Centres for Disease Control and Prevention</td>
</tr>
<tr>
<td>BCCE</td>
<td>British Columbia Centre for Excellence in HIV</td>
</tr>
<tr>
<td>BCCPD</td>
<td>British Columbia Coalition of Persons with Disabilities</td>
</tr>
<tr>
<td>CATIE</td>
<td>Canadian AIDS Treatment &amp; Information Exchange</td>
</tr>
<tr>
<td>CD4</td>
<td>a type of immune cell normally affected by HIV</td>
</tr>
<tr>
<td>CDC</td>
<td>Centre for Disease Control (US)</td>
</tr>
<tr>
<td>COCG</td>
<td>Central Okanagan Community Gardens</td>
</tr>
<tr>
<td>CORD</td>
<td>Central Okanagan Regional District</td>
</tr>
<tr>
<td>CPPD</td>
<td>Canadian Pension Plan Disability (income program)</td>
</tr>
<tr>
<td>DTES</td>
<td>Downtown Eastside (Vancouver)</td>
</tr>
<tr>
<td>EI</td>
<td>Employment Insurance</td>
</tr>
<tr>
<td>FBC</td>
<td>Food Banks Canada, the national association of food banks in Canada</td>
</tr>
<tr>
<td>GRID</td>
<td>Gay-related Immune Disease (the name given to HIV before the virus was isolated)</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner (family physician)</td>
</tr>
<tr>
<td>GVRD</td>
<td>Greater Vancouver Regional District</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>Hep C</td>
<td>hepatitis C (a viral from of hepatitis)</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>KCFB</td>
<td>Kelowna Community Food Bank</td>
</tr>
<tr>
<td>LPRC</td>
<td>Living Positive Resource Centre (Okanagan)</td>
</tr>
<tr>
<td>LTD</td>
<td>Long-term Disability (a type of disability insurance available from private companies)</td>
</tr>
<tr>
<td>MNS</td>
<td>Monthly Nutritional Supplement (a monetary allowance from the BC government)</td>
</tr>
<tr>
<td>MSD</td>
<td>Ministry of Social Development (British Columbia)</td>
</tr>
<tr>
<td>MSM</td>
<td>men who have sex with men</td>
</tr>
<tr>
<td>NAIDS</td>
<td>Nutritional Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>NIDA</td>
<td>National Institute on Drug Abuse</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health (US)</td>
</tr>
<tr>
<td>PHAC</td>
<td>Public Health Agency of Canada</td>
</tr>
<tr>
<td>PLSBC</td>
<td>Positive Living Society of BC</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV/AIDS</td>
</tr>
<tr>
<td>PWD</td>
<td>Persons with Disabilities (B.C. government income program)</td>
</tr>
<tr>
<td>poz</td>
<td>term used commonly by PLWHA to refer to their HIV-positive status</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Program on HIV/AIDS</td>
</tr>
<tr>
<td>UNFAO</td>
<td>United Nations Food and Agriculture Organization</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
Acknowledgements

I would like to thank my twelve participants for their enthusiasm and dedication to this project. They were consistently patient with my endless queries during our interviews and observation sessions, and I learned more than I ever expected about people’s complex relationships with their bodies, their food, the economy, and one another. I am also grateful to the clients and staff of Living Positive Resource Centre, particularly its Executive Director, Clare MacDonald, for facilitating this research. Clare listened to my ideas and provided feedback, and also sent out the recruitment letters to potential participants. Truly, without the existence of LPRC, this research could not have been done.

My supervisor, Naomi McPherson, was the person who introduced me to anthropology when I took her introductory class so many years ago. When I returned to UBCO to do my doctorate, she was the backbone of the anthropology department — a longtime, distinguished professor, immensely popular supporter of students, and head of the Community, Culture, and Global Studies unit. In many ways, she is also the backbone of my project. If it were not for her encouragement, optimism, and continual belief that I could finish, it might not have gotten done. Thank you, Naomi.

The rest of my supervisory committee was also enormously helpful. I am indebted to Rachelle Hole for providing crucial advice and feedback on methodology and the writing of the dissertation itself. Hugo DeBurgos, a recognized filmmaker, offered valuable insights into the use of the visual in my project and encouraged me along these lines. I am grateful to both Rachelle and Hugo for being supportive in other ways, by offering me teaching and research jobs that aided me financially over the years. Joan Bottorff was my fourth committee member,
and was particularly adept during the preliminary phase of my project at pointing out potential methodological pitfalls. Her experience as a quantitative researcher provided me with a unique perspective on this work, and I am a better researcher because of her challenges to me.

I was very lucky to have several close friends with which to share my Ph.D. experience: comrades in the grad school trenches! To Eva-Marie Kovacs-Kowalke, Michelle Walks, Robyn Bunn, Daniel Grace, Tabitha Steager, Vida Yakong, Judy van Roggen, Deb Carter, Levi Gahman, Edwin Hodge, Tammy Makhloufi, and Ashley Black, I say thank you for your love, support, and sympathetic ears.

Finally, I am supremely grateful to my family for their enduring patience and love. My partner, Ryan Curcio, has been endlessly supportive in a myriad of ways, not the least of which is being an amazing full-time dad to our two sons. Ryan provided the emotional boosts I needed when research and writing got me down, and was always happy to discuss the project. I do not exaggerate when I say that his insights were absolutely vital to my own understandings of this work, and I could not be happier to have him as my partner in life. My parents, Joseph and Dorothy Picotte, have never been anything but supportive of my work, and I am grateful to them for the many ways they have helped me over the years — by listening patiently, relieving some financial stress, being such loving, fun grandparents to our boys, and being great friends to me. My children, Luca and Felix, have been an inspiration for doing important work in the world. My interest in medical anthropology was piqued by own pregnancies, and my passion for learning about social issues and health have been fueled by my experiences of childrearing. Luca and Felix: you are my constant happiness and my freedom from the weariness of adulthood. I love you guys more than you can imagine.
Pandemics are unique agitators of the status quo, and this is especially true of the AIDS crisis. Our understanding of what is right and just is tested when some of us succumb to a contagious disease that is also fraught with stigma. The people who endured the early stages of the AIDS pandemic — those who got sick, watched friends die, and continued to fight for care and support of all those infected — were the ones who paved the way for the services, resources, and compassion for those who would live with HIV in the years ahead. It is to those people that I dedicate this paper.
Chapter 1: Introduction

This project originated while I was working as a client advocate at an AIDS service organization, when, over the course of several months, I found that affording food, buying food, and even the seemingly straightforward act of eating food, were common concerns for the clients I assisted. “Food security,” which exists when food is accessible, available, adequate, acceptable, and when people have agency in provisioning (RCSFS 2011) has become something of a buzzword in social science and health research in recent years. As climate change, economic instability, mounting fuel costs, and environmental degradation continue unabated, concerns around access to affordable, healthy, safe food are climbing higher and higher on the agendas of governments, institutions, communities, and individuals (Allen 1999; Godfray et al. 2010; Rosengrant and Cline 2003).

HIV and AIDS, by contrast, have experienced a very different trajectory within the public eye over the past few decades. In Canada and other places in the “global north,” HIV has become less and less of a concern, largely due to the advent of more effective antiretroviral therapy (ART) (Delaney 2006; Kallings 2008). In Vancouver, British Columbia, the downtown east side experienced a frighteningly high rate of infection and prevalence of HIV during the late 1980s and 1990s and, since then, numerous programs and services have been developed to deal with the health and social care of people living with HIV and AIDS (PLWHA). Home to the renowned Centre for Excellence in HIV, British Columbia has seen success in lowering AIDS mortality, providing free ART to those who need it (BCCE 2013). Infection rates are decreasing overall; however, they have not been sufficiently lowered, particularly among men who have sex with men (MSM) and among aboriginal populations, who are over-represented—Aboriginal people
carry 12-15 per cent of new HIV infections but only make up 5 per cent of the provincial population (BCCDC 2012:5). Another outstanding problem and one of the focal points for this paper, is that, outside the lower mainland, programming for those already living with HIV remains sorely lacking.

Lena Normèn and colleagues published a study revealing that people living with HIV and AIDS in British Columbia are five times as likely as the general population to be food insecure or hungry (2005:820). The findings also showed that, of the 1213 people surveyed, nearly 30 per cent had an annual income of less than CAD$10,000 (822). Despite these alarming statistics and despite research proving the positive correlation between quality nutrition and increased quality of life and longer lifespan for PLWHA, little research is being done on PLWHA and food security and even less is being done to address the problem of food insecurity for PLWHA.

My research was born out of a desire to investigate why food insecurity is such a problem for people living with HIV and AIDS and to find out how PLWHA deal with food insecurity of varying types and degrees. When I began exploring the issue, I found that some people had physical problems with food that were related directly to the virus or ART. Others had financial difficulties that hindered their ability to buy healthy food. Still others experienced social ills that weakened support networks, which further weakened the motivation to procure, prepare, and eat good food. Coming into contact with such a variety of food-related problems made me realize that food security is very complex, requiring a method of investigation that would enable me to delve into its many aspects.

Although I feel that I accomplished the task of exploring food security in a multifaceted way, the research did not progress exactly as anticipated. My findings showed that many of the
problems faced by people living with HIV/AIDS in their quest to be more food secure could be problems faced by anyone living in poverty and/or with chronic illness. HIV directly affects food security less often than I had predicted; more often it affects in indirect ways, via low income and decreased social support. I have therefore come to argue in this dissertation that living with HIV exacerbates these problems and often serves to further marginalize and renders them—the problems and the people—relatively invisible. I also found that food security was less a “finding” in itself but, rather, acted as a window through which to view a variety of individual, social, and institutional problems faced by PLWHA. So, although this project started as an investigation into food security for PLWHA, it ended up being an investigation into physical health and mobility, financial stability, social relationships and discursive conundrums, all of which are faced and felt by PLWHA in their pursuit of food security.

Theoretical Underpinnings

This research is theoretically grounded in a combination of critical feminist sociology and critical medical anthropology (CMA). Such a mixture is reflected in the use of traditional ethnographic data collection (participant observation) and institutional ethnographic methodology to analyze the interplay among individuals, institutions, and the discourse put forth by specific institutions and society *writ large*.

Double Binds

HIV and its related condition, AIDS, have likely done more than any other health crisis in the past 30 years to advance scientific understanding of the immune system and how it relates to viral infection (Zimmer 2011). HIV has also done much to facilitate understandings of
(post)modern social structures and relationships (see, for example, Paul Farmer’s 1992 work on HIV/AIDS in Haitian-Americans or Stephen Lewis’ 2005 account of the UN Millennium Development Goals in relation to HIV). However, had HIV never existed, would some of these understandings be necessary? For example, would it be as pressing to solve problems around gay men’s social support in the face of chronic illness or around older women’s struggle to care for their orphaned grandchildren? I frame HIV in this manner—at once a facilitator of understanding and a wrench in the machinery of understanding—because it reflects the dichotomous effects that the virus has on numerous aspects of life for people who live with HIV and AIDS. Sometimes HIV facilitates certain activities (such as educating oneself about proper nutrition), sometimes it hinders in simple ways (for example, by making one feel too ill to prepare a meal), and sometimes it hinders from multiple directions so that activity is, or seems, impossible (for example, by making one feel too sick to go to work and simultaneously creating the kind of stigma that inhibits disclosure of HIV status to co-workers, producing a vicious cycle of illness and lack of support).

Gregory Bateson, noted biologist and anthropologist, posited the idea of the double bind with colleagues Don Jackson, Jay Haley and John Weakland, in 1956. Bateson, his colleagues, and others in the psychiatry field subsequently developed and critiqued the theory over the following years. Originally used to explain the development of schizophrenia, double bind theory hypothesized that young people who had been exposed to close personal relationships (usually with parents or other caregivers), which were ambiguous in their messages about love, affection, and discipline were more likely to experience breaks from reality in order to cope. The double bind itself was described as a situation in which “no matter what a person does, he ‘can’t
win” (Bateson et al. 1956:1). However, the structure of the bind is sometimes more complicated
than a “no win” situation. At times, a double bind happens when the person not only gets caught
between a primary negative injunction and a secondary injunction that competes with the first,
but also, added to these is a tertiary negative injunction:

In a formal sense it is perhaps unnecessary to list this injunction as a separate item
since the reinforcement at the other two levels involves a threat to survival, and if
the double binds are imposed during infancy, escape is naturally impossible.
However, it seems that in some cases the escape from the field is made impossible
by certain devices which are not purely negative, e.g., capricious promises of love,
and the like (1956:4).

Bateson et al. give the example of a child whose mother does not show love or affection in
regular situations but asks for love/affection from the child when the child acts in a mean or
hostile way. The overriding (tertiary) injunction is that there is no other person to intervene in the
contradictory communication going on and the child is “unable to comment on the message
being expressed to correct his discrimination of what order of message to respond to, i.e. he
cannot make a metacommunicative statement” (1956:5).
Double bind theory\(^1\) has been co-opted numerous times over by social scientists to hypothesize about a myriad of social problems—women’s struggle to obtain and maintain executive business positions (Jamieson 1995), how grandparents deal with expectations of their role in family units (Thomas 1990) or the ethical dilemmas faced by caregivers of severely demented patients (Ackerlund and Norberg 1985). In this paper, I add a further use to the notion of the double bind by shifting the context for Bateson’s theory from the level of deeply personal relationships and their influence on the psyche, to much broader social and institutional relationships. Throughout the research, double binds revealed themselves in many different circumstances. I believe there are two reasons for this. One is that people living with HIV and AIDS seem to come up against difficulties in a variety of circumstances that are typical “no win” situations. Although they could be classified simply as catch-22s or being “caught between a rock and a hard place,” it was obvious that, in some cases, more was happening “behind the

\(^1\) The double bind as a cause of schizophrenia has been critiqued heavily since Bateson, Haley, Jackson and Weakland first wrote about it. Certainly it is almost impossible to study and quantify injunctions as they happen in a naturalistic setting, and so the validity of the theory is easily debunked on those grounds. As well, some feminist scholars have pointed out that because women are usually the primary caregivers of children, it is easy to blame mothers for their children’s psychiatric disorders, and double bind theory, among others, have reinforced this blame (Cook 1982; McIntyre 1981). However, as Stagoll (2006), who called the double bind “the most generative and the most misunderstood theory in psychiatry” (127, italics in original) points out, Bateson and colleagues themselves acknowledged the shortcomings of their theory as a reliable method of pinpointing the cause of psychotic breaks. I recognize these shortcomings as well, and I use the theory solely as a conceptual device with which to better understand and elucidate the difficult situations faced by study participants. The notion of primary, secondary and tertiary injunctions works very well to explain everyday experiences of being “caught” between two seemingly impossible options, while not being fully aware of why those options are so impossible to negotiate. In 1963, Bateson et al. wrote: “the most useful way is phrasing double bind description in terms of people caught up in an ongoing system which produces conflicting definitions of the relationships and consequent subjective distress” (in Stagoll 2006:42). Indeed, this aptly describes the challenges of living with HIV in Kelowna and attempting to navigate the work of food security. Thus, the double bind remains useful as a conceptual model.
scenes” that constituted tertiary negative injunctions and these warranted further investigation into the unseen, distantly-knowable realm of institutional power.

The other reason double binds became evident was the use of institutional ethnography as a methodology to carry out this investigation. Through interviews, participant observation, and text analysis, it became clear that double binds can occur on a societal and institutional level in similar ways as the classical psychological double bind. In my attempts to find out how participants provisioned, certain things came to light: options, roadblocks and dead ends that made up the primary and secondary injunctions of the classical double bind, and texts that revealed tertiary injunctions. Without specifically looking for texts that regulate social activity and without the use of text analysis to clarify how the texts actually regulate activity, double bind theory may not have come into play as strongly as it did. Most of my participants experienced numerous double binds that came simply from living within and actively participating in society and interacting with institutions that often dictate quality of life by controlling such things as income level, social and physical mobility, and access to health care services.

Finally, it is important to qualify my use of double bind theory in this paper. I acknowledge that the very essence of “theory” is largely rejected in institutional ethnographic analysis, and in using the notion of the double bind I am not attempting to say that all participants fit into a specific thematic box by imposing a theory on their experiences. Rather, I use it as a way to illustrate the fact that double bind-style situations arose so often during the research. Over and over again, people would tell me about ways in which they were “caught” in a variety of difficult circumstances that seemed impossible to escape from. The fact that this happened so often made it clear that it was vital to acknowledge them in my analysis, and I do
admit that they fit under the larger schematic umbrella of being “in a bind.” However, I understand my use of the double bind primarily as a rhetorical device that provides a thread which with to link these experiences within the context of this paper.

**Affluence and Invisibility**

One double bind was apparent throughout the research process, that is, the dichotomy of affluence and invisibility. These phenomena are not necessarily opposites but, in this research context they played off one another as such, since affluence was consistently a presence in the social, economic, and geographic landscape of Kelowna and contributed to the invisibility of marginalized people, particularly those living in poverty and with disabilities. Because the scope of my project was limited in terms of the number of participants and the region covered, I believe that one of the most significant contributions this research can make is to the literature on affluence and wealth studies in relation to HIV. Thus, I will be referring to the predominant affluence/invisibility bind throughout the paper, while also describing various other double binds (some shared by the majority of participants, some more idiosyncratic) as they pertain to the work of being food secure. To help explain how affluence and invisibility work together to perpetuate social and health inequities, I draw on Thorstein Veblen’s *The Theory of the Leisure Class* (1899) and Herbert Marcuse’s (1941, 1964, 1965, 1968) theories of ideology in advanced industrial society. Veblen’s writings on consumption and class were meant to show economics as an evolving phenomenon, one dictated largely by social and institutional pressures, particularly competition and emulation. Although some of Veblen’s language and descriptions are outdated, his theories ring remarkably true for feminist sociology, even a century after original publication. Meanwhile, Marcuse zeroes in on the ways that consumption relates to social control and the
perpetuation of working class struggle. Marcuse describes the main characteristics of an affluent society as

1) an abundant industrial and technical capacity which is to a great extent spent in the production and distribution of luxury goods, gadgets, waste, planned obsolescence, military or semimilitary equipment – in short, in what economists and sociologists used to call ‘unproductive’ goods and services; (2) a rising standard of living, which also extends to previously underprivileged parts of the population; (3) a high degree of concentration of economic and political power, combined with a high degree of organization and government intervention in the economy; (4) scientific and pseudoscientific investigation, control, and manipulation of private and group behavior, both at work and at leisure (including the behavior of the psyche, the soul, the unconscious, and the subconscious) for commercial and political purposes. All these tendencies are interrelated: they make up the syndrome which expresses the normal functioning of the ‘affluent society’ (1968:187).

While many theorists could have been used to ground this paper, Marcuse’s focus on certain areas of advanced industrial society (technology, for example) and their impact on individual emotional wellbeing fit best with my points on the effects of double binds (and of course, fit nicely with the psychological aspect of double bind theory).

It is important to note that there is very little research or theorizing about affluence to date (Massey 1996). Therefore, in the same way that this project needed to merge the literature on HIV with that of food security (as explained below), it also needed to expand existing theories of affluence and merge them with the burgeoning literature on invisible illness, illnesses that are experienced by people inwardly but not seen easily by those on the outside (Valeras 2010; invisibilities.org 2013). The result of this merge is that, throughout the paper, I use the ideas of various writers on class and wealth (particularly Veblen and Marcuse) to tie together my theory that affluence (or, more specifically, economic competition and inequality) creates poverty and, further, creates spaces in which poverty and illness cannot be seen.
Organization of the Paper

This paper contains nine chapters in total. From this introduction, I move to the background and contextualization of Chapter 2, which gives an overview of HIV and food security, both as separate entities and as a combined issue. One of the major tasks of the research was merging the literature on HIV with the literature on food security; while food security and HIV (as a combined concern) have been researched extensively in the global south (see, for example, Drimie and Mullins 2006; Gillespie and Kadiyala 2005; Gillespie 2006; Ivers et al. 2009; Quisumbing et al. 1995; Rosengrant and Cline 2003;), they seem to be of little concern to social science or health scholars in the global north.

Chapter 3 discusses institutional ethnography (IE), the methodology used in the project. I give an overview of the background and basic tenets of IE, then detail how I employed it in my research context. I also explain how participant observation, not a traditional data collection tool of IE, was utilized to enhance the findings from interviews with participants.

Chapter 4 provides a description of the participant group as a whole and then each participant individually. I do this because I believe it will lend a richer description and a better understanding of the participants’ everyday lives before getting into the intricacies of their food procuring activities and the dilemmas they face in provisioning.

The bulk of the paper is taken up by the four findings chapters (Chapters 5 through 8), each of which is conceptualized according to the work related to getting food and organized according to the degree of closeness to this one crucial activity. See Figure 1 for an illustration of this conceptualization.
Chapter 5 discusses the actual work of obtaining food. This most often refers to shopping at grocery stores but includes other, rarer activities such as gardening, going to the food bank and accessing other “free” food programs and services, utilizing social networks that contribute to communal eating and sharing of food, and other innovative ways to provision, eat, and manage food. Chapter 6 deals with the work of affording food. In order to procure food in this area of the world, where we rarely grow our own fruits, vegetables, and grains, hunt our own meat or make our own bread, one must have an income that allows one to buy food in the marketplace. This section, then, discusses the issues participants face with regard to income, whether from government disability and other income-support programs, or employment, or reliance on a spouse’s income and other innovative methods of making money. Chapter 7 discusses “the work of being well.” I consider this work to be implicitly related to food procurement, in that participants must keep themselves (and have others help them keep themselves) well enough to get food. Thus, the work of being well includes a host of activities that participants engage in on a regular basis, such as finding and obtaining appropriate health care, dental care, and other
services to assist in the upkeep of their physical health; developing and maintaining social support networks, which have been shown to help PLWHA remain both physically and emotionally healthy (Takahashi and Rodriguez 1999; Wilton 1996, 1999); and engaging with social service agencies to assist and refer them to food security programs and other health programs. Chapter 8 takes on the level of organization that is “farthest” from the everyday provisioning of participants, that is, the somewhat abstract level of discourse that happens around the issues of HIV and food security; this chapter deals mostly with the discourse of “chronic and manageable” illness as it applies to HIV/AIDS in North America and explores how this rhetoric obscures the reality of living with the virus and having to deal with its many physical and social implications. It also discusses the discourses to do with food security in Canada generally and Kelowna in particular, and how affluence is an influence on how people treat the issue of food insecurity. This discourse often serves to conceal the global implications of people’s local actions, and only furthers the problems that exist with food in the long term.

A clarifying note about text analysis throughout the paper: As I explain in Chapter 3, analysis of texts is a crucial part of institutional ethnography and was a key data collection tool for this research. Because participants dealt with a variety of institutions, a variety of texts are analyzed: these include “traditional” written documents as well as symbols and signs. I also see certain spaces and places as being influential on people’s activities, and in a sense we are able to “read” them in order to determine how they regulate action. Due to the numerous and various styles of texts involved, each chapter deals with text analysis differently. In some chapters, it was logical to group all of the text analyses together, while in other chapters, it made more sense to intersperse the text analysis among the other forms of documentation.
Finally, a few technical explanations. Quotes from participants are set in italics in order to set them off visibly from quotations from other researchers. I, as researcher have named myself “Interviewer” in passages where I am being quoted as speaking with participants. Lastly, I intend in this paper to speak in the “ethnographic present” with my work contextualized and situated against the backdrop of decades of work performed by others. Thus, when discussing the work of other researchers, I refer to them in the present tense regardless of when their work took place.

**Terminology**

It is important at the outset to define certain terms and acronyms that will be used throughout the rest of paper because there is wide variation in terminology around food, HIV, and global health inequity.

First, there are several acronyms currently being used to describe people who have or live with HIV and AIDS (PWH, PLHA, PWA, etc.). I use PLWHA, the acronym for “people living with HIV and/or AIDS” for two main reasons. One, it is probably the most widely recognized and most all-encompassing and, since the criteria for being diagnosed with AIDS is different depending on where one is being diagnosed, using PLWHA provides inclusivity for a broad readership. Two, though I fully realize saying that “living” with something lessens the everyday experiences and implications of the virus, I would much rather describe this as “living with” HIV/AIDS, rather than simply “having” it. I think the term “living with” does imply that there are things to be dealt with all the time, including physical difficulties, the emotional upset of having contracted an incurable virus, and the potential stigma and discrimination that comes with a disease long marginalized because of its association with deviant sexual practices, illegal drug
use, social and ethnic groups that were discriminated against even before HIV showed up in human populations, and even deviant dietary practices. There are some who think that using any acronym to describe a group of human beings only obfuscates individual struggle. My response is to acknowledge that risk; however, this paper is about individuals and their experience, so essentializing will not happen here. The acronym is used primarily to save space and paper.

Second, the term “food security” warrants explanation. Early on in the project I was determined to use the term “nutritional security” to reflect the fact that one can be “food secure”—that is, one can have access to a sufficient quantity of food in order to remain alive—but can still be nutritionally insecure due to the low nutritional quality of the food they have (this is explained in greater detail in Chapter 2). After completing the preliminary parts of the project before research with participants began, I realized that “food security” can bridge this gap if explained and used in a more all-encompassing way and I began to use it consistently. I also realized that “nutritional security” was alienating to many people with whom I spoke about the research. Although it seems to be on the forefront of many community and global agendas these days, food security is not a term with which everyone is familiar and so explaining it with the caveat of some foods being nutritionally void, was cumbersome at best.

Third is the concept of affluence and how I describe it in the paper. When discussing issues pertaining to world affairs such as the prevalence of HIV or the state of food security in certain regions, I have chosen to use the terms “global north” and “global south.” There are a number of reasons for this. One is that, by now, most social scientists have resolutely rejected the classification of “Third World” vs “First World” because of their neo-colonial associations. Second, the dichotomy of “developed” vs. “developing” countries I find inadequate; not only are
these terms vague but I personally do not consider many so-called “developed” nations to be such at all. Is the United States, with its refusal to provide free access to health care to its citizens “developed”? Likewise, can Canada, whose government (despite the protests of thousands of citizens) drills for oil and natural gas in areas long protected as delicate wilderness or heritage zones, be considered “developed”? One faculty member suggested I use the terms “affluent” and less affluent” and indeed, affluence is a key concept of this paper but one that I use to describe the specificities of the area in which the research took place. Thus, when talking about world affairs, I employ the broader but generally accepted terms of global north and global south.

Fourth, those who are familiar with income support programs in Canada might notice that I refer to them using a variety of terms to fit the specific situation (such as “government income” or “disability income program”) and not as disability “benefits.” I refuse to use the word “benefit” to describe this type of income because, although I recognize that having the income often makes the difference between living on the streets and having shelter or being able to buy food instead of going to the food bank, I do not consider the paltry amount given to the people who so clearly need more to be a benefit. Further to this is the fact that, as I will show in Chapter 6, these income programs are fraught with institutional barriers that almost always hinder recipients from getting ahead in the world, financially and socially. There is nothing beneficial about that.
Concluding Thoughts

Institutional ethnography, the methodology used in this research, begins with what is called a “problematic,” one element of a particular state of affairs around which investigation occurs. This paper began as an exploration into how food insecurity is dealt with by PLWHA; it has become a much broader explication of where (physically, socially, financially, etc.) PLWHA “fit” in the particular locale of Kelowna, British Columbia. The main finding is that they do not fit neatly anywhere. There is no appropriate space for HIV and the people who live with it, either in the actualities of everyday socio-economic life or in the discourses around health and social services. The double binds described and analyzed in the following chapters are illustrative of this not fitting and being caught between places and labels.
Chapter 2: Background and Contextualization

Very little work has been done on food security for PLWHA in the global north. Because the literature on HIV and food security in Canada is topically, disciplinarily, and methodologically scattered, much of my preliminary work consisted of puzzling together conclusions about HIV and food security as one issue from studies that attended to them separately. For instance, there is a wealth of literature from the health sciences on how food interacts with the human immuno-deficiency virus in individual bodies; however, this literature rarely deals with the social mechanisms by which PLWHA obtain healthy food. On the other hand, social scientists have extensively researched HIV in the global north in relation to gender dynamics, stigma, and socio-economic status but this work rarely touches on anything to do with food. This chapter discusses the process by which I came to an understanding (a theoretical one, at least) of food security in relation to living with HIV, how I have integrated that understanding into my research, and how I hope to contribute to and expand the body of work on HIV and food security in the global north.

Combing and Combining: effectively merging the literature

The bulk of research on HIV and food security has been and continues to be carried out in the global south. To be sure, such a well-developed body of work is warranted, as people in sub-Saharan Africa and Southeast Asia have suffered most harshly from AIDS and widespread
famine. Even so, I was surprised by the lack of research being carried out in the global north, Canada included. This is not to say that research is lacking on these topics separately, for there is plenty of literature on HIV in North America, as well as a growing body of research on food security. Together, however, HIV and food security in the global North seems to be a negligible issue. Indeed, almost all HIV research in the social sciences seems to take for granted that PLWHA in the global north are getting the nutrition they need. With so little to build on, I had to take an alternate route to educating myself on how these two things acted in tandem. This consisted of reviewing the literature in a number of areas I felt were the most relevant to HIV and food security together. The first body of literature concerned how HIV affects the human body, specifically the digestive system, both at the micro and macro level. The second concerned social aspects of living with HIV because provisioning and eating are highly social activities. The third was on access to support services and support networks. Again, this was because provisioning is social but also because the necessary precursors to provisioning—being physically mobile and being able to afford food—often require support from others. The fourth body of literature concerned the institutions affiliated with food and food security in Canada.

Between 1990 and 2010, the number of people living with HIV in Sub-Saharan Africa increased from approximately 6 million to approximately 23 million, while the incidence rate has slowed from its peak in 1997, at about 2.5 million newly infected people, to 1.9 million newly infected in 2010. The disparity is accounted for largely by antiretroviral therapy, which is allowing people to live longer with the virus. The number of children (ages 0 - 14) living with HIV, however, has steadily risen from approximately 500,000 in 1990 to more than 3 million in 2010. Thankfully this rise seems to be leveling off by 2012 (UNAIDS 2011:23). In Asia, similar trends have occurred, although the overall numbers have been lower. The number of people living with HIV reached approximately 5 million in 2010 (from approximately 600,000 in 1990); the number of newly infected people dropped from its peak in 1995 (500,000) to 2009 (380,000); however, by 2010 the number of newly infected was rising slightly again. There are wide regional variations on this trend (for example, the prevalence rate among sex workers in Shanghai is 1%, while in Maharashtra, India, it is 29%). Research indicates that incidence among injection drug users in parts of Asia is rising (UNAIDS 2011:28-30).
Often, these were non-local institutions, such as the federal government’s policies on food access, which have encouraged an increase in charitable giving of food to food banks across the country, and the global food system, which facilitates large chain grocery stores to monopolize food sales in the global north.

**HIV and the Human Body**

Information on how the virus interacts with nutrients and other chemicals at the bodily level came largely from the health sciences and was crucial to an understanding of the physical dimension of HIV and food security. The exact mechanisms by which nutrients and the virus interact is complex. Scientists know that certain vitamin and nutrient deficiencies can decrease lymphocyte (white blood cell) response, lymphocyte proliferation and T-cell function (i.e. specific white blood cell function), among other immune system responses (Drain et al. 2007:334). HIV can create an imbalance in the body’s pro-oxidants and anti-oxidants by accelerating the release of pro-oxidants, thus increasing the body’s use of anti-oxidants. This can lead to oxidative stress, cell damage and faster replication of the virus itself (Oguntibeju et al. 2007:4328). HIV interferes with the body’s uptake of micronutrients; therefore PLWHA need to be very careful to get high quality foods in their daily diet so as to avoid the wasting associated with HIV and AIDS (ADA 2004; Macallan 1999). That HIV upsets the body’s use of micronutrients means that both the quantity and the quality of food are crucial to PLWHA. Asymptomatic people with HIV require 10 per cent higher caloric intake per day than people who are not infected. If an opportunistic infection (OI) arises, the per-day caloric requirement rises to 20 per cent to 30 per cent more than normal (Byron et al. 2008:88). The Dieticians of
Canada, together with the American Dietetic Association (ADA), have soundly endorsed the need for quality nutrition in PLWHA, stating that efforts to optimize nutrition status, along with medical nutrition therapy, assurance of food and nutritional security, and nutritional education, are essential components of the total health care available to people with human immunodeficiency virus infection throughout the continuum of care (2004:1425).

In addition to the effects of the virus on nutrient absorption and other micro-level processes on the body, HIV can have macro-level physiological effects that interfere with people’s eating habits. Tsai et al. (2002:301) point out that nausea and vomiting are two of the most common symptoms HIV-positive people need to deal with. Antiretroviral therapy or ART (and its more recent incarnation, highly active antiretroviral therapy or HAART), causes a variety of appetite-related side-effects, including nausea, vomiting, diarrhea, and loss of appetite, according to Reynolds and Neidig (2002). Similarly, Walsek, Zafonte and Bowers (1997) describe nausea and other types of gastrointestinal upset as typical for people starting or changing an antiretroviral therapy regimen. The fact that these medications must be timed to either coincide with meals or be taken without food, can also upset the eating schedules of PLWHA (Murphy et al. 2004).

Social Aspects of HIV

Most of the work on social aspects of living with HIV came from North America and the United Kingdom and was useful in enhancing my understanding of how factors such as gender, stigma and discrimination, income level, employment status, immigration and ethnicity affect the ability of PLWHA to effectively navigate the social world in order to get the things they need to survive. One of the main findings of this literature that my research corroborates, is that more often than not, PLWHA are economically disadvantaged (Elford et al. 2008; Ibrahim et al. 2008;
Joy et al. 2008; McFarland et al. 2003); this certainly limits the ability to be food secure. In economically developed regions, PLWHA may have more opportunity to obtain employment for pay than they would in economically depressed areas of the global south. However, maintaining that employment while living with a chronic illness can be challenging. A study by Ibrahim et al. (2008:618) of more than 1687 PLWHA in London, England found that only 20 per cent of respondents were working full time, 25 per cent were employed part time, and another 25 per cent were unemployed. A further eight per cent were retired due to medical reasons. In all of Ibrahim’s demographic groups—which included white and non-white homosexual men, black African heterosexual men and women, white heterosexual men and women, and black Caribbean heterosexual men and women—economic hardship was a common challenge, particularly prevalent among black African men and women, who faced consistent difficulties with regard to housing, employment and securing UK residency. This inequality related to ethnic background can also play a part in the socioeconomic discrimination of PLWHA (621).

Some studies indicate an indirect link between HAART and socioeconomic status. In their study of British Columbian people with HIV and AIDS, Joy and colleagues (2008) found that living in neighbourhoods with lower socioeconomic status was a barrier to accessing HIV treatment even when the treatment was available free of charge. The researchers speculated that these barriers had to do with transportation problems, language barriers, and engagement in illegal activities (501). Similarly, McFarland et al. (2003) found that in San Francisco, lower socioeconomic status was associated with lower rates of using HAART and, subsequently, higher death rates.
Even in places with universal health care coverage, low socioeconomic status contributes to quicker disease progression and other ill effects. The study by Joy and colleagues in British Columbia found that, despite having universal health care, HIV progressed more quickly for people in lower socioeconomic areas (2008:504). Suspected causes were waiting to access treatment until the immune system was depressed, lack of adequate and affordable housing, mental illness, and drug use (2008:503). I would suggest that people in these neighbourhoods were also inadequately nourished.

**Access to Services and Support**

This area of literature stemmed largely from critical disability studies and human geography and explored how people with disabilities in the global north access services and maintain support networks. Some of these studies researched PLWHA directly. For example, Takahashi and Rodriguez (1999) and Takahashi, Rodriguez and Wiebe (2001) explored the access to services by PLWHA in Los Angeles and studied social networks in particular. They found that informal networks with family, friends, and acquaintances can buffer against physical and mental stress but that formal networks, while sometimes buffering stress, can also increase stress levels by forcing people to conform to certain routines that fit with institutional structures. This will be confirmed by my own findings in Chapters 5 through 8. They also found that the specific spatio-temporal needs of PLWHA, along with the way PLWHA self-identify, play a critical role in successfully accessing health and social services, including those services that help increase food security. Robert Wilton’s (1999) research on nine HIV-positive men in the Los Angeles area found that open, respectful communication with healthcare providers, as well as
certain labels around being “ill” or “living with” the virus played an important role in how the participants perceived their own agency within the community.

Other researchers in this field wrote more generally about disability. Julia Gerbrandt (2009) performed a qualitative study on the experiences of people with disabilities in B.C. (several of whom were living with HIV) with regard to food security. Gerbrandt’s work lends credence to the notion that certain institutional arrangements, even though they are in place to relieve food insecurity, can be difficult to access for people with disabilities. This resonates strongly with my findings. Overall, this literature gave me a more nuanced view of the various facilitators and barriers faced by PLWHA in their provisioning efforts and largely supported my own research.

Institutions, HIV, and Food Security

The fourth body of literature I looked into took a more theoretical approach, examining institutional factors involved in food insecurity. Satya Brink (2001), on behalf of Human Resources and Development Canada, stressed that food insecurity is a serious problem even in developed, food-rich nations and that insecurity most often happens in vulnerable populations. Brink compared the personal and social abilities of people who are food secure with those who are not and said that, overall, food security allows people to focus more on the future and on thriving, while being food insecure forces people to focus on survival in the present. Psychologically, the experience of food insecurity can also be damaging: “anxieties may be heightened by knowing the consequences of the lack of food, and previous experiences of it” (36). Rideout et al. (2007) placed food security in the context of Canadian and international human rights law. The authors question the Canadian government’s commitment to making food
security a priority for Canadians (and vulnerable populations in particular), given the state of Canadian case law, the breakdown of the social safety net, and the “institutionalization” of food banks in Canada. Graham Riches (1997) stressed that food insecurity in advanced industrial nations such as Canada, the UK, the US, and Australia can hinge on a person’s inability to fully participate in the capitalist marketplace. Certainly this is the case for many of my participants, whose income from government support programs is woefully inadequate for such participation. Probably the most useful resources in understanding global food distribution and market forces that create severe food insecurity and hunger came from Amartya Sen (1981, 1999, 2008) and Raj Patel (2008). Sen concisely illustrates that famine and hunger are not the direct result of inadequate food supply; rather, they are the result of economic relationships that put certain people at a disadvantage for procuring food. Patel’s sweeping overview of the global capitalist food system was integral to my grasp of how global forces influence local realities. Providing an example of this local/global relationship are Ruel and colleagues (2010), whose work on the effects of rising fuel oil prices on food access confirmed that the people who are already marginalized (including those with HIV) will continue to be the ones who feel the “food price pinch” most severely; thus, “the poorest of the poor are the ones who will be most affected, irrespective of the continent, country, or urban or rural area where they live” (170S).

Intersectionality

The complexity with which the above dimensions interact cannot be underestimated. One way of analyzing the social determinants of health is through the lens of intersectionality, a feminist paradigm that underscores the importance of how social markers such as gender, class,
and ethnicity, interact with one another to produce certain outcomes and relationships. Although markers such as gender and ethnicity might be more obvious and/or influential to health outcomes than others, “to assume that they are mutually independent variables that can be added together to comprehensively analyze a research question, violates the normative claim of intersectionality that intersections of these categories are more than the sum of their parts” (Hancock 2007:251). According to Simien,

Intersectionality is an analytical tool that rejects the separability of identity categories, as it recognizes the heterogeneity of various race-sex groups. Firmly rooted in an experience-based epistemology, it encompasses perspectives that maintain that such identity categories as gender, age, race, ethnicity, class, and sexuality are mutually constituted and cannot be added together...Intersectionality research therefore places special emphasis on the simultaneity of oppression and stresses the need to move beyond simple, additive models” (2007:265).

Intersectional research also attempts to highlight the role of institutions in the lives of individuals. This, combined with its “experience-based epistemology” allows intersectionality to work gracefully in tandem with institutional ethnography, the chosen methodology for this particular project.

The existing literature on health from an intersectional perspective is growing as researchers and policy-makers have begun to recognize not only the importance of social determinants of health but also that the relationships between those determinants constitute and overlap with one another and can be critical to an understanding of health outcomes and behaviours. In the realm of HIV and AIDS research, much intersectionality literature comes from work with populations considered most at risk. Because the origins of intersectionality are in Black feminist studies, this includes women in countries of the global south and marginalized women in more affluent areas (see, for example Margulies 1994; Stempniak 1999; Young et al.
Several intersectional studies have been conducted on HIV in the global north. Anna Bredstrom (2006) discusses how gender mainstreaming in Sweden’s HIV policy has been useful in advancing awareness of the role of hegemonic masculinities in the spread of the pandemic but critiques how a focus on gender can easily exclude other, equally important health determinants such as ethnicity, religious values, and age. Contrary to Bredstrom’s caution about gender mainstreaming, Sandelowski and colleagues’ meta-study of 32 journal articles on HIV-positive women and stigma showed that race/ethnicity and not gender, was most often the variable of focus in HIV social research (2009:5) Although each of these articles shows the limitations of honing in on one or two variables of health determinants, both highlight the possibilities for a more meaningful and in-depth understanding of living with HIV (and forming HIV prevention policy) using an intersectional approach. Logie, James, Tharao and Loutfy’s (2011) study of women and HIV-related stigma, one of the few Canadian intersectional studies, found that stigma for HIV-positive women in Ontario hinged on sexism and gender discrimination, racism, HIV-related stigma, homophobia and transphobia, and sex work stigma, and that all of these factors played out on personal, community, and institutional levels (3). Intersectionality is less a methodology and more an approach to analysis. I bring it up here because I believe it is valuable to realize how the various categories into which we often lump our participants overlap or converge to result in certain health-related consequences and that these consequences are themselves not fixed in time or space but in flux according to situation. Because I have
conceived of the work of food security as a complex of related and overlapping issues, intersectionality is highly pertinent to my interpretations of the research data.

“The Five A’s”: coming to a definition

Because definitions of food security have geographic and disciplinary variations, another of my preparatory tasks was developing a definition that would work best for this research. World population has more than doubled since 1960 and continues to increase steadily. Some argue that world food supplies might not keep pace with this growth (Gilland 2002:47) and several others note that both chronic and transitory hunger have increased in recent years (FAO Committee on Food Security 2005; Gilland 2002; Lupien 1996). Some reasons for this include water scarcity, climate change, natural disasters, wars, pests and plant diseases, rising energy prices, the credit crisis and, in some countries, HIV and AIDS (FAO CFS 2005; Hanjra and Qureshi 2010). In response to these developments, the concept of food security has become more and more commonly employed. In the global south, food security is often closely related to the agricultural pursuits of individuals, communities, and whole nations. This perspective usually looks at household, as opposed to individual food security, and takes into consideration such factors as the cleanliness of living conditions and access to basic services. Byron, Gillespie, and Nangami (2008), in their study of food security in Kenya, for example, describe food security as “secure access to food…coupled with a sanitary environment, adequate health services, and adequate care to ensure a healthy life for all household members” (87-88). In more economically stable regions that rely heavily on importing rather than first-hand production of food, food security refers more commonly to nutritional value of food, personal and cultural appropriateness
of food, and consistency of access to food. In their critique of Canadian policies regarding the right to food, Rideout et al. describe food security as “the availability of food, equitable access to food, and adequacy of the food supply in terms of culture, nutrition, and sustainability” (2007:566). Certainly these might seem like “first world problems” to use an increasingly popular term in the social justice arena these days: how can we really complain that we lack food security when we have food but are worried about things like “cultural appropriateness?” As I hope to illustrate in the following chapters, for PLWHA, there is much more to food security than simply being able to get food or the appropriateness of food. To put it simply for now, many PLWHA seem to suffer some of the problems of the global south when it comes to getting the food they need.

“Nutritional security” is a term used occasionally in the literature and can be seen as a more specific or refined point on a spectrum of food access. One can have access to food (and be technically “food secure”) and still not be nutritionally secure, because certain foods have lower nutritional value than others. For example, Lawn and Harvey (2003) concluded that isolated communities in Canada’s north are subject to food prices ranging from 80 per cent to 200 per cent higher than in the south. This holds especially true for heavier, more nutritious perishable foods such as fresh fruits and vegetables, dairy products, and eggs (1-3). Thus, people in those communities could be eating the required number of calories per day but they are likely to be empty calories coming from nutrient-poor food sources. The empty calorie problem of course can happen in any community if one does not have the resources to buy or otherwise obtain nutritious foods.
For the purposes of this project, I employ a multifaceted definition from Ryerson University’s Centre for Studies of Food Security. The Ryerson definition includes five components, known as “the five A’s”: availability, accessibility, adequacy, acceptability, and agency (2011:1). I use this definition because it seems the most comprehensive and covers certain aspects of food security that are particularly important for PLWHA.

“Availability” means that food, either grown locally or imported from elsewhere, exists in the here and now for people to obtain. The Okanagan Valley, of which Kelowna is at the centre, is an interesting case in terms of its food production and consumption. Although the Valley’s main industry is agriculture and white settlement in the area was historically based on farming and orchards, at least one quarter of the produce from local growers is sold overseas where it fetches a higher profit annually than it does at home (AGF 2004). Added to this is the fact that during most of the year (i.e. not during the growing season), much of the produce found in local grocery stores is imported from the United States, Mexico, and New Zealand (AGF 2004). Thus, food is available but it does not necessarily meet the other criteria of this five-pronged definition.

“Accessibility” refers to physical and economic access to food. In the Okanagan, we must ask whether all residents can either grow their own food or get to grocery stores or other outlets to buy the food. Again, despite the great number of food producers here, agricultural land is held in the hands of a few and so most people buy their groceries at stores. Whether due to difficulties with transportation, physical accessibility to the grocery store buildings themselves or the cost of food at certain stores, these venues are not always accessible to everyone, and certainly, healthy food is not economically accessible to everyone (the concept of accessibility will be explored in a more nuanced way in Chapters 5-8). “Adequacy” means that the food we can afford to obtain is
nutritious, safe, and sustainably produced. For people living with HIV, this is an especially important concept, since the nutritional quality of food, as opposed to the sheer number of calories, is critical to health maintenance. Food safety is also important to PLWHA because the virus renders them more susceptible to food-borne infections, such as salmonella (Sanchez et al. 2005). Sustainability of production is (or should be) an important issue for everyone; unfortunately, the current pattern of “grow local but buy global” is both very expensive and unsustainable over the long-term. “Acceptability” refers to personal and cultural values and choices or how appropriate certain foods are for certain people. Acceptability comes into play for people with food allergies and sensitivities, religious requirements for food to be prepared or eaten in particular ways, and medical conditions that require one to eat certain foods and/or abstain from eating others. Again, for PLWHA, acceptability has more to do with health requirements than with food preferences, although, as I will explore further in later chapters, preference comes into play as well. The fifth component, “agency,” is particularly pertinent to this project because it indicates the need for food-related policies and processes to be facilitators of food security and not barriers to it. My research has found that many policies and procedures can present significant barriers to obtaining food, even when they appear at first glance to be associated with increasing food security. In a sense, the progression from availability to accessibility to adequacy to acceptability to agency mirrors the organization of this paper - from the work of obtaining food (availability and accessibility) to the work of affording food (accessibility and adequacy) to the work of being well (acceptability) to the work of navigating discourse (agency). What I hope to show throughout the paper is that agency, something that
many people take for granted when provisioning, is the most vital component of food security and overall health for PLWHA.

**Filling in the Gaps: contextualizing the project within the larger body of literature**

Earlier I described the lack of research on HIV and food security in the global north. Apart from my own work, there have been no focused studies of HIV and food security in the Okanagan Valley of British Columbia and very little research on this topic has been done in Canada at all. One of the few studies that was carried out in B.C. is now 15 years old. In 1998, a team from the Centre for Excellence in HIV and AIDS in Vancouver sent out an exhaustive survey on food security and received 1213 responses from HIV-positive people across British Columbia. The results, published in a 2005 issue of *The Journal of Nutrition* showed that people with HIV in B.C. were five times more likely to be food insecure than the general population and, further, that hunger was prevalent in the HIV-positive population in British Columbia (Normèn et al. 2005). The Normèn et al. study provided a much-needed benchmark upon which more research could build. However, in the years since that study was published, there has been precious little of such research. The scant literature I have found has been focused on populations in Vancouver (and the Downtown Eastside in particular). The Downtown Eastside (DTES)
maintains the dubious reputation of being the “poorest postal code in Canada” and is also known for having the highest rate of HIV infection in North America3.

Recently, a study by Miewald, Ibanez-Carrasco and Turner (2010) examined food security in the DTES. They confirmed that PLWHA have high rates of hunger and food insecurity, due in large part to unstable housing, strict food access program regulations, and drug-using activities (510-511). These findings are not surprising, given the high rates of poverty in the DTES, and the close link between poverty, HIV, and food insecurity. What has not been explored, however, is how the trend of focusing on these typically “at-risk” communities lets us (researchers and service-providers alike) ignore other populations and communities—those who are equally at risk, yet relatively invisible and therefore not acknowledged as being at risk.

My project is based on the notion that the quantitative, far-reaching study by Normèn and her colleagues requires place-based, in-depth, qualitative studies that provide answers to why PLWHA are so much more likely to be food insecure and hungry, as well as how people deal with their food insecurity on an everyday basis. Because demographics in the Okanagan Valley are similar to those of certain other parts of the province—Victoria, Kamloops, and parts of the Kootenay region come to mind—the results of my work can be extrapolated to those areas. The

3 A 2006 study places the HIV prevalence in the city of Vancouver at six times that of the national prevalence. This is attributed to a higher relative population of injection drug users (IDU), as well as a relatively high population of men who have sex with men, and female sex workers (McInnis et al. 2009). Most of these high-risk populations (the IDU in particular) are concentrated in the downtown east side of the city. According to the BC Centres for Disease Control, in 2011 Vancouver’s infection rate was 24.4 per 100,000 people, with 163 new positive HIV tests (BC CDC 2012:34). This could partially be accounted for by the BC Centre for Excellence in HIV’s STOP program (Seek and Treat for Optimal Prevention), launched in 2010. The STOP program is attempting to seek out people at risk, test them, and get them on HAART as quickly as possible should they test positive.
following chapter describes the methodology and data collection methods I used to obtain this place-based, in-depth, qualitative information.
Chapter 3: Methodology

The methodology chosen for this project was institutional ethnography (IE), an alternative sociological methodology founded by Dorothy E. Smith in the early 1970s and subsequently developed by Smith and others over the following decades (Campbell 1998; Campell and Gregor 2002; DeVault 2006; Grahame 1998; Mykhalovskiy and McCoy 2002; Rankin 2003; Townsend 1992; Walby 2002). IE is “alternative” because it critiques and reacts to traditional sociological methods, such as phenomenology and ethnomethodology. For me, part of the draw of using IE was its emphasis on how things work in addition to why things are the way they are. From my interactions with clients at Living Positive Resource Centre, the AIDS service organization (ASO) where I worked, I was aware of why many of them were food insecure: they did not have enough money to buy high-quality foods, they could not regularly afford transportation to and from grocery stores and other venues, they were physically impaired in some way, and so on. The questions I wanted to pursue (in addition to exploring those “whys” more deeply), were how food insecurity came to be such a prevalent issue in the lives of PLWHA in my region and how food insecurity plays out on a daily basis; in other words, how food insecurity influences and is influenced by other facets of everyday life.

Food security is a social issue. As Amartya Sen (1982) points out, it is inequitable distribution and not inadequate food supply that drives food insecurity, both on a local and global scale. One of the Okanagan Valley’s main industries is agriculture—we have plenty of viable land and could feed all of our residents with no problem. However, due to global market demand, approximately one quarter of Okanagan produce is shipped overseas to sell for higher profits, making fresh, local fruits and vegetables financially inaccessible (particularly in the winter
months) to all but those in the most secure income brackets. I feel that one of the problems with the lack of research on HIV and food security in affluent industrial nations is the perpetuation of stereotypes, for example, that if one is living in an affluent society and is hungry, one must be a drug abuser or homeless or unemployed and lazy. Working as an advocate, I quickly found that those stereotypes were inaccurate and unfair; most of the people I would have classified as food insecure at the time (i.e. without having done any formal research) did not have any issues with drugs, were sometimes employed and were in stable, if not ideal, housing situations. If food security is a social problem, then the social institutions responsible for distribution of wealth and resources must play a role. This is where IE fit in so nicely.

**History of Institutional Ethnography**

Institutional ethnography developed in a somewhat reactionary way to the existing epistemological paradigms in place in social sciences approximately 30 years ago. I outline Dorothy Smith’s early work here because it has been so crucial to my evolving understanding of the methodology.

In the early 1970s, Dorothy Smith was a doctoral student of sociology at the University of California, Berkeley. She was also a wife and a mother to two young children. Living these two mentally and physically disparate existences led Smith to theorize that women regularly experience a “bifurcated consciousness” (2004:4). In Smith’s own life, this meant participating in the somewhat abstracted and male-dominated world of academia, while also performing all the duties inherent in being a mother and homemaker. This was not necessarily problematic in and of itself (although certainly challenging); many women gracefully handle multiple roles. But it did
illustrate to her that the way in which the university was ordered and ruled was not for women or by women. Rather, it was ordered and ruled for men, by men. In her own words:

In my earliest writing from women’s standpoint, I located a break in my own consciousness: on the one hand, my being as mother and housewife, at home, with two small children; and, on the other, my work in relation to the university as a sociologist. The latter had this strange character when I looked at it from the point of view of a woman located in the actualities of her everyday/everynight living, of being put together so that the subject participated in objectified relations organized beyond the local particularities of her domestic consciousness (2004:3-4).

Smith asserts that women have essentially been left out of the forming of culture and ideology, and therefore never get to participate fully in a great many aspects of non-domestic society. She adds that North American society is dominated by both patriarchy and capitalism, the latter being a system that is almost entirely male-dominated, both practically and ideologically. Traditional sociological research methods likewise were developed largely by men and continue to be dominated by men, excluding women.

It was this revelation, this experience of bifurcation, which informed Smith’s work for decades to come and formed the basis for what was to become institutional ethnography. Working from the notion that women’s “everyday/everynight” lives lie outside mainstream ideology and practice, she extrapolated that sociological research done in mainstream ways could not help but perpetuate the exclusion of women, even if the research was about women’s issues of marginality and even if the research was done by women sociologists. Smith then proposed the seemingly startling idea that instead of doing research on women or about women, it should be done for women. The only way to do this, she argued, was to begin from the standpoint of women. Although my study does not focus on women, it is feminist in its approach, as Smith originally set out for IE to be. I draw on the holistic view articulated by Donna Haraway (2003)
that feminist research can focus on any population or topic, provided it maintains the core function of rooting out and challenging social inequalities; thus,

feminist inquiry is about understanding how things work, who is in the action, what might be possible, and how worldly actors might somehow be accountable to and love each other less violently (7).

**Terminology of Institutional Ethnography**

It is important to state briefly at the outset that despite the name, IE is not solely about institutions in the way we normally conceive of them, as buildings or systems dedicated to a specific function such as education, health or government. Rather, IE aims to study the way in which people interact with one another within these types of systems (and without them) in order to get through their everyday lives. This can, of course, involve one or more “institutions” and it is often necessary to incorporate information about them as part of data collection and analysis. It also involves texts, which mediate the activities and actions of individuals and groups. These concepts and how they play out in the research process will be discussed in greater detail later.

In addition to using the word “institutional” in a somewhat alternative way, IE uses two others, which I like to call “derived terms,” words that, when used in a research setting, take on or derive meanings that diverge from their mainstream definitions. One of these is “problematic.” When used in IE, problematic is used as a noun. It is one of the central terms in the methodology, meant to “constitute the everyday world as that in which questions originate” (Smith 1987:91). It is not the same as a problem, nor is it the research question, but is used, instead, as Smith explains,

to direct attention to a possible set of questions that may not have been posed or a set of puzzles that do not yet exist in the form of puzzles but are “latent” in the actualities of the experienced world.
The questions themselves, the inquiry, the puzzles, and perhaps the issues are the means of developing the problematic as an inquiry. What I have done in using this term, therefore, is to shift it out of its ordinary place within a scientific or philosophical discourse and treat it as a property of an actuality lived and practiced. (1987:91).

For this project, food security is at the root of the problematic, but it is not the problematic itself. Rather, the problematic is constituted of those whys and hows mentioned earlier. Why are some people living with HIV food secure and others not? How do different people deal with food insecurity? How are institutions involved in the food insecurity of PLWHA? The foundation of IE is its use of an individual’s standpoint as an entry into research. As such, the problematic “as a property of an actuality lived and practiced” shifts according to each individual’s experience. The questions around the problematic remain the same, but the answers to them are always different depending on the individual. The notion of praxis also fits nicely within the framework of IE because examining tangible, everyday activities leads both researchers and participants into understanding the ways in which we can, as Haraway suggests, be more accountable to one another and love each other less violently.

Another “derived term,” very much related to the concept of the problematic, is “work,” which in IE describes a host of activities taken on by people in order to navigate their everyday/everynight lives. When I, as an institutional ethnographer, talk about how people with HIV deal with issues of food insecurity, I am referring to this type of “work;” not paid work or even labour as we normally conceive of it but, rather any activity and any engagement that occurs in ordinary life that could potentially resolve the details of the problematic. My research has revealed that the work of food security includes predictable activities such as making grocery lists, going shopping, and cooking meals, as well as less predictable, more peripheral (yet vital) activities.
such as filling out government forms or attending support group meetings. *Work* can be enjoyable or not, last several months or only a few minutes. The term encompasses an enormous range of things.

Getting to the bottom of what these activities are and how people go about doing them can involve a number of data collection techniques. IE relies mainly on in-depth interviews for exploration of a topic from an individual’s standpoint. Again, however, the focus is on activities, and not on simple accounts of what is done. Any accounting by participants needs to be detailed in its description of the work that has taken place. Campbell and Gregor (2002) point out that professional language simply obscures what people actually do. For instance when someone says... ‘I manage the household finances,’ the actualities of the work are missing. The alternative would be to describe how the person did it, using a narrative account that lists the steps, the time used, and so on (72)

Notice also from this quote that “professional language” does not only refer to traditionally “professional” settings but to any setting that allows for use of “ideological” language—language that describes the way things are *supposed* to happen as opposed to language that describes things as they *actually* happen (Campbell and Gregor 2002:69-72). Throughout the research, I came to see that eating and provisioning—the central components of food security—cross paths and overlap with many other facets of social, economic, cultural, and political life. As simple as it may *sound* to get food (don’t we all just go to the store and buy what we need?), it is most definitely not simple for everyone to carry out in actuality, nor is it simple to explain how this happens. IE provided the methodological means to explicate the work involved at each step in the provisioning journey—from being well enough to earn an income, for example, to being capable of “getting out into the world” for grocery shopping, to having an appetite for healthy food.
My Use of IE

Briefly, I would like to explain how my use of institutional ethnography played out in the course of this project. Having been introduced to IE by a colleague, I was intrigued and eager to employ IE in my study on food security because of its focus on people’s unique experiences in the world and how those experiences are shaped by translocal social and institutional relations. Because of my work as an advocate, I saw that much of the difficulty faced by PLWHA regarding food security was institutionally based; however, as my research progressed, I realized that my study would not end up looking quite like a “traditional” institutional ethnography. This was because I was not studying several individuals’ experiences with one institution, but rather several individuals’ experiences with numerous institutions (for further explanation of IE’s typical focus on analyzing one institution, please see Namaste 2006). As well, the institutions varied across my participant group; for example, some had significant involvement with government income programs, others had none at all. Some used public transit in their provisioning work, while others had vehicles and interacted instead with the “car culture” of Kelowna (not a formally governing institution, but one that governs through social expectations and conventions in just as powerful a way). I therefore adapted IE to include these many facets and developed a rubric with which to guide the analysis and documentation of results.

Another way of conceptualizing the diagram from Chapter 1 that showed how this dissertation is organized, is Figure 2, a prism. In the same way that light enters a prism as a concentrated white stream and exits as the colour spectrum, food security for PLWHA can, on the surface, appear as a single issue. When we examine that issue from an institutional ethnographic perspective, however, that one issue is diffused into several “bands” that show the
complexity of the problematic and illustrate the levels of work and institutional organization that
PLWHA must navigate in order to maintain and increase their food security: obtaining food,
affording food, being well, and navigating discourse. On the other hand, treating each of those
bands as entirely separate entities does not accurately capture the way they interact in everyday
life, and so thinking of them as being compacted into a single ray of white light—enigmatic,
overlapping, and difficult to capture—is also useful. This conceptualization also fits well with
intersectionality, revealing how a multiplicity of factors messily mingle with one another.
Sometimes this mingling happens uniformly across the participant group, and sometimes it
happens in unpredictable and idiosyncratic ways.

Figure 2. The work of food security for PLWHA, conceived as a prism
Data Collection Methods

Questionnaires

A demographic questionnaire was administered orally prior to each interview session to record age, gender, sexual orientation, date that HIV was acquired, most recent CD4 count and viral load\(^4\) (if known), height, weight, employment status, average monthly income and living situation (see Appendix 2). I also used the Radimer Cornell questionnaire on food security (Appendix 3), a standard tool used to gather information on food security in North America (Kendall et al. 1995:2793). It is used in economically developed areas because it focuses on socio-economic access to food, as well as the psychological aspects of food security (being worried about not having enough food or enough money to buy food, for example). I used the Radimer-Cornell for two reasons. The primary one was to come up with an accurate description of the food security status of my sample. The Radimer-Cornell is intended to evaluate household food security, individual food security (adult), and hunger (child and adult). The Radimer-

\(^4\) The term “plasma viral load,” (PVL) or simply “viral load” refers to the number of copies of the human immunodeficiency virus found in one millilitre of a person’s blood plasma. Viral load is ascertained using one of three PVL tests: the Polymerase Chain Reaction (PCR) test, the nucleic acid sequence-based amplification test (NASBAT), or the branched-chain DNA test (bDNA) (AFP 2001:1). A person is said to have an “undetectable” viral load when no copies can be detected by these tests, which generally can detect down to 50 copies per mL (WHO 2013).

CD4 cells are a type of lymphocyte (white blood cell) that identify and rid the body of viruses and other infections. CD4 cells are named such because they carry the CD4 protein on their surface (AIN 2013:1). CD4 count is an important indicator of immune system health because HIV often infects CD4 cells and, generally, the higher the CD4 count, the healthier the immune system. People who are HIV-negative (and some HIV-positive people as well) have CD4 counts in the range of 500 to 1000 per cubic millilitre of blood (mm\(^3\)) (AIN 2013:1). In all people, the count can vary significantly depending on a number of factors, including time of day, and whether the body is fighting an infection of some sort (NIH 2011). In PLWHA, CD4 count varies with these influences, but probably the most significant factor is being on a highly active antiretroviral therapy (HAART) regimen. In most people on HAART, viral load is undetectable and CD4 is kept at or near the lower range of “normal.”

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Cornell is scored quite simply: respondents answer the first 11 questions with one of three responses: “not true,” “sometimes true” and “often true.” Responses are scored positive if respondents answer either “sometimes true” or “often true.” For the last two questions, responses are limited to either “yes” or “no.” The response is scored positive if the answer is “yes.” A second reason I administered this protocol is that it helped to reveal a methodological gap that I believe is present in the Radimer Cornell questionnaire and certain other food security measurement tools—a dimension that helps describe how physical symptoms can increase the likelihood of food insecurity. As I briefly discussed in chapter 1, the physical side effects of HIV and ART/HAART can have a serious impact on a person’s eating habits and appetite. Yet, nowhere have I found a measurement system that reflects this problem. Thus, using an “industry standard” tool such as the Radimer Cornell could help identify that gap and develop new questions that reflect the extent to which physicality affects food security. I believe that if this research topic is to be advanced effectively in Canada, we require a new tool for more accurate measurement of all the possible dimensions of food (in)security for PLWA.

**Food Diaries**

At the same sessions during which the questionnaires were administered, I asked participants to keep a food diary—a record of what they ate and drank (including medications) for one week (Appendix 4). An instruction sheet was provided, asking participants to be as detailed as possible about portion size and ingredients. They were also asked whether or not they finished meals. This diary provided an enhanced understanding of the ways in which medications and meals interact, also providing me with a springboard from which to ask questions about eating habits, food preparation habits, schedules, and provisioning. Krall and Dwyer (1987) and
Karvetti and Knuts (1992) found that food diaries can be quite effective in giving an accurate portrayal of foods consumed over short periods of time. For me, the diary was used as a point of departure for discussing activities around provisioning and eating, thus, it was not necessary that the diary provide exact portion weights and measurements. In order to gain a better understanding of how much money people spent on food, where they were primarily getting their food, and what they were buying, I also asked participants to keep their grocery receipts during the initial phase of the research. The diary is not a tool regularly used in institutional ethnographic work but it proved useful for informing other aspects of the study, particularly some of the interview questions.

**Interviews**

My interviews were carried out over the course of one year. I used an interview script (see Appendix 5) as a rough guide; however, in accordance with the basic tenets of IE, I allowed the interviews to be driven in large part by the participants. I wanted them to feel free to talk about their activities and experiences of food security and insecurity and not be constrained by a structured interview and closed-end questions. Rather, I liked the idea of a “structured conversation” (Davies 1997:135). Fife (2005) explains that semi-structured interviews act as “a chance to develop a conversation along one or more lines without the usual ‘chatter’ (i.e. extraneous information) that accompanies such talk” (95). With permission of participants, I recorded all interviews with a digital recorder. After transcription, review and summarization of the interviews, I contacted participants with any further questions and asked them to review my summaries to see if they had anything to add, delete, or expand upon. Occasionally, these follow-up sessions were quite fruitful and allowed me to delve even deeper into a variety of issues. The
interviews acted as a sort of pivot point, methodologically speaking, because they were informed by the two questionnaires and in turn, informed the subsequent data-collection activities: participant observation and text analysis.

**Participant Observation**

Having a background in anthropology I was drawn to participant observation, as it forms the core of anthropological research. As well, because of IE’s strong focus on activities and because I was investigating very tangible activities done by PLWHA as they tried to afford, procure, prepare, and eat food, participant observation as a data collection tool worked into this research very nicely. I would like to take the opportunity in this section to delve a bit deeper into a discussion of my positioning in this research and begin with a quote from Timothy Diamond (2006):

> To begin in a standpoint as a methodological device remains one of the breakthroughs of this method [IE], but how to do it is still there to be explored; far from a given, how to start there remains somewhat uncharted territory. Participant observation begins in a specific setting, a starting point on a map, a ‘you are here’ point. It provides a way to start in local particularities to establish a problematic with a focus on how actualities of people’s lives come to be hooked up with institutional relations (60).

Reflecting on my positioning has enabled me to see that participant observation happened in a number of different ways at different times throughout the project. My “standpoint” at the beginning of the research was very much both institutional and participatory, although I did not see it that way at the time. My job at Living Positive Resource Centre was to help people navigate social and health services to improve their quality of life. I was a participant observer in this navigation. At times (especially early in my work there) the “way through” bureaucracy was as opaque to me as it was to the clients I was trying to assist. Over time, I became more and more familiar with policies and procedures of government and other organizations and began to accept
those processes as normal and rational, even though I empathized with my clients’ frustrations with them. At the same time, although the nature of my job (and largely of the agency as a whole) required a certain liberal-mindedness that rallied against conservative government control (which I fully recognized as “institutional” in the more traditional, negative sense), I was fully participatory in a different kind of institution, with policies, procedures, and rules of its own. Client data sheets had to be filled out regularly and in a particular way, forms had to be signed, reports had to be made, activities and requests had to be accounted for. All of this happened in what I consider the initial, “informal” research phase—the one that happened before I was approved by the university ethics board. Although it wasn’t formally conducted or approved, it was crucial in helping me come to the problematic and ground myself in an understanding of the lives of PLWHA. With time and reflection behind me, I see now that the two phases (the informal, during work at the ASO, and the formal, after my employment and with ethics approval) are far less distinct from one another than I had supposed or intended. Indeed, the structure of the project was largely premised on my own positioning within/without the agency. The main reason I left my job was so that I did not mix my advocacy work with my research; yet, now I think it may not have been such an impediment or ethical risk to have remained employed there. After the research and most of the writing phases were complete, I returned to work at Living Positive Resource Centre as an outreach and harm reduction worker.

Participant observation happened additionally during the formal phase, when I accompanied participants on shopping trips, food bank visits, and other provisioning activities. I carried out one participant observation session with several participants (seven out of 12). This included going to grocery stores, the food bank, the local compassion club, and other activities. Some people shared recipes or meals with me; one person took me to his plot at the community
garden. I also spent time with them immediately before these activities (to observe the work of planning and preparation) and after them (for example, to observe the work of bringing home the groceries and organizing the food in the house). Participant observation served several purposes. First, it allowed me to watch activities, in addition to being told about them. This not only increased validity by allowing for a comparison of interview data with observation data but, more importantly, brought up a host of details that likely would not have been discussed had they not been actually carried out. Second, it put me into contact with a variety of texts to analyze. Third, it allowed me to watch participants in their social worlds and gave me a wealth of data on how they interact with others and with institutions. A final advantage of participant observation is that it enabled me to “move beyond a merely cerebral relationship and develop more intuitive or ‘gut-level’ feelings” (Fife 2005:72). Diamond eloquently sums up the value of participant observation in IE:

Participant observations, as they are developed in the future in institutional ethnography, may also have unique contributions for understanding how ruling relations work. Very often they provide a position for exploring ruling relations from the outside ... the method lends itself to figuring out how to locate the institutional in the local, at the point of contact with the actual. As we watch for how to collapse the dichotomy of micro and macro, to find the latter in the former, in people’s doings, it can help to be anchored in specific doings. The researcher can proceed from that ground to identify texts that tie people’s work into the institutional and to study how institutional processes are coordinated as people’s work mediated by texts. Being there, one can see texts being read and come into play in a sequence and regulatory hierarchy (2006:60-61).

Text Analysis

Participant observation and interviews together helped to inform textual analysis, the last of my data collection methods. Smith describes texts as “written, printed, or otherwise inscribed words and images” (2004:33). Smith’s definition of “text” differs from traditional definitions
because she sees texts as living, dynamic things that must be “activated” by a “reader” in order to serve their purpose, that is, to mediate activity and relationships. Thus, texts can take many different forms besides the obvious written document. A text could be a road sign, a bank card, or the chit we tear off at the delicatessen to let us know where we stand in line. All of these things mediate action—they help us organize human activity and without them, our society would be chaotic. This is the reason Smith asserts that all things that are “textually grounded” are also “grounded in the ruling relations” (2004:33). One contribution that I hope to make to ethnographic methodology through this dissertation is an expanded notion of what constitutes a text. For obvious reasons, texts are usually written documents or signs and symbols inscribed in some way on material surfaces.

My interactions with participants inevitably led me to the conclusion that the surfaces themselves can act as powerful organizers of the social world. Landscapes, both natural and those altered by humans (such as roadways, offices, yards, parks, stores, and neighbourhoods) can, in a sense, be classified as texts. This is somewhat at odds with current institutional ethnographic understandings because, in IE, texts are able to regulate activity across time and space (for example, the application form for a Canadian government program is produced in one place, but affects people across the country in the same basic way because they are forced to interact with it in the same way). Certainly, landscapes differ widely across regions and nations, and therefore affect people in different ways. I acknowledge that this is case; however, spaces and places do act to influence people and regulate power. Some spaces in Kelowna work to do this in ways that are specific to this region. Other spaces in Kelowna fit within aesthetic norms that are standardized throughout North America, and therefore regulate activity evenly across
time and distance (for example, the aesthetic of the standard front yard, with a neat hedge and lawn, is one that has similar effects on activity across the continent, and has done so for decades).

Texts can inform the researcher of forces that exist outside of the participant’s immediate being, and which create and maintain certain problematics. Smith explains that texts “are what enables it [IE] to reach beyond the locally observable and discoverable into the translocal social relations and organizations that permeate and control the local (2006:66). Texts can be divided, according to Smith, into two main groups—those that control social action in terms of time sequence and those that control social action through hierarchy (2006:66). Sequence texts are read selectively and analyzed to make sense of what is going on with a particular subject in a particular time and place. They are “embedded in what is going on and going forward” (67). Hierarchical text “formulates a process. People’s doings are no longer just that but become interpretable as expressions or instances of a ‘higher’ or more distant source of organization—instances of social structures that are independent of particular people” (Smith 2006:82). Texts are the basis for formulating a schematic of activities performed by our participants. When we interview participants, we are particularly interested in finding out about the texts they encounter and “activate” in order to better understand how the ruling relations either facilitate or hinder certain activities. The texts I investigated were those related to accessing food, as well as those related to accessing financial resources, social services, and relationships that might increase food security. For example, when a participant told me in an interview that she gets food from the food bank, I followed up by analyzing the application form for accessing the food bank’s services (a hierarchical text). During the participant observation session with her, I also analyzed
texts within the food bank itself—the signs that tell clients where to line up or tell which items are available for whom (sequence texts). Another participant told me that he uses marijuana to increase his appetite, so I analyzed the federal government application form for legally accessing and carrying medical marijuana and viewed the texts in the office from which he buys the marijuana legally.

What text analysis makes clear is the disjunctures or disconnects between life as it is experienced by participants and life as institutional regulation would have it lived. These two are not the same, yet, it is only upon seeing the text and comparing it with lived experience that we realize just how disparate these “lives” are. When we cannot see or know the regulations ordering our lives, we take for granted that this ordering is normal and unchangeable—the essence of hegemony. In many cases, the tertiary injunctions of the double binds I describe are made clear by text analysis. As per Bateson’s version of the double bind created by ambiguous personal relationships in which the tertiary injunction is not immediately knowable, text analysis helps to show how the ruling regulations are “known only from within the modes of ruling” (Smith 1990:84).

Data Analysis

The analysis of my data was guided primarily by the following quote from Campbell and Gregor:

The data-collection process in institutional ethnography calls for a process of tracking back or following clues forward from the local site and the data collected there. ... Data collection cannot be done at the second level [the level beyond the local experience] without conceptualizing the connections between the two. Theory is therefore an essential background component of data collection. Bringing data together with theory happens explicitly in the process of analysis (2002:81).
This process begins with the understanding that the main goal of analyzing data is to make explicit the social connections involved in the activities that have been documented up to that point in the project.

Analysis was carried out throughout the latter stages of data collection (i.e. during interviewing, text analysis, and participant observation), while the data was fresh in my mind. One of the strategies that Campbell and Gregor suggest is storytelling. Storytelling happens when the researcher talks to another person (a person who is “outside” the research project) about what they have begun to learn from the data and the person asks questions about the story. As the researcher talks, s/he makes notes and also answers questions. Particular attention is paid to the questions that seem unanswerable at the time. These questions point to places where the problematic needs to be explicated further (2002:92-93). I employed the storytelling technique and found it to be a very useful way of articulating how people deal with the problematic. The process went like this: after completing the data collection methods with a participant, I would discuss the participant’s situation with an educated outsider, usually my partner. He would ask questions about the person’s provisioning work, interactions, relationships, etc., and I would answer. His questions and my answers to them provided a more nuanced “story” and gave clarity to the connections between individuals’ work, institutions, and texts. I made notes as we talked; at times, new questions (his and mine) arose that I had not previously considered. These I addressed in future sessions or follow-up questions with participants. When we had exhausted the issues pertaining to each participant, this storytelling component was complete. At that point,
my formal writing began; during the writing process, I was able to make connections and conclusions that further built on the results of the storytelling process.

Because IE focuses on social connections found in the work done by participants, coding, a common form of analysis in other methodologies, is not carried out in the same way in IE. Smith stresses (2004) that we need to be careful not to bring our analysis to the level of abstraction and most IE researchers believe that coding risks doing just that. As Campbell and Gregor point out:

Ethnographers who interview or observe informants may also look for themes and then code recurrent topics or words. Whether quantitative or qualitative analysis is done, these kinds of research activities are constructing objectively the phenomenon in discourse. To do so, institutional ethnographers believe, is to lose its meaning as a situated activity. Recurring events or recurring use of words have a different interest for institutional ethnographers who are looking for how things happen here, in the same way they happen over there. Recursivity in institutional ethnography shows a pattern in the world—something is organized to recur, and that is the organization that institutional ethnographers explore (2002:69).

With that in mind, I looked at patterns of activity, rather than patterns of thought that could have been generalized into theoretical abstractions. I looked for pieces of information in the data that advanced my understanding of the problematic. Overall, I think that grounding my analysis in the conceptual framework of IE, which dictates a focus on activity and social connections at the local level and beyond, provided sound guidance of the analysis and the work as a whole.
Ethical Concerns and Considerations

Because my main objective for this research was to understand how people go about their daily lives in the quest to be food secure, there were a host of issues that arose during interviews and other methods of data collection, some of which I anticipated before the research began and some I did not.

One of the concerns I anticipated was the potential for emotional trauma that participants could experience upon discussing their issues around food insecurity, as well as their experiences in their dealings with the institutions involved as gatekeepers of food security. Although participants often seemed frustrated or even angry at their situations, they never seemed traumatized by thinking about those situations or talking about them with me. Rather, most frustration and anger was balanced with humor, and many participants looked at negative situations in a comical or ironic way that balanced out how difficult they were in everyday life. I also thought that it was possible for interview sessions to be therapeutic and, for some participants, I think it did turn out to be a good opportunity to think through their relationship with food and institutions that either help or hinder food security. Additionally, some people seemed to find the research to be an opportunity to educate me about the intricacies of provisioning on a budget. Indeed, I was well educated by these participants and am grateful to them for sharing their strategies, some of which I have incorporated into my own provisioning activities. Participants were also made aware of the potential for the research to help others in the future and several of them told me that this was part of their reason for participating.

My past relationship with some of the participants was an ethical issue that I ruminated on for some time before beginning the project and was the reason I left my job at the ASO, as
described earlier. I thought it was possible that some of them would want to participate in the study because they felt they somehow “owed” me for helping them in an advocacy capacity in the past. In the end, eight out of the twelve participants were people I had never worked with one-on-one as clients; the four people who had been my clients seemed genuinely interested in engaging with the project. When I started receiving calls and emails during the recruitment phase it was clear that people wanted to get involved because the research topic itself was interesting and important to them, not because they felt obligated.

Other ethical issues did crop up, however, that I hadn’t thought of before beginning. One was that two participants mistook my new role as researcher to mean that I was employed again at the LPRC, despite my explaining that I was no longer an advocate. They asked occasionally if I could help with this problem or that; when these conversation arose, I simply explained again, and directed them to the appropriate client service worker at the agency, giving names and numbers if necessary. Another, more disturbing issue came up during participant observation sessions. Because our sessions took place in very public areas, such as grocery stores, I became worried that I would see someone I knew, which would subsequently “out” the participant I was with, since most of my friends, family, and acquaintances are aware of my research topic and it would be obvious that I was out “grocery shopping” with someone who was not my partner or children. Thankfully this did not happen, but it was something that, even now, I would be unsure of how to deal with.

The question of being too “close” to my research and my participants could also have been seen as a potential concern, as I had spent nearly two years prior to the project immersed in the lives of PLWHA. Until about ten years ago, working in one’s own community and situating
oneself in the research were seen as impediments to objectivity in anthropological settings (Caputo 2000; Messerschmidt 1981). Thankfully, this view has changed significantly to the point where many social scientists conduct research in places and populations with which they are familiar, or “at home.” (D’Alisera 1999; Shankman and Ehlers 2000). As I touched on in the discussion of participant observation, institutional ethnography works nicely in tandem with research at home because IE requires that the researcher be personally situated within her or his subject matter. Being familiar with the setting and the people certainly facilitates this process of familiarizing. Smith explains the position of the investigator in IE as being a bottom-up (or better, a “centre-out”) process:

The idea is to reorganize sociology as a knowledge of society so that inquiry begins where people are and proceeds from there to discoveries that are for them, for us, of the workings of a social that extends beyond any one of us, bringing our local activities into coordination with those of others. The project is to extend people’s ordinary good knowledge of how things are put together in our everyday lives to dimensions of the social that transcend the local and are all the more powerful and significant in it for that reason (2006:3).

Campbell and Gregor also state the importance of situating oneself firmly within the research question:

The student of institutional ethnography is required ... to see herself as a knower located in the everyday world and finding meaning there ...we teach an orientation to research as an opportunity for students to inquire into topics that are meaningful to them and to make inquiry a process of discovery (2002:11).

While it could be said that many qualitative methodologies in sociology and anthropology aim for similar goals (for instance, to “begin where people are” or to “make inquiry a process of discovery”) IE places special emphasis on the everyday world—the seemingly mundane, the work, the details—and how “everyday-ness” connects to wider social organization and power relations; these are often termed the “translocal relations of ruling” in IE.
Smith 2006:66) and they explicate how non-local forces act on local experiences. In this way, embeddedness within the problematic actually lends credence to the research. For this reason, I see my former position as advocate for PLWHA as an advantage that gives me a grounded starting point for understanding the problematic and to be an empathetic listener/observer with my participants. However, my closeness to the research came from more than working at the ASO and getting to know some of my participants before the research formally began. Because this project is based in one specific locality and because that locale is the town in which I grew up, I have an insider’s perspective on its particular culture and social relations. This knowledge—built up and honed over many years—comes into play most obviously in Chapter 8, when discussing the discourses of HIV, AIDS and food security in Kelowna. Having grown up here amidst the beginning of the AIDS crisis in North America, my perspective on how this community reacted and continues to react to HIV/AIDS is valuable. The fact that I did not know anyone with HIV until I started working at the ASO also gives me a unique inside/outside knowledge that I drew on for insights into the societal discourse around HIV, then and now: as someone unaffected by HIV until recently, I can speak with authority about how the majority of this community felt/feels about HIV; as someone who (now) has worked closely with PLWHA, I can contrast this stance of the majority with the feelings and experiences of the minority who live with HIV. I also have personal experience with how the community has changed in an aesthetic sense over a period of several decades and use this in my analysis of “landscapes as texts.” Using my personal experience of growing up in this particular locale and working in the health and social services sector, I take the liberty of crafting Chapter 8 partially through autoethnography, defined as “a self-narrative that critiques the situatedness of self with others in
social contexts. Auto-ethnography is both a method and a text of diverse interdisciplinary praxes” (Spry 2013:710). In addition to helping me provide a rich description of Kelowna’s physical and social environment, I hope that using autoethnography also helps to further situate me, as researcher, within the time-space context of the project.
Chapter 4: Participant Profiles

This chapter provides information on the twelve participants of the study. I begin with a demographic overview of the participants and go on to describe each participant’s living situation, income level (individual and household, if applicable), personal background, and health status. Although their experiences of food security will be detailed in the following chapters, I believe that giving this background information will provide a richer understanding of each person, thereby enhancing the stories and quotes in the findings chapters. Providing participant profiles is in keeping with the goals of institutional ethnography—to begin from the standpoint of the individual and to avoid reification of experience to the level of generalized abstraction. All participants’ names have been changed to protect privacy; the names of their families, friends, healthcare providers and other acquaintances have also been changed.

Overview of the Sample

As was touched on in the previous chapter, the participants for this project were recruited through Living Positive Resource Centre via a letter written by me and sent by the executive director to approximately 65 of the Centre’s active HIV-positive clients (see Appendix 1). Over the course of several months, I received phone calls and emails indicating potential interest from people who wanted to be part of the project. In total, 19 people made contact and carried out the initial stage of research with me (the food security survey and demographic questionnaire). Of those 19, 12 completed the project. One dropped out due to time commitments; two dropped out because they moved away from the area; two became unreachable early on in the project, one
was not included due to travel constraints on my part and one was considered unsuitable for personal safety reasons.

It is significant to note the reasons for attrition, since they speak to some of the difficulties faced by PLWHA in this region. Mark and Phillip, for instance, were living together as a couple in Kelowna when they expressed interest in the project but had been wanting to move to Vancouver for many months. Early on in the study, the opportunity arose for them to move to the Fraser Valley and they quickly took it. They told me they felt they would have more support for their health and social needs, more job opportunities, and better access to a thriving gay community there than in Kelowna. Thomas, who lived in Vernon (a city north of Kelowna) and expressed interest in participating, had to end his involvement because he needed to increase his hours at work in order to make ends meet. Taking on involvement in my project was too stressful and time-consuming for him. Brandon, as well as Tina, could not be reached via telephone (the only means I had of contacting them), despite numerous efforts to follow up after initial contact. In my advocacy work, this happened quite often as clients who were liminally housed or had unstable financial situations would lose the use of their home phones (which were sometimes being paid for by another adult member of the household with an equally unstable income) or would not be able to “top up” the minutes on their cell phones. This sort of “dropping off the map” as we called it, happened regularly with many clients and therefore it was not surprising for it to happen in the research setting as well.
Demographics

Age, gender, mode of transmission, and ethnicity

The 12 participants ranged in ages from 35 to 63, with a mean age of 52.5. Prevalence rates in Canada show that the percentage of people aged 40-49 and 50+ with HIV has been steadily increasing since 2005 (PHAC 2011). In 2010, the 40-49 age group made up 27.1 per cent of all case reports and those in the 50+ age group made up 19 per cent (PHAC 2011:1). This is largely due to the fact that HAART is helping PLWHA to live longer. However, there is also evidence that more people in older age categories are becoming newly infected. This can be attributed to a variety of factors, none of which are well-researched. Older adults are often presumed to not be sexually active and so HIV prevention messages rarely target this population. Erectile dysfunction medication is helping older men have more sex and the physical issues associated with aging, such as atrophic vaginitis, are putting older women at risk (Myers et al. 2009:20-21). The BCCDC reported that in 2010 there were 238 newly HIV-positive males in BC; 108 of those (45 per cent) were in the 40-59 age category, while females in the same age range made up 50.7 per cent of newly diagnosed cases (BCCDC 2011:40). Myers (2009) writes that, “as HIV-infected persons live longer, the lines between cognitive changes, such as dementia, induced by therapy and viral effects and those caused by the natural effects of aging begin to blur” (21). Studies comparing older PLWHA and the general population have shown that HIV and its medications can increase the likelihood of having to deal with multiple health problems as one ages with HIV. Onen et al. (2010) have found that HIV-positive individuals aged 50 and older have a higher prevalence of hypertension, hypertriglyceridemia, low bone mineral density, and lipodystrophy. Increased longevity is mostly a reflection of the effectiveness of
HAART. Yet, such longevity may be coming with a price. Guaraldi et al. (2011:1) note that risk factors for non-infectious co-morbidities and polypathology in older PLWHA include lower CD4 count and more prolonged ART exposure. Now that almost half of PLWHA in Canada are over the age of 40, health professionals, the public, and PLWHA themselves must begin to deal with the (largely understudied) challenges of aging with HIV.

Nine of the participants were men and three were women. Although I would have liked to speak with more women, this number does accurately reflect the percentage of women infected with HIV in Canada, at 25 per cent (PHAC 2011). The number of women also, I believe, reflects a generalized unwillingness on the part of women in this geographic area to “out” themselves as HIV-positive. While working at LPRC, I heard numerous stories of women who were repeatedly referred to the agency by a health or social service worker but who would not make an appointment to come into the office. Several women in the region had been clients for years, without ever stepping through the doors, requesting instead that a worker visit them in their homes. One client, after years of doing this, began volunteering at the office and gradually became comfortable discussing her HIV with staff (and some other clients). She told me that, for a long time, she thought she would be stigmatized just by coming into a building known for serving PLWHA. The three women who participated in the project seemed to have “gotten over” this fear of discrimination, either out of necessity by having to repeatedly reveal their status or simply because, over many years, they had become comfortable with disclosure. This will be discussed in more detail in the upcoming chapters.

All three women identified as heterosexual; of the men, five identified as gay, three as straight, and one as “versatile.” I did not explicitly discuss mode of HIV transmission with any of
the participants but the way they contracted HIV was usually mentioned as we conversed about
the impact of diagnosis on food habits. So, although I am not absolutely certain how each person
was infected, half of the people appear to have been infected with the virus transmitted via sex
(male to male) and half via intravenous drug use (IDU). This only partially reflects provincial
trends. In 2009, the BCCDC reported that men who have sex with men (MSM) was the exposure
category with the highest rate of infection (45.5 per cent of all new cases), while heterosexual
exposure (with no other known risk factors) accounted for 26.6 per cent, and IDU only
accounting for 18.9 per cent of new cases (BCCDC 2010:14). This discrepancy could be
accounted for by a number of factors. One is that the Okanagan Valley could have a higher
percentage of intravenous drug users than the province as a whole. This, however, is unlikely as
the highest per capita IDU in the country is in the Downtown Eastside of Vancouver (Maas et al.
2007:432). Another is the fact that the CDC’s measures are of newly diagnosed cases and not
overall prevalence. Earlier statistics show that the percentage of new cases stemming from IDU
has decreased significantly, from 33 per cent in 2003 to 19 per cent in 2009 (BCCDC 2010:14).
As most of my participants were diagnosed even earlier than 2003, it is likely that the six people
in the study who contracted via IDU were part of a larger trend during the 1990s, in which drug
use was a much more influential factor in the spread of the virus. Ten out of 12 participants
identified as white; the other two identified as Aboriginal. This is consistent with province-wide
statistics on HIV in ethnic groups. First Nations have the second-highest infection rate, at 981
cases out of 6712 between 1995 and 2009, after Caucasians, with 4084 cases out of 6712.
Health

The health status of participants varied significantly, but for the most part, HIV itself was controlled. Eleven out of the 12 had undetectable viral loads and most had average CD4 counts. This can largely be attributed to adherence to HAART, which all except one participant had been taking regularly for several years. However, participants discussed many other physical and mental health issues, including generalized and/or localized pain; depression; sleeplessness; gastrointestinal upset, including nausea and diarrhea; and fatigue (all participants spoke of one or more of these issues being present in their lives to some degree). Some participants also dealt with other diagnoses such as diabetes (five participants), neuropathy⁵ (five participants), arthritis (four participants), lipodystrophy (one participant), liver disease (one participant), hepatitis C (one participant), emphysema (one participant), and sleep apnea (one participant). Certainly these health issues are typical of adults aging with HIV and their implications will be discussed in detail in Chapter 5.

Income

Income levels varied and depended on a number of factors, including the type of income and whether the individual lived in a household with other income earners. Of the participants who live alone (n = 7), five received income from government programs such as Persons With

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⁵ Peripheral neuropathy is a common health concern of PLWHA. Two types of neuropathy exist: HIV-associated peripheral sensory neuropathy (HIVSN, which includes distal sensory neuropathy) and ARV toxic neuropathy (USDVA 2011). HIVSN typically affects the lower extremities, starting with numbness, tingling, or pain in the toes, and spreading into the feet over time. It is termed a “dying-back” neuropathy because it affects the distal parts of the body first, and then spreads inward (USDVA 2012). It can be extremely painful. ARV toxic neuropathy is caused by taking antiretroviral drugs—it is believed to be “associated with mitochondrial toxicities” of certain ARVs, particularly nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs). (USDVA 2011:1).
Disability (the provincial disability income program, known hereafter as PWD) or Canada Pension Plan Disability (the federal disability income program, known hereafter as CPPD). The other two had income from employment. Of the participants who lived with other earners \( (n = 5) \), two received income from government programs, two received income from long-term disability (LTD) programs with private insurers through their former employers and one was reliant on the employment income of her spouse. Individual participant income ranged from $1000 per month to $3144 per month, with an average of $1806 per month. For participants who lived with family and/or spouses, the highest monthly household income was approximately $5000.

**Food Security Status**

Food security was generally low in this sample, meaning that food insecurity was more common than outright food security. According to the Radimer Cornell Food Security Questionnaire, only two of the 12 were completely food secure. The rest were either food insecure or showed signs of psychological food insecurity; that is, they were worried on a regular basis about their ability to procure food. It is also important to note that the Radimer Cornell protocol does not ask any questions about physical health, which for people with chronic illness can be an obstacle to making an income, shopping, preparing food, and even eating. In this study, the Radimer Cornell was used to determine a baseline of food security among participants; yet, if physical health had been taken into account, I believe the results would have been slightly different, as several participants noted that their physical health was an impediment to obtaining food and to eating. However, overall, income level was the biggest predictor of food insecurity.
Individual Profiles

Adrian

Adrian is a 54 year old, widowed gay man. He lives on his own in a rented two-bedroom apartment close to Kelowna’s downtown area. Adrian lost his husband due to complications arising from AIDS six years ago, after having been together for several years. He recently had to retire from a physically demanding job in a healthcare facility, where he had worked for more than 20 years. Due to lack of pension, he now receives income from the provincial disability program, as well as a small stipend from his late husband’s pension program. Adrian has a car, which he uses to provision; there is a grocery store within walking distance of his home but he feels it is so expensive that driving to a cheaper store saves him money. Although his HIV is well controlled by careful adherence to his HAART regimen (viral load is undetectable and CD4 count is average, at 380), other health issues are eclipsing the virus. Adrian recently underwent surgery to remove a malignant growth from his leg and another from his arm. His prognosis is good but he must see a melanoma specialist regularly for the rest of his life.

My conversations with Adrian centered on income and social support. He felt much frustration around his transition from employment to retirement, which was essentially forced due to his physical limitations. At the time of retiring, he was too young to receive a pension and would have had to wait five to six months to receive a disability pension (from the healthcare facility) that would have only been paid out for two years. He decided, in consultation with social service workers, to go on employment insurance until his provincial disability income was approved. Adrian had owned an apartment prior to retiring but when he retired had to declare bankruptcy and upon doing so, was forced to sell the apartment and move into a rental unit in a
nearby building. He is happily settled in this new place but still grieves the loss of relative independence and security of owning. Being on the government disability income program has proved both a blessing and curse for Adrian. Simply getting into the program was very difficult: his first application was denied and had to be appealed (I was one of his support workers through this process and assisted him with the reconsideration). The appeal was successful and Adrian started receiving income from the program in 2010. He also began to receive a housing subsidy from BC Housing, administered through LPRC. In late 2012, the government cut $105 per person from housing allowances and now Adrian’s monthly income is approximately $1600. He says that, because rent must be paid first and foremost, his food budget has been cut significantly in recent months. During our first interview, Adrian was better off financially than toward the end of the study and he was happy to share his strategies for shopping and eating on a budget, which was workable at the time. These included shopping on certain days for good deals, using the space in his apartment so that dry goods could be stored as efficiently as possible, and using relatively cheap foods to make nutritious meals that lasted him longer than just one day. These strategies will be discussed further in Chapter 5.

Adrian also discussed at length with me, his lack of social support. He misses his husband dearly and, with this loss, seems to have had to retreat inward to a certain extent. His immediate family (brothers and sisters) is geographically scattered and friends remain scarce. He claims to have lost his one good friend during the months that my study was taking place; this was his husband’s sister, who he says simply “dumped him” after finding a boyfriend. Adrian had been a faithful attendee of the men’s HIV support group, run out of LPRC, but the group has now
ceased meeting and has broadened to include all gay men, not necessarily HIV-positive. Adrian finds this to be inadequate for supporting his health and social needs and does not attend.

Adrian is food insecure mostly for financial reasons, particularly now that his housing subsidy has been decreased. He is also anxious about the rising cost of living and his ability to afford nutritious goods. Adrian faces physical difficulties around food as well, which cause issues with mobility as he has lipodystrophy, a condition common for those on HAART, which causes loss and abnormal redistribution of fat in the body. Adrian has lost a significant amount of weight in his years on HAART and this causes pain in unexpected ways. Sitting for any length of time is painful due to fat loss on his backside, and walking any distance is equally painful on the soles of his feet. I also surmise that Adrian’s strength is limited; even though he can walk to the grocery store close to his home, he must make at least two trips because carrying a full load of groceries is burdensome. Dental care is another problem. Because dental care is not provided universally in Canada, many people go without regular check-ups or even emergency care. Adrian is one of those who cannot afford dental care even though he requires it (and is regularly reminded so by his HIV specialist). If his teeth do not get fixed, his ability to eat will eventually be compromised.

During my participant observation session with Adrian (a grocery-shopping trip and visit to the community garden), we discussed the ethics of food at length, specifically his desire to participate in a local, organic system as opposed to the mainstream food system that is largely controlled by global food conglomerates. My observation session with Adrian took place during the summer of 2012, when his income was high, relative to what it became after the housing allowance was cut, and he was able to buy specific foods from a variety of stores that sold local,
organic dairy, meats, and produce. At the time of writing, Adrian is no longer able to engage in
this type of “ethical” buying, and feels that his health is compromised as a consequence. This
moral aspect of provisioning will be discussed further in later chapters.

Daniel

Daniel is a 48 year old, straight man. He lives in an apartment with his parents, having
moved in with them three years ago during his year-long treatment for hepatitis C, which is
extremely taxing both mentally and physically. His HIV is controlled by HAART and he feels he
is in good shape now that he has rid his body of hep C. He is physically active, with a busy social
life and dates often. Generally, he seems happy and very good humoured.

Daniel receives income from the provincial disability program, which provides him with
$1200 per month. At the beginning of the project, as a journeyman carpenter, he occasionally
supplemented his PWD income (to approximately $2000 per month) by doing contract work—
usually cabinet making, painting, repairs, and other small jobs. He has good working
relationships with several individuals and small businesses who call on him to do such jobs on an
as-needed basis. The rules of PWD state that recipients are only allowed to make $800 per month
over and above their PWD income; Daniel’s carpentry jobs are sporadic, so generally “going
over” isn’t a problem but, if it is (and if he needs the money for some unexpected expense), he
will try to get paid in cash, which leaves no incriminating evidence that might jeopardize his
PWD payments. Toward the end of the project, Daniel got a carpentry job in northern BC. It is
not a permanent position but he hopes it will turn into one eventually. Until he is certain of the
job’s stability, he is keeping his PWD, willing to risk being cut off for making more than the
$800 allowable.
When he is/was in Kelowna, Daniel gets around the community mainly by bicycle or on foot and his provisioning is mostly done on foot, as he lives very close to a grocery store. Occasionally, he takes his parents’ car to get a larger amount of food than normal from one of the “big box” stores farther away from their home. Daniel classifies as food secure and notes that his eating has much improved since coming off the treatment for hep C. Although his parents act as a sort of safety net while he is living with them, he tries to pay for his share of the food and struggles to buy healthy food on a limited budget. In this way, the accessibility dimension of his food security could be more stable. The main issue that came up during my interview with Daniel was that negotiating food choices was a source of tension within the household. Daniel’s parents have specific tastes that he does not always share but puts up with because they are letting him live with them. When they are out of the house, Daniel takes the opportunity to make meals he really enjoys but it was a rare occurrence, and for this reason the acceptability of his food security was compromised. This lack of food-related autonomy was a distinct problem that Daniel was hoping to rectify. He had been waiting to get into an apartment in a nearby building run by a non-profit organization that houses people on low incomes. Daniel was planning to get a two-bedroom unit and have a roommate to cut housing costs as far as possible but these units are in high demand in Kelowna and, at the time of writing, he had still not gotten off the wait-list and out of his parents’ place.

Kent

Kent is a 58 year-old, straight man who lives with his wife of 33 years in a small condominium. He has been HIV-positive for 14 years. Kent receives income from both CPPD and private long-term disability (LTD) through his former employer for a total of $2600 per
month. His wife is employed full time at a small local company, so their combined income is $5800 per month, quite high and, for the time being, secure, but is constantly threatened by his wife’s tendency to overspend with credit cards resulting in high debt. Indeed, the couple recently sold their four-bedroom house in order to relieve some of that debt and begin to prepare for the financial hardship they will likely face when Kent turns 65 and loses the LTD.

Kent is food (in)secure due mostly to the mental toll exacted by the high debt. Because his wife works during the days, the responsibility of provisioning efforts and other errands falls to Kent. He seems to enjoy the challenge of buying healthy, interesting foods (and shared with me many of his strategies for where and when to shop for specific goods), but is simultaneously stressed by the need to shop on a tight budget in order to make up for his wife’s overspending. Another less problematic issue that came up in conversation, is knowledge of nutrition and cooking. Kent eats very healthily, avoiding many foods he knows will make him feel ill (such as fats and sugars) but claims to still be learning about how to cook, since his wife had previously taken on this responsibility for so many years. He is always looking for new recipes and new ingredients to keep food tasty and interesting and seems concerned about gaining this knowledge and experience.

Like others in the study, Kent has a low-average CD4 count (260) and his viral load is very low due to his HAART regimen; however, he suffers from several other major health problems, including diabetes and peripheral neuropathy. He has seen several physicians and specialists over the years to deal with the pain in his hands and feet; all have said that there is nothing they can do about it because it is caused by his HIV medications, which are essential to keeping the virus controlled. When I met Kent as a client, he was depressed, anxious, and
physically ill. Over the years he has undergone a transformation that is still in progress; at the
time of writing, he volunteers at least three times per week at LPRC and has decreased the dose
of his pain patch (Fentanyl) to 25mg/day, from the 75 mg/day when I met him in 2009. In the last
two years, he has weaned himself off of nearly all the medications he was on for depression,
anxiety, blood pressure, and pain (these include Crestor, venlaxine, ativan, fenofibrate, ziprexa,
xatral, gabapentin, and fentanyl; many of these he was on simultaneously, in addition to his HIV
medication). At the time of writing, he was only taking three pills daily for his HAART regimen
and a 25mg pain patch every three days. Most importantly, although physically he still endures
the pain of neuropathy, some fatigue and sleeplessness, and occasional stomach upset, Kent says
he feels better than he has since being diagnosed. He attributes these improvements to having a
busy, active life that centers around his volunteer work at LPRC. Other social supports have
helped as well: Kent has three grown children and one of his daughters has three young children
for whom he provides care once or twice per week. Kent says that although caring for his
grandchildren can be tiring, their company and energy have been instrumental to maintaining his
physical and emotional health.

Tome

Tome is a 55-year old gay man. Six years ago, Tome lost his husband to complications
arising from AIDS. They had been together for seven years. Tome works full time at a social
service organization in the area of community development for gay men’s health and has a steady
income of about $2600 per month. This is supplemented by his widower’s pension of $240 per
month. He lives on his own in a two-bedroom condominium, which he bought in 2009 after
losing his partner and moving to Kelowna from Vancouver. He has been HIV-positive for 15
years and his physical health is generally good, with an average CD4 count (350) and undetectable viral load. Tome deals with ongoing depression and this was something that came up repeatedly in our conversations. Despite having a prosaic outlook on life overall, Tome named depression as his most serious health concern.

Living alone means that one of Tome’s main issues with food security is the lack of motivation to cook only for himself. Other problems he runs up against quite frequently are the physical symptoms from HIV and HAART that affect appetite and the daily rhythms of eating, which influenced the availability (specifically the bio-availability) and adequacy of his food security. Tome uses medical marijuana on a regular basis to improve his appetite and allow him to consistently eat an adequate amount of food. Tome also discussed the fact that his work commitments constrain his ability to make appointments with his doctors and pick up his medications at the local pharmacy. This is a problem typical of Kelowna and perhaps other small urban centres like it, which are ill-equipped to deal with PLWHA and those with other chronic diseases. Tome’s GP works at a clinic that is open from 10am to 3pm, so he and others in his situation must take time off work to see her. There is only one pharmacy in Kelowna that dispenses HAART; for people with full time work or mobility issues this can pose obstacles. Adding to this stress is the fact that physician appointments and blood tests must be done regularly in order to keep the HAART prescription: if one does not have blood tests done every three months, their prescription is put on hold until the data is obtained. Although Tome’s employer is sympathetic to his missing work occasionally for these purposes, he feels badly for having to single himself out and solicit time off.
Tome is food secure financially but could be considered insecure because of his lack of consistent appetite and motivation to cook and eat. At the time of writing, Tome’s depression was at least partly being caused by work-related stress; the program he is in charge of is government-funded and funding for it is due to run out in April 2014. At that point, Tome may be out of work and having to apply for provincial disability income is a distinct possibility. He is currently interviewing real estate agents to put his condo on the market so that he needn’t be tied to a mortgage if he loses his job or needs to move to find work elsewhere.

David

David is a 49-year-old, straight man of Aboriginal descent. He has been both HIV and hep C-positive for 15 years and has never been on antiretrovirals. He refuses to take the medications because he deems them unnecessary to his physical health and believes that the multi-national pharmaceutical companies that sell them are capitalizing on people’s illness unnecessarily. David has a high viral load (18,000) and an average CD4 count (400). Despite rather precarious financial and housing situations, sporadic use of illegal drugs, and a history of medical problems, David is in very good physical shape. He is strong and has tremendous endurance, engaging in weight training at a gym for two hours almost every day and riding his bike everywhere (it is his only means of transportation) for both pleasure and utilitarian purposes. At the time of writing he was training for a triathlon. He attributes his physical health to his high level of activity and also to his diet: he eats mostly fresh vegetables and fruits, often in juiced form, as well as fresh meats, some dairy, and whole grains. He avoids all processed foods and all sugars and added fats and preservatives. He does not smoke and, unless in relapse, he does not use alcohol or other drugs, prescription or otherwise.
At the beginning of the study, David lived on his own in a small bachelor unit; the building was reserved for people on low incomes with a history of homelessness and drug use, and was run by a local Aboriginal social service organization. David worked hard to make this his home and customize it to his needs. He had been there for about a year when he was evicted due to a relapse with alcohol. He now lives in a rented house with six other adults. David receives income from the PWD program ($1200) and tries to supplement this by working casual labour jobs around town. He would like to work more often, so that he feels he is contributing meaningfully to society but finds it difficult to make this happen, mainly because he lacks a vehicle and many job sites are too far away to ride his bike. The PWD limitation on extra income is a factor as well, unless employers pay in cash, which is increasingly rare.

My interviews with David focused largely on his unique approach to living with HIV and some of the triumphs and pitfalls he encounters on a daily basis. His refusal to take HAART, for instance, hinders his relationship with healthcare providers because he feels they consistently pressure him to go on medications and judge him negatively for his choice not to. His strict routines concerning activity and diet also both facilitated and hindered social relationships. On one hand, being out in the world, at the gym, bike-riding, in support groups, etc., provides David with numerous opportunities for social interaction; on the other hand, he notes that some people seem threatened or put off by the level of regimentation with which he lives his life. He told me about several instances during which he had tried to educate people about the benefits of eating healthily and working out, but to no avail. He said he realizes the potential for such “education” to alienate people and now tries to verbalize less and lead more by example (more on this in Chapter 7).
Various aspects of his community came up in my conversations with David. The apartment in which he was living was in an area of town normally reserved for the wealthy; the building used to be a motel and was bought by the Aboriginal organization after it closed and had sat vacant for many months. There was no other low-income housing nearby David’s building and he found that the “upscale” part of town lacked a sense of community togetherness and could be alienating. The rented house he now shares is located in a lower-income part of the city, so it might be safe to say that David now feels less alienated than before. However, this brings its own set of problems. His current neighbourhood is known to be lived in and frequented by drug users and, being an addict himself, this can be a trigger. He is also reluctant to go into the downtown core of Kelowna, where many health and social services for low-income residents are located, because the drug trade thrives in that area and he does not want to be tempted to buy and use. Hence, he faces the dilemma of feeling as though he doesn’t truly belong in the “safer” parts of the city, and simultaneously feeling even more put off by the areas in which he can access support. At a more macro-geographical level, David was experiencing something similar. Kelowna has become “home” to him after several years here, far away from his family on Vancouver Island. He did not wish to go back there because of issues with certain family members and his history of addiction, which began there; at the same time, he recognized it as a source of comfort and traditional values.

Finally, spirituality and morality of provisioning and eating were major themes in David’s discussions. Having wrestled with being a vegetarian, he recently decided to begin eating meat because he was stronger and more energetic with it than without it. However, this posed a moral quandary for him; first, not being financially able to buy ethically-sourced meat vexed him;
second, David felt that eating any animal had to be done with care and respect and that this was
difficult if the animal was not procured in a traditional way. His Aboriginal identity played into
this, but it did not provide any clear resolution.

Seth

Seth is a 61-year old man who has been HIV-positive for 23 years. His health is generally
good, with a high CD4 count (900) and an undetectable viral load; because he has been HIV-
positive for many years, he attributes his good health to strict adherence to his medication
regime, as well as not drinking alcohol, doing drugs or smoking. He owns a car but uses it
sparingly, mainly to get groceries, since he lives within walking distance of several amenities.

Seth lives in a rented house on his own and receives income from both the provincial
government disability program (PWD) and the Canadian Pension Plan disability program
(CPPD). Combined, these programs give him an income of $1380 per month.

Seth’s main issue with food security, which he spoke about in the most detail with me, is
accessibility and adequacy of nutritious food, since his income is limited. He has many strategies
that he uses to get by and shared these with me during both our interview and our grocery
shopping observation session, a good learning experience for me. Seth had an intimate
knowledge of the sales cycles of grocery stores and of customer loyalty programs, built up over
the course of many years of shopping on a budget. Seth described his eating as nutritious; yet, he
did buy things that were processed and/or frozen and skimped on fresh foods due to their
expense.

Social isolation also seems to be a problem for Seth. Much of our conversation dealt with
his life in Kelowna in comparison to his life in Vancouver, where he was initially diagnosed and
lived until about 10 years ago. Although he seems content here, it was clear that he had much more social support, more employment opportunities, and access to more programs and services in Vancouver. He notes that he regularly went out to friends’ houses for meals in Vancouver but almost never does so now. He describes his social life now as “virtually zero.”

Cameron

Cameron is a 50 year old gay man, who lives in a new 3-bedroom condominium that he owns with his partner of many years. Cameron is food secure, thanks to both his own income and that of his partner, who works full time in a middle management position for a private company. His HIV is controlled, with an undetectable viral load and high-average CD4 count of 500. He occasionally experiences stomach upset and fatigue but these, he says, are manageable and his health is otherwise good. Cameron receives long-term disability income of about $2500 per month from a private insurer through his former employer; he is retired at this point and has no intentions of gaining employment again since he leads a busy and active life. He and his partner belong to numerous social and interest groups that gather regularly, so his social support networks are fulfilling and extensive. He is quite artistic and engages in creative activities on a regular basis. His parents and other extended family live in the area and they get together often. Cameron and his partner share a car; Cameron often provisions on foot as they live quite close to a large grocery store. Although Cameron is food secure, he maintains that negotiating food preferences with his partner, as well as planning meals and timing them to work within both of their busy schedules, can be mentally and physically demanding.


**Eli**

Eli is a 63-year-old gay man. His health is not good at the time of writing—he is suffering from severe sleep apnea, joint pain, and extreme fatigue (likely in part due to lack of deep sleep). He has had HIV since 1991 and the virus is undetectable; his CD4 count is high, at 940. Although Eli’s health is poor, he is quite active out of necessity. He lives in a mobile home park on the outskirts of Kelowna, a very clean, quiet place that he enjoys for its peacefulness and proximity to the woods. His house is owned by his son, who lives in another province. Eli pays him rent to cover the mortgage but this is difficult on his government income of $1150 per month from CPPD. Eli finds life much less stressful when living with a roommate to cut rent, utility, and food costs. When I first interviewed him, Eli was in between roommates; the previous one had just moved to Vancouver (see Nate, below), and Eli was hoping to find another one soon. Upon contacting him several months after our initial meeting, he still did not have a roommate but was planning on having his boyfriend of five years move in (they plan to marry soon). He had also taken on a part-time job providing respite care to an individual, in order to make some extra income and give himself “something to focus on besides the pain.” He was hoping this would turn into a full-time job eventually. Eli is food insecure due primarily to insufficient income with which to buy adequate nutritious food. His physical health plays into his insecurity significantly because shopping and preparing meals is extremely tiring for him.

Social isolation came up as a serious issue for Eli. He described the gay community as being too young and flamboyant for him and many other men his age. He seemed to desire more social interaction than he was getting but did not know how or where to find it. LPRC’s shift in mandate and location (see Chapter 7) was a heavy blow to Eli, who had visited the agency daily
prior to its transition. He now feels that it is not a safe, dedicated place for PLWHA and chooses not to go there. He laments the lack of community support for PLWHA and for older gay men.

**Nate**

Nate is a 54-year-old gay man who has been HIV-positive since 1995. His health is not good, and he attributes this mostly due to stress experienced at his place of employment. His viral load is undetectable, but his CD4 is a low 284. His doctors could not account for this; Nate said he adheres strictly to his HAART and tries to eat well and regularly. Again, he thinks stress is the cause.

At the time of interviewing, Nate was Eli’s roommate. They had shared Eli’s house for two years and the relationship worked well for both of them. Nate works full time and so has a steady but average income of $3144 per month. Being roommates helped both of them reduce rent, utility, and food costs, and Eli, being retired, had time to shop and prepare meals to share. Nate’s only trouble with this arrangement in terms of food security was trying to negotiate food choices with Eli. They differed widely in their tastes and Nate, while grateful to have someone shop and cook for him, never enjoyed the food Eli made. Nate occasionally shopped for his own food and, at those times, would buy foods he considered more interesting and tasty (describing Eli’s choices as boring and bland); however, these opportunities were few and far between because of Nate’s work schedule and limited income.

Another issue for Nate is Kelowna’s lack of a gay or poz⁶ community. Having previously lived in Vancouver, Nate bemoaned the “small-town” nature of Kelowna such as the tendency for

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⁶ “Poz” is a shortened, slang version of “positive”—a term sometimes used by PLWHA to indicate their HIV-positive status. It seems to be most often used by gay men and men who have sex with men.
businesses to close early in the day or be closed all weekend, for certain amenities not to be open in the winter, as well as the need for a vehicle to get around easily. Nate owns a car but misses being able to walk about the city and easily find things to do at all times of the day, week, and year. He said his life mostly consisted of going from home to work, then back home at the end of the day. When I interviewed him, Nate had been actively trying to get transferred to the Vancouver office of the company he worked for. Shortly after his interview, he was successfully transferred and now lives in Vancouver. He was unreachable for follow-up questioning after he moved.

**Allison**

Allison is 35 years old, the youngest participant in the study and the only one with children living at home. She is single, straight, and has lived with HIV since 2003. Allison has been on HAART since shortly after her diagnosis, so her viral load is undetectable and her CD4 count high, at 890. She has no other major health issues, but deals with depression, mostly caused by generalized life stress. Alison’s children are 15, 13, and 10 years old; they are healthy and thriving and seem to have a close relationship with their mother. Allison is their sole care provider.

Allison receives income from the PWD program, as well as from the Child Tax Benefit program. She also receives a housing subsidy through BC Housing and LPRC; her monthly income outside of the subsidy totals $2000.

My interview and participant observation session with Allison centered on the provisioning strategies used to feed a family of four on a very tight budget. Allison visits the food bank once per month (the maximum number of times a person or family can get food
there); she is eligible to receive special nutritional items because she is HIV-positive and gets more food than a single person because she has children. Allison also tries to take advantage of other food-related programs. For instance, her children all attend schools with hot breakfast programs and brown bag lunch programs. These are helpful in “filling the gaps” and taking some of the provisioning burden off Allison’s shoulders. Still, even with these services, Allison and her children qualify as being food insecure. Allison notes that, at times when there is not enough food in the house to feed everyone, the children always eat first and she goes without if necessary.

Another focus of my discussions with Allison was how she manages to provision for her family without a car. The issue of Kelowna’s predominant “car culture” came up with several participants but was most pronounced with the women, and with Allison in particular because of the number of people in her family. This will be discussed in greater detail in Chapter 7.

**Maria**

Maria is a 51-year-old straight woman who has lived with HIV since 1988. Her HIV is controlled by HAART but she faces several other health problems, including peripheral neuropathy and diabetes. Maria has pain in her hip and numbness in one of her feet that, combined, cause a lack of balance and mobility. She requires a cane to walk and provisioning can be tiring and painful for her. Maria lives with Max, her husband of 20 years, in a rented duplex. They both receive income from government programs, for a combined monthly total of $2000.

Max sat in on my conversations with Maria and together they described their strategies for grocery shopping, cooking, and eating within the financial and physical constraints they face.
One of these is lack of a vehicle. Maria and Max cannot afford a car and so take a taxi to the grocery store once per month for a “big shop.” For other errands and outings, they take public transportation but this can be difficult for Maria because walking to and from the bus stops is slow and painful. Cooking is primarily done by Max, often under Maria’s direction. She gives instructions on what to do and, when she is feeling well enough to be up and about, they work together. Truly, their provisioning is a team effort (more on this in Chapters 5 and 7).

Another thing Maria discussed was her attitude toward HIV and health; she has been positive for 24 years, first diagnosed in Edmonton, Alberta. In those early days, she was active in speaking and writing about living with HIV and dealing with addiction. She feels she was respected by her community and had a high level of care and respect from her healthcare providers as well. Since being in Kelowna, the opportunities for speaking about her experiences have diminished somewhat, although she still feels lucky to have good medical doctors and adequate health and social services.

Darla

Darla is a 53-year-old straight woman of Aboriginal descent who has lived with HIV since 1997. She has lived in Kelowna since 2010 and was previously a resident here for seven years before a short stint in her home town on Vancouver Island. She spent most of her early adulthood in Vancouver. Darla’s HIV is well controlled. She has an undetectable viral load and a CD4 count of 380. Other health problems are more pressing, particularly her emphysema, which severely restricts her ability to be active. Darla doesn’t drive and instead, walks most places. It takes her a long time to get anywhere, because she needs to stop and rest often. This aside, she is most concerned with her sobriety, which she works hard to maintain. Much of our conversation
focused on the mental and spiritual aspects of staying “clean” and the various social supports she draws on in order to do this.

Narcotics Anonymous (NA) is a source of immense strength to Darla. The people in her group seem to be like family to her; she learns from them and gets support from them and, in turn, acts as mentor for the newer members. This support is not insignificant to Darla’s food security. She lives with her husband of 15 years (also an NA member), who is a long-haul truck driver. He is often away for days at a time and, if Darla needs food while he is away, she is able to draw on her NA group for help.

Another point of discussion was Darla’s experience in the residential school system, a topic that came to the fore of her life during my research because she had recently become part of a class-action law suit against the provincial government to receive compensation for injuries incurred while living at the schools. Darla was attempting to get compensation for being hit on the ear by one of the teachers; she has suffered hearing loss in that ear ever since.

Darla classifies as food insecure; even though her husband’s income was quite high in comparison to some of the other participants ($4500), much of his money was going toward paying off a high debt they incurred during their years of heroin addiction. Their household and food budget is tight. Darla herself is not in a position to help financially. Her emphysema makes it impossible for her to be employed; frustratingly, she would easily qualify for disability income if it were not for her husband. Because he has an income and because she has acknowledged her relationship with him is a romantic one—many people in her position rent a two-bedroom apartment and claim that their spouse is a “roommate,” which makes them eligible for income assistance—Darla is ineligible for PWD or welfare.
Concluding Thoughts

To be sure, similarities existed among participants. These were most often due to personal and socio-economic circumstances. Most participants lived in low or low-middle income brackets, several faced serious health issues in addition to HIV and several also lived in relative isolation. It was their reactions to these circumstances and how they dealt with them, where differences could be found. The work of provisioning—the work of obtaining and affording food, and the work of being well enough to navigate services and maintain supportive relationships—varied widely because, although the markers of health and well-being (income level, health concerns, etc.) can appear similar on the surface, each person positions, embodies, and approaches these markers differently, thus bringing a different personality, skill set, and resources to the table. My intent in this chapter was to show the wide variation of personal circumstances of my participants as an entrée into the findings chapters, which elucidate the variation in more nuanced detail. As well, I have highlighted the importance of the use of institutional ethnography, with its grounding in the standpoint of the individual, and intersectionality, which maintains that simply adding together markers of health does little to give an accurate picture of a person’s everyday experience of health or illness.
Chapter 5: The Work of Obtaining Food

In the global north, obtaining food is primarily done at stores through the work of grocery shopping, an activity largely taken for granted in our society as the “normal” way to get food. We often think of grocery stores as offering ease, efficiency, and an abundance of choice. In this chapter, I want to problematize these “freedoms” associated with provisioning in Kelowna by detailing my participants’ experiences. Grocery shopping is the norm, yes, but the pre-conditions to being able to shop—adequate income, physical health, and mobility—are not the norm for most PLWHA in this study. The question becomes: if one cannot grocery shop, what are the other options for getting food? The main alternatives to shopping, for those who cannot afford to buy enough (quality) food, is to go to the food bank or to grow their own food. However, those alternatives are only accessible to those who already fulfill the other two pre-conditions for grocery shopping—physical health and mobility—as one cannot get to the food bank if one is not well enough to do so and one cannot grow food if one is not physically able to sow seeds, pull weeds, water, hoe, till, and tend. To make matters more difficult, patronizing the food bank and growing one’s own food are work activities that require a number of pre-conditions of their own, in addition to physical wellness and mobility. Thus, the question of provisioning options begins to take the form of a double bind: a situation in which the main option presented is unattainable and the alternative(s) are equally unattainable, and, in which the reasons for their being unattainable are not immediately clear. In order to clarify the reasons, it is necessary to investigate the work involved as well as the texts that regulate this work. In this situation, the binding injunctions, as per Bateson’s original theory of the double bind, might look something like this:
Primary injunction: If you can’t go grocery shopping, you won’t get all the food you need.
Secondary injunction: If shopping is too hard/unaffordable, you can use the food bank or grow your own food, but you still won’t get all the food you need (notice that the reasons for this are not clear until we analyze the texts involved).
Tertiary injunction: Using the food bank and growing one's own food are not socially acceptable ways to get food in an affluent society that values the capitalist marketplace, the constant accumulation of goods (including food) and efficiency in obtaining those goods (note that this is only knowable through a reading of specific socio-environmental sites).

The remainder of this chapter is organized to roughly correspond to these three injunctions. In the first section, the work of grocery shopping will be explored, along with the texts that regulate it, such as coupon policies, customer loyalty programs, sales cycles, and the stores themselves. The second section deals with food bank usage and its texts, things like policies on who can receive food, and various signs, symbols, and structures. In the third section, I discuss growing one’s own food and how a “reading” of city-spaces makes growing food either impossible or highly challenging for the PLHWA in this study, depending on their socio-economic and physical position. To round out the explanations of these injunctions, I include a fourth section that details certain food management strategies used by participants to make food last longer, cut down on food costs, and make meal planning and preparation more efficient; in short, strategies that make this particular double bind easier to live within. Finally, I examine the act of eating itself.
Grocery Shopping

In recent decades, social science has found an interest in eating and provisioning (see, for example, Counihan and Van Esterik 2008; Friedmann 1982; Gofton 1989; Mintz 2008; Poppendick 2008; Scanlan 2009). Numerous studies have investigated issues of access to healthy food and provisioning venues, describing such phenomena as the “food desert” (Morton et al. 2005); disparities in the price of food; and differential access to healthy food based on age, ethnicity, and geographic location (Ball et al. 2008; Donkin et al. 1999; McKie 1999; Power 2008). Others have closely examined how various subpopulations of the global north shop for and prepare food (Foley 2010; Gerbrandt 2009; Hall et al. 2003; Wiig and Smith 2008; Zick and Stevens 2009). One thing each of these studies makes abundantly clear is that grocery shopping is work, though we rarely treat it as such and often fail to recognize the vast amount of knowledge, preparation, time, effort, and agency it takes in our everyday lives. Findings by Aylott and Mitchell (1998) suggest that grocery shopping is the most stressful type of shopping for a variety of reasons, including time constraints, store environment, and the potentially large number of other shoppers (684). DeVault (1991) explains that grocery shopping is “a complex, artful activity that supports the production of meaningful patterns of household life by negotiating connections between household and market” and that it can be “a cruel task, fraught with anxiety and frustration, especially for those with inadequate resources” (59). Koch’s (2009) institutional ethnography of grocery shopping provides a detailed account of the multiple tasks involved in buying food, including planning, budgeting, choosing appropriate foods, scheduling the shopping trip, loading and unloading groceries, and more. Clearly, this is not a simple matter of going to a store, putting a bunch of things in a cart, paying, and going home.
Preparing for Shopping

For participants in this study, planning and strategizing are often part of their pre-shopping routines, especially for those with limited incomes or physical and mobility issues. Making lists of needed and desired items was one popular way of planning what to buy. Maria and her partner, Max, for example, would write an extensive list of items and their anticipated costs before going shopping. Once at the store, they faithfully adhered to the items on the list, only altering it if an item was on sale. For example, during the shopping trip on which I accompanied them, cat litter was unexpectedly on sale, giving them five dollars of leeway with which to buy some strawberries—a rare indulgence during the winter months when such fruits are more expensive due to their high shipping costs from the south. This type of planning requires a built-up knowledge of the store’s stock and prices. Maria and Max knew, from shopping at the same store for several years, how much they should expect to pay for each item on their list. This reduced the incidence of unexpected costs and allowed them to plan appropriately according to their budget.

Even planning the exact day of the shopping trip proved an important strategy for some. Seth has been receiving income from the federal and provincial disability programs for nearly 20 years and has a monthly income of $1380. Over time, he became well-versed in the sales cycles of the grocery store in his neighbourhood and carefully plans his “big” shopping trips, which he carried out once per month:

*So, what I do is, when I get paid by Canada Pension and the province, I don’t go out that day and buy anything. I always make sure I have something in the deepfreeze, something in the fridge, so on that day I can stay at home, and not get into habit of, uh, going out, spending a whole bunch of money when it’s really, really pricey ... So that first Tuesday of the month, I go through and buy what’s on sale at Safeway. You know, sometimes they’ll have um, fresh chicken breasts on*
sale at Safeway once a month. They have frozen chicken breasts and then they have fresh chicken breasts—fresh chicken breasts come on [sale] a week later than the frozen ones. And so, when they come on sale, I buy enough chicken breasts on that sale day to last me for the month. So you have to be really careful with how you budget out your money.

“Pay day” for people on government income programs is the third Wednesday of every month. By the time the cheques come out, many people on income assistance are having trouble getting by financially and the temptation to rush out and buy food can be great. Seth’s strategy, to wait until the first Tuesday of every month to go grocery shopping, reflects a level of control over his finances and his eating habits, as well as his accumulated knowledge of the grocery store’s sales programs and policies. As he points out:

if you’re taking your pay on pay day and you’re running down to any store, regardless of what it is, and buying what you need for the whole month, chances are you’re gonna pay at least 1.5 times what you could pay if you were careful about it.

Other participants employed different preparation strategies. Adrian, who often lacks motivation to cook for himself, says he has to “psyche himself up” to go shopping by thinking of a food he really wants to eat. He then goes onto the website of his regular grocery store and looks for sales and other deals, checking to see if his target foods will be affordable and attempting to meal plan before he gets to the store. Cameron, who has an active social life, regularly tries to meal plan for the week with his partner George, noting that it can be challenging to coordinate their busy schedules around meals.

Getting to the Store

After the trip has been planned and prepared for, the next step is to get to the grocery store. This was simple for some but challenging and complex for others. Six of the twelve participants in the
study owned their own vehicle. “Automobility” as it has been called (Urry 2004), certainly makes provisioning much simpler to plan and execute. If one has a vehicle, one does not need to tie one’s schedule to public transit or worry about calling and waiting for a taxi. However, having a car brings up other issues, mainly financial ones, which most participants found troubling. Seth, for example, used his car almost solely for his provisioning efforts; because he lives close to other amenities, he walks as often as he can to save on fuel costs (and the potential for car repairs). Despite his efforts to drive as little as possible, Seth said that he “has driven around on fumes,” indicating that his income gives him barely enough to afford fuel, insurance, and upkeep. Similarly, Adrian uses his car to grocery shop, since he prefers to shop at a store that is not within walking distance of his home and because health issues make walking difficult at times. Adrian worries about how long his car will hold out before it needs major repairs that he will not be able to afford:

_I do have a lot of anxiety around the car. It is twenty-one years old now and I am concerned about what I will do when the fateful day comes. I guess I’ll just have to have faith that I will somehow be taken care of._

Kent and Cameron both share a vehicle with their partners; provisioning is easier than if they had no car but use of it must be constantly negotiated and scheduled.

Four of the twelve participants—Daniel, Allison, Maria, and David—lack a vehicle completely; Tome has a scooter, which is legal on roads where the speed limit is 60kph or less; a sixth, Darla, does not drive but relies on her husband when he is in town. For these participants, getting groceries can be a trying task and one that requires careful planning.

Maria and Max cannot afford a car and rely on taxi cabs to get their food; they budget the cost of the cab ($20 for both ways) into the cost of food for the month and do a “big shop” at a
large chain grocery store (Walmart) once per month. Maria’s health conditions proscribe the places she and Max can go, and for grocery shopping, this proscription is very specific. Because Maria has arthritis and neuropathy in her legs, causing pain, numbness, and a lack of balance, using public transit is an option they rarely choose. Their home is more than three blocks to the nearest bus stop, and the bus line runs past this stop only once every 15 minutes. If they missed a bus or if it were late and they had to wait, the pain in Maria’s legs would become unbearable. They shop at the Walmart because it is closest to their house (hence the taxi ride costs as little as possible) and because it offers its customers motorized scooters. Without one of these, Maria would not be able to walk around the huge store.

David has no vehicle and prefers to get around by bicycle. Cycling and other activities are important to David: his physical strength and endurance are an integral part of his identity and, since he refuses to take antiretrovirals, are also an integral component of his strategy for healthy living with both HIV and hepatitis C. At the same time, however, David acknowledges that getting groceries by bike can be cumbersome. He takes a backpack with him to the store and fills it, then hangs the extra grocery bags off the handlebars of the bike. In this fashion, he rides approximately four kilometres back to his home.

Daniel lives in Kelowna’s downtown area and is only two blocks from a chain grocery store, where he usually shops on an as-need basis, every couple of days or so. He walks there, but rides his bike almost everywhere else and takes the bus or uses his parents’ vehicle in the winter or to do big shops. Tome’s scooter allows him some freedom of movement but it can be dangerous when carrying larger items and is restrictive in terms of carrying capacity. He
considered buying a small car; however, the high cost of owning a vehicle coupled with the uncertainty around his future career made him decide against it.

Darla cannot drive, so her husband, Steve, acts as the primary driver in their household. Steve works as a long-haul truck driver and is out of town at least 12 hours per day, sometimes for many days at a stretch. When he has a few days off (and ideally is rested after driving long distances), he and Darla do a “big shop” at a large chain grocery store. Because Darla is First Nations and holds a status Indian card, they visit the grocery store located on the Okanagan Indian Band reserve on the west side of Okanagan Lake. Showing her status card means she doesn’t have to pay taxes on many items. Darla estimated that they do this every two weeks, spending about $200 each time. When Steve is away, Darla is unable to drive and avoids shopping if she can. Her health, like Maria’s, is severely compromised and Darla lives with arthritis, neuropathy, and advanced emphysema. Even walking at a moderate pace, she becomes pained and winded easily and must stop frequently to rest. If she is in need of food or another item, she sometimes calls upon members of her social network to pick up the item for her. Occasionally, she must walk the eight blocks to the grocery store nearest to her home and use a small wheeled cart to more easily carry her food and medications.

Allison’s lack of vehicle seemed the most pronounced of all the participants, given that she has three children. Allison grocery shops at a large chain grocery store approximately three kilometres away from her house. Like Maria, she usually does a “big shop” once per month, on or near pay day, taking a taxi to the store and budgeting in the cost of cab fare ($20 for two ways). For everything else, Allison and her children take the bus. They live close enough to the
children’s schools that they can walk or ride their bikes; however most other amenities are not within walking distance.

The Shopping Experience

Maria and Max work as a team, dividing up jobs during their grocery trips—Maria would call the taxi, Max helps her out of the taxi and gets her a scooter cart to ride through the store, while he pushes a regular shopping cart. She holds the list and directs him as to which foods to get. While he stands in line to pay, she goes to the pay phone outside to call another taxi to take them home.

The first Tuesday of each month, when Seth chooses to shop, is Safeway’s “customer appreciation day” and everyone gets 10 per cent off their final bill. Combining this deal with others available, one can save a significant amount of food money. I accompanied Seth to the store on one of these Tuesdays; he spent $210 and saved $100 by taking advantage of the day of the month and by using his club card membership and other in-store sales. Club cards, or “loyalty cards” as are they are sometimes called, are common in North American chain grocery stores (Patel 2008). Normally, at stores with a loyalty program, most items have a “regular” price as well as a lower “card” price. If you have a card, you pay the lower price. The cards are free—customers sign up for the program by giving some personal information and, in return, the store gets to track the shopping habits of its customers and target their advertising to specific sectors of the population (Patel 2008). Shopping with Seth showed his intimate knowledge of store sales, policies, and layout. He knew the exact place to look for the meat that was on clearance; for instance, frozen chicken breasts were on sale but he knew that the customer appreciation day the next month would offer fresh chicken breasts on sale, so he opted to wait a month to buy
chicken. He had also kept a “raincheck” in order to get frozen pizzas on sale, as Safeway had
sold out of them the previous month, and was able to buy ten pizzas for $7.00. Seth’s controlled
spending and eating habits had been developed over many years, starting in 1990 when he was
first diagnosed HIV-positive and living in Vancouver. At that time, his $425 rental payments took
up the majority of his $580 per month income from PWD. On such a tiny budget, he could afford
little food:

*I was getting, like, $580 a month in Vancouver. My rent was 425$ a month and so
I had a hundred and some-odd dollars to buy food. But in Vancouver there’s lots
of, uh, Asian vegetable markets, where you can buy really cheap stuff. And for a
year and a half I ate rice and beans every day for, I mean, seven days a week. The
two of them combined make a complete protein. And so, for vegetables, I had
potatoes and peas and a little bit of, uh, tomato, pasta sauce, I would mix in with
the rice and beans, and I ate that for a year and a half.*

Adrian’s way of shopping was equally disciplined but very different from Seth’s strategy,
in that he went shopping almost daily to avoid spending money on fuel for his car:

*By the sixth of the month, that’s when all my bills are due, so I pay all the bills and
then I divide the number of days left until the next cheque, then I know how much I
have and it usually runs between ten or, on a good month, fifteen dollars that I’ll
have daily that I can spend... So I’ve already seen the flyer for the week and I
know what’s on sale. Then I decide what I’d kind of like to eat that night. So let’s
say I pick a pork butt steak. Usually, they go on sale for $2.49 a pound and I can
get a big piece of meat for three dollars. So I’ll go and get that and I’ll buy a head
of broccoli, if I don’t already have some, and I have the potatoes, so I’ll come
home, I’ll barbecue it. That’s it—very fast, just hunt and kill shopper, like I don’t
wander the aisles because I know there’s things that I’ll see that I’ll want, that I
just can’t have. And uh, like, I’m addicted to potato chips and stuff like that but
there’s just no way.*

Another shopping strategy that reflects accumulated knowledge of store pricing is buying from
various stores according to the items needed and their costs. Although this could be seen as
“convenience” shopping (Westbrook and Black 1985) because it requires a higher level of
mobility (all participants who engaged in this practice had access to a vehicle), participants who
shopped at a variety of stores did so because they felt that, ultimately, the total cost of food was
less and they were able to get exactly what they needed and wanted every time they shopped.
Kent estimates that he and his wife spend $500 on food each month. Because she works full
time, much of the provisioning work is his responsibility and he has become adept at finding the
items he wants at various stores for the cheapest price possible:

**Kent:** I shop at Shopper’s Drug Mart for food ... I shop at Costco, Walmart, a little
bit at Coopers and a little bit at IGA.

**Interviewer:** Okay ... do you go and target those places for any specific foods?
You go to Shopper’s for something specific?

**Kent:** Yeah. I go there for butter, milk, peanut butter, crackers, canned beans ... ‘cause they always have them, like, way less [cost] than anybody else. Way less ... The other day, the peanut butter, the big one like this [demonstrates size] was $2.49. Everywhere else it’s five, six bucks. It’s even cheaper than Costco. And the butter was $3.29 or something? So I buy that there. The milk is less. It’s usually 50 cents less a jug ... You know, and over a period of time, I mean it’s five or six bucks a year but still ... it adds up.

It is notable that all of the stores Kent mentioned are within five minutes’ drive of his home, so
his driving costs remain quite low.

**Texts: The Institutionalization of Grocery Shopping and its Implications**

The tagline of Marketplace IGA’s corporate logo is “We make it easier for you.”

Walmart’s is “Save Money. Live Better.” Radio advertisements for Save-on Foods sing out
“more, more, more!” Themes of ease, choice, abundance, convenience, savings, and high quality
of life permeate the discourse of all grocery stores found in Kelowna, whether they belong to
large corporate chains or not. Appealing to customer emotions and particularly their sense of
“home,” is another marketing strategy. Cooper’s Foods, for instance, (a subsidiary of the
provincial Overwaitea Food Group Limited Partnership, which also owns the Save-on Foods
chain), says “Cooper’s People Care” and claims that it is “your community, your store” (2013).
The over-arching message of this discourse is that customers not only have the ability to easily and affordably get the things they need from these stores but also that they have control over what they buy and are able to buy ethically produced foods.

Many of the participants in this study relied heavily on coupons and regular in-store sales to get food cheaply. Analysis of the texts that regulate the work of provisioning on a budget reveals that this work can be time consuming and restrictive, not easy and convenient as advertised. Policies and rules around coupon use and other types of grocery sales can be extremely strict, seemingly intending that people not bother making use of them at all. The fine print on coupons is riddled with restrictive clauses that prevent any shopper from discovering loop holes and getting a better deal on an item. The weekly coupon flyer for Safeway, for instance, reads:

Not responsible for typographical or pictorial errors. We reserve the right to correct all printed errors. Any typographical error related to any product listed on this webpage will be corrected through a retraction posted in our stores. We reserve the right to limit quantities. Plus applicable taxes. None sold to wholesalers or retailers. Not all products, offers, retail services available at all locations. (Safeway, August 10 - 16, 2012)

The formal coupon policy from Safeway Canada is a two-page document with 31 points that detail how, when, where and under which circumstances coupons can and cannot be used. Some of the more restrictive points include, not accepting a coupon if it does not have an expiration date or if it appears “distorted, blurry or altered in any way.” The policy also “reserves the right to refuse any coupons at its discretion.” The last paragraph of the policy summarily states that the policy itself may be changed at any time, without advanced notice or advertisement (Safeway.ca; 2012:1-2). The overall language of the coupon policy is peppered with restrictive words: will not, will only, must and cannot appear 27 times in just two pages. A myriad of other words an phrases
related to control appear often as well: *subject to, limit/limitations/limited, refuse, reserve, threshold, requirement(s), minimum, maximum, rules, allow, expire, criteria, exceed, terms,* and more. There are very few times throughout the document in which words are used that balance out this restrictiveness but they are illustrative of the type of atmosphere that Safeway is trying to create for its customers: one of brand loyalty. These words include *reward, award, qualify* and *earn.* This makes people feel as though they are part of a greater body of citizens and, like obedient children, should work toward getting “rewards” for the good behaviour of shopping regularly and becoming members of the “Club.” Even the names of these programs—“President’s Choice Insiders Club” and “More Rewards”—point to the idea of being allowed special privileges in return for loyalty.

When compared with the actual everyday experience of the people in this study, the ideal of a loyal customer becomes enigmatic. For people on low incomes, loyalty to one store was never the result of simple devotion to a store for its ambiance or the brands it stocks. Rather, loyalty was based on convenience, price, and familiarity—but not with the store itself or the employees, rather with prices and policies. At the same time, for some, loyalty could be fleeting, as several people noted their propensity to “promiscuous” shopping behaviour if it met their needs for convenience and/or staying within the budget. McGoldrick and Andre (1997) state that loyal shopping behaviour results from five main factors: laziness, habit, time saving, convenience, and full enjoyment, and that promiscuity results from cleverness, dedication (to getting good deals), money saving, curiosity, time availability, time killing, and multiple enjoyment (75-76). My research shows that people with chronic health problems and low incomes do not fit nicely into either of these categories. None are lazy, nor are they in the “habit”
of shopping at the same place all the time. None expressed their “full enjoyment” at shopping solely at one store. McGoldrick and Andre discount the matter of constraint as being a factor in loyalty, which is evident for several of my participants: Maria, Seth, Allison, Eli, David and Daniel were all restricted by either low income or mobility issues such that they went to the same grocery store for nearly all of their food.

Another point of control is items that are actually available at lower prices. The Real Canadian Superstore’s logo tagline is “Big on Fresh, Low on Price,” a reasonable public relations slogan for a grocery store, at first glance. However, we would do well to remember that most grocery stores these days sell much more than food; places like Walmart and Superstore carry complete lines of clothing, household appliances, and yard and garden supplies. If one is only interested in food, we should ask, exactly how low the prices on fresh, nutritious food items are. The Superstore “grocery flyer” for the week of April 26–May 2, 2013, advertises 20 pages with 143 items. Of those 143 items on sale, nine were fresh vegetables or fruits, seven were fresh meat, and three were bread; thus, only 13 per cent of the advertised items could be considered nutritious for PLWHA. Much of the grocery flyer contained items that are not even edible, including beauty products, batteries, and decorative items (seven pages contained no food whatsoever). Analysis of the Safeway coupon flyer for August 10–16, 2012, showed that out of the 172 food items listed as on sale, only 36 of these (or 20 per cent) were in the categories of fresh produce, meat, or bread products. Walmart’s flyer for the same week lists 76 food items on sale, with only 31 (40 per cent) fresh; Save-on Foods listed 40 fresh food items out of 156 food items on sale (25 per cent).
Participants’ lack of control of what was on sale (and therefore control of what could be afforded) was made up for, in part, by a strict personal control, as described earlier—people made shopping lists and rarely deviated from their planned purchases; some resisted the urge to go out on the day they got paid and instead waited until the things they needed were on sale. Many simply did not ever buy many of the foods they would like to eat but cannot afford. Thus, despite the discourse from grocery stores about freedom of choice and ease of use, buying nutritious, affordable food can be anything but easy and convenient for someone on a limited budget, particularly if that person also struggles with health or mobility issues. The lack of agency that participants experience, when it comes to being able to buy whatever they want, whenever they want, highlights a disjuncture between the discourse of capitalist food systems and the everyday experience of PLWHA. Contrary to the popular notions of freedom, ease, convenience, and loyalty by personal choice, these participants experience a type of “coercive freedom” (Sheller and Urry 2000:739) in their provisioning. They appear to have options but are unable to take full advantage of them.

At the same time, the options they can take advantage of have strict limitations. As Marcuse states:

Free choice among a wide variety of goods and services does not signify freedom if these goods and services sustain social controls over a life of toil and fear—that is, if they sustain alienation. And the spontaneous reproduction of superimposed needs by the individual does not establish autonomy; it only testifies to the efficacy of the controls (1956:7-8).

In this way, the disconnect between the rhetoric of the grocery store and the actual work of shopping forms another double bind: participants are expected to find shopping free and easy but the experience is not like that. Rather, it is restrictive and difficult and, when they attempt to take
part in the programs that are supposed to make shopping easier and cheaper (such as loyalty programs or coupons), they run up against even tighter restrictions.

**Interpreting Landscapes**

Kelowna’s population has increased dramatically in the past few decades. The heart of the city’s road system is provincial Highway 97 (also named Harvey Avenue), which runs through the middle of the city, connecting it with Vernon (and eventually Calgary, AB) to the north and Vancouver to the south. Kelowna has become a strip mall city, with most of the shopping opportunities (grocery and otherwise) concentrated on or near the highway at various points.

Figure 3. location of Kelowna’s chain grocery stores. Adapted from City of Kelowna.

Figure 3 shows a map of central Kelowna, where most of the larger grocery stores are located. Although the location of these stores along main arteries seems convenient, it is important to note that most of the residential areas of Kelowna are in outlying areas, not along the highway. Thus, most participants had difficulty in getting to and from stores and lamented the need (or
desire) for a car. Nate explained this sentiment well when comparing his life in Kelowna to his life in Vancouver, a much bigger urban centre with more accessible public transit and more small neighbourhood food stores that he could walk to.

*Interviewer:* You used to live in Vancouver?
*Nate:* Yeah.
*Interviewer:* And you’d like to get back?
*Nate:* I would prefer to, yeah. I mean it’s, I think, there is more ... I think ... all in all life has been harder in the Okanagan. It’s more isolating, there’s not as many things to do or, maybe ... that may or may not be true, but at least I don’t live in the same way. Like, on a Saturday in Vancouver, you get up and you might go take a coffee at Starbucks, and you head to the ... I mean, you left to go, to the grocery store, you might be gone for three hours to get your groceries, right? Here, you get in the car you go there, you get it, you come home, it’s a different kind of pace, I think, and I prefer the city pace. And ...

*Interviewer:* Yeah, and it’s a car culture, too. Do you think that that makes a difference?
*Nate:* Yeah. Very much. I didn’t have a car in Vancouver. Walked everywhere. Right? And here, you get in, you go, you get in, you go. The car is part of your anatomy. I never liked it.

Marcuse’s writings on technological advances in late capitalist society confirm that, although things like vehicular transportation seem at first glance to be emancipatory, to many people, they encumber and hinder true freedom:

Technical progress is identical with the increasing elimination of personal initiative, inclination, taste, and need from the provision of goods and services. This tendency is liberating if the available resources and techniques are used for freeing the individual from labor and recreation which are required for the reproduction of the established institutions but are parasitic, wasteful, and dehumanizing in terms of existing technical and intellectual capabilities (1968:195-196).

As I pointed out in Chapter 1, agency in the realm of provisioning is largely taken for granted by people in affluent areas, and this is certainly reflected in the discourse put forth by grocery stores. However, as shown above, the participants in this study lack agency in
terms of when they are able to shop, how they are able to get to stores, and what they are able to buy.

The Food Bank

Another institution closely associated with food security in Canada is the food bank. With food insecurity concerns on the rise, food banks have become an increasingly normalized way of eating on a limited budget, which in turn normalizes poverty and hunger (Riches 1997). Food Banks B.C. (2011) states that “food banks were started over 25 years ago as an emergency measure to help during a deep recession. They have now become an institution” (2). Between early 2008 (just before the global financial crisis) and 2012, food bank usage increased 30.6 per cent Canada-wide. In B.C., the increase was 23.1 percent. More strikingly, from 2011 to 2012, when some provinces saw a decrease in food bank usage, B.C.’s rate rose by 6.6 per cent, three times the national average (FBC 2012:4). In March of 2012 alone, more than 800,000 people in Canada sought out the services of a food bank (FBC 2012:1). Riches (1997) describes the disturbing nature of food bank increase in the global north since the early nineties, noting that food banks do not change the root causes of poverty and hunger, but only mask them by providing “band-aid” solutions that cannot necessarily be counted on long-term. Thus, food banks cannot guarantee that hunger will be met: they are subject to donor fatigue and run out of food, they cannot necessarily provide nutritious or culturally-appropriate food, they depend on volunteers who cannot always be counted upon and people’s experience of having to ask for charity is often degrading and stigmatizing (70).

Food Banks Canada, a national charitable organization of Canadian food banks, itself acknowledges this and has recommended that several key issues be addressed in order to
decrease the need for food banks, including increasing access to affordable housing, increasing social assistance payments, ensuring adequate pensions for seniors, and working to reverse the decline in well-paying jobs (FBC 2012:14-17). Until the root causes of poverty are tackled, food banks will continue as institutionalized services, whether that is problematic for hungry people or not. A look at the regulation of food bank use in Kelowna via pertinent texts and the “landscape” of the food bank itself, shows how the food bank both facilitates and hinders food access for PLWHA, as well as how it marginalizes and makes invisible the people who get food there.

The Kelowna Community Food Bank (KCFB) has been in operation since 1983. It has strict regulations around who is able to access its services. Potential food bank clients must have been residents of Kelowna for at least three months; they must have an income of some sort (i.e. they must either be employed or receiving income from a government assistance program) and they must have valid ID (KCFB 2013). These requirements are not problematic for most people but it is important to note that they necessarily exclude the most needy in our community and allow plenty of people to “fall through the cracks.” For example, people who are out of work but not eligible for income assistance would not be able to use the food bank. People who are living on the streets likewise would not be eligible, neither would those who are new to town and/or have not yet found employment.

Although only one of my participants regularly obtained food from the food bank, it is important to analyze the activity of accessing the food bank for two reasons. First, several participants used the food bank in the past and plan to again, if they need to supplement the goods they can purchase. Second, as stated earlier, food banks have become normalized in Canadian society as a legitimate means to obtain food. Allison was the one participant who
visited the food bank each month to obtain extra food that she was not able to purchase. As a mother of three, she was able to access a food bank program for people with children. As a woman with HIV, she was also eligible for a program for people with special nutritional requirements. Allison expressed gratitude for being able to get extra food at the food bank and praised the food bank staff for being very nice to her each time she went in. Other participants who have used the food bank in the past were hesitant to say good things about it. Some mentioned the low quality of food (stale, or past its “sell by” date); others described the strict regulations on access and how they felt degraded just by going into the building.

Eligible individuals and families who become clients of the food bank receive hampers of food and other household goods (if available) once per month (there must be 30 days between visits). Allison takes the bus to the food bank once per month and gets driven home with her hamper by a worker from Living Positive Resource Centre. Allison appreciates this support from LPRC because there would be several heavy bags to haul to the bus stop and from the bus stop to her house. I went with Allison to the food bank in early February, 2012. We walked two blocks from her home in the cold weather and waited at the bus stop for about 10 minutes. The bus trip took approximately 20 minutes; she told me that not having a vehicle of her own and having to take public transport requires careful planning if trips are to be expeditious and worthwhile. She said it normally takes at least an hour and a half to go anywhere and get anything done using the bus. We got off at the downtown transit exchange and from there walked several blocks to the food bank and waited for it to open—Allison wanted to get to the food bank as early as possible, since people are seen on a first come, first served basis. We waited for 20 minutes but, had we taken the next bus, we would have arrived at the food bank well after its opening time and waited
in line much longer. The food bank is open Monday through Thursday from 9:30am to 11am for people with children and, from 11am to 1pm for individuals. These limited hours are almost certainly in place to reduce utility and staffing costs but one wonders what patrons do if they must visit the food bank and also work regular hours during the week.

When I visited the food bank with Allison, we stood just behind a stop sign (see Figure 4) while the case worker got ready to usher clients into his office to verify their status. Allison was the first to go in; the case worker looked up her name in his computer; asked if her income level was the same as it had been the last time she was there; asked if all three children were still living with her. This happens every time she goes to the food bank. After verifying her identity and status, he asked if there was anything “discreet” she needed—he keeps things like women’s sanitary pads, tampons, condoms, etc. in his office so clients don’t have to ask for them in front of other clients or food bank volunteers. Following the “interview,” we went into the main part of the building and collected her food. This is done in a very controlled manner, much in the same fashion as a cafeteria but with less autonomy on the client’s part. We gathered bags and boxes at one end of a long counter and then slowly moved along the counter, where food bank staff gave Allison choices of what she would like; they then filled the boxes for her.
The client is limited to certain types and numbers of each item and the staff member knows in advance what category of clientele each person belongs to. Being a person with special nutritional requirements and children to feed, Allison gets more food than a single person would and different food than someone with no special dietary needs. Clients are not allowed to get their own food, even though it is easily within their reach (in fact, most of it is right in front of them on the counter).

The food bank experience is an interesting dichotomy: on one hand, clients are able to scope the food and make their own decisions about which kind of a certain item they would like (e.g. peanut butter versus chocolate chip granola bars; bags of prepared salad with mixed greens...
or head lettuce); on the other hand, their choices are strictly controlled according to their client status, as well as by how much and what kind of food is on hand at the time.

Although food bank use in Canada has become normalized in recent decades, it is not necessarily an acceptable form of provisioning and most people are not eager to go and get food there. The strict regulation of when and how people are allowed to access its services is off-putting and challenging. For some, the idea of using the food bank is understandably degrading; certain aspects of the food bank’s placement and interior environment affirm this degradation. For instance, as seen in Figure 4, the stop sign placed at the front of the waiting line near the entrance implies that strict control of people’s behaviour is required in the food bank. Stop signs are, of course, used primarily to direct traffic and are necessary for avoiding car-related injury or death. When not being used on roadways, stop signs are typically used for situations in which failure to comply with rules could result in similar danger to individuals and groups. For example, we often see stop signs in construction zones, where workers and visitors are required to wear safety equipment; or in airport check-ins and customs desks, where national security and airplane safety are taken very seriously. In short, we associate stop signs with potential danger. Should this be necessary at the food bank? In a similar vein, on the bulletin board in the client services office are posters and brochures targeted to people who have addictions issues and have been exposed to domestic violence (see Figure 5).
To be sure, the literature on the board is there to help people but it can be alienating for those using the food bank who do not have those problems and certainly does nothing to stop the perpetuation of stigma around food bank use. Also, the placement of the food bank within the city is emblematic of the affluence/invisibility bind. The following photos show the stark progression on one downtown Kelowna street block from highly visible modern affluence to the far less visible food bank building which is arguably symbolic of poverty. The first photo is of a new condominium complex called “The Madison,” located at the south end of the block (in which, at the time of writing, a fifth-floor two-bedroom apartment rents for $2250 per month). The second photo gives a long view of the southern and middle part of the block, populated with high-end shops below and new apartments above (The Madison is the farthest tall building). The
third photo shows those same shops and apartments, with the food bank beside, tucked away off the street. Even knowing where the food bank is located, I often have trouble finding it because it is so invisible relative to the other buildings on the block. It is also significant that the neighbourhood changes distinctly at just this geographical point: on the other side of the food bank is a machinist shop and across from it is a night club. Further down the northern end of the street are a variety of light industrial companies that inhabit older and more run-down buildings.

Figure 6. The Madison, an apartment located to south of the Kelowna Community Food Bank (photo credit, Heather Picotte, 2013)
Figure 7. Ellis Street, Kelowna BC, looking south (photo credit, Heather Picotte, 2013).
My point with these photos is to show the dichotomy of affluence and invisibility in this part of town and further, to show how affluence pushes poverty to the margins. The food bank itself marks the boundary between the affluent southern end, with the library, museum, tea shop, jewelry store, high-end lingerie store and others, and the grungier northern end. There is literally very little space for people who are not wealthy in Kelowna and the spaces they often need to occupy are minimal and difficult to spot.
Growing Food

All participants were well aware of their nutritional requirements and knew the importance of the vitamins and other nutrients to be found in fruits and vegetables. Most participants noted that they tried to take full advantage of the summer growing season and ate more fresh fruits and vegetables in the summer than in the winter. Most also expressed the desire for more fresh produce in their diets, but said that produce can be very expensive and few of them had the space, time or energy required to grow their own.

Adrian was one of the few who did—he has a small raised bed in a community urban garden, five blocks from his apartment, where he grows tomatoes, chard, beets, and leeks. He says the work of gardening is largely enjoyable and the time it takes to maintain his plot is well worth it in terms of fresh produce gained and pleasant time spent outdoors. Cameron and his partner grow small amounts of fresh vegetables and herbs on their patio. Eli also has a small garden in his backyard where he grows strawberries, tomatoes, peas, carrots, cucumbers, and onions that supplemented his and Nate’s meals. Some participants make use of other people’s gardens and orchards. Daniel, for example, knows someone with a large garden and orchard and gets free produce each season from there. Allison, likewise, has neighbours who share the vegetables from their garden with her.

Although it seems that growing one’s own food would be free of institutional control, it is more challenging than we might first think. Perhaps because of the constantly expanding housing developments in Kelowna, community gardens are becoming increasingly popular in the city. Within Kelowna’s municipal boundaries, there are now nine community gardens—plots of land, usually half an acre to one acre divided into sections that individuals rent each season and are run...
by the Central Okanagan Community Garden association (COCG). In total, there are 284 plots (individual garden beds) in the city (COCG 2013). More are being added as demand increases, but such a limited number means that gaining access to a plot can be a lengthy process. Adrian registered with COCG in the autumn and was on a waiting list until late spring, when he was notified that a space had opened up at the site closest to his home. Community gardens are a relatively new phenomenon in the Okanagan, so COCG is still developing its guidelines and terms of use. They have rules in place for good reason—such as, to reduce vandalism and theft from the gardens—but it is institutionalized, nonetheless. It seems the only way to be free of institutional control with regard to food is to own one’s own property and grow it all there. But restrictions exist for this type of work as well.

Most people are restricted in a spatial sense: few participants owned their own homes, and, if they did, these homes were not single-family dwellings with space for growing food. Out of the twelve, only Allison lived in a single-family house with a yard, which she rents. She does not usually grow food there but said she’d like to in the future. The three people who owned their homes (Cameron, Tome, and Kent) lived in condominiums with little or no space for growing food. Cameron had some pots of herbs and tomatoes on his deck, as did Tome; Kent does not have the space even for container gardening. Eli and Nate lived in a mobile home with a small yard for Eli’s small garden.

Aside from space constraints, the most pervasive restriction on gardening was physical health. Allison’s main reason for not having a garden was a lack of energy. Maria and Max rent a duplex with a small back yard that could hold a garden but Maria’s health would not allow her to
Seth rents a house with little space for a garden but said he doesn’t want to invest the time or energy in gardening because of a previous negative experience:

*I moved and have a front yard and there’s really no spot there for a garden. I guess I could build one but the thing is, that little place that I had, had the backyard with the garden, I’d put in a lot of effort into making the yard look nice. When I moved out … I went back to look at it and it was extremely disappointing. Everything was dead and grown over with weeds and the lawn had never gotten watered or mowed. So, since then, I thought unless it was my own place, I wouldn’t spend too much effort other than keeping it neat and tidy.*

Seth’s words remind us that a “neat and tidy” yard is highly valued in North American society. Indeed, well-manicured turf grass lawns are the ideal yard feature in Canada and considered the norm for single-family properties in particular. Feagan and Ripmeester’s (2001) description of the evolution of lawns in North America is reminiscent of Veblen’s talk of class emulation: upper-class society in the early days of White settlement in North America sought to emulate the private land of the old country; subsequently, the middle class sought to emulate the upper. In recent times, according to Robbins and Birkenholtz (2003), rapidly expanding tracts of suburbia have contributed to a steep increase in lawns across the continent. Kelowna is no exception to this trend.

The post World War II period saw the lawn become even more deeply entrenched in the urban, and especially suburban, landscapes of the U.S. and Canada. The exodus from the city to the suburbs was a tightly knit weave of a more pronounced consumer culture, a retooling wartime industrial order seeking peacetime markets, and dramatic shifts in how work, leisure, citizenry and identity, and community were being articulated. It is not an exaggeration to claim that the lawn was an integral element in the fabric of these new social constructions. It reaches beyond its physical presence to emerge as an icon of communal order, a form of manufactured consent and a taken-for-granted cultural artifact…Hence, the lawn code is embodied both as a regulatory regime of industrial society as well as a sub-conscious (turned conscious when confronted) belief about the rightness and the naturalness of the lawn (Feagan and Ripmeester 1999:83).
The above quote shows that the appeal of lawns is rooted in very specific cultural and historical values and circumstances, of which today, we are only vaguely aware. In the matter of food security, the landscape itself becomes a tertiary injunction to the bind of shopping for versus growing food, one that we cannot immediately see because it is what most of us have grown up with and take for granted as normal. Although much of the literature around lawns centers on the work required to maintain them and the amount of resources poured (literally) into them (see Freeman et al. 2004; Robbins and Birkenholz 2003; Templeton et al. 1999), I would argue here that the lawn requires far less maintenance than a food garden and, thus, reproduces the hegemonic standard of grocery shopping as the main North American provisioning activity. By doing less “food work” at our own homes, we reinforce the need to be employed to earn an income to buy food. I would also argue that for many people in the global south, the luxury of owning private yard space with only a lawn, which is essentially devoid of purpose, is unthinkable.
The issue of class also comes up this situation: people who grow gardens are in a sense critiquing the status quo of buying food and hence are critiquing the people who fall in line with the status quo. Veblen would note that perpetuation of inequities based on socio-economic class require the lower and middle classes to emulate the upper and, in this locale, most of the upper class have meticulously-kept gardens, but not for food. See, for example, the photo in Figure 9, of a hedge and boulevard in one of Kelowna’s most expensive neighbourhoods. Although this emulation occurs, it is not necessarily freely enacted. According to Marcuse:

The efficient individual is the one whose performance is an action only insofar as it is the proper reaction to the objective requirements of the apparatus, and his liberty is confined to the selection of the most adequate means for reaching a goal which he did not set. Whereas individual achievement is independent of recognition and consummated in the work itself, efficiency is a rewarded performance and consummated only in its value for the apparatus (1982:142).
Food Management Strategies to Deal with Double Binds

Several double binds have been explored in the previous sections: having to exercise strict control over one’s eating habits, while simultaneously being told by grocery stores that one has all the choice and freedom one could want; living in a city in which vehicle ownership is crucial to provisioning but not being able to easily access public transportation because of physical limitations and inadequate transit service; attempting to use the loyalty programs at grocery stores when, in actuality, one cannot afford to be loyal to only one store because of high prices (or remaining loyal not because of an affinity for a store but rather because it is the only available option); wanting to take advantage of coupons and sales but still not being able to afford healthy food because the on-sale items are not edible; having to feel grateful for being able to patronize the food bank even though it actually feels degrading and is physically challenging to access; wanting (and many times, being willing and able) to grow one’s own food but being restricted either spatially or socially from doing so. All of these can be grouped together under the common “umbrella” bind of being forced to buy most food at grocery stores, not being able to afford food at these stores, and not having any other viable alternative for provisioning that is accessible or affordable.

Peripheral to the main work of obtaining food are several less visible types of activities that help people provision more efficiently and cost-effectively. Organizing and keeping track of food, a seemingly simple task, is one way some participants made more effective use of their food, which also kept them from buying too much unnecessarily. Adrian, for example, kept his spices and seasonings strictly ordered and in sight so he always knew how much he had of which kinds. This helped him plan meals as well, since he was always aware of the types of seasonings
he could use and planned dishes accordingly. He made space in his den for canned goods and, having that space available, could stock up on items when they went on sale or when he had a bit of extra money. Adrian also used techniques for stretching food that he called “cycles:”

*When I’m watching the flyers ... say, the smoked picnic will come on sale, it’s basically ham, like, poor man’s ham. When that comes on sale, I can get a big huge ham for between 8 and 12 dollars. I’ll roast that and I’ll have roast ham that night, then the next night I’ll have ham sandwiches, then I’ll have... who knows? Maybe I’ll have fried rice with ham in it, chopped up, because you don’t need much and then I’ll take the bone and some of the meat and I’ll make a split pea soup, which I’ll get three or four servings out of, so that ham turns out to be between 1.50 and 2 bucks a serving. So that’s very economical. And I also do a roast beef cycle and a chicken cycle. The chicken cycle goes with...I’ll buy one of those ... I’ll only get it at Extra Foods, they have the best one—it’s a barbecued chicken, already cooked (and the price has almost doubled recently) but they’re still good, I can still make it work. So the first night I’ll have the two thighs for dinner with some veggies; then the next night I’ll chop up one of the breasts, with vegetables, and have like, a chicken salad and then, the third night, I will take the two legs and the carcass that’s left with the breast on it, and make chicken noodle soup, and then I’ll have chicken noodle soup for like, three days, and I’ll freeze some. So that’s very economical too. And the third cycle is a roast beef cycle, but I’m kind of picky because I only like... prime rib. So Safeway has that on sale, it looks a bit expensive (it’ll cost me twenty bucks to buy it) and that night I’ll have prime rib—all I can eat. The next night I’ll have roast beef sandwiches and the next day I can either make beef stew or I can do another fried rice with the beef. So that also turns out to be quite economical.*

Cameron planned meals in cooperation with his partner. They sat down weekly and went through their mutual schedules, noting which one of them had an activity or event to attend. By knowing this in advance, little food was wasted and often they prepared meals in advance for busy nights so they didn’t have to “cook and run.”

Some participants bought goods in bulk quantities when they had the opportunity. One of the main reasons Eli shops regularly at a big box store is that it carries his favourite oatmeal in large quantities for a low price. Kent and his wife, as well as Maria and Max, buy large amounts
of fruit in the summer when it is cheapest and preserve it to store for winter. In the long-run, this was a cost-saving measure for the months when fresh fruit is so expensive. Adrian even mentioned that proper storage conditions helped to make food last longer and saved money:

I usually buy a little one [tub of sour cream] and the expiration date is a lie, because it can last quite a long time if you keep it sealed. I also run my fridge a couple of degrees below normal fridges and that helps a lot I’ve noticed. It really extends [the life of] food.

**Once the Food is Home: Eating**

Being motivated to cook and eat can be challenging, particularly when the variety of food is limited due to budget constraints. Adrian says:

> Because I can’t eat the same thing—like some people can make a pot of soup and then eat it for four days, until it’s gone, and I just can’t do that, cause I just get sick of it. So what I’ll do is: I’ll have it the one day and then I’ll eat something else the next day and then I’ll feel like the soup again and I’ll have the soup, and it costs me maybe 50 cents for a couple of fresh buns from Safeway. So that’s how I make it work out.

He called this technique “leapfrogging” and it worked in tandem with the “cycles” previously described—when he had a large batch of soup or fried rice, he could refrigerate or freeze portions so he had the option of eating different foods even when he had not been able to buy new items.

The seemingly simple act of eating food is something that healthy people often take for granted. Most participants, at some point since being infected with HIV, experienced difficulties in being able to eat. Usually, this was due to gastrointestinal upset caused by HAART. Although the appetite-related side effects of HAART are usually worse in the early days of one’s regimen (Reynolds and Neidig 2002:80-81) most participants said that stomach upset and diarrhea still happened occasionally and unpredictably. Under-nourishment happens for PLWHA as a result of
both macro- and micro-level processes. The macro processes are those described in the previous section, that is, the challenges faced in provisioning activities. The micro processes happen in individuals because HIV reduces the body’s ability to uptake nutrients. Another double bind then, is that of having difficulty obtaining food at a macro level (but doing it anyway because one must) and then having difficulty ingesting and putting to use the food one manages to obtain. For people living with HIV, nutritious foods are vital to maintaining a baseline of health-related quality of life.

Proper nutrition ... directly affects immune status, moderates the efficacy of medications, may reduce the severity of side effects, and can affect important outcomes, including quality of life and productivity (Sztam et al. 2010:213S).

Getting enough micronutrients is required for maintaining an adequate CD4 count and keeping opportunistic infections at bay. Vitamins A, B6, B12, C, D, and E have been implicated in higher CD4 counts due to their interaction with immune function and HIV replication (Gorbach 2005:1). Participants dealt with this in various ways. Some tried to eat normally and suffered the stomach troubles as best they could; others avoided eating at certain times so that they wouldn’t have to deal with unpleasant and sometimes embarrassing problems. The Radimer-Cornell Questionnaire remains a good tool for determining food security status from a macro-level perspective. However, it does not take into account the micro-level processes experienced by so many PLWHA. Future research might delve into these physical challenges to create additional questions for the Radimer-Cornell such as “In the last year, how often did you experience stomach upset upon waking?” or “How many times during a typical month do you avoid eating meals because of worries about diarrhea?” These queries would make the questionnaire more reflective of everyday reality for PLWHA.
Concluding Thoughts

The binds described in this chapter centered on the physical ability to obtain food. Participants often had trouble getting to stores, navigating stores once they were there, getting groceries home, and preparing and eating meals. Alternatives to grocery shopping—using the food bank and growing food—were equally, if not more cumbersome because of physical constraints and mobility issues. All of these challenges are connected to institutional, trans-local ruling regimes of one kind or another. The work of grocery shopping as a stressful but necessary task is linked to the global food system, an intricate and complex web of supply chains that span continents in an effort (according to corporate grocery store discourse) to make provisioning simple, efficient, affordable, and packed with attractive, healthy food choices. In reality, the global food system is anything but sustainable and for people living on the margins of health and affluence, it is highly restrictive and expensive.

Getting food at the food bank is also work regulated by institutions; not only the controlling policies and procedures of the food bank itself but also the control imposed by the physical structure, decor, and placement of the food bank building. These physical features are largely determined by overarching assumptions about who uses the food bank, what their needs are, and how they fit (or do not) into the city as a whole.

Growing one’s own food is less regulated by trans-local relations of ruling, but is very much controlled by cultural norms and patterns that we accept as normal and natural. The turf grass lawn is one example of how aesthetics in the urban environment, which developed over centuries, restrict creative, meaningful, and productive uses of land space and serve to label people who engage in such alternative activities as deviant. Therefore, PLWHA face not only
physical, spatial, and mobility challenges in their provisioning efforts but also a variety of unseen and taken-for-granted values that dictate how, where, and when provisioning work can occur.
Chapter 6: The Work of Affording Food

Because most people buy their food, rather than growing it, food security in the global north largely depends on income. It stands to reason that people with low incomes are more likely to be food insecure or hungry but the relationship between food security and income has many interesting facets experienced by most of the participants in this study. Nutritious foods tend to cost more than nutrient-poor foods. Thus, a person might be eating a sufficient amount of food but still not taking in sufficient nutrients. Being overweight and obesity are common results of this “hunger-obesity paradox” (Wiig and Smith 2008:1726). Kirkpatrick and Tarasuk (2003) note that nutritious foods such as fresh fruits and vegetables, dairy products, and lean proteins are the items most often left out of the diets of low income people. Healthy foods are more difficult to access in low-income areas of cities (Wiig and Smith 2008) and shopping for food is generally more difficult for people with disabilities (Gerbrandt 2008; Hall et al. 2003). Although such difficulties often have to do with issues of physical access to grocery stores and other venues, low income among people with disabilities also plays a role. The study of HIV-positive people in B.C. by Normèn and colleagues (2005) showed that 66 per cent of respondents who were food insecure had low annual incomes ($10,000 or less) and that low income is the “strongest predictor” of food insecurity with or without hunger (822-823). Galarneau and Radulescu (2009) found that people with disabilities earned up to 23 per cent less than people without disabilities, and that this earning gap increases the longer the disability persists (13).

Because HAART has become so effective at prolonging life among those with HIV, employment among PLWHA is likely more common than it was in the 1980s and early 1990s, when antiretroviral therapy carried more debilitating side effects. However, the experiences of
my participants did not correspond with this general trend. Perhaps because most participants were middle-aged and have had HIV for many years, employment was not the norm, partly because the effects of the virus had become serious impediments to activity and participation in the labour force. Only two were employed full time; the rest received income through government disability programs and other supplements or had no personal income at all. One of the main double binds around finances resided in the tension between holding gainful employment and leaving (or having left) work to collect disability income. Several participants expressed frustration with these two options and felt caught, because neither mode of income generation worked particularly well for their situations. Other binds existed according to varying circumstances, which I will detail in turn. The following sections are organized according to how people gained income: full-time employment, disability income programs (the most common), part-time employment (always as a supplement to disability income), and reliance on the income of others. Analysis of pertinent texts follows those sections.

Full-time Employment

Two participants, Tome and Nate, were employed full time. They considered themselves fortunate to have work and to be employed at workplaces that were unionized with good benefits packages. Both of their incomes were average (around $3000 per month), but the stability and security made up for the wage. It is unlikely either Tome or Nate would be employed in a non-unionized setting, since their ability to maintain consistent, productive working hours was regularly compromised by physical health issues. Both of them found this a source of internal and external (or perceived external) tension. Tome, for instance, works at a social service agency that helps people with chronic health issues. Because of the setting, he can be open about his poz
status and has the support of his colleagues; however, he said he doesn’t want to “look sick.”

Maintaining the facade of being well when one is not, is quite stressful and, indeed, amounts to “work” in itself. When I was employed at LPRC, three of the staff members were HIV-positive and were obviously unwell on a regular basis. Frequent and sudden trips to the washroom because of gastrointestinal upset were common, especially in the mornings. Sometimes they looked under the weather due to lack of sleep; sometimes they came in later than their normal start time. Maintaining a happy, healthy face is not always possible, nor is explaining why one is having trouble maintaining the façade of wellness. Tome explained that he preferred to take his HIV medications at night for this very reason:

*I like to take my pills then. Then I’m not entering an active day where, if something happens due to the medications, I don’t have to deal with it in front of other people. Very vain. You don’t wanna look sick. I mean, sometimes I feel sick but I don’t wanna look sick.*

Despite his efforts to seem well, Tome felt frustrated that his coworkers might think he was just being lazy, when in actuality he was feeling ill or depressed. His particular double bind (and that experienced by many other PLWHA) was composed of a primary injunction that says if we work, we must work to our fullest potential; a secondary injunction that says sick people should actually appear to be sick, not healthy; and, a tertiary injunction created by societal expectations (not immediately clear because we take them for granted) that says, being ill is not something we like to see or discuss.

Nate experienced the need for a healthy pretense more acutely than Tome because he felt that disclosing his poz status to anyone in his office would have caused him to be discriminated against. At the time of this study, Nate was in the midst of applying for a transfer to his company’s Vancouver office. This finally happened a few weeks after I interviewed him but the
process of applying for transfer and appealing the original denial of his request had been going
on for years. In the meantime, his CD4 count had gone quite low (below 300); despite adhering
to his medication regime and eating regular meals that were as healthy as possible, he was unable
to raise the CD4. He was always tired and found the job was draining him. The Human
Resources person, to whom he appealed his transfer case, knew he was positive but he had told
no one in his own department, even after taking medical leaves of absence twice in two years.
Even though he had legitimate cause to take time off work, he suspected that his colleagues
thought him lazy or just easily stressed out. This specific situation caused him even more stress,
in addition to the routine stress he experienced as part of his job, as described below:

I find myself ... I have to really ... what’s the word? psych myself for peak periods.
Like, I’m already dreading the thought of September coming, for example. And,
when I’m in it, it’s like, oh man, I got another two months before I even get a
break, you know. And the office, where the negativity ... I go home, and I’m
zonked. I mean I eat and I just zone out for two hours.

Employment, food security, and virus progression are linked through stress. Stress
experienced on the job can exacerbate HIV symptoms, which leads to necessary time off for
recovery. This can lead to decreased pay (particularly in unstable, non-union jobs or those with
employers who refuse to follow labour standards and codes of best practice), which leads to lack
of money for food, which leads to poorer nutrition, which leads to more stress, more symptoms,
and so on. With HIV, “sudden exacerbations of illness [are] interspersed with long periods of
relative wellness” (Portillo et al. 2007:260). In this way, HIV is cyclical, meaning that its
symptoms affect the infected person in “waves.” These waves of symptom experience can
fluctuate in intensity and, at times, do not correlate neatly with any physiological markers such
as immunologic status (Holzemer 2002:50). Research (for example Cohen et al. 2007; Evans et
al. 1997; Zorrilla et al. 2001) suggests that stress can contribute to an increase in negative effects of HIV. Stress alone (i.e. when disease factors and demographics are controlled for) is associated with increased viral load, decreased CD4 count and faster progression to AIDS (Lesserman 2008:539-545). Poor nutrition can have similar effects on PLWHA. According to Oguntibeju and colleagues (2007),

changes in the immune function due to malnutrition are strikingly similar to those induced by HIV/AIDS. In fact, for many years, the impairment to immune function caused by malnutrition has been referred to as the Nutritional Acquired Immune Deficiency Syndrome or NAIDS ... Since normal immune function is dependent on good nutritional status, some researchers have come forward with the hypothesis that malnutrition is the predominant underlying cause for the full clinical expression of AIDS in HIV-seropositive persons ... inadequate nutrition may influence specific systems involved in the progression from asymptomatic HIV infection to the full-blown condition of AIDS, as well as intensify the susceptibility to opportunistic infections and may also contribute to the severity of HIV-related disease (4329).

Consequences, both physical and financial, of the overlap between stress and poor nutrition for PLHWA cannot be underestimated and makes food security a vital component of wellness. Thus, not only is HIV itself a cyclical disease but also the socio-economic environment of many PLWHA contributes to a cyclical experience of the disease. Too often, physically and financially, the cycle takes the shape of a downward spiral.

Other aspects of living with HIV made full-time employment difficult for Tome and Nate. Both described how problematic it is to maintain wellness in the ways that people are normally expected to do, because their waking hours revolved primarily around their paid work. For example, PLWHA in British Columbia have their anti-retrovirals paid for through a provincial health program run by the B.C. Centre for Excellence in HIV (BCCE). The BCCE, located in Vancouver, dispenses the drugs to certain pharmacies around the province, which in turn,
dispense them to patients. In Kelowna, only one pharmacy controls the dispensing of HIV drugs. In order for PLWHA to get their medications, they must have blood tests every three months for viral load and CD4 count. Appointments must be made to pick up ART. Simple re-fills are not allowed, presumably because of the highly fickle nature of the medications. If antiretroviral therapy is not taken exactly as prescribed, the virus can adjust and become non-responsive to the drugs; as per Fong et al. (2003), “A ≥ 95% adherence rate results in a virologic success of > 80%, while the success rate drops to 60% in patients with 80–94.9%” (137). If tolerance develops, the prescription needs to change and, because the number of HIV drugs on the market is limited, the discussion around “adherence” or “compliance” is a mainstay of HIV patient care. Generally, PLWHA are also encouraged to see their physician as often as they get their blood tested. Tome and Nate both have the same GP, who works at a street outreach clinic and is well known as an “HIV aware” doctor and an accessible alternative to the hospital-based HIV specialist in Kelowna (which will be discussed further in Chapter 7). Tome and Nate have satisfactory relationships with this doctor but found it difficult to schedule appointments, given their working hours closely approximated her schedule. Both said they didn’t want to make waves with their co-workers by darting out of the office during the work day to keep appointments.

*Nate:* Of course I have to go for bloodwork every, uh, three months and if you don’t they won’t give you your medication [chuckles]. And that’s another thing, you know. You can’t get your medication ... you have to go to the drugstore, even to pick up something that’s already prepackaged, you have to take time off from work to go...

*Interviewer:* Because you can only get it at RX Pharmacy?

*Nate:* Right.

*Interviewer:* So that’s a pain for you.

*Nate:* Yeah. And they don’t, they won’t give it to me on Saturday.

*Interviewer:* And will they deliver it to your house?

*Nate:* No. HIV ... I mean it’s a manageable disease but, if you’re a working person, everything is stacked against you.
Tome echoed these sentiments:

*They [these institutions] operate on a lot of assumptions. The assumption is that you’re going to be able to go to an appointment whenever they say you should go. ‘Cause you don’t work. The assumption is that you come when we want you to come. And that creates problems at work because, right now, we don’t have the number of staff we had, so I can’t just make a doctor’s appointment and go. It’s harder.*

The very fact that doctor and pharmacy services are available only at certain times of the day and week is an inconvenience for any person who works a full-time job. However, people with chronic illness usually have to make appointments with health care professionals on a more frequent basis and this could serve to marginalize them in the workplace. As Tome stated, the way this system works suggests that the institutions regulating these facets of life assume that making and keeping appointments are simple tasks for PLWHA to carry out. More specifically, it suggests is that PLWHA are not expected to be employed. This is contradictory to the rhetoric that HIV has become a “manageable” disease, which will be discussed in depth in Chapter 8.

In addition to the logistical complexities of making and keeping appointments, there are value judgments and expectations surrounding PLWHA and sick people more generally, which add to the barriers and binds PLWHA face in employment. What this essentially comes down to is the inability to fit neatly into either the healthy or the sick role. Renowned sociologist Talcott Parsons was the original theorist of the sick role, a functionalist concept that attempts to reconcile the needs, rights, and responsibilities of sick people with those of society at large. An overview of the sick role breaks down the components of this bind:
1. Ill people are exempt from their normal social responsibilities such as work or domestic labour. This exemption requires some form of legitimation from doctors or those in medical authority.

2. They are not held responsible for their condition and cannot be expected to recover by an act of will.

3. Ill people must want to try to get well—if not, they can be accused of malingering.

4. Ill people are obliged to seek and co-operate with medical practitioners to help make themselves well again (Bissell et al. 2002:61-62).

The first point, that ill people are exempt from work, makes full-time employment difficult for PLWHA because of the cyclical nature of the disease. Tome and Nate can work when they are well enough to work but cannot when they are not well enough. Full-time employment, however, does not allow for people to work only when they feel like it and, the fact that HIV disclosure might create or exacerbate discrimination, makes working around one’s good days nearly impossible. Adding the fact that, in order to fill the sick role, one must “look the part,” furthers the problem: as Tome expressed, in some ways, he does not want to look sick, even when he feels so.

The second point—that sick people are not held responsible for their illness or are expected to recover by an act of will, is at odds with the very nature of HIV. As an incurable disease, PLWHA will never recover, even though they can “manage.” The idea of not being held responsible is also not realistic for many PLWHA. Segall’s (1976) breakdown of the differences between the medical sick role, as originally put forth by Parsons, and the psychiatric sick role, show a more nuanced view of the sick versus healthy dichotomy and illustrates that not all diseases are valued (or de-valued) in the same way. Whereas the medical sick role allows an individual to be free of personal responsibility for being sick (and thus, not expected to fulfill his or her regular social obligations), Segall notes that these rights “apply directly to physical
conditions but not to psychophysical or psychosocial conditions ... the extent of societal agreement about admission to the sick role decreases as the social and psychological aspects of the condition increase” (1976:163). HIV carries several social elements. First, it is an infectious disease spread by close contact between individuals. The main routes of transmission for HIV in Canada are anal and vaginal sex and injection drug use (PHAC 2011), so people must be their naturally social selves in order to contract the virus. However, sex (anal sex in particular) and injection drug use continue to be highly stigmatized acts in Canadian society. If “admission to the sick role decreases as the social and psychological aspects of the condition increase,” then PLWHA’s admission to and maintenance of the sick role is tenuous at best, because so many are blamed for getting the disease in the first place. Sympathy and accommodation for regularly (or cyclically) being sick during work is less likely for PLWHA than for someone with a disease whose origin was unknown or uncontrollable.

The third point, that sick people must want to try to get well is again at odds not only with the fact that HIV is incurable but also with the way in which HIV is manageable: PLWHA can only live a somewhat normal life by regularly taking HAART, which does control the virus in the body but, can also make the patient quite sick. In this case, the only way to “get well” is to take pills that can increase un-wellness: another double bind. The fourth point, that sick people are expected to cooperate with health professionals to get well again can be problematic for PLWHA who work full time, for logistical reasons, as articulated by both Tome and Nate.

In the next sections of this chapter, I further explore how the healthy role and sick role remain double binds for PLWHA in the realm of income, with slight variations depending on participants’ specific circumstances.
Government Income Programs and Supplementation

Although earning money through paid employment is the norm for most people in Canada, the most common means of getting money for the participants in this study was from government programs. In Canada, there are several such programs, including Canada Pension Plan, Canada Pension Plan Disability (CPPD), Employment Insurance (EI), and Medical EI. British Columbia has its own income programs, including Persons with Disability Designation (PWD), Persons with Persistent Multiple Barriers (PPMB), and basic income assistance, otherwise known as welfare. For my participants, the PWD program was most common, although some people were on CPPD or a combination of PWD and CPPD, as it is possible to get monies from different programs simultaneously.

The main barrier to food security these income programs create is that they provide recipients with so little money on which to survive. The basic amount for a single person on PWD varies but averages around $900 per month (Gerbrandt 2008:2). In the Okanagan Valley, this is usually not enough to even pay rent for a small apartment.7 The three participants on PWD who were not in spousal relationships could not afford to live on their own and were living with roommates or family members. The amount received from the federal CPPD program varies, since it is based on the amount of money put into one’s pension fund during working years.

7 The Okanagan has been experiencing higher housing costs than the provincial average, particularly for rentals. In 2005, more than 47 per cent of renters paid more than 30 per cent of their income on housing costs (BC Stats 2010:3). Between 2001 and 2006, the average gross rental payment in Kelowna went from $730 to $878, an increase of 20.3 percent. The BC average gross rent only increased by 10.4 per cent during the same period. The cost of home ownership was only slightly more, with average owners’ payments in 2006 at $992. However, housing prices increased dramatically between 2001 and 2006, with a jump of 23.1 percent. The average house price in Kelowna also increased a staggering 99.9 percent in those five years (from $188,173 to $376,151, while the BC average house price saw a steep but lesser rise of 81.5 per cent (Statistics Canada 2013:1).
people have not been employed regularly, they are not eligible for CPPD at all (Service Canada 2013). Because these programs provide so little, recipients must often choose between necessities; in the literature, this is sometimes framed as the “heat or eat” dilemma in which people are forced to pay either for rent and heat or for food (Beatty et al. 2011; Bhattacharya et al. 2003; Cullen et al. 2004). Adrian experienced this first-hand during the winter of 2012, when his rental subsidy from BC Housing was cut by $105. He did not turn on the heat once during the cold months. At the extreme end of the heat or eat dilemma is the inability to pay for housing at all, let alone the ability to pay for heating it. Numerous studies emphasize the need for secure housing in order for health-related quality to life to exist at all (see Atherton and Nicholls 2008; Rog 2004; Tsemberis 2010) and forms the crux of the “housing first” model of care for vulnerable people. Being safely housed is also linked closely with increased food security (Miewald 2009). Although only one of my participants experienced homelessness during the study (David lost his housing for a period, but was safely housed when I interviewed and followed up with him), all except Cameron felt that their living situations were precarious to some degree; it was this uncertainty that partially contributed to the psychological component of their food insecure status.

Essentially, the bind of being on a disability program is that the income is so low one cannot afford to be housed in a safe, healthy place, buy healthy food, pay bills or engage in any normal social activities all at once. Rather, people are forced to choose and healthy food often does not get chosen. Because PWD and CPPD are given only to those people who are unable to perform daily living requirements, PLWHA on these programs legally cannot engage in employment that pays more than the allowable income exemption ($800); however, the income
they receive is so minimal that having any quality of life requires making more than the allowable amount. As shown later, in the text analysis portion of this chapter, the requirements and restrictions for people on PWD in particular create further binds to this situation.

**Part-time Employment**

Four participants who were on government disability income—Seth, Daniel, Eli, and David—manage to take on part time or casual work when they are physically able. PWD regulations stipulate that those on the program are allowed to earn an extra $800 per month or $9600 annually from employment (Government of B.C. 2012). CPPD regulations are slightly more restrictive, allowing recipients to earn up to $5000 (gross) annually (Service Canada 2012:8). If a person is getting approximately $900 per month from PWD, the extra allowable amount can almost double their monthly income. From a food security perspective, this is a good thing; however, there are a few barriers to taking advantage of this system.

First, the type of work predominantly available in the Central Okanagan is not easily attained or maintained by most PLWHA. Statistics show that, like most of British Columbia, the Central Okanagan’s labour demand primarily comes from intermediate and lesser skilled occupations (at 43.7 per cent). This category includes the hospitality industry, which is steadily growing (in 2006 the accommodation and food services industry employed 13,300 people, or 8 per cent of the labour force) (Our Okanagan 2010:13). Among professional occupations, the region employs fewer people than the provincial average in education, health care, arts and culture, and government positions (which are also more likely to be unionized), and more people in skilled trades, sales, and services (which are less likely to be unionized). Construction
accounts for 11.6 per cent of the labour force, which is four per cent higher than the provincial average (BC Stats 2008). These trends suggest that the labour market is ideally geared to people who are physically fit and who have been recently trained in trades and service skills. The fact that most of these jobs are in the private sector and are non-unionized, also makes it more likely that those in need of health and dental benefits, flexible working hours, and provisions for long-term disability or pensions, will be excluded.

Second, the work of maintaining employment, if one has managed to secure it, can be challenging. David’s situation was a vicious cyclical bind of not being able to get to job sites because he couldn’t afford the transportation required and not being able to make money to afford the transportation to get to job sites because he couldn’t afford the transportation required, because he didn’t have a job, and so on. When I interviewed him, he was trying to do casual labour jobs a couple of times per week but getting to a job several kilometres away from his home, by bicycle, with the necessary tools and then being expected to work at heavy manual labour, was not realistic.

Eli receives income from CPPD, but collects bottles and cans for recycling refunds every summer. He says he can make up to $6000 in one season, which contributes to his food security. Bottle money is paid in cash at recycling depots in the Okanagan, so Eli isn’t forced to claim it as income. Still, like so many employment opportunities in the Valley, collecting bottles and cans is hard work and time consuming. Eli can only do this when he is feeling well.

The constraint of only making $800 per month over and above what PWD distributes, places some people in a legal and moral bind as well as a financial one. Daniel is on PWD and receives the upper limit of approximately $1100/month. Often this isn’t enough to eat healthily
and so, being a journeyman carpenter, he takes on casual building and maintenance jobs that he gets through word of mouth. Most of the time, these jobs pay under the $800 limit and are paid in cash. However, when I last spoke with Daniel, he had gone to another city in the north of the province to work more steadily and make more money. When I asked if he had stopped receiving disability payments, he told me that he would stay on them until he was more certain of the longevity of his employment situation. This is another bind: a person has the opportunity to earn a good wage, but if s/he is found out, the government will stop payments. For people with chronic, cyclical illness, working while feeling well should be an option. It is entirely probable that at some point, Daniel’s HIV will cause him physical problems necessitating he leave his paid employment. When that happens, his disability income should be immediately re-instated. As it stands, if someone goes off PWD, they must re-apply after a certain amount of time has passed. If Daniel returned to Kelowna, unable to continue with his job and had no PWD, it could take months to get it reinstated. With no proof of income he would be ineligible to use the food bank. Also, if a person falsifies the report of his/her employment situation, there are serious financial consequences. According to the *PWD Act*:

(3) A person who commits an offence under this section is liable on conviction to a fine of not more than $2 000 or to imprisonment for not more than 6 months or to both.

(4) If a person is convicted of an offence under this section, in addition to a penalty that may be imposed under subsection (3), the court may order the person to repay the government all or part of any amount that person received under this Act as a result of committing the offence.

(5) If the court makes an order under subsection (4) and the amount ordered to be paid is not paid immediately, the government may file the order with a court in British Columbia that has jurisdiction (EIAPWD 2012:1)
B.C. policy analyst Seth Klein (2012) notes that, only five per cent of people on PWD actually claim any of the allowable income; fewer still claim the full amount on a regular basis, so very few of the PWD recipients benefit from these income exemptions. Indeed, the whole notion of being employed is at odds with the premise of PWD, which only accepts people whose disabilities make daily functioning either difficult or impossible. If people are categorized as “employable” at some point during their enrollment in the PWD program, they face a bind in which they are simultaneously expected to work and be kept poor. They also endure a certain amount of cognitive dissonance regarding their health status that further exacerbates the sick role vs. healthy role conundrum.

Reliance on Others

A few participants lived in situations of either full or partial reliance on another person for income. Eli, for instance, consistently tried to have a roommate in his house to offset costs and indirectly increase funds. Daniel did the same by living with his parents temporarily. Cameron had his own steady income through his previous employer’s long-term disability (LTD) fund, but his standard of living was greatly increased by his partner’s employment income. Kent was in a similar situation, with LTD income supplemented by his wife’s paid employment. Darla, however, was in a far more precarious position. Her husband is the sole income-earner and makes quite a good wage as a long-haul trucker. Unfortunately, their debt is high and most of his income goes to repaying what they owe and covering bare necessities. Because they are honest about being married, she is left ineligible for PWD. Many couples get out of this bind by claiming to be roommates so they can both collect PWD. They generally opt to live in a two-bedroom apartment so that the roommate relationship appears genuine if a government worker
were to check in. In typical double-bind fashion, the ability to collect two cheques increases individual income but also increases rental costs, thereby reducing total household income. The bind of Darla’s situation and others like her is that she is financially punished for creating supportive connections and attempting to be more efficient in saving money. Government income programs do not encourage people to seek useful support but, rather, to live in isolation, both financially and socially.

Text Analysis

There are several common texts with which PWLHA are forced to interact in order to obtain income and thus, be more food secure. Most commonly, people encounter government forms and policies as texts that regulate everyday activity. This section analyzes parts of two government texts: the application form for PWD and its supplement, the Monthly Nutritional Supplement (MNS).

Filling out the application for PWD cannot happen until one has the application form in hand, which in itself can be tricky for people with chronic illness and limited mobility (Gerbrandt 2008:1). An applicant can only get a PWD application form in person from the Ministry of Social Development (MSD) office or by mail. An MSD worker must sign and date the form, and hand it or send it to the applicant personally. Furthermore, the applicant must be a client of MSD before s/he can apply for PWD. Generally, this means that the applicant must already be receiving regular income assistance (i.e. welfare), which is available only to those in a very low income bracket. In other words, one’s financial need has to be legitimized and documented by the state before what I will call, one’s “physio-financial” need can even be
considered by the state. These needs are not the same, nor are they evaluated in the same way; one is purely financial and one is purely physical, yet the former is a prerequisite for the latter.

Filling out the application once a person has it, is a daunting process and this has much to do with the length, structure, format, and language of the text. The application is a total of 24 pages. The first page simply asks for the name and contact information of the applicant. The following page and a half provides space for the applicant to talk about him/herself. The first question is “Describe your disability.” The second question is “Describe how your disability impacts your daily functioning.” (MSD 2005:2-3). Interestingly, these sections are optional—the applicant does not have to fill them out if s/he doesn’t want to. The fact that this section is optional might, admittedly, lessen the stress of completing the application, as some people have difficulties expressing themselves in writing. However, at the same time it serves to privilege the professionals’ knowledge of the applicant over the applicant’s knowledge of him/herself.

The rest of the form asks questions of the applicant’s physician and the applicant’s “assessor;” these sections are mandatory. A family doctor or a specialist who is familiar with the applicant’s situation is the preferred person to fill out the physician portion; this requires the applicant to have a family doctor, which is increasingly difficult in the Okanagan (the shortage of General Practitioners will be discussed in the next chapter). Once the physician section is complete, the assessor section can be done. The assessor must be someone who holds one of seven professional designations: social worker, nurse, nurse practitioner, physiotherapist, occupational therapist, registered psychologist or chiropractor (MSD 2005). The applicant’s physician may act as the assessor if necessary or desired. The physician and assessor portions of the form are largely composed of closed-end questions and check-boxes and there is some
overlap in the subjects covered. A great deal of technical jargon is used in order to specifically define who is disabled and who is not. Words and phrases such as *diagnosis, designation, criteria, defined as,* and *refers to* appear 87 times throughout the text. In addition, there are 14 explanations or definitions of words such as *impairment, daily functioning, treatment, assistance,* and so on. These definitions are found 14 times in both the physician and the assessor portions, and so appear a total of 28 times.

The jargon, the length of the form and the detail of questions asked can all be challenging for applicants. In theory, the form should be filled out in cooperation with the physician and assessor but many doctors do not make long enough appointments to go over the form in a careful and detailed way. This can impact the success the application. Furthermore, many physicians and assessors are unaware of the specific criteria MSD uses for approval of PWD applications. If they knew more about the criteria, they might take more time with the application form and might have their patients’ applications approved more often. Referring back to the first characteristic of Parsons’ sick role, that sickness needs to be legitimated by a medical authority, we see another bind in the disconnect between what is expected by the Ministry of Social Development (not a medical authority) and what is normally accomplished by applicants and their doctors.

The Monthly Nutritional Supplement (MNS) is an add-on program for people on PWD. It is given to recipients who need extra money for healthy food items because they are living with a “chronic, progressive deterioration of health” that causes such conditions as malnutrition, wasting, muscle mass loss, or neurological degeneration (MSD 2013:2-3). The MNS provides *up to* $200 per month of extra income; the “up to” caveat is important. MSD adjudicators decide
how much of the MNS an applicant needs, based on the information provided on the application form. If an applicant is approved, the money is expected to be spent on healthy food items and nutritional supplements such as vitamins, minerals, and protein drinks. Prior to April 2010, the MNS also gave $20 per month for bottled water but that fund has since been cut. The changeable nature of programs like the MNS can, of course, be linked directly to the whimsy of government power. Prior to 2010, when the B.C. Liberal government made significant cuts to health and social services, the MNS provided $220 per month to all successful applicants. Anyone who applied and was approved automatically received the full amount, bottled water supplement and all. As well, the application form at that time was less restrictive. Prior to 2010, applicants had to fit into one of two categories and their doctors had to provide evidence of one or more persistent conditions within that category. After April 2010, an applicant had to show evidence of two or more conditions and bone density loss, common for some PLWHA, was cut from the list of approvable conditions.

This was not the first time such cuts happened. In 2001, the Liberal government abolished Schedule C, the nutritional supplement that was the precursor to the MNS. Schedule C provided $225 per month to persons living with similar conditions covered by the MNS (Guay 2001). The Federated Anti-Poverty Groups of B.C. called the cutting of the Schedule C an abandonment of government commitment to health care that would cause harm to people in desperate health circumstances (Guay 2001:1).

Institutional ethnography places emphasis on how texts can explicate various disconnects between everyday activities as they are portrayed or expected by the texts and as they exist and play out in real life. The PWD and MNS application forms are emblematic of such disconnects.
One of these is the chasm between what is required of people who apply for these programs and what is easily achievable by them. For example, many people find it onerous just to get to the MSD office to get an application form. Others do not have the capacity to fill out the form because they do not have a family doctor or a specialist who is well aware of their condition. Still others are too sick to work but not sick enough to be enrolled in the program, and are denied income. There are also those who do not get the opportunity to apply because they do not know that such programs exist. Seth experienced this in the early days after his HIV diagnosis when he was living on the meagre meals of rice and beans:

Nobody told me about the Schedule C for years and years until finally, I was in the hospital once, and this fellow told me about his income, and I said, “where do you get all this money?” And he said, ‘Well, I get this from the province and then this schedule C.’ And I said, ‘What’s that?’ So he told me and so I went to apply for it... when I went to apply, the government was just... it was where they were eliminating the schedule C and changing it to something else [the MNS]

But, those people who had schedule C at the time maintained it up till today, [those] who are alive. That was an enormous amount of money, compared to what was given out later... At least 50 per cent more. So, my income went up $225 a month, 3 years into... the time when I was taking medication.

Seth is now one of the few people who still receives the Schedule C: those who had it before the switch to MNS were “grandfathered” and maintained their $225 per month.

For those who muster the energy and support to fill out the applications, the wording of questions can pose significant barriers. For example, on page 11 of the PWD application, the assessor is asked about “functional skills” (see Figure 10, below). Use of the word “can” is key: applicants might be able to walk on a flat surface, climb stairs, lift things, and remain seated because they must. The lack of qualitative answer options does not give applicants the opportunity to describe other things that might go on during these activities. Darla was a good
example of this. She lives on the third floor of a three-story walk-up apartment building. Having emphysema makes it extremely difficult for her to walk up stairs: she must stop and take a rest often and, by the end, she is coughing and wheezing. Can Darla walk up more than five steps unaided? Yes. Does she suffer every time she has to? Yes.

<table>
<thead>
<tr>
<th>D - FUNCTIONAL SKILLS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Note:</strong> For the purposes of questions #1 and #2, “unaided” means without the assistance of another person, assistive device or assistance animal</td>
</tr>
<tr>
<td>1. How far can this person walk unaided on a flat surface?</td>
</tr>
<tr>
<td>□ 4+ blocks</td>
</tr>
<tr>
<td>□ 2 to 4 blocks</td>
</tr>
<tr>
<td>2. How many stairs can this person climb unaided?</td>
</tr>
<tr>
<td>□ 6+ steps</td>
</tr>
<tr>
<td>3. What are the person’s limitations in lifting?</td>
</tr>
<tr>
<td>□ No limitations</td>
</tr>
<tr>
<td>4. How long can this person remain seated?</td>
</tr>
<tr>
<td>□ No limitation</td>
</tr>
<tr>
<td>5. Are there difficulties with communication other than a lack of fluency in English?</td>
</tr>
<tr>
<td>□ Yes</td>
</tr>
<tr>
<td>If yes, what is the cause: □ Cognitive</td>
</tr>
<tr>
<td>Comments:</td>
</tr>
</tbody>
</table>

Figure 10. Sample page of the PWD application form (British Columbia Ministry of Social Development and Social Innovation)

Completing these forms, then, becomes an exercise in frustration, apprehension, and self-doubt.

Below, Cameron describes his frustration with similar questioning on the CPPD application.

*I think it was CPPD, sent me a form, to keep my [private LTD] disability going and the question was something to the effect of, ‘Do you cook your own meals, how are your meals prepared—do you cook them? If yes, please explain.’ I thought, ‘Yes, I can cook. What do you mean, I actually have to explain that I can cook?’ And it was one of those days I realized I really needed to really be careful how I answer these forms. Like, wait for a day when I’m really feeling crappy, because if you’re being sarcastic, like ‘I’m proficient in the use of a can opener and a microwave.’ Like, what do you want me to say, people?*
Cameron’s comments show how vague these questions can be and how easy it would be to answer them in a way that would ultimately work against the applicant. Of course, Cameron can cook; most adults can. Of course he cooks when he needs to, even when he doesn’t feel particularly well and when George isn’t home to help. However, saying that he can and does cook on a regular basis would prove him to be too capable in the realm of daily living. This is why most applicants, when assisted by a knowledgeable professional, are told to answer the questions based on what their activity would be like on days when their health is at its worst.

For PLWHA already on the PWD program, the dichotomy between “sick” and “healthy” is very pronounced. One must be incapable of “normal” functioning in order to receive PWD income and yet, the things people must do to obtain and maintain PWD (keeping appointments, regularly reporting health, living, and employment status, etc.) are not easy for chronically ill people. It is reasonable to expect PLWHA and others on PWD to feel conflicted about attempting to be well enough to function at this level, while knowing that if they function too well, they could lose their main source of income.

One last bind created and perpetuated by government income programs is the naming of these programs as “benefits.” Dictionary definitions of “benefit” associate the word with advantages, profit, concessions, gifts, and good deeds. While it is helpful to have these government payments rather than no income at all, naming them as “benefits” masks what they actually are, which is an insufficient, heavily regulated, highly restrictive income that is difficult to access. When we call them benefits, we put the people who receive this income into a category that implies they are getting something for nothing and contributes to the popular notion that they are a burden on taxpayers who often see this as money being thrown away on ne’er do well
cases who are “taking advantage of the system.” In the case of CPPD, this is certainly not the case because only people who have paid into the program can receive income later on. PWD is different in that it does not require having paid during one’s working years but, as a welfare state, our social safety net is in place specifically for people like these participants, who would like to work but cannot now or in the foreseeable future. The association of the word “benefit” with gifting also implies that recipients should be grateful for this income. Indeed, some participants do feel very lucky to be on PWD or CPPD but this feeling usually comes from a previous brush with the only two alternatives—having no income at all or being on basic income assistance (which provides about half the minimum amount of PWD), which as Klein says, is “abysmally low and unlivable” (2012:1). The discourse of “benefits” also plays into Sheller and Urry’s (2000) notion of coercive freedom. Although the authors were using the concept to describe people’s attachment to cars and the pervasive degree of global “automobility,” coercive freedom can be extended to any number of other realms experienced in late capitalist society. In this instance, when we name something a benefit, we feel as though we cannot complain about it. It gives people more freedom than if they had nothing but simultaneously coerces them into living in a very materially and socially marginal manner. As Canadians living in a relatively safe and beautiful place, it is easy to ask “who are we to complain?” Even Adrian, who articulated his anger with government-run programs more often than the other participants, felt grateful for the small amount of money he did get.
Concluding Thoughts

In terms of income, participants faced the primary double bind of not fitting fully into either the healthy role, which would enable them to work financially fruitful jobs or, the medical sick role, which would excuse them entirely from earning money. Within this bind, however, were others that made people feel equally caught. Those with full-time work frequently suffered health impacts related to stress and the inability to fit into the expected “good employee” role, as well as the inability to take care of other, crucial aspects of health care expected of “good sick people.” Having even a little bit of extra money usually means the difference between living well and simply surviving and those on government income programs were typically surviving as best as they could, but this never amounted to living well in a material or bodily sense. It is important to remember also that society expects adults to be employed and that those who are not employed are considered lazy and a drain on the social welfare system. Veblen describes how important it is for people to want to work, and how people who work are looked upon more favourably in industrial societies than those who do not:

The modern industry requires an impersonal, non-invidious interest in the work at hand. Without this the elaborate processes of industry would be impossible, and would, indeed, never have been conceived. This interest in work differentiates the workman from the criminal on the one hand, and from the captain of industry on the other. Since work must be done in order to the continued life of the community, there results a qualified selection favoring the spiritual aptitude for work, within a certain range of occupations (2003:161).

The visibility of people who are not employed makes us uncomfortable in the global north. Not only do we expect people to work, we expect them to want to work. If they are not working, it is best if they are taken care of privately: those participants who at least partially relied on the income of others were usually in a better position financially but the precarious nature of
knowing that one isn’t contributing fully to household income is a financial and social stressor that, for people with chronic disease, will never be alleviated. This stress is most acute when we consider the material expectations present in an affluent community where poverty is neither acceptable nor visible.

The texts analyzed in this chapter were the typical written documents that we find most often in institutional ethnography and their power over those with disabilities and chronic illnesses in this province cannot be overestimated. The regulations surrounding government income programs represent both hierarchical and sequential levels of regulation and are at once strict and vague. For example, as described earlier, in 2011 the allowable monthly employment income for people on the PWD program rose from $500 to $800; however, the PWD rate of pay itself has remained stagnant for many years. This sends a clear message to society at large that people with disabilities are being pushed into working roles in which they do not fit and cannot maintain. At the same time, it sends a very confusing message to people who are on the program that their health problems are not seen as serious, even though the texts regulating who is accepted into the program require that the conditions must be numerous and extremely serious. Their analysis illustrates how the provincial and federal social safety nets that have been in place in Canada for decades, precisely to aid people who cannot fit into the healthy role (and never will), are also serving to further marginalize those people in some situations.

The degree of visibility of illness plays heavily into the sick/healthy bind. Valeras (2010) notes that people who live with chronic disease are often forced to fit into one or another of these categories (i.e. either passing as healthy or fully accepting the sick role), when the reality is not that simple. Many variables determine whether someone can “pass” or not, including severity of
illness (which is cyclical and often unpredictable with HIV), medication regime, age, time of
day, and lifestyle factors, among others. Unfortunately, institutional processes do not often allow
for these nuances to be expressed or explained, as seen in the difficulties of the PWD and MNS
application process.

People with hidden disabilities (or “invis-abilities”) are often confronted with challenges
from the reactions of those around them:

When publicly identifying as a person with a disability, they are often confronted with
disbelief, minimization, or hostility. Because limitations are not immediately obvious,
their struggles are assumed to be less real or less difficult than the struggles of people
with more apparent disabilities ... The hidden disability experience, thus, falls in the
misunderstood gap between the dominant disability paradigms, the medical model and
the social model (Valeras 2010:1).

People living with HIV face this disbelief and hostility more than most because of the stigma
attached to the virus. It is for this reason that many of them choose not to disclose their status, as
Nate did. The invisibility of HIV exists in both a physical way, as it often carries no visible side
effects and, socially, as it has effectively disappeared from the social imagination of much of
advanced industrial society where HAART has lengthened life and made HIV a chronic disease,
as will be discussed in Chapter 8. Occupying the liminal space between healthy and sick in a
society that has specific expectations of “healthy” and a distinct repulsion from “sick,” creates an
“internal dissonance,” as Valeras describes it. On one hand, PLWHA want to appear “normal”
and healthy and, on the other, they long to be able to disclose their status openly in order to not
have to pass as healthy when they feel sick. Emotionally, this can be simply draining for some
and, for others, produces the kind of stress that only exacerbates illness.
Chapter 7: The Work of Being Well

Food insecurity and chronic illness seem to go hand-in-hand. Some studies indicate that people with multiple chronic conditions are more likely than other health-related demographics to experience food insecurity (Canadian Council on Social Development 2003; Vozoris and Tarasuk 2003:123). Hall, Colantino and Yoshida (2003) found that food insecurity was prevalent among women with disabilities because of physical mobility issues much like those described in Chapter 5 (such as Darla’s emphysema, or Maria’s neuropathy) but also because of impediments created by the “social and structural environment” (245). Gerbrandt (2009) similarly found that people with disabilities in British Columbia were food insecure because of physical limitations, lack of adequate income, barriers struck by the built environment, and stigma.

The purpose of this chapter is to extend the understanding of what PLWHA need and need to do, in order to successfully carry out the work of affording and obtaining food described in the previous two chapters. I label this “the work of being well” because people must be physically, mentally, and socially fit enough to afford, obtain, prepare, and eat food. Being well is normally conceived of as being related to individual bodies: thus, the work around “being well” is often characterized as an individual pursuit. There is perhaps no other disease in our society that is so stigmatized as an individual burden as is HIV (Dodds 2002). It follows that PLWHA carry a double burden of responsibility—for becoming infected with the virus in the first place and for coping with it once infected. Dodds (2002) specifically points to Canada’s 1974 Lalonde Report as the document that helped to mentally shift the responsibility for health in welfare states onto individuals, noting that such a neoliberal approach “implies that society is better off when its citizens are well and the individual is therefore responsible for the ‘greater
good” (140). She also states, with regard to HIV specifically, that individual responsibility “serves to blame those who are most vulnerable to infection” (142).

An ethnographic approach, which grounds research in lived experience, shows that, although wellbeing is individually felt and experienced, one comes to a state of wellbeing largely through navigation of the socio-economic world and through social relationships. Indeed, over the months of drafting this chapter and ruminating on what it takes to “be well,” it slowly became clear that, regardless of which aspect of wellness I was considering (whether physical, mental, or emotional), the factor of social relationships could not be ignored or even extricated. Being well on any level seems, for these participants (and likely for most everyone) to depend largely on the healthiness of one’s social life. “Social life” in this instance, can take on the standard meaning of having friends, family and other networks that one draws on for fun leisure experiences but it also takes on a more purposeful and intentional definition. Without meaning to make my participants sound exploitative, one of the common threads of the study was that participants’ chosen social networks were at least partially made up of people who could enable and facilitate the work of being well. At first glance, these things might seem quite peripheral to the actualities of getting food but, when viewed holistically and as institutionally-based processes, they are crucial to increasing food security or, at the very least, are crucial to maintaining whatever semblance of food security already exists in one’s life.

Although at times we are made well by participating in the social world, there are other times that participation in society decreases wellness. Marcuse pointed out exactly this problem in his book, Negations:

...we can say that a society is sick when its basic institutions and relations, its structure, are such that they do not permit the use of the available material and
intellectual resources for the optimal development and satisfaction of individual needs (2009:189).

Much of this is institutional in nature; most of the individuals living with HIV in this study are dependent on institutional programs, resources, and services to enhance their health and wellbeing. However, I hope to show that although many institutional services are meant to increase wellbeing (and by extension, food security), ironically, the processes inherent to certain institutions can pose barriers to some people, thereby producing the opposite of the desired effect.

Unlike the previous two chapters, in which the double bind, of say, grocery shopping versus going to the food bank, was more of a universal dilemma, the double binds found in the work of being well are diverse and situationally based. It would seem that the work of being well is akin to pushing a large boulder—it gets easier to move the boulder the more relationships one has on side to “get the ball rolling” and keep it rolling. However, some relationships that help at times to push the boulder in a person’s favour, can “switch sides” at other times and end up pushing back. This chapter is populated with examples from participants’ social lives of these very complex relationships (some personal, some institutional, some both simultaneously), which can work for or against (or again, both for and against) food security. The remainder of the chapter is divided according to relationships that facilitate food security, and relationships that both facilitate and constrain food security. There were no relationships that solely constrained food security. Pertinent text analysis is contained within each of these sections.
Facilitators of Food Security

For most participants, facilitators of food security were friends, family, and spouses. Tome, for instance, who faced difficulties in being motivated to cook for only himself, had a friend (also HIV positive) who would visit regularly for meals. Together they would cook, occasionally after having smoked marijuana together, which also increased their appetites. Tome found that having this friend over inspired him to cook more interesting, nutritious, and creative meals, which made eating far more enjoyable:

I mean, I’m really in admiration of my friend because he’s a fanatic when it comes to… for instance having colours in your meal. I’ve had him say to me, this is really good Tome, but where’s the colour? Like, where’s the red? Where’s the yellow? And that kind of makes it exciting for me, because here, this week I had that meatloaf and I thought ‘okay, what am I going to do?’ and I got the little nugget potatoes and I soaked them in olive oil and I had fresh basil on my balcony, so I cut that up and put it in and I put oregano in and I mixed it all up and roasted it in the little toaster oven and then I got fresh corn on the cob, so I had like, the yellow, but then I had the red potatoes, the little red nugget potatoes with the green herbs on, then I had my meatloaf, which of course had the red sauce on it, so I had the colours and I kind of thought to myself, well it’s too bad [his friend] isn’t here, cause look at that, it looks really good!

Maria’s husband, Max, is another good example of a facilitator. Max seemed to be helpful in a number of ways. He and Maria were partners in their provisioning (described in Chapter 5), and Max also helped with cooking food and other preparations. Maria described Max as “good at taking direction” in the kitchen. Although she was partially joking when she said it, this aspect of their relationship was also what made them successful in regularly eating enough food on such a tight budget. Maria was able to have some form of control over what they eat and how it is prepared, even though she is largely unable to move comfortably around the kitchen. Maria and Max also care deeply about one another and hold each other’s wellbeing as a top priority. This seemed to increase food security, at least to the degree that it took some of the
burden for provisioning off both their shoulders and thereby decreased the worry about potential food insecurity.

Cameron’s spouse, George, also acted as a facilitator to being well and food secure. Being steadily employed in a relatively high-paying job, George contributes significantly to the household income. Their income has allowed the couple to own their condominium and this stable housing contributes to wellbeing. Cameron and George work well together to plan, obtain, and prepare food. Cameron also has elderly parents and grown siblings who live close to him:

> Generally, if I’m over at my parents—and I’m there about twice a month over the noon hour—it means that I’m being fed while I’m there. And they eat their big meal at noon hour... as they got older, they found it was easier to cook their big meal at noon hour, then have something smaller at suppertime.

Cameron is anomalous in that he is the only completely food secure person in the study and this seems to be largely because of his income, social connections, and resulting social support.

Some personal relationships facilitate food security because they create and maintain bonds between people and their food. As Wilk (1999) states, “food is a particularly potent symbol of personal and group identity, forming one of the foundations of both individuality and a sense of common membership in a larger, bounded group” (308). In Tome’s case, food became a connection to people he loves, both living and deceased:

> So, my mother died in 1991. She was a fantastic cook. And so I went through a period where I didn’t really believe I could cook. So, it took me a few years to kind of get to the place, probably about 1998 when I seroconverted that I started thinking, ‘well I have to really start cooking.’ And I cooked a few things, and I discovered, wow, actually that turned out all right or it turned out pretty good, and there were things that I remembered from when I was a child, things that my mother would make, and that kind of encouraged me to start, although I wasn’t good at it, I wasn’t... habituated to it; you know, I would always end up not eating and then going to McDonald’s at two in the morning cause I was studying at university. And it wasn’t until I met Sebastian, my late husband, that I discovered, wow, when I cook something I can make somebody really, really happy.
Certain relationships required Allison to become a good cook. Her father’s inability to provide for the family meant she had to step up and cook at a young age; now that she has children of her own, she enjoys cooking for them and ensuring that they are able to provide for themselves:

*All self-taught. My dad was a drunk. Someone had to cook or I wasn’t going to eat. At about seven [years old] I was cooking my own meals. And then it just snowballed from there. I love to cook, though, I do. I love to cook, I love to bake, I love to be in the kitchen.*

**Interviewer:** So it’s not a chore for you.

**Allison:** No, I love it. It’s fun for me.

**Interviewer:** And what about the kids? Do you teach them to cook?

**Allison:** Absolutely. Yep, they’re all aware. [My son] just won an award at his school last year, for his food classes. They’ve always been in the kitchen with me, whether it’s just watching or helping.

Maria’s experience with family and food is similar to Tome’s, in that she has fond memories of her mother’s cooking and being taught how to cook. Now that she is less mobile, Max’s willingness to help and ability take direction gives her a sense of ownership of her provisioning and allows her to maintain her identity as a capable chef.

*Maria: I don’t mean to brag or anything, I’m a really good cook. I love, I used to love cooking. Now I don’t cook very often because I can’t stand up long enough. So I’ll direct him on how to cook everything.*

**Interviewer:** What do you think you would do if Max wasn’t here to help with all the cooking?

**Maria:** I don’t know. It would be hard. I don’t know what I would do if Max wasn’t here. I can’t cook anymore. And I love to cook. I like it when people enjoy my meals. When people come over and enjoy what I’ve made—Help yourselves, just help yourselves. Load up. Eat what you want. I always make lots. I always make lots.

At times, people found creative ways related to health and eating, to connect with others. David, an exercise enthusiast who also likes to discuss nutrition (often with total strangers), described
how he uses his physical abilities to form new relationships in a neighbourhood where he
sometimes felt out of place:

   Yeah, it’s just... a little bit more flair, I think, is what’s helped me, you know, exist
there. You know, I tend to be a little bit ‘out there?’ So, I don’t know, I take a lot of
my need for, I guess communication or conversation and stuff like that, which is
normal, like to have somebody around, and talking... for instance, if I haven’t
talked to anybody all day, I’ll be out in the front [of his apartment building] after I
run and, for like an hour, I’ll do handstands. And try to climb everything in the
front yard, that’s how I socialize. And so I bring people out and they start looking
at me. I’m not trying to show off, I just... it’s also an advertisement for what you
can do. And I feel really good about that. I feel like fuck man, I could’ve buckled,
and I could’ve been a hunchback, and fuckin’ any of these things, crippled all up,
and... look! That’s just because of this [flexes arms to show strength].

   Interviewer: Yeah. And people respond to that.
   David: Yeah, ‘cause like I said, I refuse to have it any other way. I refuse not to be
strong. I refuse it. I absolutely refuse it to the universe.

A minority of study participants had relations with groups and/or institutions that were
helpful in increasing their well-being. Cameron and George’s relationships with their hobby
groups contributed to the amount of social eating they engage in:

   Now, since moving here [their new condo], we’ve done a lot more entertaining
‘cause the house is more suited to it; like actually having a dining table makes a
big difference! And then also, we belong to a lot of groups that have potlucks and
stuff like that, so there’s always a lot of social eating.

Kent’s connection with the Living Positive Resource Centre has greatly contributed to his
wellbeing in the past two years. I began seeing Kent as a client shortly after I started working at
LPRC as an advocate. Being married with grown children, grandchildren, siblings and in-laws
living nearby, Kent was not socially isolated but his relationships were causing him a great deal
of stress. Shortly before I left my job, Kent began volunteering at the Centre and has continued
to play a vital role as receptionist/greeter/harm reduction supply distributor/all-round
knowledgeable person around the office. He gives at least 35 hours of his time per week to the
Centre and is considered an extremely valuable member of the staff. He describes the change that volunteering has made to him:

_I’m not sitting around thinking like I used to. Like I used to just sit and worry and think all the time about stuff. I’m not doing that anymore. You know, just coming [to LPRC], and talking to people and listening to people and, you know, reading the papers or articles or just not thinking about myself all the time._

A long-time member of AA and NA, Darla was able to draw support from a number of people in her group (which they call the “fellowship”). Indeed, AA is known for its use of the sponsor relationship to help members into long-term sobriety. Because Darla was one of the senior members of the group, she acted as a mentor on a casual basis for more than one of the younger members. She noted that they felt free to call her if they were experiencing challenges. In turn, she was able to call on them if she needed help getting food and other goods when her husband was away for work. Although this is a give-and-take relationship, there was no “push back” from the AA group in terms of threatening her food security and thus, AA was solely a facilitator.

**Ambiguous Relationships**

Most relationships analyzed in this study worked to both facilitate _and_ constrain food security for participants. Whether a relationship acted as facilitator or barrier, usually depended on the time frame, as well as the way in which a participant acted on or viewed the relationship. Many of these relationships, because of their varying degrees of helpfulness, often acted as double binds in and of themselves.
Close Personal Relationships

Several participants’ relationships with friends and family were dichotomous with regard to the work of being well. At the time of writing, Allison, the youngest woman in the study, was single and acknowledged that provisioning was somewhat easier with a partner. Allison was the only person in the study with children living at home; her children were both a source of food security stress and relief. On one hand, she had three extra people to feed, all of whom were at the pre-teen or early teen stage and thus at peak periods of growth. Allison noted that her children’s nutrition always came first, and that she quietly goes without food at the times when the family is running low:

*It’s the two or three days before payday, that stretch right before. I’ll just dole out basically what I have to them and, if there’s anything left, I’ll have it or I’ll just have a piece of toast or something for dinner. Cause really, for me, it’s a filler. For them, they’re trying to grow!*

On the other hand, Allison was able to make use of various programs and services solely because she has children. All of her kids took part in their schools’ brown bag lunch and hot breakfast programs. Her oldest also volunteered for the brown bag lunch program, helping school staff to pack and distribute the lunches to other students. In return, he often got to take home leftover items, such as apples and granola bars, at the end of the week. Allison was always grateful that he and his sisters had extra snacks for the weekend that she didn’t have to pay for. The food Allison got from the food bank would not have been nearly so much had she not had children. Thus, while her use of the food bank might not have been necessary without them, the children entitled her to more and better food through the family program.
Allison’s situation also illustrates that not being able to feed friends and family creates tensions, due to both social expectations and a personal affinity for cooking and entertaining. When asked if she engages in much “social eating,” Allison had this to say:

*I used to. It’s changed though. Like, the kids’ friends come over and I don’t mind feeding them, as long as it’s not all the time. I’ve had to tell the kids, look, I can’t afford to feed everybody, and I’m afraid that, if we do this, then we’re gonna have, like, a week with no food before payday. But, by the same token, I just had my mom, her boyfriend, and his dad over for Thanksgiving on Sunday, so for something like that, I don’t mind hosting. But on an everyday regular basis... I mean, I would absolutely love to feed everyone who walks into this house, it’s just a matter of how much am I willing to give up on the other end to do so.*

At times, simply living in close quarters with other people made food security easier for some reasons and more difficult for others. Daniel’s food security was stable but not entirely appropriate for him on an individual level; he felt constrained in his eating habits because he often had to conform to the preferences of his parents:

*Yeah... Usually I don’t get much of a say, unless they’re going... they do a lot of golfing in the afternoon during the summer; so, then I can pick what I want. I like to cook, so I’ll cook. But if they’re home, it’s usually, they decide and sometimes I’ll just say I’m just not into eating that and I’ll make my own, (laughs), but it would be a whole bunch easier if I could pick what I wanted to eat.*

Nate felt similarly caught between the ease with which food was provided to him by Eli, and his dislike of many of the meals Eli made.

*My roommate is retired as you know, it’s his house and he likes to putter around and... don’t misunderstand me. So, he makes breakfast; he makes porridge every morning; he has his... every morning. And he has his with milk and I use, I don’t like milk, not very much, so I mix the yogurt. So every morning it’s a porridge and yogurt. Um, at lunchtime, I normally make my own lunch and that’s that. He does all the grocery shopping. He shops at... what’s the one? Not Save-on... Walmart. I don’t think it’s the greatest place to shop for food, especially for meats and stuff. He buys a lot of red meats, very cheap cut red meat. I would never, rarely eat that sort of stuff. He was buying ground beef and I had to say, ‘okay, I’m off that. I don’t want that.’ [chuckles] So he stopped buying that. Our diet, to me, it doesn’t*
have very much variety; it’s the same thing over and over, right? If I was doing it myself I would tend to like more fish, salmon, chicken ... yeah, and he’s a very ‘meat and potatoes’ cook. Like, he has, oh, I don’t know, at least three times a week, boiled potatoes. I would never eat boiled potatoes three times a week.

**Interviewer:** Right, so you’re lacking creativity, probably, and variety.

**Nate:** Oh yeah. And uh, he’s a very ... how do I say it ... let’s put it this way. I think his limit for spices is salt and pepper. Very bland cooking. I mean it’s food, I’m ... he’s older and I don’t like to hurt his feelings, but it’s really the biggest contention in our roommate relationship.

On the other side of this complaint, Eli experienced financial relief from Nate’s income that facilitated food security but also experienced added pressure to perform food-related activities such as grocery shopping and cooking that were physically exhausting for him. When I interviewed Eli, Nate had just moved to Vancouver. Eli described how provisioning was taxing him at that point:

**Eli:** I get up and I’m just exhausted, and it used to be mornings was the time when I did everything ‘cause I had energy... So I have to pretty much force myself to do things.

**Interviewer:** Do you think that’s affecting your eating or your ability to get food and go out and do stuff like that?

**Eli:** Uh, yes, because I do put things off till tomorrow, because I may have more energy. And even when I make dinner, I’ll do it in ... I’ll peel the carrots, then I’ll sit for a while, then I’ll do something else.

**Interviewer:** You do it in stages so it’s not too much at once.

**Eli:** Yep; ‘cause even like, peeling a few potatoes, wears me out.

Kent’s family members have both positive and negative effects on his health. His three young grandchildren, a source of happy energy and joyful responsibility, have positive effects because they help Kent keep active and socially engaged. Their mother and father, however, while sometimes a source of support, can at times, be financially draining on Kent and his wife, which affects Kent’s level of stress and sometimes his ability to eat nutritious foods.
Institutional Relationships

Institutional ethnography begins at the standpoint of the individual and investigates relationships with institutions as mediated by texts. This section of the paper illustrates the double binds experienced in some of these institutional relationships, which would not be well understood without an analysis of texts. My analysis includes traditional texts such as application forms and websites, as well as less traditional but equally powerful “texts”, such as human-formed landscapes, which serve to reinforce expectations about people’s intentions and behaviour.

Frequent interaction with powerful and complex institutional bodies is a normal part of everyday life for most people. The health care system (and its numerous component parts, including physicians, nurses, specialists, alternative care providers, dentists, and so on), social support services, and various arms of the government are the most commonly encountered institutions for PLWHA in this study. The interesting thing about these institutions’ ambiguity with regard to helping PLWHA, is that, ideally, they exist solely to improve quality of life for people who are ill and/or marginalized. In reality, however, the very nature of institutional bureaucracy can contort this ideal into barriers for many people.

Health Care Institutions

The health care system in British Columbia is a good starting example of this ambiguity. “Health care” by its definition exists to provide care and to improve people’s lives. In Canada, the health care system is “universal,” meaning that prepaid “medically necessary” health services are funded through taxation and provided to Canadian residents without individual co-payments. In British Columbia, PLWHA can receive their ART free through a program run by the B.C.
Centre for Excellence in HIV (BCCE). However, even though theoretically, everyone gets the same services, in reality, this is not the case.

One of the main health issues PLWHA face in the Okanagan is finding appropriate, accessible care. Kelowna is home to only one infectious disease specialist, Dr. Green (a pseudonym), who serves a vast swath of the province’s interior. Having specialized care is vital for PLWHA; however, some participants found their relationships with this specialist to be problematic. Daniel stated:

*He won’t see me (laughs). I told him he was a dingbat one time.*

**Interviewer:** Oh well, he would not like that!

**Daniel:** Nope... I’m on his bad list. No, if I need to see a specialist, I go to Vancouver and see, uh, Dr. James [also a pseudonym].

Nate had a similar story:

*I was seeing him for a long time, and then of course the nurse, whatever her name is, was calling before to remind we. Well it’s very busy [at his workplace] in September, I never picked up the message, forgot all about it and I didn’t show up, so the next thing is, he doesn’t want to see me anymore.*

**Interviewer:** Right, he has a low tolerance ...

**Nate:** Almost a zero tolerance... so that was almost a year ago now. And um, the suggestion was to go and see this Barbara McQuade, or something?

**Interviewer:** Caroline McQuade [pseudonym].

**Nate:** Caroline McQuade. Is that her name?

**Interviewer:**Yep. At the street clinic?

**Nate:** Yeah. And, um, so I called their office and they said, ‘well she does work at a clinic but for those types of things you have to make an appointment, and it can only be on Tuesday mornings,’ and I said, ‘okay, thank you very much. I’ll call back sometime and make an appointment.’ I never did.

**Interviewer:** Right. So when was the last time you’ve seen a doctor?

**Nate:** A year ago now, more than that. I think it’s over a year ago.

Although some people attribute their clashes with the specialist to personality differences, a contributing issue is that the specialist has so many appointments to keep with so many patients
that allowing a person continually to be late for or miss appointments could compromise the care of another patient. Therefore, it is not the doctor who is the main problem, rather, it is a system that cannot provide more than one specialist to this area. In recent years, this dilemma has been partially answered by a doctor, Caroline McQuade, at a street clinic in the downtown area of Kelowna. She is not a specialist, but did train with specialists and is “HIV aware.” She is considered the best alternative to the infectious disease specialist, sees HIV patients on certain days of the week, and allows both booked appointments and drop-ins. In all, seven study participants were seeing Dr. McQuade at the street clinic instead of the hospital-based specialist.

This approach is far more accessible for meeting the needs of a diverse population but poses a couple of barriers of its own. As mentioned in the previous chapter, Tome and Nate see this doctor but have trouble getting in to see her when her hours are so limited and almost exactly match their own work schedules. Her flexibility, while entirely appropriate in some ways, means that she frequently runs late and patients can wait a long time to see her. Additionally, the “street” aspect of the clinic, as well as its location, make the clinic an uncomfortable place for some. Because the clinic is located in an area of town housing numerous social services agencies, the most marginalized community members tend to congregate there. People with substance use issues are sometimes triggered by the people and activities that go on around and in the clinic; others simply don’t feel safe. As shown in Figure 11, similar to the food bank, the clinic has several security features that one would not find in most doctor’s offices, such as plexiglass screens for the receptionists and stop sign-shaped notices about behavioural rules and regulations. Again, stop signs presume that a behaviour is already occurring and must be
curtailed. For people who do not engage in abusive language and behaviours (and most people
do not), these texts can be alienating.

![Figure 11. Reception and lobby area of the street clinic in downtown Kelowna. The
crds on the stop sign-shaped notices read “Violence, foul language and abusive
behaviours are not acceptable. Verbal threats or acts of violence will not be tolerated
and may result in removal from this facility and/or persecution” (photo credit, Heather
Picotte, 2013).]

Other people, like David, may have problems with any health care professional who deals with
HIV. David is in a unique position among the participants as the only person who is not taking
antiretroviral therapy. He refuses to go on medication for a number of reasons—he does not
believe he requires it to stay healthy, he thinks that big pharmaceutical companies are just trying
to make money, and he is not convinced that HIV is solely a virus but is also a disease that gets
expressed when people engage in unhealthy activities such as illicit substance use. He seems
quite healthy, considering he has been positive for 12 years and has been co-infected with
hepatitis C for at least that long. David attributes his high CD4 count to his strict diet and
exercise regime. His viral load is very high, but fairly stable. It is possible he is a long-term survivor\(^8\) but it is also possible that his healthy activities do contribute greatly to his wellbeing.

Regardless of why David doesn’t take HIV medication, it is interesting how this decision has impacted his use of health care services. He does not need to get his blood tested every three months because he is not on ART. Instead, he gets bloodwork done less often and even avoids the medical establishment because he feels pressure from it.

\[\text{I just feel like I just don’t wanna ... like, defend myself against the antiretrovirals ... you know, the HIV is a stigma enough that it’s probably going to leave me alone for the rest of my life, because of this. It’s going to put me onto a bit of an island, you know, and that I have to live on. But, as far as being on that island and also having to deal with side effects, ha.}\]

In addition to doctors who provide direct lines of care to PLWHA, there are other, more peripheral components of the health care system that can be ambiguous in their support.

Pharmacies are one. In Kelowna, only one pharmacy is responsible for administering ART prescriptions, which come initially from the BCCE in Vancouver. Having lived in Vancouver several years ago, and thus, having dealt with pharmacies in both cities, Tome had this to say:

\[\text{They [the Kelowna pharmacy] refuse to put my medication in blister packs cause it was gonna cost more money and takes time for them to do it. I had to contact the pharmacy in Vancouver to get them to intervene. Um, if I return medication that I haven’t taken, I’m treated like a school kid or somebody who has willingly not taken their medications. In fact the last time that happened, I had a whole bunch of them, and she said ‘You’ve got so many’... and I looked at her and I said,}\]

\(^8\) A “small population” (less than 5 per cent to 8 per cent) of people with documented HIV-1 infection can live for years without symptoms (Huang et al. 1995:93; Montefiori et al. 1996:60). They are normally classed as “long-term survivors” or “long-term nonprogressors” (Kirshhoff et al. 1995; Montefiori et al. 1996). Some show evidence of disease progression in the form of decreased CD4 count (but without other symptoms), but many do not. Research is not clear on exactly why this happens, but most agree that it is either due to viral factors, individual immune system factors, or a combination of both (Kirshhoff et al. 1995).
‘That’s because you filled my prescription a week ahead of time,’ and my antidepressants were being decreased in a certain ... But really, I felt like I was being treated like I was less than.

Interviewer: And did you ever get that feeling when you were in Vancouver?
Tome: No. No, no. I mean, they were pretty strict in Vancouver about taking your medications, they were strict about, you know, being there for your appointment time, but they were open from seven in the morning to seven at night. And, there was a 1-800 number that, if you had issues or ran out of medication or what have you ... um, no, they were always very friendly. Always asked about my partner. No, they were lovely.

Canada’s medicinal marijuana program is another, more peripheral component of health care for PLWHA. The psychoactive chemical in cannabis has antiemetic, analgesic, anti-anxiety, sedative, and appetite-stimulating effects (Koger Sr. 2006:42) and marijuana has been shown to alleviate lack of appetite, muscle pain, nausea, anxiety, and nerve pain in PLWHA (Szulakowska and Milnerowicz 2011:761). Six out of the 12 participants regularly use marijuana; some get it legally from the local compassion club via the Canadian medical marijuana program, some get it in a quasi-legal fashion from the compassion club (using the doctor-issued card but not a federally-certified card from the government) and some get it off the street from an illegal dealer. All participants said that acquiring legal access to this medicine was extremely difficult.

Truly, the process of obtaining a license to buy or grow medical marijuana is an onerous one. One must first obtain an application form, which is downloadable from the Government of Canada’s website (alternatively, one can phone to have a copy sent by mail or obtain one from a local social or health service organization that may keep them on hand or print them out). The application form for a simple license to carry marijuana for medical purposes (the most basic kind of application and license; there are other licenses to grow marijuana, to appoint a grower, etc.) is relatively short and straightforward. Simplicity aside, however, it is important to note that the power to determine eligibility for this substance is solely in the hands of the physician, not
the applicant. Within its four pages, there are no opportunities for an applicant to speak on his/her own behalf to describe the symptoms that marijuana might help to relieve.

If an applicant is successful in being granted a license to carry marijuana, s/he must re-apply each year. Given that the application process can take months and, given also that many people who apply have chronic or terminal illnesses from which they will never recover, requirements for annual re-application seem a bit like rubbing salt in the wound. Tome describes the process of applying to get his carrying card for medical marijuana renewed:

*It took me longer to get the license this year because you have to have a criminal check done, your grower does, and they send the documentation to Ottawa, and they didn’t go through the pile until ... whatever, they take their time with it. They’re very cool with you on the phone, very “officious” I think the word is. I got fed up at one point and said ‘I’ll go buy it on the street.’ ‘well, that’s illegal.’ I said ‘So what?’ You know?*

**Interviewer:** So about how long...was it months or weeks...

**Tome:** Oh, months. Six months.

**Interviewer:** This time it was six months? And you’ve had it before.

**Tome:** I had it before; it was a renewal.

**Interviewer:** It was a renewal that took six months?

**Tome:** Yeah, and it expires again in December, I think, so I’m gonna have to apply now if I’m going to...

**Interviewer:** Yeah so basically you could say that you’re spending almost half the year applying for something that you get, that you have to apply for every single year.

Some participants bemoaned how difficult it is to find a physician willing to fill out the application.

**Tome:** First of all, you have to get the forms and then you have to get a doctor to sign off on it and that’s getting harder and harder because the College of Physicians and Surgeons are telling their members to not do it.

**Interviewer:** Did you hear that from a doctor?

**Tome:** I forget where I heard it from. But physicians, especially in this area, are very loathe to do it. In fact, I went to that talk that LPRC gave at the golf club, and one of the doctors got up and pretty well trashed marijuana.
Those who do support their patients in the application form do not want to become known as the “go-to” doctor for medical pot prescriptions and they are sometimes wary of signing off on too many applications. Some doctors who will fill out the forms charge their patients for the service and this can be financially prohibitive, especially when it has to be done every year. To avoid being denied, several participants simply obtained a card from the compassion club saying that they are authorized to carry medicinal marijuana (this would be signed by their physicians) and never went through the process of getting a government-issued card. Some, like Allison and David, got their marijuana from illegal dealers:

**Allison:** It helps with everything. It definitely helps with the eating. I mean, I could go and get the card and get licensed but I don’t want to use my HIV as an excuse. ‘Cause as soon as everyone realizes ... that was the first thing somebody had told me, they’re like, ‘oh, you’re HIV positive? Did you know you can get your card to get this medical marijuana?’ And I’m not retarded, I am aware, yes. I’m just not interested. It’s ... if this is a vice that I choose to do, then it’s something that I wanna go get on my own.

Sadly for many who use marijuana for medical purposes, in March 2014 Canada’s Marihuana Medical Access Program (MMAP) as it currently operates, will cease to exist. Instead, applicants will only be able to buy marijuana from the Canadian government and not from local compassion clubs or private growers (currently, people with an MMAP carrying card are allowed to either grow their own marijuana or designate a grower, who also receives certification from the federal government, or buy from a certified compassion club) (Health Canada 2013). In October 2013, in order to bring people in line with these new regulations, the program stopped accepting new applications to carry, as well as applications to increase the number of plants or alter the site of an existing grow operation (Health Canada 2013). Access to
the program will be even more onerous, time-consuming, frustrating, and restrictive than it is now.

As in the previous chapter, where I described the process of applying for income assistance programs requiring the availability and willingness of health care professionals, attending to the specific health needs of PLWHA also requires a sound understanding of the physical realities of coping with HIV and, in the case of medical marijuana, the open-mindedness to advocate for the use of an otherwise illegal substance. We know there is a deficit of family doctors in Kelowna and around the province (Busing 2007). According to the BC College of Physicians and Surgeons, 150,000 people in the province do not have a family doctor (Greer 2006). In trying to find out exactly how much the average family doctor in the Okanagan might know about living with HIV, I visited the College of Family Physicians of Canada website and perused their online resources site where GPs in Canada can go for professional development. The only “Endorsed Practice Resource” in a search for “HIV” (which, along with “AIDS,” it should be noted, is not included in the site’s existing list of 39 topics), is from a 2004 document entitled, “Rehabilitation in the Context of HIV for Family Physicians.” A search for “AIDS” on the same page of the same site lists only one practice resource, which is a guide to all communicable diseases. From here one can link to the “HIV Insite Knowledge Base,” a comprehensive online textbook from the University of California (San Francisco), as well as the HIV/AIDS Portal, a resource site for physicians and patients run by the Canadian Public Health Association. The resources listed for health professionals on the CPHA site are as follows:
For Health Professionals

- Canadian guidelines for sexual health education (PDF)
- Canadian guidelines on sexually transmitted infections (PDF)
  - Quick reference: Canadian guidelines on sexually transmitted infections (PDF)
- HIV transmission guidelines for assessing risk: a resource for educators, counsellors and health care professionals (PDF)
- Positive thinking: a sex positive approach to HIV/AIDS education: a resource for educators, counsellors and health care providers (PDF)
- Prevention and control of occupational infections in health care (PDF)
- Rehabilitation in the context of HIV: an interprofessional course for occupational therapists, physiotherapists, speech-language pathologists and audiologists (PDF)
- Sexual and reproductive health counselling guidelines (PDF)

The listing in the manual for HIV is only half a page long and that half page does little more than refer physicians to the National College of Physicians and Surgeons and to a non-profit organization—the Canadian AIDS Treatment Information Exchange (CATIE). From the BC College site, I went to the National College of Physicians and Surgeons (NCPS) website and navigated to that organization’s resource page. Searches for both “HIV” and “AIDS” yielded only one document specific to HIV.

The NCPS website referred visitors to several other websites, one of which was the Gay and Lesbian Medical Association website and, because several of my participants are gay men, I thought this might be a helpful site to visit. The only page that looked applicable to British Columbia (the GLMA is U.S.-based) was their directory of providers, a map search tool for LGBT-friendly physicians in North America. However, none were listed for the Okanagan. Only four were listed for all of British Columbia and all of those were in Vancouver or Vancouver Island. Even the ability of the health care system as a whole to deal with HIV at this point in time should be questioned. The age of participants in relation to wellness should not be ignored.
PLWHA are living longer thanks to HAART, but age-related co-morbidities are common and not well understood (Kirk and Bidwell Goetz 2009; Myers 2009; Onen et al. 2010). With the population of the Okanagan Valley being more than half comprised of people over the age of 45 (Our Okanagan 2011), it begs the question of how the health care system will cope in the coming decades, especially with people whose health problems are potentially so severe.

I bring up all of these things not to berate doctors for their reluctance to do paperwork or for rushing through appointments, or for lacking an understanding of the difficulties faced by their patients. Most doctors would likely welcome having more time to spend with patients and work on professional development. In the interior of British Columbia, this is not possible: physicians are overworked and, in some places, certain specialists work without long-term contracts in place (Manes 2010; Plant 2011). There simply are not enough physicians to go around and the ones currently working, do not have enough time.

Dental care is another critical aspect of health for PLWHA and one of the biggest sources of stress for HIV-positive clients when I worked as an advocate. In British Columbia, dental care is privately run. There are no provisions in the Medical Services Plan for dental care, save for emergency surgery on the mouth or jaw. The oral problems most associated with HIV are linear gingivitis erythema, necrotizing ulcerative gingivitis, and necrotizing ulcerative periodontitis (Mataftsi et al. 2011:14). Although in the early days of antiretroviral therapy, HAART was effective at preventing oral lesions in PLWHA (Chapple and Hamburger 2000; Nittayananta et al. 2010), researchers over the past decade have found that long-term use of HAART is associated with an increase in oral lesions (Hodgson et al. 2006; Nittayananta et al. 2010). Most participants are in financial circumstances that do not allow for “extras” such as dental insurance or even ad-
hoc payment of dentist fees when services are necessary. For several participants, dental care is a luxury and teeth only get fixed when they are in great need of repair; regular preventative care is simply too expensive. For PLWHA, access to affordable dental care would help avoid a number of potentially serious health problems, especially considering that healthy teeth are vital to nourishment and that “HIV-associated periodontal diseases are regarded as serious complications of HIV infection and have an important diagnostic and prognostic value” (Mataftsi et al. 2011:14).

Chapter 6 illustrated that fitting into a sick role or a healthy role was critical for financial survival and that appearance was critical to fitting in. Appearance also plays an important role in the work of being well, because our notions of wellness are constructed by societal values and expectations. In Kelowna, there are numerous dental clinics that provide basic dental care, while also specializing in aesthetic orthodontic services (such as straightening and whitening). While trying to access affordable dental care, David found these values and expectations to be barriers:

_The dental system, you know, as far as accommodating ... I think it needs to be knocked down a few, you know, steps, like everything else? And it will be, I mean, everything will get knocked down. I mean, it just needs to be normalized. I don’t need to go into a place to be entertained. I don’t want a big-screen TV, I don’t care. I’m not paying for that! And I walk into some of these places, ‘cause they’re local, through an area where I live, which is ritzy and, I gotta say, well, I live there, but I don’t live there. I can’t afford any of the friggin’ services there. And especially the dental offices and clinics, you know, they’re just upscale. You know, I mean the walk-in clinics and that, that’s not the big deal, but the dental offices, yeah, every single one of them that I’ve gone into in the community, that was upper-middle class, you suffer for it and it comes out in the bill. You know, I probably saved myself a couple hundred bucks by going to a different place which is significant. That two hundred dollars was fricking enormous when it came down to it. Yeah... So anyway, now I’ve got an appointment in Westbank, and it’s native, it’s on rez and hopefully..._
At the time he told this story, David was living in a supportive housing complex for people recovering from substance use issues. It was in a higher-income part of town and he did not always feel comfortable there. Saying, “I live there, but I don’t live there,” shows how David’s physical location was at odds with how he financially and emotionally fit into his community. Eventually, David was able to get the dental care he needed at a price he could afford, but only by going to the dental clinic on the First Nations reservation, 40 minutes away from his home.

Similarly, Adrian stated that he simply couldn’t afford the dental care he needs and that he has tried to avoid the subject with his specialist because he feels that his financial situation would not be understood or sympathized with. This speaks to the notion that poverty in Kelowna is not visible enough to be taken seriously, even when people’s health is at stake. For some people, socialization that is already limited by low income is further limited by physical problems. According to Coates et al. (1996)

more than one-half of HIV dental patients reported toothache, painful aching, or embarrassment about the appearance of the teeth or mouth ... In addition, avoidance of food, difficulty relaxing, and avoiding going out (all attributed to problems with teeth or mouth) were significantly more likely among HIV dental patients (35).

Again, this becomes a cyclical problem in which social ties crumble due to the inability to live up to expectations, decreased social support networks cause further isolation and poor health, which leads to further isolation, and so on.
Social support institutions

*Tome:* I’m a member of the BC ... they changed the name from BCPWA to Positive Living BC. So I’m a member. I don’t rely that much on LPRC anymore, mainly because there’s boundary issues and also I think the shift in mandate has changed, so I don’t feel that ... it’s just not appropriate for me.

As important as the medical establishment is to the lives of PLWHA, institutions that provide social support are also critical components of PLWHA’s social lives and a potentially huge contributor to their wellbeing. Tome’s comments above are emblematic of PLWHA’s lack of “fit” with social service organizations in the Okanagan and around the province. Recent changes to AIDS service organizations (ASOs) at local and regional levels have had significant effects on the everyday lives of specific subpopulations of PLWHA.

At the time of writing, Living Positive Resource Centre—the agency at which I was employed prior to this research—is the only social service agency in the Okanagan Valley with services specific to PLWHA. Just prior to my research beginning, LPRC underwent a massive transition, which became one of the focal points of my talk with participants. Once a dedicated ASO that only supported people living with blood-borne infections (primarily HIV and viral hepatitis), in 2010 LPRC was foundering financially under poor management with a client load that was steady but not numerous or increasing. The board of directors was forced to cut staffing and other costs, while simultaneously widening the agency’s mandate to serve anyone at risk of infection; in other words, anyone at all. The cost-cutting measures included moving the office to a lower-income area of the city into a building with lower rental costs. While this broadening of mandate has increased the number of people being served overall and essentially saved the organization from being shut down entirely, it has alienated certain clients who frequented the office prior to these changes. Some people who used to come to LPRC no longer do so, because
the services they sought are no longer offered. For example, a Reiki master used to provide free Reiki in the office one day per week for clients. She now cannot provide that service because the office has moved too far away from her home. As well, LPRC used to have a support fund to help its HIV-positive clients when they were in difficult financial situations. That fund no longer exists because of budget cuts. As in the situation with local physicians, this has nothing to do with the wishes of workers at LPRC; rather, more to do with the fact that the agency is under-staffed, under-funded, and overworked. In addition to these cuts to services, some clients feel out of place in the “new” LPRC because of its wider mandate to serve anyone at risk. Adrian stated:

> When I go to LPRC every month to pick up the housing cheque, it is an unpleasant experience. It has become a hangout for junkies who are treated with more respect than I am. Last time I was there, there was a bald, tattooed guy swaying back and forth in a chair stoned out of his mind, clapping a bottle of prescription drugs. He later dropped the bottle on the floor and was drooling and completely out of it. I had to tell [the receptionist] that there was a bottle of pills on the floor next to the guy. I also saw two guys meet inside LPRC and then walk across the street and do a drug deal, then calmly walk back in. I couldn’t wait to get out of there…What happened to taking care of people with HIV and Hep C?

David echoed this feeling when he observed that certain staff members seemed burned out and did not have enough time or energy to give to clients. Cameron admits that he “misses the social aspect that LPRC had to offer,” as do Tome and Eli, who said, “I have been to LPRC a couple of times but it has changed so much that I really don’t feel comfortable there, so my life will go on without them.”

It is significant that the participants who feel the most alienation were regulars in the LPRC office prior to the transition, whereas the ones who were less negatively affected visited far less frequently. This was particularly true for the women, all of whom would only come to LPRC infrequently, for very specific reasons and who had nothing negative to say about the way
the agency currently operates. It is also significant that those feeling acutely alienated are gay men. LPRC, before the transition, as an ASO strictly for HIV and hep C, was able to meet the needs of gay men with HIV in a more targeted manner than LPRC post-transition. This is not a problem exclusive to LPRC; rather, many ASOs are facing shifts of a similar nature as HIV is becoming more widely recognized as a disease that affects a variety of subpopulations in Canada, including Aboriginal peoples, injection drug users, and women. It is fair to ask then, how older gay men with HIV are faring in this new order. If ASOs are no longer a place for gay men to find support, one would assume that other LGBTQ-specific communities would be available but, in Kelowna, this is not necessarily the case.

**Interviewer:** What do you think about the gay community here?

**Eli:** It sucks. I have nothing to do with it. They’re all 25 and younger and way too feminine for my liking, and I just don’t really fit in.

**Interviewer:** Do you think that’s a common feeling?

**Eli:** I think so. I mean, I’ve stopped in at the [LGBTQ] drop-in centre a couple of times and it ... it’s just not my crowd. I feel very misplaced and out of place.

What Eli is describing is quite typical of the gay community in the Okanagan. The activities and events run by the local LGBTQ association are mostly evening gatherings, such as dances and socials with music and alcohol. People who don’t want (or cannot afford) to drink or buy tickets for such events are excluded. Even the general climate of (non)acceptance of LGBTQ can be

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9 Between 2001 and 2010, the rate of infection in males in BC decreased significantly, from 328 new reports to 238 new reports. The rate in women has decreased overall, but the trend has been more erratic and less significant (87 new reports in 2001, 80 in 2002, 87 in 2003, 105 in 2004, 77 in 2005, 72 in 2006, 85 in 2007, 59 in 2008, 71 in 2009, and 63 in 2010) (BCCDC 2010:39). Although the majority of HIV cases in BC are Caucasian people (at 35, the second most commonly infected group is Aboriginals, and Aboriginal women in particular. Aboriginal women represented 33 percent of all new female infections in 2010. This is despite the fact that Aboriginal people only make up approximately 3 percent of the total provincial population (BCCDC 2010:42). From 2001 to 2010, in the Interior, Northern, and Vancouver Island Health Authorities, injection drug use has typically accounted for more new HIV cases than MSM (BCCDC 2010:46).
socially inhibiting for gay men in Kelowna. Adrian says, “I’ve been discriminated against lots because I’m gay. Because I’m completely out.”

It is useful to contextualize LPRC’s transition within the wider sphere of social and health services for PLWHA in British Columbia, most of which are located in Vancouver, the province’s major urban centre approximately 500 km away from Kelowna. Several organizations for PLWHA have been established in Vancouver’s downtown core over the years and many of their services are dedicated to increasing food security. AIDS Vancouver and the Positive Women’s Network (PWN), for example, have banded together to provide a food bank and a grocery delivery service for their local clients. A Loving Spoonful has been providing free meals to PLWHA in the Greater Vancouver area since 1989. Other organizations, such as Vancouver Native Health Services and WISH Drop-in Centre Society, have food-related programs that can be accessed by PLWHA, provided they fall into the organization’s population of mandate. Still others, such as the Union Gospel Mission, provide free meals to anyone in need.

The centralization of services for PLWHA in the Vancouver area has implications for how well the HIV-positive population in the rest of the province is served. For example, although the Positive Living Society of BC (PLSBC) is technically a provincial organization dedicated to serving PLWHA throughout British Columbia, only a tiny portion of their services can be accessed by people living outside of the Greater Vancouver area. Advocacy through PLSBC for people in other parts of the province can only be done over the phone or via email and this is often too impersonal or impractical to be effective for anything beyond answering the most basic of questions. The same holds true for the Positive Women’s Network, another provincial non-profit. Perusing the websites of PLSBC and PWN might lead one to assume that everyone with
HIV in BC lives in Vancouver. Certainly, a high proportion do (and this could be because the services are there, an “if you build it they will come” philosophy). However, I can say with certainty from my experience in working with PLWHA outside the Vancouver area that these agencies are simply not meeting the needs of PLWHA in other parts of province, nor can they be expected to.

**Concluding Thoughts**

The work of being well includes accessing and maintaining health care and social services (including the work of having supportive and productive relationships with health and social service providers); and having productive and supportive relationships with family and friends and other social links. Unfortunately, many participants were unable, for various reasons, to have these types of positive relationships and their wellness suffered because of it. Although only *some* participants had relationships that facilitated food security, *all* participants had relationships that both facilitated *and constrained* food security. If we widen the scope of facilitators and barriers to “social life” as a whole, it is significant that of the 12 participants, five stated that their social life was virtually non-existent. Four had social networks that were limited to close family (although they did not necessarily feel supported by family) and three had networks that extended to workmates, friends, and peers in interest groups and support groups.

Participants who were extremely isolated described their lack of relationships as the result of other issues and circumstances, some personal, some institutional. These experiences illustrate the social aspects of food security as being a personal/institutional binary, wherein institutions impact upon personal issues and vice versa. Nate, for example, has a full-time job
and a roommate; yet, describes his social life as “nil.” Having once regularly attended a men’s HIV support group, he decided to stop going to the group meetings because he found himself giving off too much negativity to those around him:

**Interviewer:** because they’re feeling isolated, or because they’re working so much that they just don’t have time, right?

**Nate:** Yeah … a combination of both. I’ve, uh, the work situation’s not been good and I’ve found what social life I did have, I didn’t like the way I was presenting myself … too much negativity. And so I’ve withdrawn more and more and more.

**Interviewer:** Can you give me an example of that, of how you were negative?

**Nate:** I find that every time I’m around, [I] never see the good in anything, and uh, consequently, I don’t want to be…um, seen that way, as a person who’s so negative? I’d rather not be seen at all.

**Interviewer:** Do you know why that was happening?

**Nate:** Well … I think it’s uh … not being able to get any resolution to this problem, with work and stuff. So I’m not, I’m not, uh … able to resign myself that I need to go on disability. And I find when I’m around the group, they push that on me too much and I’m afraid that I don’t have the strength to say no, that’s not where I wanna go.

Although Nate thought the support group would help him deal with his workplace stressors, he often found himself pressured by the group to leave his job and collect disability income. In this way, the group proved to be more a source of frustration than relief. In the end, Nate’s direct reason for pulling away from the group was personal yet, stemmed from institutional issues, including his unwillingness to receive income from a government program.

For some, isolation was more directly linked to a limited income that didn’t allow for social outings to be performed in the expected fashion or frequency. Seth was quite aware of how expensive (and taken for granted) many food-related social activities can be:

> if you’re going to go out and have coffee each day, coffee and a donut and stuff like that, you blow like a hundred bucks a month, just on coffee and a donut. I’ve just never been able to do that. Once every six weeks I’ll go for coffee and a donut.
The inability to perform socially results in a cyclical bind wherein people become isolated because of physical health, and health becomes poorer and poorer because of lack of social support.

Translocal relations of ruling—powers that exist geographically and socially “away” from the people they control (Smith 2006)—are made explicit through the analysis of texts that regulate the work of being well. Application forms, websites meant to educate healthcare professionals, lab reports for CD4 and viral load tests, prescriptions and other written forms of documentation reveal that local realities of living with HIV are not well understood by the provincial and national institutions responsible for the care and support of PLWHA. Meanwhile, an analysis of social spaces shows the influence of affluence in whether or not people make connections with one another and obtain the social and health support they so crucially need. The current office of Living Positive Resource Centre, for example, makes some participants uncomfortable and unwilling to access services, even if they would benefit from them. The decision to change the agency’s mandate and location, however, was not made by people who best understand the local needs of PLWHA in Kelowna but rather, by people in the regional health care institution who were interested in having the agency justify its existence through increased numbers of clients, regardless of whether or not they are HIV-positive.

The prevailing level of affluence in Kelowna helps to determine how comfortable PLWHA are in their city and how easy it is to access social and health support services. The fact that many of the institutions and agencies that exist to help alleviate the issues associated with poverty, disability, and hunger are located in less visible spaces only acts to further marginalize problems that few people want to acknowledge. Speaking more broadly, the fact that Kelowna...
has no visible “bad part of town” means that these problems do not get addressed, even though many people here live below the poverty line and deal with serious chronic health issues.
Chapter 8: The Work of Navigating Discourses of HIV/AIDS and Food Security

The nature of this chapter is somewhat of a divergence from the previous findings chapters, since it is based on data that happened largely outside of the official fieldwork setting, in my being raised in, living in, and working in this particular locale. The experience of growing up in Kelowna in the heyday of the AIDS epidemic, along with the cumulative effects of particular instances in which HIV/AIDS was “handled” by teachers, co-workers, friends, and others in the community over the years, gives me an insider’s eye on the culture surrounding the epidemic. Thus, this chapter is both institutional ethnography, due to its analysis of texts that have been influential in shaping people’s opinions about PLWHA, and autoethnography due to the incorporation of stories from my (distant and recent) experience with HIV/AIDS education, working at an ASO, and working with PLWHA. Nancy Taber’s institutional ethnographic work on women in the military utilized autoethnography to circumvent some of the methodological challenges of researching such a hierarchical, male-dominated institution. For her, autoethnography allowed a freedom to explore how her own experience connected to the formal organization of the military or, as she puts it, the connection “between self and social” (2010:14). In this chapter, my aim is to explicate how the broader societal discourses around HIV/AIDS and food security have come to affect PLWHA in Kelowna. This discourse has accumulated over decades, from numerous sources—the mass media, popular culture, the education system, etc.—and indeed, continues a dynamic journey into the future, whatever that may hold. What I am discussing here is how these sources have, over the years, contributed to a certain “climate” around the topic of HIV and AIDS in Kelowna. Spry defines autoethnography as “a self-narrative
that critiques the situatedness of self with others in social contexts” (710)—a methodology that rejects notions of generalizability and objective “truths,” and recognizes the importance of positioning the researcher within the research context. Embodied experience of the social world within which one exists becomes a valid way of expressing knowledge of that society so long as one’s place within it is reflexively critiqued. As Spry explains:

The autoethnographic text emerges from the researcher’s bodily standpoint as she is continually recognizing and interpreting the residue traces of culture inscribed upon her hide from interacting with others in contexts. This corporeally textual orientation rejects the notion that “lived experience can only be represented indirectly, through quotations from field notes, observations or interviews” (Denzin 1992:20). In autoethnographic methods, the researcher is the epistemological and ontological nexus upon which the research process turns (2001:711).

Having grown up in Kelowna and lived here for much of my life, I believe my experiences are shared with others of my generation, particularly those who grew up in rural areas and small urban centres. As a child of the 1980s, I feel authorized to discuss the discourse of HIV/AIDS in the same way a child of the early twentieth century might feel authorized to speak of the Spanish influenza pandemic—we would both have a localized understanding of a global phenomenon. In the following pages, I have woven together social sciences and humanities research with some personal experiences, stories of others, opinions of my participants, and media analyses to provide a distinctly small-town North American account of HIV from the early 1980s to the present and to support the notion that, in a scant 30 years, HIV has gone from “death sentence” to “chronic illness” in the HIV care and research community - a community that is very influential in the lives of PLHWA. Over the same time period, HIV has remained a death sentence in the collective imagination of much of North American society, particularly in rural areas and smaller urban centres, and this is equally influential to PLHWA. Both of these extreme
viewpoints present major social, physical, and economic challenges for PLWHA. In effect, the
dichotomy of “death sentence” vs. “chronic and manageable” is yet another double bind that
PLWHA experience on an everyday basis in the Kelowna. Faced simultaneously with health care
practitioners who say that HIV manageable and a general public who know little about HIV and
still fear it, PLWHA undergo significant cognitive and emotional stress, which can negatively
affect their provisioning and overall health.

In this chapter, I also discuss the current discourse around food security and how this
plays into the provisioning stresses experienced by my participants. Another double bind arises
in the paradox between a growing societal awareness of the importance of healthy, sustainable
food systems, and the shame and guilt brought on by not be able to participate economically or
socially in those systems.

HIV as a Unique Disease

One distinct difference between HIV and certain other pandemics like the Spanish flu or
Severe Acute Respiratory Syndrome (SARS) is that HIV has lasted for decades, whereas the
pandemics of recent memory have had a far shorter duration and, “in contrast to other major
epidemics, the AIDS epidemic has no rapid rise, obvious peak, or rapid decline” (Kallings
2008:218). Not only is HIV unlike other pandemics; it is also unlike most other chronic diseases
and therein lies its essential dichotomy of being both infectious and incurable. In Canada,
cardiovascular diseases, respiratory diseases, and diabetes together account for 42 per cent of
total deaths, whereas communicable diseases and maternal, perinatal, and nutritional disorders
only account for five per cent of total deaths (WHO 2011:1). Often, chronic diseases (i.e. those
typically classified as noncommunicable) are considered “lifestyle diseases,” conditions created in large part by individual and social behaviours. The World Health Organization (2011), for example, lists daily tobacco smoking, physical inactivity, obesity and overweight as major risk factors for chronic disease. HIV is a virus; one either has it or one does not. There is no genetic predisposition or inherent risk factor. There are, however, behaviours, such as anal sex and injection drug use, that put people at risk, and those behaviours are highly stigmatized. The tension of being both chronic and communicable and the historical progression from being a disease considered purely infectious and deadly to a disease considered chronic and manageable in the eyes of people who hold power over the health care and support of PLWHA, has shaped the discourse around HIV and AIDS. The following section looks at the way this progression happened over time and at some of the cultural manifestations of the discourse.

HIV is widely believed to have crossed the species barrier to humans through the consumption of chimpanzees or sooty mangabeys in sub-Saharan Africa over a period of decades or even centuries (Fauci 1999:1046). By 1981, the virus had found its way to North America and made itself known to the world, when cases of Kaposi’s Sarcoma, a rare form of lymphatic cancer, appeared in gay men in San Francisco (Fauci 1999; Frascino 2010:1; Treichler 1987:266). Whatever was causing the cancer (and the death that usually soon followed), quickly became known as a “gay” disease called Gay-Related Immunodeficiency or GRID (Frascino 2010:1; Wilder 2007:1). The stigma of being gay and/or having homosexual sex was fueled by media representations such as the one below:
When, in 1983, Luc Montaigner isolated the virus (NIH 2013), the faulty GRID acronym was dropped but the stigma of homosexual sex in relation to the disease was already firmly and widely established and continues to this day. The early days of the HIV/AIDS crisis were marked by widespread fear and discrimination, not just of the gay community (Goldin 1994:1360). Children with HIV in certain towns were barred from attending school out of fear that they
would inadvertently infect their classmates and teachers\(^\text{10}\) (Sotto 1986:194). Even if students were not directly affected by the virus, classrooms were places in which fear could be unintentionally perpetuated. In 1987, my grade seven elementary school class was shown an educational video about AIDS. The music was ominous and the imagery was shocking, with depictions of T-cells as warriors in the battle for the immune system and photos showing emaciated AIDS patients with piles of pills on their bedside tables. The figures below are further examples of such fear-based messaging.

\(^{10}\) There were many instances, some documented and some not, of children with HIV who were discriminated against in various ways, including being banned from attending school. Ryan White, born in Kokomo, Indiana, was probably the most famous of children who endured such stigma. Infected with HIV during a blood transfusion for haemophilia at age 13, Ryan was barred from attending school and after numerous other threatening and violent attacks (including having a bullet shot through the living room window of their home), his family relocated to Cicero, Indiana where he returned to school. His fight for rights for PLWHA garnered the attention and support of celebrities and politicians who, with his mother, helped to successfully pass into U.S. legislation the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (Saag 2009:1). The Ray brothers—Ricky, Robert and Randy—were another famous case. Living in Acadia, Florida in 1986, all three brothers were haemophiliacs and were infected via blood transfusion. They were barred from attending school, and the following year, while the family was out, their home was burned down by other members of the community. The family moved to Sarasota and the boys attended school there. Ricky died in 1992; Robert in 2000. Randy, the youngest, is still alive. The Ricky Ray Hemophilia Relief Fund Act of 1998 provides funds to people who were infected with HIV through transfusions arising from clotting-related disorders.
Figure 13. Poster from the New York City Department of Health, circa 1980s. Reprinted from the National Institutes of Health archive “Surviving and Thriving” (NIH 2013; Creative Commons)
No doubt such films and ads were intended to frighten people into avoiding risky behaviours; whether or not the approach was successful (although we may conclude, if we go by prevalence rates, that it was not) is beside the point in the discussion of stigma. What is a valid question, however, is whether in their rush to scare, the creators of such content produced useful information or helped to foster an environment in which populations were either overtly or indirectly discriminated against. A content analysis of 56 public service announcements (PSAs) from the US Centers for Disease Control and the National Institute on Drug Abuse from 1987 to 1996 (DeJong et al. 2001) shows that messaging in such ads during those years was related to
conservative values and could actually have contributed to an increase in incidence of HIV. For example, only four percent of the PSAs were targeted to gays or bisexuals (251), even though medical officers and policy makers knew that men who have sex with men were one of the highest risk populations for the virus. Of the PSAs that discussed sexual behaviour, only nine percent mentioned condom use, even though condoms were/are widely acknowledged to be the best protection against HIV. Out of that nine percent, only five per cent discussed real-world issues, such as barriers to condom use, and only four per cent discussed practical skills for negotiating condom use with a partner (254). As some cultural commentators have noted (see Herek et al. 2002; Sotto 1986), the stigma created and perpetuated by these media presentations of HIV/AIDS contributed to misunderstandings in the public that withstood years of research to the contrary:

The American public has attached to this disease a stigma far worse than that which the medical community believes is justified. Although medical experts have claimed ‘with assurance’ that AIDS is ‘an extremely difficult disease to catch’ and is not transmitted by casual contact, a recent poll shows that more than one half of the American public believes otherwise (Sotto 1986:193).

By the mid-1990s, antiretroviral therapy had been in use with HIV patients for a decade (De Clerq 2010:507) but the development of highly active antiretroviral therapy (HAART) was the real turning point in being able to name HIV as a chronic disease (Mahungu et al. 2009:125). “The transformation attributed to these treatment measures has extended life expectancy to the point where management has become longitudinal” (Baer and Roberts 2002:116).

In many locations and populations, the stigma created by the “death sentence” discourse continued. I would argue that Kelowna was one of those locations and, as a community, has still not come to an understanding of HIV in either a theoretical or practical sense. Sociologists owe
much of their understanding of stigma to Goffman, who defined it as “an attribute that is significantly discrediting” (1963, in Parker and Aggleton 2003:14). Goffman described one type of stigma as “abominations of the body” (1963, in Goldin 1994:1360), to which HIV could certainly be prescribed, if a person’s HIV is known through either obvious signs or through disclosure. I draw on Veblen, below, to ground the discussion of perpetuation of such stigma as it might happen in affluent society:

A readjustment of men’s habits of thought to conform with the exigencies of an altered situation is in any case made only tardily and reluctantly, and only under the coercion exercised by a stipulation which has made the accredited views untenable. The readjustment of institutions and habitual views to an altered environment is made in response to pressure from without; it is of the nature of a response to stimulus. Freedom and facility of readjustment, that is to say capacity for growth in social structure, therefore depends in great measure on the degree of freedom with which the situation at any given time acts on the individual members of the community—the degree of exposure of the individual members to the constraining forces of the environment. If any portion or class of society is sheltered from the action of the environment in any essential respect, that portion of the community, or that class, will adapt its views and its scheme of life more tardily to the altered general situation; it will in so far tend to retard the process of social transformation. The wealthy leisure class is in such a sheltered position with respect to the economic forces that make for change and readjustment. And it may be said that the forces which make for a readjustment of institutions, especially in the case of a modern industrial community, are, in the last analysis, almost entirely of an economic nature (Veblen 2003:129).

Although Veblen’s talk of conservatism referred to the maintenance of certain traits that contributed to the preservation of economic values and systems, the root concept, “conserve,” remains sound for this analysis. Indeed, Kelowna is “sheltered from the action” of HIV/AIDS. In my advocacy work I was reminded of this when I encountered people, told them what I did for a living, and was met with the question, “Oh, is that [HIV] a problem here?” On one occasion at work I received a call from a woman sounding rather frantic. She asked if HIV can be transmitted by drinking from the same glass as someone who is HIV-positive. I explained that it
was very low risk unless both parties had been actively bleeding in the mouth. She was relieved; our discussion revealed that she was a street outreach nurse in a nearby community. This was but one example of the level of ignorance and fear in Kelowna—shocking to witness in a nurse, but commonplace in the general population. Grounded in the activist gay community of the early 1980s, Vancouver was and continues to be set apart from the rest of the province as the centre of HIV support and research. If we take Veblen at face value, then certainly the sheltered affluence of Kelowna has contributed to its painfully slow social transformation with regard to HIV.

Unfortunately, the “forces which make for a readjustment of institutions” do not yet provide enough economic incentive for the wealthy population of Kelowna to sit up and take notice of the poverty and chronic illness that exists in their city. As discussed in Chapter 6, the expectation for PLWHA to look a certain way must factor into the lack of knowledge and understanding of HIV and AIDS in Kelowna and other places like it. My own experience attests to what might be a typical mindset toward PLWHA in this locale: Prior to beginning my work as an advocate at Living Positive Resource Centre, I was under the impression that I had a good understanding of HIV and the social determinants that put people at risk of infection. Upon starting the job, I quickly realized that understanding was partial and purely theoretical—not at all grounded in lived experience. I also realized that the fear I had of AIDS as a child persisted within me, and that it would be a detriment to doing my job well. I had to re-orient my understanding of the subject and of the people I was working with and, over the course of weeks and months, this did happen. HIV was no longer terrifying and I came to view clients very differently from when I began the job. At first, there was pity and sadness that they had contracted an incurable disease capable of producing an immense amount of suffering. Steadily, the pity and sadness turned into
respect and an appreciation of the nuances of the HIV experience. HIV was no longer terrifying, but rather a disease whose trajectory played out differently for each person I met. I am fortunate to have had the opportunity to realize this but it was necessary for my work; most people do not have such an opportunity because it is not thrust upon them like it was for me. For the majority of the population, then, HIV remains terrifying. The problem is, it is no longer visible enough for most people to even consider nowadays. PLWHA don’t look sick like they once did; AIDS isn’t a crisis anymore. This is essentially a “non-issue” in the global north. Yet, people still become infected every year and people who were diagnosed decades ago must continue to live with a disease that is still synonymous with death in many people’s minds.

**Chronic and Manageable (?)**

The word “chronic” implies something that recurs and/or happens over a prolonged period of time. The U.S. Centers for Disease Control and Prevention state that chronic diseases are “noncommunicable illnesses that are prolonged in duration, do not resolve spontaneously and are rarely cured completely” (USCDC 2009). HIV does not technically fall into this category for the CDC’s purposes because it is communicable. However, it does fit the other three dimensions for being prolonged, unresolved and incurable. The World Health Organization, likewise, would not technically classify HIV as a chronic disease but we can see how HIV would fit certain characteristics of the WHO definition as well: “chronic diseases are diseases of long duration and generally slow progression” (WHO 2013). In a similar vein, the Ontario provincial government framework for preventing and managing chronic disease states that chronic diseases are “long-
term diseases that develop slowly over time, often progressing in severity and can often be controlled, but rarely cured” (2007:3).

Despite its continued primary classification as a communicable infection, most HIV specialists, HIV-aware physicians and nurses, and HIV researchers, talk of HIV as a “chronic and manageable” disease (Baer and Roberts 2002; Broder 2010; Mahungu et al. 2009; Siegel and Lekas 2002). What are the implications for PLWHA of naming HIV “chronic”? Terry Wilder, social worker and blogger for The Body (a well-known online educational resource on HIV/AIDS) wrote that “the language that has been used and associated with this disease continues to construct images and perceptions about the meaning of this disease” (2007:1). Although Wilder was discussing the historical association of gay men with HIV and AIDS, the same could be said for the term “chronic and manageable.” Baer and Roberts (2002) note that although HIV can now technically be considered a chronic disease, it is necessary to understand that quality of life for PLWHA is individually experienced and based on a variety of factors, not the least of which is adherence to a very complex medical regimen that made HIV a chronic disease in the first place: another double bind.

Before his death in 2011, Dr. Robert Frascino, an HIV-positive physician, Fellow of the American Academy of Allergy, Asthma, and Immunology and clinical professor of medicine at Stanford University Medical Center, wrote a special column about HIV as a chronic disease for his blog, “Life, Love, Sex, HIV, and other Unscheduled Events” on The Body.com. In this post, he discusses the trials of other doctors who have written him for advice on dealing with their HIV-positive patients, as well as the troubles of PLWHA with whom he had come into contact. Lipodystrophy, lipoatrophy, accumulation of visceral abdominal fat, severe diarrhea and
constipation, and social stigma are just a few of the conditions that Frascino claims make HIV less than “manageable” (2010:1). In a similar vein, Janet, a blogger on British Columbia’s Positive Women’s Network (BCPWN) website states:

We mustn’t lose sight of the people taking pills. There are things that can get in the way of being able to be on treatment in the way it’s needed for success at managing HIV. There are primary needs issues like poverty, no housing (or crummy housing), child welfare, welfare itself, scarcity of food, a controlling or violent partner, a community where you get no privacy and don’t want to risk exposure. But even if you can put food in your belly and have a warm safe bed, things that HIV presents aren’t lacking: changes in self-image and body-image, worries about never having sex again (if you’re single) or disclosing existing sex partners (if you’re not). As a friend who’s been positive for over ten years and is a national activist once told me, “Disclosure never ends and it’s always stressful” (2010:1)

Scot Charles, another blogger on The Body.com, describes his personal experience with HIV-related dementia:

The primary targets of HIV are the mood controlling structures in the brain and then later the cognitive parts of the brain and then those parts that control the limbs. The cognitive effects of HIV infection are primarily in the executive brain functions which allow us to choose between competing actions, to assimilate new information, and to analyze data. Because the executive functions are most used by professionals, early HIV dementia is most often diagnosed among those people. I am one of those professionals. Due to damage to my executive function, I retired on disability in 2008 (2010:1).

The American Psychiatric Association provides a more clinical but nonetheless accurate picture of the cyclical effects of HIV on mental health:

Over time, these stresses and negative feelings can rob you of the emotional energy necessary to move forward with your life. Lack of progress in your recovery or worsening symptoms can trigger negative thoughts that heighten feelings of anxiety and sadness, often leading to depression. Acting quickly to address depression is essential. In studies of patients recently diagnosed with various types of chronic illnesses, the highest risk of depressive symptoms occurred within the first two years. While these symptoms usually diminished, patients with heart disease maintain a significantly higher risk for depression as long as eight years after diagnosis. Physical limitations imposed by heart disease and other chronic illnesses such as arthritis and lung disease are also a common
source of depression, particularly among older adults. Because depression often leads to poor eating habits, lack of exercise, and inconsistent hygiene, it may actually complicate your recovery from a chronic illness and worsen your overall physical condition (APA 2013:1)

Thus, when PLWHA are “managing” their “chronic” HIV, what they’re really managing is not only a potent, mutable virus, but also a host of subsidiary problems, from medication effects, to chronic pain and depression, to dementia. Some of the participants in my research described their feelings about HIV being heralded as a chronic and manageable condition. Eli had this to say about comparisons between HIV and other chronic diseases:

_Interviewer:_ I’ve heard some people [other participants] say, well, yeah it’s chronic and I can manage it, but it’s way more difficult to manage than a lot of people think it is.

_Eli:_ Oh, absolutely!

_Interviewer:_ So, I think some people go, “Oh, it’s like diabetes now. You can manage it.” And I don’t think you can really make that comparison.

_Eli:_ No. No, it’s not. It’s nowhere near the same. And I think partly why it’s not the same is because there is still so much stigma around HIV, compared to being diabetic.

Kent discussed the health problems he has faced over the years, and how difficult they were to manage:

_I find that even, even the comments now, about it being manageable ... you know, chronic disease where it’s ... no big deal anymore ... to live what I’ve gone through in the last 15 years has been hell. It has been hell. I may as well have been dead...I think, from what I’ve gone through. It’s ... way too much. Like, all the health problems I’ve had, all the hospital stays I’ve had, you know, the treatment of the hospitals and the nurses and doctors ... People with HIV... I don’t think people have any idea what we go through on a daily basis. Just, it’s... it’s like ... we may as well be in another world. That’s what it seems like, that we’re in the wrong world. That’s how I feel, like I’m not ... It’s all I think about, you know, it’s like, you know, my heart or my liver or my pancreas or something ... it either hurts or, there’s pain, constant pain, constant. I don’t know if I worry, as much as I used to, about what people thought of me with HIV; I had that for a long time, but that’s going.
Nate expressed frustration and guilt at the “chronic and manageable” label:

*I think it lowers my self-esteem to be always told that it’s manageable. ‘Cause I’m always questioning myself—okay, you’re not managing it as well as you should be. So it becomes more and more... to me it becomes a real negative reinforcement. It’s so difficult to get your meds and get those appointments and every time you... I miss a meal or anything, or, you know, you know what I mean... It’s like I’m always digging myself for not being as responsible... you know?*

*Interviewer:* Right. It’s manageable, but managing it is a big task.
*Nate:* It is a big task.
*Interviewer:* Yeah, and so if you don’t measure up to those expectations, then you can beat yourself up, basically.
*Nate:* Mhm. I’m constantly doing that. And I think similar ideas have been expressed in the [HIV support] group when I was going there. You know, the manageable ... and it’s very cyclical; there are times when it’s ... it doesn’t feel so manageable.

Janet from BCPWN echoes Nate’s concerns when she discusses the push by outsiders for chronically ill people to be optimistic.

*Optimism is important. But it is one of many avenues a person might travel in a day when dealing with life changing diagnoses like HIV or cancer. A presumption that a person should always make the best of it is like putting a bearing rein on horses that holds their heads in place and can inhibit them from putting their heads down into hard work. It’s not the best support we can offer (2010:1).*

*Stigma also must not be forgotten. I believe that the discourse surrounding HIV over the past three decades has contributed (at the very least) to isolation and perceived or “felt” stigma (Bogart et al. 2008) among PLWHA. In other words, even if discrimination is not overt and explicit, PLWHA expect that it might become so and are wary of disclosing their status and/or openly discussing their HIV with others, even those close to them. Several participants touched on the topic of disclosure in our conversations about social life. Perhaps, though, the most*
pointed illustration of wariness about disclosing came from a personal experience I had early in my time as an advocate. Not long after I had begun work at Living Positive Resource Centre, I found out (because he had been a client of the organization for some time) that a person I had known for several years was HIV-positive. When we talked about it, he apologized for not having told me sooner. He explained that he is very careful with disclosing his status and that very few people know, even in his immediate social circle. I must add here that I share numerous friends in this social circle and that they are very open-minded, loving and caring people, hardly the kind who appear judgmental or would discriminate based on health status. This double bind of guilt and fear—the guilt of not telling people about having what can be a debilitating disease, even if the potential exists to get much-needed support for coping with said disease, and the simultaneous fear that telling people would alienate them permanently, negating the chance to get support—seems typical and is another double bind faced by PLWHA in this region.

**Food Security Discourse**

For the general public, food security is a relatively new concept. However, as opposed to HIV, which seems to have largely retreated from people’s minds as an immediate concern, food security is growing in the public imaginary. Climate change is currently a major issue in news and social media and the question of consistent, affordable, and ethical food supply is brought up repeatedly in public appeals from environmental organizations and other concerned groups. In popular leisure culture, too, food is taking centre stage in a variety of media. The Internet has allowed for free and easy exchange of recipes, information on products and ingredients, as well as the capacity to provision online. People in the global north are acutely aware of what they are
eating and are being given more choice than ever in what is available to eat. Not being able to buy nutritious food and struggling with the balance between ethical buying and healthy eating was one of the prominent themes in my conversations with some participants. For example, David, who is Aboriginal and grew up on Vancouver Island where fishing is both a cultural and economic mainstay, describes eating meat in relation to his family history:

**David:** Chicken, I’m not bad with. I seem to be okay with the chicken. It’s like the fish, just so much about my family that I associate to meat eating, that it seems to be a little bit sometimes ravenous (chuckles).

**Interviewer:** Okay. ‘Cause you’re from the coast...

**David:** I’m from the coast, and it’s like oh my God, all that killing … for all the fish and all that… it’s just, there’s some … moral, not moral, but some emotional, ethical issues. … When the fish were on the boat and they were all flapping, I was weirded out, like… I honesty, if I really channeled in, like if I let my mind go to the places where it wanted to go… I was inside the fish, suffocating. And I just felt like, fuck man, I’m gonna sell that for drugs? You know, my guilt is really high around fish. It really is. You know, I really gotta make good with that again, that spirit, because I really believe if I want to walk this spiritual walk and have the spiritual feelings that I believe are entitled to all of us, that I have to make myself really, really cool with things.

Similarly, Adrian went through a period during the research process when he decided to buy organic food as much as possible for health and ethical reasons. Our grocery shopping trip took us to three different stores, one to buy fresh vegetables and fruits, one to buy bottled water, and one to buy locally-raised meats. Unfortunately, Adrian was only able to buy and eat in this manner for a few months until his income was reduced.

The widespread social discourse related to organic food and “eating locally,” plays into conundrums like those felt by Adrian and David and lead to another double bind in which people are bombarded with information about the “ideal” food to eat for good health and, simultaneously, about how the foods we typically eat are exactly the opposite—that is, unhealthy,
pesticide-laden, and shipped from the other side of the world. Meanwhile, food companies advertise decadent, fat-and sugar-laden desserts and snacks, telling us that we “deserve” them. Do-it-yourself websites and other popular web spaces such as Pinterest and Facebook provide the antidote to unhealthy eating habits in the form of thousands of ideas, opinions, projects, and instructions on growing healthy food, cooking healthy food, dieting for health, cleansing, and the like. While such information is useful in raising awareness of many valid concerns and trying to offer practical solutions to them, being inundated with the information can be overwhelming and guilt-inducing, much like the chronic and manageable discourse discussed earlier. Participants know they should be eating healthy things, but cannot afford to buy them and/or do not have the time, space or energy to grow them.

Concluding Thoughts

This chapter explored the connections between discourse and coping with HIV/AIDS and food insecurity. It was interesting that, in discussions of food and nutrition with participants, the “chronic and manageable” issue came up quite often, sometimes without me explicitly asking about it. Although wider social and medical discourse is not necessarily directly related to provisioning, the notion of manageability does connect closely with being able to afford, obtain, and eat food. These discourses are embedded in and work to create texts that regulate the socio-economic environment. Thus, PLWHA not only do work to navigate the texts that pertain to HIV in some direct or indirect way; they also work to navigate and negotiate the emotion-fueled, fear-based, discriminatory, politically-, sexually- and racially-charged discourses that represent a widely-held social imaginary.
Whether the imaginary conjures homophobia, unnecessary fear of infection or a more generalized discrimination, is largely determined by individuals’ varying circumstances and, as the quotes above show, can manifest as frustration (as in Eli’s comparison of HIV-related stigma with the more normalized diabetes), overwhelming fatigue and pain (as in Kent’s description of his myriad health issues and surprise at still being alive) and guilt (as in Nate’s description of feeling badly for not coping in the “expected” ways).

All of these manifestations can occur as double binds for PLWHA. Likely, the most broadly felt bind would be in the tension between “death sentence” and “chronic and manageable” and the inability of the virus (and therefore of PLWHA) to fit neatly into either one of those categories. Stemming from this is the invisibility of PLWHA now that HIV is widely considered a chronic disease: it bears asking if the “chronic” label has diverted attention away from HIV as a primarily communicable disease, resulting in people taking the risk of HIV infection far less seriously than they used to. Indeed, many have speculated that this message could be one of the contributing factors in the painfully slow decrease in infection rates in North America, given that HIV is entirely preventable and that, really, only long-standing fear and unwillingness to openly discuss practical prevention strategies stand in the way of eradication.

The description of World AIDS Day 2004, in Vancouver, by Tyee writer Jessica Werb, bears witness to the ambivalence people currently feel about HIV and AIDS causes. The article quotes Vancouver councilor and co-founder of the HIV service organization Friends for Life, Lorne Mayencourt:

‘I think there’s a fair bit of apathy that’s become attached to HIV/AIDS,’ he told me. ‘Some of that has to do with the fact that, as a community, we’ve gone through so much of it that you kind of get bored with it—you start to numb yourself out of being aware of it’ (Werb 2004:1).
Certainly, burn-out from depressing causes might contribute to the apathy Mayencourt describes. However, the notion of (in)visibility also plays a role. Later in the article, Werb talks to Paul Lewand, Chair of the Positive Living Society of BC who says,

‘The general public has always tended to not pay attention to poor people... They don’t care about the welfare and the wellbeing of prostitutes and drug addicts. They’re not the pretty people, they’re not the loud people … It’s just easier to forget. It’s not nice to look at’ (Werb 2004:1).

Lewand indicates that the Vancouver public chooses to support other causes because HIV is not the fashionable thing anymore. In Kelowna, we do not support HIV because we cannot even see it; it has never been on the public radar in the same way as it once was in Vancouver. Sadly, this invisibility is sometimes reinforced by the very institutions that work to eradicate the disease.

For example, the BC Centre for Excellence in HIV has produced the STOP HIV campaign over the course of several years. STOP stands for Seek and Treat for Optimal Prevention (BCCE 2013:1). Two of STOP’s main programs are It's Different Now (IDN), and Make HIVStory. The “Facts” page of the IDN website are frustratingly ironic when viewed in light of the situation in Kelowna (and arguably, other small centres like it): the four short headings, each of which is followed by a very succinct explanatory paragraph, are: “HIV doesn’t discriminate; You can’t see HIV; HIV is a treatable disease; and, Treated HIV rarely progresses to AIDS” (VCH 2013:1). These statements are true; the BCCE is not trying to obfuscate the reality of living with HIV; rather, they are trying to make people less afraid of HIV so that testing and treatment are more accessible. However, this discourse reflects a lack of understanding of how HIV is perceived (and has historically been perceived) in smaller affluent communities that never really knew HIV “was a problem” there in the first place. The double bind at this level of the problematic, then, is that PLWHA are caught between “death sentence” (something to be feared and pitied)
and “chronic illness” (something to be written off as easy to deal with). Neither fear nor apathy are helpful to people already living with the virus.
Chapter 9: Discussion and Implications

This study built on the research of Normèn and colleagues (2005), which found that people living with HIV in the province of British Columbia are five times more likely than the general population to be food insecure and/or hungry. Answering their wide-reaching, quantitative study, I attempted to provide in-depth, qualitative answers to both why food insecurity and hunger is more prevalent in PLWHA, and how PLWHA deal with issues concerning food. As mentioned in the introductory chapter, although I originally thought that my research findings would be about food and food security, what actually happened was that food turned out to be a lens through which to view a multitude of issues around quality of life and wellbeing. As research progressed, I discovered that many problems and strategies used by my participants could be experienced by anyone living in poverty and/or with a chronic illness, but that HIV tends to exacerbate concerns around physical health and mobility, the ability to earn an income, and the likelihood of receiving social support and appropriate health care. All of these things are vital to being food secure, even if at first glance they might seem unrelated to food. Asking participants questions about how they get food and what it takes for them to be able to get food brought about conversations about many other things. For example, asking participants how they afford to buy food led to discussions about government income programs and employment as described in Chapter 6. In Chapter 7, the lens of food revealed that PLWHA require close social connections in order to be physically well, and that good, trusting relationships with healthcare providers are essential to the efficacy of healthcare. Food (in) security became the single point from which numerous other things are explored. Institutional ethnography was the ideal methodology to use in this type of exploration because it requires the
researcher to begin at the standpoint of an individual participant and, from there, branch out to various aspects of everyday experience. Because I used IE, it was not expected that I would make blanket statements and generalizations about participants—everyone experienced their food (in)security in different ways and for slightly different reasons, even though the main commonality was that most participants qualified as food insecure.

**Limitations of the Study**

This study was limited in two important ways. First, geographically: all participants lived within the confines of Kelowna, a small urban centre in southwestern British Columbia. In future, it would be useful to perform a similar study or studies in other cities around B.C. in order to compare and contrast experiences of PLWHA in other parts of the province. Normèn and colleagues’ findings (2005) point to some possibilities for how such studies would look—for instance, to examine the exact role low income plays in food security by comparing low income PLWHA with low income people in the general population (2005:823). Qualitative research provides a firm ground on which to base conclusions about local realities. Institutional ethnography was and is a sound methodology for exploring the multifaceted challenges of living with HIV and attempting to be food secure, but other methodological possibilities abound. For example, the surge of interest in and programming for food security initiatives in the province might now provide opportunities for community-based research at ASOs throughout B.C.

The second way in which my research was limited was in the number of people who participated. The invitation to research was sent to approximately 65 PLWHA who at the time, were active clients of Living Positive Resource Centre. The return rate for initial interest was...
approximately 29% but attrition during the research period forced this down to 18%. Although this is low, I believe it is not unreasonable for the location and population in question. Several studies with PLWHA have similar numbers of participants (see, for example, Takahashi et al. 2001, Takahashi and Rodriguez 2002; Wilton 1996). Institutional ethnography methodologically dictates that the number of participants be kept small, as in-depth investigation over a long time period is required. The number of women was significantly smaller than the men (three women as opposed to nine men) but the demographic breakdown of participants correlates exactly to that of PLWHA in the province overall. I believe that the social conditions of Kelowna are the main factor underlying the lack of response in both men and women. As explained in Chapter 8, there is a dichotomy of fear and guilt among PLWHA in this region that I witnessed first-hand in both my employment at LPRC and in my research. This was particularly pointed for women, who are not traditionally considered as high risk for HIV in the global north. Typically, men who have sex with men and injection drug users are targeted by prevention and awareness campaigns. Sex trade workers are also considered high risk, and because the majority of visible sex trade workers are female, women living with HIV experience a high rate of stigma, or at least perceive that they will be met with discrimination if they disclose their status.

**Contributions of this Research**

This study adds to a growing body of institutional ethnographic work but diverges slightly from most IEIs in that it dealt with several institutions instead of one. This was necessary because the work of increasing one’s food security involves numerous activities spanning physical, economic and social aspects of life. Although anthropological ethnography has been
using participant observation since its inception, actively participating in informants’ lives and work is a more recent addition to IE; my incorporation of participant observation in the data collection methods was another innovative technique, and was successful in increasing my understanding of the work of food security. Additionally, I hope to have expanded the notion of what a “text” is in IE by incorporating analyses of spaces and landscapes as texts that organize expectations, behaviour, and work.

Topically, this study adds a few small bricks to the foundation of literature on HIV and socio-economic issues in Canada, the main finding being that PLWHA continue to be marginalized by society at large and challenged with regard to their physical, social, and financial wellbeing. One of the most pressing concerns in the realm of HIV/AIDS in the global north is an aging population, and this study contributes to the small amount of existing work on the socio-economic implications of aging with HIV. As the 21st century progresses, we are seeing the first of possibly several generations who are aging with HIV and AIDS and many avenues need to be explored if these people are to receive the care and support they need to age with wellbeing and dignity. My research suggests that PLWHA who are at middle age or older in this particular locale face cyclical double binds involving food, pain, and mobility, as well as serious challenges around food and social support.

This study also furthers the research on food security in North America by providing evidence that even in predominantly affluent areas, people face food insecurity on a regular basis. More and more attention is being paid to food insecurity in Canada and more programs and services are being developed to address it. However, programs and services to support
PLWHAs specifically and people living with disabilities and chronic illness more generally, remains lacking.

The notion of the double bind, first articulated by Gregory Bateson in 1956, guided the analysis of this dissertation, as situations of being caught between two seemingly impossible options (with those options often being enforced by an unseen injunction) repeatedly manifested for participants. In the work of obtaining food, the most obvious double bind was created by the inability to get healthy food in the way normally expected in the global north—through shopping at a grocery store. At the same time, getting food at the food bank and/or growing one’s own food were very difficult tasks to take on. The reasons for this double bind occurring were unclear at first, but were revealed through an analysis of related texts, which showed that grocery shopping is not as simple as corporate stores would have us believe, and that food bank usage and growing gardens rail against the norms and values we hold as a society intent on efficiency in provisioning and fitting into consumptive patterns typical of advanced industrial nations.

The work of affording food required participants to fit into one of two categories: employable or unemployable. Neither of these were appropriate for most study participants. Being employed was difficult for both health and logistical reasons, while being unemployed usually took the form of being on a government disability program. For most participants such programs do not provide an income sufficient for buying nutritious food and other necessities. “Employable” versus “unemployable” translate, for PLWHAs, to “healthy” versus “sick.” Unfortunately, the effects of HIV do not lend themselves to being neatly categorized and so PLWHAs have trouble passing as one or the other. This caused many problems subsidiary to the predominant healthy/sick double bind.
The work of being well was filled with numerous double binds that were specific to people’s social positions and relationships. Some participants had relationships with individuals and institutions that were conducive to being well and increasing food security. More often, however, participants endured relationships that both helped and hindered their wellness and therefore their food security. Some of these ambiguous relationships were influenced and mitigated by traditional texts such as application forms for support services and instructional websites for healthcare practitioners. Additionally, the spaces in which social support resides serve as a powerful indicator of whether and how PLWHA access such support.

The work of navigating the discourse of HIV and food security is likely the most difficult since discourse is often opaque and creates situations that are taken for granted as “normal.” Thus, part of the population of Kelowna, 30 years after the beginning of the AIDS epidemic, remains ignorant and fearful of HIV and AIDS while another part is simply apathetic toward it. People specializing in the health care and research of PLWHA, meanwhile, have come to see HIV as a chronic and manageable condition, which creates specific expectations around coping skills. Many people in the global north are becoming cognizant of food security concerns, and are taking active steps to support local food producers and eat in a more ethical manner. As nice as this may be, it puts undue pressure and guilt on those who cannot afford or manage ethical and sustainable eating. Not being able to participate in this new pattern of behaviour outs PLHWA as not fitting into socially accepted roles.

Perhaps the most significant contribution of this research is that of affluence theory as it pertains to current socio-economic circumstances in Canada. The dichotomy (whose consequence can for some people be a double bind) of affluence and invisibility provided the
theoretical grounding for this paper, and Veblen and Marcuse’s ideas ring even truer now than when the authors wrote them. Affluence and invisibility manifested in the social, geographic, economic, and discursive aspects of life for PLWHA, and these conditions are specific to the research location.

Kelowna is a small but very affluent city, in which poverty and disease exist but are rarely seen. The aesthetics and values of Kelowna revolve around affluence and the “four-seasons playground” mentality. Whereas some cities, such as Vancouver, pride themselves on multiculturalism or historical significance, Kelowna mostly promotes the area’s opportunities for engaging in leisure activities, many of which are expensive. The Okanagan Valley’s landscape and climate lend themselves to to sport and leisure. There are three major ski resorts, several large lakes ideal for boating, waterskiing, jet-skiing and the like, mountains for biking and hiking, and rolling hills in a semi-arid zone that houses 122 licensed wineries in just a 250 km stretch of land (winebc.com 2013). Many commercial and government institutions in Kelowna put forth discourse touting these amenities. Tourism Kelowna is a good example. Third on the list of results in a Google search for “Kelowna BC,” Tourism Kelowna’s website homepage contains eleven scrolling images of various Okanagan scenes: people cycling, golfing, eating, and swimming; golf courses, vineyards, and mountains. Everyone in these photos appears to be white, physically fit, and young or middle-aged. The natural environment features prominently in all but two photos, food and/or wine is featured in six of the eleven, and physical activity is featured in four. This website is exemplary of the reputation Kelowna has created for itself, and as suitable as this may be for people who are upwardly mobile, affluent and physically fit, it leaves very little room for people with low incomes and disabilities.
The notion of an invisible illness challenges what we think we know about disease, and about HIV and AIDS in particular. PLWHA are seemingly not allowed by society to be either sick or healthy. On one hand, sick people are supposed to look sick—that is what we expect of them. We do not expect someone with as serious a diagnosis as HIV to appear healthy and active. Because of this, PLWHA who appear reasonably healthy do not get taken seriously as having a chronic illness because they do not “look the part.” And because HIV continues to be stigmatized, they do not feel comfortable disclosing their status. Those who do look sick, however, are equally unacceptable. Adrian, for example, has expressed to me on a number of occasions that he feels conspicuous when he goes out because he thinks his lipodystrophy has made him look gaunt and sickly. His feelings are reminiscent of an interview with Joe Average, an internationally-known HIV-positive artist from Vancouver:

> It’s not just the fat wasting—it’s the meds, the pain, the wear and tear. It’s weathered me. I went from everyone saying that I was the youngest looking 35 year old they knew, to looking like Keith Richards on a bad day. I’ve got eczema and folliculitis. My face is cracked and scaly. Physically my body looks better than ever, but I’ve got Band-Aids all over my skin. My skin is rather angry all the time. I have very few mirrors in my house (Pustil 2005:1).

Disease makes us uncomfortable and, especially in a place like Kelowna, where wealth, efficiency, and cleanliness are strongly-upheld values, visible disease does not fit in (as evidenced by the lack of awareness of HIV and the lack of supportive services for PLWHA). Thus, this bind is both physically and culturally based. Because of this expectation, participants feel intense pressure to appear healthy. The sentiment is exemplified when Tome says that he doesn’t “want to look sick” even when he feels sick, or when Seth says that “people don’t want to talk to you when you’re sick.”
What this adds up to at an institutional level is a disconnect in what gets *said* about what gets done for low income, disabled people in this region and what *actually* gets done. This schism seems to be forcibly realized when one has HIV/AIDS in this particular time and place. One reason for this disconnect is the dominance of the capitalist marketplace in our society and in particular, the fact that government is increasingly bowing to the desires of corporations and private interest groups. In other words, the way bureaucracy is implemented is decidedly capitalist. Working from the food security problematic, this is evident because capitalist involvement in both our labour market and our food system is so pronounced (Friedmann 1982; Patel 2008). The move toward local, sustainable food systems provides hope that access to healthy food can become an affordable reality for people with health problems on low incomes, but this can only happen if local systems remain firmly out of reach of corporate and government grasp. I suggest that this disconnect, and the cumulative effects of the binds described in the previous chapters, produce a sort of “social schizophrenia” wherein PLWHA undergo emotional and psychological (and therefore, social) stress. Seeing such a chasm—between what one thinks one knows about the services offered by their society (because, living in a social democracy they have always believed in a social safety net) and what one actually experiences when one comes to require those services—is damaging on numerous levels. It is akin to what Marcuse describes as “surplus-repression”—the repression of individuals that occurs through “the vested interest in maintaining an established society,” and which produces “strains and stresses” on members of the society (1968:189). This is not to be misunderstood: my participants were not mentally ill and certainly none had been diagnosed as schizophrenic. But the metaphor stands: nearly all
dealt with major life stresses due in large part to both their HIV diagnosis and the difficult institutional and social relationships they were forced to deal with on an everyday basis.

The “Five As” definition of food security provided at the outset of this paper was used because of its holistic approach to understanding the numerous dimensions involved in being able to eat healthy food. However, it should be noted that availability, accessibility, adequacy, acceptability and agency hold differential values for various populations. Agency is something healthy, relatively affluent people take for granted. I, as an able-bodied person who has a steady, average income, do not normally consider the policies and procedures of government institutions and corporations as posing barriers to my ability to obtain food. PLWHA, on the other hand, often need to consider agency first and foremost in their provisioning work. Only after those barriers have been dealt with can the PLWHA in this study consider what food is accessible, available, and acceptable to them.

Overall, I believe this research holds value in its ability to give place-specific information about a serious, ongoing problem in Canada. The work of provisioning, along with the work of affording food and being well enough to shop and eat, although enacted locally, are controlled by a variety of institutions that operate on regional and global scales. Corporate chain grocery stores, food banks, government income programs, health agencies, and social support services are the main institutions that are supposed to facilitate the work of provisioning, but in many ways their policies and procedures hinder this work and make food security more elusive for people living with HIV. Qualitative analysis allowed me to uncover the many layers of this problem in Kelowna and show how it is coordinated and controlled by translocal relations of ruling. It stands to reason that if things like government income programs and grocery store
pricing policies are ruled from afar, then these rules must also apply to many other parts of Canada and affect PLWHA in other places in similar ways as they do in Kelowna. My findings are especially meaningful for cities with similar demographics—predominantly white, middle-aged, conservative, and affluent—and there are many of these types of cities in British Columbia and the rest of the country. It is also important to remember that B.C. is leading the country with regard to progressive HIV-related programs and policies. We have the BCCE, which, despite the issues discussed in Chapters 7 and 8, has done much for the wellbeing of PLWHA and for prevention of new HIV infections. We also have a provincial harm reduction program that provides clean supplies and overdose reversal kits to people who use illicit drugs. At the time of writing, Ontario is the only other province to offer these services, even though harm reduction programs are shown to reduce HIV transmission. If B.C.—where PLWHA continue to face severe socio-economic challenges and stigma—is one of the safest and most well-served regions for PLWHA, then clearly many other communities in Canada require research and interventions to increase wellbeing for this population.

I hope this study has illuminated some of the problems faced by people living with HIV in the global north with regard to food specifically, and extended more generally an understanding of the AIDS epidemic as it exists today in small urban centres like Kelowna—places in which societal knowledge of HIV stagnated in the 1980s, and in which, despite widely disseminated discourses promoting inclusivity, progress, and opportunity, continue to stigmatize, marginalize, and make invisible the people who are living with this virus.
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Appendices

Appendix A:
Recruitment Letter to Potential Participants

Dear Client,

My name is Heather Picotte. I am a PhD student at the University of British Columbia Okanagan and I am conducting a research project on HIV and nutrition in the Okanagan Valley. You have received this letter as an invitation to participate in this research.

Clare Overton, the Client Services Coordinator at Living Positive Resource Centre Okanagan has graciously agreed to send these letters out to HIV+ clients of LPRC. If you would like to participate, please contact me directly using the contact information at the end of this letter. You participation has nothing to do with LPRC, and no staff at LPRC will know whether or not you choose to participate. If you choose not to participate, your service at LPRC will not be affected.

The purpose of this project is to better understand the nutritional status of people living with HIV in the Okanagan. This includes learning about how food prices, social services, and other factors affect the nutrition of people living with HIV. It is my hope that this research will help to make relevant changes to community services and make food access easier for people with HIV. At the end of the study, participants will receive a gift card to a local grocery store.

If you would like to participate, or would like to know more about the project, please call me at 250-470-8418, or email me at heather.picotte@ubc.ca

Thank you very much for your time.

Sincerely,

Heather Picotte
Appendix B:
Demographic Questionnaire

Date:

Participant number:

Age:

Gender:

Date Acquired HIV:

Most recent CD4 count (if known):

Most recent viral load (if known):

Height:

Weight:

Sexual Orientation:

Living situation (with family, single, roommates, etc.):

Employment status:

Average monthly income:
Appendix C:  
Radimer-Cornell Food Security Questionnaire and Scoring Guidelines

1. I worry whether my food will run out before I get money to buy more.
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

2. I worry about whether the food I can afford to buy for my household will be enough.
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

3. The food that I bought just didn’t last, and I didn’t have money to get more.
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

4. I ran out of the foods that I needed to put together a meal and I didn’t have money to get more food.
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

5. We eat the same thing for several days in a row because we only have a few different kinds of food on hand and I don’t have money to buy more
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

6. I am often hungry but I don’t eat because I can’t afford enough food.
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

7. I eat less than I think I should because I don’t have enough money for food.
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

8. I can’t afford to eat properly
   [ ] Often true
   [ ] Sometimes true
9. My child(ren) is (are) not eating enough because I just can’t afford enough food.
   [ ] Never true
   [ ] Often true
   [ ] Sometimes true
   [ ] Never true

10. I know my child(ren) is (are) hungry sometimes but I just can’t afford more food.
    [ ] Often true
    [ ] Sometimes true
    [ ] Never true

11. I cannot afford to feed my child(ren) a balanced meal because I can’t afford that.
    [ ] Often true
    [ ] Sometimes true
    [ ] Never true

Please answer Yes or No to the next two questions:

12. Sometimes people lose weight because they don’t have enough to eat. In the past year, did you lose weight because there wasn’t enough food?
    [ ] Yes
    [ ] No

13. In the past year, have you had hunger pangs but couldn’t eat because you couldn’t afford food?
    [ ] Yes
    [ ] No

Instructions:

The questionnaire has 13 items: eleven statements and two questions. Answers to the eleven statements are considered POSITIVE if they are either “Often true” or “Sometimes true.” Answers to the two questions are considered POSITIVE if they are “Yes.”

A household is:
1. Food secure if: none of the answers to items 1 through 11 are positive
2. Food insecure if: one or more answers to items 1 to 11 are positive
3. Individual insecure if: one or more answers to items 6 to 11 are positive
4. Individual hungry if: one or more answers to items 6 to 8 are positive AND
   one or more answers to items 12 to 13 are positive OR
   one or more answer to items 9 to 10 are positive
5. Child hungry if: one or answers to items 9 to 10 are positive.
Appendix D:  
Food Diary Template

Participants will each receive a small booklet in which they will record the items listed on the following chart.

<table>
<thead>
<tr>
<th>Time</th>
<th>Food</th>
<th>Beverage</th>
<th>Portion size</th>
<th>Did you finish?</th>
<th>Medication</th>
</tr>
</thead>
</table>

Instructions for the food diary:

Please keep a detailed record of the foods you eat each day. For each entry, please record the time you ate, the foods you ate, the approximate portion size (in cups, spoonfuls, or how much of the plate a certain portion took up, for example), and whether you finished the meal/snack or not.

Please try to include all of the items that make up a meal or snack. For example, if you drink coffee with breakfast, please enter that under the beverage section, and note whether you had the coffee with milk or cream, or sugar. If you had toast or a sandwich, please make note of what kind of bread you used. If you have a baked potato, please note whether you had butter or any other topping on it.

For the recording of medication, please simply write the kind of medication (abbreviations are fine), and the dosage, along with the time it was taken.
Appendix E: 
Interview Schedule

**Topic area: general food in the household and food procurement**

**Line of questioning:**
Tell me about how food is dealt with in your house. (Prompts: who plans the meals, who goes grocery shopping, who cooks, etc.)

A few weeks ago, I asked you what an *ideally healthy* meal would look like for you. What does a *typical* meal look like in your house - breakfast, lunch and dinner?

**Topic area: physical health and food**

**Line of questioning:**
Do you feel like your eating habits have changed since you were diagnosed with HIV? How so?

Do you eating habits change with the seasons?

Tell me about your physical health. (Prompts: Do you normally experience any side symptoms related to HIV or side effects of your HIV meds? Describe what this is like for you on a daily basis.)

Do physical symptoms or medications ever affect your eating? In what ways? (Possible prompt: I see from your food diary that you typically take your medications in [time of day]. Does this ever affect your eating habits?)

**Topic area: Economic aspects of food insecurity** (these questions will be aimed at participants identified as insecure according to the Radimer-Cornell questionnaire results)

**Line of questioning:**
I see from the answers you gave in some of our earlier talks, that you’re spending about X% of your monthly income on food. Can you talk a bit about where you buy food, and any of the other ways you get food? (Prompts: Do you ever go to the food bank? Do you have a garden?)

**Topic area: Gender and food-related activities** (for all participants)

**Line of questioning** (if participants are members of a larger household)
What are the main ways in which you personally contribute to food activities - meal planning, shopping, preparation - in your house?

**Topic area: gender, embodiment, and stigma**
Line of questioning: (females and males)
Do you feel like your body has changed since you were infected with HIV?

You mentioned that you [go to the food bank/use a community kitchen/etc]. Can you tell me a bit about your experiences in using those programs?

Line of questioning: (females)
Do you think your eating habits change during different times of the month?

Have you been pregnant since acquiring HIV? Do you plan to get pregnant in the future?