“THE WAY I SEE IT”:
TOWARDS A COMMUNITY-INFORMED
UNDERSTANDING OF THE RELATIONSHIP BETWEEN
HOUSING AND HEALTH AMONG PEOPLE LIVING WITH
HIV IN VANCOUVER, BC.

by
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Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy

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Doctor of Philosophy program
Faculty of Health Sciences

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Abstract

Background: Vancouver, British Columbia has one of the highest HIV prevalence rates in Canada and a growing housing crisis. The limited data available on the impact of housing instability on the health of people living with HIV in this setting has been generated without meaningful involvement of the community. In order to fill this gap, we launched a community-based research project aimed at developing an understanding of the housing-health nexus that is grounded in the experiences of people living with HIV.

Methods: Eight Community Researchers – people living with HIV who have experienced homelessness in Vancouver - were recruited and trained by the Project Coordinator to co-facilitate this community based participatory action research project. The Project Coordinator proposed the use of Photovoice to ensure the meaningful engagement of the Community Researchers. Photovoice is a research method that assists people, often marginalized by social-structural inequity, to reflect on their capacities and needs, engage with policymakers and encourage social change.

Results: The Community Researchers generated over 300 photographs and engaged in facilitated discussion with the Project Coordinator to identify emergent themes. The Community Researchers described the detrimental impact of inadequate housing on their physical and mental health, and the resiliency promoted by healthy environments. The analysis culminated in the development of a multi-level ecological framework mapping the determinants and impacts of housing instability in this population, representing the first step towards building a comprehensive, community-informed definition of healthy housing as viewed through the eyes of people living with HIV.

Interpretation: The findings underscore the need to expand the focus of housing strategies to incorporate the broader political, economic and social context, and to meaningfully engage affected populations in developing policy and programming targeting housing instability.

Keywords: HIV and AIDS; photography/Photovoice; homelessness; marginalized populations; participatory action research
Dedication

Lora Bellrose, Mel Hennan, Rob Lamoureux, Jenny Mendoza, Randy Moors, Valerie Nicholson, Lynda Swanson and Daniel Wilson collected this data and shared their stories in hopes of making a difference in their communities. Together we interpreted their experiences and I hope that this work does them justice.
Acknowledgements

First and foremost I am indebted to my supervisory committee: Drs. Robert Hogg, Marina Morrow, John O'Neil and Cari Miller, without whose mentorship, thoughtfulness and relentless encouragement none of this would have been possible. Drs. Jim Dunn and Martin Laba were wonderfully inspiring and reflective examiners.

Dr. Hogg graciously employed me at the BC Centre for Excellence in HIV/AIDS, which connected me to talented individuals who lent their technical expertise to the projects I care about: Keith Chan, Wendy Zhang, Mike T. O’Shaughnessy, Brian Wynhoven, Ryan Walley, Svetlana Drascovic, Kevin Hollet, Fernando Prado, Andrea Keasy and Marlis Funk. Doreen Nicholls at SFU provided much appreciated administrative support.

The LISA team and affiliates - Ali, Aranka, Lillian, Despina, Jasmine, Allie, Cathy, Sophie and Nadia - shared ideas, instant coffee, laughs and confined spaces with me. Angela Cescon and Kate Salters in particular gave generously of their time, attention and other-worldly enthusiasm to the editing process. Friends who tolerated living with me – Byron, Fred and Shiori – or who lived vicariously through me by extending their unwavering support – Amelia, Kim, Wing, Jay C., Kate J. and Serena – also deserve mention.

I am thankful for the collaboration of our community partners and inspired by their dedication to the communities that they serve: Kim Stacey at McLaren Housing Society of BC; Sabine Silberberg and Patrick McDougall at the Dr. Peter Centre; Melissa Medjuck at Positive Women’s Network; Andrea Langois at Pacific AIDS Network; and Terry Howard, who works tirelessly to advance Community Based Research with every breath he takes. Rosa Jamal was especially impressive, finding pockets of time and energy to put into leading this endeavour in the midst of her many commitments.

I owe the most gratitude to my family, who experienced a major housing adjustment at the very moment I was submitting a dissertation on the meaning of home. I am eternally indebted to Mathaji, Mom, Dad, Sunny, Richa, Alisha, Aneil, Asha Auntie and Nana for their unconditional love and relentless cheering, and especially Nira Auntie, who showed us all that home is a state of mind, so no matter where she is, she is always home.
Written in invisible ink on the title page of this dissertation is the name of an honorary member of the study team who adamantly refuses acknowledgement. He worked behind the scenes at every event, designed knowledge translation materials, cooked and served meals, provided technical support and animated many aspects of this project, including all of the figures in this dissertation. He also animated my whole universe while I wrote. Aparecium! Jay Pai: my dissertation would be a shadow of itself without your support, but more importantly, so would I.

I received funding from the following sources: Canadian Institutes of Health Research (CIHR) Knowledge Translation Meetings Planning and Dissemination grant, CIHR Community Based Research Catalyst grant, CIHR Population Health Intervention Research grant and CIHR Doctoral Research Award. I am also thankful for the generous support of Simon Fraser University’s Faculty of Health Sciences and Dean of Graduate Studies, the International AIDS Society and the Canadian Association for HIV Research for honouring me with a CAHR New Researcher Award.

The grants that funded this and related projects would not have been successful without the valuable feedback of co-investigators, particularly Drs. MJ Milloy, Lindsey Richardson, Cathy Worthington and Victoria Smye.

Parts of this work were presented at the following conferences: The 20th Annual Canadian Conference on HIV/AIDS Research, the North American Housing and HIV/AIDS Research Summit VI; the 19th Annual International AIDS Conference; the AIDS 2012 International Leadership Summit on Housing; the 21st Annual Canadian Conference on HIV/AIDS Research; the 22nd Annual Canadian Conference in HIV/AIDS Research and the North American Housing and HIV/AIDS Research Summit VII. I am thankful to the organizers of these conferences for providing our group a platform, and often financial support, to share our progress and incorporate the feedback of colleagues.
## Table of Contents

Approval ........................................................................................................... ii  
Partial Copyright Licence .................................................................................. iii  
Ethics Statement ............................................................................................... iv  
Abstract ........................................................................................................... v  
Dedication ......................................................................................................... vi  
Acknowledgements ........................................................................................... vii  
Table of Contents ............................................................................................. ix  
List of Figures .................................................................................................... xii  
List of Acronyms ............................................................................................... xiii  
Glossary ............................................................................................................ xiv  
Preface by the Community Researchers ............................................................. xvii  

### Chapter 1. Introduction .................................................................................. 1  
Synopsis ............................................................................................................ 1  
1.1. Background ............................................................................................... 1  
1.2. Study Rationale ........................................................................................ 3  
1.3. Study Objectives ...................................................................................... 7  
1.4. Methodological approach ......................................................................... 7  
1.5. Organization of Dissertation ...................................................................... 10  

### Chapter 2. A house is not a home: definitions of housing stability ........... 13  
Synopsis ............................................................................................................ 13  
2.1. Introduction ............................................................................................... 13  
2.2. Methods .................................................................................................... 14  
2.2.1. Search strategy and selection criteria ...................................................... 14  
2.3. Results ...................................................................................................... 15  
2.3.1. Impact of housing instability on risk of HIV transmission .................. 15  
2.3.2. Impact of housing instability on HIV treatment and clinical outcomes ... 19  
2.3.3. Impact of housing instability on social well being ............................... 23  
2.4. Discussion ................................................................................................ 26  
2.4.1. Methodological issues ........................................................................... 26  
2.4.2. Recommendations for moving forward .................................................. 34  
2.5. Conclusion ................................................................................................ 36  

### Chapter 3. Theoretical perspectives grounding and orienting this research ... 38  
Synopsis ............................................................................................................ 38  
3.1. Introduction ............................................................................................... 38  
3.2. Selection and adaptation of theoretical frameworks ................................. 38  
3.3. Community Based Research Approach .................................................... 39  
3.3.1. Operationalization of Community Based Research .............................. 40  
3.4. Social Determinants of Health Framework .............................................. 43  
3.4.1. Operationalization of Social Determinants of Health .......................... 43  
3.5. Intersectionality Theory ........................................................................... 46  

ix
3.5.1. Operationalization of Intersectionality Theory ........................................... 46
3.6. Critical self-reflection ......................................................................................... 50

Chapter 4. Living with HIV in an unliveable city: historical context of housing policy in Vancouver, B.C .......................................................... 54
Synopsis ...................................................................................................................... 54
4.1. Vancouver’s housing crisis .................................................................................. 54
4.2. Political context ................................................................................................ 56
   4.2.1. Housing policy - Federal government ......................................................... 56
   4.2.2. Housing policy - BC Provincial government ............................................. 59
   4.2.3. Housing policy - Municipal government .................................................. 62
4.3. Macro-economic trends .................................................................................... 67
4.4. Social Context .................................................................................................. 68
   4.4.1. Social policy - Federal government .......................................................... 68
   4.4.2. Social policy - BC Provincial government .............................................. 69
4.5. Social issues .................................................................................................... 70
   4.5.1. Mental Health ............................................................................................ 70
   4.5.2. Addictions .................................................................................................. 71
   4.5.3. Vancouver’s HIV epidemic ....................................................................... 71
4.6. A call to action .................................................................................................. 75

Chapter 5. Raising the roof: innovative approaches to investigating the impact of housing on the health of people living with HIV .......... 76
Synopsis ...................................................................................................................... 76
5.1. Introduction ...................................................................................................... 76
5.2. Methods ............................................................................................................ 77
   5.2.1. Justification of method ............................................................................. 77
5.3. Participatory Thematic Analysis ...................................................................... 85
   5.3.1. Phase 1: Generating data through photo interviews ............................... 87
   5.3.2. Phase 2: Coding, condensing and analyzing data .................................. 90
   5.3.3. Phase 3: Draft data summary review and collaborative analysis ............ 91
   5.3.4. Phase 4: Reviewing and revisiting themes ............................................. 91
   5.3.5. Phase 5: Community consultation ........................................................... 92
   5.3.6. Phase 6: Member checking and final approval ........................................ 92
5.4. Outcomes ......................................................................................................... 93
5.5. Discussion ....................................................................................................... 94

Chapter 6. “Living like this can’t be healthy”: Housing instability and its impact on health ................................................................. 96
Synopsis ...................................................................................................................... 96
6.1. Organization of main findings .......................................................................... 97
6.2. Being without a home: a continuum .................................................................. 98
   6.2.1. Single Room Occupancy Hotels .............................................................. 99
   6.2.2. Alternatives to SROs: shelters and outdoor sleeping ............................ 110
   6.2.3. Issues that transcend “housing status” .................................................... 112
6.3. Discussion ....................................................................................................... 121
Chapter 7. Neither here nor there: the need for transitional spaces .......... 126
Synopsis ........................................................................................................ 126
7.1. Introduction ......................................................................................... 126
7.2. Home: a continuum ........................................................................... 127
  7.2.1. Being at home ............................................................................... 127
  7.2.2. Making home ............................................................................... 131
  7.2.3. Feeling at home ........................................................................... 134
  7.2.4. At home in the margins ................................................................. 136
7.3. Discussion ........................................................................................... 137

Chapter 8. Picture it: a conceptual framework mapping the pathways between housing and health .................................................. 142
Synopsis ........................................................................................................ 142
8.1. Introduction ......................................................................................... 142
8.2. Methods .............................................................................................. 144
  8.2.1. Macro-level influences ................................................................. 147
  8.2.2. Meso-level influences ................................................................. 150
  8.2.3. Micro level influences ................................................................. 152
8.3. Discussion ........................................................................................... 155
8.4. Limitations ......................................................................................... 158
8.5. Towards a contextualized, community-informed understanding of housing and health .......................................................... 158

Chapter 9. Take a picture, it will last longer: summary discussion, recommendations, future directions ......................... 160
Synopsis ........................................................................................................ 160
9.1. Summary of findings .......................................................................... 160
9.2. Policy and programming implications .............................................. 162
9.3. Situating this work in the literature ................................................... 167
9.4. Unique contributions: Knowledge Translation and Exchange initiatives .......................................................... 168
  9.4.1. Academic conferences ................................................................. 169
  9.4.2. Photo exhibits .............................................................................. 170
  9.4.3. Political engagement .................................................................. 176
  9.4.4. Other outreach ............................................................................ 176
9.5. Strengths and Limitations ................................................................. 177
  9.5.1. Measurement tools ..................................................................... 177
  9.5.2. Analytic techniques .................................................................... 177
  9.5.3. Sampling methodology and study design .................................... 179
9.6. Application of research findings and future research directions .......... 180
9.7. Picturing social change ...................................................................... 182

References .................................................................................................... 184
List of Figures

Figure 1: Example of activity to visualize social determinants of health ......................... 45
Figure 2: The City of Vancouver’s Housing Continuum ................................................ 64
Figure 3: Participatory data analysis process ............................................................... 86
Figure 4: Guiding questions to facilitate photo elicitation ............................................. 88
Figure 5: Example debrief activity: underlying causes of housing instability ............... 89
Figure 6: "Under my sink live some mice" ............................................................... 102
Figure 7: "The bathroom shared by 70 residents" ....................................................... 104
Figure 8: "This is where I had to wash my hands and dishes" .................................... 106
Figure 9: "Hard to find" ............................................................................................. 115
Figure 10: "Invisible elder" ......................................................................................... 118
Figure 11: "Until every chain has been broken and every lock opened" ......................... 120
Figure 12: "With support and without support" ............................................................ 130
Figure 13: "We don’t have a lot of flowers where I live" .............................................. 133
Figure 14: First iteration of Conceptual Framework .................................................... 145
Figure 15: Conceptual framework: housing instability among PLHIV in Vancouver ..... 146
Figure 16: Display at the Woodwards atrium ............................................................... 171
Figure 17: Premier photo exhibit .................................................................................. 173
Figure 18: Homelessness Action Week ....................................................................... 174
Figure 19: World AIDS Day exhibit ............................................................................. 175
Figure 20: “Homes now!” ......................................................................................... 183
# List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ARVs/ART</td>
<td>Antiretrovirals/Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARYS</td>
<td>At Risk Youth Study</td>
</tr>
<tr>
<td>ASO</td>
<td>AIDS Service Organization</td>
</tr>
<tr>
<td>BC-CfE</td>
<td>British Columbia Centre for Excellence in HIV/AIDS</td>
</tr>
<tr>
<td>CBR</td>
<td>Community Based Research</td>
</tr>
<tr>
<td>CIHR</td>
<td>Canadian Institutes of Health Research</td>
</tr>
<tr>
<td>CMHC</td>
<td>Canada Mortgage and Housing Corporation</td>
</tr>
<tr>
<td>CR</td>
<td>Community Researcher</td>
</tr>
<tr>
<td>DTES</td>
<td>Downtown Eastside</td>
</tr>
<tr>
<td>DTP</td>
<td>Drug Treatment Program</td>
</tr>
<tr>
<td>HEAT</td>
<td>Homeless Emergency Action Team</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HPI</td>
<td>Home Price Index</td>
</tr>
<tr>
<td>IBPA</td>
<td>Intersectionality Based Policy Analysis</td>
</tr>
<tr>
<td>KTE</td>
<td>Knowledge Translation and Exchange</td>
</tr>
<tr>
<td>LISA</td>
<td>Longitudinal Investigations into Supportive and Ancillary Health Services</td>
</tr>
<tr>
<td>MAT</td>
<td>Maximally Assisted Therapy</td>
</tr>
<tr>
<td>MVHC</td>
<td>Metro Vancouver Housing Corporation</td>
</tr>
<tr>
<td>PAN</td>
<td>Pacific AIDS Network</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
</tr>
<tr>
<td>PLPH</td>
<td>Positive Living Positive Homes</td>
</tr>
<tr>
<td>SDoH</td>
<td>Social Determinants of Health</td>
</tr>
<tr>
<td>STOP</td>
<td>Seek and Treat for Optimal Prevention of HIV/AIDS</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Seek and Treat for Optimal Prevention of HIV/AIDS</td>
</tr>
<tr>
<td>TaSP</td>
<td>Treatment as Prevention</td>
</tr>
<tr>
<td>VANDU</td>
<td>Vancouver Area Network of Drug Users</td>
</tr>
<tr>
<td>VCHA</td>
<td>Vancouver Coastal Health Authority</td>
</tr>
<tr>
<td>VHSD</td>
<td>Vancouver Health Service Delivery Area</td>
</tr>
<tr>
<td>VIDUS</td>
<td>Vancouver Injection Drug Users Study</td>
</tr>
<tr>
<td>MIPA</td>
<td>Meaningful Involvement of People Living with HIV and AIDS</td>
</tr>
<tr>
<td>Glossary</td>
<td></td>
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<tr>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>Affordable Housing</td>
<td>Affordable housing is defined as housing that should not cost more than 30 per cent of a household’s gross income regardless of whether they are living in market or non-market housing. Affordable housing can be provided by the City, government, non-profit, community, and for-profit partners. It can be found or developed along the whole housing continuum including SROs, market rental and affordable home ownership. Affordable housing is not a static concept, as housing costs and incomes change over time.</td>
</tr>
<tr>
<td>Affordable Housing Framework Agreement</td>
<td>An agreement signed by the Government of Canada and the Province of B.C. in 2001 to jointly fund affordable housing projects over a five year period.</td>
</tr>
<tr>
<td>Assisted Living</td>
<td>Assisted living units are self-contained apartments for seniors or people with low to moderate levels of disability who require daily personal assistance to live independently but who do not need 24 hour facility care.</td>
</tr>
<tr>
<td>BC Housing</td>
<td>The Crown Corporation responsible for the delivery of provincial housing programs and direct management of some of the social housing stock. Non-profit and co-op providers also play an important role, with non-profit societies owning and/or operating housing with support from BC Housing.</td>
</tr>
<tr>
<td>Co-operative Housing</td>
<td>A housing development where residents or members own and manage the building. Each member has one vote and members work together to keep their housing well-managed and affordable.</td>
</tr>
<tr>
<td>Core Housing Need</td>
<td>Core housing need is a direct measure of housing need defined by the Canada Mortgage and Housing Company using Canada Census data; the most recently available data is from the 2001 census. Core housing need reports on the number of households in a community who do not live in or are unable to find housing that is suitable in size, in adequate condition and affordable without spending 30 per cent or more of their income on housing.</td>
</tr>
<tr>
<td>Emergency Shelters</td>
<td>Emergency shelters provide single or shared bedrooms or dormitory type sleeping arrangements with varying levels of support to individuals (e.g. meals and other services), usually on a part time basis.</td>
</tr>
<tr>
<td>Housing Continuum</td>
<td>The housing continuum provides an important organizing framework for understanding housing needs and housing choices. In most cases the housing continuum can include emergency shelters, transitional/supportive housing, social housing, assisted living, market rental housing and ownership housing.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
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<td>----------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Non-Market Housing</td>
<td>Non-Market housing refers to government-assisted housing which was built through one of several government-funded programs. This housing is typically managed by the non-profit or co-op housing sectors. Most non-market housing receives an operating subsidy.</td>
</tr>
<tr>
<td>Non-Profit Housing</td>
<td>Non-profit housing is housing that is owned and operated by non-profit housing providers. This housing is typically built through government funded housing supply programs.</td>
</tr>
<tr>
<td>Private Market Housing</td>
<td>The private rental market provides the majority of low cost housing. This can include purpose-built rental housing as well as housing supplied through the secondary rental market including basement apartments as well as rented condo stock.</td>
</tr>
<tr>
<td>Rental Assistance Program</td>
<td>This program provides assistance with monthly rent payments. Families must have a gross annual household income of $35,000 or less, have at least one dependent child, and have been employed at some point over the last year.</td>
</tr>
<tr>
<td>Residential Rehabilitation Assistance Program (RRAP)</td>
<td>RRAP provides loans and grants to low-income homeowners, and landlords of properties to bring their homes up to health and safety standards. The program can also be used to make homes accessible for disabled residents, enabling them to live independently.</td>
</tr>
<tr>
<td>Purpose Built Rental Housing</td>
<td>Apartments and/or buildings that are built with the intent to be rented in the private market.</td>
</tr>
<tr>
<td>Seniors’ Supportive Housing</td>
<td>This provides housing, plus support services for seniors, and can include assisted living and independent living units. BC recently initiated a program in selected subsidized housing developments to retrofit existing stock to provide enhanced services and supports, targeted primarily to low-income seniors who need assistance to live independently.</td>
</tr>
<tr>
<td>Single Room Occupancy Housing</td>
<td>SRO Housing is the most affordable form of rental housing provided by the market. A typical SRO unit provides short or long-term accommodation and comprises one room (about 10 x 10 feet) with shared bathrooms and minimal or no cooking facilities. Over the last 20 years, a significant portion of SROs in Vancouver have been bought and are operated by the government or a non-profit partner.</td>
</tr>
</tbody>
</table>
Non-Market Housing | Housing for low and moderate income singles and families in core housing need, usually subsidized through a variety of mechanisms, including senior government support (Federal, Provincial or a combination of the two). The current model in Vancouver is a self-contained unit, with private bathroom and kitchen, owned or operated by government or a non-profit. The rents vary to enable a mix of incomes and can range from the value of the shelter component of Income Assistance to 30% of the tenant’s income including market rents. Includes public housing as well as non-profit and co-op housing.

Social Housing and Subsidized Housing | Social housing typically refers to traditional public, non-profit and co-op housing programs developed with federal and/or provincial funding; it can include public housing (managed by BC Housing) as well as non-profit and co-op housing stock. Under more recent program/language changes, subsidized housing is often used to indicate any housing that gets a provincial subsidy, and therefore may include, for example, an emergency shelter bed or a renter in the private market receiving a rent subsidy.

Supportive Housing | Non-market housing that, in addition to rental subsidy to make the housing affordable, includes ongoing and targeted support services to assist residents who cannot live independently due to health problems and/or disabilities or are at risk of homelessness, affected by mental illness or recovering from addictions. This housing type can be provided in congregate settings or in scattered apartments. Typical on-site support services include mental health and/or other health supports, life skills training, and meal preparation. There is no time limit on the length of stay for supportive housing.

Transitional Housing | Transitional housing, also referred to as second stage housing, can include a stay of anywhere between 30 days to two or three years. Transitional housing provides access to services and supports needed to help individuals improve their situation and is viewed as an interim step on the housing continuum. Transitional housing for women includes transition houses, safe homes and second stage (longer term) housing for women and their children fleeing abuse.
We are Community Researchers…

People living with HIV and passionate about housing research and advocacy. Our passion comes from our experiences – every one of us has been homeless. This project examines the impact of housing on health as seen through our eyes. Through our photos we wanted the show the conditions that people in our neighbourhoods live in. Others of us wanted to show the connectedness of our communities. Together, our photos and narratives convey the importance of stable, safe and affordable housing.

The way we see it...housing is healthcare.
Chapter 1.

Introduction

Synopsis

This chapter lays out the background, rationale and objectives of the study, explaining the need to develop an understanding of the relationship between housing and health as it is experienced by people living with HIV in Vancouver. This chapter also outlines the hybrid of theoretical frameworks that ground and orient this research and the methodological approach taken. Finally, this chapter concludes with a description of how this dissertation is organized.

1.1. Background

Although enshrined in the Universal Declaration of Human Rights (1), and explicitly named as a basic prerequisite for health by the World Health Organization (2), the Public Health Agency of Canada (3) and the Commission on the Social Determinants of Health (4), housing is a right that continues to be inadequately addressed for many, including people living with HIV (PLHIV).

The greater likelihood of experiencing housing instability among people living with HIV is owed largely to the impact of structural inequities that fuel the HIV epidemic in all societies. In its biological and social implications of transmission, HIV is essentially a disease of inequity. Following the path of least resistance, “it is in the spaces of poverty, racism, gender inequality and sexual oppression that the HIV epidemic continues today” (5). Already disproportionately impacted by social-structural inequity in its many manifestations, such as income insecurity (6) and food insecurity (7), it is of
little surprise that, on average, people living with HIV are approximately ten times more likely to be homeless than the general population (8).

There is perhaps no health issue that better illustrates the causes and effects of social inequity than HIV, and no better example of egregious inequality than that which exists in Vancouver, British Columbia, which has the dubious reputation of simultaneously being the most expensive North American city in which to live (9) and having the highest poverty rate in Canada (10). The city is home to a growing housing crisis fuelled by prohibitively high housing costs, low vacancy rates, an eroding rental housing stock (11), frozen welfare rates, a low minimum wage (12) and high cost of food (13). Furthermore, Vancouver is situated within the only industrialized country without a national housing strategy. Despite periodic injection of funding towards affordable housing initiatives from all levels of government, rising living costs, coupled with the general decay of existing affordable housing stock all across the country, led the United Nations expert on adequate housing to dub the situation in Canada a ‘national emergency’ (14). In the absence of a coordinated response, an array of fragmented responses to homelessness and housing instability have sprung up in provinces and municipalities across Canada. However, these responses fluctuate with changing economic and market conditions, and are thus unsustainable.

Vancouver’s housing crisis, arguably the worst in the country, exists against the backdrop of one of the highest HIV prevalence rates in Canada (15). The co-occurrence of a housing crisis and high HIV prevalence is a significant public health concern. In the literature focusing on the health and well-being of PLHIV, a considerable proportion of study participants report being homeless or routinely living in, or circulating through, precarious living conditions, including shelters and Single Room Occupancy hotels (16, 17) and among people living with HIV, housing stability has been identified as an important contributor to poorer health status (18-22). Housing instability and HIV and AIDS are intertwined in a self-perpetuating cycle that heightens vulnerability to, and worsens the severity of, each condition.

With their income drained by the high cost of housing and fixed due to the constraints of disability benefits and welfare, people living with HIV in BC often face impossible trade-offs between securing stable housing and meeting other basic needs
It is of little surprise that the Pacific AIDS Network (PAN), representing over 50 HIV and AIDS service organizations throughout the province, has identified housing as the most unmet need and urgent issue for PLHIV in BC.

1.2. Study Rationale

Through the systematic collection of clinical and socio-behavioural data over time, the Ontario HIV Treatment Network Cohort Study identified an association between poor health and housing instability in a cohort of PLHIV across research sites throughout the province. This finding launched the best-known Canadian study in the HIV-housing field, *Positive Spaces Healthy Places*. In BC, owing to data linkages facilitated by the provincial Drug Treatment Program, there is a wealth of clinical data that speaks to trends in virological and immunological status of people living with HIV in BC over time. However, there are little systematic data available on the socioeconomic needs of PLHIV in BC; therefore the impact of housing instability on the health outcomes of this population is not fully understood in this context. Well-established BC-based studies that aim to fill this gap have predominantly focused on illicit drug use and mental illness, both important factors that intersect with housing instability among PLHIV, however, they fail to capture all of the complexities of the relationship between housing and health.

In response to the demands of AIDS Service Organizations (ASOs) calling for action on this issue, I led a team of researchers at the BC Centre for Excellence in HIV/AIDS (BC-CfE) to conduct a series of analyses investigating the impact of unstable housing on the health and well being of a cohort of PLHIV accessing antiretroviral therapy (ART) in BC. The analyses, which I later used to justify the development of the study described herein, were based on data from the Longitudinal Investigations into Supportive and Ancillary health services (LISA) study, a closed prospective cohort of HIV-positive adults 19 or older in BC who initiated ART on or after January 1st, 1996. As described in the LISA cohort profile and elaborated upon in Chapter 5, the aim of the LISA study is to examine the experiences of harder-to-reach HIV-positive individuals who have accessed ART in the province.
The analyses conducted with LISA cohort data showed that unstable housing among PLHIV accessing ART in BC is associated with suboptimal treatment, including lower adherence to medication and inferior treatment outcomes, such as poorer immunologic responses and increased likelihood of rebound of plasma HIV-1 RNA viral load. As in other settings, PLHIV who are homeless or marginally-housed have higher rates of depressive symptoms, inferior contact with the healthcare system, including higher levels of emergency department use (30). Furthermore, housing status, along with gender and sexual orientation, are strongly associated with higher risk drug use and sexual behaviour in this cohort (31).

Findings from these analyses supported much of what ASOs had observed about the impact of unstable housing on the health of PLHIV. What was perhaps most interesting about these findings, however, was that which contradicted what one particular ASO reported. As a member of the LISA study team I was collaborating with staff at the Maximally Assisted Therapy (MAT) program at the Downtown Community Health Centre in Vancouver. The MAT program, located in Vancouver’s downtown core, supports HIV-positive clients with a history of heavy substance use or mental illness, many of whom also experience episodic homelessness. A basic descriptive analysis of the MAT program was conducted as part of a study investigating the association between ART adherence and use of support services among unstably housed PLHIV in the LISA cohort (32). The analysis suggested that 63% of MAT participants were unstably housed, in stark contrast to the results of an internal survey of MAT participants which revealed that only 4% of the clients considered themselves unstably housed (33). These differing results suggested a disjuncture between the way the LISA survey tool measured housing stability and MAT clients’ sense of housing stability – a major gap in knowledge that may hinder the ability of MAT staff and other service providers to meet the needs of this vulnerable group.

This finding prompted me to conduct a series of consultations with other BC-CfE community partners, which uncovered a widespread recognition of housing as one of the most critical concerns of PLHIV in BC. There was resounding interest amongst stakeholders to conduct a comprehensive scan of the housing challenges in BC. As the member of the LISA investigative team who had spearheaded this initiative, I contended
that we were not well placed to do so because we did not fully understand how PLHIV experience and conceptualize the intersection of housing and health.

The differing results derived from the LISA and MAT analyses hinted at a larger methodological issue endemic to the housing literature – a dissonance between the standard epidemiological assessment of housing status (stable vs. unstable vs. homeless) and individuals’ personal sense of housing stability. A review of the existing literature, narrated in the following chapter, suggested that the limited data available on the impact of housing instability on the health and well being of PLHIV in BC do not accurately reflect the experiences and perspectives of this community, largely due to the manner in which this phenomenon has been investigated.

Research on the HIV-housing nexus is overwhelmingly dominated by epidemiological methods, which are limited in their ability to capture the contextual nature of people’s lived experiences. The rich, descriptive accounts offered by qualitative inquiry hold promise for more tailored, nuanced and locally responsive research, however there is by far less emphasis on qualitative research in this field. Most research on the HIV-housing nexus has been descriptive in nature, generated using cross-sectional study designs (34) with non-probability samples, and based on narrow conceptualizations of housing status that may not capture the nuances and diversity in the realities of affected communities. Despite the unique context described above, Vancouver-based studies that have considered housing as an important determinant of health for PLHIV have relied upon definitions and measures of housing instability from studies conducted in San Francisco (35), New York (36) and, more recently in the Canadian context, Toronto (26). Furthermore, the commonly used measures may not adequately reflect important dimensions of housing, including affordability, transience, and the impact of housing on the nature of relationships. There is also a growing concern that Public Health’s focus on “the homeless” as a special risk category may shift attention away from the “broadly shared, fundamental need for stable and adequate housing among a wide range of persons living with HIV/AIDS” (17). The widely-accepted narrow definitions of homelessness and housing instability may serve to undermine our understanding of the relationship between housing and HIV (37-41).
Research on homeless and unstably housed populations has elucidated individual-level factors, such as behavioural and psychological determinants of treatment adherence and health outcomes, however, we lack an understanding of the role of housing in mediating more distal exposures (42). It has also been noted that, “considerations of the issue of housing have very seldom taken into account the intersections of resource and adversity that attend factors such as gender, race and ethnicity” (43,p2), as well as all of the oppressions imbued within and across these identities.

Finally, it has been suggested that, “…in complicating and quantifying homelessness, we risk failing to understand homelessness at its essence: the absence of a home” (44,p3), a question that can only truly be answered by individuals and communities whose sense of home, however they define it, has been threatened. Our review of the literature revealed a shortage of context-specific, community-driven inquiry, and an overemphasis on the material aspects of housing - that is, the basic need for shelter. This is particularly the case in Vancouver, where the limited data available on the impact of housing instability on the health and well being of PLHIV has been generated without meaningful involvement of the community. Thus, there is little data on what constitutes housing stability for this particular demographic.

There remain, therefore, critical gaps in our understanding of the specific mechanisms through which housing instability impacts health behaviour and outcomes (45, 46), hindering the development of evidence-informed programming and policy in the area of housing and health. We propose a conceptual shift away from understanding stable housing as a predominantly material entity comprising a roof and walls, towards a more holistic understanding of the social and cultural importance people place on home, and various spaces people find and make ‘home.’ Addressing the varied housing needs of people living with, and at risk of, HIV relies on a more careful consideration of context and a commitment to cultivating and supporting spaces which allow people to manage their health and well being. It was thus agreed by the study team in collaboration with community partners that there was a need to explore the dimensions of housing that are important to people’s sense of stability and well being in this context.
1.3. Study Objectives

In light of the gaps in knowledge and research needs described above, the overall aim of this study is to develop a comprehensive, context-specific definition of the housing-health nexus that is grounded in the experiences of people living with HIV in Vancouver, Canada. Within this aim the specific objectives are to:

1. Examine the impact of housing instability on self perceived health status, well being and quality of life;
2. Explore what constitutes a healthy environment for PLHIV in this specific context;
3. Identify specific mechanisms and processes through which housing influences the ability of PLHIV to manage their health (adhere to medication, sustain adequate rest, maintain ample nutrition, receive regular treatment and monitoring by an HIV physician and other necessary health and social support).

1.4. Methodological approach

I tailored my theoretical approach to fill the knowledge gaps identified above. This review of the literature suggested a need for a more community-based, context-specific, qualitatively-oriented approach to investigating this issue. In addition, both housing and HIV by their nature require an equity-focused research and knowledge translation agenda. Considering all of these issues I chose to ground and orient this research in a hybrid of theoretical frameworks: Social Determinants of Health (SDoH), Community Based Research (CBR), and Intersectionality theory.

The SDoH framework illustrates the ways in which environment, including housing conditions and neighbourhood context, interacts with an amalgam of factors to either provide a buffer from, or create susceptibility to, disease, disability and death. This commonly used framework provides a useful starting point to illustrate the integral role of housing in shaping HIV risk, as well as the health outcomes of those already infected. Unfortunately, the SDoH framework requires a critical analysis to adequately address the complex relationship between housing and HIV-related health. Recognizing the central role of social inequity in perpetuation of both HIV and housing instability, the SDoH framework fell short in its explanatory power. Specifically, we needed a means to
address the role of structural factors, especially social inequality, in reproducing health inequities.

Intersectionality theory, widely recognized as a promising tool to “advance the operationalization of equity in public policy,” was an ideal complementary framework to address the aforementioned concerns with the SDoH approach (47). Intersectionality examines the patterns of health inequities along major social divisions such as gender, sexuality, physical ability, race and class in new ways (48). It attempts to capture the complexity of the lived experience at the intersections of these categories of social positioning and the multileveled relationships of power that play out at these junctures to impact health (49). Through taking an intersectional approach, I hoped to be attuned to the different axes of power that shape participants’ experiences, as well as reflexive of my own position of privilege. The introduction of intersectionality gives way to a more tailored, nuanced and locally responsive program of research and KTE.

Closely tied to the use of intersectionality theory was my commitment to taking a Community Based Research approach in developing this program of research and knowledge translation. Within the broader goals of strengthening communities and improving quality of life, CBR aims to generate knowledge about health priorities by placing the issues of community organizations and the populations that they serve at the centre of research and committing to empowerment of communities through all stages of the research process (50).

With the aim of capturing the needs of individuals and communities who are often silenced in the conceptualization of traditional research agendas, I operationalized these theories principally through my choice of research method: Photovoice. Photovoice is a participatory action research tool that couples photographs taken by participants with explanations of their relevance and meaning. Using a collaborative, community-based approach, I assembled a multidisciplinary team, comprised of ASO representatives, health and ancillary care providers and housing advocates to develop a project that reflects the priorities of the communities with which they work. I strived to build a team that brings to the table the voices of men and women living with HIV, Aboriginal people, people who have been formerly homeless and people who have a history of injecting
drugs. All of these perspectives ground and contextualize our research and Knowledge Translation and Exchange work.

The multi-disciplinary team helped recruit eight people living with HIV who have experienced homelessness in Vancouver to conduct this project. Committed to the MIPA principles, which call for the Meaningful Involvement of People living with HIV and AIDS, I trained the Community Researchers to co-facilitate this project and engage in all stages of the project, including formulation of the research question, data collection and interpretation, knowledge translation and study evaluation. By virtue of the chosen methodology I hoped to ensure that the project reflected the priorities of affected communities and builds upon and creates expertise within these communities to conduct their own research.

This process also aimed to confront power imbalances inherent in traditional research. Drawing upon community members’ expert knowledge of the physical and social conditions in which they live, Photovoice destabilizes the authority of the researcher and recasts the study participant as the expert. This method also increases accessibility for communities who face barriers to participating in traditional research.

The Community Researchers generated over 300 photographs and engaged in facilitated discussion, which was transcribed and analyzed using a participatory approach. The Community Researchers’ narratives and photos illustrate the detrimental impact of housing instability on their physiological and mental health and convey what constitutes a healthy living environment for them. The findings informed the development of a conceptual framework suggesting a new, comprehensive, community-informed definition of housing stability as viewed through the eyes of PLHIV.

Reflecting back on what prompted this initiative – an observation about the epidemiological measurement versus community perception of housing stability – we have come a long way. We learned a great deal about the ways in which unhealthy environments produce and perpetuate illness, and have a better grasp of the way healthy environments promote resiliency. Importantly, we also learned that this disjuncture speaks to a larger methodological problem, which is a product of a research system that values particular types of knowledge. In the process of building a
community-grounded understanding of housing stability, we hope to challenge this system through the way we engaged in this work.

1.5. Organization of Dissertation

This PhD dissertation narrates the conceptualization and execution of a community-based project that was co-facilitated by a team of Community Researchers with me serving as the lead on the research-oriented aspects of this work. This dissertation, which I wrote with the approval of the Community Researchers, is structured into nine chapters.

By way of introduction, Chapter 1 lays out the background, rationale and objectives of the study, explaining the need to develop an understanding of the relationship between housing and health as experienced by people living with HIV in Vancouver.

In developing an argument for this study, Chapter 2 reviews current evidence and gaps in the literature on HIV, housing and health. This review highlights a number of methodological concerns and draws attention to the need for interdisciplinary collaboration to increase the depth and breadth of our understanding of this issue. This review further argues that there is a shortage of context-specific, community-driven inquiry in Vancouver-based studies, and an overemphasis on the material aspects of housing. The chapter concludes by proposing a conceptual shift away from understanding stable housing as a predominantly material entity, towards a more holistic understanding of the social and cultural importance people place on home, and various spaces people find and make 'home.'

Having identified the gaps in the literature and making an argument for this study, Chapter 3 outlines the hybrid of theoretical frameworks that ground and orient this work: Community Based Research, Social Determinants of Health, and Intersectionality, as well as the theoretical underpinnings of Photovoice. At the close of this chapter I situate myself in the research process and disclose my motivation and biases.
Chapter 4 provides detail on the study context, describing Vancouver’s challenges with housing affordability, as well as other pertinent aspects of the socio-economic backdrop, all of which is situated in a discussion of the broader economic and political context. This chapter explains the role of the Federal, Provincial and Municipal governments in producing and perpetuating these issues through housing and social policy decisions made in the context of shifting macro-economic trends affecting the Canadian economy at various points in time. This is followed by a brief look at the major social issues that have historically intersected with housing provision in BC, particularly mental health illness and addictions. Chapter 4 closes with a description of Vancouver’s HIV epidemic, and a brief discussion of how the changes in the HIV landscape have impacted the supply, demand and nature of housing for people living with HIV.

An overview of the study methods is presented in Chapter 5. The chapter provides detail on the participant eligibility criteria, the study design and procedures involved in data collection and analysis. This chapter also includes a discussion of the strengths and weaknesses of Photovoice.

Following Chapter 5 are the main findings, which respond to the first two study objectives. In Chapter 6, Community Researchers’ narratives and photos illustrate the detrimental impact of housing instability on their physiological and mental health. This is primarily a descriptive analysis, providing detail on the conditions of Single Room Occupancy Hotels, shelters and street living.

In Chapter 7 the Community Researchers describe what they perceive as a healthy living environment and, in doing so, reveal a central finding of this research project – the need for transitional spaces for PLHIV to live, socialize, heal and rebuild once they have recovered from various types of trauma.

A multi-level ecological framework for understanding the relationship between housing and health amongst PLHIV is presented and explained in Chapter 8. The framework is the product of integrating the findings of the literature review presented in Chapter 2 and the thematic analysis presented in Chapters 6 and 7. This framework, which responds to the third and final study objective, is intended to guide future research and programming. It strongly emphasizes the need to expand the focus of housing
strategies beyond individual factors, incorporating the broader political, economic and social context.

Finally, Chapter 9 summarizes the study findings, and evaluates the extent to which the study objectives were met. This chapter also describes the unique contributions, strengths and limitations of the study design, as well as the analytic methods. Detail is also provided on the knowledge translation initiatives of this study. Chapter 9 closes by suggesting avenues for the potential application of research findings to public health and housing policies, as well as future research in this field.
Chapter 2.

A house is not a home: definitions of housing stability in HIV literature

Synopsis

There exists a wealth of literature investigating the association between housing stability and the health of people living with, or at risk of acquiring, HIV. Following a review of the current knowledge and limitations of prevailing housing status measures, a typology is presented to map the concepts underlying definitions of housing status in the HIV literature. This chapter concludes by proposing a conceptual shift away from understanding housing as a predominantly material entity, towards a more holistic understanding of the social and cultural importance people place on home, and various spaces people find and make ‘home.’ Addressing the varied housing needs of people living with, and at risk of, HIV relies on a more careful consideration of context, and a commitment to cultivating and supporting spaces which allow people to manage their health and well being.

2.1. Introduction

People who are homeless or live in unstable conditions are known to experience higher rates of disability and disease, and faster progression to mortality than their stably housed counterparts (51-53). Homeless and unstably housed people suffer from a greater burden of morbidity and mortality associated with affective disorders such as psychosis and schizophrenia (52, 54); cutaneous, respiratory and blood-borne infections (55-61); problematic use of alcohol and illicit drugs (54, 61, 62); and abuse and violence (63-69). Despite these issues, it is also well documented that homeless and unstably
housed individuals are less likely to access primary care (53, 70) and ambulatory care, and more frequently use emergency departments and inpatient services (55, 71-77).

Homelessness and unstable housing conditions have long been known to heighten vulnerability to HIV infection, a relationship reflected in seroprevalence of HIV in samples of homeless individuals many times higher than non-homeless populations (8, 59, 60, 78-87). Housing instability has also been identified as an important contributor to poorer health status among people living with HIV and AIDS (18-22). Indeed, housing instability and HIV and AIDS are intertwined in a self-perpetuating cycle that heightens vulnerability to, and worsens the severity of, each condition.

Despite the growing body of literature that demonstrates the prevailing role of housing in shaping vulnerability to HIV infection and influencing health trajectories of those already HIV seropositive, important limitations persist, one of which was noted in a recent narrative review - the lack of a standard definition and absence of a consistent means of measuring housing status throughout the literature (42). Also, the reviews published to date (42, 88) and soon to be published (89) limit analysis to quantitative studies. This chapter synthesizes current knowledge on the relationship between HIV and housing, expanding to include qualitative studies, and reviews methodological limitations of prevailing housing status measures.

2.2. Methods

2.2.1. Search strategy and selection criteria

I identified and reviewed published studies from major academic databases including: MED-LINE (via PubMed), Google Scholar, Science Citation Index (via Web of Science), Psycinfo, Geobase, Sociological abstracts and Econlit. I restricted my search to studies undertaken in the USA or Canada and did not specify language or date in the search criteria. Keywords used included: HIV, AIDS, homeless, unstably housed. Additional strategies were identified by examining citation lists from relevant articles.

Based on this extensive search of the published literature on housing, health and HIV, I constructed a database containing all 1,054 abstracts and references. Duplicate
references, studies conducted outside of the USA or Canada, and those not that did not pertain to the research question were eliminated. If the abstract was not clear about the article’s relevance, the full article was retrieved. This process reduced the number of articles to approximately 500, all of which were retrieved and reviewed in full.

The data extraction and analysis process involved compiling relevant findings into narrative descriptions and summarizing key findings in thematic categories of evidence according to methodological approach, exposure and outcome. This process prompted a second review of the articles focusing specifically on definitions and dimensions of homelessness and housing instability. At this stage, care was also taken to broadly compare the ways demographic data were treated in the analysis, particularly sex, gender, ethnicity and markers of socioeconomic status. This scoping study approach used to ‘map’ relevant literature (90) is appropriate given the breadth of each of the respective topics under study: housing instability (which constitutes homelessness and precarious housing) and HIV outcomes (which includes HIV transmission, access to treatment and care, and ART outcomes), as well as my interest in considering a range of study designs.

2.3. Results

2.3.1. Impact of housing instability on risk of HIV transmission

_HIV prevalence amongst homeless and unstably housed populations_

Research on the relationship between housing status and HIV has historically contributed to prevention literature, describing the impact of homelessness and unstable housing conditions on vulnerability for HIV exposure, transmission and acquisition. Studies report seroprevalence of HIV in samples of homeless individuals three to nine times higher than non-homeless populations (8, 59, 60, 78-87), suggesting that housing instability is a risk factor for HIV exposure. Within this context, housing has been conceptualized as a structural intervention that may minimize HIV exposure among vulnerable populations and, in particular, curtail risk behaviour (85).
Determinants of HIV risk behaviour amongst people who are homeless and unstably housed

People living in precarious conditions are more often placed in situations that heighten their likelihood of engaging in behaviour that would put them at risk of HIV exposure. In a large multi-centre longitudinal study, a dose-response relationship was observed between housing status and HIV risk behaviour, with odds of both risky drug use and sexual practice nearly four times as high among the homeless and three times as high among the unstably housed when compared to those who are stably housed (85). Another multi-site study of over 8,000 homeless and unstably housed people living with HIV (PLHIV) in the U.S. found that homeless people were significantly more likely to have higher numbers of sexual partners and to engage in transactional and unprotected sex with partners whose serostatus was unknown. They were also more likely to inject drugs, both recently and over their lifetime (91). In the Canadian context, Roy et al. found a reciprocal relationship between residential housing instability and HIV risk behaviours (92).

A complex web of factors interacts with inferior housing status to inform HIV risk behaviour. Increased levels of risky drug use and unprotected sex have been observed in populations of homeless individuals with mental health issues (56, 93-98) and those who have histories of sexual and physical abuse (99). As well, individuals living with addictions (40, 65, 100-104) or who have been formerly incarcerated (105, 106), report elevated levels of risky drug use and unprotected sex. Courtenay-Quirk and colleagues also found a number of homeless or unstably housed individuals in the Housing & Health study intentionally abstained from sex, suggesting that the complexity of this relationship warrants further investigation (107).

Housing instability associated with injection drug use

Housing instability impedes sense of attachment to a place, establishing and keeping social networks, and engagement in health and social services (44, 100), all factors known to impact drug use patterns. The relationship between injection drug use and unstable housing is complex, as there is evidence that injection drug use is both a cause and effect of housing instability. Drug use is a known barrier to finding and keeping adequate housing (44, 108). A study by Corneil and colleagues (109) investigating unstable housing and risk behaviour amongst people who inject drugs
speaks to the concept of marginalization (110), the process by which spiralling drug use often leads to homelessness. Substance dependence may be exacerbated if people depend on drugs to cope with the stress and volatility associated with housing instability. Also, living alongside people who are actively using drugs, in shelters or SROs, can pose a formidable challenge for people who seek to stop or decrease substance use (111, 112). Being homeless is also an independent predictor of injection drug use initiation (113).

**Housing instability associated with sex work**

Sex work is associated with unstable living conditions (44, 101, 109), and in some cases it is a means to secure temporary shelter (112). Unstable housing has also been associated with inconsistent condom use (109), higher numbers of sex partners (101, 114) and increased numbers of unprotected sexual acts (36, 85), demonstrating the complex and powerful ways housing shapes and informs intimate relations (115). Higher risk sexual behaviour amongst unstably housed populations is thought to be a consequence of economic disadvantage, transient living and social vulnerability (116, 117), all of which increase the need and opportunity to exchange sex for subsistence needs such as food, shelter, drugs and money. Conversely, involvement in transactional sex may also pose a barrier to finding and maintaining adequate housing. For example, sex workers in the DTES report facing higher rates of eviction and restrictions in the form of curfews, guest policies and discrimination by landlords and housing managers (118).

Previous work has identified factors that put homeless and unstably housed women at increased risk of HIV exposure, including high rates of unprotected intercourse, multiple sexual partnerships (119), more sexual activity while under the influence of substances (120) and the increased need and opportunity to exchange sex and other services (e.g. cooking and cleaning) for shelter (121) and drugs (122, 123). In a Vancouver-based study, 86% of a sample of women involved in transactional sex in Vancouver’s Downtown Eastside (DTES) reported being currently or formerly homeless, and identified housing as one of their most urgent needs (124). The BC-CfE’s Gender and Sexual Health Initiative has found that women enter into relationships with clients, non-client sexual partners, or stay with spouses in order to access resources such as housing (125). This type of dependence exacerbates women’s vulnerability, impacting power dynamics and control over sexual encounters, including condom negotiation,
potentially forcing them to stay in abusive relationships (126). Such circumstances put this population at risk for sexual violence (66, 119) and loss of tenure in the case of domestic breakdown (111).

Male sex workers, a less-frequently studied population, often live in poor conditions, compounded by addictions and mental health disorders, which impacts the need and opportunity to engage in sex work. A comparison between male sex trade workers and other young gay and bisexual men revealed that those who exchanged sex were more likely to be unstably housed (127).

**Housing instability associated with seroconversion in ‘at-risk’ populations**

Among individuals at highest risk for HIV acquisition due to high-risk drug and sexual activities, those in stable living conditions are less likely to become infected over time, including young men who have sex with men (128, 129), people who inject drugs (40, 109), women who use illicit drugs (108), incarcerated women (38) and street-involved youth (114). Homelessness and unstable housing were independently associated with a shorter time to HIV seroconversion among a cohort of people using illicit drugs (87).

**Housing instability and engagement in care amongst ‘at risk’ populations**

Homeless and unstably housed PLHIV are less likely to access harm reduction services and preventative health care than individuals who are stably housed (130-135). Sub-optimal use of preventative social and health care services among the homeless contributes to risk of HIV exposure at the individual level.

With evidence confirming the efficacy of antiretroviral treatment as a strategy to prevent transmission (136), health care engagement of individuals living with HIV increasingly has implications for the health of entire communities. Milloy and colleagues note that there are numerous barriers to implementing seek, test, treat and retain strategies amongst homeless and unstably housed people, including the prevalence of concurrent mental and physiological health disorders, inferior contact with the healthcare system and limited funds to engage populations who may require more resource-intensive support (42). In the BC context, Treatment as Prevention (TaSP) is being implemented through the Seek and Treat for Optimal Prevention of HIV/AIDS (STOP-
HIV/AIDS) pilot project. As part of the pilot, a number of patients were offered stable, supportive housing with integrated clinical and social supports to help improve treatment uptake, adherence and retention. Evaluation of STOP-HIV/AIDS and the supportive housing component is in its early stages (137).

2.3.2. Impact of housing instability on HIV treatment and clinical outcomes

Three review papers synthesize the evidence from studies employing quantitative methods to examine the impact of housing instability on treatment, care and clinical outcomes among people living with HIV and AIDS (42, 88, 89). Within the context of these studies, housing has been conceptualized as an important tool to improve the physiological and mental health status of people living with HIV, particularly by increasing accessibility and adherence to treatment. The following sections elaborate upon the major themes of these narrative reviews.

Prevalence of housing instability among PLHIV

Homelessness and housing instability is a pervasive experience for PLHIV. It is estimated that people living with HIV are ten times more likely to be homeless than the general population (8). In the literature focusing on the health and well being of PLHIV, a considerable proportion of study participants report being homeless or routinely living in, or circulating through, precarious living conditions, including shelters and SROs (16, 17). Aidala and colleagues examined housing and engagement to care in a large probability sample of PLHIV in New York City. At the time of the baseline interview, 33% of study participants were homeless or marginally housed and 70% of the participants reported some sort of housing need over the course of the study (17).

Health status of PLHIV who are unstably housed

Poor health outcomes, described in detail below, have been observed in studies of HIV positive homeless populations (18, 19), and PLHIV with unmet housing needs experience worse health outcomes than their stably housed counterparts across a number of studies (17, 20-22, 27, 138-141). Also, receipt of housing assistance has been shown to improve health outcomes of PLHIV (16, 142). Evidence from these
studies has led to housing being conceptualized as a structural intervention to improve health outcomes amongst PLHIV.

**Concurrent morbidity and co-infection**

In addition to the day-to-day challenges of living with HIV and AIDS, homeless and unstably housed positive individuals face a myriad of barriers to achieving optimal therapeutic outcomes, including concurrent morbidities. PLHIV who are homeless suffer from high rates of tuberculosis (82, 83) as well as infectious hepatitis (19). Braitstein and colleagues observed that stable housing was independently predictive of decreased odds of co-infection with hepatitis C (OR: 0.16, 95% CI: 0.004-0.59) (143) and being homeless was significantly associated with HCV infection among a cohort of PLHIV in California (144) and Ontario (145).

**Immunologic and virologic outcomes**

In terms of HIV-specific health outcomes, stable housing has been associated with superior virological [plasma viral load] and immunological [CD4 cell count] status (18, 21, 27, 141, 146, 147) and a decreased likelihood to report opportunistic infections (34). Receipt of housing assistance is associated with improved virological status. As part of the Seek and Treat for Optimal Prevention of HIV/AIDS (STOP-HIV/AIDS) pilot project, clients were offered stable, supportive housing with integrated clinical and social supports in Vancouver. Preliminary findings suggest that the provision of supportive housing was associated with viral suppression and increased capacity for sustained self-management (137).

**Impact of housing stability on mental health**

The stress associated with homelessness or unaffordable and otherwise inadequate housing may exacerbate the aforementioned health issues and interfere with disease management and self care. A recent randomized control trial showed a significant association between stable housing and better mental health (34). In analyses conducted by Riley et al., reporting unmet subsistence needs, including housing, was the key explanatory variable for overall physical and mental health of homeless and unstably housed HIV-positive men (148) and HIV-positive women (149). Among jail detainees living with HIV, homelessness was associated with decreased mental well-being (150).
Impact of housing stability on survival

A number of studies have observed an association between unstable housing and mortality (18, 20, 22, 151-153). In an examination of the impact of supportive housing on survival, homeless PLHIV who obtained supportive housing had a lower risk of death than those who did not (adjusted RH 0.20; 95% CI 0.05-0.81) (20). In a randomized control trial in which homeless PLHIV were provided permanent housing, 55% of the intervention group were alive at one year follow-up, compared to 34% in the control group (18). The association between housing and survival was not found to be significant in two studies, although one study was conducted prior to the development of highly active antiretroviral therapy (HAART) (154) and the other did not include PLHIV with stable housing as a comparison group (19).

Impact of housing stability on healthcare utilization patterns

An extensive body of literature has focused on healthcare utilization patterns of PLHIV who are unstably housed. Across multiple studies, participants who were homeless or unstably housed reported less uptake of primary care (155), ancillary services (156), alternative therapies (157) and HIV-specific medical care (17), as well as poorer overall satisfaction with care (158). Decreased use of prophylaxis against opportunistic illness has also been observed in homeless populations (16, 86, 135, 159, 160). According to a national supplemental surveillance system for PLHIV accessing care in Los Angeles County, homelessness in the past 12 months was the strongest factor independently associated with having any unmet need (AOR=2.3 95% CI: 1.1-6.1) (161). Leaver et al. pooled findings from multiple studies in a systematic review examining the relationships between housing status and the health, therapy adherence and treatment outcomes on PLHIV, and found a significant positive association between housing stability and medication adherence, as well as use of health and ancillary services (88). Some findings have differed (162, 163), suggesting the need for further exploration of the healthcare utilization patterns of vulnerable populations.

A range of factors contribute to homeless and unstably housed PLHIV being less likely to access care than individuals who are stably housed. These include mistrust of healthcare providers, discomfort with healthcare environments, competing priorities, depression, HIV-related stigma and chaotic lifestyles (17, 135, 156, 164-167). On the
other hand, intensive medical service utilization is widely documented amongst populations of homeless and unstably housed PLHIV, who are more likely to frequent emergency departments (16, 30, 159, 168-170), and utilize inpatient services (165, 166, 171-173) and less likely to use ambulatory care (169). In addition, homeless PLHIV on average have longer and more frequent hospital visits than their stably housed counterparts (16, 135, 168, 169, 174).

**Receipt of HIV-specific care: adherence and access to antiretroviral treatment**

Since the development and widespread availability of HAART, the literature on healthcare utilization has overwhelmingly addressed issues of access and adherence to treatment and its relation to housing. Because of concerns among some health providers regarding patient non-compliance and the possibility of promoting the emergence and transmission of drug resistant HIV (175-177), homeless and unstably housed individuals may not be offered life-saving treatment (160, 178-180). Provider concerns have thus contributed to the lower levels of access and exposure to treatment observed in PLHIV who are unstably housed (16, 139, 151, 165, 171, 181).

Such concerns are not entirely unfounded. A number of studies conducted in the U.S. and Europe have provided compelling evidence that unstable housing is an independent predictor of sub-optimal adherence (16, 27, 138, 151, 182-187), defined as adhering to ≥95% of prescribed treatment (188). In a longitudinal study of individuals in a methadone maintenance program, participants with a lack of long-term housing were 16 times more likely to report poor adherence than their unstably housed counterparts (182).

However, recent studies have demonstrated that homeless and unstably housed individuals can realize the benefits of ART given adequate levels of adherence (19, 27, 189). There is also evidence that homeless and unstably housed PLHIV can achieve similar rates of adherence compared to other populations (190) and, even in cases of less than perfect levels of adherence, viral suppression is still possible (191). In the first high-profile published commentary on this topic, David Bangsberg and colleagues assert that housing stability must take precedence over treatment initiation and clinicians and health care support staff are “obliged to develop interventions that maximize the chance of adherence” in homeless populations (192).
Determinants of poor treatment outcomes amongst PLHIV who are homeless and unstably housed

Without a secure dwelling and health-enabling environment, PLHIV may lack the sense of order, security and continuity that is requisite to focusing on disease management and self care. This includes regularly attending health and ancillary care appointments (20), having a safe space to refrigerate medications and adhering to instructions to take medication with food (193).

Compounding and interacting with the de-stabilizing effects of poor housing conditions are a constellation of other factors that inhibit positive people’s ability to adhere to their medication regimen. These factors include, but are not limited to, depression, psychological stress, high intensity substance use, recent release from the correctional system and involvement in the sex trade (21, 35, 87, 194-205). Concurrent food insecurity and housing instability further compromise treatment efficacy. In a cohort of unstably housed individuals accessing HAART, severely food insecure participants were less likely to achieve adherence ≥80%. Severe food insecurity was associated with 77% lower odds of viral suppression (95% CI = 0.06-0.82) when controlling for all covariates (206).

Programming, services and interventions for PLHIV who are homeless and face barriers to adherence

Numerous interventions have emerged to support homeless and otherwise vulnerable populations in realizing the benefits of antiretroviral therapy. Examples include: pharmacologic programs (207, 208), supportive housing programs (18), provision of housing assistance (16, 34, 142) and multidisciplinary programs that provide a range of services including directly observed therapy, outreach and case management (209-214). These programs have been correlated with improvements in adherence, retention and viral load suppression (32, 210, 215, 216).

2.3.3. Impact of housing instability on social well being

As can be seen in the preceding sections, a majority of the evidence on the relationship between housing and HIV has been the product of quantitative methods, usually cohort studies and, more recently, randomized control trials. Qualitative studies,
although less common, have played an important role in contextualizing these findings. For example, a qualitative study of active drug users who transitioned in and out of stable and unstable housing over a period of four years documented how participants’ physical and mental health and drug use were negatively impacted by lack of control of housing (37). In a qualitative study of women living with HIV in Vancouver’s Downtown Eastside, Robertson echoes this sentiment about the importance of control over private space in helping the women to manage their health and medical needs (111). Control over one’s housing situation is a nuance that enriches the wealth of quantitative studies that measure the impact of unstable housing on the health of PLHIV.

Perhaps the most crucial contribution of qualitative studies is the production of new knowledge about phenomena that are not easily quantified. As Stephen Lewis asserted in his remarks at the AIDS 2012 International Leadership Summit on Housing, “…for people living with AIDS who understand the indelible relationship between the virus and housing, a sense of having a home is not merely a structure in which to live, it is almost an organic extension of oneself, it’s an organic extension of dignity, of self worth, of feeling secure” (217). These are compelling sentiments, not easily conveyed through quantitative methodologies. Qualitative studies have filled this gap, exploring the ways in which neighbourhood and housing situation are intimately linked to sense of identity, pride, self esteem, belonging and social well being of PLHIV (111, 112, 218, 219).

Robertson found in her study that the women’s identities were tied to their housing conditions and that neighbourhoods and homes carry stigma and meanings for the inhabitants. In contrast to all that we assume to know about unstable housing, the women in this study forged strong social ties and cultivated a sense of belonging while living on the street and in shelters (111). Robertson’s study echoes Dupuis’ description of home as “a secure base around which identities are constructed,” (218) but goes further to suggest that sense of identity, pride and social well-being are not tied simply to home as a structure, but instead to the wider community to which people belong.

In a qualitative sub-study of the Ontario-based Positive Spaces, Healthy Places Study, Green et al. note that among HIV positive mothers, these sentiments extended to the well-being of the participants’ children. The women in this study described facing
choices between accessing affordable supportive housing for PLHIV and maintaining confidentiality about their children’s serostatus. For these parents, their own health, well-being and treatment outcomes were outweighed by issues such as accessibility to schools and neighbourhood safety in choosing housing (220). Stigma, often discussed in the literature but not easily operationalized or captured in research, is the focus of Furlotte’s study of aging PLHIV in Ottawa. The study participants, living in retirement homes, faced challenges in accessing treatment for pain management, specifically medical marijuana, and with respect to their sexual autonomy (221). Another qualitative study in Toronto sought to better understand the perspectives of African and Caribbean communities, specifically how stigma, discrimination, denial and fear impact their access to treatment and support services. The study unearthed an urgent need to address: housing instability; challenges related to immigration and settlement; and the lack of culturally sensitive support services for these communities (222).

The Urban Health Research Initiative, a research institute based in Vancouver’s downtown core, produces informative and influential qualitative research with respect to people who use illicit drugs which often touches on HIV prevention and treatment. The At Risk Youth Study (ARYS) is one such study involving semi-structured qualitative interviews supplemented by ethnographic fieldwork with a cohort of young people who use drugs. ARYS has provided rich data on the importance of social relationships amongst people who inject drugs (223), as well as the social structural processes that push young drug users into risky situations (224). This body of work has revealed potential points of intervention to prevent higher risk behaviour.

**Neighbourhood effects on HIV prevention, treatment and care**

A number of studies have looked beyond housing and explored the effect of neighbourhood context on health and social well being. Self-reported health is strongly correlated with perception of the quality and social cohesion of a neighbourhood, relative standard of living (225), civic engagement and collective self-efficacy (226), which may serve as buffers against exposure to HIV and create health-enabling environments for PLHIV. Conversely, factors such as neighbourhood deprivation (227) and characteristics of the broader “risk environment” (228) increase vulnerability to HIV exposure. For PLHIV, additional issues such as proximity to HIV service providers impact health
outcomes (229). Although it is beyond the scope of this paper, it is integral to consider the intersection of neighbourhood context in the pathways that link housing and health.

2.4. Discussion

2.4.1. Methodological issues

These findings are situated within an expanding body of literature that demonstrates the prevailing role of housing in shaping vulnerability to HIV infection and influencing health trajectories of those already HIV seropositive. Despite this growing body of work, important limitations persist, one of which was noted in a recent narrative review examining the relationships between housing status and the health, treatment adherence patterns and HIV treatment outcomes of PLHIV: the lack of a standard definition of housing status used across all studies included in the review (42). We sought to map out how housing was measured across these studies, expanding our search to include research outside of the realm of public health and epidemiology. The remainder of this chapter will elaborate upon the gaps and methodological issues identified in this literature review. This section will especially focus on definitions and ascertainment of housing status, and the indicators used to assess and measure housing stability.

Study Design

Researchers struggle to uncover the specific causal pathways linking unstable housing and poor health outcomes and to understand the role of housing status in mediating distal exposures (42). However, they have a limited number of methodological tools at their disposal because of the nature of the largely complex social phenomenon under investigation. Most research on the HIV-housing nexus has been descriptive in nature, generated using cross-sectional study designs (34). In the first published systematic review of this topic, Leaver et al. noted the dearth of longitudinal studies (88). Those studies that have been able to apply this more costly approach are limited by short follow-up periods (17). The study of housing and homelessness does not easily lend itself to the application of research designs beyond observational studies, particularly not the ‘gold standard’ of epidemiology - the randomized control trial (RCT).
Randomization of participants into usual care (i.e. remaining homeless) is wrought with ethical issues (230) and has been resisted by community stakeholders (231). Furthermore, it is impossible to conduct blinded studies.

In the search to establish a causal relationship between housing instability and poor HIV outcomes, a team of researchers in Baltimore, Chicago and Los Angeles launched the most well-known RCT in this research area. The Housing & Health study is a multisite RCT evaluating the effects of providing rental housing assistance to homeless PLHIV in the above-mentioned study sites. Kidder et al. describe how the study team overcame the methodological, operational and ethical challenges of conducting an RCT that seeks to rigorously evaluate housing as a structural HIV prevention intervention for homeless or unstably housed PLHIV. The Housing & Health study prioritized ethical concerns over epidemiological rigour. For example, although it would have impacted the findings, the comparison group was provided some assistance from the study staff, and crossover was permitted during the course of the study (16).

While epidemiological studies have made important contributions to the housing-HIV field, they are limited in their ability to fully flesh out the nuances in participants’ experiences. In their investigation of the role of gender in shaping housing access for people with severe mental illness, Kidd and colleagues observe that, “considerations of the issue of housing have very seldom taken into account the intersections of resource and adversity that attend factors such as gender, race and ethnicity” (43, p2). These authors draw attention to fact that important aspects of participants’ identity, and the systems of marginalization attached to these identities, are erased to some extent by the nature of epidemiological study designs. To begin with, in order to study these factors using quantitative methods, the factors must be reduced to categories, collected as unproblematic demographic variables. Even if care is taken to study every combination of gender, race, class etc., quantitative methods cannot speak to the multiple and variable oppressions imbued in these combinations. The most recent and comprehensive snapshot of homelessness in Canada states that, “the homeless population in Canada is quite diverse, in terms of age, gender, and ethno-racial background” (232, p25). The statistical technologies that inform such blanket statements cannot detect and meaningfully convey the experiences of people who exist at the intersections of these ‘categories.’ Epidemiology’s methodological tools, which sum up
the effects of gender and ethnicity, for example, are not meant to explain the unique oppressions of people who exist at these complex intersections. These studies are designed to report objective findings, such as the disproportionate burden of homelessness in Aboriginal populations; they cannot speak to the impact of colonialism and racism that shape the experiences of Aboriginal communities. It has been suggested that “the scholarship that best captures these fluid mechanisms of identity construction and disadvantage involve rich descriptive accounts of the contextual nature of people’s lived experiences” (233, p3). Indeed, qualitative studies have played an important role in contextualizing quantitative findings and deepening our understanding of the complex relationship between housing and well-being. These methods allow for investigation of why we see differences between the groups that are differentiated by these pre-determined categories (gender, ethnicity, income) and, importantly, “at the intersections of these categories of social positioning” (49). Qualitative inquiry thus allows for more tailored, nuanced and locally responsive research.

As can be seen in this review of the literature, the housing-HIV field has been overwhelmingly dominated by epidemiological studies, which have critical limitations that must be addressed in order to produce meaningful, effective research. Drawing on Hanson’s prescription for mixed method research designs (234), Trahan and colleagues assert that, “narratives, images, text and other forms of qualitative data can lend meaning to often unintelligible numerical data used in quantitative research. Conversely, quantitative findings can give precision to qualitative data” (233, p12). This brief critique of study designs that have dominated the HIV-housing literature demonstrates a need to expand our methodological scope beyond standard epidemiological approaches and encourage inter-disciplinary collaboration to increase the depth and breadth of our understanding of this issue.

**Recruitment and Retention**

An important limitation of research to date is the issue of recruitment. A systematic review conducted in 2007 revealed that the majority of the research in this area has been conducted with study populations comprised of “United States based samples of urban populations of easily identifiable HIV positive persons” (88). Others have noted the great number of studies based on non-probability samples that recruited participants from clinics (17). Sampling from clinic settings likely excludes people who
are not engaged in care, or have inconsistent patterns of care use. Individuals excluded from such study designs may be more likely to be unstably housed (235). Kidder et al. describe the many barriers that impede recruitment and retention to research studies amongst homeless and unstably housed people, including competing priorities, chaotic lifestyles, suspicion and distrust of institutions and reluctance to provide identifiers (16).

**Conceptualization and categorization**

The labels and categories used to define the experiences of homeless and unstably housed people present an important concern widely debated in the literature on homelessness in general (236). Weir and colleagues assert that the fundamental question underlying the HIV and housing literature is whether an individual’s basic needs are being met, giving way to the most crude categorization of study participants: housed vs. homeless (38). Amongst people who are housed, the most important distinction is the level of self-determination in maintaining current living arrangements, leading to the characterization of individuals as unstably vs. stably housed. Early research on the housing-HIV nexus almost exclusively relied upon this dichotomous (housed vs. homeless) or trichotomous (stably housed vs. unstably housed vs. homeless) categorization of housing status. The majority of the articles reviewed here describe their populations in binary terms, such as homeless vs. housed/ non-homeless. Among those who have shelter, distinction is made between people who are stably housed vs. unstably housed, or some variation (marginal, precarious). The most common characterization of housing status is trichotomous, effectively capturing both of the key concepts: homeless vs. unstably housed vs. stably housed. Where housing status is the primary area of focus, concepts such as housing adequacy, suitability, affordability and control over personal space are also taken into consideration in categorizing study participants.

Following this review of the literature, we suggest that the standard definition of each of these categories is as follows: stable housing is defined as living in one’s own home or apartment, either renting or owning; unstable housing is usually defined as living in transition - in a single room occupancy hotel or rooming house; drug treatment facility; temporarily with family/friends/strangers. Where homelessness is defined explicitly, definitions vary but usually include some or all of the following parameters/elements: sleeping or living on the streets, in a car, homeless shelter,
abandoned building, or other places not meant for sleeping. Some studies also include Single Room Occupancy hotels in this list (88). There is, in general, an exclusive focus on the spaces where people sleep, not often where they live, love, work, socialize and simply dwell during the day.

‘The homeless’ as a catch-all

Within the fields of public health and public policy, the conceptualization and operationalization of homelessness has been hotly contested, at times described as “an odd job word, pressed into service to impose order on a hodgepodge of social dislocation, extreme poverty, seasonal or itinerant work, and unconventional ways of life” (236, p3). The Canadian Homeless Research Network (CHRN) recently put forth the first official definition of homelessness in Canada, describing it as “the situation of an individual or family without stable, permanent, appropriate housing, or the immediate prospect, means or ability of acquiring it” (237). After studying homelessness across Canada, the authors organized their observations of people’s living arrangements into a typology that includes: unsheltered, emergency sheltered, provisionally accommodated and at risk of homelessness. Shortly after publishing their findings, the CHRN research team was criticized for putting forth a definition that was too broad and inclusive (238).

Within HIV literature there is an analogous concern that Public Health’s focus on “the homeless” as a special risk category may shift attention away from the “broadly shared, fundamental need for stable and adequate housing among a wide range of persons living with HIV/AIDS” (17). Despite research that has unearthed findings about variations in patterns of homelessness, a majority of the articles reviewed here use the term ‘homeless’ without providing a case definition, treating it simply as a risk factor.

A more critical arm of HIV research has expressed concern over treating homelessness as an individual characteristic (17, 74, 135). These authors have looked to the general housing literature, which has, over time, established a continuum of housing stability to better explain the difficulty of very low-income persons in securing permanent housing and to more accurately convey the recurring, episodic nature of homelessness (239-241).
**Women: the invisible homeless**

The over-representation of single adult males in homeless populations has been well documented, including in the most recent assessment of the state of homelessness in Canada, which reported that 47.5% of Canada’s homeless population is comprised of single, adult males between the ages of 25 and 55 (237). The assertion that men bear the greater burden of homelessness has been critiqued by feminist scholars and housing advocates who suggest that the way we define and measure homelessness renders women invisible. More likely to couch surf, double-up and stay in dangerous and precarious relationships and situations, homeless women elude researchers and service providers alike (242). However, in some urban settings, homeless women have become more visible, launching a relatively new scholarship that has helped shed light on the unique experiences of women who experience unstable housing. A recent example is a Photovoice study that worked with a group of street homeless women “to help them own their voice and perspectives on housing and health” (243, p739). This review of the literature suggests a critical need to tailor every aspect of the research process to capture the gendered nature of homelessness.

**Home: a euro-centric vision**

The meaning of home has been the focus of centuries of theorizing. Robertson asserts that, “‘being-at-home’ is not always grounded in one particular site; it may refer to a state of well-being that extends to communities, cities, nations or ancestral territories” (111), drawing attention to the fact that our vision of home is euro-centric and, for some, home may extend beyond brick and mortar structures. The cultural origins of the meaning home and homelessness are erased by dominant definitions, and so too are the historical roots of chronic homelessness that burden some populations. In the Canadian context, Aboriginal notions of ‘home’ are marred by a history of dispossession and dislocation through the reserve, residential school and child welfare systems (44). Policy, programming and research addressing Aboriginal people’s overrepresentation in Canada’s HIV epidemic and homeless population must be contextualized in an understanding of the systemic dismantling of ‘home’ in Aboriginal communities, however, this is not often the case. The studies reviewed here report some variation of race, ethnicity or Aboriginal status as a demographic variable. Unfortunately, the differences observed between groups within these categories are often problematized in an
ahistorical fashion, and beg for a greater reckoning of the role of racism and colonialism in shaping these differences.

**Assessment of housing stability**

As of yet, there is no standardized validated instrument to measure or assess housing status. Housing status is typically ascertained by collecting data on where an individual sleeps/has slept. Housing stability is typically assessed via function of housing type. In studies where housing is the primary variable of interest, additional data may be collected, including receipt of housing assistance, frequency of change of residence, proportion of income spent on rent and specific material concerns with the adequacy and appropriateness of housing, such as information about infestation, ventilation, etc.

The bulk of the literature reviewed here is informed by objective assessments of housing status based on a priori categories. One or more questions will be asked of participants, usually pertaining to where they sleep or have slept, and the responses will be coded accordingly and grouped into the aforementioned categories. Subjective assessments - people’s perceptions of their own circumstances - are much more rare. These open-ended questions ask some variation of: ‘have you ever/recently been homeless?’ With few exceptions (36, 244), these subjective assessments are not accompanied by objective descriptions of people’s living conditions. Consequently, one cannot decipher what aspects of the participant’s housing situation led them to identify him or herself as ‘unstably housed.’

A number of studies reported prevalence or incidence of homelessness or unstable housing, or compare ‘the homeless’ and ‘non homeless’ with no clear case definition or explanation as to how the assessment was conducted and what the basis of comparison was. Similarily, several studies label the study population as ‘homeless’ or ‘unstably housed’ based on the sampling strategy used. This assumption is typically made when recruitment has taken place in homeless shelters, free meal programs, low-income SROs and food banks. A number of studies are based on retrospective review of secondary data sources, such as census or administrative databases linked to clinics, hospitals and treatment registries. Secondary data sources have the benefit of appearing objective and providing a large sampling frame, however studies that rely on these data are limited by the nature of the information collected and the rigour and
consistency of the collection methods. Specifically, the definitions of outcome and exposure in these studies are determined by the theory, structure and content of the available data source, which is typically driven by concerns with functionality. It is uncommon to find systematic data available on housing conditions and the information that is collected does not adequately reflect: 1) the experiences of people living with, or at risk of, HIV or 2) the changes and variations within the housing sector (for example, the experience of living in an SRO varies depending on a number of factors). Furthermore, long-running cohort studies based on clinical data do not often account for changes in housing status. Aidala et al. problematize the use of a single indicator to represent broader, complex constructs, for example, treating outpatient visits as a representation of engagement in appropriate HIV care (17). Most data sets also lack variables that may occupy an important place on the causal pathway between housing status and health of PLHIV. Researchers in this field are also confronted with the challenge of isolating the effect of homelessness from other related, concurrent issues, such as lack of economic resources, addictions and mental health disorders (159).

**Measurement and definition**

Some authors within the housing-HIV field have criticized this body of literature, suggesting that the widely-accepted narrow definitions of homelessness and housing instability serve to undermine our understanding of the relationship between housing and HIV (37-41). Weir and colleagues note that the standard objective housing stability indicator reflects multiple aspects of housing, making it challenging to decipher which of these aspects account for the associations between housing and HIV risk. The authors acknowledge the importance of each of these aspects - access to basic amenities, having some control over one’s local environment, and whether one perceives their residence to be their own - but feel that, “characterizing housing more fully would aid in the evaluation of the varied hypotheses on how housing may influence HIV risk” (38). Perhaps more importantly, the commonly used measure may not adequately reflect other important dimensions of housing, including affordability, transience, and the impact of housing on the nature of relationships. Dickson-Gómez et al. point out that housing affordability is often overlooked as a component of housing stability and over-all well being, even though it is well known that people who face affordability issues are vulnerable to exchanging sex and drugs for shelter (41). Thus, it is not enough to
differentiate between those who are ‘housed’ and ‘not housed,’ and more thought should be put into whether people have access to other buffers, such as housing subsidies. The authors also question the assumption that, ‘doubling up’ with family or friends is a marker of housing instability, as people who share accommodations are less likely to face challenges paying rent and having to face trade offs between rent and food.

Recently, more accurate measures have been developed to recognize the many dimensions of housing status beyond the material aspects. Some researchers have differentiated between people living in their own apartment and living with someone else (108). Weir et al. investigated housing and HIV risk behaviour through multiple housing indicators, looking at whether participants benefit from access to supportive housing programs, as well as perceived need for housing supports. German’s work is the most often cited piece on ‘residential transience,’ introducing another important indicator that is typically assumed to be synonymous with, or inherently connected to, housing instability (100).

2.4.2. Recommendations for moving forward

*A greater consideration of social-structural factors*

Milloy et al. note that research on homeless and unstably housed populations has elucidated individual-level factors, such as behavioural and psychological determinants of treatment adherence and health outcomes, however, an important unanswered question is the “relative contribution of homelessness and how it mediates more distal exposures” (42). Over the past two decades, there has been a growing recognition among public health bodies that HIV prevention, treatment and care are also strongly influenced by the physical, social, economic and policy environments in which PLHIV negotiate health-related decision making (245). This conceptual shift has given way to a more nuanced understanding of how living conditions, including housing status, may shape vulnerability to HIV infection, and influence health trajectories of those already HIV seropositive. Owing to the shift in interest towards social-structural level exposures, and evidence of their impact on treatment adherence and health outcomes (246, 247), more must be done to understand these associations among PLHIV who are homeless or unstably housed.
Two studies conducted among homeless and unstably housed people in San Francisco demonstrated how structural factors impact treatment adherence, specifically how changes in health insurance regulations are associated with treatment interruption (248) and uninterrupted health insurance is associated with better health care uptake (249). Through in-depth qualitative interviews with 12 HIV-positive, formerly incarcerated injection drug users, Small and colleagues identified contextual barriers to HAART adherence within correctional settings (250). The spaces in which people are permitted to dwell says a great deal about broader economic and political structures. Following the path laid by researchers in the drug policy field (246, 247), we must seek a better understanding of the position of housing “...as an intermediate structural factor, linking broader social processes to the more immediate physical and social environments within which we carry out day-to-day life” (115, pS1). As Angela Aidala points out in the introduction to a Special Supplement of AIDS and Behaviour focusing on HIV and housing,

Housing provides a clear example of the ways in which broader economic and political factors shape the context of health. Many societal factors seem far beyond the reach of public health...we can however address a more proximal manifestation of these influences by addressing the day to day context of human behaviour shaped by housing/lack of housing, particularly since much of this context has been shaped by deliberate laws, policies and regulations (115, pS4).

**Increased emphasis on context-specific and community-engaged research**

Much of the evidence on this issue gathered to date has been derived from a few key cohort studies based in the United States. The Research in Access to Care in the Homeless (REACH) study is a community-based cohort of HIV positive adults systematically sampled from free meal lines, homeless shelters and SROs in San Francisco (see (35) for methods). The Community Health Advisory & Information Network (CHAIN) project is an ongoing prospective cohort study of a representative sample of PLHIV in New York City (see (36) for methods). In the Canadian context the most well known study focusing on housing and HIV is Positive Spaces Healthy Places, an observational cohort of adults living with HIV in Ontario, recruited through community-based AIDS Service organizations (see (26) for methods).
Comparable studies have not been conducted in BC to date, although some important progress has recently been made to fill this gap. The Pacific AIDS Network (PAN) membership, comprising over 50 AIDS Service Organizations in BC, requested that its board secure funding to examine the existing gaps in services and develop a KTE strategy to influence housing programs, services and policies in such a way as to promote greater access to affordable housing to enhance the health and well being of PLHIV throughout the province (24). Following the PAN board’s request, a proposal was submitted to CIHR to launch the Positive Living Positive Homes (PLPH) study, a community-academic partnership developed to investigate how local, regional and provincial housing and HIV policies, programs and services impact PLHIV’s abilities to manage their health and well being, and to document policies and programs that can be used as models across jurisdictions in BC and beyond. The PLPH study team has heeded the call for a community-driven research agenda targeting this issue that has been identified as the most urgent, unmet need of PLHIV in BC (24). As this study unfolds it will illuminate the unique housing concerns of PLHIV in this specific context, filling a major gap in the literature.

2.5. Conclusion

There is now unequivocal empirical evidence of the powerful role of housing in shaping vulnerability to HIV infection and influencing the health trajectories of those already HIV seropositive (17, 115). These observations have been corroborated by studies with other populations in varying contexts (8, 59, 60, 78-87), demonstrating the impact of housing on various aspects of the health and well-being of PLHIV.

Despite all that we know, however, this review of the literature has revealed a number of limitations of our commonly used methods, and consequent knowledge gaps. Our knowledge of the HIV-housing nexus is primarily built on a body of research that is descriptive in nature, generated using cross-sectional study designs and based on narrow definitions of housing status that may not capture the nuances and diversity in people’s experiences. In addition, this area of research is overwhelmingly dominated by epidemiological methods, with minimal inter-disciplinary collaboration to increase the depth and breadth of our understanding of this issue. We also lack an understanding of
the role of housing in mediating more distal exposures. In particular, there is a critical need for a greater reckoning of the gendered nature of housing instability and the role of racism and colonialism in shaping definitions of, and responses to, housing instability.

It has been suggested that, “…in complicating and quantifying homelessness, we risk failing to understand homelessness at its essence: the absence of a home” (44), a question that can only truly be answered by individuals and communities whose sense of home, however they define it, has been threatened. This review further suggests there is a shortage of context-specific, community-driven inquiry, and an overemphasis on the material aspects of housing - that is, the basic need for shelter. This is particularly the case in Vancouver, B.C. where the limited data available on the impact of housing instability on the health and well being of PLHIV has been generated without meaningful involvement of the community. With the exception of the Positive Living Positive Homes initiative, which is in its early phases, no major published study to date has focused exclusively on the housing experience of PLHIV in this context. In particular, there has not been any major body of work that reflects the experiences of affected populations in this context.

There remain, therefore, critical gaps in our understanding of the specific mechanisms through which housing instability impacts health behaviour and outcomes (45, 46), hindering the development of evidence-informed programming and policy in the area of housing and health. We propose a conceptual shift away from understanding stable housing as a predominantly material entity comprising a roof and walls, towards a more holistic understanding of the social and cultural importance people place on home, and various spaces people find and make ‘home.’ Addressing the varied housing needs of people living with, and at risk of, HIV relies on a more careful consideration of context and a commitment to cultivating and supporting spaces which allow people to manage their health and well being.
Chapter 3.

Framing the issue: theoretical perspectives grounding and orienting this research

Synopsis

This chapter describes the process of selecting and operationalizing the hybrid of theoretical frameworks that ground and orient this research: Community Based Research, Social Determinants of Health and Intersectionality. This chapter concludes with a critical reflection, which discloses the motivation behind this research, as well as challenges and successes of adhering to the tenants of these theories.

3.1. Introduction

Traditional research has long been criticized for concentrating power in the hands of academics who gaze upon affected communities, identify ‘the problem,’ and conceptualize the research agenda without meaningfully involving members of the study population. Critics charge that the research process, as it is traditionally enacted, produces knowledge that is not beneficial to the communities involved and, at its worst, reproduces inequities and power imbalances. I was mindful of these criticisms and sought out theoretical frameworks that would help avoid producing research that perpetuated and further entrenched inequities.

3.2. Selection and adaptation of theoretical frameworks

I looked to previous studies utilizing Photovoice to orient this study and found many failed to explicitly name the theoretical lens of the authors. A recent study
employing Photovoice employed Constructivist Grounded Theory in the analysis (251), which answers the call for reflexivity in the research process; however, it is limited in its ability to surface relations of power as they shape participants’ experiences. Whether issues of power emerge from the data is contingent upon how the researcher frames questions and what methods of analysis they select. If a participant does not recognize power issues at play in their own narrative, the researcher cannot extract this in the analysis. I continued to search for a theoretical framework and through a deductive, iterative approach spanning the duration of the project, a hybrid of frameworks were selected to ground and orient this work: Community Based Research, Social Determinants of Health and Intersectionality. Originally, the frameworks were selected because of their connectedness to the methodological tools, the goals and sentiments of the research team and through my ongoing reflection of my positionality. As the project progressed, additional frameworks were adapted to address the ontological and epistemological constraints of the theories originally selected.

3.3. Community Based Research Approach

Projects guided by research questions that have been identified by the community have been shown to have a more meaningful impact on policy, as well as program and service delivery (252, 253). With this in mind, I took a community driven approach in developing this project. Within the broader goals of strengthening communities and improving quality of life, Community Based Research (CBR) aims to generate knowledge about health priorities by: i) placing the issues of community organizations and the populations that they serve at the centre of research; ii) developing multidisciplinary partnerships between community members and academic researchers to ensure that research is relevant, ethical and methodologically rigorous and sound, and iii) committing to empowerment of communities through all stages of the research process (50).
3.3.1. Operationalization of Community Based Research

**CBR begins with a research topic of importance to the community**

As explained in Chapter 1, the need to conduct this project was identified through collaboration with the MAT program. A comparison of an internal survey of MAT participants and LISA cohort data revealed a stark disjuncture between the standard epidemiological assessment of housing status and individuals’ personal sense of housing stability. Consultations with other community partners, including the Dr. Peter AIDS Foundation, Positive Women’s Network and Positive Living BC (previously the BC Persons with AIDS Society), uncovered a widespread recognition of housing as the greatest unmet need for PLHIV in BC. The project thus grew from a community-identified need to explore the dimensions of housing that are important to PLHIV’s sense of stability and well being in this context.

Housing has been named as an issue of crucial importance by other groups as well. As mentioned, at the provincial level, PAN, the body which represents over 50 HIV and AIDS service organizations throughout BC, identified housing as the most urgent unmet need PLHIV (24). At the federal level, the Canadian AIDS Society has demanded that, “policymakers address the lack of adequate housing as a barrier to HIV prevention, treatment and care, and that governments fund and develop housing as a response to the HIV/AIDS pandemic” (254). On behalf of their diverse memberships across Canada and BC, these organizations have expressed an urgent call to action on the issue of housing.

The use of Photovoice as a research tool also helps ensure that the research topic reflects the priorities of affected communities, and hopefully facilitates the meaningful use of the study findings. In Photovoice, the conversation begins with the research participant taking a photo of an issue or object that they prioritize, thereby setting the research agenda and increasing the likelihood of creating processes and outcomes that are of importance to the community.

**CBR encourages the development of multi-disciplinary, collaborative academic-community partnerships**

From the time that this project was first conceptualized, a number of organizations and individuals have joined this multi-stakeholder team: leaders of
community-based AIDS service organizations who represent the interests of their diverse memberships; health and ancillary care providers; housing advocacy workers; health researchers and individuals with expertise in arts-based research and knowledge transfer and exchange.

I personally approached individuals and organizations to join our study team. I created a short project proposal and a handout explaining the different roles individuals and organizations could hold, as well as the time commitment associated with each level of engagement. For the purposes of fulfilling the requirements of the Canadian Institutes of Health Research (CIHR) CBR grant submission, the roles included: Co-Investigator (available only to individuals with an appointment at a CIHR-approved institution); Knowledge User (available to community partners who were willing to create a CIHR Knowledge User CV) and Collaborator (available to any organization or individual who had interest in involvement but did not feel able or willing to engage in the CIHR process). I approached Ms. Rosa Jamal, a staff member at the Dr. Peter Centre, to act as the Principle Knowledge User on the grant. I knew Rosa had an interest in crossing over into academia and I felt it was more appropriate to have a community representative as the lead on the CBR grant and in the project itself.

This project values the unique strengths of the diverse team of academic researchers, Knowledge Users and Collaborators and I took care to ensure that all members of the team were given the opportunity to engage in the project as much or as little as they wanted. Those who desired active involvement were welcome to attend meetings, assist with participant recruitment or join working groups to review draft documents (e.g. consent forms, study invitations, grant applications). Those who sought out more passive engagement were added to a mailing list so that they would be updated when there were important developments. A desire for passive involvement did not preclude individuals and ASO representatives from signing on as Knowledge Users, as I offered support in the process of creating CIHR Knowledge User CVs. Moreover, I was able to offer a modest honorarium to study team members who engaged in the project as an individual, as opposed to study team members representing an organization that was remunerating them for their time. I hoped that these gestures would mitigate barriers to engagement.
Rosa and I first approached the HIV and AIDS Service Organizations that were engaged in the LISA project to form a steering committee for this study. The following sites were approached by virtue of their mandate to deliver HIV and AIDS-specific health and/or ancillary care, their interest in investigating housing as a determinant of health, as well as the unique needs of their respective memberships: the Dr. Peter AIDS Foundation (the organization responsible for funding and overseeing the operations of the Dr. Peter Centre), Positive Women’s Network, the MAT program and Spectrum clinic. I also engaged McLaren Housing Society of BC, RainCity Housing and Portland Hotel Society so that the project would be informed by the perspective of organizations involved in housing provision for low-income and otherwise marginalized individuals. I invited academics with experience in using Photovoice to act as Co-investigators on the grant. Colleagues at the BC Centre for Excellence in HIV/AIDS who took notice of the project unfolding in their office space naturally became involved in the process. They were invited as Co-investigators on the grant, but their true value lay beyond research expertise, as they provided moral support and free labour that kept the project afloat.

Through these processes I strived to build a team that brings to the table the voices of men and women living with HIV, Aboriginal people, people who have been formerly homeless and people who have a history of injecting drugs. Alongside the lived experience of these team members, academics and service providers added clout to our CIHR submission. All of these perspectives ground and contextualize our research and Knowledge Translation and Exchange (KTE) work, and were pivotal in the success of this project.

**CBR empowers communities through all stages of the research process**

From the outset, I was committed to enacting the MIPA principle (Meaningful Involvement of People with AIDS). MIPA demands the meaningful and emancipatory participation of people living with HIV in all stages of this project, including formulation of the research question, data collection and interpretation, knowledge translation and study evaluation. In this project, Community Researchers shared their personal and community housing challenges and successes, as well as generated and analyzed data. Additionally, Community Researchers played a central role in presenting research findings to the community and brainstorming ways to mobilize the knowledge generated for social change.
By virtue of the chosen methodology I hoped to build upon and create expertise within affected communities to conduct their own research, which is one of the central tenets of CBR. A number of public health studies have successfully adapted this method for use with marginalized populations (255-274), many of which have documented the empowering effects of this method (255, 256, 275-277) and, in particular, homeless populations in London, England (278, 279), Auckland, New Zealand (243) and Los Angeles, California (280). These studies suggest that through the action of taking photographs and narrating the stories behind them, participants acquire a greater authority to advocate for social change in their communities.

3.4. Social Determinants of Health Framework

The burgeoning body of literature on housing and health is increasingly framed through a Social Determinants of Health (SDoH) or Population Health framework to illustrate the ways in which environment, including housing conditions and neighbourhood context, interacts with an amalgam of factors (i.e. education, employment, healthcare access) to either provide a buffer from, or create susceptibility to, disease, disability and death (281). Viewing the relationship between housing and the health of people living with HIV through this theoretical lens, housing is positioned as one among many intermediary factors that shapes vulnerability to HIV infection and influences health trajectories of those already infected. According to this framework, inadequate housing is one of several underlying social causes that undermine people’s ability to take care of their health. Many studies adopt this framework because it provides solid empirical evidence of the causal relationship between housing and HIV. For these reasons, this project drew heavily upon Dunn’s Population Health Approach to Housing to help organize the analysis (282). This framework provides a useful starting point to illustrate the integral role of housing in shaping HIV risk, as well as the health outcomes of those already infected.

3.4.1. Operationalization of Social Determinants of Health

The SDoH framework was operationalized through the use of debrief activities that encouraged participants to identify and discuss the multiple factors that influence
At the outset of the group process, participants were asked to individually create a visualization of good health and all of the factors that contribute to good health throughout the life course. The members of the group then came back together to discuss their thoughts with the larger group. An example of Rob’s visualization of the role of social determinants in influencing his health can be seen in Figure 1. We kept these diagrams and pinned them up around the room each time we engaged in analysis of results so that we were always mindful of the powerful role of these factors in shaping health.

Unfortunately, the explanatory power of the SDoH and Population Health framework is curtailed by its failure to recognize that social inequality, produced and sustained through political and economic systems, permeates every aspect of peoples’ existence throughout the life course and is the root cause of health inequities. This framework assigns equal theoretical weighting to all social factors, including social inequality, in explaining health inequities. If we recognize the integral role of social inequality, it is clear that acting on intermediary factors without critiquing the structural causes will not yield sustainable solutions. In addition, the over-simplified models that result from this analysis do not accommodate structures and circumstances that produce particular relationships between factors. Finally, the SDoH framework does not adequately conceptualize possibilities for real change or leave room for agency (283).

The SDoH and Population Health frameworks require a critical analysis to adequately address the complex relationship between housing and HIV-related health. Specifically, there needs to be a broader reckoning of the role of structural factors, especially social inequality, in reproducing health inequities. Without investigating and addressing the mechanisms, institutions and systems that produce health inequities, we run the risk of generating knowledge and interventions that reproduce inequities, rather than alleviating them.
Figure 1: Example of activity to visualize social determinants of health
3.5. Intersectionality Theory

The theory of intersectionality is widely recognized as a promising tool to “advance the operationalization of equity in public policy” and, as such, was an ideal complementary framework to address the aforementioned concerns with the SDoH approach and make recommendations for “more inclusive, just, effective and efficient health policies” (47, p7). Intersectionality examines the patterns of health inequities along major social divisions such as gender, sexuality, physical ability, race and class in new ways (48). It attempts to capture the complexity of the lived experience at the intersections of these categories of social positioning and the multileveled relationships of power that play out at these junctures to impact health (49). Through wearing an intersectional lens, the researcher is attuned to the different axes of power that shape participants’ experiences, as well as reflexive of their own position of privilege. The introduction of intersectionality provides a means of attenuating the tendency towards reductionism, giving way to a more tailored, nuanced and locally responsive program of research and KTE. An intersectional lens was applied to addresses the concerns around the power imbalance embedded in the positivist research tradition, as well as the limitations of the SDoH framework.

3.5.1. Operationalization of Intersectionality Theory

Of all of the selected frameworks, intersectionality holds perhaps the most promise for transformative change, although it is perhaps the most challenging to operationalize (47). Photovoice, a research tool that is used in the pursuit of social justice, addressing inequities and capturing lived experience of affected communities, provided a concrete mechanism through which to operationalize intersectionality. Photovoice, when stripped down to its theoretical underpinnings, and when operationalized in practice, bears a striking resemblance to intersectionality theory.

Photovoice: Operationalizing intersectionality in theory and practice

Theoretical underpinnings of Photovoice

The major theoretical pillars upon which Photovoice is built are Empowerment Education, Feminist Theory and Documentary Photography. Wallerstein and Bernstein’s
The concept of Empowerment Education is an adaptation of Paulo Friere’s ‘problem posing education’ (284). Friere’s model calls for learners to come together as equals to understand the community’s main concerns, engage in problem-posing dialogue and work towards positive change, the ultimate goal being human liberation. Problem posing dialogue is structured by ‘codes,’ physical representations of issues identified by community members (285). In the case of Photovoice, photographs serve as the ‘codes’ to which participants respond (256). In the tradition of ‘problem posing education,’ Photovoice facilitators encourage participants to move from reflecting on their individual experiences to uncovering the roots of their community’s challenges and strengths.

Feminist theory, while diverse in its manifestations, has a few key features that are integrated in the Photovoice methodology. Photovoice is intended to shift authority from the researcher to the research participant, as feminist theory seeks to destabilize positions of power, representation and voice. In addition, Photovoice participants are viewed as the experts of their realities and are meaningfully included in the process of informing the research agenda and constructing and disseminating knowledge, echoing the inclusive knowledge production process for which feminist theorists advocate. Importantly, Photovoice re-situates participants’ every-day realities within the political, socioeconomic, cultural and historical contexts in which they are rooted, demonstrating how ‘the personal is political,’ another marker of the feminist origins of this method.

The final pillar of Photovoice is Documentary Photography, a form of visual representation in which the photographer attempts to capture ‘the truth’ through candid photography. In keeping with the objectives of Documentary Photography, Photovoice is meant to “accurately describe otherwise unknown, hidden, forbidden, or difficult-to-access places or circumstances” (256).

**Methodological cornerstones of Photovoice**

Photovoice, a research tool that situates social justice as a goal, provided a concrete mechanism through which to operationalize intersectionality, a framework that seeks to illustrate how “…marginalized populations can occupy multiple social locations to advance their own cause for justice” (286, p254). A participatory action research tool, Photovoice was developed as a means for groups who tend to be marginalized by
social-structural inequity, to reflect on their community’s capacities and needs, engage with policymakers and encourage social change (256, 260, 261).

Intersectionality encourages research systems to address questions of power in a subjective and locally grounded way. Photovoice generally, and our project specifically, answers this call through its confrontation of power imbalances inherent in traditional research. Projects using Photovoice methods are conducted with, and by, research participants who take on the role of the researcher by gathering data in the form of photographs and analyzing that data through their own experiences. This method increases accessibility for communities who face barriers to participating in traditional research. Grounded in the concept of lay epidemiology, Photovoice draws upon community members’ expert knowledge of the physical and social conditions in which they live, and prioritizes their concerns to inform healthcare interventions (287), destabilizing the authority of the researcher and recasting the study participant as the expert.

In their study of the health practices of immigrant and refugee women in Vancouver, B.C., Dyck and Dossa assert that there has been a lack of attention towards how macro-level structures affect everyday realities of women and suggest that “what are perceived as mundane and less important activities (food preparation, catching the bus, shopping) hold promise to reveal the fault lines of the system while showing how people from the margins of society remake their worlds in relation to the wider socio-political and economic relations…” (286, p241). Christensen and Jensen similarly argue for “taking everyday life as a point of departure” (p120), which they put forth as a tool to discuss the interplay of categories in a “non-additive way.” That is, intersectionality is concerned with the convergence of multiple identities, with the belief that, “something unique is produced at the intersection point of different types of discrimination” (288, p3). This convergence is seen as distinct from the simple summation of racism, homophobia etc. With everyday life as the subject of analysis, we are able to analyze the very site of convergence of categories, such as ethnicity and sexual identity. Analyzing everyday life also allows for the discussion of these categories in an indirect way, without constructing and reifying these categories. Similarly, Photovoice re-situates Community Researchers’ everyday realities within the political, socioeconomic, cultural and historical contexts in which they are rooted. The Photovoice
workshops aimed to cultivate a space where Community Researchers could articulate how their intersecting and shifting identities position them in society. The Community Researchers have an intimate knowledge of these processes; Photovoice simply creates a platform for them to articulate and illustrate their understanding.

Inspired by Dyck and Dossa (286) who see their study participants as “creative agents in negotiating their otherness as they seek to construct healthy lives” (p243), I sought to emphasize and celebrate the ways in which the Community Researchers advocate for their health and well being amidst the challenges they confront day-to-day. I actively created opportunities to do this in the design and facilitation of the Photovoice workshops and in the analysis process. In the analysis phase, this project drew on life-story narratives. Following Prins (289), Christensen and Jensen suggest life-story narratives produce valuable data about processes of identification and social structures (290). The authors also warn against the pitfalls of this approach, however, drawing on earlier critiques of feminist claims to truth and authenticity (291). Ramazanoglu and Holland balance their skepticism of the ‘objective truth’ and the problematization of the possibility of any kind of knowledge production. In the end, I situate this work in Christensen and Jensen’s summation of the issue, that narratives contain important information, however, they can be viewed as representations. As the authors prescribe, “it is of central concern to intersectionality research both to take the actual information given in such narratives seriously and to analyze how gender, class, ethnicity, etc. intersect in the discursive construction of meaning” (p114). In practice, this meant that the data analysis phase involved a balance between taking Community Researchers’ narratives as truth and subsequently re-viewing their narratives with an intersectional lens. Christensen and Jensen view this methodological approach as a way of understanding identity construction and how structures, institutions and policies shape and inform people’s day-to-day lives.

Increasingly, intersectionality is being used as a policy analysis tool. Theorists advancing intersectionality emphasize the importance of interrogating health-related policy to uncover how these policies prioritize the concerns of some citizens at the expense of others. I looked to Hankivsky’s framework for Intersectionality-Based Policy Analysis (292) to critically examine housing policy and other social and public policy that
impact people’s ability to secure and maintain adequate housing. This approach was used in considering program and policy recommendations, presented in Chapter 9.

This combination of theories – Community Based Research, Social Determinants of Health and Intersectionality – has enormous promise for illuminating the complex, interacting factors that are embodied in the individual and expressed through health.

3.6. Critical self-reflection

Critical research calls on the researcher to reflect on their positionality and their relationship with the study participants. Speaking to power as it is enacted in visually guided research in particular, Rose asserts that, “effective collaboration requires reflexive vigilance: careful and consistent awareness of what the researcher is doing, why, and with what possible consequences, in terms of the power relations between researcher and researched” (293). In conceiving of this project, I questioned what perspectives and experiences had led me to take an interest in this work and, in particular, the values I held that informed the methods and frameworks I had selected. This questioning and reflecting manifested mostly in the form of vigorous journaling. I wrote in my journal before and after each meeting or major event that directly or indirectly related to the project. I also met with community partners on a regular basis, which helped me keep a pulse on how the project and I were being perceived. Colleagues with whom I shared an office were an incredible sounding board for confidential reflections on how the project was progressing, as was Rosa, the staff member from the Dr. Peter Centre who I invited to join as the Principle Knowledge User. A few reflections that are central to this narrative are presented here.

First and foremost, I have no personal experience with homelessness or housing instability. I identified a need to conduct work of this nature during my tenure as a Research Assistant for the BC-CfE, where I was charged with the task of interviewing people about their experience living with HIV and taking antiretroviral therapy. With only

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1 As I was in the midst of an urgent housing hunt, followed by a frantic move into an apartment with a stranger from Craigslist. At this time, my journal was peppered with a lot of reflection about my own feelings of housing instability.
a box to check pertaining to housing stability, a question that should have taken only a moment to answer often led to detailed descriptions of housing conditions beyond my wildest imagination. Unable to cut off these stories, among the other Research Assistants I became infamous for drawing out “60 minute interviews” to upwards of 90 minutes. The experience filled me with a deep-seated sense of injustice, and to be honest, some guilt about my relative power and privilege in the researcher-participant relationship, which at times felt exploitative, echoing what Connolly describes as the “challenge of reciprocity” (294). Based on this experience, I strived to develop a research project that destabilized the typical relationship between the researcher and study participant, and to work collaboratively and build meaningful relationships with members of affected communities. Most importantly, I wanted to develop a program of research that directly benefited study participants.

It was at times challenging to adhere to my beliefs about how research should be conducted in the face of strict institutional requirements. Specifically, I encountered barriers while seeking ethical approval from the SFU Research Ethics Board and applying for funding from the Canadian Institutes of Health Research. SFU’s REB, striving to protect the interests of study participants was at times paternalistic and CIHR’s application structure posed challenges to inviting non-academics to collaborate on grants. These barriers compromised my relationships with AIDS Service Organizations, who were disillusioned by past experience with exploitative research projects and did not immediately ‘buy in’ to the project. I found myself joining in the institution-bashing, partly because I too was frustrated, and partly as a way of distancing myself from these institutions.

Institutional requirements are rigid but I worked hard to soften the impact of this rigidity on the community partners and Community Researchers. As described in the previous section about operationalizing intersectionality, I strived to cultivate a space in which all members of the study team felt equal, where the power of ‘the knower’ did not rest with one person. I actively destabilized the traditional researcher-researched role in a number of ways. I invited Rosa from the Dr. Peter Centre to act as the Principle Knowledge User and a co-facilitator of the Photovoice sessions. I also invited a peer support worker from the Dr. Peter Centre to co-facilitate the sessions and help liaise with the Community Researchers. In all of my interactions with the Community Researchers
– in meetings, coffee shops, street corners, gardens, buses and ASOs – I took care to engage with them as I would any colleague or friend. At each meeting, I tried to erase markers of their role as study participants by inserting their honorarium and bus tickets in personalized thank you cards that celebrated their contributions to the project. I tried to avoid the use of an audio recorder and instead worked with the co-facilitators to keep notes during sessions. We distributed these notes at subsequent meetings in the form of minutes and agendas, so that the note-taking was not seen as a research tool, but instead as an administrative task that we all relied upon to keep track of our project. In our meetings, Rosa and I repeatedly explained that the Community Researchers were the experts and the work they would produce would help us engage researchers, service providers and the public in a topic they know little about. Through my words and actions I painted my role as insignificant and my knowledge and skills as less valuable than that of the Community Researchers.

In practice, it was a challenge maintaining the integrity of the research and sharing power in a productive way. Some members of the group needed me to act as a leader, a role which I continued to resist. In addition to my contested role, I struggled with boundaries, feeling compelled to help members of the team when they voiced problems unrelated to the project. I awkwardly balanced my compulsion to help with my fear of creating dependent and paternalistic relationships. These challenges persisted throughout the duration of the project and I continued to be cognizant of my position of privilege. I critically reflected on my role, especially as it was perceived by the Community Researchers. I came to understand (or at least suspect) how I was perceived by the Community Researchers by being mindful of how members of the team engaged with me versus how they engaged with one another or third parties, such as service providers. I noted subtle cues such as body language, eye contact, language, as well as more conspicuous cues, such as the titles they used to describe my role to others (leader, colleague, mentor, friend, daughter, supervisor). I also gained a great deal of insight from team members who would seek me out in between meetings, calling me or showing up at the Immuno Deficiency Clinic and asking the receptionist to page me. These little asides signalled to me that I never quite shed the cloak of group-leader.

Inviting study participants to co-create knowledge in this way, in truth, probably alleviated some of the guilt I felt about my privilege. However, if I reflect back on the
sentiments that launched this project, my sense of injustice only became more deeply ingrained as I became closer to the Community Researchers and experienced small doses of their every-day realities. Above all else, I felt strongly that the Community Researchers hold valuable, firsthand knowledge that would bring ‘truth’ to this work in a way that was not possible without genuine community ownership. In solidarity with the Community Researchers, I hope to contribute to “unravelling complex webs of privilege and disadvantage” (295).
Chapter 4.

Living with HIV in an unliveable city: historical context of housing policy in Vancouver, B.C

Synopsis

Vancouver, British Columbia is home to a growing housing crisis and one of the highest HIV prevalence rates in Canada, leading the Pacific AIDS Network (PAN), representing over 50 HIV and AIDS service organizations throughout the province, to identify housing as the most urgent unmet need of people living with HIV and AIDS in BC. This chapter provides a brief policy history of low-income housing provision in BC, as well as a description of Vancouver's HIV epidemic. Special emphasis is paid to housing challenges experienced by people living with HIV.

4.1. Vancouver’s housing crisis

Vancouver, British Columbia (BC) was ranked among the top three most liveable cities in the world for the last two years, following five consecutive years of ranking first place in the Economist Intelligence Unit Global Livability Report (296). However, by many accounts, Vancouver is also one of the most unliveable cities in Canada (297). According to the latest reports from Statistics Canada, the province of BC continues to have the highest poverty rate in the country (10), with 16.9% of households in Vancouver living below the Low Income Cut-off (298). These statistics are partially a function of the high cost of living - in 2013 the Economist named Vancouver the most expensive North American City in which to live (9). Compounding the high cost of living are factors such as inadequate income assistance (with welfare rates that have been frozen since 2007), low minimum wage (12), and high cost of food (13). The
consequences are dire: low-income residents face impossible trade-offs, forgoing necessities in favour of paying rent (23). Such trade-offs are due, in large part, to exorbitant housing costs. Vancouver has the second least affordable housing market in the world (9) and the highest housing costs in Canada, with the average price for a single family dwelling in July 2013 set at $921,900 (299), and the average rent for a two-bedroom apartment in April 2013 listed at $1,255 (11). The pressure of prohibitively high housing costs is compounded by low vacancy rates (2.9% as of April 2013) (11), an eroding rental housing stock and the decline of purpose-built rental stock in favour of condominium development (11).

It is of little surprise then, that housing instability is deemed a serious problem in the province of British Columbia, particularly in the city of Vancouver. High demand and limited supply of land has created significant housing challenges for persons of all income levels, but the impact is felt most deeply by households in the bottom 20 percent of the income range. Vancouver's 'shelter gap' - the difference between what lower income households can afford to pay for shelter and the price of available stock - is approximately $4,000 (300). According to the most recent assessment by the Canada Mortgage and Housing Corporation, approximately 79,365 (31.2%) of Vancouver households are in core housing need, defined as housing that falls below the CMHC standard of: adequacy (good repair), suitability (suitable in size) and affordability (does not cost more than 30% of household's gross annual income) (301, 302). Homeowners, of whom 27% were in core housing need, fared slightly better than renter households, of whom 43.8% were in core need (303). BC Housing, the division of the provincial government responsible for provision of housing to low income residents in BC, reported that 12,000 households were on the supportive housing wait list at the end of the 2011 fiscal year (304).

At the extreme end of the housing spectrum, homelessness remains a critical issue, with Vancouver's 2013 Homeless Count at 1,600 (305). According to a recent snapshot of the homeless population, people are staying in emergency shelters for shorter periods of time, reflecting persistent patterns of transiency despite the increase in the number of sheltered homeless people. The 2011 Homeless Count revealed the most frequently cited reasons for homelessness are low income (58%) and high rents (54%). Of the sheltered and unsheltered homeless people surveyed, 98% said they
would prefer housing to homelessness. These respondents represent the worst-off of the many residents of ‘the most liveable city’ for whom accessible, affordable housing remains an elusive dream.

4.2. Political context

The challenges described above exist within the broader economic and political context. The Federal, Provincial and Municipal governments have played an ongoing role in the production and perpetuation of these issues through policy decisions made in the context of shifting macro-economic trends affecting the Canadian economy at various points in time.

4.2.1. Housing policy - Federal government

At the root of the aforementioned housing and related social challenges is Canada’s particular approach, and underlying philosophy, to the supply, allocation and maintenance of the nation’s housing stock. The Federal government is primarily responsible for the creation and maintenance of this approach through housing policy decisions (306).

Canada’s housing system is founded on government legislation in the realm of: banking and mortgage lending practices, tax and regulatory measures affecting building materials, professional practices, subsidy programs and incentive patterns for average households. The Federal government has mainly been involved in supporting home ownership, a reflection of what Hulchanski argues is a two-tiered housing system which discriminates against renters and privileges home owners (306). Through the establishment and enforcement of housing legislation, the Federal government has been largely responsible for the financing, development and allocation of Canada’s housing stock, including a significant stock of social housing. In 1963, the Federal government initiated a subsidized rental housing program requiring joint provincial funding and in 1986 responsibility for the provision of not-for profit housing was transferred to the provinces. In BC alone, from 1986 to 1992, between 1,000-1,300 new social housing units were added annually, not including co-op units and special needs housing (307). In 1993, the Federal government halted funding for the National Affordable Housing
Program. In 1996, responsibility for the administration of federal social housing programs was shifted to the provincial and territorial level, with some provinces further devolving power to municipal governments. Most provinces, other than BC and Quebec, were unable to continue building social housing in the absence of the federal program. The federal government continued to support housing cooperatives through contractual agreement in the form of preferential mortgages, operating subsidies and assistance to low-income households with their rent. However, most of these agreements are ending over the next 20 years, posing major concerns for people with a low or fixed income who rely on this support to subsidize their rent (308).

In the years following withdrawal of support for social housing, the Federal government has provided funding for housing-related programming in different capacities. In 1998, the Canadian Mortgage and Housing Corporation (CMHC) provided funding to improve Canada’s housing stock, with a particular focus on improving housing for people who were homeless or at risk of homelessness (309). CMHC has maintained a trimmed down version of the Residential Rehabilitation Assistance Program to assist with the repair of substandard housing (310). In 2001, the Affordable Housing Framework Agreement was signed by the Federal government, Provinces and Territories, committing $680 million over five years to increase the supply of affordable housing in partnership with provinces and territories (311). In 2007, the Homelessness Partnering Strategy was launched, awarding funding to organizations that work towards preventing and reducing homelessness. The Federal government has committed $119 million per year from March 2014 until March 2019 to continue running this program under Employment and Social Development Canada (312).

In 2007, the Canadian Mental Health Commission funded a five-year $110 million homelessness-focused research initiative, of which 15% of funding went to research and 85% went towards service provision, including housing. The At Home/Chez Soi project was conducted across five Canadian cities - Moncton, Montreal, Toronto, Winnipeg and Vancouver. A full discussion of the methodology (313), preliminary findings (314) and controversy surrounding this research initiative is beyond the scope of this dissertation.

A forthcoming PhD thesis by SFU Faculty of Health Sciences PhD student Christopher van Veen promises an excellent critical analysis of the project.
A short summary of the Vancouver study is provided here, only insomuch as it has had a direct bearing on the housing landscape in Vancouver and conveys the ideological stance of the federal government on housing.

At the Vancouver site, the research focused specifically on homelessness and addictions. Briefly, individuals with concurrent mental health and addictions issues were assigned to one of four research arms. Two arms tested the ‘dispersed housing’ model, in which participants were provided access to scattered-site housing with support from either the Assertive Community Treatment (ACT) team (for participants with complex needs) or the Intensive Case Management (ICM) team (for participants with moderate needs). A third arm tested the ‘congregate site’ model, in which high-needs participants were housed at a single site at the Bosman Hotel, where they were provided access to on-site mental health and addictions services (315). A fourth group of people were randomized into an arm labeled ‘Treatment as Usual,’ (TAU) meaning that they remained in whatever housing situation they were in and “continued to receive the services regularly available in their city” (316, p2).

The federal government committed to funding the housing and services for the duration of the ‘At Home/Chez Soi’ project plus one transition year, with provincial governments providing the supports. As the initiative drew to a close in April 2013, pockets of funding were allotted to continue the research component, with Vancouver Coastal Health Authority (VCHA) and BC Housing funding one year of follow-up of all study participants, and the Mental Health Commission of Canada funding a second follow-up in April 2014. However, the housing and other services can no longer be provided at the same level. With the withdrawal of federal funding, the Vancouver site has managed to keep the ACT team functioning with a limited number of rent subsidies provided by BC Housing. The services provided by the ICM team are closed; for those who are still housed there is a continuation of subsidies, also provided by BC Housing. There is ongoing work led by VCHA and BC Housing to transition people from the congregate “to other community services,” (317) which essentially means that the participants in this arm will join the TAU arm in receiving no benefit from their involvement in this study.
In short, since 1993, the federal government has distanced itself from the social housing agenda, save the intermittent funding injections described above. The support which has been provided, such as briefly funding an experiment testing the benefits of housing, signals a paradigm shift towards viewing housing as a form of treatment for health issues, rather than a fundamental human right. These piecemeal measures fall short of what is needed: a national housing strategy. The housing crisis observed in Vancouver, and across communities in Canada, is a legacy of the retreat of senior governments from their historical role of providing capital and operational funding to create affordable housing. The shortage of affordable housing, triggered by the abrupt demise of the National Affordable Housing Program and downloading of the social housing agenda to the provincial level in the early 90’s, is noted as one of the most important factors in explaining the housing crises observed across Canada (318).

4.2.2. Housing policy - BC Provincial government

As the Federal government slowly retreated from its traditional role of providing social housing, the province’s role grew. In 1992, the Provincial Commission on Housing Options was established with the aim of exploring new ways to meet the housing needs of British Columbians in the context of declining federal commitment and limited provincial and municipal resources (307). The HOMES British Columbia initiative was officially launched in 1994 with the intention of increasing BC’s stock of affordable housing for vulnerable populations. The initiative developed and supported: not-for-profit and co-operative housing; supportive housing for seniors; and support for people who have been homeless, or who are at risk of homelessness, to help them transition into stable housing.

HOMES British Columbia is one of many initiatives coordinated by the British Columbia Housing Management Commission (BC Housing), the crown corporation mandated to fulfill the provincial government’s commitment to the development, management and administration of subsidized housing. Established in 1967 under the Ministry of Lands, Parks and Housing Act, BC Housing works with the Ministry Responsible for Housing to “address critical gaps across the housing continuum, ranging from emergency shelter to rent assistance in the private market and affordable home ownership” (319, p5). Working in conjunction with the private and not-for-profit sectors,
provincial health authorities and ministries, private partners, community groups, the federal government and municipal governments, BC Housing provides rent subsidies, operating funds, and financing options to BC residents. Programming targets populations who are homeless or at risk of homelessness: seniors, people with disabilities, Aboriginal people and families, women and children at risk of violence, and low-income seniors and families. BC Housing currently works with approximately 800 housing providers serving over 98,000 households in 200 communities through subsidized housing (320).

The province’s housing strategy, Housing Matters BC, was launched in 2006 to help British Columbians in greatest need of safe, affordable housing. Two policies form the basis of the strategy: i) Individuals or households with special housing needs will be given priority access to subsidized housing and ii) Provincially-owned subsidized housing will be renovated to better meet the needs of low-income households with special needs, such as seniors with enhanced accessibility requirements. Older, obsolete buildings built on under-utilized land will be redeveloped over time to serve more households in need of housing assistance (321). In 2007, in alignment with this strategy, the Province directed BC Housing to purchase and lease 27 Single Room Occupancy hotels (SROs), 24 of which are located in Vancouver, in order to preserve them for social housing. However, the upgrades failed to completely improve the living conditions in the dilapidated hotels and, in October 2011, BC Housing launched the SRO Renewal Initiative to restore 13 of the 24 hotels (322).

Over the years, CMHC has granted greater responsibility to BC Housing, and the two levels of government have worked together to develop a number of initiatives and programs. In December 2001, the Canada-British Columbia Affordable Housing agreement, the first bilateral agreement between the Province of BC and the Federal government, was signed. From this agreement, 3,900 housing units were created under the Provincial Housing Program, the Independent Living BC Program and the Community Partnership Initiatives program. In December 2004 the agreement was renewed, bolstered with a $42 million dollar commitment from both the Federal and BC provincial governments to support the Provincial Homelessness Initiative. In 2006, the federal government signed an agreement transferring the administration of 51,600 social housing units to the province of BC. Six years later, the agreement was amended to
include the Rental Assistance Program. In April 2009, the Extension to the Canada-BC Affordable Housing Initiative was signed, with a financial commitment from both levels of government for the Provincial Homelessness Initiative, Senior Rental Housing Initiative and the Housing Renovation Partnership. In July 2011, both the province and the federal government announced they would commit $90 million each over three years to help create affordable housing options in BC under the Affordable Housing funding agreement. The largest component of the agreement is the Federal-Provincial Housing initiative, announced in March 2013. It represents a $155 million Federal-Provincial commitment to affordable housing in BC, with the support of municipalities and community partners through various means (323).

Despite these policy developments, there is growing concern that the nature of the province’s response does not address the fundamental causes of housing instability in Vancouver. Critics suggest that policies implemented at the provincial level have contributed to the erosion of affordable housing over the years. To begin with, Vancouver suffers from a lack of supply of housing in the private rental sector. A report from TD Canada found that, “the overall supply of rental housing in Canada has stagnated in recent years, and has actually been receding at the lower end of the rent range - the segment of the market where lower-income individuals with affordability problems are concentrated” (300, p ii). The introduction of the BC Strata Titles ACT in 1966 stimulating condominium developments, coupled with the withdrawal of federal tax incentives in the 1970s that made rental properties less attractive for investors, resulted in limited development of purpose-built rental housing. Consequently, Vancouver’s rental housing stock is primarily comprised of apartment buildings constructed between the 1950s and the 1970s, which are at risk of demolition and/or conversion into condominiums (232, 300). Indeed, approximately 21% of the market-rental stock is at risk of being redeveloped into condominiums in the next decade (324). Low supply keeps vacancy rates low and rents high, which impacts people at all income levels. In addition to impacting affordability, a shortage in rental units may lead to over-crowding of dwellings and poor maintenance of buildings, impacting suitability and adequacy (324). Thus, by all three of CMHC’s standards, Vancouver’s housing stock is failing to make the grade.
Compounding the lack of rental stock is the diminishing supply of social housing for low-income people. In 2002, the Provincial Liberals cancelled the provincial housing program, causing the number of social housing units to plummet to 85 units per year between 2001 and 2007, from an average of 664 units per year between 1982 and 1993 (325). Klein and colleagues point out that the province’s focus on SRO renewal, assisted living, supportive housing, increasing emergency shelter beds and providing rent assistance equates to the end of government-funded social housing provision. Funding has gone towards provision of supportive housing for homeless people with addictions and/or mental health disorders or assisted living for seniors, all at the expense of basic social housing for people with low incomes. Existing social housing stock is also being retrofitted and converted into supportive housing units. Thus, in addition to the fact that there has been limited investment in developing new social housing, the new supportive housing units represent social housing units that were converted into more intensive ‘housing plus’ units (326). These changes signal a troubling paradigm shift towards viewing housing as a health issue, rather than as a fundamental human right to which all citizens are entitled.

The provincial government’s rental assistance programs for people who are low income have also fallen under criticism for being too passive and inaccessible, having eligibility requirements with thresholds that put this support out of the reach of many families in need. Another serious issue with rental assistance programs is that in a market with a low vacancy rate, as that seen in Vancouver, these programs can actually encourage rent increases when rent and income ceilings are not adjusted. These programs typically benefit landlords, as low income people use their subsidy to compete for a fixed supply of rental units. Unsubsidized households are also faced with increased competition with subsidized households. Thus, those who are not eligible for assistance, the ‘working poor,’ are adversely affected by rental assistance programs (300).

4.2.3. Housing policy - Municipal government

Municipalities increasingly play a prominent role in the housing sector. Although they have no jurisdiction over income support programs, Municipal governments help shape housing supply. The form and density of housing and residential districts is shaped by Municipalities through fiscal measures (direct funding using municipal assets,
provision of city land, and permit fee exemption); regulatory measures (community and area land use plans, inclusionary policies, density bonuses, zoning requirements); education and advocacy (raising community awareness of the need for affordable housing); and direct service provision (through partnership arrangements and corporations that support low income households) (327).

The Metro Vancouver Housing Corporation (MVHC) owns and operates over 50 affordable rental housing sites throughout the Lower Mainland (328). The goals of the MVHC, outlined in the Metro Vancouver Affordable Housing Strategy, are to: increase the supply and diversity of modest cost housing; to eliminate homelessness across the region; and to meet the needs of low income renters (329). This strategy represents the first time the region developed a framework to address housing affordability challenges at the municipal level.

Within this larger regional framework, the Vancouver City Council has worked to address housing affordability challenges and homelessness in the city. Most recently, the City of Vancouver put forth the 2012-2021 Housing & Homelessness Strategy with the goals of ending street homelessness by 2015 and increasing affordable housing choices for all Vancouverites (330). Much of the strategy is beyond the scope of this chapter, which will focus on policies addressing the segment of the housing continuum encompassing shelters, SROs and supportive housing (Figure 2), as well as some of the criticisms these policies have drawn.

**Shelters**

In order to accomplish the goal of ending street homelessness by 2015, the City of Vancouver, in partnership with the Province and the Streetohome Foundation, introduced the Homeless Emergency Action Team (HEAT) initiative in 2009. The controversial initiative included the opening of five low-barrier shelters, offering relaxed rules regarding pets, possessions and intoxication. The number of homeless people has been stable over the past three years, with a 72% increase in the number of sheltered homeless people since 2005, a change largely attributed to the HEAT shelter initiative (305). However, shelter operators and housing advocates remain wary of “warehousing” the homeless, as it lessens the sense of urgency to find stable, appropriate housing for people (232, 326).
Figure 2: The City of Vancouver’s Housing Continuum (330, p7)
**Single Room Occupancy Hotels**

Protecting the SRO stock has been another major component of the City’s plan to end street homelessness. In partnership with BC Housing, the City funded a portion of the SRO renovations described in the previous section. In 2003, Council adopted the Single Room Accommodation (SRA) by-law. This requires developers to seek Council approval prior to conversion or demolition of any SRA, which includes most SROs. Under the by-law, conversion permits cost developers a fee, which goes towards supporting social housing initiatives. In 2007, Council adopted regulations requiring one-to-one replacement of SROs and rooming houses (331).

The SRO renovations have been met with waves of criticism, including claims of ‘renovictions’ - renovations undertaken for the purposes of evicting some tenants (332). In addition, the one-to-one ratio has recently been abandoned, and the SRA by-law revised, waiving the fees charged to developers. With these changes, the SROs are increasingly vulnerable to developers (333).

**Supportive Housing**

Increased importance has been placed on the supportive housing segment of the housing continuum, representing one of the priority actions of the City’s 2005 Homeless Action Plan. The Homeless Action Plan identified the need to develop 8,000 units of social housing from 2005 to 2015, with a development target of 3,800 supportive housing units. The City adopted the ‘Supportive Housing Strategy’ in 2007, fostering partnerships with the Vancouver Coastal Health Authority (VCHA) to better support people who are homeless and dealing with addictions and mental health issues. A mental health and addictions supported housing framework, developed by the VCHA, exemplifies the City’s shifted approach from housing people with mental health disorders in heavily staffed residential facilities to providing supportive housing (334). Much of the City’s progress described in the Homeless Action Plan update describes advances in supportive and transitional housing. Less progress has been made, however, in producing independent affordable housing (335).

The 2005 plan also targeted the root causes of homelessness, calling for reduced barriers to accessing welfare for homeless people, creating jobs for homeless
people and increasing mental health and addictions services. To facilitate access to income assistance, the City and the Ministry of Employment and Income Assistance launched the Vancouver Homeless Outreach Pilot Project in 2005. The project entailed the tenant assistant program coordinator and volunteers identifying people who wanted to be on income assistance and obtain housing but needed support, and the Ministry removing any barriers that impeded this process. In 2006, the pilot project was taken over by BC Housing and expanded to the provincial Homeless Outreach Program. The Homeless Action Plan also recommended increasing the BC Income Assistance amount; the province responded by increasing the Support and Shelter Allowance rate, marking the last time the welfare rates have increased to date. In response to the need for improved service delivery in mental health and addictions, VCHA formed a partnership with not-for-profit organizations to form the Clinical Housing Team in order to provide integrated primary care and mental health and addictions treatment to clients living in specific SROs (335).

In 2007, the City of Vancouver and the Province agreed to expedite 1,500 new units of social and supportive housing on 14 city-owned sites with funding for the construction provided by the Province. Upon completion, the buildings would be leased to not-for-profit housing providers for 60 years at nominal pre-paid rents and would be exempt from paying property taxes. Priority for these units would be given to people who are homeless, both living on the street and in shelters (331).

The proposed supportive housing sites have been the subject of criticism over the past six years. The sites were to be opened by the end of 2013; at the time of writing this dissertation, seven sites have been completed. Moreover, the City’s recently-released draft plan for the Downtown Eastside promised 800 units of social housing in this area in the next decade. However, these much-needed units do not represent new social housing, but are instead part of these 14 sites which have been deferred since 2007 (333).

Despite periodic injection of funding towards affordable housing initiatives from all levels of government, rising living costs, coupled with the general decay of existing affordable housing stocks in cities and communities all across Canada, led the United Nations expert on adequate housing to dub the situation in Canada a ‘national
emergency’ (14). In the face of criticism and urgent calls to action on this issue, Canada remains the only industrialized country without a national housing strategy. In the absence of a coordinated response, an array of fragmented responses to homelessness and housing instability have sprung up in provinces and municipalities across Canada. However, these responses fluctuate with changing economic and market conditions, and are thus unsustainable.

4.3. Macro-economic trends

Fluctuations in the economic and market conditions have largely been due to globalization in its many manifestations. High rates of in-migration to Canada’s urban centres has driven housing costs up and kept vacancy rates low, particularly in Vancouver (336). Increased tourism, specifically around the World’s Fair, Expo ’86, impacted the supply of housing through the conversion of Single Room Occupancy and budget hotels into tourist or backpacker accommodation, dislocating low income residents (337). The 2010 Winter Olympic Games saw similar trends, with evictions of low-income single rental housing units and rental increases to provide accommodation to labourers and visitors. There was also evidence of building owners neglecting proper maintenance of hotels, leading the buildings to be condemned by the City and sold for redevelopment into market housing (338). One of the harshest displays of Olympic-related gentrification took the form of the ‘Assistance to Shelter Act’ passed by the Provincial government, giving police powers to forcibly remove homeless people from the streets and into shelters (339).

Perhaps the most significant impact is that made by the forces of economic globalization. Trade liberalization has increased pressure to harmonize social policy with economic policy. Deindustrialization, outsourcing, downsizing, automation and improved technology have led to a significant restructuring of Canada’s labour force, characterized by a decreased demand for manufacturing and administrative jobs and an increased demand for jobs in the service sector (340, 341). In BC specifically, there are fewer people employed in resource industries, which historically provided stable employment (342). As a consequence of these changes, a greater proportion of the labour force is engaged in part-time, low-paid, unskilled service jobs with greatly reduced benefits and
security. These changes in the economy have resulted in stagnant or declining household incomes, reduced purchasing power and an increasing number of Canadians relying on income support programs, employment insurance and pensions (340).

4.4. Social Context

4.4.1. Social policy - Federal government

As more and more Canadians were increasingly relying on federal social transfer payments, the federal government was cutting back on provincial transfers under a banner of deficit reduction and increasing Canada’s competitiveness in the context of economic globalization. In 1995, the Budget Implementation Act was introduced, allowing the Federal government to replace the Canada Assistance Plan (CAP) with the Canada Health and Social Transfer (CHST). The re-vamped program shifted from a system with matching federal funds to a block fund which was not targeted to social programs. As described in the forthcoming section, this change led to provincial cutbacks on social programming, including income support and social services. At the same time, there was a 25% cut in federal transfers for health, education and social welfare, dramatically reducing the pot of money available to provinces and municipalities to run these programs (343). In April 2004, the CHST was disaggregated to introduce two distinct transfer payment programs: the Canada Health Transfer, in support of health systems, and the Canada Social Transfer, which supports post-secondary education, social assistance and social services. The disaggregation has drawn attention to the fact that the social transfer amount is not meeting the needs of low-income people (344).

Another significant change in Federal social policy was the Employment Insurance Act of 1996, which introduced reforms to Canada’s Employment Insurance program, formerly the Unemployment Insurance program. The reforms built upon changes to the program introduced earlier in the decade, intended to address the federal deficit and the ‘disincentive to work’ caused by the Unemployment Insurance program. The reforms to the Employment Insurance program included reduced duration of benefits, lowered rates, and tightened entrance requirements (including the exclusion of people who voluntarily quit without just cause) (345). In BC, and all over Canada, these reforms have led to a decrease in the number of people eligible to apply for benefits and
reduced total benefit payments (346). The dismantling of the welfare state is a significant node in the causal chain explaining the housing crises observed all across Canada.

### 4.4.2. Social policy - BC Provincial government

The steady decline of Federal transfer payments over the past 20 years has impacted social programs and other provincial services all across Canada, but BC is infamous for implementing the deepest cuts in Canadian history (347, 348). Reforms to the Employment Insurance program in 1996, compounded by welfare cutbacks by the Provincial Liberals in 2002, made it harder to qualify for, and remain on, income support in BC (346, 349). The cutbacks reduced the number of people eligible for welfare and increased the amount of time people had to wait before receiving benefits. The stated intention of the cutbacks was to help get welfare recipients back to work. In reality, the cuts hurt the most vulnerable segments of society - lone parent households, low income seniors and people who were homeless (347, 348). One of the unintended consequences of increasing the wait time before qualifying for benefits was that some people who lost their jobs defaulted on rent and mortgage payments, and subsequently lost their housing as well (349).

The determinants and impacts of housing instability in Vancouver are further shaped by provincial social policies that do not account for regional differences in cost of living. Most significantly, the shelter allowance, which has remained at $375 for a single adult since 2007, does not adequately cover the cost of shelter in Vancouver, where the average one bedroom apartment rents for $918/month (11). Single Room Occupancy hotels, which represent a crucial segment of the city’s affordable housing stock, are also increasingly inaccessible to welfare recipients, as landlords seek out clientele who can pay higher rents to cover the cost of renovations of the decrepit buildings. The City of Vancouver estimates that privately owned SROs are charging an average of $416, and many rent rooms upwards of $500. In 2011, only 27% of SRO hotels rented rooms at the maximum shelter rate of $375, down from 67% in 2007 (350). This means that nearly three-quarters of Vancouver’s cheapest rental housing is beyond the grasp of welfare recipients. The Carnegie Community Action Project, a local advocacy initiative, estimates that another 437 SRO units, previously rented at the welfare rate, were recently put out of the reach of people on social assistance due to rent increases. This
equates to the loss of 2,000 units for welfare recipients over six years, representing almost one half of the total SRO stock (333). With welfare rates frozen since 2007, welfare recipients are faced with the choice of dipping into their living allowance of $235 to afford rent, leaving them unable to meet their other basic needs, or having to sleep outside. Either way, welfare recipients are made vulnerable by these policies (351).

4.5. Social issues

As BC’s social safety net was eroding, the need for it was dramatically escalating, particularly in the realms of mental health and addictions, which, in turn had a significant impact on housing stability. Without stable housing, people living with mental health and addictions issues, even when engaged in treatment, are prone to cycling through correctional facilities, emergency departments, shelters and SROs. Substance use and mental illness both have a destabilizing effect on people’s ability to acquire and maintain housing, and the likelihood of housing disruption is greater with people who are dual-diagnosed. In BC, there are an estimated 15,500 adults with severe addictions and/or mental health disorders who are homeless, and another 39,000 are inadequately housed (352).

4.5.1. Mental Health

BC’s challenges supporting people with mental health illness traces back to the downsizing of psychiatric hospitals that occurred across Canada in the 1960s and 70s, a step aimed at integrating people with mental illness into communities. As part of this trend, Riverview Hospital, BC’s only long-term psychiatric facility, discharged 4,000 patients between 1955 and 1990. The deinstitutionalization wave was sweeping across Canada, but much more rapidly in BC, where days of care provided to patients of psychiatric hospitals between 1985 and 1999 dropped by nearly 65%, in sharp contrast to a national decline of 40%, (353). BC’s faster rate of releasing psychiatric patients into the community was a reflection of a more significant political commitment to deinstitutionalization. However, this commitment was not consistently and adequately backed by funding for community-based health care supports for people released from Riverview into the community. There was a surge in demand for housing, without a
supply of housing with appropriate supports for people living with mental health illness or
addictions (349). There were incidents of people in acute psychiatric hospital beds who
were ready to be discharged, but unable to leave because they lacked suitable housing.
As discussed in the above section on the Municipal government’s housing policy, BC
has gradually shifted towards a ‘housing first’ approach, providing supportive housing for
people with mental health and addictions issues.

4.5.2. Addictions

A wealth of literature documents Vancouver’s history with addictions (349, 354),
and the factors that fuel them - childhood trauma, sexual abuse, mental health issues,
poverty, chronic illness and isolation (355, 356). It is a narrative that takes place
primarily in the Downtown Eastside, once the economic and cultural hub of Vancouver
before its decline to ‘the poorest postal code in Canada.’ Most accounts of Vancouver’s
drug history start in 1908 with the passing of the Opium Act, marking the beginning of
prohibition and the criminalization of drug use. This was followed by increasingly punitive
anti-drug legislation over the decades, particularly in the 1920’s. As the cultural and
economic hub of the city shifted westwards to Burrard and Robson in the 1960s, the
once-vibrant Downtown Eastside began its decline, at which time the drug of choice on
the streets of the neighbourhood was alcohol - beer, liquor and noxious substances like
Lysol. Vancouver’s infamous open-air drug market was first seen in the mid 1980’s,
when South American cocaine became more readily available, likely due to the influx of
people and money related to Expo ’86. Cocaine was followed by ‘China White,’ a new
grade of dangerously pure heroin that flooded the streets in the early 90’s. Rampant
injection drug use, crime, violence and overdose deaths drew attention to another
epidemic that was brewing on the streets of Vancouver in the 1990’s: HIV and AIDS.

4.5.3. Vancouver’s HIV epidemic

Epidemics of improperly treated mental health illness and addictions, set against
the backdrop of retreating provincial and federal support, lack of a provincial poverty
reduction strategy and lack of a provincial HIV/AIDS strategy pushed BC to have one of
the highest HIV prevalence rates in Canada. With 13,312 positive HIV test reports as of
December 2009, representing 19.6% of all positive tests in the country, BC has the third
highest prevalence of HIV among the provinces, following Ontario and Quebec (357). There were 301 new HIV cases identified in 2010, for a provincial incidence of 7.4 per 100,000 in 2010. BC’s epidemic continues to be concentrated among men who have sex with men, who make up 50% of HIV cases. People infected through heterosexual exposure make up 26% of infections, followed by people who use injection drugs, who make up 13% of new cases (358). Hepatitis C and HIV co-infection is a growing concern in this context as well (359).

The highest rates of new positive HIV tests in 2010 were in the Vancouver Health Service Delivery Area (VHSD), at 22.7 per 100,000. The VHSD is home to two neighbourhoods that have emerged as the epicentres of the province’s HIV epidemic. The Downtown Eastside (DTES) is an inner city neighbourhood characterized by an open drug scene, high levels of poverty and unemployment, lack of affordable housing, poorly maintained single room occupancy hotels and high rates of homelessness. These social conditions underlie the high rates of addictions, mental health disorders, violence, crime and sex work that are also prevalent in the DTES (360). The West End is a middle-class urban neighbourhood known for its high concentration of gay men (361). In the beginning of the epidemic, the West End had one of the highest AIDS mortality rates in Canada (362) and currently houses a number of HIV services (363).

**Housing and HIV in BC**

Housing stability and HIV and AIDS are intertwined in a vicious cycle in BC. Findings from the Longitudinal Investigations into Supportive and Ancillary Health Services (LISA) study suggest that 32% of people accessing antiretroviral therapy (ART) in BC are unstably housed and, of those, 83% live in, or frequent, the City of Vancouver (364). Unstable housing among PLHIV accessing ART in BC has been associated with suboptimal treatment, including lower adherence to medication and inferior treatment outcomes, such as poorer immune function and increased likelihood of rebound of plasma HIV-1 RNA viral load. As in other settings, PLHIV who are homeless or marginally-housed have higher rates of depressive symptoms, inferior contact with the healthcare system, including higher levels of emergency department use (30), and a greater likelihood of engaging in activities that increase their vulnerability and risk to HIV exposure (31).
Despite what is known about the relationship between housing stability and the health of PLHIV, there are limited housing services to meet the demands of this population. The BC Non-Profit Housing Association reports that there are fewer than 235 non-profit housing units dedicated to PLHIV, none of which are located outside of Greater Vancouver (365). While there are additional units across the province designated for people living with mental health issues or addictions, this relatively small number of HIV-dedicated units concentrated in one urban centre reflects the lack of an HIV-specific approach to the allocation of non-profit housing. Program entry guidelines, long wait lists, and the limited number of housing subsidies allocated specifically to PLHIV are a few of the limitations of current housing models. The Seek and Treat for Optimal Prevention of HIV/AIDS (STOP HIV/AIDS) project, implemented in Vancouver and Prince George, added a few HIV-specific units and subsidies to those available to PLHIV in Vancouver, but as of yet this project has done little to influence housing options for PLHIV across the province (137, 366, 367). The need for secure, adequate, accessible, affordable housing persists throughout BC’s HIV positive communities.

Amidst this dearth of resources, McLaren Housing Society of BC has been working to address this need since 1987. McLaren is one of two organizations in BC that is solely dedicated to providing secure, affordable housing and support services for individuals and families affected by HIV. Its mandate is to increase the opportunity for improved health, wellness, independent living and sense of community. McLaren works with families and individuals in BC living with HIV who have low or limited income, are inadequately housed or are at risk of homelessness and require additional resources to maintain suitable housing. McLaren provides housing options, including government subsidized housing, portable subsidies, supportive housing and community partnerships, catering its services to distinct sub-populations with diverse needs.

**Long-term survivors**

Since the advent of highly active antiretroviral therapy (HAART), there has been a substantial reduction in HIV-associated morbidity and mortality (368, 369). In resource-rich settings like Canada, the life expectancy of HIV-positive individuals on therapy now approaches that of uninfected individuals, (368, 370, 371) resulting in a greater number of older Canadians living with HIV (372). This demographic shift is reflected in McLaren’s membership: over 40% of clients have been positive for greater than 15 years and, of
those, approximately 30% have been positive for 20 to 25 years. The changing face of the HIV-affected population impacts the demands on AIDS Service organizations and housing providers. There is a growing need for support for the physiological and psychosocial issues associated with HIV and aging: the effects of being on treatment for many years, including long-term toxicities of organs and systems; other health conditions associated with aging, including dementia, menopause and mobility issues; and the effects and evolution of HIV on the body, such as chronic inflammation and accelerated aging. McLaren has seen a growing demand for seniors’ housing and support services for the aforementioned issues (373).

**Aboriginal people**

As of 2003, Aboriginal persons accounted for 13.4% of AIDS cases, despite comprising 3.8% of the Canadian population (374). Rising HIV rates among Aboriginal people are propelled by the on-going effects of discrimination, cultural disruption, and systemic poverty experienced by many Aboriginal peoples in Canada. Aboriginal women, in particular, are at the intersection of multiple vulnerabilities (375, 376), as reflected in the increase in the number of applications for McLaren’s housing subsidies from First Nations women (373).

**People living with mental health and addictions issues**

A wealth of studies describe how housing status interacts with a constellation of other factors that inhibit PLHIV’s ability to adhere to their medication regimen, including depression, psychological stress and substance use (21, 35, 194, 196-203). McLaren provides support tailored to clients, many of whom cope with these challenges (373).

**Families**

It has been well documented that HIV-positive parents experience heightened stress and anxiety, with attendant risks for poor health outcomes (220, 377). Housing providers such as McLaren have had to respond to the unique challenges faced by HIV-positive parents, as there has been a rise in families, often new immigrants who have escaped life-threatening situations, applying for housing. Some of these families, including young children, have witnessed violence and torture and, in addition to the usual supports needed to help new immigrants transition to life in Canada, require post-traumatic stress counselling (373).
People living in poverty

At the core of PLHIV’s negotiations around health-related decisions are financial challenges: income of PLHIV may be drained by the cost of healthcare or fixed due to the constraints of disability benefits and welfare; many face trade offs between paying rent and accessing nutritious food. Preliminary analysis of BC data from the national Food Security and HIV Study show that in a sample of 328 PLHIV across BC, food insecurity was associated with 5.9 increased odds of having difficulty meeting household expenses, and 2.8 increased likelihood of moving at least once in the last year (23).

In addition, HIV-related stigma, episodic illness and complications associated with aging with HIV threaten individuals’ employability (219, 378), which further undermines financial stability and, in turn, housing stability. Many McLaren residents managing their HIV through treatment and, though interested in working, lack resources and job experience. Once employed, they may face challenges communicating the need for workplace flexibility to their employers (373). There is a steady flow in the number of applications from people in temporary housing situations, such as shelters and SROs, reflecting the growing need for permanent, secure, stable housing – a need which cannot be met with temporary solutions.

4.6. A call to action

With their membership citing such concerns, PAN, representing over 50 HIV and AIDS service organizations throughout the province, identified housing as the most urgent unmet need of people living with HIV and AIDS in BC (24). At the federal level, the Canadian AIDS Society has demanded that “policymakers address the lack of adequate housing as a barrier to HIV prevention, treatment and care, and that governments fund and develop housing as a response to the HIV/AIDS pandemic” (254). On behalf of their diverse memberships across Canada and BC, these organizations have expressed an urgent call to action on this issue. Heeding this call, a team of researchers based at the Drug Treatment Program at the BC-CfE set out to investigate how physical and social environments impact the health of PLHIV.
Chapter 5.

Raising the roof: innovative approaches to investigating the impact of housing on the health of people living with HIV

Synopsis

The limited data available on the impact of housing instability on the health of people living with HIV (PLHIV) in Vancouver, BC has been largely generated without meaningful involvement of the community. This chapter outlines the process of launching and facilitating a community-driven research project aimed at developing an understanding of the housing-health nexus that is grounded in the experiences of PLHIV. This study used Photovoice methodology, a participatory action research tool that involves research participants gathering data in the form of photographs and analyzing that data through their experiences. Eight Community Researchers, people living with HIV who have experienced homelessness or unstable housing in Vancouver, were co-facilitators of this project. These eight individuals generated over 300 photographs and engaged in facilitated discussion which were transcribed and analyzed to identify emergent themes. Photos and accompanying narratives describing the living conditions in which PLHIV must negotiate health-related decisions are powerful tools for building a comprehensive, community-informed definition of healthy housing as viewed through the eyes of PLHIV.

5.1. Introduction

A growing body of evidence describes the powerful role of housing in shaping vulnerability to HIV infection and influencing the health trajectories of those already infected. To comprehensively understand the determinants and outcomes related to
experiences of housing instability in Vancouver, British Columbia (BC), one must acknowledge the physical, social and economic context of housing, specific to this area. Residents of Vancouver are situated within a unique context characterized by prohibitively high housing costs, low vacancy rates, an eroding rental housing stock (11), frozen welfare rates, a low minimum wage (12), high cost of food (13) and the highest poverty rate in the country (10). These challenges exist against the backdrop of one of the highest HIV prevalence rates in Canada (15). Despite the unique context, BC-based studies that have considered housing as an important determinant of health have used definitions of housing stability developed in other settings; these narrow conceptualizations of housing status may not capture the nuances and diversity in the realities of people living with HIV in Vancouver. This chapter outlines the process of launching and facilitating a community-driven research project aimed at developing an understanding of the housing-health nexus that is grounded in the experiences of PLHIV in this context, and leveraging this information to engage the wider community in a dialogue about housing and health.

5.2. Methods

5.2.1. Justification of method

I had identified a need to engage affected communities to better understand the dimensions of housing that are important to their sense of stability and well being. Photovoice emerged as an ideal research tool to achieve the stated research objectives for a number of reasons. The primary motive for utilizing Photovoice was to increase accessibility for communities who face barriers to participating in traditional research. Grounded in the concept of lay epidemiology, Photovoice draws upon community members’ expert knowledge of the physical and social conditions in which they live, and prioritizes their concerns to inform healthcare interventions (287). Photovoice destabilizes the authority of the researcher and recasts the study participant as the expert. As the conversation starts with the research participant taking a photo of an issue or object that they prioritize, they begin to set the research agenda and thus increase the likelihood of creating processes and outcomes that are of importance to the community.
By virtue of the chosen methodology I hoped to build upon and create expertise within affected communities to conduct their own research, which is one of the central tenets of CBR. A number of public health studies have successfully adapted this method for use with marginalized populations, many of which have documented the empowering effects of this method (255, 256, 275-277), suggesting that through the action of taking photographs and narrating the stories behind them, participants acquire a greater authority to advocate for social change in their communities. This project also provides tangible skills in basic photography.

The use of Photovoice is useful in bridging the gap between epidemiological and lay definitions of housing, as the sensory nature of the phenomena under study—physical and social environments—“necessitates the employment of a more sensually complete methodology” (379, p231). Visual methods provide insight into human conditions that language cannot reveal and are thought to be the most authentic representation of an individuals’ experience: “Photographic data are closest approximation to primary experience we can gather” (380, p171). Harper suggests that photos add validity and reliability to word-based surveys (381). In conducting a review of the literature, I discovered a number of studies that also elected to use Photovoice to work with homeless individuals in London, England (278, 279), Auckland, New Zealand (243) and Los Angeles, California (280).

Furthermore, Photovoice is a research method that is accessible to the general public. Photos lend themselves well to engaging people in dialogue about issues that they may not be familiar with – in this case the mechanisms and processes that produce varying rates of disability, disease and progression to mortality across different housing and neighbourhood contexts. For audiences who have had no exposure to the realities of homelessness or the conditions of Single Room Occupancy hotels, visual evidence was necessary to cultivate an understanding of the experiences of the Community Researchers. Pictures tell a story in a way that words alone cannot.

For all of these reasons, I recommended that we draw upon Photovoice methodology to undertake this project. With the methods identified, a project title was coined, “The way I see it: a photographic exploration of housing and health among people living with HIV in Vancouver, BC.” The title was derived from a quote by a
participant of the LISA study, which, as mentioned in Chapter 1, led to the conceptualization of this project.

**Participant eligibility/inclusion and exclusion criteria**

This study employed a mix of purposive and snowball sampling techniques to establish a sample of PLHIV who would represent the spectrum of housing experiences in Vancouver. The inclusion criteria for the study were being aged 19 years or older; having been on ART for any period of time since 1996; residing in the metro Vancouver area; demonstrating an interest in housing issues; and being willing to complete the project procedures and being able to provide informed consent.

Participants were recruited from the Longitudinal Investigations into Supportive and Ancillary health services (LISA) study, a closed prospective cohort of HIV-positive adults 19 or older in BC who initiated ART on or after January 1st 1996. The aim of the LISA study was to examine the experiences of harder-to-reach HIV-positive individuals who have accessed ART in BC.¹

Recruitment for the LISA cohort remained open until a sample size of 1000 was achieved. Of the 917 interviews with usable data, 82% reported postal codes in the metro Vancouver area. Housing stability was one of the components of the comprehensive interviewer-administered questionnaire. Study participants were asked about their reported place of residence and how long they had resided there. As in previous studies with similar populations, unstable housing was defined as living in a Single Room Occupancy (SRO) hotel, shelter, hostel, treatment centre, prison or having no fixed address at the time of interview (382). Stable housing was defined as living in an apartment or house that they either rented or owned. Based on these criteria, 32% of

¹ The LISA cohort has been previously described in detail (29). Participants were actively recruited through letters distributed by ART-prescribing physicians, invitation letters received when refilling their antiretroviral prescription at the pharmacy, by word of mouth, and through advertisements at HIV/AIDS clinics and AIDS service organizations throughout BC between July 2007 and January 2010. LISA participants are closely representative of the numbers of people on treatment by health authority in BC, meaning that the sample has representation from various parts of the province, similar in proportion to those accessing treatment. However, particular sub-populations were deliberately oversampled in order to sufficiently power sub-analyses. Consequently, women, people who inject drugs and people identifying as Aboriginal are overrepresented in the LISA cohort.
LISA study participants reported being unstably housed at the time of interview and, of those, 83% live in, or frequent, the metro Vancouver region (364).

**Study sample recruitment**

HIV and AIDS Service Organizations that were engaged in the LISA project were approached to form a steering committee for this study. The following sites were approached by virtue of their mandate to deliver HIV and AIDS-specific health and/or ancillary care, their interest in investigating housing as a determinant of health, as well as the unique needs of their respective memberships: the Dr. Peter AIDS Foundation (the organization responsible for funding and overseeing the operations of the Dr. Peter Centre), Positive Women’s Network, McLaren Housing Society of BC, the MAT program and Spectrum clinic. One staff member from each designated recruitment site volunteered to act as a Community Liaison for the project and to conduct targeted recruitment. I met with the Community Liaisons one-on-one to brief them on the goals of the project and the expectations for the participants in order to help determine which clients would be well suited to participate.

The guiding criteria for participant selection included cases that yielded maximum variation in the factors of interest. The Community Liaisons targeted recruitment to achieve variation in the study sample both in terms of participant’s current housing situations (e.g., long term stable, at risk, homeless) and history, as well as variation in terms of their experiences with support and housing services (whether specific to HIV, mental health, addictions or other) and their position on the housing spectrum, both past and present. The Community Liaisons also sought out extreme (particularly good or bad experiences) cases. Without attempting to achieve full representation across all possible experience types, we were cognizant of recruiting so that we achieve diversity in terms of age, sex, sexual orientation and Aboriginal ancestry. We hoped this spectrum provided the richest data for analysis as it would highlight most strongly the experiences of PLHIV in Vancouver.

With this guiding criteria in mind, Community Liaisons approached prospective participants based on their intimate knowledge of clients’ readiness to contribute to, and likelihood to benefit from, involvement in such a study. Using the inclusion criteria outlined above, each Community Liaison distributed five invitations to prospective
participants at their recruitment site. The same method was applied at each recruitment site with the exception of Spectrum clinic, our only clinical recruitment site. The liaison for Spectrum opted to place a poster in the clinic waiting room as opposed to distributing study invitations due to the heavy workload of the physicians.

A group of seven to ten participants is the suggested ideal size for Photovoice projects (261). I was contacted by ten prospective participants who I screened over a period of four weeks. Screening involved taking the person’s full name and birth date to verify they met the inclusion criteria for LISA. Community Liaisons were also contacted to ensure that each participant had access to a qualified support worker. Following this, I met with each prospective participant individually to carefully explain the project goals and expectations. I took this opportunity to draw attention to the possibility of the project triggering difficult memories and feelings, and asked whether they had someone to turn to for support. Prospective participants were given time to reflect and consider whether they would be interested and able to participate; in practice every person who I screened demonstrated interest immediately. When it was determined that everybody was eligible, interested and adequately supported, it was decided enrolment targets had been met and I asked Community Liaisons to cease recruitment efforts.

**Demographic characteristics**

Three individuals were recruited from the Dr. Peter Centre; three from Positive Women’s Network; and one from McLaren Housing. The final three participants were recruited by three of the individuals who already enrolled in the project, bringing our membership to ten. None of the participants were specifically recruited through the MAT program; however, one participant is a former MAT client. The team recruited for this project was comprised of four men, one of whom had children and, four women, three of whom had children. Five members of the group identified as Aboriginal, two identified as white/Caucasian and one group member identified as Black/Caribbean. The median age at time of project launch was 54. All of the participants identified as having experienced homelessness at least once and currently residing in the metro Vancouver region. All of the participants resided in the downtown core, with the exception of one person who lived in the suburb of Surrey and another who lived in South Vancouver.
Sample size justification

As our partner sites serve distinct sub-populations, recruiting within these strata yielded a diverse group. Participants recruited from these sites bring unique perspectives based on their experiences accessing different models of supportive housing in Vancouver. The sampling strategy is known as statistically non-representative stratified sampling, a technique in which participants are selected based on demographic characteristics important to the theory, yielding a group that is statistically non-representative but “informationally representative” (383). This method will not yield a random, representative sample of PLHIV in Vancouver, however a non-random sample of respondents is appropriate when the intent of the research is to understand the lived experience of a group. Selecting participants with the expectation of their particular experiences informing a theory and has been successfully used in previous studies employing Photovoice methodology (257).

This approach does not promise generalizability in the classical sense in which the findings from a sample can be extrapolated to be representative of a population. The details of one individual’s experience cannot be generalized to an entire group since single members of a group are poor representatives of whole populations (384). In addition, one participant may ‘represent’ multiple sub-groups; even within sub-groups there is immense heterogeneity in terms of housing needs. For instance, the type of support required by a person with a history of addiction depends on a range of factors: whether the person is actively addicted; whether they require assistance with harm reduction or abstinence; whether they have appropriate social supports to adhere to a particular addiction management program; whether they are coping with additional co-morbidities that require the support of health and social support workers. Individuals labelled ‘Injection Drug User’ have diverse, complex and competing needs that are dynamic over the life course.

Many qualitative researchers are sceptical of the concept of generalization because it strips away context, which results in research findings that lack meaning and utility (385). The study design is capable of generating meaningful findings that are applicable in broader contexts if ‘generalizability’ is re-conceptualized. The concepts of ‘fittingness’ (386) and ‘comparability and translatability’ (387) are more aligned with the goals of qualitative inquiry than is ‘generalizability.’ Fittingness refers to the degree to
which the case studied matches or ‘fits’ cases in other contexts. Comparability emphasizes thorough description of all study components, including units of analysis, concepts generated, population characteristics and settings. Transferability requires a coherent description of study procedures and theoretical underpinnings, such that study findings can be used as a basis for comparison. Also integral to ‘maximizing the fit’ between cases studied and cases to which one wishes to generalize is selecting a research site that is ‘typical’ (388). In collaboration with the AIDS Service Organizations and housing providers who facilitated participant recruitment, I aimed to select participants whose demographics and housing situation represent the ‘typical’ case. Schofield warns that appropriate site selection will not ensure generalizability because a case that is typical in one sense might not be typical in another. Community Researchers know best whether, and in what regard, their situations are typical. To assess the typicality of participants’ experiences I planned to use techniques such as member checking and peer debriefing, described below.

**Design and Procedure**

After participants were selected, I scheduled an orientation with each participant one-on-one to thoroughly explain study aims, criteria and procedures, as well as review the confidentiality form in detail. When the participant had a good understanding of expectations and procedures they were asked to sign the consent form. A printed copy of the consent form was made available for the participant to keep, including contact information for the Principal Applicant and Principal Knowledge User and the UBC and SFU Research Ethics Boards.

Over a period of ten weeks participants were invited to participate in a series of workshops co-facilitated by three members of the study team: A staff member at the Dr. Peter Centre, a peer support worker from the Dr. Peter Centre and myself. There is no precise number of workshops prescribed by authors of previous studies using Photovoice (255-274), thus the number and duration of the sessions were based on consultations with partner organizations that had experience facilitating similar activities. While we originally intended to meet over a period of six three-hour sessions, the group came to a consensus to meet more frequently to support one another through the process. We thus began to meet on a weekly basis, with sessions typically lasting one to two hours. The sessions took place in the basement of the head office of McLaren
Housing Society, one of our community partners. At each session, participants were offered lunch, two bus tickets, $30 in compensation for their time, personalized thank you cards and reimbursement for childcare expenses if necessary. After completion of data collection and analysis, additional funding was acquired and at the time of writing this dissertation, members of the group continue to meet periodically to discuss next steps. The meetings are now of a more informal nature, taking place at local coffee shops. Each session begins with a “check-in,” wherein everyone is given an opportunity to share an update. I take minutes that are distributed at the subsequent meeting, along with a brief agenda.

At the outset of the project, participants worked with facilitators to describe their role in the context of this project. The participants and co-facilitators coined the term ‘Community Researcher’ – a person living with HIV who has experienced unstable housing and is passionate about housing and health. The group discussed the importance of practicing self-care and demonstrating consideration of fellow group members. A set of guidelines was developed collaboratively with the aim of ensuring the safety and comfort of all group members. The group composed a list of goals to guide the project, and discussed their hopes and concerns about using Photovoice. Notably, participants expressed concern about walking around alone and taking photographs. It was decided we would meet more frequently to check in with one another and, in the event that somebody felt unsafe, another group member would accompany that person.

I independently designed the format of the first few group sessions, which included introductions and a self-reflection activity where participants visually depicted their definition of health, and the relationship between their health and the wider environment. ‘Health’ was defined individually and then collectively when the group members shared their self-reflections. The group conceptualized ‘health’ in a holistic sense and incorporated physical, emotional, mental, spiritual and cultural well-being in their definition. The group discussed the issues of importance to them that they hoped to highlight through this work. Reflecting on Shaw’s conceptual model of the direct and indirect ways housing affects health (389), participants were prompted to consider the various dimensions of housing and how their environment helps or hinders their ability to take care of their health. Participants were encouraged to think about both the direct and indirect impacts of their physical and social environments on their health.
Following the introductory sessions, the group was joined by Marlis Funk, a professional photographer who conducted a basic photography seminar. In addition, the Community Researchers became familiar with consent forms and the ethical boundaries of photography (258), in particular how to balance protection and intrusion when using the consent forms. At the conclusion of the session, Community Researchers were each given a disposable Kodak camera and invited to take photos over the course of two weeks that convey how environment impacts health. The process was adapted to the needs of participants in order to ensure their comfort and safety and capture their perspectives. A few members requested additional time and additional cameras. Thus pictures were taken over a period of four weeks in total. Arrangements were made to collect the cameras to develop the photos before the debrief session. Between June and August 2011, the Community Researchers collectively took over 300 photographs, all of which were recorded digitally but were not viewed by the facilitators until the Community Researchers were given printed copies to review. Participants had absolute control over which photos they shared in the sessions, which were discarded, and which were discussed privately with the facilitators.

5.3. Participatory Thematic Analysis

I endeavoured to apply a community-based approach to the analysis of the data obtained through this project, with components similar to other studies that used a participatory group process to analyze qualitative data (390), and being mindful of limitations of this approach (391). The Community Researchers and I collaboratively engaged in inductive and deductive thematic analysis during group and one-one sessions, revisiting the data and revising emergent themes over the course of 24 months, from August 2011 to August 2013. It should be noted that although the participatory data analysis was an iterative and reflexive process (Figure 3), for the sake of clarity, the various phases of the analysis are described as a linear, step-by-step procedure here.
Figure 3: Participatory data analysis process
5.3.1. Phase 1: Generating data through photo interviews

After an initial discussion about the experience of taking photographs in their communities, the Community Researchers reviewed their photos individually and were asked to select up to six pictures that represented their most important concerns or priorities. Community Researchers reflected on photo content using an adaptation of the SHOWED model (Figure 4).

I was mindful of the limitations of this approach in some settings (265) and was prepared with open-ended questions and a debrief activity to engage group members in facilitated discussion. The Community Researchers were provided with the option of graphically displaying their images to the group by creating an outline of a tree and mapping their photos onto the tree diagram to illustrate the relationships between the images. An example is shown in Figure 5.

The ‘fruits’ of the tree were meant to show visible phenomenon (i.e. people sleeping on the street); the ‘branches’ were meant to show the intermediary cause (i.e. inadequate shelter allowance) and the ‘roots’ of the tree were meant to show the underlying causes of what is observed on the surface (i.e. ideological underpinnings of public policy addressing the causes of, and solutions to, systemic poverty). The activity was intended to help the Community Researchers see beyond their own experience and make connections to broader socio-economic and political forces in which their realities are grounded.

After taking time to graphically display the relationships between the images and the meaning of their display as a whole, the Community Researchers shared their tree diagrams and a brief explanation with fellow group members. This first session provided group members with the opportunity to ask one another questions and provide feedback; derive preliminary captions and titles; and observe commonalities and discrepancies between their experiences.
What do you see here?
What is really happening here?
How does this relate to our lives?
Why does this concern, situation, strength exist?
How can we become empowered through our new understanding?
What can we do?

Figure 4: Guiding questions to facilitate photo elicitation (392).
Figure 5: Example debrief activity, depicting the underlying causes of homelessness and housing instability.
In the week following this group session, each Community Researcher met with me one-on-one to further discuss their experience and explain why they had chosen each particular photo. I initially assumed that the Community Researchers would be more comfortable with the presence of the peer support worker during these sessions, as she shared their experience of living with HIV and being formerly homeless. After conducting two sessions collaboratively, however, we realized that this was not the case. When given the option, the Community Researchers preferred to debrief with me in private. We adapted our approach and carried out the remainder of the ‘one-on-one sessions’ with only the individual Community Researcher and me. A review of the existing literature on housing, health and HIV informed the development of a semi-structured interview guide. However, in practice, the conversations were primarily led by the Community Researchers, with me asking questions to clarify and expand upon explanations of photo selection.

The group and one-on-one photo reflections were audio-recorded and transcribed with the written permission of each group member. I also recorded field notes and reflections on emergent themes following each session. Transcriptions and an edited version of the field notes were verified by the Community Researchers, who either read or had their transcript and associated field notes read back to them at a later time. The Community Researchers were also asked to write a title, caption or short commentary on their selected photos. The titles emerged in a number of ways over the course of the project: individual reflection during or between sessions, suggestions from the group, transcript review, and through assistance from me.

5.3.2. Phase 2: Coding, condensing and analyzing data

Following the photo interview phase, a great deal of data had been generated including: the diagrams conceptualizing health, the photo tree diagrams, the interview transcripts, captions/titles and my field notes. At this time, I condensed the study material into a format that would be manageable for the group to analyze together, heretofore known as the ‘draft data summary.’ I employed the ‘ocular scan method’ suggested by Bernard (393), reading and reviewing the transcript data a number of times, employing an open coding method for analysis. This involved looking for common themes that pertained to the study aims and grouping these themes into categories of
interest, which were then broken down further into sub-categories containing relevant attributes. Interviews and field notes were coded first for demographic variables and according to Community Researchers’ self-described housing situation at the time of the interview, and their housing history. Data were then coded a second time for content in search of identifying broad categories, for example social dynamics within living situations. The third level of analysis further refined categories and emerging themes. I then transferred the blocks of highlighted text onto a separate document, taking care to omit any personal identifiers.

5.3.3. Phase 3: Draft data summary review and collaborative analysis

A ‘reunion’ meeting was organized to review the draft data summary with the Community Researchers for their critical consideration (394). Prior to presenting the draft data summary to the group, the photos and captions were posted around the meeting room for everyone to review. The Community Researchers worked independently and then in small groups to generate an initial list of salient themes based on their review. Notes from this group review were later compared to the themes I generated independently.

I took notes as the Community Researchers’ talked through these two activities. The Community Researchers’ insights and feedback were incorporated into the summary as we moved to higher levels of consequent analysis allowing for a mutual negotiation of meaning (395). In cases of difference in opinion and experience we endeavoured to come to a group consensus. By reviewing interpretations with the entire group, descriptive and interpretive validity were checked, and the Community Researchers’ perspectives informed how the data were constructed and presented. I thus hoped to avoid imposing perspectives that were not consistent with the Community Researchers’ experiences.

5.3.4. Phase 4: Reviewing and revisiting themes

I once again reviewed the raw data, as well as the list of themes and other feedback from the Community Researchers generated during the reunion meeting. The draft data summary was revised to highlight themes that overlapped between my
reflections (the “outsider” perspective) and those of the Community Researchers (the “insider” perspective).

The processes described in phases 3 and 4 were iterative, with the Community Researchers and I collaboratively interpreting findings and developing and revising technical analytic draft themes. Analysis continued until we develop a synthesized account of Community Researchers’ experiences. The goal of this process was to move analytically between the data and theory so that there was a relationship of reciprocity between the data, Community Researchers’ perspectives and the emerging theoretical perspectives. In doing so, we hoped to take the data to a higher level of conceptualization to generate broader theoretical constructs or propositions.

5.3.5. Phase 5: Community consultation

Recognizing that the experiences of the Community Researchers’ were not generalizable to the entire HIV positive community in Vancouver, we sought to confirm our findings through some of our knowledge translation and exchange initiatives. The group explored emergent themes with community members by organizing two community outreach events: the first for Homelessness Action Week at Jacob’s Well, a Community Organization attached to a Single Room Occupancy Hotel, and the second for World AIDS Day at the Dr. Peter Centre. These events are described in further detail in Chapter 9. Through this process we reviewed themes to confirm accuracy, make modifications and identify additional emergent themes. Community members’ perspectives were documented and incorporated into the final results.

5.3.6. Phase 6: Member checking and final approval

The revised data summary was reviewed by the group for member checking and further editing over a series of meetings. Community Researchers also took this time to identify relevant photos that corresponded with the themes, and finalize titles for each theme. Themes were examined for theoretical constructs that may have been related to the data. The result was a summary that was presented to the Community Researchers for final approval.
5.4. Outcomes

In order to accommodate various degrees of interest in, and comfort with, sharing findings and experiences with the project, several options were made available to conclude participation in this study or transition to further work. As described above, ten participants were originally recruited for this project, although one individual did not attend any of the sessions. Nine members of the group provided written consent for use of their photos and narratives in the thematic analysis and knowledge translation and exchange materials, although we considered one person’s consent withdrawn when he experienced irreconcilable challenges working with the group. Thus the analysis is based on the photos and narratives of the eight individuals who participated in the entire project and whose consent was considered valid. After the conclusion of the analysis phase, two additional members of the group formally opted to conclude participation in the project because of health or personal reasons. Whether or not they were able to be present, all of the group members wanted their work included in photo exhibits and promotional material (websites, blogs etc.). For any displays, I negotiated with photographers individually regarding how the photos were credited, with the option of using pseudonyms. None of the Community Researchers opted to use pseudonyms. All of the participants wrote or were assisted in writing a short biography to display alongside their photos and captions at photo exhibits and on the project website. Chapter 9 describes the knowledge translation initiatives that the Community Researchers engaged in, including community outreach events, photo exhibits and academic conferences. The Community Researchers have been co-authors on all presentations of preliminary results at conferences, and in many cases members of the group have been the first/presenting author. I also hope to invite the Community Researchers’ contributions as authors on papers published based on this work.

Through the process of participatory thematic analysis, the Community Researchers and I identified key conceptual categories that were organized into two domains: the detrimental impact of inadequate housing on physical and mental health and resiliency promoted by healthy environments. A discussion of these findings are presented in Chapters 6 and 7. One of the main intended outcomes of this project was to use the findings to develop a community-informed understanding of the impact of
housing instability on the health of PLHIV in this context. This is presented in the form of a conceptual framework outlined in Chapter 8.

5.5. Discussion

There are a number of strengths to applying photo-based methods to investigating housing issues. We found Photovoice to be a dynamic and adaptable medium that allows for rapid knowledge exchange with diverse audiences. Notably, within a few months of taking photos and analyzing transcripts, the team was positioned to host their first photo exhibit. In addition, the nature of the medium is inclusive. Through the photos and narratives our team managed to engage with researchers, healthcare and social service providers, regional and provincial decision makers in the health and housing sectors, members of affected communities, as well as the general public. We also endeavoured to cultivate an accessible culture surrounding our project, reflected in our low barrier KTE events and outreach materials. By doing so we were able to reach out to PLHIV and members of marginalized groups who are often excluded from engagement with traditional KTE activities (i.e. academic conferences) because of literacy barriers or stigma and discrimination, both perceived and overt.

While there is a growing recognition of the validity of arts-based research methods to engage with marginalized populations, there are limitations to employing Photovoice as a research tool. Because social change is one of the goals of this method, there is perhaps a heightened sense of frustration of behalf of participants, facilitators and community partners when efforts do not translate into immediate results. I found that an important part of managing expectations was reminding the Community Researchers that their advocacy and hard work, while incredible, was one part of a larger socio-economic and political system. Thus, gradual change, or even no change at all, was not to be seen as a failure. In addition, I endeavoured to build and sustain capacity of the people involved in this study, and the communities to which they belong. I found that outlining manageable personal goals at the outset of the project and revisiting them periodically helped the group map their progress on a personal level.

There is a dearth of evidence supporting the scientific merit of arts-based tools to elicit important information, and reviews from two unsuccessful grant submissions
confirmed that there still exists a perception of lack of rigour with Photovoice specifically. When the project was finally funded the grant application had incorporated a follow-up study, which employed a quantitative survey instrument. The survey component likely legitimized the Photovoice component and led to the study being awarded a CIHR CBR catalyst grant. We have strived to demonstrate rigour in our methods with hopes of contributing to the growing body of literature that speaks to the benefits of arts-based methods.

Several cycles of revisions from two Research Ethics Boards, particularly SFU’s, unearthed concerns around the application of photo-based methods with vulnerable populations. That these concerns were unfounded points towards an opportunity to caution REBs against taking an overly-paternalistic approach to evaluating the risks of study involvement. With a growing trend towards formalized community based/engaged/driven research, the research community would benefit from revisiting the role of REBs in policing prospective study participants’ engagement in, what can often be, an enlightening and emancipatory experience. Indeed, contrary to the concerns of the REBs, our experience has illustrated the potential of arts-based methods to meaningfully engage our communities in research. Our diverse team has collaborated to write funding applications, develop workshop outlines, organize community engagement events and present at conferences. “Through this project the we have gained recognition of our ability to enact change, as well as a sense of accountability to our peers,” said one Community Researcher preparing an abstract for a conference. Indeed, this study adds to the growing body of evidence that research methods such as Photovoice work towards bridging inequities that are inherent within dominant health research paradigms.
Chapter 6.

“Living like this can’t be healthy¹”: Housing instability and its impact on health

Synopsis

It is well established that inadequate living environments are associated with poor health outcomes. However, the way housing inadequacy has been conceptualized has not often been grounded in the perspectives of individuals and communities affected by HIV. This is the first of two chapters presenting a selection of themes collaboratively identified in a participatory thematic analysis of photos and narratives of Community Researchers who are living with HIV and have experienced homelessness. Following an explanation of the organization of the main findings, this chapter describes and compares the conditions of Single Room Occupancy hotels and shelters, as well as accounts of sleeping on the street. The chapter also explains the detrimental impact of these environments on the physical and mental health of the Community Researchers. This interpretation suggests that it is not the absence of shelter that Community Researchers link to poor health. Instead, it is the physical and social environments of marginal housing, namely SROs and shelters, which are considered to have the most adverse affect on health. The issues of greatest concern to this group – food security, stigma, untreated mental health illness – transcend housing type.

¹ Jenny speaking about Single Room Occupancy hotels
6.1. Organization of main findings

Despite all that is known about the relationship between housing stability and the health of PLHIV, important limitations persist in how we conceptualize and respond to this issue. This CBR project, co-facilitated by eight people living with HIV and having a history of homelessness, worked towards filling this gap. The Community Researchers generated and analyzed photos of their dwellings and neighbourhoods, as well as accompanying narratives, to inform a community-grounded understanding of the relationship between housing and health of PLHIV. The group engaged in participatory thematic analysis, described in detail in Section 5.3. Briefly, the Community Researchers and I engaged in inductive and deductive thematic analysis of the data, which included the diagrams conceptualizing health, the photo tree diagrams, the interview transcripts, captions/titles and my field notes. This information was condensed into a draft data summary that we reviewed to generate themes. We revisited the data and revised emergent themes, and verified them through member checking and community consultation - an iterative, collaborate effort that spanned two years.

A great deal of data was generated as part of this project, and each time the data was reviewed, new information would emerge and become part of the project's growing database. After careful review of the data that amassed over the course of this project, I have selected key themes to present here which continually re-emerged in discussions and/or directly related to the study objectives. The data are organized in a sequence that is meant to offer a logical progression from describing problems (Chapter 6), to identifying positive policies/programs/issues (Chapter 7), to situating these issues in a wider socioeconomic and political context (Chapter 8) and, finally, offering policy and programming recommendations (Chapter 9). This representation of the findings was approved by the Community Researchers. As noted in the previous chapter, options were given to use pseudonyms but none of the Community Researchers wished to be anonymized. Thus the accounts presented here use the true names of the members of the research team.

Chapter 6 works toward achieving our first study objective, which was to examine the impact of housing instability on self perceived health status, well being and quality of life amongst the Community Researchers. This chapter describes the conditions of
Single Room Occupancy hotels and shelters, as well as aspects of sleeping on the street. Woven within these descriptions are Community Researchers’ reflections on how these conditions and environments impact their physical and mental health.

Chapter 7 relates to our second study objective, to explore what constitutes a healthy living environment for people living with HIV in Vancouver, BC. Specifically, this chapter describes how healthy spaces promote resiliency for the Community Researchers, particularly those offered by low-barrier AIDS Service Organizations. The chapter concludes by suggesting a need to cultivate transitional spaces and opportunities for individuals who are post-street to live, socialize, heal and rebuild.

In Chapter 8 we situate the Community Researchers’ experiences within the wider socioeconomic and political context in the form of a conceptual framework. This framework responds to our third and final objective, to identify specific mechanisms and processes through which housing influences the ability of PLHIV to manage their health.

Because of the open-ended nature of the group and one-on-one discussions, and because people’s narratives about housing spill over into topics and issues outside of housing, important themes emerged that did not directly relate to the study objectives. These themes are included in Chapter 9 in the form of policy and programming recommendations.

6.2. Being without a home: a continuum

When asked about times in their life when they have felt unstably housed, the Community Researchers’ accounts refer to three situations: living in Single Room Occupancy hotels, staying in shelters and sleeping on the streets. These environments are described and compared in the following sections in order to map out Community Researchers’ perceptions of housing instability on health. In doing so, we will work towards achieving our first study objective, which is to examine the impact of housing instability on self perceived health status, well being and quality of life amongst the Community Researchers.
6.2.1. Single Room Occupancy Hotels

Community Researchers identified a number of health issues they dealt with that they linked back to their substandard housing conditions. Lora, who worked in the hotel she lived in, proudly proclaimed many times, “I have horseshoes up my butt,” having bounced back from CD4 cell counts as low as 40. She feels that whatever illness she deals with now is linked to the stress caused by the living and working conditions of her hotel. The health impact of SROs was a major theme that reverberated through the group discussions.

The history of Vancouver’s SROs has been previously described in detail (349). The buildings, some of which are 100 years old, served as rooming houses in the early 1900’s, providing short-term accommodation to migrant and seasonal labourers. The rooms average 100 square feet in size and include a sink and sometimes a hotplate. Residents share toilets and shower facilities. Today SROs have become the only housing option for many people with low or fixed incomes (396). With their low barriers to tenancy, Vancouver’s 7,100 Single Occupancy Hotel rooms are “often the only alternative to homelessness” (397, p1413). Navigating the substandard conditions of SROs was a ubiquitous experience among the Community Researchers. The following descriptive analysis highlights the concerns with the physical and social environment of SROs that the Community Researchers had stayed in.

Physical environment

Infestation

Infestation was the most prevalent material concern for occupants of Single Room Occupancy hotels. All of the Community Researchers described ongoing issues with mice, rats, cockroaches and bed bugs in hotels they currently or formerly inhabited. Even for those members of the group who were not currently dealing with infestation, memories of past experience caused them to tread cautiously. Randy described his frustration trying to exterminate bedbugs in his hotel:

Well, you know that there’s bugs there. You don’t see them, but they’re there. You’ll wash your damn bed, you can do whatever you want. You can spray it, you can powder it, you can do whatever you want, but they’re still there. You know, when I leave from there, I’m taking nothing with me, because…everything is infested. Everything’s infected with
bugs. You know, everything that's in those places. You get them in your—
they get into everything. It's a slum.

Randy's account conveys how the stresses of infestation are drawn out over time, as people feel compelled, or are required, to dispose of furniture and any belongings that were compromised by bed bugs. This is particularly disconcerting for people who are low income, as the cost incurred in replacing these items may be a source of further stress and anxiety.

In addition to the discomfort and inconvenience brought on by bed bugs, many of the Community Researchers spoke of the health impacts of bug infestations. Both Lora and Lynda had suffered badly from bug bites. Between bites and lack of sleep Lynda described herself as “traumatized” by her experience explaining, “it’s a pain - it’s depressing, you know…it plays with your mind. You know you’re not going to get any sleep when you’ve got a place with these.” Lynda’s experience captures the direct health impacts of infestation (i.e. bug bites and lack of sleep), and hints at the indirect health impacts. Sleep deprivation may, in turn, exacerbate existing physiological and mental health issues.

The presence of mice and rats was another major cause for concern. Valerie recollected moving into a hotel after being homeless and, rather than feeling relief at the idea of settling in, she remained transient in some ways, having to keep her belongings packed up because of the mice in her hotel:

I was still living out of bins because – you know, Rubbermaid bins – because the mice would, you know, I went in the closet and the mice had actually climbed up in between two shirts and actually made a nest and had babies, plus had eaten all my clothing to make a nest. It was disgusting.

Dealing with the droppings left behind by mice was a major focus of Randy’s collection of photos, one of which is depicted in Figure 6. Here Randy describes a picture he took of what it looks like underneath his sink:

Well, I mean, I clean it. Like, I sweep that out once a week. And then a week later, there it is again. Same thing. Hey, how many mice is in the walls? There must be hundreds of them, because they keep eating that rat poison. And they just—they eat it up. Don’t ever see them again. And
then—but you fill that mouse hole again with more rat poison, and it’s gone again. So, what? Are they super mice?

The constant presence of rodents and bugs, and the energy-intensive and time-consuming process of extermination appeared to be a universal struggle in the SROs. In addition to the inconvenience they posed, and the threat to residents’ physical health, the infestations held meaning in the narratives of the Community Researchers. The bugs, rodents and cockroaches in SROs were a powerful symbol of the perceived worth of the people who are forced to dwell alongside them. The passive acceptance that some members of society live in such conditions indicates that the general public views SRO residents as lesser people. Randy would often talk about his hotel as the best he could do, or a lot that he deserved, conveying the ways in which these spaces lead residents to accept these narratives, contributing to low self worth.
Figure 6: Under my sink live some mice. And if you pull the stuffing you can say, “hi.” How nice! - Randy
Absence of basic necessities

Another characteristic of SROs was the absence of basic necessities. There are often no cooking facilities in the rooms save a basic hot plate, and no fridges to store fresh food - major barriers to eating nutritious meals. Valerie resorted to hanging bread from the sprinklers, which worked for a short while until mice eventually began ripping at the packaging and eating the food she had hung up. The lack of basic infrastructure to facilitate consuming healthy and nutritious foods is particularly troubling in the context of constrained economic circumstances. Once rent is paid, people who are on income assistance are often left with a meagre amount of money to purchase other basic necessities such as food. In this context, the lack of basic infrastructure to store and cook food is a major risk factor for food insecurity.

In addition to basic necessities that are absent in SROs, all of the Community Researchers generated list upon list of items in need of repair in these spaces - walls, ceilings, floors, windows, roofs, pipes, light switches, smoke detectors, heaters. Researchers reported that repair requests go unanswered for months at a time. Residents were caught between the futility of lodging complaints and the at-times unfathomable hope of moving into a safe, well-kept space with properly functioning utilities.

Poor sanitation

Poor conditions of sanitation facilities were another major concern cited by Community Researchers. The shared facilities often do not have sufficient capacity to service the traffic flow in the buildings. Showing a photo of the bathroom in her hotel, depicted in Figure 7, Lora talks about how the residents are frequently asked to walk over to a neighbouring Community Centre in order to shower:

This is one of the washrooms. We have six toilets, two showers, two baths for 70 people, and that's just one of them. And a lot of times when they’re not working we’re told to go to the Gathering Place or whatever [to shower].
Figure 7: The bathroom shared by 70 residents - Lora.
As alluded to in Lora’s account, the bathroom facilities in hotels are often in need of repair. Valerie recalled shower door locks and showerheads being stolen from the bathrooms in her SRO. At one point a shower door was unhinged and stolen, which she reported to a representative from BC Housing:

one shower for 93 suites, 93 rooms, and then when they finally got all the rest [of the showers] put in – instead of taking one out and replacing it, they took every one out and there’s only one per floor – and the door was gone. And they said, ‘Well hang a shower curtain, that’s safe enough.’ And I said, ‘Would you shower like that?’ to [the representative from] from BC Housing and she said, ‘No, of course not.’ Then why do I have to?

Valerie’s experience speaks to the ways in which these spaces overtly violate tenants’ rights to basic privacy and safety. Gender, sexual identity and other innumerable components of identity and vulnerability converge to expose each tenant to a unique level of risk of physical, emotional or verbal assault. Valerie appealed to the representative from BC Housing, expecting she might empathize as a woman, who presumably would feel unsafe showering in these conditions. The woman’s privileged position as a white middle-upper class employee of a crown corporation placed her in a social location that put Valerie’s plight out of the realm of possibility. Although she was implicated in Valerie’s account of why the hotel repairs were neglected, the BC Housing representative could not fathom showering in a public, co-ed bathroom with only the safety of a plastic shower curtain.

In some cases, these unsanitary bathrooms serve as multi-purpose washing facilities, as described by Valerie, who was forced to wash her dishes in the bathroom, depicted in Figure 8:

to wash your dishes in a sink where they dump the mop water, where people urinated in it, plus the urinal right beside it was disgusting. The toilets were never cleaned, the showers were disgusting, if the shower head was still there when you got there that day, because they would steal that. So at times I wished I was still in the field because it was so much cleaner.

Unsanitary conditions impacted Community Researchers’ sense of self worth and, by extension, their mental health and well being.
Figure 8: This is where I had to wash my hands and dishes - Valerie.
Social environment

The social environment of Single Room Occupancy hotels appeared to weigh as heavily as the physical conditions in our group discussions. Everyone agreed that the SROs they had lived in provide little sense of security. The Community Researchers listed a number of issues, including the constant fear of eviction, threat of violence, disruptive neighbours and doors without proper locks, leading to frequent break-ins.

Hotel staff

“Crooked managers” of private hotels played a key role in Community Researchers’ narratives. Many members of the team spoke of hotel managers and staff who had access to the rooms and would rifle through their belongings and even steal from residents. The Community Researchers explained that fear of “inside job” thefts encourages some residents to remain in their rooms to guard their possessions, even though this equates to staying isolated in spaces that have adverse affects on their mental and physical health. In these ways the staff and managers contribute to the culture of mistrust in some SROs.

Managers of private hotels were also blamed for allowing their buildings to fall into disrepair. However, it was noted that managers’ disregard for their buildings is sanctioned by the Ministry of Social Development. The Community Researchers were referring to an optional Ministry program that facilitates rental payments on behalf of income assistance recipients. Through this program, the Ministry pays the shelter allowance portion of the income assistance cheque directly to landlords. The purpose of the program is to ensure housing stability for people at high risk of defaulting on rent payments (398). The direct payment of rent to landlords can be requested by the income assistance recipient or by the landlord.

In making a case for their Intersectionality-Based Policy Analysis Framework, Hankivsky and colleagues call for an interrogation of public policy, including the way it is revealed “through texts, practices, symbols and discourse” (399) as cited in (47, p9). An intersectional analysis of this policy implies that some welfare recipients are not capable of paying their rent and, if given the opportunity, would squander their money on drugs. The policy is implemented blindly without any recognition of the perverse incentive structures it promotes. As Jenny asserts: “you cannot just be dishing out money to them
[landlords] every month and not inspect any of these places. Landlords get the cheques right from [the] Ministry. The group agreed that this policy is a major disincentive for managers to comply with safety regulations and respond to complaints. The fact that private hotels are falling into disrepair was traced back to this program, which appears to favour landlords over tenants rather than the stated purpose of ensuring housing stability for people at risk of homelessness. It was agreed that this program was an important point of intervention in the pursuit of improving the conditions of privately run hotels.

**Housing the 'hard to house'**

Poor conditions of some of the hotels, described above, breed a sense of indifference towards the environment, causing some people to neglect or even further abuse the space. Chronicling the life of a friend who lives in a Downtown Eastside SRO, Jenny says of her photos, “…if your building looks like this, again, that’s another reason why you don’t want to clean up because the building is crap anyways.” Many members of the group echoed these sentiments and further suggested that neglect and abuse of these places is exacerbated by the increasing number of people moving into hotels directly off of the streets. The group felt that people in this situation often lack basic life skills in the realms of personal hygiene, domestic responsibilities and social etiquette in a communal living environment.

The issue most commonly brought up in discussion was hoarding, the compulsion to collect and unwillingness to discard large quantities of objects that appear to have little use or value (400). Risks associated with hoarding, including fire, infestation and sanitation-related issues impact the individual and their neighbours. Tweaking, a symptom of methamphetamine use, was another problematic behaviour mentioned by one of the Community Researchers. Tweaking is a side effect associated with long-term use of crystal methamphetamine, characterized by irritability and psychosis (401). Lora showed pictures of one manifestation of tweaking - a fellow hotel resident in a fit of paranoia compulsively chipping away at his floor, creating a hole that eventually went through her ceiling.

The group cited issues such as hoarding, tweaking and open drug use with the increasing emphasis on housing the 'hard to house.' Dan explained:
And then gradually, because of the homeless issue, a lot of people with mental issues were moving into the building. The building started to run into disrepair. A lot of stuff was happening, and it sort of took away a lot of that hopefulness.

Three group members who perceived themselves as stably housed at the time of the project launch no longer feel stable at the time of finalizing our analyses. One Community Researcher has moved and the other two hope to move because their hotels are becoming increasingly chaotic with people moving in directly from the streets without adequate support. The Community Researchers were experiencing the ramifications of the City of Vancouver’s goal to eliminate street homelessness by 2015. Under this platform, City policy has focused on housing the 'hard to house' by increasing the number of low barrier beds, sometimes at the expense of beds for individuals who are not perceived of as 'at risk of homelessness.' The Community Researchers described how people are being “picked off the streets” and being put into hotels, sometimes after years of living outside. There was a sentiment that some of these individuals are ill equipped and unprepared to live in a communal living environment. The Community Researchers’ accounts echo Skeggs’ work on ‘respectability,’ which involves behaving properly and distancing oneself from groups who are perceived as less respectable (402), as well as Bourdieu’s concept of ‘distinction,’ the tendency to look down upon the behaviour of people who occupy a lower social location (403). From their perspective as ‘good tenants’ the chaos in their buildings was not a result of misguided policy, but instead it was the ‘bad tenants’ who were to blame.

For individuals who were trying to abstain from drug use or were in recovery of any sort, addictions relapse was always a looming threat in these environments, as Dan experienced when he moved into a downtown SRO:

…the housing was atrocious. Everybody was on welfare. Everybody was a drug addict in that building. Before you know it I’m—I’d lost it, and I got involved in drugs and I became addicted and ended up trying to get into treatment.

Dan’s narrative supports previous studies that have found that being immersed in an environment where people are actively using drugs poses serious problems for individuals who seek to cease or decrease substance use (111, 112).
Hotel policies

Posing solutions to this sense of insecurity was a contentious issue. On the one hand, there were feelings of resentment around the paternalistic rules that govern SROs. For example, in many hotels there are no guests permitted on the premises after a certain hour and clients must present identification at the front desk. Some members of the group felt offended at the heightened level of surveillance in their hotels.

each one of them [SROs] has rules, like, ‘We're adult’s man, why can't I have visitors after 11 o’clock at night? Why can’t my visitors come in before 10?’ I mean they even turned my son away one time because it was before 9 o’clock in the morning and he was having a diabetic low and he wanted, he needed to come in. And they wouldn't let him in and I didn’t have a phone at the time and I am still pissed at that. I am an adult I mean, you know, you’re telling me I can’t have an overnight guest? What am I supposed to do have sex at 10 o’clock in the morning?

On the other hand, Lora, who worked at a downtown hotel felt that these measures were necessary to protect people’s security. She gave an example of a situation in which a drug dealer was using a guest’s room to sell drugs to hotel patrons. The rules of the hotel allowed her to deny entry to the dealer, thereby ensuring the security of the other hotel patrons. The group did not come to a consensus on the ideal balance between protecting the autonomy and confidentiality of hotel patrons, and ensuring their safety and security. As discussed in Chapter 9, this tension could be relieved by drug policy that promotes harm reduction rather than punitive measures to manage drug sale and consumption. Because drug use is driven under ground, hotel owners and managers are forced to react by imposing rules that violate the basic rights of tenants. Lora’s story underscores the ways in which public policy outside of the realm of housing policy indirectly impacts the health and safety of tenants.

6.2.2. Alternatives to SROs: shelters and outdoor sleeping

Community Researchers expressed disappointment and disgust as they described the hotels they had lived in, Lora likening it to the “conditions in third world countries.” The conditions of the hotels were uninhabitable for two Community Researchers who spoke of instances in which they had a room at a SRO but opted to sleep in a shelter. Other members of the group had heard of similar stories of people
utilizing SROs as a storage space for their belongings but sleeping in shelters to avoid the chaos of the hotel. Everyone acknowledged that this was a wasteful use of resources but this practice was an unfortunate necessity given the conditions of some of the hotels.

Shelters provided refuge from the chaotic SRO culture for some. However, as Jenny describes here, sleeping in homeless shelters invites other concerns:

it’s [homeless shelter] not safe, let’s put it that way. Because you’re sleeping with strangers, with people off the streets. Whereas if you’re on the streets, you find a nice little place by yourself, you know, and you don’t have to sleep beside somebody that you don’t know.

Interestingly, although homelessness is generally characterized as a situation in which one dwells in public spaces, Jenny pointed out that sleeping on the streets provides an opportunity to find privacy, which is impossible in the context of a homeless shelter.

In addition to the relative privacy afforded by sleeping on the street, the Community Researchers listed a host of reasons why living on the street was, in many respects, preferable to living in a SRO. The foremost reason was the unsanitary conditions of SROs, as explained here by Valerie:

I was very grateful for a roof over my head and at times being dry in there because the roof did leak and the pipes did burst – but there was times when I wanted to be back outside because it was just so filthy and degrading.

More specifically, infestation was less of a concern when people were sleeping outside, a major reason cited for preferring sleeping outside to staying in a hotel. Valerie continued:

When I was homeless how clean it was, we never had mice we never had rats, and other than getting wet and cold and lonely, it’s much better than living in shit dives like the Gastown Hotel.

Randy, who spent three and a half months homeless, said he slept better outside than in his hotel because of poor ventilation in the hotels, even considering that it was winter. When probed further he carried on:
It's a room. It's stuffy. It's—and I tell you this truthfully, I wake up every morning with my sinuses plugged up solid. Even with the window open. I don't get that outside. I wake up in the morning, I can breathe. That was one thing I liked about sleeping outside, is the fact that you could get a good sleep.

Lora also recalls the fresh air from the times she has camped outside. In contrast, the air of the hotel she and her partner live and work in has led to Lora’s partner being hospitalized for respiratory issues – she suspects from exposure to asbestos and mould.

### 6.2.3. Issues that transcend “housing status”

The City of Vancouver’s Housing Continuum, depicted in Figure 2, provides an organizational framework for understanding the diverse housing needs of citizens of Vancouver, as well as the housing options available to target their needs. In the “high needs” segment of the spectrum, the hierarchy of options are: shelters, SROs and supportive housing. With the ultimate aim of “ending homelessness,” sleeping on the street is obviously not reflected as an option on the continuum. As illustrated by the Community Researchers’ narratives in the previous section, moving along the housing continuum does not necessarily equate to improvements in perceived health and quality of life. People’s needs are more complex than what is assumed in this bricks and mortar solution. The Community Researchers cited barriers to their health that persisted whether they were sheltered or not. The following section describes some issues that transcended the materiality of the Community Researchers’ dwellings.

#### Health services access

There was a widespread recognition of how homelessness impedes access to healthcare and ancillary services. Said Rob:

> how can we access what we need, the meds, the housing, the blood tests, the doctors? We can’t when we’re homeless, we just don’t have the resources or we may not even know of the resources that are out there.

When Lynda became homeless, her health spiralled downwards, as she explains: “I lost a lot of weight. And I wasn’t taking my ARVs, and I ended up in the hospital with
pneumonia.” Accessing healthcare, including picking up and taking ART as scheduled, was simply not a priority for Lynda when she was homeless. The day-to-day challenges of survival - finding a place to sleep, securing food, staying safe - superseded all other concerns.

A number of programs and services have emerged to provide outreach to PLHIV who are living in precarious conditions and require adherence support. Valerie relied on such programs to stay on her meds while she was homeless. However, in Lynda’s experience, the efforts of the outreach workers did not make a difference: “sometimes I just avoided them [outreach workers] – I did. You know, I just didn't want to deal with them. I was in, like, total depression.”

**Mental health illness**

Mental health illness, and the need for support to manage it, was a cross cutting theme throughout all of the Community Researchers’ narratives. It is an issue that significantly impacts quality of life and other aspects of health, whether or not a person is sheltered. When asked about how living in his hotel has impacted his health, Randy immediately clarified that the most severe blow was to his mental health, not his physical health. When probed further he explained:

> It doesn’t do much for your self-esteem, it doesn’t do much for your, you know—you live in a room, often a bug-infested, mouse-infested room. What does that say about you? I don’t like it. I don’t like it, no, I don’t like it.

The adverse psychosocial effects of these environments were a major issue. Isolation and depression were common and were described as mutually reciprocal, with isolation causing depression and depression further encouraging isolation. Most Community Researchers felt they could not keep in touch with their families, particularly those who had children, because they did not want them to know what they were going through. Cutting themselves off from their social supports during what was already a challenging time further contributed to their declining health. Lynda explained that there was seasonal variation in the ebb and flow in her tendency to isolate.

> Lynda: when winter comes, here we go again – all the isolating, you know, kind of thing.
Surita: So in the winter you end up spending more time there [in the hotel]?

Lynda: Yeah, yeah you have to. You can’t be out in the rain.

**Food security**

The compounding effects of living with HIV, hunger and homelessness was a recurring theme whether dwelling in a SRO, shelter or on the streets. High cost of food in Vancouver (13) teamed with assistance rates that barely cover the cost of rent leaves people to face trade offs between paying rent and accessing nutritious food. The challenge of accessing food is substantially mitigated by the wide array of programs and services that offer free meals to low income people and people living with HIV, particularly in the Downtown Eastside. "There's always a food line somewhere," said Rob as he recounted being able to survive without a home for a short while in his youth. However, many Community Researchers took issue with the lack of nutritious, wholesome food offered by these programs, as depicted in Valerie’s photo entitled, "Hard to find" (Figure 9). Compounded by the absence of appropriate means of storing and cooking food described in the previous section, food insecurity is almost inevitable for members of this community.

In addition, the stigma associated with food line-ups, especially those designated for people living with HIV, posed a barrier for some people:

…to even get healthy food or even extra food we still have to wait in a lot of line-ups. And I mean this one especially – like, AIDS Vancouver is wonderful, you walk in the building, you go in – here you have to actually stand outside for half an hour and people ask you, ‘Why are you standing in line? What’s it for? How can I get in?’ you know. And if you just say, ‘It’s the food bank line,’ ‘Well can I join, come?’ and then you have to explain, ‘Well, you have to have HIV.’

In Valerie’s experience, accessing this particular food bank involved implicit disclosure of one’s HIV status. She carried on to talk about how accessing some services required forgoing one’s anonymity and dignity, which she perceived as unjust.
Figure 9: Hard to find - Valerie

The Downtown Eastside Right to Food Philosophy upholds the Human Right of Downtown Eastside residents to:

abundant, local, fresh and nutritious food that is available across the neighbourhood and delivered in a dignified manner.
Poverty and privilege

Valerie’s account speaks to the “simultaneity of discrimination and privilege,” which is revealed when an intersectoral lens is applied to understand the experiences of individuals who are multiply marginalized (233). Many of the Community Researchers shared similar stories, where their status as a person living with HIV afforded them privilege amidst experiencing oppression on the basis of gender, sexual identity, ethnicity, indigeneity and socio-economic status. Here, Dan describes the resentment of his peers when he received subsidized housing and additional rations from the food bank because of his HIV status:

when I had the housing, that a lot of the street people that I—would bug me all the time and I’d always give in and yeah, okay you can sleep on my couch and whatnot. And I would come back from even the AIDS food bank or something and they’d go, “Oh, you’re so lucky, you get this free food. You’re so lucky. You’re getting free housing. You’re getting subsidized housing.” Well, sorry, I mean—and I think some people, I’ve heard rumours that people even giving themselves HIV because they figure that those that are sick are getting such a wonderful deal, okay.

Dan’s narrative echoes a concept coined by Kantola and Nousiainen whereby “new laws, especially in Europe, are institutionalizing an interpretation of intersectionality as multiple forms of discrimination and thus encouraging an ‘oppression Olympics’ for scarce state resources” (404, p130). In BC, where the poverty rate is the highest in the country and being HIV seropositive makes you eligible for a higher level of benefits, the competition for resources is intense. This observation about the perverse incentive structures created by the disability benefit highlights how public policy that is blind to the politics of intersectionality can do more harm than good. As Crenshaw aptly points out:

Intersectional subordination need not be intentionally reproduced; in fact, it is frequently the consequence of the imposition of one burden that interacts with preexisting vulnerabilities to create yet another dimension of disempowerment” (405, p1249).

Dan’s story suggests the need to re-evaluate income assistance so that all low income people are properly supported without needing to resort to self-harm to meet eligibility criteria for disability assistance.
Stigma

There was a great deal of discussion about how alienating it is to live on the margins, specifically to be homeless. A pervasive theme in the photographs and narratives was that of members of the general public actively and systematically avoiding homeless people on the streets. Other than Lynda, who was determined to show only positive aspects of her situation, every Community Researcher referred to the invisibility of people who are homeless. Here Rob talks about a photo he took of a person begging on the streets while people walked around him (Figure 10):

Everybody is just looking in any other direction but his, so...again invisible, unseen. And we have a beautiful blanket wrapped around an elder who has to beg on the streets, again that person is unseen, hidden behind the cover of that blanket.

Valerie likened homelessness to the plague to explain the great lengths people once took to avoid homeless people on the street. Now she feels it is more common to see people stepping over and around individuals sitting or lying on the streets. Visible homelessness in Vancouver is not a new phenomenon. The visibility of Vancouver’s homeless is common news (406), a central issue during elections, and a source of embarrassment when the city is on the world stage (407). While this is not a new issue, the Community Researchers have sensed a growing complacency towards homelessness in the general public. The public’s response mirrors the public policy response, and both reflect our society’s dominant narrative about the type of problem homelessness is. Homelessness is not often spoken about as a social injustice and instead is depoliticized, cast as a health issue that can be remedied by increasing low-barrier shelter beds. An intersectional approach calls on an evaluation of these responses, “in terms of how different perspectives of problems are recognized as legitimate or ignored” (47, p12).
Figure 10: Invisible elder - Rob.
A related issue was the stigma attached to the places that the Community Researchers inhabited. Here, Valerie describes her experience of trying to find housing outside of the Downtown Eastside and feeling that she was discriminated against because she had previously lived in a DTES SRO.

The chain here represents—I tried to move out of the Downtown Eastside. And when I went to the scummiest area in Surrey, you know, which is really the Guildford area where all the projects are, and had great references and the guy that ran the building really liked us and everything. But, whoever the management company was as soon as they read that I was from the Downtown Eastside, I lived in an SRO, they didn’t even check my references, they wouldn’t—guaranteed they’d phone me back by Friday to let me know if I had an apartment or not…they wouldn’t even phone me and tell me and I left many messages. But, so this here to me represents we’re locked out of a lot of things, like, here we’re locked out of this beautiful little garden, we’re not allowed in there, they’ve got the biggest chain lock on it. But, we’re also locked into the Downtown Eastside, they won’t let us out, like as soon as they find out we’re here they don’t want us, which is really, that really hurt, that was really tough.

Valerie’s feeling of being simultaneously “locked out” of a better life and “locked into” the DTES is depicted in Figure 11. The group agreed with these sentiments. Lora added, “we’re just basically trapped in this and we can’t get out.”

Valerie’s experience of being discriminated against when she was seeking to move out of the DTES sharply illustrates how multiple forms of oppression converge to discriminate against individuals who are already subordinated by other factors. Her narrative echoes research on the rental housing market in Canada, showing that single, black women are especially challenged in finding apartments. The challenge is amplified for women on social assistance or who are single parents. An intersectional analysis reveals that being single, black and female cause this demographic to be discriminated against by landlords, who stereotype them as less dependable tenants (288). Valerie felt that her association with the DTES, rampant with crime and addictions, imbued her with all of the attendant stereotypes, casting her as a bad prospective tenant. It is a powerful example of the ways in which perceptions and social constructions create and perpetuate systems of exclusion.
Figure 11: Until every chain has been broken and every lock opened I am making a difference in the DTES and will till the day I die - Valerie
6.3. Discussion

This chapter sought to respond to our first study objective, which was to examine the impact of housing instability on self perceived health status, well being and quality of life amongst the Community Researchers. The Community Researchers, all living with HIV and having experienced living on the street and in Single Room Occupancy Hotels in Vancouver, described how unstable living conditions negatively impact one’s physiological and mental health.

One of the few housing options available to this group and the communities to which they belong are Single Room Occupancy hotels. With their low barriers to tenancy, SROs are “often the only alternative to homelessness” (397). The Canadian Mortgage and Housing Corporation defines below-standard housing as falling short in one of three categories: adequacy (good repair), suitability (suitable in size) and affordability (does not cost more than 30% of household’s gross annual income) (301, 302). Similarly, Dunn asserts that there are three dimensions of housing relevant to population health: 1) materiality, which refers to the physical and economic aspects; 2) meaningful, which refers to sense of control, self-identity and expression of social status; and 3) spatial, which includes systematic exposure to health hazards and proximity to health promoting or health-diminishing opportunities (282). Our findings suggest that by all of these measures, SROs are detrimental to the physiological and mental health of tenants.

The most obvious impact on health is in the realm of materiality. SROs are infamous for their unsanitary, unkempt conditions (408). In fact, it has been suggested that SRO residents represent the ‘relative homeless’ (409) by the United Nations’ definition because they lack consistent access to safe water, sanitation, affordable accommodation, security of tenure and safety (410). Corroborating this assertion, Community Researchers in this study described the deplorable conditions of SROs they live in or previously lived in, including: the absence of basic necessities; ongoing issues with infestation and inadequate sanitation facilities.

The group expressed frustration at the lack of recourse for managers to improve the conditions of their buildings, particularly in cases where the Ministry of Social
Development paid rent directly to landlords. The Ministry website and online reports make no mention of this option, which led us to call the Ministry to inquire about it. The representative with whom we spoke explained that the Ministry was solely responsible for providing landlords with the shelter allowance amount, either at the request of the income assistance recipient, or the landlord. When we mentioned the conditions of the hotels, the representative explained that the fact that buildings were in need of repair was not an issue within the Ministry’s jurisdiction.

That the Ministry of Social Development operated in a silo, intentionally distanced from the realities of marginalized citizens was seen as counterintuitive and unacceptable. There was a resounding call for government to overhaul policy and programming so that it no longer favours landlords and instead prioritizes the rights and welfare of tenants. Specifically, the Community Researchers called for the development of a system that holds SRO owners accountable to uphold basic standards of hotels; and for the introduction and strict reinforcement of legal mechanisms to protect the rights of SRO residents.

Echoing Dunn (282), Aidala and Sumartojo assert that the material qualities of safe spaces go beyond direct physical aspects and include economic considerations (115). SROs, which represent a crucial segment of the city’s affordable housing stock, are increasingly inaccessible to welfare recipients, as landlords seek out clientele who can pay higher rents to cover the cost of renovations of the decrepit buildings. The City of Vancouver estimates that privately owned SROs are charging an average of $416, and many rent rooms upwards of $500. In 2011, only 27% of SRO hotels rented rooms at the maximum shelter rate of $375, down from 67% in 2007 (350). This means that nearly three-quarters of Vancouver’s cheapest rental housing is beyond the grasp of welfare recipients. The Carnegie Community Action Project, a local advocacy initiative, estimates that another 437 SRO units, previously rented at the welfare rate, were recently put out of the reach of people on social assistance due to rent increases. This equates to the loss of 2,000 units for welfare recipients over six years, representing almost one half of the total SRO stock (333). With welfare rates frozen since 2007, welfare recipients are faced with the choice of dipping into their living allowance of $235 to afford rent, leaving them unable to meet their other basic needs, or having to sleep outside. Either way, welfare recipients are made vulnerable by these policies (351).
The social environment of SROs was also a major concern, impacting the meaningful dimensions of housing. The group described how SRO policies and managerial staff breed a culture of mistrust. In particular, Community Researchers were offended by the guest policies of many hotels, which alienated them from their family and friends. In a qualitative study with sex workers in the same setting, Lazarus and colleagues uncovered similar concerns and described the guest policies as an example of how the “‘liberalization’ of neo-liberalism is selectively applied, and the promise of increased freedoms is just as selectively delivered” (118, p1605). Building on previous work in this area (411, 412), the authors explain how the neoliberal government model simultaneously calls for minimal government intervention but, in the case of poor and marginalized citizens, individual freedoms are infringed upon and the level of government surveillance is heightened to levels that, “would be unthinkable in other socio-economic contexts” (118, p1605). Krusi and colleagues also highlight the “tensions between providing safe and secure housing, and the protection of residents’ privacy and confidentiality” in light of increased police presence and heightened security in the DTES due to growing attention towards women’s safety in the neighbourhood (413, p2). The women in this study had concerns similar to the Community Researchers regarding guest policies and ID checking. The study found that the threats to privacy for these women, marginalized HIV-positive sex workers, was particularly damaging. The findings pointed to the need for a continuum of housing options with multiple levels of support and the authors concluded that, “women living in poverty need to be included in discussions on the delivery of housing programs” (413, p6).

Also impacting the social environment of SROs are the tenants, particularly those who have moved into hotels directly off of the streets. Anecdotal evidence suggests that there is resistance on the part of some housing organizations to introduce the ‘hard to house’ into their residences under their current mandates. The organizations with whom we spoke, who we choose not to identify, felt that without adequate support, individuals living with mental health disorders and active addictions can pose a danger to themselves and others. These organizations did not feel they were properly consulted or adequately supported in the City’s plan to house these individuals. These concerns suggest that the push to eliminate street homelessness is targeting surface issues, such as creating low-barrier beds, without genuinely considering underlying causes of homelessness, or recognizing the ramifications felt by the rest of the community by the
City’s agenda. We were unable to retrieve documented empirical evidence of the dissonance between the city’s political agenda and the actual supports people receive once they are housed. This represents an important area of inquiry that should be further explored in future research.

According to Dunn’s framework, the final dimension of housing that impacts health is spatiality. Closely related to materiality, the spatial dimensions of housing refer to the segregation of socio-economic groups, which effectively prevents marginalized people from acquiring skills and knowledge that may improve their health (282). For example, concentrating SROs and other low-barrier services in the DTES facilitates access for people who are most in need, however, this placement also contributes to ghettoization. Dunn asserts that elements of spatiality, particularly proximity, influences “the formation of attitudes, identities and the internalization of disempowerment” (282, p28). Fast similarly speaks about the internalization of stigma associated with place and how “those experiencing marginalization internalize forces of exclusion, stigmatization and poverty, which are then understood and experienced as personal deficiencies or shortcomings” (414, p11). Robertson also found that women’s identities in the DTES were tied to their housing conditions and that neighbourhoods and homes carry stigma and meanings for the inhabitants (111). Community Researchers shared sentiments of feeling “trapped” in the DTES and described how the neighbourhood and all that it represented had become etched onto their identity. This internalization of stigma is exacerbated in instances where poverty is juxtaposed against extreme wealth and those who have housing are treated differently (415).

Public Health historically focused on the role of overcrowded, unsanitary conditions in the spread of infectious disease (416). More recently, the characteristics of inadequate housing, such as dampness/mould (417), pest infestation (418), fungal contamination (419) and poor temperature control (420) have been associated with heightened risk of chronic illness, particularly respiratory disease (421). Characteristics of substandard housing, such as crowding, have also been linked with mental health illness (422). With time our understanding of the relationship between housing and health has evolved, with a heightened recognition of the different aspects of housing that impact health, including the material, meaningful and spatial impacts. A growing body of literature looks beyond housing and explores the effect of neighbourhood context on
health and social well being, including perception of the quality and social cohesion of a neighbourhood, relative standard of living (225), civic engagement and collective self-efficacy (226). The Community Researchers’ narratives are aligned with the findings from a recent study that showed a prospective community sample of adults living in SROs in the DTES had high levels of co-occurring substance dependence, mental and neurological illness, infectious disease as well as high levels of mortality (397). In an 11-year follow up study of mortality among residents of shelters, rooming houses and hotels in Canada, it was found that people who are marginally housed have mortality rates similar to that of homeless populations (423).

In short, the findings of this analysis are not novel; they add to centuries of research describing the ways in which unhealthy environments produce and reproduce vulnerability. However, with most housing research focused on homeless populations, and with persistent challenges gaining access to SROs, the general health of people who are marginally housed remains relatively under-researched (424). Still, it is distressing that despite all that is known, members of our communities continue to live in substandard conditions known to contribute to disease. Taken together, these findings call for further action-oriented investigation into the health of marginally housed people.
Chapter 7.

Neither here nor there: the need for transitional spaces

Synopsis

Stable housing is associated with better physical and mental health outcomes, an assertion supported by a dense body of literature theorizing on housing and health. Less is known about the precise mechanisms and pathways connecting health and housing, as perceived and experienced by affected communities. This chapter presents a selection of themes collaboratively identified in the participatory thematic analysis of Community Researchers’ photos and narratives. Specifically, this chapter describes how healthy spaces promote resiliency for the Community Researchers, particularly those offered by low-barrier AIDS Service Organizations. The chapter concludes by suggesting a need to cultivate transitional spaces and opportunities for individuals who are post-street to live, socialize, heal and rebuild.

7.1. Introduction

It is well established that people living with HIV who have unmet housing needs face a myriad of barriers to achieving optimal therapeutic outcomes. Housing instability among PLHIV has been associated with superior virological and immunological status (18, 21, 27, 141, 146, 147), better mental health and a decreased likelihood to report opportunistic infections (34). The idea that housing saves lives is supported by evidence of associations between housing instability and mortality among PLHIV across many studies (18, 20, 22, 151-153). While there is a plethora of evidence of a strong positive association between housing stability and positive health outcomes among of people
living with HIV, less is known about the precise mechanisms and pathways connecting health and housing, as perceived and experienced by affected communities. In this chapter we sought to contribute to the literature a community-grounded account of what ‘home’ means to people living with HIV, a concept that has hitherto remained elusive in this context. Specifically, the selection of themes presented in this chapter work toward achieving our second study objective, which was to explore what constitutes a healthy living environment for people living with HIV in Vancouver, BC.

7.2. Home: a continuum

7.2.1. Being at home

At the time of this project’s launch, four Community Researchers identified as having found a place to call home after struggling in SROs and on the streets. Dan, Valerie, Mel and Rob expressed how housing stability led to improvement in their physiological health, psychosocial health and over-all sense of control over their environment and life trajectory.

A common theme in these discussions was that of people’s health rebounding. The stability of a permanent, secure place to call home freed up time and energy to tend to their health - take their antiretroviral therapy as prescribed, attend doctor’s appointments and prepare more nutritious meals. The most immediate sign of health rebounding was weight gain.

By far the greatest emphasis was placed on improvement in mental and psychosocial health. Those who found a place to call home talked about coming out of isolation and finally being able to get in touch with family. For Valerie and Dan, who were both estranged from their children while they were homeless, finding a home made it possible for them to connect to their children and grandchildren. The shame they had felt living inadequate accommodations or on the streets subsided. They felt there were able to invite their loved ones into their homes, into their more stable world.

At the same time, housing provided much-needed isolation. Once he finally had a self-contained suite, Dan says he “…got away from people basically, and managed to
find who I was.” He no longer had to fend off acquaintances and connections from when he lived on the streets. Dan further explained:

…it's that big common denominator of poverty and addiction and disease and everything else, where you’re really faceless and nameless, and you don’t have a history. And by moving out on my own, I started to reconnect with who I am.

Isolation from his former life allowed Dan an opportunity for self-reflection, something that he had missed while living on the streets. Dan further underscored this sentiment, “it gave me back my individuality, and that’s what I’m trying to nurture right now.” Housing stability allowed Dan to find work again, which restored his dignity and sense of independence.

Home is also an important outlet for self-expression, a place that one controls and defines as they like. Here, Rob talks about the apartment he is able to rent thanks to his portable housing subsidy, and how he has made it his own space:

…it sure contributes to my creativity, and that's really a very important—very important aspect of human life. We all need to be creative and express ourselves. And one way is to decorate your house or your apartment.

For Rob, being able to define his living space to reflect his personality and style provided him a sense of belonging: “I'm able to express myself...and that's the really important thing of having housing...I can decorate. I can feel like I'm a part of society.” Mel expressed similar sentiments about moving into his apartment and, for the first time in his life, buying a plant and making a space his own.

Stable housing also afforded these members of the group a sense of safety and personal security, which they could not have while living in SROs or on the street. Rob feels a peace of mind from having somewhere safe to go at night explaining, “I don’t have to keep my eye—one eye open and one shut. I can get a good night's sleep under a safe roof.” Mel is adamant about not letting strangers into his building and that he is careful never to lose his keys and has no respect for people who do. He feels it is a sign that they do not value security and comfort.
Home also serves as a refuge, a place to escape the challenges and stresses of everyday life, as described by Rob:

I have a retreat from the harshness of my day. I have harsh days...and I can have a TV and a couch, you know. And I didn’t have everything all at once. I got one piece at a time. No money, no income. Doesn’t really matter, as long as you have a roof over your head, you know. There’s always a food line somewhere. But if I have a roof over my head, I can retreat from that world.

Dan created a visual to demonstrate how his life has changed drastically with the support of a housing subsidy. The juxtaposition of Dan’s life “with support” and “without support” resonated with everyone and became a reference point we came back to on many occasions. Here Dan explains in full what his photo is meant to convey:

I did a little picture of just what it’s like to be with support and without support. Without support I was unemployed, on welfare. As you can see, picking up cigarette butts, because no money and I still can’t quit smoking. I used to have such a hard time before because I wouldn’t even get a bus pass. So I’d have to find used bus tickets and have a hard time by the bus drivers and whatnot. Then the scale. I put on this scale, 140 pounds. I was down to 140 pounds. Then on the right-hand side, you can see where it says, “support.” And instead of that unemployment cheque or welfare cheque, it’s actual paycheque. I managed to go back to work. Full pack of cigarettes. Now I’ve got money, I can buy my own smokes. Hold my head up a little bit higher. Don’t have to show the whole world that I’m a bum. Got a bus pass. And then on this scale, 170, 175 pounds. My health’s come back.

Dan provided a very literal depiction of what housing stability meant to him. However, it was not always so simple to capture the essence of home, either in photo or narrative. When probed on what makes his apartment ‘home’ Mel explained that he did not wish to complicate it - it is just home. Mel resides in a supportive housing unit, where there are some meals and support provided on site. He spent a majority of his life in unstable living conditions and that, “even if I was homeless, I had a place to go to, but it wasn’t home until I moved in there [his current place of residence].” This apartment is Mel’s “longest place of residence...either personally or with family” and the only place he’s “actually ever called home.” When asked what makes it home he responds, “it’s a place to house my sore head sometimes or a happy head” and “I get to hang my hat somewhere.”
Figure 12: With support and without support - Dan
7.2.2. Making home

In speaking of times in their own history that they experienced unstable housing and homelessness, or in speaking of the experiences of their peers, each Community Researcher made some reference to the idea of making a place feel like home despite substandard conditions. Jenny had connected with a peer to depict life as seen through the eyes of a person with mental health issues living in a SRO in the Downtown Eastside. Here she describes her friend’s situation:

even though he’s living in this mess...he’s still got the flowers and you know he’s sort of tried to make it home. You know? Yeah, he—even amongst all of the garbage and—you know, he’s still trying.

Randy talked extensively about the lengths he goes to so that he can bring order to the disorder of his room, which has a major infestation issue:

You don’t see that in the closets here that all my clothes are hung up and that up in the drawer there—you know, my socks and stuff are all put away nice and neat and everything, and my bed’s made and—you don’t see that part. You just see this shit that is there and is there and is there and it’s never going to go away.

Jenny and Randy’s narratives convey the ways in which people living in marginal conditions assert power and control over their surroundings. What appear to be mundane objects and routines – artificial flowers and folded socks – can be viewed as symbolic gestures and signals through which they challenge the dominant narrative about inhabitants of SROs.

An important part of the ‘making home’ narrative was finding beauty and serenity amidst the chaos of daily life. Many of the Community Researchers who remain in living situations that they do not feel good about took pictures of the places that give them strength and peace of mind despite the challenges that they face.

In this vein, the importance of outdoor spaces, such as gardens, parks and patches of greenery in the downtown core was a recurrent theme. For many members of the group and the communities to which they belong, these are the only spaces where they are able to meet and socialize. For people living in a Single Room Occupancy hotel, parks provide the living room that they otherwise do not have access to. Randy spends a
great deal of time in the Dr. Peter Centre garden where he took many photos. Here he explains the symbolism of the garden: “living in loneliness, HIV, alcoholism, addiction and all the rest of it. You’re living in squalor but there’s still a hope, a beautiful flower.” Randy’s building has no garden, and he described how members of the community came together to paint some on the side of his building (Figure 13).

Lynda took pictures of her local community garden, where she seeks out solitude, and Pigeon Park, where she is able to connect with friends and acquaintances:

I live in a hotel, and it’s small. And it’s like being closed in. And if it’s nice I’d rather be outside, yeah. And if I find if I’m staying in too much it’s closing the world out and I’ve got to get out, so.

She further explains, “It’s just a nice feeling to be in there [community garden], you know. You can block out the street.” Interestingly, for Lynda, visiting a community garden that is planted in the midst of a busy intersection in downtown Vancouver allows her to “block out the street,” something she is unable to do when she is inside her residence.
Figure 13: We don’t have a lot of flowers where I live so we painted some on the wall - Randy
When asked about her decision to take pictures of exclusively positive things Lynda explained, “…I was going to do the hotel scene…but then I thought, nah. You know, I see enough of it.” Because Lynda “lives with it” she didn’t see the point in capturing it in pictures. She also felt that not many people in the general public got to see the “normal” side of Pigeon Park and she was able to show that through her photos. The park, in the heart of the Downtown Eastside, is a popular gathering spot for people who live in the surrounding area who might not otherwise have a place to socialize.

I wanted to keep my photos simple. I didn’t want to show the bad part. There are some good things about living in Vancouver. It helped me mentally seeing there is peace and serenity here. That’s the part of pigeon park I wanted to show. Normal things do happen in pigeon park. People visiting with each other sharing - it’s not all chaos.

Lynda describes wanting to take a picture of her friends at Pigeon Park while they were sober: “Yeah, you have to catch them really early in the morning. Because by ten o’clock they’re pretty well…they’re gooned.” She later returned to the photo and said,

I don’t see them like that very often…and it’s kind of nice to see them sober. Well it is nice, yeah. And they all sat together. Like if they were all drunk and I was trying to get a picture of them…it would have been hard for me to get them together.

Lynda took pride in being able to show her friends in a light in which they are not often seen, a light in which she, herself, does not often see them. Although she is not perfectly happy with her current place of residence, Lynda took care to show the home she ‘makes’ – in the parks and gardens with her daughter, partner, elder, and friends.

7.2.3. Feeling at home

Seeking a definition of ‘home’ that could capture their collective sentiments and experiences, the group broadly conceptualized ‘home’ as any sanctuary where one is able to rest and momentarily forget their trauma. In this regard, an important part of the ‘feeling at home’ narrative were the AIDS Service Organizations that provide low threshold support to PLHIV, in particular the Dr. Peter Center, AIDS Vancouver and Positive Living Society of BC. These organizations were consistently described in terms
of a ‘home away from home,’ providing space and support that create a feeling of stability and security while people live in unstable and insecure conditions.

For example, Randy considers his hotel a place to sleep and nothing more:

…right now I’m only sleeping there [hotel room]—if I could get out and go to work everyday, it would be great. I wouldn’t have to look at the place. But when you’re living there, it means you’re spending a lot of time there. In one room. This is your room. This is it. You’ve got your bed in the corner, and a little stove over here and a little fridge on the right, about this high. That’s it. You won’t come out, and some people don’t come out of their room for weeks at a time—amazing—that live there. I want to get out of there after that and run to the Dr. Peter Centre.

Even though Randy’s accommodation offers the basics – a bed, a little stove top, a kitchen – in all of his conversations the only time he uses the term ‘home’ is in reference to the Dr. Peter Centre. Well-known by the staff and members at the Dr. Peter Centre, Randy finds a sense of belonging there.

There were numerous images of the Dr. Peter Centre, particularly the garden, which provides peace and quiet to members. Mel sees the Dr. Peter Centre as,

a place to empower people living with HIV of all walks of life through collective engagement. It allows the HIV community a place to seek refuge in the creative spirit, relating to each other and ourselves in a good way - and how we can do this is through art therapy, trips, community walkabouts and meals.

Dan described the powerful impact of the social environment of these spaces, explaining how there can be negative or positive repercussions, depending on “the vibe” of the centre:

if you’re not feeling well and you to go someplace and the whole thing and all you’re picking up is negative, crappy vibes, you know, you’re going to go home and you’re going to go, oh, that was a crappy day, you know what I mean? Or if you go someplace and you’re not feeling well and everybody’s—maybe tell you a joke or positive feedback or, you know, share with one another some positive feelings, you’re going to come back and retire from the evening, you’re going to have those positive thoughts of the day.
There was some disagreement about the idea of ‘a home away from home’ that continued to arise in our group discussions. None of the Community Researchers could dispute the value of the AIDS Service Organizations upon which they depended. The services and, more specifically, key staff members, provided integral support throughout their most challenging moments. However, some group members felt strongly that these organizations could never replace the need for, or replicate the feeling of, closing one’s own door and shutting out the world. It seemed unjust to accept a society where some people have homes and other people must seek out a ‘home away from home’ because they have no home of their own. There was also a concern from some group members that broadly labelling home as ‘any sanctuary where one is able to rest and momentarily forget their trauma’ could lend itself towards being interpreted as any space, including an SRO. However, for group members who had not yet found a ‘home’ of their own, this broad definition made sense in some way. This tension remained throughout the group discussions.

7.2.4. At home in the margins

Street life

Community Organizations that provide low-barrier resources aimed at supporting people who use illicit drugs were also highlighted, including Insite, VANDU, the Health Contact Centre, the Life Skills Centre and Pender Clinic. The Community Researcher who particularly valued these organizations identified them as a "place to call home, or a home away from home, and a safer place to use [drugs] or to network." He further specified that these organizations can provide or facilitate access to: a place to sleep; clean syringes; listings for recovery houses, shelters and treatment centres; opportunities to call the welfare office or family member; meet with friends and connect with peer support workers and other counsellors. He spoke fervently about how important these spaces are for the drug user community:

…it allows drugs users to go somewhere to rely on something other than their place, which they may not even have…It's more reliant than let’s say some back alley door, or they won’t get kicked out of that doorway because some neighbour thinks that just because they’re illicit drug users that they’re no good, that they’re up to no good. And out of sight, out of mind. It gives illicit substance users a place to actually be housed for a while and not be seen.
All of the Community Researchers had been touched by addiction and whether or not they were actively using drugs during the course of this project, every member of the group expressed extreme gratitude for the presence of these services, which were labeled “life saving” on a number of occasions.

**Life post-street**

The group as a whole felt that while there is a great deal of programming targeted towards people living in active addiction, there is a dearth of services to support people who have overcome their addiction and other barriers. This included housing and extended to counselling, general healthcare and other life skills support (i.e. recreation, nutrition, employment). Lora talks about no longer having urgent health concerns and not being characterized as a priority case:

> when you’re better and you’re healthy, the doctors kind of sometimes—well, we got to deal with this issue first because you’re not a hardcore issue. Like, for housing and stuff like that.

Many of the group members agreed that there are plenty of accessible support programs and services available, but when you do not want to talk about addiction and re-hash your trauma, the system does not offer a place to go. Community Researchers felt a sense of abandonment in this regard and wanted to carve out “normal” spaces for people in this life stage. Otherwise, isolation was the only alternative. Consequently, the most prevalent unmet need identified by the group was transitional spaces and opportunities for individuals who are post-street to live, socialize, heal and rebuild.

**7.3. Discussion**

In contrast to the descriptions of how SROs harmed their physical and mental health, presented in the previous chapter, the Community Researchers spoke of the positive impact of healthy environments on their well being. Members of the team who had found a place to call home described how housing stability had changed their trajectory. Community Researchers who felt unstably housed talked about the places in which they ‘found home.’ A theme that cut across all of the narratives was the need for
transitional spaces and opportunities for individuals who are post-street to live, socialize, heal and rebuild.

The results of this participatory thematic analysis of Community Researchers’ photos and narratives highlight the ways in which a ‘sense of home’ - whether real, made or found - positively impacts physical and mental health. These findings underscore the importance of places and spaces in which individuals who are marginalized by social-structural inequity can be ‘at home’ when they do not have a home of their own. These spaces are important for people along all segments of the spectrum of need. The Community Researchers emphasized that alongside advocating for sustainable affordable housing solutions, policies and programs must contribute to cultivating spaces to support PLHIV who are on the post street end of the spectrum.

The meaning of home has been the focus of centuries of theorizing. “An idea encompassing much more than a physical dimension,” home is imbued with meaning far beyond its role in providing shelter (425). The universal positivity associated with home is contested, with feminist scholars asserting that home exists, “not as an individual and homogeneously experienced unit of harmony, but as a potential site of struggle and conflict” (426, p226). A full exploration of the meaning of home is beyond the scope of this dissertation. Instead, Smith’s literature review on the essential qualities of home is used to orient this discussion. Smith identifies five essential qualities of home, many of which are woven throughout the narratives of the Community Researchers. Home provides centrality, continuity, privacy and a medium of personal identity. Finally, social relationships play an important role in the meaning of home (427).

The stress associated with homelessness or unaffordable and otherwise inadequate housing may exacerbate health issues and interfere with disease management and self care. The Community Researchers explained how moving into a stable environment facilitated ART adherence and improved their physical health. Their narratives mirror the wealth of evidence of the association between stable housing and superior virological and immunological status (18, 21, 27, 141, 146, 147) and a decreased likelihood to report opportunistic infections (34). Dan and Rob’s experience of their housing subsidies changing their health trajectory echo previous studies demonstrating improved health outcomes of PLHIV linked to receipt of housing
assistance (16, 142). As in the analysis presented in Chapter 6, the greatest emphasis was on improvements in mental health, an association that has been observed in previous studies of PLHIV (34, 148-150). Related to improvements in mental health, Community Researchers who found a place to call ‘home’ spoke of coming out of isolation.

German asserts that prolonged periods of housing instability, or ‘residential transience,’ impedes sense of attachment to a place, and establishing and keeping social networks (100). For Community Researchers who had children, having stable housing meant that they were able to re-connect with their families, mirroring Smith’s emphasis on the importance of social relationships to the meaning of home (427). On the other hand, Dan described how housing stability helped him separate from social networks that were not contributing positively to his health and well being; this phenomenon has been previously observed in individuals who are trying to abstain from drug use (428). Dan’s narrative of shutting out his old peer group and reconnecting with himself echoes Smith’s discussion of privacy as one of the essential qualities of home, which she describes as, “control of social interactions within that space...or control of access to the self” (427).

Both Mel and Rob spoke about what it meant for them to freely exercise their creativity and decorate their homes. Decorations communicate information about the person who inhabits the dwelling (427), situating home as a crucial site of self-expression, a place to ascribe ones personal identity: “Home is a symbol of both how people see themselves and how they want others to see them” (282, p25). Dupuis similarly describes home as “a secure base around which identities are constructed,” that has a powerful impact on social well-being (218).

In Dan’s comparison of his “unstable” and “stable” lives, the factors he discusses relate to how he perceives himself and how he wants to be perceived. Markers of stability - having a bus pass versus used bus tickets, a full pack of cigarettes versus cigarette butts, a pay stub versus a welfare cheque - afford him some dignity, as he describes it, to not “show the whole world that I’m a bum.” Dan’s poignant statement captures the essence of the dense body of literature that describes how neighbourhood and housing situation are intimately linked to sense of identity, pride, self esteem,
belonging and social well being of PLHIV (111, 112, 218, 219), how housing is, “...an organic extension of dignity, of self worth, of feeling secure” (217).

Some dimensions of home are intuitive, for example, its role in promoting a feeling of security. However, as illustrated by Mel, who did not want to overcomplicate the idea, the meaning of home and how it is experienced can be unclear at times. “The difficulty in coming to grips with the concept of home is its increasingly central role in everyday life, coupled with its rich social, cultural and historical significance” (429, p207). Mallet discusses 'being at home in the world,' illuminating the work of phenomenologists who, rather than attempting to define the essence of home, focus on the “diverse ways people ‘do’ and feel home” (430, p79). A related body of research conceptualizes ‘home’ as rooted in the activity that occurs in a place, as opposed to the place itself. Similarly, Robertson asserts that, “‘being-at-home’ is not always grounded in one particular site; it may refer to a state of well-being that extends to communities, cities, nations or ancestral territories” (111). Opposing all that we assume and know about unstable housing, the women in Robertson’s study forged strong social ties and cultivated a sense of belonging while living on the street and in shelters.

For those Community Researchers who had not yet found a place that they considered home, other places filled this gap. Specifically, parks and community gardens, as well as low-barrier AIDS Service Organizations provided a sense of belonging and connection to a community, a “sense of rootedness.” Through services such as daily meal provision, ASOs were places where one could, “feel a sense of belonging that engenders feelings of continuity, stability, and permanence” (427, p32). The Dr. Peter Centre, often mentioned in the narratives of many Community Researchers, uses an integrated approach to providing low-barrier primary care to PLHIV who have complex medical, mental health and psychosocial problems, including experiencing episodic homelessness. The Centre provides a sense of community, a safe and non-judgemental space and highly individualized psychosocial support. The findings of this analysis suggest that these characteristics of the Dr. Peter Centre, taken together, bridge the housing gap for individuals who are unstably housed and lacking the sense of order, security and continuity that is requisite to focusing on disease management and self care. Parks and gardens, meanwhile, provided a space to find peace and solitude, or socialize with peers - space that is crucial for people who experience marginality.
The idea of other spaces serving as ‘a home away from home’ did not rest comfortably with the group. In her thesis on homeless outreach in the tri-cities, Bakker points out that the meaning of ‘home’ has changed from ‘house’ to a ‘place of belonging,’ which poses a challenge to service providers. She notes that housing provision is easier to facilitate and evaluate than is helping a person find a sense of belonging (431). Bakker and the Community Researchers highlight the danger of expanding ‘home’ to mean anything and everything that contributes to a person’s well being. In interrogating the multiple dimensions and meanings of home, we must caution against defining the problem of housing instability so vaguely that viable solutions become elusive.

Despite the concerns of the Community Researchers, the centrality of ASOs in their narratives of home were pervasive. The group felt strongly that low-barrier services were plentiful, however, there are far fewer programs targeted to people who are recovered or in recovery. There appears to be an implicit understanding that once you are stabilized, that you will simply re-integrate into mainstream society, which is a considerable leap for people who do not perceive themselves as ‘high functioning.’ The Community Researchers explained that transitioning from highly-individualized psychosocial support to complete independence felt like an abrupt change that may lead to feelings of loneliness and isolation. On the other hand, it was not desirable to continue to access services alongside people whose trauma is fresh and addictions active - the group members viewed this as tiring and, at worst, triggering. Thus, the most prevalent unmet need identified by the group was transitional spaces and opportunities for individuals who are post-street to live, socialize, heal and rebuild.
Chapter 8.

Picture it: a conceptual framework mapping the pathways between housing and health

Synopsis

Until recently, BC-based studies that have considered housing as an important determinant of health have used definitions of housing stability developed in other settings; these narrow conceptualizations of housing status may not capture the nuances and diversity in the realities of people living with HIV in Vancouver. To fill this knowledge gap, a team of Community Researchers generated and analyzed over 300 photographs of their homes and neighbourhoods in Vancouver. Key conceptual categories emerging from the participatory thematic analysis were integrated with themes identified in a literature review. This chapter proposes a multi-level ecological framework mapping the determinants and impact of housing instability on the health of people living with HIV in Vancouver. Modelling this complex relationship at multiple levels underscores the need to expand the focus of housing strategies beyond individual factors, incorporating the broader political, economic and social context.

8.1. Introduction

The past two decades of HIV research have been characterized by a growing recognition that HIV prevention, treatment and care are strongly influenced by the physical, social, economic and policy environments in which PLHIV negotiate health-related decision making (245). This conceptual shift has given way to a more nuanced understanding of how living conditions, including housing status, may shape vulnerability to HIV infection, and influence health trajectories of those already HIV seropositive.
Indeed, housing instability and HIV and AIDS are intertwined in a cycle that heightens vulnerability to, and worsens severity of, each condition.

The role of individual-level factors, such as behavioural and psychological determinants of treatment adherence and health outcomes, have been extensively documented in the growing body of literature focused on the relationship between HIV and housing. However, as suggested in the most recent review of the literature, we still lack an understanding of the “relative contribution of homelessness and how it mediates more distal exposures” (42). Owing to the shift in interest towards social-structural level exposures, and evidence of their impact on treatment adherence and health outcomes (246, 247), more must be done to understand these associations among PLHIV who are homeless or unstably housed.

There is furthermore a shortage of context-specific, community-driven inquiry, and an overemphasis on the material aspects of housing - that is, the basic need for shelter. In Vancouver, B.C., the determinants and impact of housing instability among people living with HIV are situated within a unique socio-economic and political context. However, until recently, BC-based studies that have considered housing as an important determinant of health have used definitions of housing stability developed in other settings; these narrow conceptualizations of housing status may not capture the nuances and diversity in the realities of people living with HIV in Vancouver. As well, the limited data available on the impact of housing instability on the health and well being of PLHIV in this setting has been generated without meaningful involvement of community.

In order to fill this knowledge gap, Community Researchers recruited for The way I see it project generated and analyzed photographs of their homes and neighbourhoods, and engaged in group and one-on-one discussions about their understanding of the relationship between housing, health and living with HIV. The group then analyzed the photos and transcripts of our discussions in order to identify emergent themes. In this chapter, we propose a conceptual framework to explain the relationship between housing stability and health of people living with HIV in Vancouver, B.C. in order to inform research and programming priorities. The framework responds to our third and final objective, to identify specific mechanisms and processes through which housing influences the ability of PLHIV to manage their health.
8.2. Methods

As described in Chapter 5, Community Researchers conducted thematic analysis of photos and narratives to identify broad conceptual categories that were used to organize transcript data. We then engaged in more refined coding within and across the transcripts. The codes were reviewed to generate initial themes. This process was iterative, with the Community Researchers revising, developing and interpreting themes and incorporating feedback. The variables, relationships and themes identified by the group members during the analysis of the transcript data were mapped onto a conceptual framework that hypothesized the mechanisms and pathways through which environment impacts health outcomes of PLHIV, first using pictures and captions (Figure 14).

In later stages, data from the Literature Review (Chapter 2) and Context (Chapter 4) were integrated into the final framework, depicted in Figure 15. The Community Researchers’ experiences are not meant to be representative of Vancouver’s heterogeneous HIV positive population, and the mechanisms and pathways highlighted here are not meant to be comprehensive but rather illustrative. There are certainly other factors that have not been identified in this framework.

We strived to take a structural perspective to better understand proximal factors and also examine more distal factors, such as social forces contributing to growing inequality. Having identified a need for a social-structural approach to conceptualize the relationship between housing and health, we modelled our framework after Rhodes’ ‘risk environment.’ Rhodes’ seminal framework conceptualizes the physical and social space in which a multitude of factors exogenous to the individual interact to produce or reduce drug-related harm (432). Rhodes’ framework calls for a recognition of the interplay between factors that operate within and across physical, social, economic and policy environments at multiple levels of influence: macro-level, meso-level and micro-level (228). This framework helped situate Community Researchers’ experiences within the physical, social, economic and policy contexts that shape the options available to them.
Figure 14: First iteration of Conceptual Framework
Figure 15: Conceptual framework mapping the determinants and impacts of housing instability among PLHIV in Vancouver
8.2.1. Macro-level influences

Macro-economic

At the broadest level, the widespread proliferation of neoliberal ideology and its political and economic ramifications have contributed to the social inequalities and widening income gap that frame the HIV epidemic and the housing crisis described in Chapter 4. Trade liberalization has increased pressure to harmonize social policy with economic policy, resulting in stagnant or declining household incomes, reduced purchasing power and an increasing number of Canadians relying on income support programs, employment insurance and pensions. Community Researchers’ narratives were peppered with examples of economic inequality, a major theme in the group discussions. In particular, Community Researchers' narratives sharply illustrated the seemingly incongruous overlap of two distinct versions of Vancouver. There was a general sense of discontent about living in the margins, being poor and living right alongside extreme wealth, as expressed here by Dan:

Like, I know it was tough on me living in the entertainment district when you saw all the yuppies down there partying and drinking and going—cheering the sky, whatever it is, fireworks displays and that. When you’re sitting there, you got no cigarettes, you got no money, you don’t even have a beer, you know. And you don’t feel like getting up because you’re too damned tired, and everybody’s yelling and screaming and partying around you. I mean, that’s—after a while that kind of weighs you down. And then you start getting a little bit angry at society because you’re going well shit, I can’t even have a beer and party with the rest of you guys.

Prior to his HIV diagnosis, Dan once occupied a vastly different social location. He explains, “I’ve had a life before all of this. I was pretty productive. I travelled. I was married. I had children.” Dan is now in a situation where, along with his sero-status, his socioeconomic status has shifted, leading him to experience his surroundings differently.

Gentrification is a manifestation and consequence of the growing inequality in Vancouver, widely spoken about in the group discussions and described here by Randy:

There’s going to be a high-rise going up there. There’s a high-rise going up on the other side of my building, on this side, some place. Well, you know it’s only a matter of time before yours is going. You know, and it
looks like a sore thumb in the middle of all that beautiful concrete and steel [and] glass.

Randy’s observation is part of a larger debate raging in the Downtown Eastside about the increasing presence of high-end businesses in the impoverished neighbourhood. The recent establishment of upscale restaurants in a neighbourhood rampant with poverty and food insecurity launched ongoing picketing by anti-gentrification protesters in 2013 (433).

Geographic

At the macro-level, the model also considers geographic influences. This includes Vancouver’s relatively mild climate, which makes it a desirable destination in general, specifically to people who cycle in and out of homelessness. Also included within this category are the high rates of in-migration to Canada’s urban centres, which has driven housing costs up and kept vacancy rates low, particularly in Vancouver (336). As elaborated upon in Chapter 4, tourism patterns have also impacted the supply of housing through the conversion of Single Room Occupancy and budget hotels into tourist or backpacker accommodation, dislocating low-income residents (337, 338).

Political

Moving to the political sphere, the focus shifts to the laws and policies that inform the availability of affordable housing. Here, Randy expresses frustration over the lack of housing for people with low incomes:

all the places that used to have ‘For Rent’ signs don’t have ‘For Rent’ signs anymore. Now it’s ‘For Sale.’ They’re walk-ups, they’re old walk-ups, but they’re for sale. What are they doing? No, no, it’s a—selling this place and turning it over and making a dollar, making a bloody dollar is—there’s no more places for rent. That’s an idea that’s sort of—they’re phasing it out. You—now you have to buy a place. And then when you move, you have to sell it. Well, you know, that’s what’s happening here in Vancouver. So of the course the poor people, there’s no room for them now. You’ve got to go somewhere.

What Randy is observing is not an unfortunate inevitability; it is the product of deliberate policy choices made at all three levels of government.
Federal

As explained in Chapter 4, at the root of housing and related social challenges is Canada’s particular approach, and underlying philosophy, to the supply, allocation and maintenance of the nation’s housing stock (306). Canada’s two-tiered housing system discriminates against renters, privileges homeowners (306) and is unaccommodating to the development of policy to tackle the root of housing issues. Perhaps most significantly, Canada remains the only industrialized country without a National Housing Strategy.

Provincial

By many accounts Vancouver’s housing stock is failing to make the grade by all three of CMHC’s standards (300, 324). As suggested in the literature and confirmed by the experiences of the Community Researchers, the province’s response to housing instability and homelessness does not address the fundamental causes of these issues. Critics assert that policies implemented at the provincial level have contributed to the erosion of affordable housing over the years. As elaborated upon in Chapter 4, there is a lack of rental stock and a diminishing supply of social housing, as there has been limited investment in developing new social housing and existing social housing stock is being retrofitted and converted into supportive housing units (326).

Municipal

If you’re in a dire strait and if you’re in a real emergency…you can get housing right away? They’re picking and choosing who. What’s the criteria that you have to be to get a place right away…?

In the above quote, Jenny voices frustration at the City of Vancouver’s prioritization of the supportive housing segment of the housing continuum at the expense of social housing. The City adopted the ‘Supportive Housing Strategy’ in 2007, fostering partnerships with the Vancouver Coastal Health Authority (VCHA) to better support people who are homeless and dealing with addictions and mental health issues (331). Much of the City’s progress described in the Homeless Action Plan update describes advances in supportive and transitional housing. Less progress has been made, however, in producing independent affordable housing (335). The City’s 2005 Homeless Action Plan also recommended increasing the BC Income Assistance amount; the
province responded by increasing the Support and Shelter Allowance rate, marking the last time the welfare rates have increased to date (335).

**Social**

The dominant societal norms, values, types of knowledge and ways of knowing that permeate all aspects of the framework are also represented at the macro-level. Characteristics traditionally understood as individual demographic factors (ethnicity, socio-economic status, gender, sexual orientation, ability) must also be conceptualized as important macro-level forces with social interpretations and understandings through which inequalities and discrimination are fostered and perpetuated. The model thus accounts for oppression and discrimination related to these factors (racism, sexism, ableism, classism, homophobia/heterosexism) - all of which are deeply entrenched in the politics of both housing and HIV. Institutionalized discrimination shapes people’s attitudes and influences how we respond to these issues in terms of policy, programming and research.

Also important at the macro level but not the focal point of this framework are the ways in which we approach other issues including, but not limited to, sex work, drug policy, mental health and redressing colonialism.

**8.2.2. Meso-level influences**

A number of studies have looked beyond housing and explored the effect of neighbourhood context on health and social well-being. To conceptualize the interplay of factors at the neighbourhood level we draw on the well-established body of literature focusing on neighbourhood-based variations in health (434, 435). Neighbourhood-based variations in health are not simply a reflection of similar types of people (i.e. people who are low income) congregating together. More sophisticated studies have isolated the impact of context: “Although ‘who you are’ explains a lot of geographical variation in health outcomes, there is also an effect of ‘where you are’ (436, p26). Theories about the impact of neighbourhood focus on the features of the natural and built environment and psychosocial factors, both of which are summarized below.
**Physical**

At the physical level, features of the natural and built environment have an impact on health outcomes. One of the processes through which physical environments influence health outcomes includes resource access. That is, segregated neighbourhoods often have poor housing and lack of employment opportunities. For PLHIV, additional issues such as proximity to HIV service providers impact health outcomes (229), although it is less of a concern in the DTES, where there is a high concentration of low-barrier services. Also important here is the extent to which physical structures provide cues to residents about what constitutes socially acceptable behaviour. Factors such as neighbourhood deprivation (227) and characteristics of the broader "risk environment" (228) also increase vulnerability to HIV exposure. Features of the natural and built environment considered in this category include street lighting, presence of parks and community gardens and buildings that have run into disrepair. The underlying premise of this concept is that people who are struggling to survive in spaces that are deteriorating may engage in behaviours that would not be socially sanctioned in other neighbourhoods (434).

**Social**

it’s just dog eat dog, stab you in the back, rob you and cheat you and terrible living conditions and the whole thing.

In the above quote, Dan captures the essence of meso-level psychosocial impacts on health outcomes. Psychosocial mechanisms include factors such as social disorganization, community social capital, culture and norms, as well as community members’ sense of belonging, pride and attachment to their neighbourhood. Self-reported health is strongly correlated with perception of the quality and social cohesion of a neighbourhood, relative standard of living (225), civic engagement and collective self-efficacy, all of which may serve as buffers against exposure to HIV and create health-enabling environments for PLHIV. In their study of neighborhood effects, Hannon and Cuddy demonstrate how instability leads to reduced social control and support, which in turn elevates risk for negative health outcomes (437). On the other hand, collective efficacy creates a sense of trust, cohesion, and engagement among neighbours (226, 438). A related psychosocial process involves the notion of developing
a sense of belonging and attachment to a community (439). The role of behavioural and psychological determinants of treatment adherence and health outcomes has been extensively documented in the growing body of literature focused on the relationship between HIV and housing. Knowledge, beliefs and attitudes are not developed in a vacuum. Socio-economic forces, community norms and social networks influence health behaviours exhibited by individuals. These behaviours, in turn, influence community norms and social networks.

The cumulative impact of neighbourhood health effects, whether operating through the built environment, psychosocial processes, or both, have powerful implications for the health of communities and individuals. The environments described here may increase the need and opportunity to engage in high-risk sex and drug use, which in turn may fuel addictions, violence and crime and potentially incarceration.

8.2.3. Micro level influences

Physical environment

Chapter 6 elaborated on the physical environment of marginal housing. In addition to having little living and storage space, tenants deal with an array of problems with: temperature; ventilation (mould, asbestos, air quality); infestation (mice, rats, cockroaches, bedbugs); lack of natural light and inadequate security. Community Researchers’ narratives add to a well-established body of literature explaining the impact of the physical environment on the health of individuals. It has long been known that overcrowded, unsanitary conditions facilitate the spread of infectious disease (416). More recently, the characteristics of inadequate housing, such as dampness/mould (417), pest infestation (418), fungal contamination (419) and poor temperature control (420) have been associated with heightened risk of chronic illness, particularly respiratory disease (421). Characteristics of substandard housing, such as crowding, have also been linked with mental health illness (422).

Social environment

Wilkinson (440) writes: “it is the social feelings that matter, not exposure to a supposedly toxic material environment. The material environment is merely an indelible mark and constant reminder of the oppressive fact of one’s failure, of the atrophy of any
sense of having a place in a community, and of one’s social exclusion and devaluation as a human being” (p215). Mirroring the sentiments in this statement, the Community Researchers described how the social conditions of their poor housing conditions became etched onto their identities. The culture of SROs promoted feelings of shame, insecurity and stigma, similar to Robertson’s findings that women’s identities in the DTES were tied to their housing conditions, and that neighbourhoods and homes carry stigma and meanings for the inhabitants (111). This phenomenon is summarized well by Depres (441):

   Poorer quality social environments, characterized by, for example, crime, vandalism, threats to personal safety and property, transiency, a lack of personal investment, and so forth, undermine one’s ability to construct a dignified set of social meanings around one’s home (p26).

The pathways through which unhealthy environments impact health are well-established. With time, our understanding of the relationship between housing and health has evolved, with a heightened recognition of the different aspects of housing that impact health, including the material, meaningful and spatial aspects. Community Researchers explained how features of the physical and social environment contribute to sleep deprivation, impact the immune system (resulting in allergies and infections); respiratory illness (asthma and lung infections) and skin conditions. Most notably, they emphasized the impact of these environments on their mental health, including tendency to isolate and misuse substances.

**Expressions and perceptions of identity**

Finally, this model considers expressions and perceptions of identity, such as gender, sex, ethnicity, age and ability. Differences in biology, psychology and cognition exist among the Community Researchers, as well as the communities to which they belong. In addition, it is well established in the literature and highlighted throughout this work that within defined groups, people exist at complex intersections of identity, exemplified here by Valerie: “What mask am I wearing today? Am I the mom, am I the drug addict, am I the caregiver? You know, like which mask am I going to put on today?” People’s experiences are lived through expressions and perceptions of identity markers. These facets of identity - as they are internally experienced externally perceived - shape social networks and inform health-related decision making.
The model accounts for oppression and discrimination related to ethnicity, social class/socio-economic status, gender, sexual orientation, ability - all factors associated with acquisition of HIV and known to shape health outcomes of those who have seroconverted. With this background, this model aims to illustrate the influence of expressions and perceptions of identity, as well as the oppression imbued in these identities, at multiple system levels. Also influencing housing options and experience navigating the system are factors such as relationship status, parental status, existence of other sources of support and companionship. Past experience of trauma (abuse, domestic dispute) and how people cope (substance use) or seek out other buffers (spirituality) are also crucial issues to consider. In addition, the effects of socio-economic status is lived through, tightly bound to, and exacerbated by the physical and social environment one lives in (282) and is woven throughout the Community Researchers’ narratives.

Illustrative of the powerful impact of perceptions of identities, Lora recalls being denied housing because of stereotypes held by hotel managers:

And a lot of times too, it is hard to find hotels downtown as well I think. Like—because there are actually a lot of hotels that, they’ll rent you. But then you’ll get other ones that they just don’t. They look at you and they won’t give you a reason why. They just—no, yeah. And that’s happened to me before, and I was very offended by that because they were saying no dealers or prostitutes. We don’t accept people like that in here. And I’m, like, well, where’s the dealer and where’s the prostitute? I says, “I’m not any of that, right. ” Well,” they says, “I’ve seen you”— you know, like, stuff like that.

Being an Aboriginal woman who is low income and known to use illicit drugs, Lora stands at the intersection of multiple, layered identities that put her at a heightened disadvantage when looking for stable housing.

Health status is also an important issue, although through this study we learned that HIV status was perceived as a minor part of people’s struggle but a major part of their identity.

Randy: I’m just going to live with it. I try to not...dream too big. No, there’s no sense in dreaming too big. You’ve got all...these problems that have to be fixed. This one here is a minor problem.
Surita: HIV is minor?

Randy: Yeah. That’s a minor one. The HIV comes from addiction and alcoholism. Of course the loneliness and misery comes from the addiction and the alcoholism, too.

In the conceptual framework, the boxes labelled, ‘primary’ and ‘intermediate’ capture the outcomes that are traditionally the area of focus in HIV research – CD4 cell count and viral load, as well as engagement in care to facilitate treatment. Addiction and alcoholism are important insofar as they act as barriers to treatment adherence. Randy’s experience, echoed by the rest of the group, strongly suggests that their day-to-day concerns do not revolve around their serostatus. More important to people’s well being was dealing with feelings of rejection, loneliness, stigma, as well as addictions and its co-occurring problems, conveyed here by Dan:

It’s beautiful the whole thing, but if you’re feeling that total aloneness, I don’t know, it’s—BC and Vancouver’s a beautiful city. And yet there’s a lot of lonely, lonely times and lonely souls that, you know, are—aesthetics can only be so much, right? You need that feeling of belonging and feeling of I guess love or whatever, right, rather than rejection.

Also crucial in linking individual-level actions with the broader environment is the concept of hope, which Barnett describes as “a link between the pathogen, the individual and social and economic structures” (442). The factors operating at other levels - housing options, conditions of buildings, culture of neighbourhood, welfare policies - all influence sense of hope in the individual. According to the “ecology of hope,” the extent to which the environment facilitates a sense of hope for the future, or lack thereof, impacts the individual’s actions. In our group sessions, the Community Researchers shared some very painful memories. Some people were farther along in their healing than others. Hopefulness was something that we could rally around - the idea that things could get better, that change was possible.

8.3. Discussion

Moore asserts that a shift towards more neo-liberal governmentality has brought with it a focus on health promotion and prevention, downloading responsibility on the individual to make the right choices to stay healthy (412). One implication of this
paradigm shift is an explanation of homelessness that is rooted in the individual rather than in the economic and political system in which they operate. This shift has informed studies that focus on the poorer health status of homeless populations compared to their housed counterparts. Indeed, people who are homeless or live in unstable conditions are known to experience higher rates of disability and disease, and faster progression to mortality than their stably housed counterparts (51-53). Homeless and unstably housed people suffer from a greater burden of morbidity and mortality associated with affective disorders such as psychosis and schizophrenia (52, 54); cutaneous, respiratory and blood-borne infections (55-61); problematic use of alcohol and illicit drugs (54, 61, 62); and abuse and violence (63-69).

The study of health outcomes of PLHIV (poor adherence, low viral load, dropping CD4) must be situated within an understanding of the socio-economic and structural factors that mediate a person’s entry to, and journey through, the care system. The pathways leading to engagement in care, meanwhile, are shaped by a series of intermediate and proximal factors; where these factors intersect is where health is negotiated. Although many studies claim to take a social-structural approach, the focus of this body of work is on prevalence and incidence of specific diseases, or service access, rather than on the underlying causes of homelessness (282). As Dunn points out, the way we understand, research and respond to these issues has become depoliticized. He charges that:

much of the research writes about homeless persons as simply another demographic sub-group, with certain agnosticism about issues as crucial as whether homelessness is preventable. Where homelessness is problematized, it tends to be done so uncritically, and relatively superficially (p17).

In his analysis of Vancouver’s housing crisis, Drummond implicates the government, adding that dominant solutions are flawed in three ways: we do not problematize or target the root cause of the issue, that is, the great number of low income households. In addition, we have focused on the supply side of housing, which has very little impact on affordable housing. Finally, the new supply of housing has a high public cost per unit of affordable housing created. His conclusion is for governments to,
build better safeguards against the low income trap. And, they must complement these efforts with measures to boost income subsidies for vulnerable segments of the population and rectify the shortage of supply - by funding new supply, preserving existing stock, and removing the market imperfections that contribute to the supply shortage (300).

There is an urgent need to situate poverty and marginality in the broader socio-economic and political picture. Housing is an ideal intermediary factor to ground a discussion of macro-level determinants because of its unique position as an “intermediate-structural” factor. Housing links broader structural processes—economic, political and social arrangements, as well as resources that shape differential access to power—to the more immediate physical and social environments within which people live day to day, as Aidala writes,

Housing can be seen as a ‘vector’ or a ‘vehicle,’ an intermediary by which the pathogenic inequality that inheres in broader economic and political structures is carried to susceptible hosts: those born to poverty, race/ethnic minorities, persons affected by mental illness or drug addiction, and those victimized by persons or circumstance, who have insufficient resources to carry them through prolonged or repeated periods of crisis. Housing is a manifestation of, and contributes to, the generation of economic and social inequalities (115, pS1).

The proposed model aims to explain the pervasive inequities in the housing sector, providing a more critical perspective that highlights the role of broader structural determinants in shaping access to adequate, stable housing: neoliberal economic systems that threaten the income security of the most vulnerable, a culture of acceptance towards poverty and inequality, and environments that constrain individuals’ ability to ‘elect’ to secure adequate housing. This more nuanced view of social determinants of health recognizes a hierarchy of importance in terms of which determinants are root causes in relation to others, which are in turn the product of structural inequality embedded in social systems. Accordingly, “treating” housing instability without addressing the political, economic, taxation, credit and other policies and institutional practices that shape the availability of housing will result in this problem being replaced by other challenges that are rooted in the same inequities.

This project poses the problem of housing instability and its impact on health from a social structural perspective with an intersectional lens. Through encouraging
participants to situate their every-day realities within the political, socioeconomic, cultural and historical contexts in which they are rooted, Photovoice introduces the possibility of deeper exploration of the hierarchy of health determinants, and inserts the potential for agency and social change. The photo exhibits invited the wider public to see how different environments produce vulnerability by constraining individuals’ ability to protect their health. Through such efforts, we challenge people to consider their own social positioning and our society’s culture of acceptance towards poverty and inequality.

8.4. Limitations

Individual-level factors were not extensively discussed in this model, as we wanted to prioritize issues at the macro-level of analysis. In situating the individual and community narratives collected through this project within Vancouver’s political, economic and social context, a potential limitation of the proposed model is that, at first glance, it appears to take for granted the agency of individuals and communities. This model does not mean to convey that poor health outcomes and housing instability in this population are structurally determined and inevitable. There are factors that prevent or mitigate risk at all levels, as highlighted by the resiliency of Community Researchers in the face of extreme hardships. The context described here can simultaneously promote risk and protective effects. For example, the segregation of lower-income communities has been shown to have a protective effect, in that these neighbourhoods serve as an important loci of support and solidarity for community members (439). Indeed, the DTES has been described as one of the most engaged and politically-organized communities in Canada (349). We reiterate that the Community Researcher’s experiences are not meant to be representative of Vancouver’s heterogenous HIV positive population, and the mechanisms and pathways highlighted here are not meant to be comprehensive but rather illustrative and a launching point for further exploration into these issues.

8.5. Towards a contextualized, community-informed understanding of housing and health

The determinants and impacts of housing instability amongst PLHIV in Vancouver occur within a complex multilevel system as modelled in this conceptual
framework. The proposed conceptual framework illustrates how individual-level characteristics interact with social and physical factors at the micro-environmental and meso-environmental levels, all of which is influenced by the larger social, political and economic context. These interactions, in turn, impact intermediate and primary health outcomes at the individual and community level. This framework represents a first step towards building a conceptualization of the housing-health nexus as viewed through the eyes of people living with HIV in this context, helping us work towards solutions that are specific to the needs of this community. Importantly, the framework highlights the pathologies of the Canadian housing system, underscoring how the environments that contribute to vulnerability and disease at the micro level are products of pathogenic social, economic and political structures. Without interrogating the systematic reproduction of inequity and dismantling these systems, we risk further entrenching, rather than alleviating, health disparities.
Chapter 9.

Take a picture, it will last longer: summary discussion, recommendations, future directions

Synopsis

This concluding chapter provides a brief summary of the project’s findings, as well as policy and programming implications, which we situate within the HIV and housing literature. Following this, the chapter describes the study’s unique contributions to the field. In particular, the knowledge translation and exchange initiatives are elaborated upon. Strengths and limitations of the project are considered before looking at future directions of this work.

9.1. Summary of findings

This community-driven qualitative investigation unearthed evidence of the impact of poor living conditions on the health and well being of people living with HIV in Vancouver, B.C. Eight Community Researchers provided visual evidence accompanied by personal narratives of their experiences living with HIV and being homeless or at risk of homelessness. The conclusions presented herein are a product of a collaborative and multi-stage analysis process whereby the Community Researchers and I collectively identified thematic categories of interest.

The Community Researchers highlighted the substandard conditions of Single Room Occupancy hotels. The physical environment of the SRO scene was described as unsanitary, inadequate and dangerous. The social environment was characterized as contributing to a culture of mistrust and a deep sense of insecurity among clients.
Policies that favour landlords over tenants, and political priorities that do not align with the reality on the ground further contribute to these physical and social problems in the SROs. The conditions were so challenging that many Community Researchers felt that living on the streets was preferable to sleeping in a SRO. Being absolutely homeless came with its own distinct issues - finding nutritious food and battling the sense of alienation and isolation. Community Researchers identified a number of health issues they dealt with that they linked back to their substandard housing conditions, whether it was living in an SRO or on the street. Housing instability impedes access to healthcare and ancillary services and contributes to poor mental and physiological health outcomes.

The study findings also demonstrated how healthy environments promote resiliency. Those Community Researchers who had secured stable housing experienced improvement in their physiological health, psychosocial health and over-all sense of control over their environment and life trajectory. Those who did not consider themselves stably housed found strength and a sense of peace in other spaces they were able to access - parks and gardens, as well as low-barrier AIDS Service Organizations. The most prevalent unmet need identified by the group was transitional spaces and opportunities for individuals who are post-street to live, socialize, heal and rebuild. These study findings underscore the critical need for social-structural interventions informed by the lived experiences of affected populations. The findings also point to the need for intersectoral collaboration between public health practitioners, policymakers and urban planners.

Developed in response to the realization that there exists a disjuncture between the standard epidemiological assessment of housing status and individuals’ personal sense of housing stability, this project culminated in the development of a framework that offers a more comprehensive, context-specific understanding of the relationship between housing and health in this population. The proposed conceptual framework illustrates how individual-level characteristics interact with social and physical factors at the micro-environmental and meso-environmental levels, all of which is influenced by the larger social, political and economic context. These interactions, in turn, impact intermediate and primary health outcomes at the individual and community level. The framework aims to explain the pervasive inequities in the housing sector, providing a more critical perspective that highlights the role of broader structural determinants in shaping access
to adequate, stable housing. It is from within this framework that the following policy and programming recommendations are proposed.

9.2. Policy and programming implications

Theorists advancing intersectionality theory emphasize the importance of interrogating health-related policy to make visible how these policies prioritize the concerns of some citizens at the expense of others. Hankivsky’s framework for Intersectionality-Based Policy Analysis (IBPA) was used to critically examine public policies that impact people’s ability to secure and maintain stable housing, and to make recommendations based on our findings (292).

Our findings suggest first and foremost the need for subsidized housing for all low-income people. As mentioned in Chapter 4, Canada remains the only industrialized country without a National Housing Strategy. The housing crisis observed in Vancouver, and across communities in Canada, is a legacy of the retreat of senior governments from their historical role of providing capital and operational funding to create affordable housing (318). Since the demise of the national housing program in 1993, Housing activists have demanded continued support for social housing subsidies, increased funding of social housing and homelessness programs, and the development of a national housing strategy (443). Within a national program that addresses the housing needs of all Canadians, special attention must be given to individuals and groups who are marginalized by social structural inequity, including people living with HIV and AIDS.

This research supports the well-established body of evidence demonstrating the role of housing stability in improving health outcomes of people living with HIV and AIDS (16, 88, 142). This evidence has informed ‘housing first’ and ‘low demand housing’ service models, which view housing as a structural intervention for both the prevention and treatment of HIV and AIDS (444, 445). Clients are neither required to demonstrate sobriety nor access treatment services as a condition to secure shelter. This type of low-barrier housing is provided through the City of Vancouver’s Supportive Housing strategies for VCHA’s Mental Health and Addictions Supported Housing Framework, but additional supportive housing units are needed to meet the demand (446). This type of housing is also needed outside of the urban core, as gentrification of Metropolitan
Vancouver is pushing low income and otherwise marginalized residents into peripheral urban areas, reducing their access to specialized social support and clinical services (447, 448), including housing. We caution against an over-emphasis on the development of supportive housing at the expense of social housing. In our discussions, a concern arose that the city’s goal to eliminate street homelessness is targeting surface issues, such as creating low-barrier beds, without genuinely considering underlying causes of homelessness, or recognizing the ramifications felt by the rest of the community by the City’s agenda. We were unable to retrieve documented empirical evidence of the dissonance between the city’s political agenda and the actual supports people receive once they are housed. This represents an important area of inquiry that should be further explored in future research.

The experience of the Community Researchers points to the need to incorporate a strong outreach component in low-threshold care models. Transient populations have different patterns of uptake and access to standard medical care, which necessitates the development of adaptations to this model. In particular, structured collaborations between pharmacies and transitional housing services are necessary to coordinate daily medication dispensation and other medical and social service provision for unstably housed people living with HIV and AIDS. The Clinical Tenant Support Team, Clinical Outreach Team, Clinical Housing Team and Community Transition Care Team are prime examples. Through these programs, the VCHA provides mental health and addictions support in Single Room Occupancy hotels and shelters in Vancouver’s Downtown Eastside (446).

In this vein, research emerging from the Cedar Project demonstrates the “value of programs that respond to the moments in time when young people are in transition, including acute housing crisis, relationship breakdown, and moving into new environments” (44). The Community Researchers’ narratives suggest that there is also value in programs that respond in moments that don’t look like traditional crises, pointing out a gap in programming for people who are not actively addicted or in urgent trauma. One of the most pressing needs identified by the Community Researchers was to carve out spaces and opportunities for people who are post-street to live, socialize, heal and rebuild.
It is clear that within the matrix of social determinants of health, stable housing plays an integral role in influencing health trajectories and shaping health outcomes. Our study findings suggest that alongside advocating for secure, affordable, safe, clean housing for all, we must encourage the development and expansion of programs that have been proven to help unstably housed PLHIV access and adhere to treatment and just generally be well. The programs that the Community Researchers highlighted provide a model for other urban centers dealing with concurrent and interrelated barriers to wellness: high-risk drug use, mental health disorders, food insecurity and homelessness. In the absence of sustainable housing solutions, programs such as these are crucial to PLHIV’s well-being and sense of home when they have no home of their own.

The present analysis suggests that these low-barrier programs play a critical role in identifying and ameliorating barriers to good health amongst the most vulnerable populations. However, we must be diligent in monitoring and evaluation efforts of these programs and intermittently survey clients to ensure that the programming is meeting their needs. Evaluation is also the first step to sharing effective program models with other jurisdictions. This is one of the aims of the REACH National Housing Blueprint initiative, which our project is linked into (449). The ultimate goal of this collaborative of researchers, service providers and activists is a revitalization of the social housing agenda. Part of their advocacy efforts is drawing attention the many services and programs that fill the gap left by the withdrawal of federal government support:

In the absence of a national housing strategy or policy, front-line service providers continue to work locally to build partnerships, develop strong collaborations with community services, gain support from their communities, and find and foster local champions in order to find housing solutions for people living with HIV (p4).

Among other goals, the collaborative aims to better understand the efficacy of these different service models through research. We aim to continue working with the collaborative to further these excellent monitoring and evaluation efforts.

As part of these evaluations, we suggest that there is a continued need to generate evidence of the association between housing and health outcomes in a collaborative intersectoral fashion. ASO program staff are an invaluable resource to
researchers and policymakers, both in terms of their access to longitudinal clinical data and their unique understanding of the complexities of their clients’ situations. This knowledge should be leveraged to inform evidence-based policy and programming that recognizes housing as an issue that intersects multiple sectors. As elaborated upon below, this project has led to a long-term partnership between the BC Centre for Excellence in HIV/AIDS and McLaren Housing Society to evaluate a supportive housing program for PLHIV.

The Community Researchers spoke a great deal about the problems with Vancouver’s SRO stock, including the constant fear of eviction, threat of violence, disruptive neighbours and doors without proper locks, leading to frequent break-ins. The Community Researchers called for the development of a system that holds SRO owners accountable to uphold basic standards of hotels; and for the introduction and strict reinforcement of legal mechanisms to protect the rights of SRO residents.

A tension arose when we talked about balancing the protection of tenants’ autonomy and confidentiality, and ensuring their safety and security. Pivot Legal Society provides an excellent example of a service model that actively contributes towards cultivating environments in which people can protect their own safety, security, autonomy and confidentiality. Through plain language summaries and community forums the Society helps make vulnerable populations (sex workers, people who use illicit drugs, people who are homeless, SRO tenants) aware of their rights (450). Pivot aims to arm individuals with tools to redress injustice, re-casting disadvantaged populations as agents of change.

Similarly, organizations that offer opportunities for PLHIV to engage in peer work for their own causes in their own communities were seen as extremely valuable. In addition to providing compensation, these experiences are helpful in teaching life skills, integrating people into their communities, creating a sense of camaraderie with peers and increasing people’s confidence and sense of purpose.

The Community Researchers provided many examples of the ways in which public policy outside of the realm of housing policy indirectly impacts the health and safety of homeless and marginally housed PLHIV. A consistent, cross cutting theme was the need to re-evaluate income assistance and disability benefit amounts and
procedures in BC, so that all low income people are properly supported without needing to resort to self-harm to meet eligibility criteria for disability assistance. Benefit amounts need to be aligned with the cost of living, and consideration must be given for regional differences. The shelter allowance, which has remained at $375 for a single adult since 2007, does not accurately reflect the cost of shelter in Vancouver, where the average one bedroom apartment rents for $918/month (11). Procedural barriers should be mitigated where possible to facilitate access to benefits and services.

Other important policy areas that intersect with and impact the housing sector are drug policy and mental health. The issues that the Community Researchers brought forward about the environment of SROs would be attenuated by drug policy that promotes harm reduction rather than punitive measures to manage drug sale and consumption. Otherwise, drug use is driven under ground and hotel owners and managers are forced to react by imposing rules that violate the basic rights of tenants. In addition, there must be a stronger commitment to supporting people living with mental health illness to thrive in their communities with appropriate supports.

The Community Researchers called for the demonstration of more compassion within policy and programming. These systems must demonstrate sensitivity and understanding towards the unique situations individuals are in, rather than attending to people as they are defined by their risk category.

This analysis makes clear that we must consider the role of Public Health in producing research that actively shapes how ‘research subjects’ perceive themselves, and how policymakers and service providers conceptualize, measure and strive to address health issues. The very process of researching health and social issues has the potential to reify pre-conceived understandings of disadvantaged populations. These perceptions are especially problematic when they shift our attention way from the larger structural issues that marginalize individuals and contribute to health inequities. Uncritical research may generate knowledge and interventions that exacerbates health inequities, rather than alleviating them. Thus, in addition to policy interventions, we must be vigilant about resisting and challenging the way knowledge is created and presented. Researchers must collaborate across disciplines and work with the community to generate research projects that are guided by the same principles Hankivsky prescribes.
for IBPA: interrogate power, do not prioritize any one category, value diverse knowledge, and advance social justice and equity (292). If we demand this of policymakers, we as a community of researchers should hold ourselves to the same standards. In short, this work also emphasizes the need for knowledge production that attends to all of these issues with compassion.

This analysis suggests that the dominant framing of the housing-HIV nexus, both in how it is researched and respond to, has served to depoliticize the issue, reducing it to a health issue that can be remedied by the creation of low-barrier beds. Thus, our final recommendation is a call for more passion in our understanding of, and response to, this issue.

9.3. Situating this work in the literature

Clearly there is a public health and human rights imperative to respond to the well-established body of evidence that poor engagement in care and poor health outcomes is driven by social inequity. Housing, among other interventions at the social-structural level, may contribute to improved health outcomes. The findings that emerged from this study complement and contextualize the wealth of studies that describe the impact of inadequate housing on the physical and mental health of people living with HIV and AIDS.

The Community Researchers narratives add to the growing body of literature conceptualizing housing as a crucially important barrier to, or facilitator of, HIV care and treatment. They explained how moving into a stable environment facilitated ART adherence and improved their physical health. Their narratives mirror the wealth of evidence of the association between stable housing and superior virological and immunological status (18, 21, 27, 141, 146, 147) and decreased likelihood to report opportunistic infections (34). Dan and Rob’s experience of their housing subsidies changing their health trajectory echo previous studies demonstrating improved health outcomes of PLHIV linked to receipt of housing assistance (16, 142). The greatest emphasis was on improvements in mental health, an association that has been observed in previous studies of PLHIV (34, 148-150). A number of studies have found the receipt of housing assistance is associated with regular use of primary care (156),
ancillary services (157) and HIV-specific medical care (17), mirrored in the Community Researchers’ accounts of being unwilling and unable to stay on treatment during the times that they were homeless.

The Community Researchers described the ways in which their housing conditions become etched onto their identities. These narratives also complement the growing body of literature that shows housing is an important determinant of a patient’s overall well-being, including in “the formation of attitudes, identities and the internalization of disempowerment” (111, 282).

In a field primarily concerned with harm reduction amongst ‘most at risk populations,’ there has been little sustained attention on individuals and populations who no longer ‘at risk.’ People who have been treated for, or cured of, their health issue, be it addiction, mental health illness or HIV, are increasingly pushed to the peripheries of clinical and research focus. This represents one of very few studies that have shed light on the experiences of individuals who have, or are in the process of, migrating to the periphery – a group that sees themselves as ‘post-street,’ requiring a different kind of support and drawing attention to the fact that existing systems do not respond to their unique and evolving needs.

It has been suggested that, “…in complicating and quantifying homelessness, we risk failing to understand homelessness at its essence: the absence of a home” (44), a question that can only truly be answered by individuals and communities whose sense of home, however they define it, has been threatened. The photo evidence and narratives shared in this study underscore the need to engage affected populations in understanding the impact of these spaces on health, and developing policy and programming targeting housing instability amongst people living with HIV.

9.4. Unique contributions: Knowledge Translation and Exchange initiatives

In addition to the development of the framework and these policy recommendations, this project offered a number of important contributions to the field. One of the aims of this project was to engage diverse audiences in a dialogue about the
mechanisms and processes that produce varying rates of disability, disease and progression to mortality across different housing and neighbourhood contexts; and highlight the resiliency of the HIV and AIDS community. This objective was addressed through a multi-pronged knowledge transfer and exchange (KTE) strategy. We strived to address the unique information needs of various knowledge users, many of whom are not integrated in the HIV and AIDS community, and are thus unfamiliar with the realities of living with HIV. We endeavoured to ‘push’ key take-home messages from the study to traditional knowledge users and facilitate ‘user pull’ efforts to engage with individuals and organizations who may not be effectively reached through traditional academic and research dissemination methods (110, 160, 444, 451).

9.4.1. Academic conferences

Key study findings were ‘pushed’ to researchers and service providers, who, through their theoretical and practical work in this field, are acutely aware of the importance of housing in ensuring optimal health outcomes. We reached this audience presenting findings at local, national and international research conferences, including the 5th, 6th and 7th annual North American HIV/AIDS Housing Summit; the 20th, 21st and 22nd Annual Canadian Conference on HIV/AIDS Research; the 19th International AIDS Conference and the 2012 Forum on Health, Homelessness and Poverty. We were also invited to share their expertise in community-based health research at the Pacific AIDS Network’s Knowledge to Action - Strategic Directions for Community Based Research conference; a session for the SFU Literacy Lives Community Capacity Building program; and at SFU’s Grassroots to Global: Showcasing collaborative & interdisciplinary research in HIV/AIDS conference. Wherever possible, Community Researchers attended the conferences and either presented or co-presented their findings alongside me. With the exception of one of the group members, none of the Community Researchers had ever been involved an academic conference prior to joining this project. I worked collaboratively with the Community Researchers to develop abstracts, write scholarship applications to subsidize travel and conference registration costs, co-present findings and network with conference attendees.

Organizers of two conferences approached us about hosting photo exhibits in addition to presenting a poster or oral as part of the standard conference proceedings.
After a well-received presentation in the Best Abstracts in Social Sciences session at the 21st Annual Conference on Canadian HIV Research, we were asked to display their photos at the subsequent annual conference in 2013. The organizer of the Forum on Health, Homelessness and Poverty also asked to play the slideshow presentations throughout the 2012 meeting to promote discussion among the Forum attendees. Neither of these conferences traditionally incorporated art installations and organizers and attendees appeared to appreciate seeing evidence presented in an alternative medium.

9.4.2. Photo exhibits

We concurrently facilitated “user pull” efforts to draw the interest of community members who may not be familiar with social determinants of health or the lived realities of living with HIV. Photo exhibits were the principal community engagement tool of this project. The exhibits aimed to help alleviate stigma and discrimination against PLHIV and increase lay peoples’ understanding of vulnerability produced by environments, and gain an appreciation for the resiliency that these communities develop to buffer themselves. The Community Researchers worked closely with the rest of the study team to cultivate an accessible environment for people living with HIV and members of marginalized groups who are often excluded from engagement with traditional knowledge translation activities, such as academic conferences, because of literacy barriers or stigma and discrimination. Through invitations distributed to key stakeholders and posters advertising the events to the general public, we strived to appeal to a wide range of audiences for these events including researchers, healthcare and social service providers, regional and provincial decision makers in the health and housing sectors, members of affected communities, as well as the general public. Publicly elected officials attended both exhibits that were open to the public.
Figure 16: Community Researchers mount their photos and narratives for display in the Woodwards atrium.
At the time of writing this dissertation, we have organized three local photo exhibits that were independent of the academic conferences at which we presented our work. The launch reception and premier exhibition took place in the Woodwards Atrium in April 2012, depicted in Figures 16 and 17. Over 100 people attended the launch and watched video presentations made and presented by the Community Researchers. The exhibit remained on display for 10 weeks and attracted a lot of attention to the issues raised by the project.

A second photo exhibit was held during Homelessness Action Week in October 2012 at Jacob's Well, a community organization attached to an SRO where a member of the team lives. The Community Researchers and I strived to create a more interactive event, where members of the Downtown Eastside community were welcome to view the photos and video presentations, but more importantly, engage in dialogue about their own experiences of housing instability. The team also cooked and served over 100 hot meals to attendees, shown in Figure 18.

On World AIDS Day 2012 the team hosted a private photo exhibit at the Dr. Peter Centre, which was open to Dr. Peter residents, day-health program participants and program staff. This exhibit, captured in Figure 19, was meant to “bring home” the photos to the community with which most members of our team identify.

When the Community Researchers and I decided that the photos had travelled enough, we sought out a permanent home for them. The full set is permanently mounted on the walls of the Vancouver Injection Drug Users study (VIDUS) office in the Downtown Eastside. Many members of the team are participants of the VIDUS study, and saw this as an opportunity to have their work connected to the community of injection drug users whose struggles they readily identified with. The team was also adamant about finding a venue that was part of the realm of research, which they saw as playing an integral role in the solutions to the problems in their community. A partial selection resides at McLaren Housing Society’s Howe Street building, where two members of the group found permanent supportive housing during the course of this project. This building is also the site for the next phase in the study, described below.
Figure 17: At the premier photo exhibit, Community Researchers shared video presentations with over 100 attendees. Councillor Kerry Jang and M.L.A. Shane Simpson spoke about the City’s approach to end homelessness.
Figure 18: As part of Homelessness Action Week the team organized a community engagement event. The team cooked served hot meals to over 100 people in the Downtown Eastside while talking about shared experiences of being homeless and struggling to take care of their health.
Figure 19: The Community Researchers organized a private photo exhibit at the Dr. Peter Centre in honour of World AIDS Day.
9.4.3. **Political engagement**

An overarching goal of this research initiative was to encourage decision-makers in the health and housing sectors to take our findings into consideration. Publicly elected officials attended both exhibits that were open to the public. Vancouver-Hastings M.L.A. Shane Simpson and Councillor Kerry Jang attended the exhibit launch where they spoke about the City of Vancouver’s approach to end homelessness. We have launched the next phase of the study with commitments from new partners in the public and not-for-profit sector to take action on the study findings, including: BC Housing, the Vancouver Coastal Health Authority, the Streetohome Foundation and two Members of Parliament: the honourable Libby Davies and Hedy Fry. We have not been successful in engaging the Ministry of Housing and Social Development, however we remain committed to this goal.

9.4.4. **Other outreach**

Our knowledge translation and community engagement work beget additional opportunities to present in different mediums, including video, print, radio, web-based interviews and university lectures. Summaries of salient research findings were distributed through Forecast, the BC-CfE monthly journal and the group developed a webpage on the BC-CfE website (http://www.cfenet.ubc.ca/research/lisa/photovoice). Shortly thereafter, the study team was approached by a number of groups that had heard about the project and wanted to share the study findings in their own networks. The Community Researchers’ work was featured in Megaphone, a local newspaper focusing on poverty issues. The project was also highlighted in blog posts by the Pacific AIDS Network, Canada without Poverty, and Positively Positive. Co-op radio also invited representatives from the team to provide a synopsis of the study findings.

We developed a number of KTE materials based on this work. A compilation of photos and narratives were made into a book, which served as a community engagement tool and a souvenir for the Community Researchers. With the support of a study investigator with a graphic design background, the team also made pamphlets to distribute at events and help advertise the exhibits. A selection of photographs were made into postcards, which were distributed to exhibit attendees for the purposes of
directly expressing their housing-related challenges and concerns to policymakers. Many people treated the postcards as souvenirs, however, and the team realized that this tool would have been more effective if the postcards were postage-paid.

This integrated KTE approach was embedded in the development and implementation of the project. At every stage of the project, the community partners - PWN, Dr. Peter Centre, McLaren Housing - have provided direction and advocated on behalf of their diverse constituencies. Community Researchers have been consulted at every stage to ensure that the study findings are relevant, actionable and meaningfully improve the lives of people living with HIV. Based on the application of the “linkage and exchange model” increased input from these various partners and audiences strengthen the interpretation of results and reduce the widely recognized gap between research and practice (160).

9.5. Strengths and Limitations

9.5.1. Measurement tools

The characterization of housing status commonly employed in epidemiological studies does not reflect individuals’ personal sense of housing stability by virtue of its narrow definition. Most studies demonstrate strong and significant associations between housing and health by identifying and measuring single quantifiable indicators of exposure and outcome, which do not take into account the multidimensional nature of housing or health. The single indicator, which conveys whether basic needs are met, does not adequately capture other aspects of housing that may be important to individuals’ sense of stability, for example affordability, housing transience and social cohesion (38). By taking a holistic approach to both housing and health, this project introduces the possibility of identifying multiple indicators to reflect the relationships between different aspects of housing and health outcomes.

9.5.2. Analytic techniques

Photovoice is a powerful tool for building a community-informed definition of stable housing. The use of narrative in this project facilitated the inclusion of voices that
have traditionally been excluded, thus placing people in control of their own stories. The reliance on personal stories also acknowledges the expertise individuals have regarding their own life experiences. In this way, our chosen methods challenge traditional Western beliefs in objectivity (452). Furthermore, through use of visual methodologies “...meaning is actively created in the interaction between the researcher, respondent and the image, rather than passively residing in either one or the others” (379, p239). Schroeder notes that by viewing participants as co-producers, we “acknowledge both their co-humanity and the social production of knowledge” (453, p83). In Photovoice, inclusive knowledge production is ensured via the accessibility of the method, control of the agenda and ownership of the resulting image. Co-construction of narratives was validated by participants throughout the data collection and analysis phases. Transcripts and the themes that emerged from data analysis were verified through techniques such as member checking and peer debriefing, which helped ensure that they accurately reflected participants’ perspectives.

The project’s focus on structural causes of inequities in housing experience and health outcomes made intersectionality a natural fit as a theoretical framework and analytic tool. Intersectionality theory helped to elucidate how policies, institutions and societal norms create and perpetuate systems of inclusion and exclusion. There were a number of strengths in our combination of Photovoice and Intersectionality. However, the concept of co-production of knowledge is wrought with challenges. Viewing the Community Researchers as the authors of their narratives that offered the only possibility for an authentic account was not always feasible. Instead, following Christensen and Jensen’s approach (290), Community Researchers’ narratives were treated as extremely valuable representations of truth that I re-viewed with an intersectional lens. Still, there remained gaps in the analysis where answers simply did not emerge from the data. I set out with questions about the meaning of home for this community and the Community Researchers were sometimes challenged in articulating responses. Such challenges are referenced in the literature: “The difficulty in coming to grips with the concept of home is its increasingly central role in everyday life, coupled with its rich social, cultural and historical significance” (429, p207). I never pressed very hard when challenges arose, particularly in reference to the importance of past experience in shaping their current situations, thus the answers are limited to what Community Researchers people felt comfortable sharing.
9.5.3. **Sampling methodology and study design**

The study findings are limited in that they were based on a small sample size. However, the small sample qualitative study is an appropriate approach to tease out important differences among the project participants, as the selected methods allow for an in-depth exploration of individuals’ unique perspectives and experiences.

Thick description provides the depth and breadth of information required to make a judgment about whether findings are applicable in other settings and “depending on the degree of temporal and contextual similarity” working hypotheses developed from one case can be transferred to other cases (386), a process also known as ‘naturalistic generalization’ (384). The participant-generated visuals and accompanying narratives further enrich the thick descriptions of individuals’ lived experiences.

I recognized that my inability to observe important similarities or differences between Community Researchers’ accounts may have led me to incorrectly emphasize or ignore certain aspects of a case. To counter this effect, member checking and peer debriefing helped ensure that the descriptions have internal validity (454). While internal validity does not guarantee that the findings speak to situations beyond those studied, the descriptions from which generalizations are being drawn accurately reflect the perspectives of the cases studied.

From the outset I was aware that the meaning of ‘stably housed’ would likely vary between the sub-populations that would be represented in this project. Every person is uniquely positioned along the housing-needs spectrum and this research study is not designed to comprehensively speak to all of the nuances of individual perspectives and experiences. By thoroughly describing context and creating a platform for individuals to voice their housing struggles, this study creates the possibility of reforming how and what data is collected by housing providers from their clients and potential clients. There were instances in which the individual members of the group sought similarity in their individual accounts so the team could advance one unified message about housing and health. This may raise some concerns about generalization of diverse accounts. Where possible, I strived to counter the trend towards homogenization of narratives in my reviewing of the data.
9.6. Application of research findings and future research directions

Williams and Popay assert that,

if public health research is to develop more robust and holistic explanations for patterns of health and illness in contemporary society, and contribute to more appropriate and effective policies, then the key is to utilize and build on lay knowledge—the knowledge that lay people have about illness, health, risk, disability and death (455, p267).

Heeding this call to action, this project has helped inform a community-informed and context-specific conceptual model that holistically integrates biological, cultural, economic, political, psychological and social factors to explain the complex relationship between housing stability and the health of people.

The findings from this project were intended to improve standard epidemiological methods to more accurately capture housing instability, by developing indicators that individually measure specific aspects of housing more precisely, and more nuanced housing categories that collectively characterize housing more fully. These indicators and categories have informed the development of a community-informed and context-specific conceptual model that explains the complex relationship between housing and HIV-related health. The model is now being operationalized in the next phase of this program of research, a prospective cohort study investigating the impact of a new supportive housing complex for individuals and families affected by HIV.

McLaren Housing Society has recently opened the doors to a 110-unit housing complex that provides permanent housing to PLHIV, as well as their families, who are either homeless or at-risk of homelessness. I led the submission of a successful application to the CIHR Population Health Intervention Research call to assess the impact of this intervention. Individuals accepted into the new housing complex, as well as a control arm, will be offered enrolment in a longitudinal cohort study and asked to consent to linkage to health service databases. A baseline pre-intervention questionnaire will be administered, including a module eliciting comprehensive information on housing history, reflecting the categories and themes identified by the Community Researchers in the Photovoice workshops and included in the conceptual framework. Individuals in the
cohort will be followed-up every six months for a period of three years for ART initiation, adherence to treatment and changes in HIV risk behaviour, as well as other socio-demographic characteristics.

This next phase of the project remains grounded in the community. As the project unfolds, opportunities will be made available to the Community Researchers who wish to undertake a CBR instructional program to be trained as Peer Survey Consultants or Peer Research Associates. Survey consultants will assist in the development of a survey instrument with modules reflecting the themes they identified in the participatory thematic analysis. Two Peer Research Associates will undergo training in order to administer the longitudinal survey and assist with data analysis.

The way I see it officially concluded with the photos being mounted in the VIDUS and McLaren buildings. However, we intend to pursue follow-up meetings with municipal politicians who attended KTE events and demonstrated interest in learning more about the issues documented in this work. We plan to work with the BC-CfE Clinical Education and Training Program at the Immunodeficiency Clinic to help inform curriculum and educational tools to sensitize service providers who work with PLHIV who are homeless or unstably housed. On a similar note, we would like to work with community partners that are mandated to provide housing to PLHIV (McLaren Housing Society of BC, Wings Housing Society) and other vulnerable populations (BC Housing, Portland Hotel Society, Raincity Housing) to modify housing needs assessment surveys to reflect the issues that emerged from the findings. By sensitizing the systems and institutions that all PLHIV must navigate in order to secure and maintain housing, we aim to help identify the unique needs of PLHIV on a broader scale. In the future we would also like to work with the health authorities to develop a standardized system for logging and tracking patients’ postal codes. In the current system there is a code to denote homelessness but not whether a patient is residing in a shelter or SRO. Implementing such a system would generate reliable administrative data about the most marginally housed PLHIV in the Metro Vancouver region.
9.7. Picturing social change

In 1901 Jacob Riis wrote, How the Other Half Lives: Studies among the Tenements of New York, a photo-journal that used a combination of graphic descriptions, sketches, statistics and photographs to illustrate the conditions of slums in the Lower East Side of Manhattan. The slums were primarily inhabited by poor immigrants and Riis felt strongly that the inequality he observed was a product of greed and neglect of the upper class. People were shocked and appalled at what Riis had uncovered. His work eventually led to marked improvements in living conditions of poor immigrants, a powerful example of the power of photography in instigating social change (456).

A century after this ground-breaking work, a team of Community Researchers in Vancouver ventured into their neighbourhoods armed with cameras with a similar objective - to render visible living conditions that one would never believe existed in the developed world, unless they saw it for themselves. Similar to Riis, the Community Researchers are committed to social change, to taking “bolt cutters” to the chains that keep their communities locked into poverty, and simultaneously locked out of opportunities to escape it, to paraphrase Valerie.

There is still much work to be done before the team realizes their vision of “a home for all,” depicted in Figure 20. In the mean time, these eight individuals have joined an important dialogue, contributing evidence of the ways in which environment produces and reproduces vulnerability, as well as the resiliency of affected communities. Grounded in the lived experiences of a group of people living with HIV and personally touched by homelessness, this project has unearthed important findings about the relationship between housing and health, as well as a vision of social change, the way they see it.
Figure 20: “Homes now!” - Rob
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196


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