

“I’d be dead without it”

PERSONS LIVING WITH HIV/AIDS DESCRIBE THE IMPACT OF ADEQUATE  
HOUSING ON THEIR HEALTH AND HEALTH PRACTICES

by

Miranda Compton

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## Abstract

There is a growing body of research connecting lack of housing to HIV vulnerability and disease progression. There is very little data addressing changes to health and behaviour once stable housing is obtained, and few studies incorporating the lived experience of persons living with HIV/AIDS (PHAs). A diverse group of 5 PHAs were asked to describe the impact of adequate housing on their health and health practices. All participants were living in poverty with HIV, and had experienced a significant period of housing instability before securing adequate housing. Minimally structured qualitative interviews were conducted to document each participant's journey from unstable to stable housing, and the impact on their health along the way. A narrative approach to analysis was employed to provide a detailed depiction of each participant's unique experience. Despite differences among participants, their stories were remarkably similar: All 5 participants referred to the life-prolonging impact of housing. Each described dramatically increased capacity for self determination, and increased control over health practices and daily decision-making upon securing adequate housing. A significant reduction in engagement in harmful activities, and increased engagement with healthcare providers, was described by all participants. Each also referred to enhanced life satisfaction and optimism for the future. The study illustrates the power of adequate housing to transform mental and physical health, and the importance of housing as a central component of HIV/AIDS prevention, treatment and care.

## Table of Contents

Abstract .....	ii
Table of Contents .....	iii
Acknowledgements .....	v
Chapter 1 – Introduction .....	1
HIV Treatment and Care: A Brief Overview .....	1
Personal Connection to HIV/AIDS .....	4
Chapter 2 – Housing, Health and HIV: Conceptual Context .....	7
Models of Health Behaviour .....	7
Population Health .....	10
HIV/AIDS and Housing in the Research Literature .....	16
Housing and HIV vulnerability .....	16
Housing and HIV care .....	16
Critique of the Research Literature .....	17
Gaps in the Research Literature .....	18
Housing in Vancouver .....	20
Research Question .....	22
Chapter 3- Research Design .....	24
Sampling .....	25
Recruitment .....	26
Ethical Considerations .....	27
Data Generation .....	29
Data Analysis .....	31
Validity Issues .....	33
Participants .....	37
Chapter 4 – Narratives .....	38
John: “I’ve got a reason to live” .....	38
Christine: “I’m healing, I’m getting better, I’m getting stronger” .....	48
Marie: “I can just die here” .....	57
Tim: “Housing provides hope toward living a real life” .....	66
Derek: “This is as good as it gets...from what I’ve seen” .....	77
Summary .....	86
Chapter 5 – Discussion .....	88
Common Themes .....	88
Control, autonomy and hope .....	88
Strengthened identity .....	90

Increased participation in healthcare decisions and improved health practices .....	91
Unstable mental health .....	93
Poverty and stigma: Continued experience of oppression .....	94
Findings Related to Health Behaviour Models .....	95
A Return to Population Health .....	98
Findings Related to Housing/Health Research .....	103
Research Directions .....	106
Reflection on Research Method .....	108
Data Credibility .....	110
Personal Response .....	112
Chapter 6 – Conclusion .....	114
References... ..	115
Appendices .....	125
Appendix A .....	125
Appendix B .....	126

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## Chapter 1 – Introduction

### *HIV/AIDS Treatment and Care: A Brief Overview*

In 1996, the medical community heralded the development of combination drug “cocktails” for persons living with HIV/AIDS (PHA). Ten years later, these treatment regimens, known as Highly Active Antiretroviral Therapy (HAART), have dramatically reduced overall rates of HIV mortality and morbidity throughout North America and Western Europe, where HAART is widely available via public health systems. This development prompted many in the medical world to re-characterize HIV/AIDS from a terminal illness to a chronic, manageable illness (Hogg et al., 2001). Yet the advent of HAART can also be seen to have highlighted the role of socio-economic marginalization in the health outcomes of PHAs (Merithew & Davis Satterla, 2000; Strathdee et al., 1998). In 2004, global HIV/AIDS data indicated that HAART remained inaccessible to nine out of ten people living with HIV (UNAIDS, 2004). In Canada, where HAART is available through public health systems, a significant portion of the affected population continues to face barriers to accessing this treatment. Wood et al.’s 2003 study of HAART uptake found that one-third of the people who died of AIDS in British Columbia between 1995 and 2001, did not receive HAART prior to death. The study found that aboriginal ethnicity, female gender, and low income were all associated with dying without treatment.

Many of those who have successfully gained access to HAART are living longer, but with increasingly complex needs. Many side-effects and debilitating conditions are associated with HAART, including heart, kidney, and liver diseases (Selik, Byers, & Dworkin, 2002). It has been estimated that 40-60% of persons living with HIV suffer

from depression (Sledjeski, Delahanty & Bogart, 2005), and 20% are co-infected with Hepatitis C (Public Health Agency of Canada [PHAC], 2005). In Canada, a growing majority of people living with HIV are living in poverty (Chapman, 2004).

I believe that the HIV/AIDS epidemic has much to teach us about the pervasive inequities in our systems of care, whether we are considering the local, regional or global communities of which we are each a part. The spread of HIV/AIDS over the past twenty-five years has made abundantly clear that universal or equal access to treatment and care is of limited efficacy if we do not simultaneously address the underlying conditions for vulnerability to HIV infection and disease progression.

In their 2004-2008 plan for addressing HIV/AIDS in Canada, the Public Health Agency of Canada (PHAC) wrote,

HIV is more than a health problem. Social injustices – racism, stigma, discrimination, poverty and homelessness – fuel the epidemic and frustrate our ability to stop HIV. The inequities, stigma and discrimination experienced by those most vulnerable to HIV ...threaten their ability to protect their health. HIV is not only the product of social injustices, it compounds them, adding more stress to already stressful lives and making it difficult for people to maintain their health (PHAC, 2003, p.5).

Epidemiological data confirms that an effective public health response to HIV/AIDS does not lie exclusively within medical treatment and research. Rather, the pandemic presents a clear opportunity for the collaboration between medical and social science domains.

An introduction to a 2003 issue of the medical journal, *Perspectives in Biology and Medicine*, proclaimed:

Confidence in our ability to achieve medical solutions has been shaken by the rise of the AIDS epidemic. Clearly, even in developed countries, control of AIDS requires not just effective anti-viral medicines, but also adjustments in personal behavior, improved public health measures, and changes in such social factors as legal regulations, education, income, and access to care (Siegler & Epstein, 2003, p.S2).

Community-based care, treatment, and support of persons living with HIV/AIDS are integral components of public health initiatives to stop the spread of HIV: The likely consequence of inadequate treatment uptake and adherence is a virus that will continue to progress (Wood et al., 2004), and may replicate and mutate, becoming increasingly complex through the development of drug resistance (Bangsberg et al., 2000). The development of HAART helped clarify the role of systems of health and social support in providing persons living with HIV/AIDS with the tools they need to take care of themselves. The management of the HIV epidemic has challenged epidemiologists to look beyond medical solutions to consider the interplay between physical health and social factors. Yet even in the face of mounting data to support the integration of clinical and social interventions, prevailing approaches to HIV treatment and care remain firmly rooted in medical domains.

The role of housing in sustaining health and quality of life provides arguably the best example of the connection between social capital and clinical outcomes. Given the socio-economic marginalization of populations vulnerable to, and the growing majority of persons living with, HIV/AIDS (Zamprelli, 1998), it stands to reason that adequate housing (or lack thereof) is among the primary concerns of the majority of persons living

with HIV/AIDS throughout the world. "Every kind of illness is made worse by homelessness" (Carter & Polevychok, 2004, p.16), and HIV/AIDS is no exception. Homelessness has been shown to put individuals at greater risk for seroconversion (Andia et al., 2001), and HIV-infected individuals at greater risk for disease progression (Pach, Cerbone, & Gerstein, 2003). Lack of housing provides a powerful illustration of the impact of HIV on marginalized populations. And yet public policy and epidemiological research continue to consider housing and health as two very separate domains. The following study seeks to add to the body of evidence that the solution to the HIV/AIDS epidemic lies in bridging the gap between clinical care and community resources.

#### *Personal Connection to HIV/AIDS*

I have spent the majority of my professional life as a social worker practicing in the HIV/AIDS field, and I therefore brought to this research a close relationship to the rapidly developing and changing AIDS epidemic. This relationship consumes me alternately with fire and passion, cynicism and doubt, inspiration and hope. My analysis of the epidemic has developed over time, primarily through my direct practice with the broadest diversity of clients imaginable. I have emerged with a well-defined, but by no means static, personal stance on HIV/AIDS: I feel strongly that no amount of public health information on safer sex or addictions will stem the spread of HIV. I believe that we, as a society, have the responsibility to provide the best possible care to those persons already living with HIV, and that we must do this through the provision of adequate resources, and social acceptance. The tools to achieve this are already available to us via harm reduction initiatives, treatment access programs, subsidized housing resources, disability assistance, and legislative change (to name a few). The idealist in me feels

passionately that we will have the greatest success at eradicating AIDS by supporting and valuing those who are living with HIV today. The optimist in me believes that this is possible to achieve. From this passion comes a deep desire for the stories of persons living with HIV/AIDS to be heard. In my front-line practice, I am moved and educated by these stories on a daily basis. I believe that they have much to tell us about what is wrong, and what is right, with our systems of care.

One of the things that interest me most about the HIV/AIDS epidemic is its impact on people who are seemingly so different from one another. I feel strongly that the common thread between these disparate groups and individuals is an experience of marginalization, and I am frustrated by existing health programs, policies and strategies that fail to take this into account. It was this frustration that inspired me to focus my research on the impact of housing on the health of persons living with HIV/AIDS.

Through my years of frontline practice, I am aware of the role of stable housing, above all other factors, as a catalyst toward improving care planning and individual health status. Without stabilized housing, it is extremely challenging to access regular medical services, attend to nutritional needs, and engage in self-care. As a practitioner, I have had multiple opportunities to witness the tremendous impact of stabilized housing on the lives of persons living with HIV. I have also seen many lives unravel, and health deteriorate, after years of housing instability. Securing adequate housing has played a key role in most of the major personal transformations that I have observed in my clients. For this reason, I firmly believe that each individual's experience in moving from unstable to stable housing has much to teach us about the contribution of housing to health status and quality of life.

While I entered the research process with a strong conviction that stable housing had a critical role to play in improving health, I readily anticipated a diversity of perspectives on the impact of housing. My practice experience has also taught me that obtaining stabilized housing does not necessarily have the life changing, health-improving impact that I (and my clients) would like it to. My hope was that this study would reveal the many issues and challenges that characterize each unique experience of living with HIV, and the power of housing to mitigate this inherent complexity.

## Chapter 2 - Housing, Health, and HIV: Conceptual Context

This chapter begins with several frameworks for understanding health and health behaviour within the context of the interplay between biological and environmental factors. I also discuss the concept of population health, and the role of social determinants of health. Following this, I offer a review and critique of existing research on housing and HIV/AIDS, with particular focus on the role of housing in HIV vulnerability and access to care. I also identify what I perceive to be the gaps in existing research. I will provide a brief overview of housing in Vancouver, and conclude with the central research question for this study.

### *Models of Health Behaviour*

Three models emerging, respectively, from sociology, nursing, and social work disciplines offer effective frameworks for considering the link between individual health status and the environments in which we live. Ronald Andersen's behavioural model of health services use (1995) theorizes that access to health services depends upon the interaction between: individual predisposition to service use; intervening factors that enable or impede use; and individual level of need. Developed in the 1960's, Andersen's behavioural model is widely applied in the research from the United States relating to the socio-medical aspects of HIV/AIDS (Conover & Whetten-Goldstein, 2002; Conviser & Pounds, 2002; Lo, MacGovern & Bradford, 2002; Masson, Sorenson, Phibbs, & Okin, 2004; Messari, Abramson, Aidala, Lee, & Lee, 2002; Uphold & Mkanta, 2005). Andersen's framework provides a mechanism to consider the combined impact of what he terms pre-disposing factors (demographic characteristics such as age, gender, ethnicity and sexual orientation), enabling factors (socio-economic characteristics such as

education and income-level), health beliefs (attitudes, values, knowledge), and the health needs (illness, chronic conditions) that determine both health behaviours and healthcare access. Andersen, a prominent sociologist in the United States, posits that the dynamic between each of these elements determines an individual's access to, and experiences within, the healthcare system. According to this model, the challenge for public health systems is in addressing the *enabling* factors toward improving health behaviour and supporting individuals to make better choices.

Bonuck (1996) critiques Andersen's attribution of enabling characteristics to the individual, rather than the environment. Bonuck theorizes that, "unmet needs represent problematic transactions between individuals and the social and physical environments in which they function" (p.31). While Andersen's model acknowledges the multiple environmental factors influencing an individual's health practices, it focuses on individual-level change rather than environmental or structural change. Working from a social work perspective, Bonuck draws attention to the ways in which existing systems of care and support can generate unmet needs within individual consumers. As an example, she offers the experience of formerly financially independent PHAs who have had to stop work due to illness and consequently subsist on inadequate disability benefits. Bonuck points out that this situation leads to the generation of unmet needs related to nutrition, finances, transportation, as well as social isolation. Bonuck's approach focuses on the resources required to restore health in individuals living with chronic illness, and recognizes the reciprocal nature of the interaction between the person and their environment. This model makes the case for the role of social work as the intervention

best equipped to address unmet needs, in that social work addresses the more practical aspects of people's lives, such as access to adequate nutrition, housing and income.

Flaskerud and Winslow (1998) offer a model for addressing health inequities specifically within vulnerable populations. This model defines vulnerable populations as "social groups who have an increased relative risk or susceptibility to adverse health outcomes" (p.69). They propose a conceptual framework that considers the relationship between resource availability, risk, and health status. Where Bonuck's (1996) model attributes unmet needs to structural/environmental factors, the "vulnerable population" model places the responsibility for ensuring adequate opportunities and resources to achieve and maintain health squarely on communities. Writing from a nursing perspective, Flaskerud and Winslow take this community responsibility a step further, arguing that, "in order to reduce vulnerability to disease, society as a whole is responsible for ensuring justice and human rights" (p.70). Within this model, the concept of "resource availability" is defined according to four key components: human capital (access to income, employment, education and housing); social connectedness (level of stigma, isolation); social status (relative power within social structures); and environmental resources (access to healthcare and quality of care). "Risk" refers to the complex combination of lifestyle, behaviours, and choices; use of preventative and health promotion services; and exposure to stressful, abusive, or violent events. "Health status" refers to rates of morbidity and mortality within groups and communities. Like the unmet needs model, this framework focuses on the interaction of various environmental factors in setting the conditions for poor health and inequitable access to resources.

The strength of all three of the above models is in their consideration of contributions to individual and collective health status beyond bio-medical factors. Each model provides a mechanism to address health issues through means other than strictly medical treatment and care. These models provide a tool by which to deepen understanding of why some individuals are more vulnerable to poor health than others and why some face more barriers to accessing quality healthcare. The models offer their respectful disciplines a tool to connect biological well-being with social circumstance, but they have limited viability as a framework for the traditional medical discipline to step outside traditional clinical frameworks to find new ways to address health discrepancies, disease management, and treatment and care within communities: The health behaviour model focuses on barriers individuals face; the unmet needs models focuses on the structure of existing systems to generate unmet needs; and the vulnerable populations framework focuses on the responsibilities of communities to look after all members. Each provides a mechanism to identify what is missing from existing health systems, but none provides a framework by which to challenge the structure of public health systems themselves. The HIV/AIDS epidemic has made the holes in healthcare systems abundantly clear; I would argue that Canada's population health framework provides the most comprehensive framework to address these deficiencies at a structural level.

### *Population Health*

The Public Health Agency of Canada (PHAC)'s adoption of population health as an overarching framework represents an encouraging move toward an integration of systemic contributions to individual and collective health within healthcare planning. The

Canadian Government's 1974 Lalonde Report was considered groundbreaking in its linking of social and biological factors to address individual and collective health status within communities. In its preface, the report wrote, "It is evident ... that further improvements in the environment, reductions in self-imposed risk, and a greater knowledge of human biology are necessary if more Canadians are to live a full, happy, long, and illness-free life" (Minister of Supply and Services, 1981, p.6). The Lalonde Report introduced the "health field concept" in which, "answers to health problems [were] to be sought in each of the four categories of human biology, the environment, lifestyle and health care organization" (p. 55). This report led to the development of a population health framework that was endorsed by Canadian national and provincial health ministries in 1994. This framework offers perhaps the most comprehensive model for addressing systemic inequities that contribute to poor health, in that it is based on the understanding that health inequity within populations is directly linked to material and social inequity:

A population health approach focuses on improving the health status of the population. Action is directed at the health of an entire population, or sub-population, rather than individuals. Focusing on the health of populations also necessitates the reduction in inequalities in health status between population groups. An underlying assumption of a population health approach is that reductions in health inequities require reductions in material and social inequities (Health Canada, 1997, p.7).

The population health approach posits that socioeconomic circumstances are as important to health status as medical care and personal health behaviours (Evans & Stoddard,

1994). Within this framework, ensuring equitable access to resources becomes a public health priority, on par with quality treatment and care, and health research. At the core of the framework is a series of social determinants of health: These include income, employment, housing and food, culture and gender, physical environments, support networks, and individual skills and capacity. Within the population health approach, social determinants are considered an integral component to an effective health care system: It is the system itself, rather than the nurses and social workers within it (as in the unmet needs and vulnerable populations models), that seeks to ensure that adequate resources are in place. The integration of clinical, epidemiological and social sciences, therefore becomes critical to the efficacy of the health system, in that population health stipulates the interdependence of bio-medical and socio-economic status.

In 2005, PHAC produced its “blueprint for Canada’s response to HIV/AIDS” (PHAC, 2005, p. 3). Entitled *leading together: Canada Takes Action on HIV/AIDS*, this document is intended to guide the development of Canadian HIV/AIDS policies and programs to the year 2010. This document emphasizes that,

Although HIV is caused by a virus and exacerbated by stigma, its spread is also fuelled by many factors in our society, including poverty, homelessness, lack of social support, physical and sexual abuse, childhood experiences and lack of education. These social determinants of health can lead to powerlessness in relationships, lack of self-esteem, lack of a sense of community, and other health issues (e.g. addictions or mental health problems) that interfere with people’s judgement or ability to protect themselves (PHAC, 2005, p.11).

While Canada can be considered a leader in promoting the importance of social determinants in the health of individuals and communities, HIV/AIDS epidemiological data emerging from the Canadian context provides ample evidence that, despite a well-defined population health approach, current systems of care do not adequately address issues of socio-economic inequity (Kerr et al., 2005; Spittal et al., 2006; Strathdee et al., 1998; Wood et al., 2003). These studies highlight the enduring inequities that continue to fuel the HIV/AIDS epidemic within the context of the Canadian universal healthcare system. It would appear that the challenge for public health systems and epidemiologists at this juncture, is to agree upon how to concretely address these inequities.

The population health framework, the health behaviour model (Andersen, 1995), the unmet needs model (Bonuck, 1996), and the vulnerable populations conceptual framework (Flaskerud & Winslow, 1998), all highlight the role of socio-economic resources in individual health. In 2002, the *AIDS Care* journal published a group of studies addressing the role of ancillary services in the treatment and care of persons living with HIV/AIDS. The studies examined a number of community-based HIV/AIDS case management programs operating in the United States. The studies found that the provision of services that worked to increase access to resources (such as disability benefits, housing assistance, drug treatment, transportation, and treatment of mental health), had a positive association with engagement with medical care and HAART treatment uptake and adherence (Ashman, Convier & Pounds, 2002; Chan, Ashber, & Sabatier, 2002; Conover & Whetton-Goldstein, 2002; Lo, MacGovern & Bradford, 2002; Messeri et al., 2002). These data point to a central role for community-level health and social service interventions in improved health, and provide evidence of PHAs' broad

service needs for managing their health. However, it is difficult to ascertain from the data which resources or services, if any, made a pivotal difference in the lives of persons living with HIV/AIDS. Further, the studies neither challenge nor address the social structures that set the conditions for PHAs' inadequate access to ancillary services, but merely advocate for increased support to help connect PHAs to existing resources.

A 2002 Canadian Ministerial Report addressing the application of the population health framework to address HIV/AIDS, wrote:

There is a strong body of literature that considers the population health concept and provides evidence of the social determinants impact on the health and well being of individuals and communities. There is very little literature, however, that places HIV/AIDS in this broad population health context. Instead the literature most often explores the association between a particular social determinant and the behaviour that places a person at risk of HIV infection ... [Researchers need] to accommodate the complex, ever changing nature of HIV/AIDS, the characteristics of the different at risk groups, and the epidemic's entrenchment in the most marginalized communities (Spigelman, 2002, p.9).

The *AIDS Care* studies on the value of ancillary services provide ample evidence to support the integration of community-based social and practical support with the primary care of persons living with HIV/AIDS. But these studies do not reveal much about the role each social determinant (for example, housing, income, access to service) plays in improving the health status and self care of PHAs. Rather, the studies consider ancillary services as a group, and do not indicate if some resources had more of an impact on

improved health than others. This suggests a fundamental problem with each of the four models of health presented above. Whether one is talking about enabling characteristics, unmet needs, resource availability, or social determinants, neither the Andersen (1995), Bonuck (1996), Flaskerud & Winslow (1998) models, nor population health, take into account the inherent hierarchy of needs to which individuals must adhere in order to thrive. Without stable housing, it is difficult to improve access to other enabling factors or determinants of health. In concrete terms, successful adherence to a complex HAART regime depends upon adequate resources for eating, sleeping, and personal hygiene. When placed in this context, access to adequate housing ceases to be seen as an “ancillary service.” Rather, it is an essential service, on par with access to quality healthcare.

This failure of the population health framework to consider the differential impact of social determinants of health was identified in the 2002 Canadian Ministerial Report on HIV/AIDS and population health:

If a particular community is vulnerable to HIV infection ... is it because of their poverty, their social circumstances, their housing, their working conditions, their ethnicity or their gender? While the population health model acknowledges the relationship among these, the ability to influence public policy requires some distinguishing among them (Spigelman, 2002, p.10).

By focussing specifically on the role of housing in health, this study seeks to deepen our collective understanding of the pivotal role of housing as a social determinant, and therefore an essential component in systems of care.

### *HIV/AIDS and Housing in the Research Literature*

Current epidemiological research provides considerable data on the connection between housing status and HIV. Lack of housing has been found to have a role in both vulnerability to HIV infection (Aidala, Cross, Stall, Harre, & Sumartojo, 2005; Andia et al., 2001; Culhane, Gullub, Khun & Shpaner, 2001; Robertson et al., 2004; Stein & Friedmann, 2002), and disease progression (Berg et al., 2004; Masson et al., 2004; Parruti et al., 2006; Stewart, Cianfrini & Walker, 2005). Existing research repeatedly identifies the role of homelessness and marginal housing in health deterioration and poor health decision-making among persons living with, and vulnerable to, HIV. The following is a review of the literature focussing specifically on the relationship between housing and HIV vulnerability, and access to treatment and care.

*Housing and HIV vulnerability.* Several studies have explored the interplay between housing status and HIV risk activities. Robertson et al.'s (2004) study of the indigent population in San Francisco found that HIV seroprevalence was five times greater in the homeless and marginally housed population than in the general population. Aidala et al.'s (2005) study of risk activities among HIV positive individuals found reports of risk behaviours 2 to 4 times higher among unstably housed PHA's at baseline, and that improvement in housing status over the course of the study was associated with significantly reduced engagement in risk activities. Other studies (Andia et al., 2001; Stein & Friedmann, 2002) have identified an association between HIV risk activities and unstable housing among injection drug users.

*Housing and HIV care.* Numerous studies have identified stable housing as a means toward increased engagement in health care, and homelessness as a definite barrier

to treatment uptake and adherence. Smith et al. (2000) found that individuals living in unstable housing conditions experienced more hospitalizations and were less likely to be accessing regular medical care in the community than individuals who were stably housed; Masson et al. (2004) identified that homelessness exacerbates the health care needs of persons living with HIV, and is associated with increases in emergency room visits and inpatient services. Bonuck's 1997 study of factors influencing length of hospitalizations among persons living with HIV/AIDS found that homelessness was associated with an average hospital stay of five days longer than those who were unstably housed. Several studies point to the role of stable housing in increased medication adherence (Berg et al., 2004; Parruti et al., 2006), and improved health status (Stewart, Cianfrini & Walker, 2005).

#### *Critique of the Research Literature*

Many of the studies identified above define housing status according to three broad categories: homeless (in a shelter or on the street), doubled up (sharing living space with others) or stable (living alone). The generalizing of housing into these categories is limiting in several respects: First, it does not take into account an individual's housing preferences. For some individuals, the choice to remain in marginal housing is deliberate, based on personal history, difficulties interacting within mainstream worlds, and the lack of housing options to meet their specific needs. Second, there are likely to be differing levels of quality within each category. All shelters, for example, are not created equally, and some offer significant additional resources (food, 24-hour staff, mental health outreach) that could affect an individual's level of engagement in health services. Third, the stably housed category does not take into account the percentage of the individual's

total income that is going toward housing. Some individuals are compelled to place their entire income toward their rent in order to maintain adequate housing. The percentage of income spent on rent is an important indicator of the individual's overall financial stability, and is an important consideration in assessing the impact of housing on health status, engagement in health services, and personal health practices.

Numerous studies looking at adherence and/or harm reduction among persons living with HIV/AIDS neglect to take housing status into account at all. Two studies on HAART adherence (Bottonari, Roberts, Ciesla & Hewitt, 2005; Sledjeski et al., 2005) focus on the role of stress and depression in reduced adherence and poor health outcomes, but do not consider potential contributors to life stress- of which housing status would almost certainly be a significant contributing factor. Similarly, Knowlton, Hua & Latkin's 2005 study of the role of social support networks in medical service use among PHAs confirms the importance of social support in improved health care usage, but does not consider the contribution of housing status in strengthening and/or improving access to support networks. This study considers a number of social determinants such as education, income and employment, but not housing status. While it is important to note the causes of poor treatment adherence and deteriorating health, the studies provide little information about how best to address deficiencies identified (i.e. stress/depression, lack of social support).

#### *Gaps in the Research Literature*

While housing is sometimes referred to as a form of healthcare within the research literature (Saegert et al., 2003), much of the existing literature focuses on lack of housing, and therefore yields insufficient information on the potential transformative impact of

housing on individual health. Few studies address what happens in an individual's life when their housing improves. Also missing from much of the body of research is the actual lived experience of persons living with HIV. The studies discussed above left me wanting to know more about the lives of the research participants. Somewhere within the sea of statistics on health outcomes and probabilities of medication uptake and disease progression, there must be the voices of PHAs describing the barriers and challenges they face in improving their health and quality of life. In the introduction to their 2005 *Federal Initiative to Address HIV/AIDS*, PHAC wrote;

Ultimately, the people best situated to understand the reality of HIV/AIDS, with all its complexities, are those already living with the disease. The key to understanding the epidemic and how best to respond is found in their life stories - stories that can reveal truths about ourselves as individuals, how we live in society and how we can work together to foster healthier living environments for all, and particularly for people living with and vulnerable to HIV/AIDS (PHAC, 2004, p.16).

The vast majority of the research data on housing, health and HIV identified above is quantitative in nature. While the data make a compelling case for the importance of housing in HIV/AIDS prevention, treatment and care, there is a dearth of actual voices of PHA's describing the impact of housing (or lack thereof) on their lives. Smith & Pynoos' 2002 qualitative study of the experiences of PHAs in HIV/AIDS specific housing is an exception, in its presentation of the data from 57 interviews with PHA's who were living in HIV/AIDS housing complexes. This study focused on the efficacy of housing complexes designated specifically for persons living with HIV, rather than the journey of

individual PHA's to securing, and maintaining, housing. Interview content in this study provides data on resident's overall life satisfaction, but does not speak directly to changes in health status upon securing housing.

I believe that in order to achieve a more comprehensive understanding of the role of housing in health, we need information about what happens to health and self-care when housing is elusive, what is transformed when housing is obtained, and what changes when housing is lost. The diversity within the population of people affected by HIV/AIDS renders the experiences of living with HIV increasingly varied and complex. Much of the data on HIV prevention and support intervention are often designed to address the particular needs of a particular demographic such as women (Andersen et al., 2005; Magnus et al., 2001; Raveis, Siegal & Gorey, 1998;), injection drug users (Kerr et al., 2005; Knowlton et al., 2005; Masson et al., 2004; Wladrop-Valverde & Valverde, 2005) and particular ethno-cultural groups (Andia et al., 2001; Shedlin & Shulman, 2004). Population health provides a framework to look beyond particular demographic groups, to address the systemic conditions leading to marginalization and vulnerability.

#### *Housing in Vancouver*

Maintaining adequate housing is one of the major challenges of living in poverty (Carter & Polevychok, 2004), and within Canada, Vancouver is arguably the most challenging place to secure safe, affordable housing. All the participants interviewed for this study relied on a provincial disability income for their housing needs. At the time of the study, recipients of disability income in the province of BC received a maximum of \$325 toward their monthly shelter costs (BC Ministry of Employment and Income Assistance, 2005). At the same time, the average monthly rent for a bachelor apartment

within Vancouver market was \$678 (Canada Mortgage and Housing Corporation, 2005). This renders affordable housing virtually unattainable for people living on disability assistance, let alone those on regular income assistance. Other than shared living situations (i.e. family members or roommates), many of which present their own challenges, the only affordable option for people living in poverty is to secure government subsidized housing. Subsidized housing ensures that individuals do not have to pay more than one-third of their total monthly income on rent, or that rents do not exceed the maximum allowance provided by income assistance.

There are two main forms of subsidized housing available for persons living at or below the poverty line: The first is social housing buildings in which all units are subsidized via government grants. These buildings tend to be located in high-need areas, and are administered either by non-profit societies, or by the government housing agency, the British Columbia Housing Management Corporation. Some buildings are designated for people with particular needs such as seniors, families, and persons with disabilities.

The second form of subsidized housing is known as "portable subsidies." Portable subsidies enable individuals to choose where they want to live in the community. Recipients secure market rental housing, and a government or privately fund-raised, subsidy pays the balance of their rent, so that they do not pay more than a third of their income on their housing. These too are administered either directly via the government housing agency, or a non-profit housing agency. In Vancouver, there are two non-profit housing societies that administer subsidized housing specifically for persons living with HIV. Both of these agencies offer a combination of social housing and portable subsidies. There are very long waiting lists for both options. While eligibility criteria

differ between housing providers, with some prioritizing individuals who are in extremely poor health, the wait for subsidized housing is unpredictable and substantial: Recent estimates have identified 800 PHAs on waiting lists for affordable housing within the Vancouver area (Gallo, 2005).

### *Research Question*

This qualitative study asked the question: How do persons living with HIV/AIDS describe the impact of adequate housing on their health and health practices? My central goal in this inquiry was to generate information on housing as a health intervention for persons living with HIV/AIDS. In embarking on this research, I anticipated that the data that emerged would reveal additional information on the interconnection between housing and other health determinants such as access to quality health care, adequate nutrition, support networks and socio-economic status. I was equally interested in hearing stories in which housing did not have a perceptible, or positive, impact on health.

It should be noted that there is a case to be made that the journey from housing stability to instability is equally significant, perhaps particularly in the case of those whose stable housing ceases to be affordable following debilitating illness. As indicated in the review of the literature earlier in this chapter, there is considerable data on the negative effects posed by lack of housing (for example, increased hospitalizations, engagement in drug use, inadequate access to healthcare). Given the challenge of securing housing while living in poverty, and the prevalence of poverty among those with a chronic, progressive illness such as HIV, I was interested in identifying what is achieved when an individual finally secures the resource that is arguably the most elusive for PHAs who are living in poverty: Stable housing. While Canada's "universal"

healthcare system should be lauded for ensuring the availability of HAART, the reality is that housing is a key resource that is needed to ensure successful HAART uptake and adherence. Logic suggests that the impact of securing housing would likely be overwhelmingly positive. But I contend that there is insufficient information about what changes, how it changes, and for whom it has the greatest impact. I believe that in order to strengthen the case for housing as a core healthcare intervention, more concrete data is needed on the role of housing in stabilizing health.

I chose to conduct a qualitative study using a method that would preserve each participant's unique experiences within the findings. My hope was that the stories that emerged would reveal a close connection between housing and health status, and could potentially deepen our collective understanding of the significance of the quantitative data already produced regarding housing and health. Losing one's housing can be devastating. Conversely, the experience of securing adequate housing after years of homelessness or marginal housing can be life changing. This study sought to bring PHAs' lived experience to the body of research on the impact of housing on the health of persons living with HIV/AIDS.

### Chapter 3 – Research Design

The central research question for this study was as follows: How do persons living with HIV/AIDS describe the impact of adequate housing on their health and health practices? Given the research question's emphasis on the participants' own descriptions, the study design sought to maintain focus on each participant's account of their journey from unstable to adequate housing. To achieve this, the primary method that I used to design the study was that of qualitative description. Sandelowski (2003) identifies qualitative description as "a comprehensive summary of an event in the everyday terms of those events" (p. 336). Rather than seeking to reduce participants' contributions to a series of housing/health successes and failures, this method ensured that each unique story held its own space within the research. The qualitative descriptive design served to protect the integrity of each story. According to Sandelowski, qualitative descriptive studies seek to ensure, "an accurate accounting of events ... and an accurate accounting of the meaning of those events" (p.336). This approach fit well with my plan to represent each interview individually. Rather than breaking up each story to group data under common themes, I was interested in faithfully documenting the *process* each individual underwent to secure and maintain adequate housing, against the considerable challenges posed by poverty and poor health. My re-presentation of the interview data was informed by the understanding of narrative form from Mishler (1986), Laslett (1999), and Reissman (2003). The narrative approach put forth by these three individuals will be discussed in greater detail later in this chapter.

### *Sampling*

As the central goal of the study was to explore the effect of improved housing on the overall health of persons living with HIV/AIDS, I sought participants who had experienced a significant period of homelessness or housing instability while living with HIV, and who had since secured adequate housing. Recognizing that economic marginalization is inevitably a factor contributing to the experience of unstable housing, I looked for participants who were living below the poverty line. In order to ensure sufficient perspective on the impact of adequate housing, I required participants to have been living in adequate housing for a minimum of three months prior to the interview. I also confirmed that each participant had gone through a period of housing instability prior to securing housing.

Potential participants were asked if they would describe their housing as adequate. I determined “adequacy” according to the participants’ self-assessment of the sustainability of housing costs within the context of their monthly income, and the home’s capacity to provide sufficient resources for safety, sleep, nutritional needs, and personal hygiene.

I employed the illustrative/evocative approach to sampling described by Mason (2002). I sought a range of participants who reflected the diversity within the population of persons living with HIV, while not making any claims as to their representation of the broad population of persons living with HIV. According to Mason, “this approach to sampling seeks only to provide a flavour – sometimes a very vivid or illuminating one” (p.126). I used this sampling approach in order to bring a range of PHA voices to the

issue of housing and health, and to use the diversity of perspectives to highlight both unique and shared experiences.

### *Recruitment*

Participants were recruited through posters distributed at the community-based HIV/AIDS agency at which I work, as well as at two agencies providing housing to persons living with HIV (see Appendix A). Interested participants contacted me via phone, e-mail, or in-person, at which point I gave them an overview of the study. I informed participants that my study was focussing on the impact of housing on the health of persons living with HIV, and that I was seeking participants who were willing to describe the ways, if any, their health status and health practices changed after securing adequate housing. I briefly reviewed the range of potential topics with respect to their mental and physical health, and emphasized that I was employing a holistic approach to health. I explained that our discussion might explore their experiences of: HIV-related symptoms and conditions; levels of strength and stamina; stress and anxiety; sleep patterns; nutrition; access to health care; connection to social support; adherence to treatment; self-care strategies; sexual health; and alcohol and drug use.

To determine their suitability for the study, potential participants were asked a series of questions concerning their current and past housing. Following is the list of initial questions, and the rationale for each.

1. Where do you live now? How long have you lived there? (Does participant meet the 3 month minimum of having lived in stable housing.)

2. Are you satisfied with your current housing? Is it affordable? Do you feel safe? Do you have sufficient amenities for eating/sleeping/personal hygiene? (Does participant consider current housing adequate.)
3. Where were you living before? (Did participant go through period of housing instability prior to securing housing.)

### *Ethical Considerations*

The safety and confidentiality of participants was a paramount consideration throughout the research process. During their initial contact with me, and before setting up the interview, I acknowledged the deeply personal nature of the data sought through this study. I offered potential participants assurance that every effort would be made to protect their confidentiality should they decide to participate. To ensure that they were making an informed decision to participate, I first reviewed the nature of qualitative research with each participant. I let participants know that their interviews would be transcribed verbatim by me, and that portions of the interview would be published in the completed study. I assured them that identifying characteristics (such as names of people, places) would be removed from all documents, and that apart from me, only my thesis advisor, as principal investigator, would have access to the raw data. I encouraged each participant to take some time to consider their comfort level with participating, but in all cases, they stated that they did not need this time and were ready to participate. In order to give them time to reflect and/or reconsider, I ensured that at least one week elapsed between our initial contact and our actual interview.

At both the initial contact and just prior to beginning the interview, I acknowledged my professional position at an AIDS organization at which the participants

accessed services. In fact, I already knew several of the participants who came forward from my work in the field. The recruitment posters were posted at the agency where I work (along with two other agencies), but I did not actively recruit any participants. Those who came forward had seen the sign of their own accord and volunteered to participate. In acknowledging my role in the HIV/AIDS field, I made it clear that my research was completely separate from my professional role, and that the information each participant gave me would be specifically for the purposes of the research study. All of the participants stated explicitly that my dual roles as researcher and practitioner did not pose a problem for them, and several participants indicated that their knowledge of my work in the field increased their trust in me.

Prior to the start of each interview, the participants signed a consent form (see Appendix B). I also chose to give each participant a \$20 honorarium as compensation for their time. I made this decision based on my knowledge that, as a population group, PHAs are regularly asked to participate in community-based research initiatives, clinical trials, and surveys. The honorarium was intended as a gesture to acknowledge the value of their time. I made it clear that the interview length was up to the participants, and that the \$20 would be given to them whenever they decided to end the interview. This ensured that if a participant chose to participate only because they needed the honorarium money, they had the opportunity to end the interview at any point. As it turned out, all of the participants were extremely generous with their time, and all but one waited for me to signal the end of the interview. All indicated that they were pleased to participate, and would have done so regardless of the honorarium.

Prior to beginning each interview, I acknowledged the personal nature of the interview topic. I noted the potential for the participants to become distressed during the interview due to the personal, and potentially painful, content, and let them know that if they became distressed they were welcome to end the interview. I brought a cell phone with me to each interview, along with contact information for various community resources that participants could connect with should they encounter a need to. I again emphasized their right to withdraw from the interview process at any time.

At both the beginning and end of each interview, I invited participants to contact me should they want to review their transcript, or my findings. All participants whose narratives appear in this study indicated that they were comfortable telling their story, and indeed welcomed the opportunity. Each also stated that they did not anticipate a need to review the data or findings.

#### *Data Generation*

I conducted six interviews for the study, though only five appear in the findings section of this paper. The sixth participant, like the others, had a fascinating story to tell, but expressed a considerable amount of anxiety about signing the confidentiality form, and having the interview audio-taped. Despite his repeated assurances to me that he wanted to participate, his hesitation persisted throughout the interview, and his answers were very guarded. Given his obvious inhibition, I decided, following our interview, that I would not include the data from this participant's interview in my findings and discussion.

Because the participants' housing was the focus of the research, I had hoped that I would be able to conduct the interviews within their homes. I gave each participant the

option of conducting the interview in a more neutral setting, but all were comfortable with situating our meeting in their homes. Indeed, most seemed exceedingly proud to host me, and took great pains to ensure that I was comfortable. Consequently, our physical surroundings played a significant role in the interview, both for prompting questions, but also as a visual testament to the role of housing in the participant's lives.

I used broad, open-ended questions to prompt participants to tell the story of their journey to stabilized housing, and the relationship of this journey to their overall health, quality of life, and capacity for self-care. Although the questions varied according to the flow of each discussion, the following are key interview questions asked in all five interviews:

1. How did you obtain your current housing? What was your housing like before?
2. What was a typical day like for you before you secured your current housing?  
What is it like now?
3. What was your experience of your health before you secured this housing? What is it like now?
4. Can you describe the quality of your life before and after securing housing?
5. How do you look after your health needs now? How did you look after yourself before attaining this housing?

The interviews varied in duration from one to two hours. I transcribed each of the audio-tapes myself, within two weeks of the interview. I discovered that the act of transcription added greatly to the data-generation process, in that I was able to take note of participants' tone of voice at different points of the interview, as well as background

noises that I had not noticed during the actual interview. In this way, the process of transcribing served to deepen my understanding of the stories the five participants told.

### *Data Analysis*

In re-presenting the data, I drew from a number of narrative methods. In order to depict the connections between housing and health, and the lived experiences of each participant, I employed Mishler's (1986) approach to analysis of narrative interviews. Mishler advocates an alternative to analysing qualitative data according to standardized codes, in order to provide a means to address "the intertwined problems of language, meaning, and context" within interview narratives (p.233). Mishler's approach embraces the capacity of individual narratives to teach us "...about the structure of social relationships, about the rules governing how social status is affirmed, challenged, and negotiated and about the ways in which the meanings of events and actions are expressed in language" (p.240). This approach provided a means to extend the data beyond a mere exploration of housing and health, but to connect housing and health within the larger social contexts in which the stories were told. Mishler asserts that to achieve full understanding of the social context of narratives, they must be analysed within their own "naturally-ordered sequence" (p.241). Within the study, this method allowed space for recognition that, while the participants share a common experience of living with HIV disease, marginalization and poverty, their unique descriptions of the impact of housing reveals a great deal about the unique and complex social realities within which each lives. The narrative method provided a good fit with my goal to re-present the stories of a diverse group of PHAs in that it offered a means to present differing perspectives on a shared experience (that of securing housing after a period of housing instability). The

content of each narrative is reflective of the convergence of the experiences, relationships, and social contexts that shape each participant's perspective on their life.

As Laslett (1999) points out,

The richness in ... life stories is rarely captured well in survey data, however innovative the data collection ... Personal narratives...are likely to present fuller pictures- ones in which the meanings of events and relationships are more likely to be told than inferred" (p.391).

Reissman (2003) describes narrative analysis as, "slow and painstaking, requiring attention to subtlety; nuances of speech, the organization of a response, relations between researcher and subject, social and historical contexts" (p. 342). It is precisely this kind of subtlety and attention to the diversity of experiences within the population of PHA's that I found missing from the existing literature on housing and health. The narrative method provided a means to honour the inherent complexity within each of the life stories I heard. Where individual nuances and differences in experiences are lost in larger quantitative and qualitative studies with multiple participants, this method of narrative analysis served to bring the layers of individual experience to the forefront. As Laslett (1999) describes, "personal narratives provide a unique perspective on the intersection of the individual, the collectivity, the cultural, and the social. As an analytic technique and source, they can access motivation, emotion, imagination, subjectivity and action in ways less available from other sources"(p.392). My goal in analysing the interview narratives was to uncover the layers of information and experience that I found lacking in the existing research on housing, health and HIV.

Mishler (1986) identifies that, in answering the research question, respondents tend to, “make one general point in a variety of ways” (p.242). In re-presenting the interview data, I pulled out a main point from each of the narratives which then became the title of each participant’s story. In each case, the main point speaks to the role that stabilized housing has played in the participants’ life. The variation in the central message of each narrative is reflective of the complex mix of gender, culture, sexual orientation, socio-economic status, social relationships, education and family experiences that form each participant’s identity. Mishler’s method also seeks to pull out a core narrative from the participants’ full responses that reflect the main message within the stories. As my research question asked participants to describe a journey, rather than one particular event in their life, I chose to depart from Mishler’s approach in this respect. In reviewing the individual narratives in their entirety, I noticed that each contained a very different orientation toward time, which was reflective of the point within their journey that each found participant found themselves at the time of the interview. The time orientation within the narratives revealed much about the convergence of each participant’s time spent waiting for housing, their health status, and their experiences within, and without, housing. In this way, the main message that I extracted from each narrative essentially provides a synthesis of each participant’s past struggles, present reality, and hopes for the future.

### *Validity Issues*

Riesman (2003) states that, “the truths of narrative accounts lie not in their faithful representation of a past world, but in the shifting connections they forge among past, present and future”(p.341). I embarked on this research process with an awareness

of the risk that participants, and myself as the inquirer, might be tempted to enhance the relationship between housing and health, to fit the housing/health connection implied by the research question. I was concerned that the focus of the interview questions on health before and after securing housing, might also prompt participants to speak to differences conjured up for the sake of the interview process, rather than speaking to their lived experience. I responded to this threat to data credibility by structuring interviews to inspire participants to tell the story of their journey to improved housing, and the fluctuations in their health status and health practices along the way. By soliciting a detailed chronicle of this journey, I sought to draw out a comprehensive picture of the unique experience of each individual. Over the course of the interview, I encouraged participants to identify elements in their life beyond housing that may have played a role in improved health and/or changed health practices.

I entered this process very aware that the stories I would hear would be as much a reflection of what was preoccupying each participant on the day that we spoke, as it would be a depiction of their journey to housing. I anticipated that had we spoken on a different day, month, or year, I would have heard five completely different stories. Reissman (2003) points out that, “the meanings of life events are not fixed or constant; rather they evolve, influenced by subsequent life events” (p.341). This is true of interview data provided to researchers regardless of method, and the narrative approach enabled me to make explicit each participant’s perspective on housing and health within the context of their life outlook on the particular day that we spoke. This outlook was inevitably informed by what had happened in the participants lives before our interview

session, what they were thinking about on the day that we met, and their vision of the future at that particular moment of their lives.

In their discussion of validity in qualitative research, Whittemore, Chase & Mandle (2000) caution that, “the infinitely differing interpretations, assumptions, and knowledge background of investigators ... can potentially influence the research process [and] require a devout attention to integrity and criticality” (p. 531). All of the study participants were aware of my own role as a practitioner in the HIV/AIDS field, and specifically as someone who has devoted a great deal of time to attempting to secure adequate housing for persons living with HIV/AIDS. As I approached the research process, I was concerned that the participants would be tempted to tell me as a researcher, what they thought I would like to hear as a practitioner. To address this concern, I acknowledged my professional role in the field at the outset of each interview. I also emphasized that I was conducting this research in a different capacity, and that my central goal was to provide as accurate a picture as possible of the relationship between housing and health. Following the process of transcribing the interviews, I concluded that the participants’ knowledge of my own intimate awareness of the topic of discussion ultimately served to add to the thickness of the data that was generated. Their awareness of my background in HIV/AIDS seemed to encourage them to provide greater detail in telling their stories. They knew that the context of their story was familiar to me, and this prompted them to give me a high level of detail in their descriptions.

Because of my dual roles as researcher *and* practitioner, I approached the research process with a profound awareness of my own investment in the outcomes of this study. It was important for me to remain explicitly reflexive throughout the research process.

Laslett (1999) writes that, “analysis requires some distance – a capacity to separate the selves of story teller and analyst. And this is not done without a conscious and sometimes difficult reflexivity” (p.401). Throughout the research process, I strived to make explicit my own reaction to the data, and to ensure that my presence in the data was apparent throughout as interviewer, transcriptionist, and researcher. Although I began this inquiry with a strong conviction that quality of housing is inextricably linked with quality of health, I approached the research process in the constructivist paradigm: I welcomed the opportunity for participants to tell me a very different story about housing and health than the one I was anticipating, and I was very aware that my own background as an HIV/AIDS practitioner would inevitably interact with the data. I approached the research process as fascinated to hear stories where housing did not have a positive impact on health, as I was to hear about housing/health successes. To me, these “negative cases” represent a crucial component to the research on housing and health, in that they provide an opportunity for us to identify what is needed beyond, or perhaps in spite of, adequate housing.

This research focused on bringing to the forefront the voices, and lived experiences of persons living with HIV/AIDS. By remaining faithful to the words and experiences of each participant, it is my hope that the reader emerges with a detailed understanding of the transformative impact of housing on the health of PHAs, as well as knowledge of the relationship between health, housing, and HIV that goes beyond epidemiological numbers and statistical probabilities.

### *Participants*

My goal for the study was to talk to as diverse a sample as possible. The five eventual participants were indeed quite different from each other, but nevertheless shared a number of common characteristics: The participants ranged in age from 38 to 52 years of age. All were born in Canada and spoke English as a first language. All were living with advanced HIV disease with self-reported CD4 cell counts\* at or below 200 at the time of the interview. All were living alone, and depended upon monthly income through the provincial disability benefits program. All had annual incomes of roughly \$12,000. Four of the five had experienced years of homelessness or marginal housing in Vancouver's "downtown eastside" neighbourhood before securing housing. All had a history of drug use (to varying degrees of severity). All five participants were living in apartment buildings within, or in close proximity to, Vancouver's downtown core.

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\* CD4 cells are the part of the immune system for fighting infections and are directly targeted by HIV disease progression. A CD4 count of 200 or less indicates significant immune suppression. Clinical practice standards suggest that treatment regimens should be initiated or changed when/if CD4 counts fall below 200 (Biel-Cunningham, 2004).

## Chapter 4 - Narratives

Vancouver's downtown eastside (DTES) neighbourhood figured prominently within four of the five narratives: This neighbourhood is notorious for its high concentration of poverty, drug use and prostitution. The vast majority of residents of this neighbourhood are living either on the street, in shelter, or in single-room-occupancy hotels. HIV prevalence rates in this neighbourhood have been estimated as high as 26% (CHASE, 2004). This neighbourhood is significant in that three of the five participants connected their move to stable housing with their concurrent departure from the downtown eastside.

To protect their confidentiality, I have given each participant a pseudonym: John is a white heterosexual man in his early forties; Christine is a white transgendered woman in her early fifties; Marie is a heterosexual aboriginal woman in her late forties; Tim is a white gay man in his late thirties; and Derek is a white heterosexual man in his mid-forties.

*John: "I've got a reason to live"*

John was the first to respond to my poster seeking research participants. He was anxious to participate because, as he put it, "housing changed my life." John asked me to call before I left to come over so that he could have fresh coffee on the stove, and, as promised, the coffee had just finished percolating as I entered the door. Over the course of the interview I came to realize that this simple gesture in many ways summed up John's story: He now has a place to make coffee, money to buy it, and a social network with whom to share it. John's narrative focused on social connection, and particularly his relationships with family and friends. He leapt frequently between his estrangement from

his family which he believed was a result of his HIV status, his years of chaos while living in the downtown eastside, and the sense of stability, control, and connection that stabilized housing has given him. John's tendency to jump between distant past, recent past and present stages of his life revealed a sense of amazement about where he had come from, and where he found himself at the time of the interview. At one point, while describing his family of origin's irrational fears of being infected with HIV as a result of their contact with him, John stated "I couldn't have coffee at my brother's place, like you having coffee with me, my brother would be bleaching the cup!" This comment reveals John's sense of abandonment as a result of his disclosure of his HIV status to his family, and the pain of his subsequent years of social isolation and despair. John described the immense challenges that he had experienced over the course of his adulthood in considerable detail, but his narrative consistently returned to the sense of social connection that stabilized housing gave him.

I was initially somewhat taken aback by John's exuberance: His was my first interview, and his perspective on the impact of housing in his life almost seemed to make my job as a researcher too easy. In the end, however, I recognized that John's story is a beautiful illustration of the transformative impact of housing. Attaining adequate housing provided him with a sense of hope and belonging. I realized that this is really the main message of John's narrative: In his words, housing gave John, "a reason to live."

At the time of the interview, John had been living in a subsidized housing building for persons living with HIV for one year, after sitting on housing waiting lists for over eight years. Early in the interview, John summed up his response to my research question:

I'm happy, I got a girlfriend, I volunteer. But basically I was driven to almost insanity. I can honestly say that because I lived from hotel to hotel... [I] felt like there was no way of getting out, trapped in drug abuse, low self esteem, landlord stealing [my] damage deposit, seeing all sorts of crime, or even selling marijuana myself... And I didn't like myself anymore... And I was begging for housing, but I couldn't get help to get out. It's like a glass jar, you just can't get out.

John recounted his arrival in Vancouver in his late teens. He explained, "I just, you know, never planned to be a drug addict or get HIV. I was just a dumb country boy who moved to the city." This was the first of many examples of John's sense of a lack of control in his former life: When life events happened, John felt as if he had no power to stop or change them. John developed a heroin addiction while living in Vancouver, and moved back to his hometown in his mid-twenties to go through a recovery program. Shortly after completing the program, John was diagnosed with HIV. He described becoming estranged from his family as a result of his HIV diagnosis: "I came back to Vancouver after I told friends [in the small town I was living in], and was basically pushed out of town ... so I have no family, no support system." He frequently contrasted his new-found community with his family of origin: When describing his connections with the people in the building in which he now lives, he stated, "Basically, these people are my family. I have no [traditional] family. When I pass away, my [childhood] family [already] considers me dead, you know, it's sad but true." Again, this statement reveals the importance of a sense of belonging in John's life. Securing adequate housing within a community of people that care about him gave John a renewed sense of purpose, and in

increased sense of community and connection to those around him. Given the rejection he felt by the family of his childhood, this rendered housing a truly transformative experience.

John structured his story around the loss of his support network (his childhood family), the years spent with no social support in the downtown eastside, and the creation of a sense of connection and support in his current housing. He described being at the lowest possible point when he finally gained access to housing: “When they finally got me housing here I was like a nervous wreck, robbed, beat up, [I had seen] all sorts of horrific things down there and I couldn’t handle it anymore ... I was using [drugs]...” John attributed his success in securing housing to the community-based support workers who assisted him. He repeatedly described the experience of getting housing after years of homelessness and marginal housing as “a rope that pulled me out.”

In addition to struggling to secure housing, John’s narrative revealed a concurrent struggle to gain access to adequate healthcare and to take charge of his health. He expressed profound frustration with his medical care, beginning at the point of diagnosis: “I was told I had two years to live so basically I was on valium for a year and a half waiting to die! So here we are how many years later...and jeez, I’m not going to die right away!” His story reveals a profound distrust of the medical system, and a strong connection between housing stability and healthcare stability: Securing housing enabled John to exert control over his healthcare. He described his experience with haphazard medical care while living in the downtown eastside:

I had problems with the doctors down there. They overdosed me on [a nucleoside], I had neuropathy for three months, it almost killed me. Like I

couldn't see, taste, I literally had a club foot, like I had to drag my leg, you know, I thought I was dying, like what's going on? I was poisoned and so I went off the meds, didn't have, you know, the proper medical doctors...

John contrasted the above experience with a description of his medical care after attaining subsidized housing: "I finally got a family doctor, since I moved out of the [eastside] I got accepted at [a clinic] and I've had a doctor for about a year now." He indicated that since securing a regular family doctor, his health had stabilized on an antiretroviral regimen.

John's increased capacity to engage in effective healthcare can be seen as linked to his increased capacity for choice. He frequently drew comparisons between his life in his current housing and hotel-living in the downtown eastside:

Because I have a clean place, it's a safe place, I'm not tempted by drugs in the building, outside, I'm not saying that there are people here that aren't struggling, but we have a chance, you have a choice, and I'm closer to services... And in a hotel, it's just the atmosphere... no privacy, people are dirty, they're unhealthy, it's just unhealthy living! It's no proper cooking facilities, and you can't do anything to get ahead. At least here I get a chance to get ahead. I care about myself, I want to do better. I got a girlfriend, you know, people look out for me, and I got a reason to live, you know, otherwise, it's too easy to give up and die, you know what I mean? It's hard to stay alive especially when you have no support.

John's mental and physical health status continued to fluctuate after securing subsidized housing. At the time of the interview, his immune system remained

significantly compromised. He also described on-going struggles with stress and anxiety. But John's narrative revealed a sense of empowerment and control over his HIV treatment, and overall health. When I asked him whether he was able to take his medication regimen consistently, John stated that he did, along with complementary therapies to boost immunity and to help tolerate the toxicity in the medication regime. Yet he also described taking a break from medication when he went on a vacation that he knew would involve significant alcohol consumption. His decision to take a break from the medications while on holiday reveals a sense of control over health care decision-making: Using the knowledge that combining alcohol with his HIV medications would further compromise his health status, he made a plan to ensure his safety while on holiday. Over the course of the interview, John described a lifelong struggle with substance abuse. Given this, his account of his decision-making process regarding his holiday exemplifies the role of housing in increasing his capacity to substantially reduce harm in his life.

When I reflected that John's new life gives him the power to make choices in his life, he responded, "I *choose* to not do drugs, not do crime. I *choose* to do laundry, I *choose* to go volunteer, I *choose* to go for a walk with my girlfriend." I found it significant that John depicted the acts of doing laundry or going for a walk as a privilege. His description of these seemingly mundane activities reveals the power of stable housing to provide a sense of meaning and purpose in daily life.

I asked John to describe a typical day before securing housing. His response again reflected the lack of control he had experienced: "A typical day in the east end was just surviving the day, I was window washing on the street for years [and] I made good

money but it just went to drugs.” John spoke specifically about his difficulties in single room occupancy hotels reflecting that had he stayed in marginal housing,

I would have been in jail or killed myself, through drugs or suicide or whatever. But there’s not too many more nervous breakdowns a person can handle [without] screaming and melting, ‘Somebody hear me, I’m drowning!’

John’s strong sense that he would have died had he not attained adequate housing stands in contrast to his description of his life since securing housing:

I volunteer, I [have] options, like have breakfast out. I work part-time, I do painting, a little bit here, odd moving jobs, go out for long walks, I take care of myself, I got a bike, go on outings, plan on trips.

Throughout his narrative, John wondered at his own seemingly unprecedented control over the choices he makes in his life. At one point, in recounting a recent vacation he took he exclaimed,

I went out fishing. *I went* -spent \$150 - for 12 hour’s fishing! Would someone like you know, I would never even think of doing that two years ago, the thought to spend \$150 for one day, ... and go work part-time, and save, and build up your home, like I had nothing, you know?

John frequently juxtaposed his sense of new-found control against descriptions of his former life. His narrative reveals a sense that his improved quality of life felt somewhat surreal, yet he also expressed a strong commitment to not return to his former life of instability. John’s narrative repeatedly returns to the idea that housing gave him a reason to live, something he clearly lacked while living on the street.

Reflecting upon his life living in the downtown eastside, John described,

You're just overwhelmed, everything is right on your doorstep. The violence, the drugs, no healthcare, it's human depravity, squalor, landlords stealing your damage deposits, social services just basically laughing at you.

The discriminatory impact of social service agencies played a prominent role in John's narrative. As evidenced by his statement regarding social services above, while living with housing instability, John clearly felt that his voice was not heard by the systems that were theoretically there to provide support. But he also made it clear that dealing with these systems continued to be extremely stressful after securing housing. Throughout his narrative, John referred to problems with income assistance workers, and his on-going dealings with the social service system were clearly a stressor that transcended housing stability. The following story regarding the bureaucratic process involved in claiming part-time wages while living on a disability income exemplifies the way in which these difficulties remained a preoccupation for John:

I work part-time. This is a true story. I was very upset. I reported the money [to the welfare office]. I made \$300 painting, I declared it. I'm allowed to make \$400 [on top of my disability benefits]. And then you have to un-report it, I've never heard of any silly thing, and then [the welfare office] forced me to apply for [government pension plan] but I didn't pay enough into it, so there's nothing to get. But it's just red tape! You're being honest and ask for help when you really need help like I did, or most people don't get it, and they don't know how to access services or the way to go through it, or you're judged once an addict you're always treated as a drug addict.

Listening to John describe the barriers he continued to face in dealing with social service systems, I had the sense that while the experience of stigma and discrimination for a person living in poverty with HIV often feels inescapable, stabilized housing provides a key tool toward coping with, and rising above oppressive systems. John's narrative revealed a life time of dealing with systemic barriers, but the tone of his comments left the overwhelming impression that he no longer felt debilitated by them. In spite of the discrimination and "red tape" that he continued to face in his dealings with welfare, the sense of control that he felt over his finances, and his social relationships, appeared to have worked to isolate this particular stressor: The experience of stigma or discrimination no longer defined his life, as it had while living on the street.

Before beginning the interview, John expressed that he was feeling sad as he was dealing with the deaths of a couple of close friends. He frequently contrasted his alienation from his family, with his community of friends living with HIV, referring to them as the "2% club" as, "only 2% of us old-timers are still alive." As a man in his early forties, his description of himself as an "old-timer," seems on the surface to indicate a skewed sense of time. When considered in the context of his experience of living with a chronic, progressive disease, and his years of despair living on the margins of society, this term seems appropriate, in that it reflects his identity as a survivor.

John stated that his housing has provided him an opportunity to care for himself and others. He proudly introduced me to his cat, his fish and his plants, commenting,

I went and spent \$300 on my cat because he had an ear infection, like a person who doesn't give a shit about his life or himself wouldn't do something like that, you know what I'm saying? I find with a pet and plants

and fish and stuff like that, I care, I'm nurturing something...it needs me,  
I'm needed!

John employed a tone of incredulity at many points in the interview, as if he still cannot quite believe his own transformation. This is not surprising, as fifteen months in adequate housing can hardly be expected to erase the 20 years of pain that preceded it. Housing gave John a sense of hope and pride, and a strong resolve not to return to his former life.

John's concluding thoughts reflected a strong sense belonging, control and autonomy: "I finally found my little niche here...where I'm not going to go insane because I have no one to hug or no one to tell me I'm worth anything...I'm alive now, I consider myself re-born." These parting words describe the powerful sense of increased mental, physical, and spiritual health that adequate housing can bring to individuals who have lived a life impacted by poverty, illness, stigma and discrimination. It would appear that John's simple bachelor apartment on a busy downtown street did indeed give him "a reason to live."

*Christine: "...I'm healing, I'm getting better, I'm getting stronger..."*

Christine is a transgendered woman in her 50's who describes herself as an "elder in the transgender community." At the time of our interview, Christine had been HIV+ for six years. She had lived in unstable housing in the downtown eastside for seven years before securing subsidized housing six months prior to our interview. Christine's apartment was in an independent-living building for persons living with HIV/AIDS. Our meeting began with a detailed tour of her small one-bedroom apartment located in the downtown core. She showed me her extensive hat and shoe collections, and an impressive selection of found and donated vintage art and furniture. It was immediately evident that obtaining stable housing had strengthened Christine's sense of self, and increased her capacity for positive self-expression. Her ensuing story confirmed this.

Christine took the lead in our interview process. She appeared both eager and business-like: She was clearly aware that she had an important story to tell, and wanted to make sure that she was giving me an adequate level of detail. Christine spoke openly and at length. She was the only participant to take control of the end of our interview, letting me know directly when she was too fatigued to talk anymore. I took this as further evidence of Christine's commitment to self care and to taking control of her life. Like John, Christine expressed considerable awe over the transformative power of stable housing. Where John concluded his interview telling me that he felt "re-born," Christine opened the interview with the statement: "This is more than I thought. Being here, being able to put a home together, has really woken me up." At one point in her interview, Christine exclaimed, "I'm healing, I'm getting better, I'm getting stronger." Reading over the transcript of our discussion, I came to realize that this is really the main point in

Christine's story. After years of feeling out of control in unstable, substandard housing, and surrounded by violence and immersed in drug abuse, subsidized housing provided Christine with a means to leave past pains behind, and to move forward with strength and determination. Like John, she attributed much of this transformation to her housing.

On the day of the interview, Christine was eagerly anticipating her first official appointment with a new doctor, and referred to the appointment frequently as evidence of her new-found stability and focus.

I'm finally meeting with [my new doctor] today...and he's going to bring me off the methadone and bring me off the 'benzos.'<sup>†</sup> If I want to be HIV, that's cool, I'm HIV, but I don't need to be gooned, you know?

Christine's story is similar to John's in that she too felt her control over her health slip away from her while living on the street, in the grips of addiction. Describing her healthcare while living in the downtown eastside, she stated,

I had a nasty little pill habit, so [my doctor] put me on methadone! And I said well let's just make sure that this is temporary... Well, then [the methadone] got up to 150 [millilitres]. I was getting kind of scared, then it went up again, and again...

Christine described a period of seven years spent living on the street after experiencing a major psychiatric breakdown following the death of her spouse.

I was living in the downtown eastside, and I'm like a chameleon, you know what the chameleon is, if you're there that's what you're gonna do! You gonna blend in, hon! You know, you're gonna be *part of*, part of *that*, and I

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<sup>†</sup> "benzo" is slang for benzodiazepines – a highly addictive psychiatric medication used primarily for treatment of anti-anxiety and sleep disturbances.

know there are people down there who don't do drugs, but they don't have that little thing in their head that's called an addiction problem. I do. I am the queen of the drugstore junkie. The queen.

With this comment, Christine summed up the impact of housing, and by extension a more supportive environment, in her life: It surrounded her with a positive, healthy environment, which in turn, prompted her to live more positively and healthily.

The cumulative impact of drug addiction, social marginalization, and the loss of her spouse evidently placed dark clouds over Christine's life for many years. Like John, Christine was very clear that securing housing served as the turning point toward regaining control.

But look at this, it's been eight years since my [spouse] died, and [on the anniversary] I actually only cried for about three days! This time. That's pretty cool. And I haven't done any drugs, like illicit drugs? In almost, well, since I moved in here I haven't done any...nada nada nada and I don't wanna wanna wanna... And that's because I have a home now. I consider this place home. This is my *home*.

Christine's comment that she felt better able to cope with the anniversary of the loss of her spouse again emphasizes her commitment to looking forward, and to shed the more painful aspects of her past.

Like John, Christine expressed a sense of gratitude for the more ordinary aspects of daily living. In honour of her British heritage, Christine made me traditional English tea upon my arrival at her home, and throughout the interview she expressed amazement at the simple things that stable housing has now made possible:

To wake up, to make by bed, and yes I make my bed everyday, I didn't just do it cause you're coming over, you know? I'm the type of person, I'm very ritualistic.

It occurred to me how difficult it must be to be a self-described "ritualistic" person, while living with so much uncertainty and unpredictability that the combined forces of homelessness, poverty, HIV disease and drug addiction represent. In the same way that John celebrated his new found ability to do laundry and go on walks, Christine honored the act of making her bed, simply because she had been deprived of that basic ritual for so long.

Christine's pride in her home was apparent throughout the interview. It was clear that she had put great thought into every aspect of her home. After living in a series of bleak hotels in the downtown eastside, she described her initial hesitance to furnish her new apartment.

On the first day through the first three weeks, I slept [in the living room], the mattress was right there, I didn't even have a TV, because I didn't want that, and I just had a mattress and a little radio for the first two or three weeks, cause I wanted to make sure that this was where I wanted to be. But then after that, everything started to come together.

Christine's profound gratitude for her housing was evident throughout the interview. But she also maintained an awareness of how, as a woman, and particularly as a transgendered woman, she felt especially fortunate to have secured safe and stable housing. She made reference to the fact that there was only one other woman living in the 30 unit building.

It kind of makes me sad, cause I think of all [the women], there's a couple of women I wouldn't mind having move in here, because I know that they would appreciate the beauty of this place.

This comment points to Christine's appreciation for the quality and aesthetic of her housing, but also suggests her on-going sense of isolation as one of the only women in the building. Unlike John, Christine did not describe a tremendous sense of connection to those around her. Where for John, housing provided access to a new "family," housing for Christine provided a sense of peace and predictability, but not necessarily belonging. In spite of her obvious sense of comfort in her new home, she still seemed to identify as an outsider.

Christine's narrative does, however, reveal the power of housing to create increased opportunities to make positive health choices, and increased sense of connection to the broader community. In answer to my question regarding a typical day since she secured housing she responded,

Well, I'm much more out and about, hon! Typical day is, I get up, and it feels good to be here, and I'll go to the [AIDS health centre] for breakfast, and today I meet with my new doctor to get off the meds, oh I can't wait until they're all gone! And then, what I might do is go second hand shopping ... and then sometimes I'll go for lunch, and on Tuesdays it's lunch at the [agency for HIV positive women]....

Like John, one of the major impacts of stabilized housing was Christine's increased capacity for positive social connections. When I asked her to contrast her present life with a typical day before, she described her extreme isolation:

When I lived at the [downtown eastside hotel] there were no typical days. It was just pick up my methadone, get home, and stay in bed all day. I was depressed. *Majorly*. You know, it was [welfare] cheque day, it was get your money, buy a little food, and pssht. But now, I don't even want to think about that, now I'm making a home. It's just so cool.

Christine tempered many of her descriptions of the past, with a statement of hope for the future. Unlike John's sense of incredulity about where he had come from and where he had arrived, Christine's statements revealed a sense of determination to leave past challenges behind and focus on future goals, such as getting a new doctor and getting off methadone. She indicated that housing gave her a new found strength, and that she had no interest in looking back. When describing the process of getting furniture and putting her home together, she stated, "...all that just kept saying to me, hey, wow, I'm healing, I'm getting better, I'm getting stronger...I can only go one way...and that's up!" This became the central point of Christine's story, in that it reveals housing as the catalyst for positive life changes.

Given Christine's history of chaotic healthcare and high level of medication prior to getting housing, her excitement over her impending medical appointment with a new doctor is not surprising. Like John, she described an experience of feeling "poisoned" by her former healthcare providers. Christine described her first meeting with an HIV specialist while she was living in the downtown eastside:

I said, look, I'm already on 180 [millilitres] of methadone, I said please, I don't want to have to be on one of those [HAART regimens] that sop it up? And so he said ok we'll do this and we'll do that... and this is another

thing I can be happy about the housing and how much strength it gives you, it woke me up once I had done all this to realize that I am the master of my own body, and these doctors they just downtown lied to me. [The doctor] knew damn well the one anti-viral [medication] they were putting me on was going to soak up the methadone. They knew it! And I went from 185, up to 246 [millilitres of methadone].

Christine's sense of a lack of control over her health, gave way to mistrust in the healthcare system and providers within the system. Christine described her frustrations with not feeling heard by her doctor when she was experiencing significant side effects from the medication:

I kept telling [my doctor] I couldn't feel my toes, I couldn't feel anything and my feet were bleeding! The skin was getting dry and it was cracking and I didn't know what the hell was going on. I was getting these shooting pains up my legs, then I said what's going on here? And sure they got a good report back that the CD4 counts were great, but that was just one [test result]! And then, it did a flip turn, and the toxicity started to happen. And I said to [my doctor], I'm being poisoned. 'Oh! You're not being poisoned, we know what we're doing.' I said, 'oh really?' And I never said anything to anybody for the longest time.

Christine's account of having her concerns dismissed and ignored is interesting in that it describes a process of gradually giving up her participation in healthcare decision-making. Christine only felt able to initiate a search for a new doctor, and to renew her

request for a different medication regime, after securing stabilized housing. Describing her elation about finding a new doctor, she exclaimed,

And I couldn't do that if I wasn't living here, cause I feel good about myself and that's why I make an effort at getting up every day even if I just get dressed up to go for breakfast, but I'm doing it for me. There's this cute little girl [at the AIDS centre] and she calls me 'The Glamour Glory Girl.' She says, 'you always look just like you've stepped out of a magazine!' She says, 'do you *ever* have a bad day!'

Christine's narrative revealed an on-going struggle to live with dignity. This sense of dignity had clearly been challenged while living in unstable housing. Describing her life on the street, she revealed the constant violence and discrimination that she was confronted in her daily life;

I got mugged, and I had my head split open, you know, and that was a transgendered bashing you know, because I am proud of who I am, and I don't keep it a secret, you know, yeah, so what? I had a sex change, get over it, you know? Move on!

Later in the interview, while talking about her goal to get a documentary on her life story made, Christine stated, "If my dream comes true...then every owie and every boo boo, and every single solitary blow to the head, and every rape, and every naming I've been called will have been worth it." Her strong sense of self stood in contrast to the obvious stigma and violence that she endured throughout her life. But this statement again exemplifies the role of housing in giving Christine the freedom and space to express herself. Gesturing around her apartment, Christine exclaimed,

I did this! And each day I do a little more. And people started giving things, I mean look at that chair you're sitting in! To buy something like that, that chair is worth \$500! They gave it to me! You know, and that makes me feel so good about myself once again.

When I commented that it sounded like she had taken charge of her health, she responded,

I'm proud of myself. I feel good. I have a home. And one of my neighbours who I have become friends with told me something that I had long since forgotten. And funny that I should forget that considering who I am. He said, 'Christine, you are the master of your body, and if anybody should know that you should'... And I went, 'wow, you are absolutely right.'

As a transgendered woman, Christine represents one of the most marginalized groups in North American society. Housing provided her with a stronger sense of self, and a recognition of her own value. Shortly following this comment, true to her new-found mastery over her own body, Christine ended the interview, stating that she was tired and that the medications she was on severely limited her capacity to focus. The impact of her story comes from her absolute commitment to taking care of herself, and to looking forward, not back.

*Marie: "I can just die here"*

Marie is an Aboriginal woman in her forties, who I have known for many years. Marie attained subsidized housing seven months prior to our interview, after over ten years on waiting lists. I was particularly interested in talking to Marie because her quality of life did not appear to have improved dramatically since her move: She remained only moderately engaged in health services, and her health had continued its rapid deterioration. After years of hard living in unstable housing throughout the Vancouver area, Marie had secured a bachelor apartment in a subsidized building for persons with mental health diagnoses and/or HIV/AIDS. Her story focused initially on the powerful social stigma that impacts the lives of women like her who are sex trade workers, who have active addictions, and who are HIV positive. At several points in the interview, it was difficult to ascertain whether Marie was referring more broadly to the needs of marginalized women in similar circumstances, or to her own personal situation. She appeared more determined to identify service gaps for women in general, than to tell her personal story. I knew Marie to be someone who had bared her soul in media and in public speaking many times through her life as a woman living with HIV, so I understood her reluctance to open up her life for consumption once again. Toward the end of the interview, however, Marie began to discuss the role of housing in increasing her own sense of self-determination and peace. While she had given up the hope of an improvement in her health, her appreciation for a secure and stable place to rest was clear. Summing up her answer to my question about the role of housing in her life, Marie stated "I'm in a clean place, I can just die here." I realized that this was really the central point of Marie's story. After years of living in profound poverty and pain, she had found

a place to die in relative peace. Over the months following our interview, Marie's health continued to decline. Shortly before I began to write up my research findings, Marie was admitted to hospital and deemed palliative. For once, she consented to stay in hospital and to be looked after. She died several weeks later. While housing provided the other participants a safe place to live, I realized that housing provided Marie with something equally important: A safe place to die.

Marie's bachelor apartment was more sparsely furnished than John's and Christine's, but it was tidy and organized. Like Christine and John, Marie's décor served as an expression of herself and the things that were important to her. She had created a striking photo collage to hang above her bed, featuring photos of her children, her family, her elders, and herself at different stages of her life. Marie explained that while she liked to keep her living space clean, she had very little energy to do so: The collage was accomplished while on a "crack high."

Marie's story differed significantly from John's and Christine's, and this was immediately evident with her choice to begin the story of her journey to housing with the more negative aspects of her experience in her new housing: "You're very monitored here, and no privacy. You know, we pay rent and get treated like children, like [we're] being monitored 24 hours a day." Much of Marie's discussion focused on the stigma and discrimination she faced in daily life. She clearly felt very aware of the assumptions that were made about her by the building administrators on the basis of her history of drug addiction and prostitution. She described her experience of feeling watched and judged, at the expense of being cared for and supported.

I was upfront, I told [the manager] that I prostitute sometimes and I told them that I use drugs, and I made sure that I wasn't disturbing anybody on the floor. I don't work for myself in this building, I don't have dealers coming into the building, to buy, I mean he thinks I do, but I don't. You know, what I do has no bearing on who I am, right? If they're so concerned about what goes on in here, I don't get bed check calls, if somebody is locked in their room for a few days, I don't see anyone knocking on doors...

Marie's statement reveals that the discrimination she experienced as a woman living in the downtown eastside was not eradicated by a move to a new neighbourhood. Her narrative highlights one of the many ways social services (such as housing agencies) can perpetuate the marginalization of those they are trying to serve. Marie felt that she was being monitored by the housing manager for illegal or disruptive activities, but that this concern for her activities did not extend to a concern for her well-being: The staff were only concerned about her to the extent that she disturbed others. The impact of this negative attention only intensified her experience of stigmatization. In some ways, she felt more isolated within her new housing than she had while unstably housed in the downtown eastside.

Unlike John and Christine, Marie identified aspects of her life in unstable housing in the downtown eastside that she missed:

In the downtown eastside there's more of a family sort of feeling, like when I was living at the hotel? We helped the old guys. I mean, there weren't any females in there, but if one of us was stuck for something, you know, we always looked out for each other...

The prominent message in Marie's story was the impact of marginalization on her health, and indeed her life as a whole. Marie frequently turned her more personal responses to broader political statements on the lack of housing options for women. Unlike John and Christine, she retained a strong connection and identification with the downtown eastside. When I asked her if she felt more marginalized in her current housing than she did in the downtown eastside, her response revealed a strong sense of resignation. She indicated that she was aware of the assumptions that were made about her as an aboriginal woman, prostitute and drug user. To Marie, a continued experience of discrimination and oppression within systems of care was simply a foregone conclusion.

Well, I'm a drug addict and all the people I associate with in the downtown eastside are people who are drug addicts. [The staff here] don't realize that I have the absolute capabilities. If you want to boot me out of here? I'll take you to court for it. I'm not an idiot.

Following this statement, Marie again made the connection between her personal experience, and the oppression of HIV+ women generally.

And, there's just so little support for women, I believe, *still*, as far as HIV and AIDS. And housing is one of the biggest problems. We don't even have a 24-hour a day shelter for women, yet there's tons of shelter downtown for men. Our detox [facilities] don't even have enough beds for women. And I still believe that a lot of them favourites, in this game, are the gay men! Only now they're putting women in [housing]! You know, why is it the men were getting subsidies?

Marie's comments expressed the cumulative impact of having her needs overlooked and ignored over many years. Her perception of a social hierarchy within the HIV/AIDS population is an important point. Given that the common denominator within the majority of persons living with HIV/AIDS is an experience of stigma and discrimination, the group with the most resources can be seen to have shifted from marginalized to empowered within the context of the HIV/AIDS movement. The gay community is credited with leading the grassroots response to the HIV/AIDS health crisis, and consequently, are perceived by other affected groups as holding the most power. Marie expressed that her sense of marginalization as a woman was compounded by a sense that gay men living with HIV/AIDS had disproportionate access to resources.

When describing her wait to secure housing, she expressed considerable anger at what she perceived as the inherent gender discrimination within public policy:

When I was first diagnosed, I should have got housing right away! But, I believe that this was the government, you know, they wouldn't outwardly encourage it, but they'd think, well, she'll find a man, and he'll say oh ya, and it'll all go away - and that's bullshit! Social housing needs to be to the point where people keep themselves healthier.

Marie's statement identified a key failing of the current system of affordable housing. Because it is based on individuals who are most in need, existing systems often miss the opportunity to establish housing as a preventative mechanism: To provide adequate resources for quality of life, before an individual's health deteriorates. Marie's narrative points to the potential of housing to slow disease progression, and the impact on health

when it comes too late. When I asked her about her health while waiting for housing, she spoke of the barriers to self determination while unstably housed.

I was always fairly healthy, through most of that, right? I mean, you know, I was living with men and getting kicked out, and losing places, right? And I couldn't even get emergency housing. If it had not been for [community advocates] I would not have housing. [If I didn't get housing when I did] I would be living in a skid, you know, where I don't want to be. In fact, I think I would be dead now.

Marie's comments here reflect a sentiment expressed by all of the research participants. Each in their own way was quite convinced that they would have died had they not secured housing.

Listening to the audiotape of our interview, I had to strain to hear Marie's words. Her voice is weak throughout, and at times barely audible. While the interview content demonstrates the wisdom that Marie's incredibly hard life gave her, her words also reveal an enduring sense of powerlessness, and anger over the assumptions mainstream society makes about women in her situation. Translating her personal pain into political statements about the needs of women in similar circumstances appeared to be a means for Marie to ease the pain of having her needs ignored for so many years.

Speaking as a woman, social housing is not enough... I don't know why they prioritize men, and putting housing in places like the downtown eastside for women, where she gets evicted because she's got all these guys coming and going, you know?

For Marie, securing stable housing, did not fully achieve the sense of control and empowerment that other participants described. And yet, when I asked her how she spent her time since securing housing, she described a similar sense of peace as that of the others:

I like quiet. You know, sometimes I don't think the [building managers] realize, I spend a lot of time in this room with nothing on [no TV, music]...

I just like quietness. I don't go out much during the day - I sleep a lot.

Mid-way through the interview, Marie expressed that she was tired and requested that we keep talking while she lay down. At this point, her mood shifted. She began to discuss about some of the benefits of her new housing:

I am always playing the waiting game. I don't want to fight any more. I just want a decent place to live and die - that I call my own. And I've had bad relationships in the past, and I was always the one who left. Right from my marriage. Now, I finally have my own apartment. I can do what I need to do for myself.

It was here that Marie's narrative began to address the role of housing in increasing her self determination and control in her life. I noticed that Marie deflected a lot of my questions regarding her health. She described her daily crack use as a means to manage her pain and to provide the energy she needed "to get through each day." She was unable to identify an improvement in her health as a result of securing housing, other than an increased capacity for rest. While housing did not significantly transform Marie's physical health, it gave her a sense of autonomy that she had lacked before. These are clearly things that she needed to live, and die, with some degree of dignity.

I miss companionship, so I miss having a man in my bed that I can hold on to. But I owe nobody anything in here anymore! I don't have to respect men, right? And if they're disrespectful to me? There's the door! Get out, this is *my* place.

Marie's sense of autonomy was tempered by her obvious isolation. Unlike the other participants, housing gave her increased safety and some predictability, but not necessarily comfort or social connection. Clearly, her sense of stigma remained strong. In describing her relationship with the management of the building, Marie again expressed a desire to simply be looked after.

I think sometimes management comes in my room. I think they're checking out to see what I got, right? Like even [the manager], OK, he'll come in, but he never ever checks in to see if I need anything to eat.

When I commented that it sounded like she was ready to be taken care of, Marie responded,

That would be nice, like just to vacuum and stuff. That's what I'm saying. Like even right now, I'm even contemplating trying to get into the respite for a while? Cause I'm really sick, I know I'm really sick - I know by my body how sick I am. I don't usually get like this.

Throughout the interview, whether Marie was talking about her own circumstances, or those of women living in the downtown eastside generally, I had the overwhelming sense that for Marie, housing simply came too late. Toward the end of our exchange, I asked Marie what she thought would have been different if she had got access to stable housing sooner. I was unsure whether to ask this kind of hindsight question for fear that

it would be too painful, but Marie's answer spoke once again about the role of housing in creating a stronger sense of self-determination.

If I had got housing when I first became HIV positive? I wouldn't be in the mess I'm in now. I think I would have taken better care of myself, and I take good care of myself anyways. But through each break up of a relationship, I lost part of me. And as I've gotten sicker with the HIV, I'm losing more of me. So losing all that stuff, it's bringing me to the point that I just want contentment and this is great, this is all I need. I'm in a clean place, I can just die here.

There was a tone of resignation running throughout Marie's narrative: She lived a life of profound stigmatization, addiction, and pain, and had reached the realization that she would not overcome this in her lifetime. Housing provided her a means by which to increase her safety, and experience a sense of control over her life that she had not had before. Within the context of her story, this sense of moderate peace nevertheless represents a powerful transformation.

*Tim: "Housing provides hope toward living a real life"*

Tim is a gay man in his late 30's, who had been living with HIV for approximately eight years. When I interviewed Tim, he had been living in subsidized housing for over six years – far longer than any of the other study participants. This was one of the many aspects of Tim's story that differed from the others. Yet despite these differences, I found that the overall content of his story followed remarkably similar themes, particularly with respect to the role of housing in increasing a sense of control, freedom of choice, and hope.

Tim had a "portable subsidy." With a portable subsidy, he was able to choose where he wanted to live and a government subsidy ensured that he did not spend more than one-third of his total income toward rent. Unlike the others, he was living without the stigma of a subsidized building that is known in the community for housing persons living with HIV. Tim's apartment was located in a high-rise market rental building in Vancouver's West End, a neighborhood with a strong gay community. His apartment was carefully decorated and featured a small balcony overflowing with potted plants, and an expansive view of the ocean. As we sat on his comfortable sofa sipping tea, I had the impression that Tim had created a sanctuary for himself within his housing. Indeed, much of Tim's story focused on his quest for mental, physical, and spiritual well-being.

Tim was one of the first participants to contact me, and we exchanged several e-mails in our attempt to set up an interview time. At one point, however, we lost track of each other: One of my e-mails did not reach him, and I became occupied with responding to other participants. I knew that I still wanted to talk to Tim, because I felt his experience of long-term affordable housing would provide an interesting contrast to that

of the others. He was the only participant who had moved through the different stages of affordable housing, from living in a subsidized housing building, to fully independent and confidential living in a market apartment subsidized by the government. I also felt strongly that I wanted to include his story as a gay man, given that gay men continue to represent the population group most disproportionately affected by HIV/AIDS in Canada (Public Health Agency of Canada, 2005). As Tim attained affordable housing fairly early in his disease progression, I was excited to hear his story of his health and health practices over the period that he did not have to worry about the adequacy of his housing. I was also interested in hearing about the shifts in his life from unstable housing, to living in a subsidized building, to fully independent living in the community. When we finally did re-connect, Tim revealed that the intervening two months after our first contact had been mentally and physically draining, and he felt much better able to cope with an interview now than when we had first spoken over the phone. When we sat down to talk, I was interested to learn of the role of housing in his process of coping with the inevitable unpredictability of living with HIV disease, and this led me to what I discovered was the main point of Tim's story: As we were coming to the end of the interview, Tim told me, "housing provides hope toward living a real life." I selected this statement as his central point in that I think it illustrates that the journey toward healthier and more positive living does not end with securing subsidized housing. Living below the poverty line and with fluctuating health inevitably imposes significant stress on daily living. But I wondered if having safe, secure housing, acted as a buffer against losing hope completely during the more challenging times. Through the many ups and downs of Tim's journey living with HIV, it appears that his housing has indeed served as an indispensable coping tool.

Tim began with a chronological telling of the events that led him to apply for, and secure, affordable housing. He had moved back to Vancouver following the break up of a relationship, and found himself sleeping on the couches of various friends. He was unable to work due to debilitating HIV symptoms, and could not afford Vancouver rents on income assistance. Tim described,

My health was waning, dwindling, I had the flu and basic leg pain and stuff, shin splints and stuff like that, and I was working, prior to that but had to stop because of my legs... and I was very persistent I guess, a lot of people when they apply [for housing] they put their name on the list and they walk away and wait for the phone call, but, [the housing administrator] saw my need first of all, and I was persistent and got everything done that he wanted me to do, jumped through all the hoops, got back to him and within a month [of applying], actually, I had an apartment.

Tim's emphasis on the persistence that is required to secure adequate housing reminded me of the other interviews in which participants lamented the length of time that it took to get into subsidized housing. The other participants had credited community support workers for advocating for them to finally assist them in securing housing. Tim's story highlights the role of life skills toward advancing ones goals within social systems, and the importance of a sense of empowerment: Tim believed in his right to be adequately housed, and this firmly-held belief propelled him forward.

At the time he found himself homeless, Tim was also dealing with a sudden shift in his health. He described how his symptoms took him by surprise:

[My health] was declining, and it was premature also because I was told I would have nothing to worry about for about ten years, medication-wise and HIV-wise, and four years later that turned out to be not true. Four years later. So a lot of it played with my emotions... it really affected me more so in that way, than it did physically, it was like a major depression for me, because I assumed, I didn't want to be in that category, you know, I was getting across the fence and I was going back... and not having anywhere to live was depressing as well.

Tim's comments illustrate the importance of resources such as housing being available when individuals most need them. His experience also demonstrates the role of chronic illness in setting the conditions for poverty. During the period that he was dealing with homelessness and declining health, Tim used all available inner-resources to aggressively pursue affordable housing. His experience struck me as particularly interesting in that unlike the other research participants, Tim's period of extreme hardship was quite brief. He essentially secured adequate housing in his first moment of need. Tim was then able to use the security provided by affordable housing to focus on his needs related to his fluctuating health.

While living in the subsidized apartment building, Tim found the stigma of being associated with a building for persons living with HIV had a significant impact on his quality of life. He recounted his exchange with a friend, "...she used to come over and she'd call it the hospice, and I would say ...It's not a hospice! A hospice is a place you go to die, I came here to live!" It occurs to me that with this statement, Tim identified a key dichotomy of subsidized housing buildings for persons living with HIV: While all

participants reported a sense of relief upon securing affordable housing, Marie and Tim described a negative experience of living in a building that is specifically for people living with a chronic, stigmatized illness. This is in contrast to John and Christine, who appeared to appreciate the solidarity and sense of community in living with others who were in similar circumstances.

In Tim's case, the experience of living in a subsidized building was compounded by his sense of a lack of safety in terms of the building's location, and the abundance of drug activity within and around it. Like John and Christine, securing subsidized housing was a major factor in Tim's shift toward a healthier and safer lifestyle.

In my past, I dabbled in drugs, I had been a party boy, kind of thing, and all these people, eh? Fun fun fun! And kind of getting out of that portion of my life...in the [subsidized building] it's kind of there, I mean you walk out, you walk in, it's there, and that did kind of, I don't know, it didn't drive me to do drugs, but it was something I considered to be an unsafe atmosphere for myself, I didn't feel comfortable... one of my goals because of that was to be persistent again to get my outside subsidy.

Again, Tim utilized his own life skills and self-advocacy to agitate to be selected for a portable subsidy. But even once he had secured housing in the broader community, he continued to feel affected by the stigma of living with poor health and poverty. He explained,

I'm on the shy side, a little bit reserved, care a bit too much what people think... but just wanting to be in the real world I guess basically, to have that choice. And I am ever so grateful that I have that choice now, but now

I was thinking about it on the bus today... It's sort of like, being invited to the ball, but not having a gown... So I feel like that at times here, because I get in my head, oh I want this, I want to do that, and then, well, wait a minute, I don't have the cash for that, that requires time and planning, you know, and money.

Tim's comments describe a feeling of perpetually feeling on the outside looking in, from the periphery to the mainstream. Yet throughout his narrative, he emphasized the importance of the power to choose. Despite the challenges presented by poverty and poor health, the capacity to make choices within daily life was critical to Tim's emotional, physical, and spiritual well being. When I asked him to describe his social networks now, and how they have shifted over the years, he responded that his social network stayed essentially the same,

I've had the same sort of group of friends for the last 15 years or so, some of them have moved, and whatnot, some of them have alcohol or drug problems, and I choose not to be with them because I am not there anymore.

Tim's response again points to the role of housing in providing individuals with control over various aspects of their life. Like Marie's description of housing giving her the power to invite people in, and to ask them to leave, Tim's matter-of-fact description of his friendships expressed a strong sense of control over those he spent time with. This stood in contrast to the beginning of his story, in which he described being very much at the mercy of his friends' good will, while couch-surfing and looking for affordable housing.

The issue of control was also apparent in Tim's description of his experiences in coping with the unpredictability of living with HIV, and the fluctuations in his health. When I met with Tim, he was just emerging from what had been his most challenging year of living with HIV disease, and he spoke about how the experience of a sudden decline in health and the complexities of treatment had affected him:

It's quite interesting, I had a partner who passed away a year and a half ago, who was also living in [the subsidized building], my health started to decline when his did, I was off meds for about four years, and had to go back on, my [cd4 count was] dropping, and my health kind of hit the floor in the winter...for the first time my [cd4 count] went well below 200 and my viral load went up... and I've become resistant to meds through what I like to think of no fault of my own ...started taking them religiously, then they didn't know what to do with me, which just added to my panicked state. I used to be a very grounded person, when I hear these medical things, it just gets me all dialled up...my humorous way of dealing with it is that I've graduated. You know, now I'm going to [the top AIDS specialist]. They don't know what to do with me, I'm on salvage therapy after being basically on minimal therapy, to salvage therapy and that's a major mind fuck.

The term "salvage therapy" refers to the medication regime that is prescribed when a patient has demonstrated resistance to all other HAART combinations. It is essentially the last tool that the HIV medical field has in halting or slowing disease progression in their patients. Given the complexity of Tim's medical situation, his story suggests that stabilized housing precludes neither disease progression, nor medication resistance. Tim

frequently referred to the debilitating psychological impact of changes in his physical health, and the stress of dealing with increasingly complex medical decision-making. He acknowledged that housing has nevertheless provided him with a stable base from which to better cope with shifts in his health.

The impact of housing on health care decision-making was further evidenced by Tim's description of his experience in coping with side-effects from his medication regime:

I was trying to figure out the whole [antiretroviral] thing, because it was nothing with my head, I thought I was near dementia, I would reach for a cup of tea, and get there and think what is this, why am I doing that? But that's how it affected me. I guess what I'm saying that the doctors wouldn't buy that, that the [antiretroviral] was affecting me because it's such a small dose? They wouldn't hear about it...you know, 'there's nothing wrong with you, what you're experiencing is from something else, you must be taking something else' – until it showed up in the blood test, and it was like, 'thank you!'

Like John's and Christine's experience, the story Tim told about responding to medication side effects revealed a feeling of not being heard by the medical system. Tim's tenacity – perhaps the same tenacity that got him the housing he needed so early on, was what ultimately brought him vindication with his doctors, and eventually, increased control over his health issues.

Tim's control over his health was further evidenced by his description of daily activities many of which focused on improving his spiritual and physical well-being.

When I asked him about the community resources he connected with, he listed off a number of activities including weekly meditation, yoga, and Qi Jong through a local wellness centre, various food and nutrition programs, and attending retreats through the local PHA member group. He also spoke about the role of housing in improving his nutritional status.

I like to eat at home as much as possible, oatmeal in the morning, I cook, but you know, I'm not a chef. I do prepare food, and I do make it for myself.

Sometimes I do have issues with hunger, I don't know why I let myself get to the starvation point, and it's like, 'gotta have something now!' So I'll just go to a fast food place and get something because it affects my mood.

This passage demonstrates the role of housing in assisting PHAs in organizing their lives and controlling the ups and downs of their health. Tim maintained an awareness of the ways in which the fluctuations in his mental health affected his appetite, and stable housing provided a tool to respond concretely to these fluctuations.

Tim also referred to his sense of stigma of living with HIV. Tim had seen a number of friends, including his ex-partner, go through rapid disease progression and death from HIV. I noticed that he tended to minimize his own mental anguish, because it was not combined with rapid disease progression that he observed in others. He relayed the experience of watching his partner decline, comparing it to his own more recent experience of physical decline:

Sometimes, like my ex, he had [an opportunistic infection] on his legs very badly, and he had a lot to deal with, but he'd do it with a smile on his face, and still working and he'd pop some morphine and go to work, and he had a

lust for life, I kind of haven't, I don't know that I ever really had a lust for life like that, and being someone in his position looking at me and thinking, 'there's nothing physically wrong with you, what's stopping you from getting over this HIV, um, stigma.' And that's what it was, it was all, like I say, it was a mind fuck, it's like, 'I'm here, I know what's going to happen, it's just a matter of time,' and all that negative kind of thinking and it's very interesting what actual illness does to you, it makes you look at things differently and to struggle and fight, and mine's by no means that extreme, I can't even say that, but it's not a nice place to be.

Tim appeared almost ashamed to express how difficult the mental side of living with HIV/AIDS can be – particularly the stress of the tremendous unpredictability that he experiences in his life. He expressed a sense of guilt that his health appeared more stable than that of others, and this appeared to be tangled up in his fears of his own disease progression. When I commented that housing appeared to have given Tim stable ground on which to cope with the ups and downs of living with HIV, he agreed, and began to speak of his spiritual journey to get to know and like himself more.

I've just discovered that I've had choices all my life. I've lived my life just kind of going with the flow, and not even considering that I had the choice, and all this time I've been making choices, but I mean sometimes the wrong ones... its sort of a spiritual discovery thing, but I found myself a reactor and not an actor and the thing that I have to do is act and not react.

When I asked Tim about the intimate relationships in his life, he stated that he had recently chosen not to pursue a relationship with someone he had grown close to while at

a healing retreat for men with HIV. Here again, his comments turned spiritual as he told me,

I discovered that I was looking for love on the outside, where I should be looking for it on the inside... and so that's where I'm at now is looking for self-love and hopefully eventually, but I am focusing on myself, and not looking outward to see what's missing.

In spite of the differences between Tim's experiences and those of the other participants, his interview ended on the same introspective, peaceful note that the three other interviews did. When I asked him what he felt most grateful for with respect to housing, Tim responded, "freedom to choose where I want to live." At several points in the interview, Tim used the term "mind fuck" to illustrate the sense of lack of control he had over his health, his healthcare, and over the way he felt when he woke up each morning. In the context of a life in which so much feels beyond one's control, the impact of being able to choose where one lives, and to have the security in knowing that it will not be taken away, cannot be underestimated. In Tim's case, housing provides what perhaps he needs most: "Reason to hope."

*Derek "This is as good as it gets...from what I've seen"*

Derek is a 50 year old man who had lived for many years with a mental health diagnosis. When I met with him, he had been living in subsidized housing for about six months, after becoming homeless following a lengthy hospitalization one year before. Of all the participants, Derek was the most inhibited in telling his story, and the existence of the tape recorder played a prominent role in our interview. In reviewing the transcripts, I debated whether there was a way to include Derek's story. During our interview, Derek had difficulty providing complete responses to my questions. At regular intervals, his voice would trail off as he became reminded of the fact that he was being taped. I noticed that I talked far more in this interview than in the others. I think I did this as a means of rescuing us both from the awkwardness of the taped interviewing process. Consequently, there were many points in his narrative that were cut short by one of my questions or comments, and in retrospect I wish that I had left Derek more space within the silence to find a way to finish his thoughts. The process of writing up the findings from the interviews with the other four participants convinced me of the importance of Derek's story. Derek differs from the others in that he secured housing after a lengthy hospitalization for AIDS-related pneumonia. With respect to health status, Derek's experience represents the most startling transformation of all the participants in that his life before securing housing was characterized by frequent readmissions and visits to the hospital emergency department. After securing housing, Derek connected with stabilized healthcare, and had not been readmitted to hospital, nor utilized emergency services since.

Derek's housing was located in a government-subsidized building in the downtown eastside. The building was only several years old, and very clean. It was the only one of the buildings that I visited that had 24 hour staffing. It was also located on one of the busiest drug-trafficking blocks in the city. I was pleased when Derek contacted me to participate, because I had heard of the dramatic impact of Derek's housing on his physical health. After hearing so many stories of people's relief about finding a way out of the downtown eastside, I was also interested in exploring the impact of housing location. Derek was the only participant still living in the downtown eastside, and I was curious whether the safety and condition of the building was enough – or whether Derek, like the others, had aspirations to move out of the neighbourhood.

Derek's apartment was the most minimally furnished of all the homes I visited, making the depth of his poverty readily apparent. We sat on pillows on his futon-less couch frame, and rested our cups of green tea on a cardboard box that Derek had draped with a decorative cloth to use as a coffee table. There were a number of reasons for Derek's exceptionally sparse furnishings. He had been moving from one shelter to another prior to securing housing, and had lost all the furniture and household items from his old apartment when he was hospitalized. Since his discharge from hospital, Derek had had on-going problems accessing income assistance. The total lack of stability in his financial situation was amply evident from Derek's physical surroundings. Before we even began to talk, I had the distinct impression that securing housing was a starting point for Derek in re-establishing stability in his life. The journey to optimal health was certainly far from over, and this was evidenced by the jumble of details of the past and present that characterized his responses. Unlike the others, Derek's story was less

oriented to the future. Housing had given him the beginnings of a sense of stabilization, and he was relieved, if not yet content. In describing his apartment, Derek stated, "this is as good as it gets... from what I've seen." This somewhat hesitant statement became, for me, the main point of Derek's story: He was satisfied with his housing, and cautiously optimistic about the future.

Derek learned that he was HIV positive and living with advanced AIDS during the four month hospitalization he endured just one year prior to our interview. It was clear that he was still adjusting to the shock of his compromised health status.

I had no idea, I just got really sick, it happened like within one week, I guess I caught some kind of minor pneumonia, and they elevated me to a ... plural [effusion], and it hurt to breathe, and I think I lost about 30 pounds within two weeks, you know, like it just hit me like that! I had no idea...

Prior to his hospitalization, Derek had been working part-time and living in a Vancouver suburb. During his four months in hospital, he had to give up his apartment as he was unable to pay his rent. Upon discharge, he stayed in shelters, where he found it impossible to attend to his considerable health needs. As a result, he found himself in a cycle of continuous readmission to hospital.

I was out and then I was in for a couple of weeks. Because I was staying in a shelter, I didn't have [anywhere to go]. When I found out I had HIV, first of all it took me a while to, you know, accept the fact that there's a lot of dying over there. And I didn't want to tell my friends that I had it, you know? It was quite a mind thing for me, you know?

Derek took a layered approach to answering my questions: In the response above, he began by answering my specific question regarding hospital admission, but then moved on to intervening factors such as the emotional impact and sense of stigma of living with HIV. Derek's story again exemplifies the role of HIV stigma in compounding the experience of illness-induced poverty. His lack of adequate income, and the absence of a support network to whom to disclose his HIV status, contributed to Derek's inability to realize improvements in his health. When he was discharged from hospital, Derek had minimal HIV knowledge, no awareness of services, and no regular doctor. "I didn't know what was available like service-wise, right? I was in one shelter and... I was just out of the hospital, and they didn't try to hook me up with anybody of any kind." Derek described continual re-hospitalizations until he finally secured a space on a shelter that, in addition to finding him a bed, provided him with supported referrals to local HIV/AIDS services. In describing his experience in the first few shelters, Derek stated,

I was in a lot of pain, you know. I ended up going to emergency every time something would happen. Even after I was out, [I would go] for after care kind of thing, right? So it's a shame there's, like not a hospice, but something like after-care for people like that, because you need a lot of rest. They weren't even letting me sleep in that first shelter that I was in. They would not let me sleep in. I had a hell of a time. I had to get notes from different doctors to get bed rest. Because the routine was, they would wake you up at seven in the morning and kick you downstairs for breakfast, and then, that's it, you can't come back until like twelve or something.

Derek's story illustrates the lack of choice and control that is often associated with shelter-living. In this case, his personal health needs were at odds with the daily routine of the shelter, placing him in a cycle of poor health and hospital re-admission. Getting into the shelter that provided him with referral services proved to be a major turning point for Derek. He connected with an AIDS case manager who assisted him in connecting with a clinic specializing in HIV care. The clinic gave him access to a program that dispensed HIV medications daily and provided meal and social service, nursing support to support people in managing their medication regime. The AIDS case manager also advocated to get Derek subsidized housing. Due to his health situation, he was prioritized. When I asked Derek to describe his life since securing housing, he responded,

Oh well I sleep-in in the morning so, rest. Rest and being able to, prepare your food. The food thing, like nutrition, that's what got me better pretty much. But routine also gave me, like that's the thing about [the clinic medication program], it gets people to the point of taking their meds.

Like the other participants, the role of ritual and routine was prominent in Derek's development of positive health practices. Stable housing enabled Derek to create control and predictability in his life. He credited this with enabling him to embark on an HIV medication regime. Stable housing also provided Derek with the opportunity to take advantage of the community services available to him. He frequently mentioned the role of the clinic medication program, his case manager, and addictions programs in his life. He described a state of optimism that he clearly did not have before. In the following passage, Derek describes the depths of his despair following his diagnosis.

In the beginning, you know, I thought, I don't know if I want to go through this. I was really thinking about, I wasn't feeling that well, and you know, I was in a fair amount of pain and I literally, I really, sort of struggle with it sometimes, but I'm not mentally in the same space at all. The housing, it's big. It's big, you know, if you don't have housing you can't clean up the rest of your life, whatever you have going on, health or whatever? It's so important. You know, although I'm living in the downtown eastside, this building is as good as it gets, really, from what I've seen.

When I asked Derek to describe his life prior to securing housing, his words echoed that of the other participants.

Before I got stabilized housing, oh god, well, it was just exhausting. I had nowhere to rest, and I wasn't on [HAART] meds, I would go to [drop-in spaces] but, like, not a place to actually rest. I wasn't even eating, I couldn't, I didn't have much of an appetite. Someone gave me some [nutritional supplement drinks]. I thought actually, I thought I was going to end up back in the hospital so I didn't really care. You know, I thought I'm so sick, I'm ...well, I'm dying. I thought, this is it. I really sort of gave up. I thought, I'm going to be back in the hospital and that's it! That's the way it goes, you know? Until something drastic happens, that's it. That's what I thought! [The hospital] became a home, actually, well for four months, and then out for a week, and then back in or a couple of weeks. You know in reality, that hospital becomes your living space.

Again, Derek's multi-layered description took me through his sense of hopelessness regarding his health while unstably housed, to becoming resigned to making the hospital his home. Derek's transformation was perhaps the most dramatic of all the participants: Without stable housing, he was in a cycle of hospitalization-homelessness-re-hospitalization. Securing adequate housing put an immediate stop to this cycle. It is difficult to find a more concrete demonstration of the role of housing in stabilizing health.

In describing his health practices since securing housing, Derek's words echoed those of other participants.

Since I got hooked up with [services] I have not been in the hospital. And you know, I actually feel good about getting up. I have rituals I do, like I do coffee, I take the bus down to [the coffee shop]. That's all I do, I smoke and I drink coffee, I shouldn't but I do.

Similar to John, Derek admitted to continuing to engage in moderately unhealthy activities, but he was doing it on his own terms, in that he was able to weigh out the risks within each activity and make informed decisions.

Securing stable housing also enabled Derek to reconnect with a social network. In addition to the health care workers at the clinic that he accessed on a daily basis, Derek described the process of re-forming connections with his peers.

Most of my better friends are in some kind of [recovery] program, you know? The people I hang out with. I don't really hang out with anyone that uses. I used to have a good ...job, but I played music, so it's like my life style was a party kind of a life style for a while.

Derek described how he had taken on teaching guitar to others in the building in which he was living. But it was clear that his connection to his community, beyond his appreciation of the work of community agencies, was minimal. While he offered what support he could to those around him, it was not entirely a reciprocal arrangement.

If I can help someone that's sort of trying to help themselves, no problem, I don't mind, it used to be just about the money but it's not any more.

[Getting HIV] has changed my thinking so much. I'm grateful for all the things I wasn't before. My life is not bad, my life is not bad. I'm much happier, you know, I have good connections.

Throughout the interview, Derek was preoccupied by his financial situation. He explained that he was on the phone with a legal advocate when I arrived, and he made several references to his on-going problems with income assistance, and the stress of his outstanding debts. His comments about dealing with income assistance echoed the experiences of other participants, and it was clear that, like the others, financial issues were an enduring stressor in his life.

Dealing with the Ministry [of Social Services], I can't. I'm not used to it and it's hard enough for me to [have to ask for assistance]. I appreciate what they have to deal with, but like I'm down here [in the DTES], and I walk into the office, and like, I guess I expect some kind of respect that I'm used to getting, right, and it's like, that take a number kind of attitude.

Derek's descriptions of life events in the year since his hospitalization and AIDS diagnosis revealed the transition of a formerly pro-active individual in relative control of his life, to a remarkably passive participant, to whom it would seem, life just seemed to

be happening. His words were those of someone waiting to see what might happen next. Yet at the same time, I could hear in Derek's voice that something was beginning to shift, that he had begun to take control, not to simply react, and he appeared to have started to set goals. Several months after our interview, Derek decided to move across the country to another city. While I do not know his exact personal reasons for the move, I took this action to mean that Derek had truly taken charge of his life. He had reached a place in which he was beginning to move beyond the uncertainty of life since his AIDS diagnosis, and to make concrete plans for the future. I wondered if this meant that Derek had moved on to see if the world would offer something beyond, "as good as it gets."

### *Summary*

The interviews conducted for this study sought to contribute to our collective understanding of the impact of adequate housing on the health and health practices of persons living with HIV/AIDS. Other than a shared experience of living in poverty with HIV disease, the study participants were quite different from one another. My decision to assemble the stories of a diverse sample of persons living with HIV was deliberate. I was interested in exploring the idea that the impact of housing on health transcends demographic differences among individuals. While the narratives each described unique journeys from unstable to adequate housing and the impact on health along the way, there were a number of common themes running through each story. The most obvious is the increased sense of control, autonomy and hope described by each participant: Each also described, in their own way, increased participation in healthcare decision-making, and improved health practices (though the degree to which these increased and improved varied among participants).

The participants' stories did not depict housing as a miraculous antidote to the complexities of living with HIV disease. Indeed, there were a number of elements that participants described as continuing to present challenges to the quality of their daily life. Each participant referred to psychological health issues as much as to physical health issues – in some cases, the psychological impact appeared to be stronger than diminished physical capacity. The experience of depression was revealed to have had a profound impact on the lives of all five participants. Each participant referred to the stress involved in dealing with unpredictable health issues, challenging and toxic medication regimes, and healthcare that was complex to negotiate, and often chaotic. The difficulties

associated with living in poverty appeared to play a role in the high stress levels among participants, particularly the experience of dealing with social systems that consistently discriminate and pose frustrating barriers. Finally, the experience of living in government subsidized housing was in some cases described as compounding the impact of living with a stigmatized illness. While the experiences of these five participants should not be generalized to that of the broader population of persons living with HIV/AIDS, the commonalities running through the participants' disparate and unique stories deserves some discussion. In the next chapter, I will provide a brief exploration of these common themes.

## Chapter 5 – Discussion

In this chapter, I explore the common themes running through all five narratives. These are: Control, autonomy and hope; strengthened identity; increased participation in health decisions and improved health practices; and poverty and stigma. I then reflect on how the narratives illuminate and/or add to the health models and population health framework discussed in Chapter 2. I also discuss how these findings fit with the existing body of research on housing and health, and identify areas for future research. I offer a critique of the study design, with particular attention to issues of validity. The chapter concludes with my personal response to the research data and process.

### *Common Themes*

*Control, autonomy and hope.* All five participants described a marked increase in control, autonomy and hope in their lives upon securing housing. I refer here to control in terms of power over daily decision making; autonomy as the ability to live and make daily decisions independently; and hope as an overall sense of optimism about the future. For John and Christine in particular, the impact of adequate housing on their capacity to reduce engagement in harmful activities was substantial. Both reported an immediate decline in drug and alcohol consumption upon securing housing. Adequate housing gave all five participants greater autonomy in deciding how to structure, and live, each day. Each identified the role of housing in increasing their capacity for rest. Each also referred to the contribution of stable housing in empowering them to determine who they did, and did not, wish to spend time with. All the participants identified the importance of routines in their daily life, and the role of housing in enabling them to create rituals in their daily life. While Marie differed from the others in this respect (most

likely due to the complicating factors of chronic pain, extreme fatigue and active drug use) she nevertheless expressed appreciation for the increased sense of order and predictability that housing provided her. The participants each referred at some point to the significance of seemingly mundane, every day activities in their life (for example, making the bed and doing laundry). Given their lack of capacity to attend to these basic needs while unstably housed, the ability to determine the order of each day, and to fully attend to their basic needs, had become a highlight in their lives.

The participants also described the importance of the process of furnishing their individual physical living spaces into unique expressions of themselves. This provided further evidence of the role of housing in instilling a sense of pride, strengthening identity, and increased control over the content and structure of daily life. In the case of Marie, whose health remained severely compromised, the photo collage featuring images of her family, friends, and images of her former, healthier self, acted as a means of establishing her presence within her living space. In the case of Derek, whose apartment was the most sparsely furnished of the five, a sense of self was evidenced through the guitar propped up against his bed, and his account of his recent practice of offering fellow residents in his building free guitar lessons. For each participant, the physical surroundings provided a much needed sense of predictability and order. This, in turn, appeared to give each an increased capacity for creativity.

Housing also provided participants with a means to look forward, and a sense of optimism about the future. For John, Christine, and Derek, housing provided a starting point from which to plan a healthier, more hopeful, life. The main message that emerged from these three narratives was that they were on their way to something better. Housing

represented a new reality, and a new set of possibilities. Marie's sense of hope was markedly different but equally significant: Stable housing appeared to provide her with a sense of hope for a dignified death. And Tim's story demonstrated the contribution of housing in maintaining a base level of hope and optimism while coping with the challenges posed by the volatility of HIV disease.

*Strengthened identity.* Strengthened identity refers to the role of housing in validating each participant's sense of individuality and self expression. Each described an increased capacity to express themselves, through decisions about what activities they engaged in, who they spent time with, and how they structured each day. As mentioned above, the physical living environments of all five participants played a key role in giving each an opportunity to express their identities and their individualities. I was struck by the importance each participant placed on serving me a hot beverage while we talked. Each had evidently put some thought into what I might like, and what would best express the life they wanted to reflect to me. Marie, who in many ways brought the most intensity to her interview, made sure that my cup of mint tea was kept full, while barely skipping a beat within her politically-charged rants. Derek served me raspberry-infused green tea boiled in a saucepan on the stove, while lamenting that his lack of finances prevented him from offering me the locally-roasted coffee that he liked to keep stocked in his apartment. Each participant had clearly put significant effort into furnishing their living spaces, in spite of the fact that most had very little to work with. For John, self identity was expressed through filling his apartment up with things that "needed" him to grow and thrive, such as his fish and plants. For Christine, the acquisition of various found and donated furniture gave her an opportunity to express her identity, but also gave

the message that she finally felt cared for, in spite of her continued experience of marginalization. Marie and Derek had not decorated extensively, but had done enough to establish their presence in their spaces, which seemed to express their sense of relief in not having to stay on the move, and to reflect how much they valued their new access to at least a modicum of peace and comfort. Tim's meticulously-furnished high-rise apartment with its panoramic view served as a symbol of his success at moving beyond the enduring stigma of with HIV disease. It was clear that he remained deeply affected by the challenges of living in poverty and poor health, but that his living environment afforded him the privacy and confidentiality that he needed to maintain some optimism even when life felt overwhelmingly bleak. Within the context of these five stories, I found the concept of housing as an expression of identity significant, in that it suggested the importance of a strong sense of self in increasing each participant's capacity for self care, reducing harm in daily life, and enhancing positive connections to the social world.

*Increased participation in health decisions and improved health practices.* All of the participants referred to increased capacity to make decisions about their health following their move to stabilized housing: These ranged from daily personal decisions regarding what to eat, and when to sleep, to more major decisions regarding their treatment and care. It is significant that four of the five participants spoke explicitly of the experience of feeling poisoned by toxic HIV treatments. While I am familiar with the challenges involved in HAART adherence, I was surprised at the extent of the participants' mistrust of medical practitioners and the barriers they identified to being fully engaged in decisions about their health. None of the participants had effective healthcare while they were unstably housed. Derek was discharged from hospital with

advanced AIDS but with no concrete plan for treatment and care, while Marie's consistent refusal of any form of HIV/AIDS treatment and care appeared to be linked to her profound mistrust of the healthcare system. Christine, John, and Tim all had the most experience with HIV treatments, and all spoke of the challenges of debilitating side effects, chaotic treatment, and not feeling heard by healthcare practitioners. While Tim's story of continued challenges within his healthcare suggests that housing did not necessarily have a direct impact on his ability to receive responsive, individualized care, it nevertheless illustrates the role of stable housing in providing individuals with the tools to take charge of, and become active participants in, their health decision-making. At the time of the interview, Marie was very clear that she was not interested in engaging with the conventional medical system, although it is significant that she ultimately accepted hospitalization and palliative care at the end of her illness.

All participants described a marked reduction in harmful and unsafe activities immediately upon securing housing. This was evidenced best by John's and Christine's stories of housing as the pivotal factor in giving up illicit drug use. Tim and Derek also referred to the role of housing in abandoning their former "partying" practices. In Marie's case, reduction in harm was evidenced by the role of housing in providing her with a safe space to use drugs, and to control which sexual partners and/or dealers she allowed within her home. Despite the variety in experiences, the role of housing in increasing each participant's engagement in safer health practices is remarkable.

The participants also referred to the importance of daily routine in managing their health. All highlighted their appreciation of the opportunity to develop nutritional practices in which they could decide where, when, what, and with whom they consumed

meals. This represented a freedom that was unavailable to them while unstably housed. All five spoke of simple straightforward activities such going for walks, as elements in the dramatic improvement in their daily life. All but Marie reported making better use of the community-based health services as part of their routine, and referred to the role of these resources in increasing social connection, support, and belonging.

*Unstable mental health.* The experience of stress and anxiety associated with living with HIV disease figured prominently within all five narratives. There are many factors that pose challenges to mental health stability among persons living with HIV/AIDS: The cumulative impact of complex and often toxic HIV treatments, fluctuating and unpredictable illness trajectories, and alienation from friends and/or family, was described by all participants. Clearly, stable housing was not enough to completely reduce psychological distress in participants' lives. However, housing appeared to provide all five participants a tool to better cope with the reality of stress, anxiety and depression in their lives. This is significant in that depression is increasingly a central component within the experience of living with HIV/AIDS (Sledjeski et al., 2005): All five participants referred to periods of debilitating depression that did not dissipate once stably housed. Tim, in particular, described long periods of depression that substantially affected his overall well-being and quality of life. The role of housing in reducing the impact of mental health instability could be seen in the participant's descriptions of their lives prior to securing housing: All described their lives being at the most chaotic and out-of-control when they were depressed. Their emotional state could be seen to have had a significant role in the activities that they engaged in. It is notable that for the three participants for whom drug use was a major issue, two described a

complete cessation of drug use upon securing housing (John and Christine), and the other (Marie) described far more control over her drug use and dramatically increased capacity to reduce harm in her life than she had while unstably housed.

*Poverty and stigma: Continued experience of oppression.* The impact of living well below the poverty level was a prevalent theme through all five narratives. Affordable housing made a substantial difference to the practical manageability of the participants' lives, and certainly provided a key tool in stabilizing their financial situations. But all five struggled in their dealings with the government ministry upon whom they relied for their disability incomes. In spite of the demographic differences among participants, all described an experience of oppression within the social service system, and all named this issue as their chief stressor. The similarities between experiences suggest that social services systems do not discriminate between individuals who have been dependent upon systems over the long-term (John, Marie, and Christine) and those that find themselves applying for welfare as a result of sudden illness (Tim and Derek). Each individual reported feeling silenced, labelled, and misunderstood by social service systems. This experience cannot necessarily claim a direct connection with housing, but it is significant in that it suggests another way in which persons living with HIV/AIDS are denied control over their lives and decision-making processes. Housing, in this context, gives individuals a safe space while dealing with the discriminatory impact of social services offices. In this respect, adequate housing appeared to be somewhat of a sanctuary for each of the participants – a buffer from the challenges they continued to experience within their lives.

The role of on-going stigmatization in the participants' lives also deserves particular attention. I refer here to stigma as the experience of being viewed negatively by society at large: All five participants expressed the feeling of being outsiders within the mainstream world. While all five narratives referred to profound experiences of marginalization and social isolation, the capacity to overcome marginalization appeared strongly connected to gender: For John, housing immediately provided him a new world of social connections. For all five participants, housing provided a means to be more selective about who they spent time with, and what social activities they engaged in. Christine and Marie both made reference to increased isolation due to an over-representation of men in their buildings. Stabilized housing provided Christine with the capacity to develop strong connections with local support agencies, but Marie's sense of marginalization in her male-dominated housing building remained potent. This may have been connected to her multiply-oppressed identity as a female, aboriginal, sex trade worker and active drug addict.

#### *Findings Related to Health Behaviour Models*

The adjustment of each participant's living environment from unstable to stable housing appeared to provide a catalyst for substantial changes to individual health practices and overall quality of life. Securing adequate housing led to enhanced health status, and vastly improved engagement in health care. While housing was central to the life changes described in all the narratives, the participants each described a unique combination of elements contributing to their quality of life once they had secured adequate housing. This included issues related to their culture, gender, disease progression, financial situation, community, and neighbourhood. Each participant

referred to the complex interaction between these elements to depict the trajectory of their life before and after securing housing. In this way, the interview narratives provide a powerful operationalization of the frameworks put forward by Andersen (1995), Bonuck (1996), and Flaskerud & Winslow (1998). Each of these models considers the interaction between the individual and their social environments in shaping individual health status and engagement in healthcare. Derek's narrative provides perhaps the most concrete depiction of "unmet needs" in that his lack of stable housing during the year following his AIDS diagnosis had a direct impact on his inability to stabilize his health. John, Christine, and Marie provide strong examples of the applicability of the vulnerable population framework in that their narratives each revealed the interdependence of resource availability, risk, and health status: Put simply, their health status and the level of risk in their life were directly connected with the adequacy of their housing and, by extension, financial stability. Tim's story fits well within Andersen's health behaviour model, in that the combined impact of pre-disposing factors (his identity as a Caucasian male), enabling factors (his capacity for self-advocacy), and health beliefs (his belief in his right to optimal health and quality health care), all combined to set the conditions for increased access to services and adequate quality of life. It is notable that Tim obtained the resources he needed far earlier in his disease progression than the others – Andersen's focus on "enabling factors" provides some clues as to why this is the case.

An argument could be made for the applicability of all three models to the five narratives presented in this study. However, the unmet needs model and vulnerable population framework, are particularly useful in their focus on the role of inequitable distribution of resources and inaccessible health care in setting the conditions for poor

health within particular population groups. The narratives presented in this study provide concrete illustrations of the mutually dependent dynamic between different environmental characteristics that either enhance, or detract from, health and quality of life. This complex interaction is evidenced throughout each narrative in small and big ways: Christine's description of increasing drug use stemming from the need to "blend in" to the downtown eastside neighbourhood in which she was living; Derek's inability to access secure housing until he found a shelter that actively supported his efforts to do so; Marie's feeling of being alternately monitored and ignored by the building staff.

The study narratives strengthen the case for adequate housing as a pivotal element in improving overall health, increasing engagement in the health care system, and setting the conditions for positive and proactive health decisions. They also demonstrate that the extent to which the potential of housing is optimized depends upon a range of individual and systemic elements affecting an individual's life. The predominance of people living with HIV who are significantly marginalized creates a complex tangle of unmet needs. As these five stories evidence, these include poverty, social isolation, complex healthcare, and insufficient mental health support. As Bonuck's model (1996) suggests, the ideal discipline to address this web of unmet needs, particularly within the context of unpredictable health, is social work. Social work provides a bridge between medical and social service domains. Indeed, in all but Tim's case, community-based support workers played key roles in nurturing the participants' journeys toward stable housing. Perhaps we can take from this that, for those groups for whom Andersen's "enabling factors" are elusive, and in the absence of a system that truly ensures equitable access to services, social systems are forced to play the role of mediator between individuals and their

clinical care. Until a system is in place that can truly boast equitable access to resources, social work is best placed to help individuals maximize those resources that are available to help them better manage their health.

### *A Return to Population Health*

I began this research with the purpose of exploring the idea of housing as a catalyst for improved health status and health practices. Specifically, I wondered what other aspects of an individual's life changed upon securing housing, beyond the obvious increased capacity for eating, sleeping and personal hygiene. Within the population health framework, housing is considered a key component of the income and social status determinant. Regarding this determinant, the Public Health Agency of Canada (PHAC)'s (2004) population health document reads, "considerable research indicates that the degree of control people have over life circumstances, especially stressful situations, and their discretion to act are the key influences [in improving health]" (¶1). The income and social status of the five study participants did not dramatically improve upon securing adequate housing. Securing affordable housing did, however, increase the participants' ability to manage their financial situations, and in all cases increased their sense of control over their daily lives. As I described in the thematic discussion above, adequate housing provided the means for all five participants to radically reduce harm in their lives. Housing also enabled the participants to increase engagement in their health practices and decision-making. The result was improved overall health status, and strengthened ability to cope with HIV/AIDS-related symptoms and side effects. For each participant, securing housing presented a critical turning point in their lives.

As I considered the five stories through a population health lens, I was struck by the connection between housing, and the other social determinants of health identified within PHAC's population health framework (PHAC, 2004). Securing adequate housing offered opportunities to strengthen social support networks, improve health services, and enhance personal health practices and coping skills. Where housing was not completely successful, there appeared to be a continued experience of culture and/or gender discrimination and unsupportive social environments. Each of these other determinants of health figured prominently in the narratives, but the contribution of each played out in very different ways within each life story. The narratives provide a rich depiction of the complex inter-relationship between determinants, and the role of housing as a catalyst for improved health. Writings on population health tend to focus on the causal relationship between social environments, physical environments, and genetic endowment (Evans & Stoddart, 1994). The population health framework stops short of identifying priority components of social and physical environments. The framework lends itself toward thinking of social determinants as a group, rather than in terms of individual elements. I believe that the five narratives in this study make a compelling case for the value of exploring the differential impact of social determinants.

All of the narratives provided strong illustrations of housing as the catalyst for strengthening social support networks, thereby improving health practices, and overall health status. Housing set the conditions for each of the participants to increase their connection with support agencies, and to choose supportive individuals to spend time with. Though Marie remained profoundly isolated after securing housing, stabilized housing nevertheless provided her with control over who she allowed in to her home, and

who she did not. In the context of the life that she described, this new found power in relationships was no less transformative than that of the others.

The participants' descriptions of the role of housing in improving their mental, physical, and spiritual health exemplified the importance of housing in setting the conditions for good health practices and coping. Having safe, stable, affordable housing enabled each to create a home that expressed their identity and, in most cases, increased their sense of belonging. Stable housing provided each with the opportunity to increase their participation in healthcare decisions, to establish routines for self-care, and to develop better daily health practices.

Marie's story obviously differs quite significantly from the other four in that her overall health continued its rapid decline after securing housing; her crack addiction had continued unabated, and she continued to be resistant to accessing medical care. But her narrative provided a clear message of what remained missing in her life after securing housing. Her repeated comments about access to housing for women highlighted the roles of culture and gender as social determinants of health. Marie's narrative made clear that the cumulative oppression presented by her female gender, her aboriginal ethnicity, and her identity as a sex-trade worker and drug addict, all affected her capacity to realize the full potential of housing to stabilize life and improve health. It is significant that many of Marie's responses within the interview related to the plight of women in her situation. Marie's attribution of her chronic housing instability to her lack of power in her relationships with men provided a clear picture of her experience of gender discrimination in gaining access to the resources she needed to survive and thrive. It is significant that the multiple sources of oppression that Marie struggled with in life were

not eased as a result of securing housing. Her experience, combined with Christine's expression of a sense of isolation in her male-dominated building, point to the ways in which subsidized housing structures remain steeped in dominant social/cultural values: Those who were most marginalized in the broader community, were the ones most marginalized within their housing community. The contrast between Marie's experience, and to a lesser extent Christine's, and that of the other three participants, indicates that addressing cultural/gender inequities is an essential component to ensuring successful housing. This suggests to me that while housing is a pivotal determinant with the potential to establish access to other determinants (support networks, coping skills, quality health care), the mere provision of housing is not enough. Challenging social structures to address enduring discrimination based on cultural or gender identities and the locating of housing within supportive environments is a key underlying principle to this determinant. This point is echoed in a recent paper focusing on what is needed to provide adequate housing for individuals who are deemed "hard to house."

Unless we can remove the morality from drug use and see human beings, we will continue to deprive them of their most basic human rights which includes more than just a roof over their head. To optimize health, we need to ensure that all persons have access to health care and food in addition to social inclusion or a sense of membership that comes from being treated with the dignity and respect that many of us take for granted (Evans & Strathdee, 2006).

Marie's continued sense of oppression contributed to her failure to feel a sense of belonging in her new housing. Her story stands in contrast to Tim's, whose portable

subsidy provided him the dignity of truly independent living, in the neighbourhood of his choosing. The opportunity to realize a supportive social environment in which to live clearly played a tremendous role in Tim's sense of optimism and capacity for self-care.

I believe that the five narratives presented in this study confirm the central role of housing as a determinant of health, and as a mechanism to mobilize other determinants. The narratives also provide a strong case for the need for systems of care and support to address issues of gender and culture in the creation of supportive social environments. In order to concretely address the role of social determinants of health in our systems of care, we require a greater understanding of the interdependency of these determinants:

- Successful access to healthcare depends upon adequate housing;
- Adequate housing depends upon a supportive environment;
- And supportive environments depend upon structures and systems that provide respect and dignity for all, regardless of culture, gender, or life history.

In reflecting upon the contributions of these narratives to our collective thinking about population health, I began to picture social determinants as a house of cards: Housing and economic security are the foundational, bottom layer of cards, and the other determinants (culture, gender, physical environment, social support, health practices and skills) form the other layers. The strength of the card structure depends on the stability of all its components, but it could not have been built at all without the first layer.

#### *Findings Related Housing/Health Research*

All five narratives describe a journey from chaos and unpredictability, to relative peace and hope. In each case, housing was seen to increase capacity to exert control over

life choices. John, Christine, Derek and Tim acknowledged on-going drug activity around them, yet all expressed firm resolves not to re-engage in drug use. Marie continued to manage her pain through drug use, but housing afforded her the capacity to determine how, when, and where she used. I took this as concrete evidence of the participants' increased sense of control: Each in their own way described the experience of making unsafe choices when feeling a lack of control in their lives. Indeed, each referred to the absence of a capacity to choose at all while unstably housed. These vivid and detailed accounts of the role of housing in providing opportunities for peace, predictability and routine, are what was missing from much of the research literature discussed in Chapter 2: It is not surprising that adequate housing made a difference in the participants' lives. What is remarkable is that despite broad differences in their life stories, the impact of housing on their health and health practices was strikingly similar.

In Chapter 2, I referred to several studies that looked at the role of ancillary services in improved health and quality of life of persons living with HIV/AIDS. I wondered specifically if there was a particular service or resource that made a pivotal difference. These studies, published in a special 2002 supplement of *AIDS Care*, (Ashman et al., 2002; Chan et al., 2002; Conover & Whetton-Goldstein, 2002; Lo et al., 2002; Messeri et al., 2002) made a strong case for the role for non-clinical services in HIV treatment and care. The five narratives presented within this study strengthen that case, and take the findings one step further by presenting housing as a pivotal non-clinical service that enables access to other ancillary services (psycho-social, nutrition support, increased financial stability). As evidenced by the epidemiological literature referred to in Chapter 2, strict adherence to appropriate HIV/AIDS treatments (HAART) is critical to

disease management (Riley et al., 2005). HAART is known for its complex treatment regimes and debilitating side effects. To be successful, HAART regimes require commitments from the patients to maintain the regimens, and to work with their healthcare practitioners to address treatment issues. Ensuring the *capacity* for adherence to HIV medications is therefore critical to mounting an effective response to the HIV/AIDS epidemic. The data re-presented in this study strongly indicate that housing is an integral component in this response.

Shortly after I conducted the research for this study, the National AIDS Housing Coalition (NAHC) in the United States convened their first housing and HIV/AIDS research summit. The summit presented research confirming the role of housing as a public health intervention, much of which is cited in the research context chapter of this thesis. In the ensuing summit policy paper, the authors wrote:

[A] growing body of evidence refutes the predominant 'risky person' model for understanding the co-occurrence of homelessness, HIV infection, and poor health outcomes among persons living with HIV/AIDS who lack stable housing. The 'risky person' model assumes that behavior follows the person. This research shows instead that housing status has an independent effect on risk behaviors and treatment access .... It is not the homeless or unstably housed person who is risky but the person's situation (NAHC, 2005, p.1).

This statement provides a synthesis of the messages from many of the studies linking lack of housing with engagement in harmful activities (Aidala et al., 1995; Andia et al., 2001; Robertson et al., 2004; Stein & Friedmann, 2002), disease progression and inadequate

healthcare (Bonuck, 1997; Masson et al., 2004; Smith et al., 2000). All of these studies emphasize the role of the environment in mitigating risk, but Aidala et al.'s 1995 study is one of the only quantitative studies addressing changes in risk behaviours following an *improvement* in housing. The data re-presented in this thesis offer a contribution to the discourse on risky environments vs. people, in that each story provides a detailed picture of the many ways in which the participants' level of risk was reduced, and their overall safety greatly increased, upon securing housing.

The 2005 NAHC summit paper set a number of imperatives for HIV/AIDS housing in the United States. These include: Making subsidized, affordable housing available to all low-income people living with HIV/AIDS; making housing homeless persons a top HIV prevention priority; and incorporating housing interventions as a critical element of HIV care (NAHC, 2005). The five narratives presented in this thesis serve to expand upon, and deepen understanding of, the research referred to at the summit. Each narrative emphasized the role of housing in improving health status, increasing access and adherence to treatments, reducing harmful behaviours and improving health practices. They also delivered powerful depictions of the role of housing to provide stability, hope, and a sense of value and belonging. The value of this data comes from the testimonials on the substantial life changes that occurred in the lives of each of the participants upon securing housing. It is my hope that the information that emerged from these five unique stories serves to strengthen the call to operationalize the connection between housing and health within policies and programs: The participants' stories reveal the ways in which each individual's unique mix of experiences, social

environment, and sense of identity come together to determine housing/health successes and challenges.

The findings from this study strengthen the call to public health planners and policy makers to integrate housing into the treatment and care of persons living with HIV/AIDS. The individual narratives demonstrate that the mere provision of affordable housing is not always enough: Housing/health planning must ensure that the right kind of housing is provided, that housing is available at the right time, and that it is accessible to the broad diversity of people who need it.

#### *Research Directions*

A number of issues emerging from this study deserve further exploration. The first relates to the diversity of affordable housing options, and the relative impact of each on health and quality of life. Within the narratives, two participants spoke of their time spent in shelters, and both referred to the experience of shelters in which staff appeared truly invested in assisting residents in improving their health. For Derek, the support of one shelter in particular, after staying in a string of shelters that were unable to respond effectively to his health needs, proved to be a critical turning point in his journey from despair to hope. Tim's description of his transition from a subsidized building to fully independent and confidential living also spoke to the impact that different forms of housing have on health and quality of life. My sense is that effective housing policy lies in keeping a range of accessible options available. Existing housing research does not tend to differentiate between types of housing. Further research in this area would deepen our understanding of the role of different types of housing in meeting PHA needs.

The narratives also spoke to the contribution of housing to health status, at different points in the trajectory of HIV disease. The contrast between Tim's and Marie's stories suggests the need for further exploration of the role of housing in coping with health fluctuations and disease progression. While this study provided a relatively brief snapshot of participant's view of the role of housing in their lives, further studies conducted over the long-term could look at what happens when someone secures housing, as Tim did, fairly early on in his disease progression, against Marie's experience of securing housing less than a year before being deemed terminal. A more focused and extensive inquiry into the impact of securing adequate housing at different stages of illness would undoubtedly add further depth to the concept of housing as a healthcare intervention.

Marie's and Christine's stories also suggest a need for greater exploration of the role of gender in both gaining access to housing, and women's capacity to thrive in male-dominated living environments. Their experience of being in the minority within their mixed-gender buildings presents an interesting area of inquiry for the HIV/AIDS field, particularly as the seroprevalence rate among women in Canada continues to rise (Public Health Agency of Canada, 2005).

It is also worth noting that the five participants I interviewed were all living alone. Consequently, this study had no input from participants who were actively parenting, and the impact of housing from the perspective of a family living with HIV. This was disappointing to me, as I know from my practice experience that the experience of seeking and securing housing for families affected by HIV/AIDS is tremendously challenging. The issues that arise for families regarding housing, both in terms of

housing complexes and the broader community, are often extensive and complex. I believe that this group deserves a study that focuses specifically on their needs. The voices of parents are missing from much of the research on PHAs and housing, and this should be a priority for future research on housing, health and HIV.

Finally, as the 2005 HIV/AIDS Housing Summit in the United States indicated, there is a need for further exploration of the idea of adequate housing as a public health intervention. In upcoming years, it would be useful to track what happens to a population's health when public health interventions to those at risk move beyond mere messages about how to keep safe, but provide tangible, concrete resources to help individuals keep themselves safe. What happens when individuals are given adequate resources for self care? If they develop the capacity for privacy, safety, and stability, and are able to cook, sleep and attend to their personal hygiene needs, do seroprevalence rates for communities actually decrease? If PHAs are guaranteed adequate resources to express who they are, and the power to decide how they want to spend each day, does treatment uptake and adherence also increase? Until public health systems ensure the availability of safe, affordable housing, it will be difficult for epidemiologists to answer these vital questions. The five narratives within this study certainly suggest that the impact of housing on all these areas is potent. Further research in this area will hopefully only strengthen this assertion.

#### *Reflection on Research Method*

Sandelowski's (2003) qualitative description method provided an effective means to stay close to the participants words and to make explicit the intention of each participant's story. Drawing on the narrative form to represent the five interviews

allowed me to provide a detailed account of participants' journey to housing. The combination of qualitative description/narrative analysis worked well with the study's grounding within the population health framework, as each provided an illustration of the interdependence of the person and the environment, and the key role of social determinants in improving health status. The open-ended interview format enabled me to listen for the varying degrees to which each participant experienced increased quality of life after securing housing. Setting the interviews in participants' homes deepened the narratives in that, fittingly, the homes themselves became a part of the participants' stories. Our surroundings were a concrete depiction of the role of housing in each of their lives, and the final picture that emerged from each story was more complete as a result. I was concerned that the setting risked being seen as intrusive, but each participant appeared to take pride in hosting me in their home, and I felt that the dynamic between us was more equal and respectful than it might have been in a more neutral setting. The intimacy of the home-setting suited the narrative method well, in that the emergent stories were rich and layered.

My research process was also somewhat hindered by stringent recruitment guidelines stipulated by the university ethics committee. Because I had to rely on posters placed strategically in pre-determined locations to get the word out about my research, and had only a limited capacity for research participants, I felt obligated to select the first handful of respondents. In the days and weeks that followed my initial interviews, several other potential participants came forward who had equally fascinating journeys to housing to recount. My capacity for participants was further limited by my decision to apply the narrative approach to data analysis. In order to adequately represent the data

within each story, I realized that I had neither the time to transcribe and analyze, nor the reader the stamina, to read through dozens of narratives. While I was pleased with five unique stories I received, I would have liked to ensure greater age diversity and increased cultural diversity among the participants.

### *Data Credibility*

I feel confident that few would argue the role of adequate housing in individual health. This study did not seek to introduce the housing/health connection as a new health concept, but rather sought to broaden understanding of *how* housing affects health, using the experience of living in poverty with HIV as the lens. Regarding the validation of findings from interpretive inquiries, Angen (2002) writes: "A good piece of research needs to have generative promise; it should be fertile and raise new possibilities, open up new questions and stimulate new dialogue; it should reveal greater 'horizons of meaning'" (p.389). The five stories, and my responses to them as the inquirer, certainly do not claim to be a definitive assessment of housing, health and HIV. There are as many unique stories as there are persons living with HIV. Indeed, had I interviewed these five individuals on a different day, at a different stage of their life, I would inevitably have heard a different story. Essentially, the data that emerged from this inquiry seeks to increase insight, increase awareness, and inspire further inquiry into the housing/health/HIV connection: I entered this research process with the knowledge that while it is unlikely that anyone would challenge this connection, it remains on the periphery of most epidemiological inquiry and healthcare planning. This study, therefore, represents "an invitation to continue the conversation and to take the dialogue in new and more fruitful directions" (Angen, 2002, p.389).

Clearly, the detailed accounts of the five individuals is limited in that it cannot be considered necessarily representative of the larger population of persons living with HIV: Marie's experience cannot be considered typical of all HIV positive aboriginal sex trade workers, nor can John's experience be considered representative of all street-involved men living with HIV. Nevertheless, the small sample of participants, and the thickness of the data detail that they were able to provide about their lives, provided an opportunity to develop a better understanding of the layers of issues related to housing and health.

Given my role in community-based AIDS work, and the participants' pre-existing connection with the agency at which I work, I continue to encounter the participants over the course of my daily work. In the months that transpired between my data collection and the writing up of my findings, I observed the majority of participants go through a number of ups and downs. As mentioned previously, Marie declined quite rapidly and died, and Derek moved away fairly suddenly. But I noticed that the others also went through some very difficult periods and this included some very significant stresses related to their housing. I realized that the stories I heard were as much a reflection of the moment in time in which I heard them as they were the period of time that they recounted. I believe that this does not take away from the value or credibility of the narratives: By explicitly locating the narratives in precise moment of time that they were told in, the fluidity of each participant's life became part of the story. The focus in each story was on the ways in which the participants made meaning out of their journeys from unstable to stable housing. But it was clear in each case that the journey was far from over: Rather, each would continue to shift and evolve according to each participant's unique mix of biological, psychological and social needs.

*Personal Response*

The process of interviewing these five individuals was both a privilege and a source of inspiration for my continued work in the HIV/AIDS field. I was familiar with each of the participant's basic stories from my HIV/AIDS work, but the uniquely compelling content of each interview took me by surprise. I remain profoundly grateful for the trust that each participant offered me, and for the time each took to tell their stories with honesty and care. The process of sitting before them as an interviewer, rather than a task-focused social worker, was incredibly liberating. I relished the opportunity to focus on the power and beauty of each story, and this was further emphasized by the depth that I discovered within each story during the process of transcribing and analyzing the narratives. This process was helped by the fact that each story was remarkably positive and filled with hope. Each strengthened my belief in the transformative power of safe, supportive environments, and the importance of equitable access to the basic resources each of us needs to live and thrive. Marie's story stands apart from the others in its tone and content, but I found it an equally compelling account of survival. For Marie, housing provided an opportunity to end her struggle for stability and predictability. Hers was a powerful transformation in that she had learned to accept life for what it had provided her, and to pursue what sense of peace she could find. Like the others, housing provided Marie with a clearer picture of what lay ahead in her life's journey, and the capacity to prepare for it.

The stories I heard have strengthened my conviction that consideration of social determinants of health is a key component of an effective healthcare system. As the stories within this study illustrate, and mounting research emerging from medical and

social science domains confirms, housing is a key starting place for integrating determinants into healthcare systems. At the outset of this project, I had difficulty finding research that examined housing's connection to health status and personal health practice. During the research process, I began to discover other movements within social science research regarding the role of housing in health (the National AIDS Housing Coalition in the United States is the most comprehensive). Yet I continue to attend HIV/AIDS research conferences that feature medical presentations lamenting the challenges in finding effective strategies for medication uptake and adherence among impoverished and unstably housed populations. During the process of researching and writing this thesis, I have presented my study findings at both the Canadian Homelessness Conference and the Canadian HIV/AIDS Research Conference. At both these conferences I have sought out the few social science researchers who are also considering the connection between housing, health and HIV. It is my hope we can work together to continue to promote the role of housing in improving health and quality of life. It is clear to me that there is much more work to be done to achieve a full integration of medical and social sciences toward the improvements in health and quality of life for persons living with HIV/AIDS.

## Chapter 6 - Conclusion

The quote appearing in the thesis title, "I'd be dead without it..." reflects a sentiment that was expressed by all five participants within their interviews. All five participants were very clear that housing had saved their life. All five expressed a strong resolve to not return to the housing instability of their past. During the transcription process, I was struck by the constant, sometimes deafening, traffic noise on the audiotapes (the exception was Tim's). It occurred to me that the small, spare apartments that I visited can hardly be considered oases away from the fray: There were drugs being sold within these buildings and on the street outside. Within the content of their interviews, each participant referred to multiple stressors in their daily life: Systemic oppression from the social services agencies upon whom they rely for their disability income; generalized discrimination from living on the margins of society with a highly stigmatized condition; and the cumulative impact of watching their peers become sick and die, to name a few. Yet housing appeared to give each participant a sense of hope for the future that they did not have before. Clearly, the role of housing in healthcare cannot be overestimated: Adequate housing provided the opportunity to meet sleeping, eating, and personal care needs. It afforded each the power to shut that which is un-safe out, and to let that which is supportive in. Housing increased each participant's capacity to live with dignity and self determination. Given the complexities presented by a life lived in poverty with HIV, the safety and predictability that housing provides is crucial. Housing is not merely a means of enhancing healthcare- It is a central component of the healthcare system. Put simply, housing *is* healthcare, and *adequate* housing is a human right.

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