

The Health and Social Service Experiences of Eleven Older Adults Living with
HIV/AIDS in the National Capital Region

by

Charles Furlotte, BA (Hons.), Mount Allison University

A Thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
Master of Social Work

School of Social Work
Carleton University
Ottawa, Ontario

January, 2009

© Copyright
2009, Charles Furlotte



Library and
Archives Canada

Published Heritage
Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et
Archives Canada

Direction du
Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 978-0-494-47543-0
Our file Notre référence
ISBN: 978-0-494-47543-0

NOTICE:

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protègent cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

■ ■ ■
Canada

The Health and Social Service Experiences of Eleven Older Adults Living with
HIV/AIDS in the National Capital Region

by

Charles Furlotte, BA (Hons.), Mount Allison University

A Thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
Master of Social Work

School of Social Work
Carleton University
Ottawa, Ontario

January, 2009

© Copyright
2009, Charles Furlotte

The undersigned recommend to the Faculty of Graduate Studies

And Research acceptance of the thesis

The Health and Social Service Experiences of Eleven Older Adults Living with
HIV/AIDS in the National Capital Region

submitted by Charles Furlotte, BA (Hons.)

in partial fulfillment of the requirements for

the degree of Master of Social Work

Dr. Karen Schwartz

Thesis Supervisor

Diana Majury.

Acting Director, School of Social Work

Carleton University

January 25th, 2009

Date

ABSTRACT

This study investigates health and social service experiences of eleven older people living with HIV/AIDS (oPHAs) in the National Capital Region. Participants, recruited through an AIDS Service Organization, completed demographic and service use questionnaires, scales measuring barriers to care and depressive symptoms, and were interviewed regarding their service experiences. Participants reported using both HIV-specific and mainstream services, and reported lacking long term care, housing and mental health services. Stories revealed some participants feel lack of recognition, uniqueness, and confusion in their services. oPHAs also reported several discriminatory service experiences, and spoke of professional, institutional, and PHA power. Finally, experiences were framed as barriers or facilitators to service use. Overall, participants' stories included phenomena articulated in previous literature. Social workers in this niche field may wish to do interdisciplinary work with other professionals, as well as act transdisciplinarily with PHA community members.

ACKNOWLEDGEMENTS

First and foremost, I would like to acknowledge the participants of this study: although you remain nameless you will be remembered for opening my eyes, touching my heart, and inspiring this project; you are all amazing. Thanks to Mr. Khaled Salam at the AIDS Committee of Ottawa for his help with recruitment and emotional support over the years. I would also like to thank Ottawa's PHA community for their support and friendship.

I would like to thank the amazing Dr. Karen Schwartz for her dedication, encouragement, guidance, knowledge and support. You are an inspiration, and I am a better researcher because of you! I thank the brilliant Dr. Sarah Todd for her expertise, honesty and for challenging me to grow as a student. Also, thanks to Dr. Connie Kristiansen for her most generous willingness to act as external reviewer and lending her expertise to this project. I thank Dr. Stephen Hick for encouraging research and facilitating a mindful connection and Dr. Adje Van DeSande for his understanding of student reality, and consistent support. I'd also like to thank Dr. Odette Gould, always an inspiration.

I would like to express my gratitude the staff at the Carleton University Library, MADGIC, School of Social Work, and the Awards office. In addition, I would like to send a warm thanks to staff at the Dalhousie Centennial Library, for encouragement and cheer while I completed this work. Thanks for Jennie for the excellent transcribing. I'd like to send a shout out to my social work colleagues, who put up with me constantly talking about my research, and were very supportive throughout this very stressful process. Thanks to the Ontario HIV Treatment Network and the Ontario AIDS Network for their generous support and opportunities to engage Ontario's HIV research communities; the Canadian Institutes of Health Research for is aging pillar; and the Ontario Association of Social Workers for allowing me to share my research.

I would like to send sincere thanks to my parents, for being now more open and always most loving and helpful, and to my Nanie Geralda, whose joy in her golden years shared with my grandfather sparked my interest in aging. I'd like to acknowledge my friends: Lucille, Melinda, Adele, Jason, Laser, Chris, Tanya, Karla, and my Dalhousie crew for listening to my rants, as well as everyone else who helped me achieve this goal! Thanks again!

Finally, I wanted to acknowledge that older people, regardless of HIV status, have been treated as used goods, viewed as useless, dependent, asexual; often forced into dependency, and subject to elder abuse and patronizing elderspeak. Members of society need to challenge these realities, respect their elders, and opt instead for a more inclusive, loving world.

TABLE OF CONTENTS

ABSTRACT	i
ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS	iii
LIST OF APPENEDICES	viii
LIST OF TABLES	ix
LIST OF ABBREVIATIONS	x
CHAPTER 1: INTRODUCTION	1
Rationale	1
Research Question	1
Literature Review	3
HIV/AIDS in Canada	4
Prevalence	5
HIV Transmission Among oPHAs	9
Health Outcomes of oPHAs	12
Demographic Characteristics of oPHAs	14
Service Experience and oPHAs	16
Barriers to Service Experience for oPHAs	22
Experienced Stigma and oPHAs	23
CHAPTER 2: THEORETICAL FRAMEWORK	27
Toward a Theoretical Framework for Service Experiences of oPHAs	27

Structural Social Work	28
Structural Analysis	30
Social Justice	34
Oppression	38
Forms of Oppression	41
Focus on Stigma	45
Social Determinants of Health	51
Intersectionality	53
Closing	57
CHAPTER 3: METHOD	59
Conducting a Thematic Analysis	59
Ethics	60
Participant Recruitment	60
Materials & Procedure	61
Analysis	63
Introduction to Participants' Stories	64
CHAPTER 4: HEALTH AND SOCIAL SERVICES OF OLDER ADULTS LIVING WITH HIV IN THE NATIONAL CAPITAL REGION	67
Introduction	67
Participants and Group Description	67
Types of Service Use Reported by oPHAs	71
Perceived Lack of Services	77

Long Term Care	77
Housing	80
Mental Health Services	82
Chapter 5: PROBLEMS OF RECOGNITION, UNIQUENESS AND CONFUSION IN SERVICES FOR OPHAS	85
Introduction	85
Recognition	86
Uniqueness	87
Intersectionality Focus: Older Women Living with HIV/AIDS	89
Intersectionality Focus: Homelessness & oPHAs	92
Confusion	94
CHAPTER 6: DISCRIMINATION IN THE HEALTH AND SOCIAL SERVICES OF OPHAS	108
Introduction	108
Examples of Discrimination and Exceptionalism in Services for oPHAs	108
Anticipated Stigma in Services of oPHAs	115
Assumptions of HIV-related Stigma	121
CHAPTER 7: POWER IN SERVICE EXPERIENCES OF OPHAS	127
Introduction	127

Violation	127
Power Struggles	129
Professional Power	133
Institutional Power	137
Bureaucracy	138
Integrated Services	140
Wait Times	144
PHA Power in Health and Social Services	150
CHAPTER 8: CONCLUSION & DISCUSSION	158
Putting it All Together: Barrier to Service	158
Discussion	163
Summary of Themes	163
Strengths and Limitations	165
Relevance to Social Work Practice	167
Relevance to Social Policy	170
Future Directions	174
REFERENCES	175
APPENDIX I: PHA SERVICES IN ONTARIO AND THEIR NEOLIBERAL CONTEXT	207
APPENDIX II: THE RESEARCH ENTERPRISE AND OLDER ADULTS LIVING WITH HIV/AIDS	213

APPENDIX III: LETTER OF INFORMATION (INFORMED CONSENT)	219
APPENDIX IV: DEBRIEFING FORM	220
APPENDIX V: COPY OF RESEARCH INSTRUMENTS	224
APPENDIX VI: COPY OF ADVERTISEMENT	225
APPENDIX VII: COPY OF THEME LIST	226
TABLE 1: GERIATRIC DEPRESSION SCALE SUMMARY TABLE.....	226
TABLE 2: BARRIERS TO CARE SCALE SUMMARY TABLE	227

LIST OF APPENDICES

**APPENDIX I: PHA SERVICES IN ONTARIO AND THEIR NEOLIBERAL
CONTEXT**

**APPENDIX II: THE RESEARCH ENTERPRISE AND OLDER ADULTS LIVING
WITH HIV/AIDS**

APPENDIX III: LETTER OF INFORMATION (INFORMED CONSENT)

APPENDIX IV: DEBRIEFING FORM

APPENDIX V: COPY OF RESEARCH INSTRUMENTS

APPENDIX VI: COPY OF ADVERTISEMENT

APPENDIX VII: COPY OF THEME LIST

LIST OF TABLES

TABLE 1: GERIATRIC DEPRESSION SCALE SUMMARY TABLE

TABLE 2: BARRIERS TO CARE SCALE SUMMARY TABLE

LIST OF ABBREVIATIONS

- AD: Alzheimer's disease
- AIDS: Acquired Immune Deficiency Syndrome
- ARC: AIDS-related complex
- ASO: AIDS Service Organization
- CPP/QPP: Canada Pension Plan/ Quebec Pension Plan
- HAART: Highly Active Anti Retroviral Therapies
- HIV: Human Immunodeficiency Virus
- IDU: Injection drug use(r)
- LHIN: Local Health Integrated Networks
- MSM: Men who have sex with men
- NCR: National Capital Region
- OAN: Ontario AIDS Network
- ODSP: Ontario Disability Support Program
- OHIP: Ontario Health Insurance Plan
- OHTN: Ontario HIV treatment network
- oPHA: Older persons living with HIV/AIDS
- PHA: Persons living with HIV/AIDS
- PHAC: Public Health Agency of Canada

CHAPTER 1: INTRODUCTION

Rationale

A critical gap in social work research is the lack of attention paid to older adults living with HIV/AIDS in the national capital region (Emlet, 2004). People over age fifty make up a small but growing segment of the PHA¹ community. Promising HIV therapies combined with our aging population trends means more people will age into intersections of oppressions, and merit further attention from health and social service providers. There is limited but growing acknowledgement within the social work profession of HIV/AIDS among older adults, insofar as very limited research addresses the health and social service experiences of oPHAs, or the barriers to care this marginalized group may face (Fritsch, 2005; Emlet, 2004; Poindexter, 2004). As such, clients are left with a real need for improved services, and social workers are left with a gap in best practices guidance for helping a group challenged by this specific constellation of concurrent health and social problems.

Recent increase in scholarly emphasis on older oPHAs identifies a shift in the response of the health and social sciences to HIV; that is, a shift away from a goal of aging *without* to aging *with* HIV². Older adults living with HIV represent the optimistic notion that HIV can be incorporated into the idea of successful aging³ (Vance & Robinson, 2004; Kahana & Kahana, 2001), signaling a new frontier in experience and thought surrounding HIV/AIDS⁴ (at least in westernized nations where HIV is not

¹ PHA is an acronym for *persons living with HIV/AIDS*.

² It is questionable what this meaning bodes for the emphasis of finding a definitive cure for HIV-infection.

³ For review of successful aging, please see Baltes & Baltes, (1998); Vaillant & Mukamal (2001).

⁴ This has led some authors in the field of HIV to question whether oPHAs in the western world are “past it?” (Dougan, Payne, Brown, Evans & Gill, 2004). While this is an optimistic assessment, it is likely that

endemic and effective treatments are available and well-distributed). An increase in the prevalence of HIV in older adulthood, coupled with longer life expectancies due to advanced HIV treatments (e.g. HAART, protease and fusion inhibitors; ATCC, 2008) means that practitioners from a variety of disciplines will need to learn to integrate their knowledge of aging and HIV, and formulate new and innovative approaches to working with older adults living with HIV/AIDS (Emlet, Gusz & Dumont, 2002).

The present study provides new insight into the health and social service experiences of older PHAs using a lens of critical, structural analysis focused on social justice and anti-oppression. By examining the experiences of oPHAs in the previously unexplored national capital region (or, NCR), this study provides insight into the experiences of oPHAs in an urban setting in which both publicly funded aging and AIDS-related services are perceived to be readily available⁵. It is my hope that this present study (a) makes visible older adults within Ottawa's PHA community, (b) encourages these people to speak freely about their health and social service experiences, and (c) encourages continued participation of oPHAs in driving PHA services, as mandated in social justice inspired international policies like the *Greater Involvement of People Living with HIV/AIDS* (GIPA) principles (UNAIDS, 1999; Travers et al., 2008).

Research Question

The present study was guided by the question: 'What are the health and social service experiences of older adults living HIV in the national capital region?' In the present study, health and social services are defined as (a) personally experienced

reaching old age introduces a plethora of health and social problems that add to the challenges of aging with HIV.

⁵ Furthermore, this information will assist in informing social work practice in Ottawa and the NCR, and serve as a basis for further research into practice with older, HIV-positive Ottawa citizens.

encounters between clients (or, patients) and service providers, and (b) social opportunities.

Literature Review

Introduction

The present study draws upon a broad range of previous research conducted with older adults living with HIV (or, oPHAs⁶) to better contextualize health and social service experiences. First, previous research informs a brief overview of HIV/AIDS in the western world. Older adults make up more than one tenth of people living with HIV (or, PHAs) and their proportion has and continues to increase due to improved drug treatments. While transmission rates among oPHAs are similar to younger PHAs, older adults are particularly at risk, and experience different health outcomes than their younger counterparts. Also, oPHAs fare better than younger PHAs economically, but worse than adults living without HIV, and marginal groups (e.g. women, racial minorities) are overrepresented across age groups in the PHA community. Several studies of service experience of oPHAs have been conducted, outlining the type and source of services oPHAs use, and there has been debate as to whether oPHAs are more or less likely to access certain services. Emerging literature suggests PHAs may experience barriers to care, and several of these barriers are found to be based on stigma. While oPHAs have been largely ignored in social work research of PHAs, there is an

⁶ This diverse group, also referred to as older persons living with HIV/AIDS, is referred to herein as oPHAs. I created acronym for the purpose of abbreviation in this project. This group has also been referred to as older people living with AIDS (or, older PLWAs) older adults living with HIV/AIDS, people living with the human immunodeficiency virus (or, PLWHIV) or, in some cases, long term survivors.

established body of literature from various disciplines of research, the PHA community, and the popular media.

HIV/AIDS in Canada

The human immunodeficiency virus (HIV) crisis significantly impacts the reality of health and social services in Canada and internationally. HIV is an acronym developed by the scientific community to signify a set of chronic diseases that became a pandemic over the last quarter century. HIV is transmitted when human bloodstreams come into contact through unprotected sex, sharing equipment associated with injection drug use, or tainted blood transfusions (Canadian AIDS Society, 2004). The progression of the virus follows a predictable trajectory. Once a person tests positive for HIV antibodies, they are considered to be infected with the virus, or HIV-positive⁷. Following a positive diagnosis, a person may continue to feel perfectly healthy, despite the replication of the virus' RNA taking place in the body. The most common method of tracking the impact of the virus has been to measure (a) viral load; high numbers indicate disease progression, and (b) immune function via amount of CD4 T-cells, also known as *helper* T-cells; low numbers indicate damage to the immune system (CASW, 1997, p. 95). A person is considered to have progressed from HIV infection to acquired immunodeficiency syndrome (or, AIDS) when their viral load and CD4 counts reach levels that allow co-infections to occur⁸ (Wooten-Bielski, 1999, p. 269).

While HIV remains a leading cause of death worldwide, advanced treatments such as highly active antiretroviral therapies (HAART), and more recently highly

⁷ Society has created the categories of HIV-positive and HIV-negative, and HIV-unsure.

⁸ When a person's CD4 count falls below 200, they are generally considered to have developed AIDS (Emlet, Gusz & Dumont, 2002, p. 53). AIDS leaves a person susceptible to further opportunistic infections, resulting in compromised health.

effective protease and fusion inhibitors have reduced the disease from an acute, fatal illness to chronic disease, at least in westernized countries (Scott & Constantine, 1999; Manton & Stallard, 1998; Tashima & Carpenter, 2003; Vance & Robinson, 2004). Proper adherence to these novel therapies creates an increased period of time between initial diagnosis and disease progression, and thus longer survival times for people living with HIV (Barclay, 2007; Siegel, Schrimshaw, & Dean, 1999; Wooten-Bielski, 1999, p. 272). As a result of increased longevity, it is now possible for people to age well into older adulthood with HIV/AIDS; a phenomenon that has been referred to as the *Lazarus* effect (Scott & Constantine, 1999). However, our social climate may present barriers for oPHAs from actualizing the positive potential of this effect. Specifically, older adults living with HIV may experience structural barriers (e.g. ageism, HIV-related stigma) to optimal health and social care services that prevent them from aging well, and exclude them from the dominant discourses on HIV/AIDS.

Prevalence

The prevalence of HIV infection among older Canadians remains small, but nonetheless merits a serious response from health and social service providers. Canada, like many other countries, is made up of a quickly aging society (for review, Lubben & Damron-Rodriguez, 2006). Statistics Canada (2004) reported that adults over age fifty made up 30.7% of the Canadian population, an estimate that has been predicted to grow to 41.3% by 2026 (Eldred & West, 2005, p. 21). Similarly, people sixty-five years of age or older have recently been predicted to grow from 13.2% in 2006 to 21.2% in 2026 (CTV, 2007). It has been predicted that as the number of older adults increases across Canada, HIV cases among this population will also rise.

It is estimated that approximately 40 million people are living with HIV/AIDS worldwide (Public Health Agency of Canada, 2008; United Nations Joint Program on HIV/AIDS & World Health Organization, 2007). In Canada, the total number of people living with HIV infection at the end of 2005 was over 58,000 (Public Health Agency of Canada, 2008). The total number of AIDS cases has been estimated to be 18,000. It has been suggested that 42.6% of all HIV-positive cases and 23.8% of all AIDS cases in Canada occur in the province of Ontario (Fritsch, 2005, p. 35). Other sources report that there were 26,300 PHAs in Ontario in 2006, an increase from 18,000 in the 2000 (City of Ottawa, 2008). In 2007, there were 145 newly reported HIV infections in Ottawa, accounting for 13.5% of infections in Ontario that year (Ontario HIV Epidemiologic Monitoring Unit, 2008). It is important to note that the prevalence and incidence surveillance of HIV/AIDS in Canada is often misinterpreted, primarily because the Public Health Agency of Canada (PHAC) differentiates between documented cases of HIV infections (e.g. positive HIV antibody tests reported) and AIDS cases (e.g. people who have reached the AIDS stage of the HIV trajectory), and cannot possibly account for people who are living with HIV but have not been formally diagnosed. Thus, there is some discrepancy in the public domain regarding how many Canadians are in fact living with HIV/AIDS.

Older adults make up a substantial proportion of people living with HIV/AIDS both in Canada and abroad. In addition, the number of both HIV and AIDS cases among this age group is on the rise worldwide. Generally, the prevalence of HIV/AIDS in older adults living in westernized nations has been suggested to range from 10 to 12%. In Canada, it is believed that older adults make up 10 to 12% of people living with

HIV/AIDS (Eldred & West, 2005; Public Health Agency of Canada, 2004)⁹.

Interestingly, the general numbers of AIDS cases in Canada have decreased over time (due to HAART), however the proportion of AIDS cases that are 50 years of age and older has increased (from 11.3% in 1994 to 20% in 2002; PHAC, 2004). Similar age-related HIV trajectories are unfolding internationally. In the United States, research has consistently shown an incidence of between 10% and 11% (Joyce et al., 2005; Emlet & Poindexter, 2004; Zingmond et al., 2001; Wooten-Bielski, 1999; Meadows, Marechal & Catalan, 1998; Emlet, 1997). Similarly, the proportion of older adults living with HIV/AIDS in Britain has been suggested to be 11% (Meadows, Marechal & Catalan, 1998).

Research has suggested that HIV in older adults is on the rise. For example, in the United States, the number of oPHAs has increased by 138% between 1993 and 2000 (Moore & Amburgey, 2000, p. 873), representing about 8,000 PHAs over aged 50. In addition, a 1998 study in the United States reported that HIV rates are growing twice as fast in older rather than younger adults (Emlet & Poindexter, 2004, p. 87). In Canada, the proportion of annual HIV-positive test results among older adults has risen from 7.2% in the period between 1985 and 1997, to 11.3% in the period between 1998 and 2002 (PHAC, 2004). In 2003, 293 new cases of HIV were diagnosed among Canadian older adults (Eldred & West, 2005, p. 20). There is also evidence that HIV is affecting the senior citizens. In the United States, for example, between 2001 and 2002, the number of HIV/AIDS cases among persons 65 and over has risen from 1.4% to 2.0% (CDC, 2003; in Elmet & Poindexter, 2006, p. 92).

⁹ The Public Health Agency of Canada (2004) noted that this 12% equated to 2,222 out of 18,929 reported AIDS cases in Canada (e.g. people living with HIV who have progressed to AIDS status).

Researchers familiar with public health agency data collection procedures have suggested that a critical examination of HIV prevalence rates among older adults is necessary (e.g. Lieberman, 2000), primarily because most studies report either new HIV infections, or largely ignore statistics associated with people who have ‘aged into AIDS’ (Emlet & Poindexter, 2004, p. 87). Poindexter (2004) reports that by 2001, more than 90,000 Americans had become ill with AIDS at or beyond age 50, *excluding* persons over 50 diagnosed with AIDS at younger ages who are now over 50 years old (CDC, 2002; in Poindexter, 2004, p. 3). Emlet (2005) suggests that “When numbers are adjusted to reflect actual age rather than age at diagnosis, the proportion of persons older than 50 living with AIDS is closer to 15%” (Emlet, 2005, p. 291). Mack & Ory (2003) reported that 18.9% of persons living with AIDS in the United States were over 50 years of age or older.

It is been suggested that the conservative underestimate of oPHAs may be because AIDS goes undiagnosed in older people to a larger degree than the younger counterpart (El-Sadr & Gettler, 1995¹⁰; Wooten-Bielski, 1999, p. 43), and research points to a lack of HIV testing among this age group (Eldred & West, 2005, p. 21). In other words, although older adults living with HIV represent a significant shift in the demographics of HIV/AIDS, they are largely ignored and inadequately tallied by government health agencies. This has led to authors referring to oPHAs as ‘overlooked’ (Riley, 1989), ‘silent’ (Hall Gueldner, 1995), ‘hidden’ (Emlet, 1997), ‘unseen’ (Emlet &

¹⁰ El-Sadr & Gettler (1995) conducted a landmark study at a U.S. hospital to investigate missed HIV diagnoses. Researchers tested all blood specimens from persons over the age of 60 who died at the hospital between 1992 and 1993 ($n = 257$). Results indicated that 5% were found to be HIV positive, even though none of these patients were diagnosed with HIV while alive. Furthermore, a retrospective chart review of these patients’ medical histories failed to identify any risk factors for HIV infection, illustrating the importance of improved screening measures for older adults. It is unknown whether this remains the case.

Poindexter, 2004) or ‘invisible’ (Genke, 2000). It is questionable whether this obscurity translates into barriers to services and care for older adults. As numbers of oPHAs increase, health and social service providers will need to formulate innovative ways to reach people who experience this particular combination of marginalities.

HIV transmission among oPHAs

The present study of health and social service experiences of oPHAs did not ask participants to indicate how they believe they became infected with HIV. Routes of HIV transmission do not shed very much light upon social location or identification with a particular social group. Rather, knowledge of transmission route can only describe behaviors that may either (a) represent isolated sets of actions, or (b) reinforce stereotypes (and oppressions) experienced by certain groups (e.g. gay people, women, shared injection drug users, etc.). This being said, transmission routes have traditionally been used in research to allow for comparative analyses. Therefore, the present study is informed by recent research into transmission routes for oPHAs. Specifically, it is likely that the failure of service providers to acknowledge sexuality and shared injection drug use among older adults creates an effective barrier to service use among this group, and such ageist, ‘closed thinking’ concerning oPHAs impedes effective service.

The two most common ways of transmitting HIV are through unprotected sex and shared injection drug use (or, IDU). This is a particularly problematic reality for older people, who are subject to ageist stereotypes of asexuality or celibacy and abstinence from drug use. This is far from the case, as demonstrated by research documenting both active sex lives and substance use/abuse in older adulthood¹¹ (e.g. Winningham, Ritcher,

¹¹ *Time* magazine recently ran an article about sexually transmitted diseases in midlife and older adulthood (Sharples, 2008)

Corwin, & Gore-Felton, 2004; Winningham, 2004; Gott, 2001; Murray & Adam, 2001; Topolski, 2002). The fact remains that while routes of HIV transmission among oPHAs are considered highly variable, they remain strikingly similar to the transmission routes of younger PHAs. However, this was not always the case. Recently, there has been a shift in acknowledgement of transfusion-based transmission to sexual and shared IDU transmission among both heterosexual and homosexual older adults¹² (Eldred & West, 2005, p. 21; Coleman, 2003; Savasta, 2004; Topolski, 2002). Specifically, the PHAC (2004) also reports that 47% of HIV positive test results among those age 50 and over were attributed to homosexual sex, 27% to heterosexual sex, and 20% to shared IDU.

The majority of sexual transmissions among oPHAs occur among men who have unprotected sex with men (MSM)¹³. The Public Health Agency of Canada (PHAC, 2004) assessed reported HIV/AIDS cases in older adults and found that transmission between MSM accounted for 70% of infections among those aged 50-59 year olds and 52% among adults over age 60. This is unsurprising considering the gay community was initially most affected by HIV/AIDS, and demonstrates the need for acknowledgement of MSM and homosexuality among senior citizens in Canada. While transmission between MSM continues to dominate this age group, there is also a documented increase in transmission stemming from unprotected heterosexual sex (Emlet, 1997, p. 70)¹⁴. Also, older adults share equipment associated with injection drug use (IDU). Savasta (2004)

¹² Traditionally, HIV infection among people over age 50 had been attributed to tainted blood transfusions. However, the continued rate of infection among this age group following the introduction of national blood screening suggests this is no longer the case (Emlet, 1997, p. 70).

¹³ Research suggests that more than 40% of men living with AIDS over age 60 have engaged in homosexual sex (Meadows, Le Marechal & Catalan, 1998, p. 105).

¹⁴ Gordon and Thompson (1995) analyzed data collected by U.S. Centers for Disease Control between the periods of 1982-88 and 1989-91, (n = 6,207) and found that unprotected heterosexual contact became a significantly higher risk factor for older adults during this period (Gordon & Thompson, 1995; in Emlet, 1997, p.70). While this study was conducted in 1995, transmission rates among heterosexuals have become accepted as a fact of the pandemic.

conducted a review of literature concerning HIV transmission risk factors among older adults, and noted that 76% of scholarly articles mention IDU. Furthermore, Topolski et al. (2002) outlines research and practice guidelines for dealing with substance abuse, HIV and aging.

Several explanations are offered to account for the alarming increase of infection among both homosexual and heterosexual older adults. There are several physiological transmission risks identified as specific to older adults. These include age-related thinning of anal and vaginal mucosal linings causing increased susceptibility to HIV (Eldred & West, 2005, p. 22), as well as an age-related reduction in immunity, causing higher susceptibility to infection in general (Eldred & West, 2005, p. 22).

Since aging heterosexual women typically outlive their male partners, it is suggested there is increased sharing of older male sexual partners among older heterosexual women, leading to an increased number of sexual partners among this age group (Eldred & West, 2005, p. 21). It is also suggested that older adults are likely to participate in the sex trade while vacationing in warmer climates and these areas may have a higher HIV prevalence (Eldred & West, 2005, p. 21). Also, there is a documented increase in on-line dating, attendance at singles clubs, and use of sexual aid devices (e.g. Viagra) among this age group (Eldred & West, 2005, p. 21).

Older adults may not perceive themselves as at risk for becoming infected with HIV (Wooten-Bielski, 1999, p. 268). Sadly, many in the present older adult cohort who have recently divorced or been widowed may not have been actively dating since before the AIDS epidemic first occurred, and thus have not learned to incorporate safety measures into their sexual behaviors. In addition, it has been suggested that the

decreased likelihood of pregnancy associated with old age results in low condom use among this age group (Emlet, Gusz & Dumont, 2002; Goldman, 2006). These physical and social factors, along with lack of education, compounded by an ageist society place older adults at increased risk of becoming infected with an otherwise preventable disease, and this may render oPHAs invisible. This review of transmission literature informs this project in that the I (and future service providers) will likely intersect with older adults who have sex and share injection drug equipment. Thus, the study was designed to be nonjudgmental of and open to discussing these behaviors.

Health outcomes of oPHAs

While it is suggested that advanced HIV treatments are improving the life expectancies of PHAs in high income countries, recent research suggests that these therapies extend life by only a little more than a decade or so¹⁵ (ATCC, 2008). It is well-documented that oPHAs experience particular health issues (for review, see Emlet & Nokes, 2006) that potential service providers should be aware of. HIV/AIDS in older adults is characterized by delayed testing and diagnoses (e.g. Siegel, Scrimshaw & Dean 1999b; Zingmond et al., 2001) missed diagnoses (El-Sadr & Gettler, 1995), misdiagnoses¹⁶ and symptom ambiguity¹⁷ (e.g. Segal, Schrimshaw & Dean, 1999a; 1999b; Wooten-Bielski, 1999, p. 268), which in turn results in delayed treatment for many oPHAs. Once diagnosed, oPHAs experience accelerated disease progression (Kohli, 2006; Manfredi, 2004; Meadows, Le Marechal & Catalan, 1998; Adler et al., 1997,

¹⁵ The Canadian Broadcasting Company (CBC) reported recently that life-saving drugs improve life expectancy by 13 years (Draaisma, 2008)

¹⁶ The most common misdiagnoses among older adults infected with HIV are Alzheimer's disease, Parkinson's disease, cancer, chronic obstructive pulmonary disease and pneumonia (Emlet & Poindexter, 2004, p. 89).

¹⁷ HIV among older people has been called 'the great imitator' (Whipple & Scura, 1996, pp. 23-24), leading people to question whether symptoms should be attributed to "H-I-V or A-G-E?" (Caffazo, 2004, p. D1, 4)

Emlet, 1997, p. 72), increased disease co-morbidity¹⁸ (Kilbourne et al., 2001; Skiest et al., 1996; Wooten-Bielski, 1999; Emlet, 1997, p. 72), and weaker immune function attributed to the combination of both HIV status and natural age-related immune suppression (Eldred & West, 2005, p. 22). To this end, the present study administered several measures to investigate disease progression, co-morbidity and treatment regimens of oPHAs.

Research has also been conducted on the mental health of oPHAs. Specifically, oPHAs may experience neuropsychiatric and neurocognitive problems (Hinkin, Castellon, Atkinson & Goodkin, 2001; Wilki et al., 2003) dementia (Valcour & Sacktor 2002), depression and suicide (Heckman, Kockman & Sikkema, 2004; Heckman, Kochman & Sikkema, 2002; Heckman, Kochman, Sikkema, Kalichman, 1999; Meadows, Marechal & Catalan, 1998; Badger, 1998; Kalichman, Heckman, Kochman, Sikkema, Bergholte, 1996), and other psychosocial issues (Lavick, 1994), all of which may relate to the overlap of age and HIV disease progression. Because of the central roles of social workers demonstrated in the literature on mental health and PHAs (e.g. Emlet 1993; Emlet & Poindexter, 2006; CASW, 1997; Beauger, Dupy-Godin & Jumelle, 1989) and the questionable impact of mental health as a facilitator or barrier to health and social service experience, the present study investigated depressive symptoms among participants.

Additional health-related research has been conducted on oPHAs and drug use (Topolski, 2002), smoking (Crothers, 2006), adoption of celibacy (Siegel & Schrimshaw, 2003), and medication adherence (Barclay et al., 2007; Segal, 1999). Shockingly,

¹⁸ It has been reported that the major comorbidities of HIV/AIDS in older adults are pneumonia, herpes, tuberculosis, cytomegalovirus, oral thrush, mycobacterium avium complex, HIV-related dementia, cervical cancer, and in some cases COPD (Wooten-Bielski, 1999, p. 268; Crothers, 2006).

medication interactions that could potentially occur in this population are largely uninvestigated. Also, it is suggested that oPHAs have been traditionally excluded from clinical HIV drug trails based on age¹⁹ (Chiao, Ries & Sande, 1999; Emlet, 1997; Goldman, 2006)²⁰. Finally, it is important to note that much of the research described was conducted over a decade ago, and may not represent the health outcomes for older adults today. Thus, researchers would be wise take into account variability among oPHAs and avoid health-related assumptions.

Demographic characteristics of oPHAs

There is emerging literature asserting that social inequalities, as determined by socioeconomic demographics, impact access to health and social services, and health outcomes of Canadians (e.g. Raphael, 2004; Wilkinson & Marmot, 2003). Older adults experience similar oppressions and social determinants of health as do younger adults, and these similarities surely extend to older PHAs. Specifically, racial minorities, women and the economically disadvantaged are all overrepresented in this age/disease group. This overrepresentation of the traditionally oppressed suggests the existence of structural forces that may be especially salient (or, compounded) for oPHAs²¹.

According to Poindexter & Emlet (2006, p. 92), blacks, Latinos, and females are all over-represented across all age groups living with HIV, including oPHAs. For instance, Joyce et al. (2005, p. 22) conducted a comprehensive study that found African and Hispanic American men were overrepresented across both younger and older PHA

¹⁹ The common belief is that age confounds health outcomes in clinical drug trial results.

²⁰ Since older adults have been more likely to take more medications than younger adults, it is suggested that medication interactions may also contribute to reduced health in older adults living with HIV/AIDS (Emlet, 1997, p. 73). However, there have been very few studies conducted regarding how medications commonly distributed to older adults will interact with HAART therapy (Emlet, 1997, p. 73; Goldman, 2006). In addition, clinical drug trials have typically excluded older adults living with HIV on the basis of their non-HIV medications confounding research findings (Goldman, 2006).

²¹ Black feminist writer Deborah King (1988) described this as double jeopardy.

groups. Specifically, whereas African Americans made up only 10.3% of the general older adult population in the US, they represented over 40% of the older adult population living with HIV (Joyce et al., 2005, p. 22). Emlet, Gusz & Dumont (2002, p. 43) suggest that older women of color are profoundly affected by HIV. Particularly, African American women represent twice the proportion of AIDS cases than white women (Emlet, Gusz & Dumont, 2002, p. 44). This increased prevalence among African American women may stem from multiple forces of oppression operating in their lives, such as gender and racial inequalities inherent in western society and articulated in black feminist literature (e.g. King, 1988).

Limited research has been conducted into the socioeconomic conditions of oPHAs. Meadows, Le Marechal & Catalan (1998) measured people living with HIV in the United States ($n = 52$), and found that oPHAs reported significantly more employment and financial concerns than did younger PHAs. Crystal et al. (2003) studied data from the U.S. HIV Cost and Services Utilization Study and found that oPHAs in the United States were mostly gay men with higher education, income and rate of private insurance plans than the PHA population in general. The largest study conducted on economic conditions of older adults has been Joyce et al. (2005), who compared large samples of participants from the U.S. HIV Cost and Services Utilization Study ($n = 2,864$) to participants from the U.S. Health and Retirement Services Study ($n = 9,810$). Researchers compared older adults living with HIV/AIDS to both the older adult and HIV-populations in general. Interestingly, while oPHAs in the United States reported more financial resources than did younger PHAs, they reported fewer resources than

older adults in general²². HIV was also associated with lower levels of employment in older adults. Specifically, 40% of oPHAs reported being employed, which sharply contrasts with the 71% of older adults in general.

Together, these findings suggest that oPHAs are economically disadvantaged compared to older adults in general, and that decreased socioeconomic status is especially pronounced among participants of minority status. Also, oPHAs may be better off financially than their younger counterparts. This research focuses on samples of Americans, whose economic situation exists in the context of the U.S. health, economic social policy. For instance, Emler (1997) suggests that older Americans living with HIV/AIDS may experience financial problems associated with the high cost of medications (Emler, 1997, p. 73), whereas this may not be the case in Canada, where access to nationalized public health insurance and drug plans covering HIV treatments are available (e.g. Ontario's *Trillium* drug plan, etc.). Currently, there remains a critical gap in Canadian research into the economic condition of oPHAs; how they fare economically compared to younger PHAs, and older adults in general. A review of the socioeconomic demographics of oPHAs is important to the present study, as this information will assist in identifying ways in which race and class are treated in society (e.g. racism and classism), which in turn may influence access to and experience of health and social services for these oPHAs.

Service experience and oPHAs

The present study focuses on the experience of health and social services among oPHAs in the national capital region (NCR). Service experiences are defined here as a

²² Specifically, results indicated that while the 67% of older adults in general had assets of at least \$50,000 USD, only 14% of oPHAs met these criteria (Joyce et al., 2005, p. 22).

phenomenon experienced between clients (or, patients) and a service provider, and as social benefits, or opportunities. Social work research identifies service utilization, or service use as crucially important to planning (Harel, Noelker & Blake, 1985, cited in Emlet, 2004, p. 10)²³. Agencies, whether AIDS service organizations (ASOs), community health centers, homeless shelters, or women's groups must be prepared to use sound research into the types of services sought and used by potential clients in order to make appropriate, optimal, and economically efficient programming decisions.

Previous research into service use, accessibility, and satisfaction with health and social services of oPHAs is scarce and ambiguous, and a Canadian perspective of health and social service experiences is limited to one previous study (i.e. Fritsch, 2005). In addition, no research to date employs a structural theoretical lens to examine service experiences among oPHAs in North America. Instead, most employ behavioural models like those proposed by Andersen (1968; Andersen & Newman, 1973). This lack of research emphasis on *service* experiences, despite increased research into the *life* experiences of oPHAs (Siegel, Raveis & Karus, 1998; Sankar, Luborsky, Rwabuhemba, & Songwathana, 1998) may in fact identify a critical gap in Canadian health and social service research.

Social work professor Charles Emlet (2004, p. 9) notes that older adults with HIV require complex care. Several authors have contributed articles on providing services for oPHAs (Emlet & Poindexter, 2006; 2004; Nokes & Emlet, 2006; Nichols et al., 2002).

²³ The phenomenon of accessing services has been referred to as service *utilization* (e.g. Andersen, & Newman, 1973; Wan, 1989; Emlet, 1993; Emlet & Farkes, 2002; Kouzis & Eaton, 1998; Philips, Morrison, Andersen & Aday, 1998; Hays et al., 2000; Stein, Andersen, R. & Gelberg, 2007) and service *use* (e.g. Andersen, 1968; Badger, 1998; Bradley et al., 2000; Emlet & Berghuis, 2002; Emlet, 2004). These terms are often used interchangeably. The present study refers to these phenomena as service *experiences*, to better identify the constructed phenomenological nature of service relationships.

What resonates throughout the research is that older PHAs must manage their medical, social and economic well-being, which presents significant challenges. Crystal & Sambamoorthi (1998; 1999) outline several critical issues of healthcare service needs and services for oPHAs, including length of hospital stay and need for long term care. In addition, improvements in medical and social care for people living with HIV are changing the nature of the services now available and accessed (for a review, see Emlet & Poindexter, 2006).

Poindexter and Emlet (2006) suggest that social services commonly accessed by people living with HIV/AIDS include: case management, PHA support groups, individual and group counseling, HIV education, benefits advocacy, and legal services (Poindexter & Emlet, 2006, p. 95). While the nature of services required remains similar across age groups of PHAs, it is suggested that oPHAs may have an increased need for outreach care in addition to these services (Poindexter & Emlet, 2006, p. 95).

Emlet & Poindexter (2006, p. 568) identify three central providers of services for this group: (a) mainstream public health and social service organizations, (b) university medical centers and clinics, and (c) AIDS Service organizations²⁴ (or, ASOs). In addition, oPHAs may have several options when seeking health and social care, as there are services in place directed specially at both PHAs and older adults. Emlet & Poindexter (2004) suggest that an optimal response to the needs of oPHAs, requires the inevitable integration of service networks developed for HIV, and service networks developed for

²⁴ HIV services seem to be incredibly need driven, and it has been suggested that the strength of HIV models of service utilization has been that needs have been traditionally determined by members of the PHA communities (Cain, 1993; Poindexter, 1999). This focus on client driven programming has been reflected in more recent models of service use, which have placed increasing importance on individualized service plans, and an overall movement toward 'consumer direction'-based programming, or *CD* (for review, see Yamada, 2001).

older persons, although this is not presently the case (Emlet & Berghuis, 2002).

Undoubtedly, as PHAs age, their needs and service use trends will continue to evolve and change.

A few studies addressing service utilization among PHAs have included older adults, while others have focused exclusively on oPHAs (i.e. Turner, Kelly & Ball, 1989; Solomon, Hogan, Bouknight and Solomon, 1989; Solomon, Frank, Vlahov and Astemborski, 1991; Emlet & Frakes, 2002; Emlet & Berghuis, 2002; London, LaBlanc & Aneshensel, 1998; Emlet, 2004; Fritsch, 2005; Nokes, Chew & Altman, 2003)²⁵. It is been cautioned that studies of service utilization among PHAs conducted before 1996 should be interpreted with caution, as drugs which improve the health outcomes and mobility of oPHAs have changed the meaning of what it is to be old and living with HIV, and this has impacted service utilization (Crystal and Sambamoorthi, 1998; Wellons et al., 2002). Nonetheless, Turner, Kelly and Ball's (1989) finding that oPHAs experience fewer, yet longer hospital stays than younger PHAs, nicely illustrates how a focus on quality of health services experiences, as opposed to quantity, may render a better picture of health and social care services for oPHAs.

Most of the service utilization studies conducted with oPHAs compare younger and older PHAs, and reveal different findings. For instance, Solomon, Hogan, Bouknight and Soloman (1989) conducted an early study of Medicaid service use among American PHAs, and found no age differences between older and younger PHAs. Similarly, Soloman, Frank, Vlahov and Astemborski (1991) found no age differences among PHAs in use of inpatient/outpatient hospital services. To date, these initial findings have not

²⁵ Older references have been included to reflect the totality of research concerning service use and older adults living with HIV.

been refuted, despite the increase in longevity among PHAs since the introduction of effective drug therapies. More recently, Emlet & Farkas (2002) conducted a study ($n = 571$) of adults living with HIV aged 30-81 years, all enrolled in case management services, and found that age was not a significant variable in a multiple regression analysis of service use.

Conversely, Fritsch (2005) found that older Canadian PHAs accessed *fewer* health and social service organizations than younger PHAs. A study by Emlet (1993) found oPHAs were less likely to access 'emotional support' services targeted at HIV than their younger counterparts, which supports the widely held finding that older adults are less likely to seek mental health services than middle aged adults (Emlet, 1996, p. 180). London LaBlanc & Aneshensel (1998) found old age was associated with a decreased likelihood to initiate case management services among PHAs. Emlet & Berghuis (2002) reported that oPHAs were significantly more likely than younger PHAs to report using services like physical therapy, adult day care, home chore services, and home delivered meals (Emlet & Berghuis, 2002, p. 307).

Emlet & Berghuis (2002) investigated the perceived importance of services to Americans living with HIV. The study's sample ($n = 287$) included sixty-eight older adults. In a comparison of younger and older adults, both groups rated primary medical care, case management, the U.S. AIDS drug program, and dental care as most important. Emlet (2004) conducted a study ($n = 41$) comparing knowledge of 'HIV-related' services to 'aging' services among oPHAs. Results indicated the sample had similar knowledge of both types of services²⁶, albeit, oPHAs used more services from the HIV-network ($\mu =$

²⁶ Further analyses revealed that the principal predictor of service access was awareness of service availability (Emlet, 2004, p. 9).

2.61) than the aging network ($\mu = .68$ services). While several studies asked participants to rate degree of use and perceived importance of health and social services, only two studies to date have attempted to determine satisfaction or effectiveness of service: Fritsch (2005) asked about satisfaction with services, and Nokes, Chew & Altman (2003) conducted a program evaluation revealing that oPHAs did not benefit from the use a telephone support group.

A mixed method Canadian study, the only of its kind, revealed older adults are able to access medical and social services they needed; and report positive service experiences. Fritsch²⁷ (2005) conducted a services utilization study with younger and older Canadian PHAs in the Toronto-Hamilton area, ranging from 30 to 65 years of age ($n = 34$)²⁸. The researcher divided services into categories, consisting of: counseling, education, employment opportunities, financial, nutrition, health and wellness info, housing, legal, medical and dental assistance, and recreational and social opportunities. Results indicated that oPHAs accessed significantly fewer medical services than younger adults. In addition, older adults accessed fewer health info services than younger adults in the study (Fritsch, 2005, p. 47). Interestingly, older participants reported accessing social and emotional supports to a similar or greater degree than did younger PHAs, and oPHAs accessed significantly less social organizations than did younger people. The author concluded although they accessed certain services less than their younger counterparts, oPHAs were no less able in accessing specialized services, and in fact were more directive and proactive in seeking care.

²⁷ Fritsch (2005) operationally defines access to medical and social services as “the availability of services and personnel and/or having the opportunity to use, to make use of, or to reach a service, but not necessarily having gained entry to it or to have used it” (Fritsch, 2005, p. 39).

²⁸ Fritsch’s (2005) sample consisted of 12 oPHAs.

The present study will address service experience in several ways. First, participants will be asked to indicate their service use by indicating which of twenty-seven services available in the National Capital Region they use, don't use, or need but can't get, and their importance. Also, participants will be given the opportunity to comment on their past, present and future experiences with both health and social services, and will be asked for suggestions of how to improve quality of service.

Barriers to service experience for oPHAs

It is unclear how barriers to care impact the health and social experiences of oPHAs in the national capital region. Generally, PHAs are thought to experience several barriers to accessing care, regardless of age. Heckman et al. (1998) developed the *Barriers to Care Scale* (BACS) based on twelve of the most common barriers PHAs report. These barriers include: medical personnel who decline to provide direct care to persons with HIV/AIDS, lack of health care professionals who are adequately trained and competent in AIDS care, shortage of staff to address mental health issues, lack of psychological support groups for persons with HIV/AIDS, and lack of adequate and affordable housing²⁹. In a landmark study of Canadian PHAs, Fritsch (2005, p. 44) examined barriers to medical and social services, and found that barriers to health and social services emerged from qualitative interviews in three categories: *organizational* (service availability and operational issues), *individual* (income, illness, transportation), and *informational* (lack of information, education).

²⁹ Other barriers included on the BACS were: long distances to medical facilities and personnel, lack of transportation to access services, level of knowledge about HIV/AIDS among community residents, community residents' stigma against persons living with HIV/AIDS, lack of employment opportunities for people living with HIV/AIDS, lack of supportive and understanding work environments for people living with HIV/AIDS, and personal financial resources.

It remains unclear whether older adults living with HIV/AIDS experience more or fewer barriers in accessing services than do their younger counterparts. However, Fritsch (2005) found that older adults living with HIV/AIDS experienced fewer barriers to care than did younger adults living with HIV/AIDS, and this finding, although not statistically significant, was derived from a heterogeneous sample of participants who accessed services regularly (much like the present study). It is also unknown exactly how Heckman et al.'s (1998) or Fritsch's (2005) proposed barriers to care and service impact the well-being of oPHAs. One study found that the presence of barriers to care was not a predictor of depressive symptoms among this group (Heckman, Kochman & Sikkema, 2002), and there have as of yet been no studies conducted which examine the relationship between barriers to service experience and overall health.

The present study will use the twelve-point *Barriers to Care Scale* (BACS; Heckman et al., 1998) to determine whether participants experience barriers to health and social service experience. In addition, participants will be asked to report which of twenty-six services they used, didn't use, or need and couldn't get (and, rate their importance), which will provide an additional measure of experienced barriers to care services. It is important to reiterate that while several studies have been conducted concerning services and oPHAs, no study to date has approached this relationship from a structural perspective espousing social justice and anti-oppression, and such an examination undoubtedly views barriers as indicative of social injustice.

Experienced stigma and oPHAs

HIV has been referred to as the most intensely stigmatized physical condition (for review, see Crawford, 1996), and this form of stigma may serve as an impediment to

support services³⁰. Charles Emlet (2007a,b; 2006, p. 781) found that oPHAs experience “double” stigmatization, as stigma has been suggested to (a) be a common experience of people living with HIV/AIDS (i.e. HIV-related stigma³¹), and (b) has also traditionally been directed toward older adults (i.e. ageism³²). Emlet (2006) conducted a study consisting of semi-structured interviews with oPHAs ($n = 25$), and found 68% of participants experienced both ageism and HIV-related stigma. The participants reported that the experiences often occurred separately. The author identified several common themes relating to experienced stigma among oPHAs, including: rejection, stereotyping, fear of contagion, violations of confidentiality, internalized ageism, all of which fell into four categories: social discrimination, institutional discrimination, anticipatory stigma, and other.

There is evidence that stigma experienced by oPHAs may pose aversive mental health risks. Green & Platt (1997, p. 71) suggest that stigma in health service experiences can be ‘traumatizing’. Heckman, Kochman, Sikkema & Kalichman (1999, p. 311) found that oPHAs who reported elevated levels of depression experienced HIV-related stigma and discrimination more often than those with low depression scores. Also, Heckman, Kochman & Sikkema (2002) suggest that HIV/AIDS related stigma is positively correlated with anxiety and depression in HIV patients; however their results also indicated that it is not a significant predictor of depression.

³⁰ For a detailed explanation of the concept of stigma, please refer to the ‘theoretical framework’ outlined in Chapter 2.

³¹ HIV-related stigma has been defined as prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV or AIDS (Herek, Mitnick & Burris, 1998). It is suggested that stigma among PHAs can be either enacted or felt (Green & Platt, 1997, p. 72).

³² Ageism has been described as the belief that aging “makes people unattractive, unintelligent, asexual, unemployable, and mentally incompetent” (Atchley & Barusch, 2004, p. 439; in Emlet, 2006, p. 782).

Stigma has been identified as a barrier to care and services for PHAs (Green & Platt, 1997; Heckman et al., 1998). Green & Platt (1997) measured stigma experienced by Scottish PHAs ($n = 61$) in health services, and found fear of contagion led health care workers to stigmatize HIV-positive patients. Further, Heckman et al. (1998) took stigma into account in the construction of the *Barriers to Care Scale*. Despite evidence that older adults experience increased stigma, Fritsch (2005) found that older adults felt that stereotypes interfered with services less than did younger adults.

The relationship between stigma and health and social service experiences could be multidirectional. For instance, someone having experienced stigma may be fearful of accessing future services. Conversely, experienced stigma may increase one's likelihood of accessing specialized, HIV-community-specific services offered at ASOs. It is questionable whether participants of this study experience stigma as a barrier to care.

The past research enterprise with oPHAs has several important implications for the present project. First, a solid framework for examining HIV and aging has been established, particularly within the field of social work (e.g. Emlet, 1993-2007; Maclean & Clapp, 2001a, 2001b; Poindexter, 2004; Geneke, 2000, etc). Second, there has been much work done addressing the experiences of oPHAs, which has revealed several factors the present study will address (e.g. health and social demographics, health and social service use, barriers to care, stigma, etc.). A challenge presented by the current body of literature surrounding HIV and aging is the lack of Canadian content. Specifically, there has been little research produced examining service experiences and barriers of older PHAs in the context of a national public healthcare system under threat by neoliberal trends in governance, as is the reality of older PHAs living in the national

capital region. Finally, there is a lack of emphasis on structural relations and factors experienced by oPHAs, a gap the present study aims to fill. To this end, a theoretical framework for the study was developed, and is described next.

CHAPTER 2: THEORETICAL FRAMEWORK

Introduction

This chapter outlines the theoretical framework used for the present research study of health and social service experiences of these oPHAs in the NCR³³. This study is shaped by a lens that acknowledges structural social work theory and the social determinants of health. The study engages structural social work theory, and describes its roots in critical theories, and its emphasis on structural analysis. Within this framework, the concepts of social justice, oppression, and stigma, and the experience of multiple, intersecting marginalities emerge as most relevant to the current research. Where appropriate, major concepts within this theoretical framework are described with relevance to the service experiences of older PHAs, how each guided the project design, and what each potentially makes visible (and obscures) in this study.

Toward a theoretical framework for service experiences of oPHAs

The present study takes into account the unstable, transdisciplinary and multi-faceted nature of knowledge concerning the service experiences of oPHAs in our national capital region. Developing a theoretical framework to employ in this exploratory study of service experiences of older PHAs reveals several important insights. First, no stable, single set of theories has been used this far to articulate the service experiences of oPHAs. In fact, research regarding older PHA service experiences did not exist until very recently, mainly because no one anticipated the post-HAART reality of the western AIDS

³³The theoretical framework employed in this research project fits nicely with both social work practice education at Carleton University's School of Social Work ("Misson"; www.carleton.ca/ssw/), and the belief and value system of Ontario's PHA research community of (i.e. OHTN; www.ohtn.on.ca/), both of which have strongly emphasized the importance of anti-oppression and social justice in all aspects of professional intervention, including research practices.

movement; very few thought we would ever get here. Therefore, the paucity of research in this area reflects that it has only been within the last decade or so that aging into older adulthood truly became a possibility for PHAs.

Theories addressing service experiences and older PHAs need to be not only interdisciplinary, but also *transdisciplinary*³⁴ (for review, see Klein, Grossenbacher-Mansuy and Häberli, 2001), and reflect that Canadian HIV knowledge is concurrently informed by research from a broad range of sources including fields like social work and healthcare, the physical and social sciences, as well as an ‘indigenous’ or public knowledge outside of academia. To further complicate the matter, different disciplines and fields espouse different, often fundamentally conflicting discourses, thus making the possibility of a coherent theoretical framework for viewing service experiences of oPHAs less clear.

Structural social work

Since health and social service experiences of oPHAs are contextualized by social structures independent of the bio-medical aspects of the HIV/AIDS, they have the potential to be changed. Specifically, while we cannot yet cure the AIDS virus, we can mitigate social ills PHAs often endure, a task better suited to social work. As a social work research project, this study breaks away from the dominant biomedical underpinnings HIV-related research, and allows for a broader examination of the social structures that influence health and social care service experience. Such a framework for social change is presented by structural social work (Moreau, 1979). There is some debate over whether structural social work is a practice approach, or a theory. Structural

³⁴ *Transdisciplinary* (Klein, Grossenbacher-Mansuy & Häberli, 2001) differs from multidisciplinary or interdisciplinary in that this concept transcends the decorum of disciplines altogether, and takes into account other forms of knowledge that exist outside of structured departments of knowledge (e.g. indigenous knowledge, like that of Ottawa’s PHA community).

social work as a practice *approach* builds on social and critical theories to provide social workers with a transformative framework from which to approach social problems³⁵. This involves a dialectical practice approach involving micro and macro interventions³⁶.

Structural social work as a *theory* is based on reconstituted socialist and feminist ideologies. Further evidence that structural social work is a theory in and of itself is its particular method of structure analysis, which has been developed over time.

Structural social work (Moreau, 1979; Moreau & Leonard, 1989; Moreau, 1990; Mullaly, 1997/2007; Lundy, 2004) developed from the work of the late professor Maurice Moreau, conducted at Carleton University in the late 1970s. Moreau's work represented a radical shift in focus (or, emancipation!) from traditional "eco-system/humanist pairing approaches" that informed social work practice, and is considered a radical, or political economy approach to social work practice³⁷. Many aspects of Moreau's legacy in structural social work remain stable, despite subsequent developments, clarifications, and refinements of the idea of structural social work, particularly around the role of materialism and social versus individual change (e.g. Mullaly, 1997/2007; Lundy, 2004, etc.)³⁸.

As a theory, the power of ideology in structural social work is undeniable. For instance, Moreau (1989, p.1) originally engaged in a Marxist analysis of ideology,

³⁵ As a practice approach, structural social work has been suggested to be "the most promising and fruitful way of addressing social problems" (Lundy, 2004, p. 55).

³⁶ Lundy (2004) summarized the macro-micro dialect inherent in structural social work: "[structural social work] situates seemingly individual problems within social and material conditions and alienating social structures while at the same time emphasizes the importance of human agency while offering to help individuals and their families" (Lundy, 2004, p. 57).

³⁷ Mullaly and Keating (1991) provide a good overview of radical social work. Coates (1992) provides a good description of how these fit into social work education.

³⁸ Moreau & Leonard (1989) proposed five goals of structural social work: (1) defense of the client, (2) collectivization, (3) materialization, (4) increased client power in working relationship, and (5) enhanced client power through personal change.

describing it in and of itself a politicized “material force” that asserts itself within the social structure. Structural social work theory was founded on a central ideology of socialism, and is informed by critical theories of the social sciences (e.g. Marxism, feminism). Structural social work theory embodies a *socialist* ideology which takes an anti-capitalism stance with the broad goal of transforming our society from capitalist to socialist structures (Mullaly, 2007, p. 206)³⁹. Authors in structural social work are careful to note that the socialism discussed within structural social work theory is not traditional socialism, which has been considered to be rooted in domination and materialism, but rather a ‘reconstituted’ or ‘revitalized’ socialism, informed by contributions of feminist and anti-racist knowledge (Mullaly, 2007, pp. 206-209). Specifically, this revitalized socialism expands upon the classical socialist perspective, originally class-based and critical of material distribution (e.g. Marx & Engels, 1948/2004; Marx, 1974), to include a feminist analysis based on social group and identity differences like gender, race, and sexuality (e.g. Young, 1990; Bishop, 1994; West, 1982; Weeks, 1991). This shift toward a better informed socialism was instigated most notably in Moreau’s approach to structural social work theory, which viewed both Marxist and feminist theories as informing structural analysis (Lundy, 2004, p. 57).

Structural Analysis

It is suggested that HIV has evolved from a biomedical epidemic into a “human drama” (Moriset, 1989, p. 6; cited in Treichler, 1999, p. 149). Therefore, research into the health and social service experiences of PHAs could benefit from an examination of the ‘players’ that make up service experiences. Specifically, service experience as a phenomenon consists of (a) service recipients and (b) service providers, as well as (c) the

³⁹ For a detailed analysis of neoliberalism and its role in PHA services in Ontario, see Appendix I.

institutions under which these services are produced. Undoubtedly, all players in service experiences are influenced by (d) ideologies. Together, these formations constitute the social structures conceptualized by structural social work theory⁴⁰. While a focus on structures makes visible the players and phenomenon inherent in service experience, such an analysis must be careful not to generalize structures based on the experiences of the eleven participants interviewed in this study. However, in keeping with transformative critical-structural tradition, it is important for the present study to explicitly identify (or, as Paulo Freire (1970/2007) would suggest to ‘name’) specific structures that should be changed. The present study draws upon two popular authors of structural social work theory who identified two separate models that inform structural analysis (e.g. those of Maurice Moreau and Bob Mullaly). While these differ slightly in their content, both attempt to articulate the interconnected aspects of the social structure that is argued here to constitute health and social care experiences of these oPHAs in the NCR.

Moreau placed social structures into two categories: *primary* and *secondary* structures (Moreau & Leonard, 1989; Carniol, 1992). Moreau’s (1989) primary structures include phenomena like patriarchy, racism, heterosexism, ageism, ableism, capitalism, etc; all of which Moreau theorized as existing both concurrently and non-hierarchically (Carinol, 1992, p. 4). Moreau’s secondary structures include social institutions like communities, bureaucracies, families, as well as structures like personality⁴¹. Secondary

⁴⁰ In order to conduct structural practice, social workers must be well-informed about the social structures that contextualize their clients’ experiences.

⁴¹ Both ‘personality’ and ‘family’ are referred to as secondary structures in Moreau’s work (Carinol, 1992, p. 5), but both are excluded in Mullaly’s (1997/2007) analysis. Both theorists may have been making strategic statements. First, Moreau’s inclusion of a these structures could have curtailed criticism from the then-dominant social work theories that focused on individual psychology and family systems (Moreau & Leonard; 1989, pp. 10-11). Conversely, Mullaly’s (1997/2007) conceptualization of structural social work blatantly rejects the dominant mental health model, and is strictly focused on institutional and ideological (rather than personal) change.

structures were proposed to be influenced *by* and provide the ‘architecture’ *for* the continuity of primary structures (Carinol, 1992, p. 4-5).⁴² Moreau also conceptualized all of these structures as ‘interwoven’ (Moreau & Leonard, 1989, p. 23).⁴³ Following Moreau’s death, Robert (Bob) Mullaly (1997/2007) would re-conceptualize the nature of social structures.

In his book, *Structural Social Work* (1993; 1997/2007) Mullaly places structures into two levels: *sub*- structural and *super*-structural, consisting of three structure categories: ideologies, institutions, and social relations (Mullaly, 2007/1997). In addition to renaming Moreau’s (with Leonard, 1989) social structures, Mullaly (1997) further developed Moreau’s concept of a structural ‘architecture’. Mullaly conceptualizes this architecture, or ‘structural arrangement’, as forming a bridge. Specifically, Mullaly (1997/2007) describes the *sub*structure as a foundation (or, base) of the bridge upon which the rest of the bridge stands. The substructure of Mullaly’s structural view of society consisted of “dominant” *ideologies* (e.g. neoliberalism, socialism/social democracy, patriarchy, heterosexism, racism, etc.)⁴⁴ Mullaly (1997/2007) describes the *super*structure as consisting of two categories of social structures. First, *social institutions* (i.e. economic, political, social welfare and other organizations) serve as the bridge’s pillars, or columns, which carry or support the deck of the bridge while resting on a foundation of sub-structural ideologies. Second, *social relations* are represented by the deck of the superstructure, consists of ways in which people relate to one another in

⁴² The terms ‘primary’ and ‘secondary’ were used by Moreau because he viewed primary structures as having a greater impact on the secondary structure than vice versa (Carinol, 1992, p. 5).

⁴³ At Moreau’s death, this was as far as structural social work theory was developed. Since Moreau died in the early 1990s tragically from AIDS-related causes, one cannot help but wonder what kind of framework concerning structural realities of PHAs would have emerged using Moreau’s theoretical base.

⁴⁴ Mullaly (2007, pp. 245-6) points out that the substructure of a bridge is usually situated underwater, or out of sight, and therefore is an ‘invisible’ structure of the bridge.

society (e.g. discrimination, oppression). In the superstructure, social relations rest on and were supported by the social institutions (Mullaly, 2007, p. 245).

In terms of how Mullaly's (2007, p. 246) structures influence each other, social relations are proposed to be *determined* by both foundational ideologies and social institutions, and foundational ideologies are *reinforced* by both social relations and social institutions. Mullaly (2007, p. 250) also clarifies the difference between an 'institution' and 'structure'. Institutions were described as "organizations that carry out certain functions" (e.g. a welfare system that attends to the needs of economically disadvantaged), while these same institutions, "along with their procedural rules of operating, the policies governing their operations, and their social practices" are social structures (Mullaly, 2007, p. 250). Therefore, the goal of structural social work is not to dismantle the welfare system, but rather change the rules, policies and practices they enact.⁴⁵

Moreau and Mullaly's separate conceptualizations of structures have much in common. For instance, Moreau's primary structures can be compared to Mullaly's substructure, while Moreau's secondary structures can be compared to elements of the superstructure. However, there were several ways in which the structural views of society are distinct. First, Moreau conceptualized primary structures having a unidirectional 'influence' on secondary structures. Conversely, Mullaly conceptualizes the relation between the 'sub' and 'super' structures using language like 'determining' and

⁴⁵ Structural social work is often misinterpreted as concerned solely with provoking institutional change, which often gives it the reputation of being *anti*-institutional. Mullaly's (2007) analysis negates this idea, and asserts that the locus of change rests in the broader structures that support the institution.

‘reinforcing’, but does not explicitly identify one form of structural level as dominant.⁴⁶

Second, Moreau (with Leonard, 1989) did not explicitly state that his primary structures consisted of necessarily ‘dominant’ ideologies, as Mullaly (1997/2007) suggests. Mullaly, meanwhile, explicitly conceptualizes the substructure as consisting of ‘dominant’ ideologies, which, in turn, (a) makes it easier to form a politicized analysis or critique (for instance, Mullaly blatantly guided readers to focus on neo-liberalism and capitalism), and (b) lends better to oppression work through the implied emphasis on social transformation.⁴⁷ Finally, while both Moreau and Mullaly define structural social work as aimed at social change, Mullaly’s (1997/2007) account of structural social work better articulates structural social work’s focus in the context of social justice and anti-oppression (ideas that perhaps were not yet a part of the popular vernacular during Moreau’s lifetime).

Social justice

As espoused by structural social work literature, the concept of social justice is relevant to the present research question in that it is used as a yardstick to ‘measure’ the health and social service experiences of these oPHAs in the NCR. The idea of *social justice* (e.g. Rawls, 1971; Reisch, 2002; Young, 1990) has emerged as a fundamental concept within structural social work theory (e.g. Mullaly, 2007; Lundy, 2004). The concept of social justice is ancient⁴⁸; however is best equated with the Marxist idea of

⁴⁶ Mullaly’s use of the word ‘determinism’ is much stronger language than Moreau’s ‘influence’, and better asserts causation between social structures. Conversely, Moreau’s use of the term ‘influence’ leaves structural analysis much more open to exploring the true nature of the interplay between social structures.

⁴⁷ For example, using Moreau’s theorization, one could consider ‘socialism’, or ‘acceptance’ primary structures even though they are not currently dominant structures in Canadian society. Mullaly, on the other hand, would identify structures like ‘capitalism’ or ‘heterosexism’ as true sub-structural elements, because they are dominant in our social reality.

⁴⁸ Reisch (2002, p. 343) traces the origins of the notion of social justice back to Plato.

distributive materialism. Further development of the concept of social justice examined issues of individual difference, and redress. For instance, feminist scholarship expands these notions, shifting the process of social justice to acknowledge social group differences, power, and oppression (e.g. Young, 1990).

While social [in]justice is often a felt experience, several authors attempt to articulate its definition. In doing so, Reisch (2002) acknowledges the “paradox of attempting to develop principles of justice within a political, economic, and social context based largely, or tacitly, on the preservation of injustice” (Reisch, 2002, p. 346). Social justice’s first treatment by critical social science can be credited to Karl Marx, who originally conceptualized social injustice as having to do with problems of unequal distribution of material goods among classes in society (Reisch, 2002, p. 345)⁴⁹.

Traditionally, theorists framed social injustice as a system in which one group has a monopoly over a particular good. However, the notion has been expanded beyond the equal distribution of material goods. For instance, feminist Iris Marion Young (1990) asserted that equating the scope of social justice only with distribution was misleading as it ignored the underlying processes and social practices that constituted the inequality. Thus, Young’s (1990) feminist analysis suggests that people relate to others in many ways beyond relationships based on goods (and these should be subject to justice as well).

Young (1990) distinguished material goods from non-material benefits like rights, opportunities, and power. Young (1990) defined rights not as things, but relationships (Young, 1990, p. 25), and defined opportunities as “condition[s] of enablement, which

⁴⁹ Young (1990, p. 15) notes that later in life, Karl Marx recommended a shift away from a purely distributive paradigm, acknowledging the source of social injustice rests in social relations of the mode of production.

usually involves a system of social rules and social relations, as well as an individual's self-conception and skills (Young, 1990, p. 26). Young (1990) was explicit in her assertion that some people are unable to exercise rights-based relationships or enabling opportunities because of particular constraints on class, status, social group, etc.

Several authors (i.e. Reisch, 2002; Young, 1990) refer back to Rawls' (1971/1999) progressive theory of justice which posited "all social values...are to be distributed equally unless an unequal distribution of any, or all, of these values is to everyone's advantage" (Rawls, 1971/1999, p. 62; cited in Reisch, 2002, p. 346). In addition, Rawls (1999) delivered a clear call for the inclusion of redress in a concept of social justice: "society must give more attention to those with fewer native assets and those born into less favorable social positions...to redress the bias of contingencies in the direction of equality" (Rawls, 1999; cited in Reisch, 2002, p. 346).

While Rawls' (1971/1999) concept takes into account individual difference, feminist scholarship produces a more substantive account of the politics of difference as pertaining to social justice. Feminist scholar Iris Marion Young (1990) argued that social justice should (a) be expanded to acknowledge social group difference, as well as (b) shift its focus from distribution of benefits to dominance and oppression (Young, 1990, pp. 3, 9). Young (1990) asserted that the definition of injustice is domination and oppression (Young, 1990, p. 33)⁵⁰ and that "for a social condition to be just, it must enable all to meet their needs and exercise their freedom; thus justice requires that all be able to express their needs" (Young, 1990, p. 34). Therefore, Young argued for an

⁵⁰ Young (1990, p. 15) defined social justice as "the elimination of institutionalized domination and oppression". This definition extends beyond better (or more equal) distribution of benefits or treatment, and calls for the elimination of oppressive structures altogether.

“enabling concept of justice” (Young, 1990, p. 39), which calls upon the “emancipatory imagination” of all (Young, 1990, p. 36).

Reisch (2002, p. 351) echoes the feminist call for inclusion of oppression in a social justice framework for the social work profession. Reisch (2002, p. 347) also credits feminism with defining social justice as process as well as an outcome. In addition, he defined socially just social work practice as: (1) recognizing clients’ strengths, (2) an awareness of the role of power in professional relationships, and (3) a focus on positionality (Reisch, 2002, p. 349). Craig (2002; cited in Lundy, 2004, p. 61), also writing from a social work perspective, defines social justice as:

[the] acceptance of difference and diversity, and informed by values concerned with: achieving fairness and equality of outcomes and treatment; recognizing the dignity and equal worth and encouraging the self-esteem of all; the meeting of basic needs, maximizing the reduction of inequalities in wealth, income and life chances; and the participation of all, including the most disadvantaged. (p. 61)

In this vein, Lundy (2004, pp. 61-62) outlines the ethical obligations of social workers to work for social justice, and positions workers as having intimate knowledge of their clients’ experience of social injustice.

Social justice is important to the present study in that the concept is used as a moral yardstick to measure the health and social service experiences of the study participants. In addition, social workers are ethically required to work for social justice-in practice and research, and thus this should be an aspect of all research conducted in the social work profession. Finally, social justice is demanded by the PHA community of Ontario⁵¹. Social justice has indeed been an ever-evolving concept, and has increasingly

⁵¹ This study’s concept of social justice fits well within the proposed planning of the Ontario HIV Treatment Network (OHTN; Summer Learning Institute on HIV & Social Justice, 2008), which espoused the importance of social justice through the greater involvement of people with HIV/AIDS principles (or,

acknowledged unjust social relations such as oppression, which is described in detail next.

Oppression

This research project is informed by the concept of structural oppression. This section focuses specifically on the emerging theory of oppression: its evolving definition and nature as well as its forms, with the explicit intention of providing a nuanced explanation of oppression as may be experienced by oPHAs in health and social services.

The concept of oppression has been developed over time by various scholars (e.g. Young, 1990, Freire, 1971, Bishop, 1994; Mullaly, 1997/2007). Consistent between all of these writers is the idea that oppression is a felt experience. Anne Bishop (1994) noted that in order to become an ally, one must first address their own role in oppression, as both oppressor and oppressed⁵². Iris Marion Young (1990) was the seminal writer on oppression. In her book *Justice and the Politics of Difference* (1990), Young described oppression as housed in a broader social justice framework, which was originally based on inequality, or unequal distribution of social goods. Young (1990) emphasized the

GIPA; UNAIDS, 1999; 2004; Travers et al., 2008, etc.). GIPA was considered a major victory for the HIV/AIDS movement (Travers et al., 2008, p. 1), in that it outlined an “obligation to act with compassion for, and in solidarity with, those with HIV or at risk of becoming infected, both within our societies and internationally”, and “to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances” (European Coalition of Positive People, 1994). Travers et al. (2008) reaffirmed that GIPA “has evolved into a broad philosophy meant to underpin all forms of intervention (prevention, treatment, support, policy and research) with persons living with HIV/AIDS (PLWHA)”, and thus social justice, as a component of structural social work theory, can be seen as a key concept of the theoretical framework used in the present study of these eleven oPHAs, particularly in Ontario.

⁵² As a social work student, it was important for me to ask myself: ‘What does oppression feel like?’ I contemplated this, and developed a list of characteristics of my own oppression. For instance, he reflected having experienced oppression on the basis of my sexuality, body appearance, and economic class, all of which entail the felt senses of (a) pain, (b) inhibition, (c) anger, (d) unfairness, (e) lack of control/lack of power over situation, (f) being ignored, unacknowledged or invisible, (g) taken advantage of, (h) out of commission, and (i) being different. Conversely, I also investigated how I was privileged by oppression. For instance, as a white, well-educated male, I am privileged compared to non-white, female, less-educated people.

quotidian nature of oppression by clarifying that it occurs among groups of people in their everyday social relations with each other, or in the 'normal processes of everyday life' (Young, 1990, p. 41). In addition, Mullaly's *New Structural Social Work* (2007, p. 262) characterizes oppression as located across social structures, or *panstructural*⁵³. Finally, two broad responses to oppression are proposed: (a) accommodation and compliance (or buy-in through a process of inferiorization), or (b) a rejection (Mullaly, 2007, pp. 276-282).

Central to the concept of oppression is the idea of *power*. Young (1990, p. 32) borrows Foucault's (1980) metaphor of power as a net: "employed and exercised though a net-like organization... individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising their power" (Foucault, 1980; cited in Young, 1990, p. 32). In this sense, power is not viewed as something people wield or even have; rather, it is believed to be something that has people, or protects them from vulnerability to oppression. In Young's (1990) theory of oppression, power was proposed to be the main social commodity unequally distributed among social groups. Specifically, power plays out in one's ability to access resources (such as healthcare and social services).

Oppression is proposed to occur when one group's power is used as a basis for inequitable treatment of another group with less power, a concept also referred to as 'power over' (Bishop, 1994, p. 30). Bishop (1994) states: "It becomes right, even admirable, for those who have more power and value to help themselves to...those who have less power and value" (Bishop, 1994, p. 10). Power over has also been referred to as

⁵³ For instance, Mullaly's (2007) structural social work makes use of Thomson's (1997) three basic levels of oppression: (a) personal (b) cultural, and (c) structural (or institutional) (aka the 'PCS' model of oppression).

conquest⁵⁴ (Freire, 2007, p. 138) and domination (Young, 1990, p. 32). Domination was suggested to both lead to and be based on the idea of *dehumanization* (Freire, 2007, p. 167; Bishop, 1994, p. 19), which reduces people from humans to things.

Another central concept of oppression is the idea of *internalization*. Paulo Freire (1971/2007) observed that the oppressed internalize the image of the oppressor and “adopt his guidelines” (Freire, 2007, p. 47). Similarly; Bishop (1994) describes groups that internalize oppression as being “only able to play the roles expected of them by those more powerful than themselves” (Bishop, 1994, p. 53). Bishop (1994) provides further evidence for internalization by pointing out that it is common for oppressed groups to know a great deal more about the oppressor than the oppressor knows about the oppressed (Bishop, 1994, p. 96); particularly because oppressed groups internalize the normative dominance of privileged groups. Undoubtedly, the internalization of oppression occurs through a process of socialization (e.g. Berger & Berger, 1975, pp. 49-75). This socialization, however, is based on dominance.

While earlier oppression work focuses on oppressed and oppressor as two distinct roles (e.g. Freire, 1971)⁵⁵, it has become increasingly acknowledged that there is no ‘who’ behind oppression. Specifically, Young (1990) suggested that the identification of an oppressor was not really necessary to understanding, but rather social institutions were responsible⁵⁶. Mullaly (2007) supports this idea by stating “modern day oppression is structural” (Mullaly, 2007, p. 261). However, Young (1990, p. 42) explicitly stated that

⁵⁴ Young, (1990, p. 38) defined domination as “constraints upon oppressed people to follow rules set by others”. Young (1990) argued that concepts of domination and oppression overlap, but distinguished between them: “oppression usually includes or entails domination...but not everyone subject to domination is oppressed” (Young, 1990, p. 38)

⁵⁵ Freire (1971/2007) describes the oppressed and oppressor as social roles.

⁵⁶ Young (1990, p. 124) outlined the difference between blame and being responsible.

“for every oppressed group, another group is privileged.” This distinction allows or a more detailed analysis of roles in oppression⁵⁷.

Young (1990) suggested that oppression occurred for everyone within a single system: everyone is simultaneously oppressed and oppressing, and shifts in these performances across situations. Bishop (1994) suggests that this duality of roles is implicit even in our attempts to break free from oppression, stating “as long as we try and end our oppression by rising above others (the oppressed), we are reinforcing each other’s oppression, and eventually our own” (Bishop, 1994, p. 10). In addition, it has been suggested that passivity among the oppressed influences oppression. For instance, Freire (1971/2007) characterized the oppressed as ‘hosts’ to the oppressor (Freire, 2007, p. 48). Likewise, Mullaly (2007, p. 261) posits that oppression occurs “through the systemic constraints on subordinate groups that take the form of unquestioned norms, behaviors, and symbols, and in the underlying assumptions of institutional rules”. Therefore, it seems that oppression cannot be attributed to a specific oppressor per se, but rather was evoked by dominant social structures, which in turn come to be internalized by the oppressed, who then may engage in an unintentional, non-conscious reproduction of normative structures.

Forms of oppression

Oppression as a concept is vague and complex. Therefore, a nuanced examination of the forms of oppression is necessary to better situate oppression in the present study. Specifically, older adults living with HIV in the NCR may report having experienced one or several forms of oppression or none at all. Several authors agree that oppression takes

⁵⁷ The language here is also important: defining oneself as privileged rather than as oppressor lends to a higher likelihood of constructive self-analysis.

several forms (Young, 1990; Freire, 1971; Bishop, 1994) and these forms have informed structural social work (Mullaly, 1997/2007). Bishop (1994, pp. 64-65) describes forms of oppression explicitly as social group-specific; referring to group-based inequalities as oppression unto themselves, and distinguishing class as a distinct form. For instance, Bishop (2004, p. 65) conceptualizes oppression as existing on two axes: the first, diagonal axis consists of oppressions based on social groups (e.g. racism, sexism, heterosexism, ableism, etc). The second, vertical axis consists of class, which intersects with all other forms of oppression⁵⁸.

In contrast, both Freire (1971) and Young (1990) viewed oppression as phenomena that can occur to any social group. Freire's (1971) description of antidiological action referred to several forms of oppression, all of which stemmed from the idea of conquest. These included: divide and rule, manipulation, and cultural conquest. Young's (1990) development of oppression theory proposed five forms or 'faces' of oppression: (a) violence (b) exploitation, (c) powerlessness, (d) marginalization, and (e) cultural imperialism. Young (1990, p. 42) also asserted that these 'faces' could be experienced in different combinations by different groups, and that the experience of any one form was enough to be considered 'oppressed'. Thus, no single form of oppression should be considered more important than another (Young, 1990, p. 42); a notion also espoused in Moreau's treatment of oppression in structural social work theory (Moreau & Leonard, 1989, p. 23).

Violence, the most explicit form of oppression, was theorized to be based on fear and hatred of a particular group (Young, 1990; p 62). Young (1990, p. 62) argued that

⁵⁸ Bishop (1994, p. 65) suggests that class is an end product all other oppressions, or that oppressions constituted class.

violence was a normalized social practice that has often been viewed as appropriate and ‘called for in certain situations’⁵⁹. Violence manifests itself not only in performed violent acts, but also in a person’s fear of violence, or the understanding of liability to violation solely on account of their group membership (Young, 1990, pp. 61-63)⁶⁰. Young (1990, p. 49) defined *exploitation* as a ‘transference of labor’, stating that “oppression occurs through a steady process of transfer of the results of the labor of one social group to benefit another” (Young, 1990, p. 49). In addition, the notion of exploitation has been expanded to include: “ways in which the labor and energy expenditure of one group benefits another, and reproduces the relationship of dominance between them” (Young, 1990, p. 50).

Young (1990) referred to *powerlessness* as another face of oppression. Young (1990) described this concept as a professional/non-professional split centered in dominance: “most people in most societies do not regularly participate in making decisions that affect the conditions of their lives” (Young, 1990, p. 56), suggesting the decisive power of authorities. Young (1990) emphasized the power differential between professionals and those in their stead, suggesting “the powerless... must take orders and rarely have the right to give them” (Young, 1990, p. 56). This is incredibly relevant to health and social care experiences as conceptualized in the present study.

Young (1990, p. 53) posited that *marginalization* is the most dangerous form of oppression. Marginalization is considered to be an oppression of recognition and interaction (Young, 1990, p. 55) or, participation. Social marginals are excluded from the system of labor, and include older adults as well as mentally and physically disabled

⁵⁹ For instance, violence is approved by society in instances of war (and some sport).

⁶⁰ It is unlikely that violence will present itself in the service experiences of oPHAs, however the fear of violence may influence access to services, so it is mentioned here.

people (Young, 1990, p. 53). Young (1990, p. 54) asserted that marginalization is unjust because it blocks the opportunity to exercise capacities in socially defined and recognized ways (Young, 1990, p. 54). Young (1990) boldly posited that dependency⁶¹ on health and social welfare systems in and of itself constitute people being treated as marginal, suggesting that rights and freedoms of the dependent have often been limited. Young (1990, p. 54) stated that people who depended on social welfare programs have been “subject to patronizing, punitive, demeaning and arbitrary treatment by the policies and people associated with welfare bureaucracies” (Young, 1990, p. 54). Young elaborated on the power differential dependency creates:

Being a dependent in our society implies being legitimately subject to the often arbitrary and invasive authority of social services providers and other public and private administrators, who enforce rules with which the marginal must comply, and otherwise exercise power over the conditions of their lives. (p. 54)

In articulating this misuse of ‘power-over’ ideology, Young (1990, p. 54) suggested that dependent people must forfeit their right to self-directed care and the determination and expression of needs in exchange for health and social care services:

With the aid of social scientific disciplines, welfare agencies also construct the needs themselves. Medical and social service professionals know what is good for those they serve, and the marginals and dependents themselves do not have the right to claim to know what is good for them. (p. 54)

Young (1990) asserted that the dominant view of dependency in our society implies, “a sufficient warrant for suspending basic rights to privacy, respect, and individual choice” (Young, 1990, p. 54). Feminist scholarship heavily critiques this idea, suggesting that we should have the right to dependency *without* marginalization (Gordon & Fraser, 1994;

⁶¹ Gordon and Fraser (1994) trace the genealogy of the word ‘dependency’ up to modern day dependency on the welfare state, and suggest that it has come to be associated with negative, even pathological, connotations.

Young, 1990, p. 55). In addition, Young (1990) argued that dependency should be a right, and that the dominant idea of a independence as normalized is contrary to the feminist view of social justice.

Cultural imperialism is perhaps the form of oppression most dependent on the notion of group differences. Young (1990) stated that cultural imperialism “means to experience how the dominant meanings of a society render the particular perspective of one’s own group invisible at the same time as they stereotype one’s group and mark it as the Other” (Young, 1990, p. 59). Culturally imperialized groups are compared and are marked as different or inferior (Young, 1990). In contrast, the dominant group asserts its power by comparing oppressed groups to dominant norms. Young (1990) asserted that the injustice of cultural imperialism is an inequality of influence between groups. She elaborated on this inequality, stating that “the oppressed group’s own experience and interpretation of social life finds little expression that touches the dominant culture, while that same culture imposes on the oppressed group its experience and interpretation of social life” (Young, 1990, p. 60). One way that cultural imperialism is enacted is through the process of stigma, which is described next.

Stigma

The concept of stigma is very relevant to the exploration of health and social service experiences of oPHAs, particularly as a component of oppression. Specifically, the concept of stigma can be used to account for cultural imperialism, a ‘face’ of oppression (Young, 1990) experienced in health and social care, as reported by research participants. Thus, including the concept of stigma allows for a further nuanced analysis of oppression. Several subtypes of stigma relevant to the service experiences of oPHAs

have been identified, and are described herein. The concept of stigma developed from the classic work of Erving Goffman (1953), who proposed that human relations could lead to the 'spoilage' of one's social identity. Goffman (1953) defined being stigmatized as being disqualified from full social acceptance (Goffman, 1953, preface; cited in Smith, 2006, p. 84). Further, it is suggested that stigma can be either enacted or felt (Green & Platt, 1997). Specifically, *Enacted* stigma is defined as individual or collectively applied sanctions, whereas *felt* stigma refers to feelings of shame or guilt and the oppressive fear of enacted stigma (Green & Platt, 1997, p. 72).

Stigma is proposed to be based on social group membership⁶². Social groups are formed by a felt affinity with others in their groups, and have been proposed to be based on shared experiences (Young, 1990, p. 43; McMillan & Chavis, 1986). Young (1990) maintained that social groups come to be compared to each other, and from here the ideas of difference and differentials emerge (Young, 1990, p. 43). Conveniently, groups are usually based on identifiable differences (Bishop, 1994, p. 19). Some groups have more public visibility than others⁶³. The most visible groups are also usually the most powerful or dominant, and this constitutes the ideas of normalcy, and much of the superiority and privilege enjoyed in society.

Stigma has psychological roots, and relates to the idea that we are all somewhat insecure and threatened. Specifically, Young (1990) suggested that stigma is based on a fear or phobia represented by the 'Other' (Young, 1990). Young's (1990, p. 129) analysis

⁶² Goffman distinguished between three types of identity: (1) social identity, including everyday ways persons are identified and categorized, (2) personal identity: what marks out the person as distinct from all others and (3) felt identity: feelings a person has about their identity (Smith, 2006, p. 85). The idea of social group would most likely be considered an aspect of Goffman's social identity.

⁶³ Thus, a felt sense of 'envy' applies to both visible and invisible groups: visible groups are envious of invisible's ability to blend in; the invisible envious of greater progress made on visible issues (Bishop, 1994, p. 62).

of stigma explained that we experience a self/other (or, object/subject)⁶⁴ split as the basis for the feeling of aversion that leads to stigma. Specifically, the separation of subject from object sets a very important security boundary, or ‘border’, which effectively produces a sense of stability and coherence for the person, or subject. Young (1990, p. 143) deepened her analysis of the subject/object split, suggesting that stigma forms from a feeling of aversion when the separation between subject and object was threatened. This felt phenomenon has been famously referred to as the *abject*⁶⁵ (Young, 1990, p. 143). The border crisis people experience in response to collapse of the subject/object split is proposed to be varied based on how permeable the border is. For instance, racism may involve less border anxiety because one cannot simply become another race. However, structures like homophobia, ageism, ableism, and diseaseism may cause extreme anxiety, particularly because the possibility (and in some cases likelihood) of becoming the other is greater⁶⁶ (Young, 1990, p. 147).

Young’s (1990) analysis also referred to the obscured components of enacted stigma. For instance, she distinguished between the symbolic aspect of social interaction (e.g. speech, language) and the *semiotic* (aspects that are not part of the verbal communication, but nonetheless displayed), that still exert influence (Young, 1990, p. 143). In addition, Young (1990) noted that stigma may be applied differently in public

⁶⁴ Young (1990, p. 127) attributed this to the positivist scientific discourse and its object/subject dichotomy

⁶⁵ Young (1990, p. 143-145) analyzed Kristeva’s (1982) psychoanalytic account of the abject. The idea of the abject is based on an unconscious relationship with existence beyond the body border. Young (1990, p. 143) focused on processes of (a) childbirth, and (b) excrement as metaphors for the abjection. Childbirth represents a ‘reluctant struggle’ (Young, 1990, p. 144) for independent borders (the abject is tempting and sparks our desire). Excrement creates another type of separation or expulsion; when we come into contact with our own bodily excretions, we respond with disgust (often characterized by further urge of nausea).

⁶⁶ Young (1990, p. 29) referred to this as a consequence of the ‘medicalization of difference’: since both normal and abnormal existed on the same scale, there is a risk of sliding from one to the other; the border is permeable.

and private spheres, arguing that, for the most part, stigma is no longer part of the dominant discursive consciousness, but still however exists in the behavior, images, and attitudes at the levels of practical consciousness and the “basic security system” (Young, 1990, p. 138). This is particularly important for the present study of health and social care experiences in that service recipients may “experience nervousness or avoidance from others, even from those whose discursive consciousness aims to treat them with respect” (Young, 1990, p. 142). Specifically, oPHAs may report experiencing stigma from within the health and social care service system.

Goffman (1953) viewed stigma as experienced by everyone, and as having many varieties (Goffman, 1953; cited by Smith, 2006, p. 89). For instance, stigma can be based on a response to visible attributes of a person or group, as well as non-visible information that was learned about a person or group. Specifically, stigma may be enacted in response to (a) body appearance (i.e. bodies outside of the traditionally dominant norm), (b) aging bodies and learning someone’s chronological age (i.e. ageism), (c) appearance of the infected body or learning of someone’s HIV status (i.e. HIV-related stigma), as well as (d) what we do with our bodies (e.g. heterosexism and drug-related phobia).

Stigma may be skin-deep, that is, based on the appearance of the human body⁶⁷. The notion of stigma concerning body appearance is well documented in the areas of feminist and anti-racism scholarship (e.g. Young, 1990; West, 1982/2002), and more recently in research focusing on infected bodies (e.g. Landman, 2008). Young (1990, p. 128) suggested that we engage in a process of ‘scaling the body’ when appraising people,

⁶⁷ In fact Young (1990, p. 123) refers to Slaughter’s (1982) notion of the ‘epidemilizing’ of oppression.

and that this scale measures the appearance of physical health⁶⁸. West (2002) argued the notion of superiority based on body type or characteristics. According to West (2002), who wrote from an afro-Christian perspective, stigma based on body appearance is reflective of the normalized white, male, heterosexual masculinity of the nineteenth century⁶⁹.

Stigma may be enacted against the aging body, particularly in response to changes produced as the human body ages (Novak, 1993, p. 105). For instance, the normative processes of change and deterioration in height, weight, muscle, hair color and skin composure and speed of performance that accompanies aging may be a basis for this stigma. In addition to aging body appearance, stigma may also be attached to learning someone's chronological age. Ageism proposes dehumanization as a basis for stigma (e.g. Freire, 1970/2007; Bytheway, 1982) in which 'people ceased to be people, ceased to be the same people or became people of a distinct and inferior kind, by virtue of having lived a specified number of years' (Comfort, 1977, p. 35). More recently, ageism was described as being associated with a fear of death, and a prejudice against our 'feared future selves' (Nelson, 2005), affirming the idea of fear of becoming the other.

The infected or diseased body is presented as an interesting source of stigma (Patton, 1990; Treichler, 1999). HIV, often associated with wasting and lipodystrophy, typically alters the body's shape and appearance, which effectively challenges the notion of 'normal' body (e.g. Mooney, 2005; Persson, 2005; Chapman, 2000)⁷⁰. Stigma is also

⁶⁸ Physical health most likely defined by masculine/feminine norms, as well as body weight and other aspects of physical appearance.

⁶⁹ Foucault referred to this as the 'normalizing gaze' (1975, p. 45).

⁷⁰ It is questionable whether body stigma based on age is as problematic as stigma related to HIV/AIDS, mainly because (a) aging is a normative process, and, (b) aging with a chronic illness is often viewed as an achievement. Therefore, a stigma framework based of both HIV-status and aged identities may be well-

suggested to be enacted in response to learning someone's HIV status. Specifically, *HIV-related stigma* has been defined as prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV or AIDS (Herek & Capitanio, 1993; 1999; Herek, Mitnick & Burris, 1998; Emlet, 2006; 2005).

HIV/AIDS is referred to as the most intensely stigmatized physical condition (Crawford, 1996)⁷¹. On this point, it is important to ask how HIV as a component of identity differs from other medical conditions, or why it is subject to such intense HIV-related stigma while other chronic, perhaps even more fatal, diseases are not? Some scholars refer to this discrepancy in treatment of disease as 'HIV exceptionalism' (Bayer, 1999, 1991).⁷² According to Parsons (2008), HIV is exceptional because (a) it is *treated as such*, and (b) it is an *infectious* disease in which certain communities have been disproportionately affected, (c) it entails specific reporting requirements, (d) it has is subject to more stigma than other diseases, (e) it involves a high level community activism, and (f) there is a rapid evolution of treatment (Major & Parsons, 2008; OHTN Summer Learning Institute). On this basis, HIV can be conceptualized as a distinct and exceptional illness particularly prone to stigma.

In addition to information related to the condition of the body, what we do with our bodies also presents a basis for experiencing stigma. This is documented in feminist and queer scholarship (e.g. Young, 1990; Bishop, 1994; Weeks, 1991). Young (1990, p. 128) suggested that in addition to 'scaling bodies' on the basis physical health, we also

suitied to account for some of the stigma and discrimination inherent in the service experiences of oPHAs in the present research project.

⁷¹ Several authors have made similar assertions about leprosy (e.g. Heijnders, 2004; Gussow & Tracy, 1970)

⁷² HIV exceptionalism also encompasses "policies that emerged in response to the AIDS epidemic which differ from conventional approaches public health threats" (i.e. Major & Parsons, 2008 OHTN Summer Learning Institute lecture; Bayer, 1999; 1991).

scale them based on the normative sense of morality. Sex (particularly homosexual sex) and shared injection drug use have long been considered immoral behaviors in western society. Specifically, aspects of one's sexuality are systematically subject to intense stigma⁷³. Jeffery Weeks (1991) suggests the idea of abnormal, 'perverse' or 'unnatural' sexuality is heavily influenced by developments of physical sciences in the nineteenth century and persists today. Bishop (1994) contends that during this period every oppressed group was assigned at least one negative sexual myth, "usually that the oppressed is sexually out of control, or immoral sexually" (Bishop, 1994, p. 68). Thus, Bishop (1994, p. 68) cites that a commonality of all oppressed groups is some form of negative sexual assumption. For instance, homophobia is an irrational fear based on heterosexism of what people who identify as queer or engage in non-heterosexual sex do with their bodies, is manifested in stigma enacted against and felt by this group. Together, the concepts of social justice, oppression, and stigma constitute forms of oppressive relations that may impact the service experiences of the oPHAs interviewed in the present study. In addition, there is growing evidence of social determinants of health.

Social determinants of health

The *social determinates of health* (SDOH; Wilkinson & Marmot, 2003) approach is engaged in the present study to bridge the gap between theories of social theory and the health of oPHAs. In essence, service experiences, as independent phenomena, are worth examining, but their role in the actual health of the participants may also be an important element of service experience. The *social determinant of health* approach to healthcare is used to link the health of Canadians to its social roots. In addition to explicitly linking the

⁷³ In participant interviews of this research project, sexuality was defined as encompassing both sexual identity and sexual acts.

social to health, the approach holds potential to create much needed dialogue between structural social work and health care, which is particularly important for an epidemic such as HIV/AIDS. In terms of social work practice, the social determinants of health has heritage in critical theory⁷⁴ along with structural social work⁷⁵, and have emerged as an increasingly used practice approach of social workers in healthcare⁷⁶. It is important to note that while the social determinants of health approach shares common ancestry with structural social work, to date there has been a lack of research linking the two.

Social determinants of health (SDOH; Wilkinson & Marmot, 2003; Edwards & Stoddahart, 1990) are defined as the “economic and social conditions that influence the health of individuals, communities, and jurisdictions as a whole” (Raphael, 2004, p. 1). These conditions include non-material and material social goods, including: income inequality, social inclusion and exclusion, social support, employment and job security, working conditions, education, food security and housing (Raphael, 2004). The present study proposes that the main social determinant of health impacting oPHAs in this study are (a) social exclusion within the ever-changing health and social services system (e.g.

⁷⁴ The development of the SDOH owes itself to earlier sociological theorists, which posited that every aspect of life, including health, was determined by the social location people occupied in society (e.g. Mills 1959). The social determinants of health have roots in critical social theory, and were investigated by Frederick Engels in 1845 (Raphael, 2004, p. 3). Later, Pearlin (1989) and Edwards & Stoddart (1990) would explicitly make the case for social determinants of health.

⁷⁵ This is particularly important, since clinical social work, often considered the dominant practice modality within healthcare settings, does not espouse critical social theory, but rather positivist psychological theories.

⁷⁶ The *social determinants of health* (SDOH) approach have become increasingly used in social work practice, specifically within healthcare. Reiterating what social workers have traditionally held as central to their practice, other participants in healthcare including practitioners, administrators, and policy-makers have begun to value the immense impact of the social domain in determining multidimensional, or holistic health and quality of life (Raphael, 2004, p. xi). However, it remains questionable whether an increased focus on the social determinants of health represents a shift away from bio-behavioral ways of thinking, toward social justice frameworks.

Labonte, 2004; Galabuzi, 2004), and (b) housing (e.g. Shapcott, 2004). According to Raphael (2004, p. 1), the social determinants of health:

[determine] whether individuals stay healthy or become ill (a narrow definition of health)... and also determine the extent to which a person possesses the physical, social and personal resources to identify and achieve personal aspirations, satisfy needs, and cope with the environment (a broader definition of health). (p. 1)

Based on its emphasis on factors beyond the individual person, such as the inequitable social relations of society, the *social determinants of health* approach may be of particular use to structural social work, which is also based on critical social theory⁷⁷. Up to this point, I have discussed the social forces that may be at play in the experiences of the participants interviewed in this study. Next, I explore the intersectional nature of these social forces.

Intersectionality

The current study engages in a theoretical framework which acknowledges the existence of oppression (and, stigma) based on social group affiliation. An extension of this framework particularly appropriate for the study of oPHAs is the acknowledgement of concurrent oppressions, constituted by multiple occupied social locations. Specifically, stigma based on body appearance, sexuality, HIV-status and age may be compounded to form a particularly oppressive reality for older PHAs. I refer to this as experiencing ‘intersecting’ ‘interwoven’, or ‘multiple’ marginalities (e.g. Hall Collins, 1998; Moreau & Leonard, 1989; Denis, 2001), however it has also been referred to as double (or triple, or multiple) jeopardy (e.g. King, 1988). Based on the concepts of social group-based oppression and stigma previously presented, I argue herein for the acknowledgement of

⁷⁷ The social determinants of health and structural social work represent approaches with similar theoretical underpinnings, but different areas of focus: health and social care. Undoubtedly, in the case of integrated services (such as the work done at ASOs for PHAs), one informs the other.

total system of oppression (Mullay, 1997, p. 105) based on multiple, intersecting marginalities⁷⁸.

Past research concerning intersecting marginalities examined the intersection between race, linguistic culture, class, gender and disability, and age (e.g. King, 1988; Denis, 2001; Collins, 1998; Petersen, 2006; Mahalingamhas & Trotman-Reid, 2007; Krekula, 2007). Hall Collins (1998, p. 27) reflects:

Scholarship in the 1980s and 1990s increasingly focused on uncovering connections among systems of oppression organized along axes of social class, gender, race and nationalism. Within paradigms of intersectionality, any specific social location where such systems meet or intersect generates a distinctive group history or experience. (p. 27)

The idea of more than one oppressed identity owes itself to Black feminist scholarship⁷⁹ (King, 1988, p. 43). The seminal author on double jeopardy, Deborah King (1988, p. 47) likened double jeopardy to arithmetic equations:

Most applications of the concepts of double and triple jeopardy have been overly simplistic in assuming that the relationships among the various discriminations are merely additive. These relationships are interpreted as equivalent to the mathematical equation, racism plus sexism plus classism equals triple jeopardy. (p. 47)

Rather than conceptualizing numerous oppressions as additive, King (1998) asserts that instead, a better way of conceptualizing is “racism multiplied by sexism multiplied by classism” (King, 1988, p. 47). King (1988) explained that the “modifier “multiple” refers not only to several, simultaneous oppressions but to the multiplicative relationships among them as well” (King, 1988, p. 47). Thus, there is interplay and overlapping between oppressed identities. Patricia Hall Collins (1998) introduced the term

⁷⁸ The present study attempts to examine a previously ignored pair of *intersecting identities* within Ontario service users: HIV status and aging.

⁷⁹ King (1988, p. 46) noted that the term ‘double jeopardy’ was first introduced by feminist Frances Beale (1979), to describe the dual discriminations of racism and sexism that subjugate black women.

intersectionality, and (1998) further developed King's (1988) argument of multiplicity. Specifically, Hall Collins (1998) suggested that "rather than examining gender, race, class, and nation as distinctive hierarchies, intersectionality examines how they mutually construct one another" (Hall Collins, 1998, p. 62).

The notion of intersecting marginalities is also found in aging literature. The idea of double jeopardy was introduced in social gerontology by Dowd and Bengtson (1978), however the most popular gerontology scholarship in this field focuses on recognizing diversity in aging (e.g. Kolb, 2004) and the emerging field of 'ethnogerontology' (Edmonds Crewe, 2004, p. 48). Gerontology has critiqued previous work for not fully acknowledging the Black feminist idea of a "qualitatively different" experience of multiplied oppression, defaulting to the more simplistic, additive approach (Krekula, 2007, p. 162). Krekula's (2007) review of double jeopardy in aging literature reports that social gerontology uses the concept of double jeopardy to better articulate the experiences of aging women and immigrants and "stresses how subordinate positions are added to each other, producing a problematic interplay" (Krekula, 2007, p. 161). Interestingly, Krekula (2007) acknowledges that the interplay need not be conceptualized solely as problematic. Specifically, Ahmadi and Tornstam (1996) conducted interviews with older immigrants, and argued that these intersecting identifies can result in a double asset. This advantageous intersectionality was also the case of a qualitative study of interviews with oPHAS revealing perceived advantages and disadvantages of aging with HIV (Siegel, Raveis & Karus, 1998).

It is important to note that an aging population (for review, see Lubben, & Damron,-Rodriguez, 2006) means that eventually, old age (as a marginalized identity)

will inevitably intersect with most other social identities, many of them already marginalized along lines of race, gender, sexuality, class, etc. Thus, it has been well-acknowledged that age complicates many other forms of marginality, perhaps even the experience of HIV.

Interestingly, the idea of interwoven marginalities was present in Moreau's (and Leonard, 1989) original conception of structural social work, and reaffirmed in Mullaly's (2007) new structural social work theory. As a part of his "holistic interweaving of oppression" (Moreau, in Carinol, 1992; Albert et al., 1986, p. 16; Wineman, 1984; cited in Moreau, 1989, p. 23), Moreau suggested an inter-relational or inter-sectional nature of oppressions, underlying the importance of acknowledging how oppression can be particularly challenging for people who assume multiple oppressed social locations, or identities. Additionally, Moreau (e.g. 1989; Carniol, 1992) championed the notion of viewing oppressions as 'non-hierarchical', but rather similar structures that have common structural roots⁸⁰.

An analysis which acknowledges multiple marginalities makes visible multiple forms of jeopardy OPHAs may experience in health and social care. Obviously such an analysis may also obscure the impact of any one particular form of oppression. However, an understanding of a 'total' system of oppression (Mullaly, 1997, p. 105) will likely prove more beneficial than compartmentalizing clients and participants. The project design takes both views into account, and qualitative interviews were conducted with a dual focus on HIV and aging, as well as their intersection.

⁸⁰ Of multiple identities, Mullaly (2007) states that while individual characteristics may be a 'major marker' of an identity, "one's identity is seldom, if ever, determined solely by one characteristic". The same could be said of groups; we expand and contract our social group memberships across our lifetimes. Similarly, Mullaly (2007, p. 263) dubbed this reality as a 'multiplicity of oppression'

Closing

The theoretical framework of this study of oPHAs in the NCR reflects current, relevant knowledge used to conceptualize the health and social service experiences of oPHAs. A novel use of structural social work and the social determinants of health approach were used to inform this study, which espouses the role of structures in social justice and oppression. The framework places a nuanced focus on stigma and intersectionality, or multiple marginalities. Together, the concepts described may constitute central aspects of the service experiences of oPHAs in the NCR, and may emerge as appropriate lenses to view the current study. These perspectives make visible the possibility of oppressive social relations between these oPHAs and their service professionals being propped up by structures or ideological, institutional and psychological nature. Conversely, the theoretical framework employed herein obscures (a) the significance of the biomedical discourse and its impact on the reality of PHAs (for instance, mortality rates, developments in epidemiology, treatment and prevention cannot and should not be ignored), (b) cultural construction of HIV/AIDS⁸¹ (c) meanings of aging with HIV (or, lifespan) outside of North America, (d) significance of other aspects of social group affiliation outside of HIV-status and age⁸² (and thus lives of participants before HIV infection) and (e) the experience of the service *providers* as a distinctly

⁸¹ It has become increasingly evident that HIV is a disease that lends to cultural as well as medical constructions (Treichler, 1999; Patton, 2002; 1990, 1986; Weeks, 1991). Jeffery Weeks (1991) suggested that “AIDS has been culturally interpreted, signified and given strong moral meaning” (Weeks, 1991, p. 114). Cindy Patton (1990) also asserted the existence of ‘cultural narratives’ for understanding AIDS. Paula Treichler (1999) produced the most work on the cultural construction of HIV/AIDS. She argues that meaning has been constructed through the language we use to describe aspects of our reality.

⁸² In this study an attempt is made to address the significance of sexuality, gender and race to service experience, but these aspects of group identity are not the present focus.

experienced phenomenon.⁸³ Using this conceptual lens, a method of analysis was developed.

⁸³ This could be considered something that is obscured by the study overall, however it is likely that in a study of servicer providers the social discourse would be forfeited for a biomedical one since health and social care organizations (including ASOs) exist predominantly within a biomedical discourse.

CHAPTER 3: METHOD

Introduction

This chapter details the method of the present study. Following this, a description of the study's procedure and mode of analyses are presented.

Conducting a thematic analysis

The present study was a thematic analysis of the stories of eleven oPHAs in the National Capital Region. A thematic analysis is a method of study that points to patterns of themes in describing qualitative data. In addition, thematic analysis interprets the various aspects of the research topic (Braun & Clarke, 2006). Thematic analysis is flexible in that it is not wedded to a particular theoretical perspective (Braun & Clarke, 2006, p. 78) Thus, this method was deemed appropriate for the present study. For the present research, themes were developed from a review of literature concerning oPHAs (for list of themes, see Appendix VII). In addition, the study was influenced by reviews by Creswell (1998) and guides my Tutty, Rothery & Grinnell (1996), who outlined the most appropriate methods for studies of this sample size that measure personal experience.

Finally, the type of study was influenced by who I am as a researcher. Specifically, I am (a) a former placement student at the service organization that recruited the participants, and (b) a member of Ottawa's queer community. My identification as queer is significant to the study since (a) this community is differentially impacted by HIV/AIDS, and (b) I could potentially someday be an older PHA (a reality which undoubtedly added to the poignancy of the study for me).

Ethics

The project was reviewed and approved by the Carleton University Ethics Committee on June 19th, 2007. Major considerations taken into consideration included anonymity and confidentiality, financial remunerations, and risk. The study was accepted as a 'mid-level' of risk, in that discussing service experiences may be traumatic for some participants. This risk was adequately mitigated by establishing a counseling referral service through a local ASO that participants could access if needed.

Recruiting Participants

The present study examines interviews with eleven participants aged 50 and over living with HIV/AIDS in the National Capital Region. The age group 50 and over was selected in order to be consistent with previous American, British and Canadian research (e.g. Poindexter, 2004; Meadows, Marechal & Catalan, 1998; Public Health Agency of Canada, 2004). Self-reports determined whether someone was living with HIV/AIDS, as well as referrals from the ASO case manager. Recruiting was conducted through posters placed strategically at an ASO in Ottawa. In some cases, participants were referred to the project by the case manager at the ASO. In this case, the case manager contacted participants they deemed suitable for the study and described the project to the potential participant. If interested, the case manager either forwarded the contact information of the principal researcher on to the client, or arranged a time for them to come in to participate. This type of sampling has been referred to a convenience or purposive sampling (Patton, 1990). This method of participant recruitment has been utilized widely in studies of oPHAs (e.g. Fritsch, 2005; Emler 2004; Heckman, Kochman & Sikkema, 2002; Heckman, Kochman, Sikkema & Kalichman, 1999), and has proven effective. In

addition, a snowball sampling technique was utilized, in which participants were asked to recommend the study to appropriate others (Neuman, 1997). While I attempted to recruit a broader diversity in terms of the sample, this presented a challenge. Within the subgroups (i.e. women, gay men, homelessness), many of the same themes began to emerge until I reached saturation (Tutty, 106) and is similar to previous qualitative research with this population

Materials/Procedure

Upon arriving at the study site and seating themselves, participants were asked to read and fill out an informed consent form, and were given the opportunity to ask any questions they may have concerning the study. Participants were then asked to fill out the demographics/ descriptive information questionnaire. Participants were asked to answer demographic questions regarding age, sex, marital status, education, language, employment, income, overall health/HIV status (e.g. symptomatic, asymptomatic, AIDS, co-infections, etc.), medications used (including HIV medications; excluding HIV medications), and age first diagnosed with HIV.

Participants were then administered the Ottawa Older PHA Services Questionnaire (OOPS)⁸⁴ attached to the demographics survey, and were given the opportunity to indicate whether they access a series of health and social care services, and rate their importance⁸⁵. Following this, participants were asked to complete an affect/depressive symptoms inventory. The scale used was a short form of the reliable

⁸⁴ The OOPS questionnaire was developed by the researcher based on service use inventories of Emlet & Berghuis, (2002), Fritsch, (2005), the researcher's personal knowledge of PHA services in Ottawa, and in consultation with a local ASO case manager.

⁸⁵ Participants were asked to indicate whether they used/didn't use/needed, but couldn't get/ or have been waitlisted for each service.

and valid *Geriatric Depression Scale* (Yesavage et al., 1983)⁸⁶. Next, participants were asked to complete the *Barriers to Care Scale (BACS)* developed by Heckman et al. (1998). This twelve-item scale has been previously tested for reliability and validity, and aimed to measure how heavily a series of twelve barriers impacted the participants' access to services.

Following this, participants participated in an audio recorded⁸⁷ interview⁸⁸ in which they were (a) asked to respond to a series of questions regarding their experiences regarding issues related to living with HIV (e.g. health and social services experiences, mental health, housing, spirituality, oppression, disclosure of HIV status), and (b) asked to elaborate on their needs, preferences and barriers associated with health and social services. Following the completion of these tasks, participants were thanked, handed debriefing forms, and asked if there were any questions regarding their participation. Participants were then given an \$20.00 honorarium that came from Graduate Student Bursary and OAN/OHTN funding. The entire interview sessions lasted between one and two hours. Pilot testing was conducted prior to the study to determine estimated timeframes, and the order in which the materials were presented. Accommodations were made for participants with literacy and health challenges (i.e. the investigator administered scales verbally and manually recorded participant responses) and snacks and rest breaks were permitted⁸⁹. Following the interviews, recorded data (stored in .mp3 format) were copied to a password protected computer folder.

⁸⁶ The short version of this test reduced the number of items from 30 to 15, and has been used reliably among older adults.

⁸⁷ The interviews were recorded in digital audio format using a RCA digital voice recorder.

⁸⁸ During this process, the researcher made notes about responses in the form of memos. Following each interview, the researcher filled out his thoughts and observations from the interview.

⁸⁹ These guidelines were suggested in Siegel, Bradley & Lekas (2004) article addressing fatigue among oPHAs.

Analysis

The method of this study consists of both quantitative and qualitative data analyses, a method also referred to as triangulation (Morgan, 1998; Denzin, 1970; Jick, 1979)⁹⁰. First, quantitative data (i.e. data from demographics questionnaire, the OOPS, GDS (Yesavage et al., 1983), and BACS (Heckman et al., 1998)) were tallied and summarized⁹¹ using *SPSS*. Next, the qualitative process began.

The qualitative data was analyzed using methods outlined in qualitative research guides (i.e. Tutty, Rothery & Grinnell, 1996; Creswell, 1998; Heppner & Heppner, 2004 and Bazeley, 2007), as well as through personal conversations with the thesis project supervisor, Dr. Karen Schwartz. Tutty, Rothery & Grinnell (1996) outlined five systematic steps for analyzing qualitative interviews. They include: (1) preparing interviews in transcript form; (2) establishing a plan for data analysis, (3) first level coding, (4) second level coding, (5) interpreting data and theory building. Transcripts were prepared by a paid transcriber, who recorded anonymous interviews in verbatim form. The transcriber was provided with a transcription guide, which included general instructions, common HIV terminology and a list of service organizations in Ottawa, etc. For each participant, a separate word document was produced. Transcripts were returned to the researcher, who then double spaced, page numbered and printed the transcripts.

Next, the coding process took place. A code is an abstract representation of an object or phenomenon (Strauss & Corbin, 1998; cited in Bazeley, 2007, p. 67). Codes are

⁹⁰ The concurrent use of quantitative and qualitative methods has been referred to as triangulation (e.g. Denzin, 1970; Jick, 1979). For further details how this is achieved in the present study, review, please see Chapter 8.

⁹¹ While means for age, among other variables were calculated, the present sample ($n=11$) was far too small to conduct any further statistical analyses, and therefore the present project did not infer association using quantitative methods.

a form of topic, 'category', or 'theme name' that becomes a shorthand method of identifying common or central findings (Tutty, Rothery & Grinnell, 1996, p. 105). The type of coding utilized in this study was *a priori*, or theoretically-driven coding⁹². Examples of themes that emerged from interviews three or more times were considered to be evidence of strong themes, as per recommendations outlined by Tutty, Rothery & Grinnell (1996; p. 107). In sum, the present study is a thematic analysis of mostly qualitative data that engages in a sophisticated process of theme identification, coding and meaning development. Together, these methods of analysis were used to examine participant stories that informed social policy and practice. These stories are described next.

Introduction to the participants' stories

Several themes emerge from the study of health and social service experiences of eleven older adults living with HIV/AIDS in Canada's national capital region.

Throughout this section, themes are framed in relevance to previous literature and the theoretical framework outlined in earlier chapters. In Chapter 4, participant stories are introduced through a description of each participant, along with important contextual themes relating to aging with HIV/AIDS. Together, these themes set the stage for a detailed examination of health and social service experiences. Next, the types of services participants used are described, with an emphasis on perceived lack of specific services.

Chapter 5 presents oPHAs accounts of feeling lack of recognition, uniqueness, and confusion in their health and social services. Specifically, lack of recognition in

⁹² According to Bazeley (2007), a priori coding is particularly appropriate for those who (a) work from a background of extensive literature review, (b) have a prior experience with what is being studied, (c) bring a strong theoretical bases to their study and (d) have a time-limited focus (Bazeley, 2007, p. 76). The current project met all these criteria for a priori coding.

society in general, and in services in particular, leave oPHAs in the region feeling particularly isolated. Likewise, uniqueness is viewed as problematic, however also as constructive to community building among this segment of PHAs. The chapter then focuses on two particularly marginalized groups: women and homeless oPHAs. It is argued that these participants experience compounded or multiple marginalities. Finally, confusion is evident in participants' accounts of symptom ambiguity, as well as in stories of lack of service provider knowledge of life expectancies, medical treatments, medication interactions, etc. These experiences are linked to form an argument that these people experience marginalization (Young, 1990).

In Chapter 6, I present examples which suggest that oPHAs in the region experience discrimination in health and social services. Specifically, in several situations HIV is treated as exceptional (Bayer, 1999), which presents barriers to some services. This discrimination is argued to link to HIV-related stigma (Herek & Capitano, 1999). Specifically, while it is unclear whether stigma is enacted in instances of discrimination, it is definitely felt by participants, through anticipated discrimination, lowered expectations, and internalization of stigma. Further examples from participants' stories are provided which suggest HIV-related stigma operates on several assumptions.

Chapter 7 focuses on the role of power in the health and social services of oPHAs. Service experiences are presented in terms of power struggles that lead participants to resist professional power or feel futility. Several forms of power are argued to exist for these participants, including professional power, institutional power, as well as PHA power. Particular emphasis is placed on how power is shared and enacted to mitigate previously mentioned service deficiencies.

In the conclusion, the study's emergent themes are examined in terms of which presents barriers and facilitates to this group. Themes suggest that older adults in the national capital region experience and interpret many barriers to their health and social service experiences. However, several factors facilitate these experiences and are engaged to optimize services for this these people. Finally, I argue that together, the themes that emerged from these stories of health and social service experiences suggest oPHAs are oppressed.

CHAPTER 4: HEALTH AND SOCIAL SERVICE EXPERIENCES OF OLDER ADULTS LIVING WITH HIV/AIDS IN THE NATIONAL CAPITAL REGION

Introduction

In this chapter, a brief description of the study's sample is presented, followed by a detailed description of individuals interviewed. Next, services used by participants are presented. Participants indicated the importance of HIV-specific services, and indicated they lacked adequate long term care, housing, and mental health services.

Participants

This section provides important contextual information to better aid understanding the major themes that emerged from participants' stories, presented later in this thesis. Specifically, participant descriptions are presented, followed by a brief summary of the group. This study consisted of interviews with eleven oPHAs living in the national capital region. The mean age of the participants interviewed was 60 years; the youngest participant was 52, the oldest participants were 67. The group consisted of two females (18%), and nine (81%) males, and no one identified as transgendered or inter-sex. The participants were mostly white, European, English-speaking, well-educated people of varying sexual orientation, relationship status and income. All but one participant identified as 'retired'⁹³. Five participants reported receiving Ontario Disability Support Program (ODSP) benefits and four reported receiving Canada Pension Plan or Quebec Pension Plan (CPP/QPP) benefits. Several of the participants also reported having private insurance plans.

⁹³ Of the ten people that identified as retired, the mean number of years since retirement was 11.40.

In terms of health status, six participants (55%) reported being HIV-positive and asymptomatic, two (18%) reported being HIV-positive and symptomatic, one (9%) reported having AIDS, and two (18%) either did not know of their HIV disease progression or preferred not to disclose. Six participants reported having experienced co-infections or co-morbidities, which included: hepatitis C, hepatitis B, thrush, lipodystrophy and buffalo hump, Kaposi's sarcoma, yeast, bladder, heart, and e coli infections. A brief description of each participant follows, although every attempt was made to retain confidentiality and anonymity. The participant descriptions were constructed by the researcher based on: (a) information gathered in the demographics questionnaire and OOPS tool and (b) indistinct personal details revealed over the course of the qualitative interviews⁹⁴. In order to maintain confidentiality and anonymity, the researcher assigned each participant an alias. These are outlined below.

Bette

Bette is a straight grandmother in her sixties. She engages in PHA advocacy and volunteers for various community organizations. She receives benefits from the Ontario Disability Support Program (ODSP), and lives in subsidized housing with her partner. She accesses an HIV specialist physician, case management services, open drop in, food banks, transportation vouchers, housing assistance, counseling services, peer support, HIV support groups, and participates in HIV clinical drug trials.

Jimmy

Jimmy is a single, gay, retired professional in his late fifties. He lives with a family member and receives a private pension. Jimmy reported accessing an HIV

⁹⁴ Pertinent details are solely subject to the researcher's perspective, and participants did not have the opportunity to articulate how they wished to be described in the study.

specialist physician, a nurse/nurse practitioner, open drop in services, and participates in HIV support groups and HIV clinical drug trails

Timothy

Timothy is a gay, disabled professional in his early fifties. Timothy lost his partner to AIDS. He receives national disability and private insurance benefits from a previous employer. He accesses an HIV specialist physician, a chiropractor/occupational therapist, a psychologist/psychiatrist, uses alternative therapies, open drop in services, food banks, meals, internet/computer use, legal assistance, counseling services, peer support, and an HIV support group.

Caleb

Caleb is a single, bisexual retired professional in his late sixties. He lives alone, volunteers, explores alternative therapies, and is estranged from family. He accesses an HIV specialist physician, a chiropractor or occupational therapist, a social worker, nursing services, holistic and alternative therapies, case management, open drop in, spiritual services, internet computer services, HIV-related internet sites, legal assistance, counseling services, peer support, HIV support groups, and seniors' groups.

George

George is single, gay, retired professional in his late sixties. He has been retired for nearly two decades, recently moved to Ottawa, and lives with his son. He accesses an HIV specialist physician, nurse/nurse practitioner, open drop in services, meals, peer support, and participates in HIV support groups and a gay man's group.

Philippe

Philippe is a single bisexual male in his early fifties, who is disabled and retired from a helping profession. He receives ODSP benefits, and lives alone in subsidized housing. He accesses an HIV specialist physician, open drop in and spiritual services, food banks, meals, clothing, laundry facilities, peer support, and participants in HIV clinical drug trails.

Jacques

Jacques is a single, disabled, gay retired healthcare professional in his mid-fifties. He reported receiving benefits from federal and provincial support payments (ODSP/ CPP/QPP), and lives alone in subsidized housing. He accesses an HIV specialist physician, alternative therapies, a social worker, case management, open drop in, spiritual services, food banks, meals, clothing, internet/computer, housing and legal assistance, counseling services, peer support, and an HIV support group.

Jon

Jon is a straight man in his early fifties, who reported receiving ODSP benefits, and is homeless. He accesses an HIV specialist/physician, open drop in services, food banks, clothing, laundry facilities, legal assistance, counseling services, peer support, and an HIV support group. He has past experience with drug use, and was very concerned with improving living conditions for oPHAs.

Violet

Violet is a straight female in her early sixties. After retiring from her profession, she remains employed part-time and volunteers. She owns her home, and receives national and private pension benefits. She accesses an HIV specialist physician, holistic medicine, alternative therapies, open drop in, spiritual services, food banks, meals,

transportation, peer support, an HIV support group, and HIV-related internet sites. Violet has experienced depression and reports being very protective of her HIV status.

Wesley

Wesley is a two-spirited aboriginal male in his late sixties. Wesley, a retired professional, receives national pension benefits and owns his home. He accesses an HIV specialist/physician, nursing services, as well as holistic medicine, open drop in services, spiritual services, food banks, meals, clothing, laundry facilities, and internet/computer use. Wesley was misdiagnosed twice by medical professionals, the first time with Alzheimer's disease rather than AIDS dementia complex, and the second time with bad laundry soap rather than renal failure.

Sam

Sam is straight man in his early sixties. He retired from a skilled trade nearly a decade ago. He receives benefits from ODSP and is currently homeless. He accesses an HIV specialist physician, a social worker, open drop in services, food banks, meals, clothing, and laundry facilities. Sam was very tired during our interview.

This section describes the participants of the present study. Together, these descriptions set the stage for a thorough examination of the health and social service experiences of older adults living with HIV/AIDS in the region.

Types of Service Use Reported by oPHAs

This section provides a detailed account of the health and social service experiences of eleven older adults living with HIV/AIDS in the national capital region (NCR). This study builds upon previous research on this topic. For instance, while the Fritsch (2005) study measured service experiences using mixed methods, it did not

explore the experience of service from a structural lens that the present study engages. Nor did it describe services in relation to social justice. For instance, some of the participants framed their health and social service experiences in term of structures (institutions, ideologies, etc.), which is consistent with lens of structural social work theory and analyses applied to the data from the present study (Moreau & Leonard, 1989; Mullaly, 1997/2007). Thus, the present study can be viewed as building upon the Fritsch (2005) study with a nuanced structural account of health and social service experiences among older adults living with HIV in Ontario.

In order to get a general idea of service use of oPHAs in the NCR, participants were asked to complete a short questionnaire about service use and access (OOPS), which the researcher looked over and incorporated into the interview. Participants were asked to complete a short questionnaire which asked whether they ‘used/did not use’, ‘had been waitlisted’, or ‘needed but couldn’t get’ a battery of services. In addition, participants were asked to rate importance of each service. Participants used between using 5 and 16 services, with a group mean of 10 services ($n = 11$). The most frequently used health services were those of *HIV specialist physicians*. Three participants reported using the services of a *nurse* or *nurse practitioner*. A particularly important theme that emerged was health management. For instance, participants reported having many medical appointments, and many saw their physician more than twelve times a year⁹⁵. Together, this picture of service usage is congruent with previous research (i.e. (Fritsch, 2005) that suggested oPHAs frequently accessed health care services in Ontario. Also, participants reported using many medications and, interestingly, they used more non-HIV

⁹⁵ Four participants (36%) reported having seen a physician between two and six times in the last year, four (36%) reported between seven and twelve times and three (27%) reported seeing a physician more than twelve times in the past year.

related medications than HIV related medications⁹⁶. This finding supports literature concerning complex HIV treatment regimens (e.g. Hammer et al., 2008), and suggests that older PHAs may be prescribed more medications because of conditions related to aging or aging with HIV. This was a particularly important finding considering that little research has been conducted on medication interactions among this age group of PHAs, and lack of physician knowledge of these potential medication interactions were discussed by a participant in relation to service experience.

In terms of people's experiences with mental health services, five participants reported using *counseling* services, five did not, and one indicated that they need but cannot get access to counseling. While these finding suggest the utilization of mental health services among oPHAs, as suggested by Fritsch (2005), it remains unclear whether Emler's (1993) finding that oPHAs accessed low levels of emotional support services is the case here, or if the development of improved HIV treatments has changed this. In addition, it remains unclear exactly where these services came from⁹⁷. For instance, lack of emotional support services in the present study may have been mitigated by alternative forms of support, such as peer-support networks. Peer support services may be more important than institution based services. While a small portion of this small sample have access to institutional services (three participants use the services of a *social worker*, one indicated they needed but could not get a social worker, three used *case management* services) more have access to peer support services (*open drop in services* at local ASOs ($n = 11$)⁹⁸. Eight participants used *HIV support groups* and *peer support* services also at

⁹⁶ Of the sample, the mean number of total prescribed medications used was 8., The mean number of prescribed HIV medications was 3; while prescribed medications not directly related to HIV were 5.

⁹⁷ Participants reported using psychiatrists, psychologists, social workers and counselors.

⁹⁸ This was an interesting finding that spoke to increased de-professionalization in this field.

local ASOs, which is unsurprising considering this is a feature of how I obtained this sample. Perhaps this indicates a shift from the earlier days of the epidemic that were characterized by increased medicalization and professionalization within Ontario's community-based ASOs as described by Cain, (2001;1993). This shift to peer-driven services (Travers et al., 2008) emerges again later in this study. Also, participants used *spiritual services*⁹⁹. Only one participant reported accessing *seniors' groups*, and no one reported using *home care* services. This is particularly interesting considering the age of these participants, and may be suggestive of barriers to accessing senior communities and services.

Many of the examples provided in the present study suggest that HIV-specific services, like ASOs and HIV specialists exceeded participants' expectations, while many examples are provided that non-HIV specific health and social service providers were oppressive. Participants felt that the AIDS Service Organization (ASO) was particularly important component of their constellation of¹⁰⁰. ASOs in Ontario have been described in detail by Cain (1993; 2001; Cain & Todd, 2001), and can be viewed as what Mullaly (2007, p. 332-4) calls 'alternative social service organizations'. In particular, two types of

⁹⁹ A particularly interesting finding was that oPHAs in this study accessed spiritual services. For instance, Philippe described a prayer group he attended: "I was in a circle of Christians...we used to pray a minimum of 5 to 6 hours a week...my belief is pretty, pretty strong." Similarly, Caleb discussed disclosure of his HIV-status within his prayer group: "people who used to go to the prayer group would stop me in the street or in the church and say 'How come we are praying for you?'" I would say 'That's between the Lord, me and [group leader]; you want to discuss it, ask her!'" Caleb's response suggests that while he attended the prayer group, he did not feel appropriate disclosing his HIV-status. George expressed that he did not fit into his church community: "I tried a church group that played euchre; I didn't fit into that very well". Finally, Violet expressed that the inspirational group she tried to start at her local ASO was not successful: "It was a spiritual group but ... [the word] 'spiritual' was a little bit too hard so it was changed to 'inspiration' group, ...and nobody signed up". This finding supports recent research that has been conducted with oPHAs concerning spirituality (e.g. Siegel & Schrimshaw, 2002; Vance & Royal, 2006).

¹⁰⁰ These participants framed their local ASOs as incredibly diverse environments. Wesley made reference to ASOs who cater to very different people sharing a common ailment: "I found the major adjustment...is getting used to be with a...bunch of people...thrown together as a common ailment but come from all different stratus of life".

ASOs were mentioned by participants in the national capital region: an open drop-in and support services center and a housing support agency. The idea that ASOs were very important to oPHAs was affirmed by several participants. For instance, Timothy suggests that his local drop-in ASO provided “services that I couldn’t get elsewhere”. He also said: “It’s been a place for me that [has] been a bit of a refuge...to be able to find support”. Similarly, Jon noted: “Without this place I would be lost”. These statements suggests that participants view their HIV-specific social services important, as is the case with Timothy, and also in terms of the space they provide, as seems to be the case with Timothy and Jon. In addition, several oPHAs in this study reported accessing vital subsidized housing through local ASOs, adding to the idea that services are viewed in terms of space. Caleb argued that specialized needs of oPHAs merited PHA-specific housing services provided by his local ASO:

They wonder why HIV patients should be segregated, like why we have [housing ASO; name withheld], why can’t they just go into a hospital or a recovery home or something, they don’t understand that this is specialized field, and [PHAs] need the extra care, and they need people knowledgeable. (16/11/07)

To better understand Caleb’s comment, we can draw upon Bayer’s (1999; 1991) concept of HIV-exceptionalism. Specifically, Caleb may be suggesting that HIV is exceptional and requires complex care outside of mainstream health and housing services. This finding, along with the emphasis many participants place on ASOs, further identifies the importance of HIV-specific services in our region. In several participants’ stories regarding their local ASOs, particular emphasis was placed on staff and volunteers. For instance, Bette praised the case manager at her local ASO: “[The ASO case manager; name withheld] treats everybody like...we’re a member of his family. If he were to leave

[this ASO] would be in trouble, our living would be in trouble, cause you would never find anyone like him, to replace him, nobody.” She continued that this level of service was the “same with the rest of the staff”. Bette’s statement, when examined using a lens of structural social work (Mullaly, 2007, p. 245) reveals that social services are also based on social relationships, particularly with staff or service providers. In turn, the quality of these relationships seems to determine the quality of service Bette receives. Additionally, Bette referred to the volunteer-driven nature of her local ASO:

I’m so happy [with] the staff we have, the volunteers we have, people are wanting to volunteer here....It’s so good to hear “Well, we got another volunteer”, you know; they’re crying to come in and help us out.
(15/11/07)

This statement implies that Bette’s experience with social services has been influenced by volunteerism. In addition, her joy surrounding people’s enthusiasm to volunteer at an ASO suggests that she considers willingness to volunteer as expressions of people’s acceptance of PHAs. However, when examined through a structural lens (e.g. Moreau & Leonard, 1989), we can see how a capitalist ideology which influences neoliberal policies espousing welfare state retrenchment places an increased onus on volunteerism at local ASOs. This in turn impacts the availability and quality of the social services Bette receives.

Together, the themes that emerge through examining services usage are congruent with Fritsch’s (2005) findings that older PHAs accessed social services¹⁰¹, and supports the idea that oPHAs accessed more services from PHA/HIV networks than aging networks (i.e. Emler & Berghuis, 2002). These examples indicate that health and social

¹⁰¹ In the Fritsch (2005) oPHAs accessed significantly less social organizations than did younger PHAs. In contrast, although the present study did not compare PHA age groups, most of the participants are involved with local social service organizations. This difference in findings could be attributed to the different sampling techniques employed by the two studies.

service institution (i.e. secondary social structures; Moreau, 1979; or super-structural elements; Mullan, 2007), such as the ASO, play an important role in the lives of these oPHAs in the NCR. Participants described health and social services in terms of social opportunities, space and relationships. In addition to these examples of service usage, several specific service gaps were identified, and are outlined next.

Perceived lack of specific services

There were several specific services that oPHAs in this study identified as lacking or unavailable. These included long term care, housing, and mental health services. This was important to the present study because it identified specific examples which support the theme of a lack in available services, opportunities, benefits, or 'goods'. This allows for an interpretation of service experiences based on critical social theory (Marx & Engels, 1948/2004) and social justice work concerning the distribution of social opportunities and benefits (Reisch, 2002; Young, 1990). It remains unclear exactly why specific services are not available for this segment of the population, or if this group was alone in being unable to access them. However, this finding suggests the lack of available services is due to obscured visibility of need, or marginalization as proposed by Young, (1990; p 55), which may or may not be specific to these participants. Also, participants seemed to be equally concerned over the availability of culturally competent services, which suggests that cultural imperialism (e.g. Young, 1990, p. 42) may be at play here.

Long term care and services

Long term care was a concern for many of the oPHAs interviewed. For instance, Timothy noted: "I think about services that I may require later on, you know geriatric

care, long term nursing placements, those kinds of issues, and worry...if there's going to be a place with appropriate care". Similarly, Caleb asked: "What happens when you become [a] senior and need the extra care, you know is there going to be a place that's going to have a nurse available?"¹⁰² George acknowledged:

There probably might come a day when I'm going to be living on my own and that's kind of a scary situation for me, like I have grown used to living with...my [family member]...but before that I was living alone and I had to have help, I had to have a paramed and a social worker come in, and if I go back on my own again, I'm going to need those services, and that's been on my mind. (16/11/07)

George's comment spoke to the importance of family support in offsetting care burdens for oPHAs. However, his response suggests that his family support was not sustainable, which causes him concern.

Several participants identified a specific concern of being gay in long term care. For instance, Timothy wondered if long term care would "be sensitive to my issues as a person aging with HIV, a person who is gay" Similarly, Jimmy asked: "Where do we [long-term survivors] go when we retire? What about us who have money to go into a retirement home...You have the hots for the old boy, 72, with his walker, you know...So, what about *us*?" Jimmy's comment brings to the surface the very critical question of sexual practices in old age, and how this will be valued and negotiated as older adults living with HIV enter retirement homes or long term care. This anticipated exclusion links to the ideas of marginalization, and powerlessness, and cultural imperialism (e.g. Young, 1990, p. 53; 56; 59), as well as social exclusion (e.g. Labonte, 2004; Galabuzi, 2004). Specifically, Jimmy worries that he will be challenged asserting his sexuality in a

¹⁰² Caleb specified "now nurses have been given the power to do needles and so on and write prescriptions", implicating the role of nurse practitioners (or, NPs) as appropriate in the long term care for oPHAs in the NCR.

potentially heterosexist environment that may frown upon sexual activity, and that this will render him invisible and incapable of expressing affection outside of the dominant heterosexual norm.

Violet emphasized the importance of pain management in long term care, and the potential problems this may present for oPHAs: “A lot of them [PHAs] use pot because of the pain”. She observed: “Folks who don’t have HIV [are] saying ‘I don’t ever want to go to a residential area, because I want to keep smoking my pot, and they might not let me, so I’m not going there.’ So we’re a different generation.” She observed: “residential homes for older people are going to have to make some adjustments as we start coming in”. These comments surrounding acceptance into long term care can be better understood by drawing upon a structural lens. Specifically, these participants fear that institutional practices will be influenced by ideological structures like heterosexism, HIV and drug-related stigmas, and render them excluded from long term care. To better understand Violet’s comment, we can draw upon King’s (1988) idea of multiple forms of jeopardy as it relates to being older, a woman, living with HIV/AIDS, and a user of marijuana. Specifically, Violet could be discriminated against on the basis of any, or all, of these factors.

Caleb asked “Is there ever going to be something available like that, say an extension of [current housing ASO], a pipe dream that might have an extension on it or another building just for seniors that have HIV?” Caleb identified that oPHAs may have increasing long term care needs that were not currently being met by the NCR’s PHA housing service. Also, by referring to this extension of existing services as a ‘pipe dream’, Caleb identified pessimism regarding his long term care and housing for seniors

living with HIV in our national capital region. This supports earlier statements about lack of adequate housing in mainstream services, but also identifies a gap in HIV-specific housing services these participants access.

Together, these examples suggest that that oPHAs are concerned about the lack of future long term care services. These finding suggest these people have internalized an anticipated discrimination, in the sense that oPHAs expect a shortage of services for them, perhaps based on their oppressed, intersecting identities (e.g. Hall Collins, 1998). Specifically, these participants doubted whether society would accept oPHAs into long-term care, whether PHA-specific services would follow them into old age, and thus whether they will receive adequate care as they get older.

Housing Services

Concern by oPHAs regarding housing extended beyond long term care services to include adequate housing in general. Jon, a homeless man, spoke to the impact of adequate housing on the health and well-being of oPHAs: “There’s got to be more housing, there has to be, and how many of us are living in rooms and shelters? I mean, give us some dignity for our last years. Give us some dignity, give us something to feel good about, help us to live longer”. This suggests that some participants feel inadequately supported by by Canadian public housing policy. Specifically, primary structures of capitalism that espouse self-sufficiency may inform contemporary institutional practices that pose barriers for people like Jon to access stable housing.

In addition to homelessness, participants reported living in unhealthy spaces. For instance, Bette, despite her positive experience with a local housing ASO, reported that her neighborhood is noisier than she would like: “You can hear the traffic at night; the

big trucks go by, the exhaust, that's the only problem". In addition to noise, Philippe and Jon referred to the dangerous health ailments associated with living in unhealthy public spaces. Jon suggests that oPHAs' immune systems may be particularly weak:

I will tell you right now the longer I live in the shelters, I'm [susceptible] to more things...I wake up everyday, and pretty much everyday I got a sniffle, you know, I have to get out of there, I get everyone else's germs, I mean, I'm not saying I'm germless, but I can deal with mine, but I can't deal with other peoples. I constantly get colds, constantly. (06/12/07)

In addition, Jon continued to describe how his environment has impeded his recovery from addiction. He said "It's very, very hard for me to stay away from the drugs living in a shelter, and I would like to get better". He added: "You know, you sit in a barber chair long enough, you get a haircut. Living there is virtually impossible". This comment can be viewed from a structural lens, which suggests that ideologies that inform institutional housing practices in Canada not only interfere with people's ability to secure, safe housing in general, but in the process subject vulnerable segments of the population to situations which prevent them from recovering from addiction.

Together, these examples tie into previous literature which identifies housing as a major social determinant of health (e.g. Shapcott, 2004; Bryant, 2004). Specifically, housing (an acknowledged SDOH; Raphael, 2004) was described by participants as a social good or opportunity that is inequitably distributed among Canadian citizens; thus producing social injustice as proposed by Young (1990) and Reisch (2002). Therefore, social justice literature ties into the *social determinants of health* approach. It is unknown whether these examples of oPHAs and housing are congruent with other research that was conducted in this area. However the upcoming results of the *Positive Spaces, Healthy Places* (e.g. Tucker & Koornstra, 2008) project conducted in Ontario these past

few years should shed some light on housing and whether the issues of homelessness and long term care emerged as important issues to other older PHAs in the province.

Mental health services

Participants identified shortages in mental health services as a major service issue. This is particularly important because most of the participants reported symptoms of depression¹⁰³ and discussed mental illness on many occasions. Mental health professionals were identified as important to oPHAs' well-being, although participants experience a critical shortage of these professionals in the NCR, specifically for oPHAs who access service from local ASOs. The critical role of peer support in mitigating mental health was also mentioned.

Violet perhaps best articulated the importance of the availability of mental health professionals. She recalled "I was suicidal, and so I saw a doctor at [the infectious diseases clinic] just twice and right away they sent me to the psychology department...I was seen for a year and a half regularly...that was a very key point in my survival, was that psychologist that I saw". Violet's statement provides further support for the idea that suicide is an issue for some oPHAs (e.g. Kalichman, Heckman, Kochman, Sikkema, Bergholte, 1996).

Despite the perceived efficacy of mental health professionals, several participants referred to a critical shortage of mental health professionals in the national capital region. For instance, Timothy reported a "huge lack of affordable resources in psychology and those areas". Timothy referred to multiple or intersecting oppressions as they play into

¹⁰³ Each participant was asked to complete the *Geriatric Depression Scale* (Yesavage et al., 1983). For this scale, a score of less than 5 indicated that a participant was non-depressed, while a score above 5 indicated the possibility depression. Of the participants, eight scored more than 5, while only three scored less than 5. One participant reported a score of 10. These quantitative findings suggested that the majority of the present group experienced depressive symptoms. Interestingly, one participant indicated a score of 0.

increased need for mental health services among oPHAs, and identified: “A huge need; especially with those socially [and] ecologically depressed and homeless and HIV [positive], they have all kinds of great needs for [mental health] services and I don’t think that’s been provided enough”. In addition, Timothy also referred to the availability and financial cost of mental health services: “[There] probably need[s] to be more practitioners in the city and more practitioners prepared to see people...who have limited income...and maybe seeing them on sliding scales”. This suggests that even if more mental health professionals were to become available, financial barriers may still prevent oPHAs from accessing these services.

Several participants reported that mental health services available through their local ASO may not be adequate. Jacques reported: “We need professionals! A psychiatrist or something HERE, here at [the ASO]”. Violet further explained:

There’s a case worker here, but I don’t think that is enough, I think [ASO clients] need psychological, psychiatric support and I don’t know that they are getting it... I do believe that a lot of people here should be under psychiatric care, psychologist care anyway, and I don’t know if they are, I don’t know if they are not, if it’s because of the system, I’m not sure.
(07/12/07)

We can use structural social work theory (Moreau, 1979; Mullaly, 1997/2007) to better understand her comment. Specifically, Violet referred to ‘the system’ responsible for the shortage of mental health services for oPHAs at the ASO level, suggesting that she is cognizant of the structural determinants of her service provision. Jimmy reiterated this, referring to a discontinued counseling program at a local ASO: “We used to have a counseling service which worked very, very, very well...but everything depends on the almighty book”. Violet and Jimmy’s descriptions of mental health services as dependent on structural factors relating to money fit well within the current study’s framework of

structural analysis. Specifically, by referring to ‘systems’ that depend on the ‘almightily book’, these participants are identifying institutional service gaps due to limited funding. Since funding is based on government policy, conservative ideologies that either devalue mental health, PHAs (or both), and function based on cost containment strategies leave oPHAs without mental health services that have worked well in the past, but are currently lacking.

Finally, several participants, while maintaining that more professional mental health services were needed at both the national capital and ASO levels, mentioned the importance of alternative mental health care through peer support programming and services. In essence, peer support services are constructed by participants as mitigating the shortage of mental health professionals¹⁰⁴. For a detailed account on peer support services, please see the Chapter 7, which focuses on how oPHAs enact power to mitigate service deficiencies. In conclusion, the participants of the present study identified several service gaps (i.e. long term care, housing and mental health), all of which are problems faced by society in general. Next, the focus shifts from services that cannot be accessed to the experiences within services that are accessed by oPHAs in the national capital region.

¹⁰⁴ This finding is controversial, as it questions the legitimacy of professional mental health services at the ASO level.

CHAPTER 5: PROBLEMS OF RECOGNITION, UNIQUENESS, AND CONFUSION IN SERVICE EXPERIENCES OF OPHAS

Introduction

An important theme emerging from this study is that older PHAs feel lack of recognition, uniqueness and confusion in health and social services. In this chapter, I explore how these feelings link to the ideas of marginalization as proposed in Young's (1990) theory of oppression, and social exclusion as defined by the *social determinants of health* approach (Labonte, 2004; Galabuzi, 2004). Feelings of uniqueness, isolation and confusion emerged as major components of marginalization and social exclusion for these participants. This is particularly important because being marginal and excluded may impact acknowledgement or visibility of need and thus influence the people to whom service providers direct their services.

Marginalization was proposed by Young (1990, p. 55) to be the 'face' of oppression that denies recognition, interaction, or participation. In the present study, 'recognition' is viewed as acknowledgment and visibility; 'interaction' is the relationship between service provider and user; and 'participation' is the ability of oPHAs to access and actively participate in their own health and social care. Similar to these concepts is the idea of social exclusion, which is a recently acknowledged *social determinant of health* (e.g. Raphael, 2004; Labonte, 2004; Galabuzi, 2004). Social exclusion has been defined as a set of "societal processes that systematically lead to groups being denied the opportunity to participate in commonly accepted activities of societal membership" (Raphael, 2004, p. 233). Using this definition, health and social service experiences are viewed herein as commonly accepted activities in which people participate. In essence, a

theoretical link emerges between concepts relating to oppression (Young, 1990; Mulllay, 2007) such as marginalization and the *social determinants of health* approach to healthcare which posits social exclusion (Raphael, 2004).

Lack of recognition

Interviews with oPHAs in this study reveal that they suffer from lack of recognition (Young, 1990, p. 55). For instance, Bette reported: “I guess they [physicians] figure old folks don’t have [HIV]”. To make sense of Bette’s comment, we can draw upon Young’s (1990, p. 55) idea that to be marginalized is to be denied ‘recognition’ or acknowledgement. In Bette’s case, physicians operate on a faulty assumption that old people do not contract HIV/AIDS. From a structural perspective (e.g. Moreau, 1979), it is possible that this assumption is related to ageist ideology (e.g. Bytheway & Johnson, 1990) that assumes asexuality and lack of shared injection drug use among this age group. This clearly does not seem to be the case, based on Bette’s experience, as well as other participants in this study. Specifically, most of the participants interviewed have known of their HIV status for 10 years or more, and most became aware of their HIV status between the ages of forty-five and fifty-five, or, in middle to older adulthood¹⁰⁵. This supports the idea that these people contracted HIV later in life (e.g. Emlet & Poindexter, 2004; Moore & Amburgey, 2000; Eldred & West, 2005).

Lack of recognition of oPHAs is important in the sense that older people are obscured from the conventional discourse on HIV transmission. That is, the disease of HIV, long associated with certain and untimely death has only in the last decade come to include long-term survivorship or the possibility of aging. This has important

¹⁰⁵ Sam spoke to this in our interview: “It doesn’t bother me as much because I caught it [HIV] when I was older. It would have bothered me a lot more if I was younger and got it”.

implications for health and social services ability to respond to the needs of oPHAs in the NCR. For instance, Jimmy uses the city of Ottawa as a metaphor to describe lack of recognition of oPHAs: “It’s almost like our infrastructure in Ottawa [and] the streets; we never caught up with the traffic we have today. It’s the same thing with aging and HIV. It’s not looked upon”. Jimmy’s notion that the needs of people aging with HIV was not ‘looked upon’ further suggests that participants needs are not ‘recognized’ (Young, 1990, p. 55). This comment is important for the present study, since it directly links lack of recognition to the adequacy of services in the region, and thus the idea of social exclusion in health and social services (e.g. Galabuzi, 2004). Interestingly, Jimmy’s description of being ‘not looked upon’ links with previous literature that suggests oPHAs in our region feel ‘invisible’ (Genke, 2000), ‘overlooked’ (Riley, 1989), or ‘hidden’ (Emlet, 1997).

Uniqueness

The theme of marginalization also emerges for these participants through a shared sense of uniqueness. I argue that the sense of uniqueness is particular oppressive because of the isolation being unique may entail. For example, Bette recalled: “All I remember is sitting in the doctor’s office and him telling me that I was HIV-positive and I was his first patient [with HIV]”. Bette’s tone while recalling this memory was one that carried the confusion and fear of any ‘first’ patient; an experience which seemed frightening and demoralizing. Likewise, Jimmy observed: “I am the only old fucker that he has, that is HIV positive.” These examples suggest that Bette and Jimmy feel a sense of isolation from being the only older patients under the care of a healthcare provider who are HIV-positive, or a sole example of a particular kind of medical patient. In addition, Jimmy observed: “I am the only patient my GP has who is gay”. This supports previous research

suggesting isolation of people who identify as queer in health services (for review, see Daley, 2004). Further, when viewed from the perspective of intersectionality (e.g Denis, 2001; Hall Collins, 1998; King, 1988), the overlap of isolation that is experienced by Jimmy based on PHA status and sexuality suggests that being a PHA and gay represents a particularly good example of being multiply marginalized. This suggests that being a PHA and gay may represent a particularly challenging barrier to achieving recognition by health and social services.

Emerging from the theme of marginalization via uniqueness and isolation is the sense that oPHAs derive a sense of community through these shared experiences.¹⁰⁶

Violet described the sense of community among older PHA participants of the long-term survivor's group:

There are quite a few people that are long term survivors, so we, we often have conversations that is of our age group , you know, we're many in there, and so sometimes I go in there, I call this one man, I call him grandpa and he calls me grandma "Hi Grandma." And we hug. (07/12/07).

Clearly, Violet's statement lends to the idea that long term survivorship is a component of community building. She continued:

We've got the aches and pains of aging, the look, the hair, the wrinkles we've got it and we can see beyond that and look in the eyes of the person and feel a lot of, a lot of connection with the people, so in that group I find myself with a good group of people my age, so I don't feel that I'm always with a bunch of young people and I don't feel that my needs are being met. (07/12/07)

Violet's statements suggest that older adults within the PHA community share distinct common phenomena (appearance changes like graying and wrinkling, aches and pains, etc.), and have developed a sense of community based on these common experiences.

¹⁰⁶ Members of the national capital region's oPHA community reported they shared a wide variety of experiences, such as long-term survival, symptom ambiguity, a sense of uniqueness and isolation within health and social services, fear over availability of PHA services, and participating in peer-driven services.

These shared experiences are a central factor in building a 'sense of community' (for review, see McMillan & Chavis George, 1986; McMillan, 1996) acknowledged by Young (1990, p. 43). However, Violet's statement that her "needs are not being met" by services geared towards younger PHAs expands the idea of shared experience in community building to include the shared sense of inadequate response to unique service needs. Together, these examples suggest that these participants felt a lack of recognition, and a sense of uniqueness, that constitutes marginalization as proposed by Young (1990). In addition to older PHAs, other intersecting identities were subject to marginalization.

Intersectionality Focus: Older women living with HIV/AIDS

The two women of the oPHA community interviewed for this study reported feeling particularly marginal. Females are over-represented across all age groups of Americans living with HIV, including oPHAs (Poindexter & Emlet, 2006, p. 92), yet the participants in the present study still reported being on the margins of the PHA community. For instance, Bette spoke of an inadequacy of response to the unique needs of female PHAs in our region: "In Ottawa, we have the second highest [rate of] affected women and nobody wants to do anything for us". Bette's comment suggests that although statistical data exists speaking to the presence of women in PHA communities, women experience a lack of 'recognition' (e.g. Young, 1990, p. 55) and poor response to their service needs within Canada's national response to HIV/AIDS¹⁰⁷.

¹⁰⁷ The theme of marginalization among women represents a persistent stigma associated with the idea of a woman living with HIV/AIDS. In addition, Bette's construction of 'affected' women meant that women were affected, not just infected; suggesting that openness was required to women in the PHA community regardless of her HIV-status. For instance, Bette reported being HIV-negative when she married her first partner, who died of AIDS. Indeed, women have very often been the friends, family, and partners of men (and women) living with HIV/AIDS (as was alluded to by some of the participants).

Bette described an experience of gender bias in HIV research. She recalled an experience she had at a medical research conference when she was in her fifties: “I had noticed the workshop had men, 20-40; no women....I walked up to [the researcher] and I said... “[Researcher], why is it that they are no research on our women my age?” Bette recalled the researcher’s response: “Oh, there [are] only ten percent of you.” Bette interpreted: “In other words us ten percent mean nothing, we’re not important enough to do research on”. The way Bette’s experience as a woman is described here speaks beyond lack of recognition, but also to the idea of social exclusion (e.g. Shapcott, 2004; Galabuzi, 2004). Specifically, Bette’s experience at the research conference implies that women of a certain age are excluded from important PHA research. Moreover, Bette came to understand that women do not merit a response from the sexist research community. She clarified: “I guess at that time, it [HIV/AIDS] was still sort of called the ‘gay mans’ disease” Bette’s clarification allows us to draw upon structural social work theory, which suggests that institutional practices lead to women being overlooked are rooted in patriarchal ideology men over women, even within the PHA community.

Violet experiences the feeling of uniqueness within the PHA community. She described her ordeal of finding a legitimate place in the PHA community as a process; involving the feeling of uniqueness and isolation along her several stages of ‘coming out’ and finding agency with other female professionals. Later, Violet reported success in locating an appropriate peer network. She recalled: “Finally I was directed to a group of professional women, I was like “Oh my god, I can’t believe that there is such a group, HIV infected women, *professional* women? I thought I was the only one in Canada.”

Again, this supports the idea that a sense of shared experience was a building block for a sense of community (e.g. McMillan & Chavis, 1986; Young, 1990, p. 43) was confirmed, in this case among female PHAs. Violet spoke to this shared experience among women at her local ASO:

With time we have learned to love each other because we share a lot of same, same things and we're worrying about, we're worrying about our pills, What are we doing with our children?, Do we tell them?, Do we not tell them?, What do we tell our families? What about your menstruations? And so finally I ended up with another group of women that I would not normally associate with but that had some of the same needs that I did.
(07/12/07)

The narrative of these two women also builds upon McMillan & Chavis' (1986) theory: in addition to shared experiences, shared *needs* constitute a sense of community, as was the case for the women in this study, as represented by Violet.

Based on these examples of lack of recognition, uniqueness and isolation among female participants, it appears that women within the PHA community also feel marginalized (Young, 1990) and excluded (Shapcott, 2004). I argue that these feelings are compounded for older female PHAs. Specifically, these themes are congruent with previous findings that women disproportionally experience some form of compounded oppression (e.g. Mahalingam & Trotman-Reid, 2007; Petersen, 2006; Ward, 2004). These are women doubly or multiply oppressed (King, 1988) based on the marginalization of their intersecting female and PHA identities (Hall Collins, 1998)¹⁰⁸.

¹⁰⁸ In addition, the theme marginalization plays out in that woman are not only overlooked, they are excluded from and denied the ability to share their experiences with PHA service and research communities. The denial of language is viewed here as a social injustice based on human rights, such as the right to healthcare and freedom to speak freely. It is also viewed as an emotional blockage for these women, who may have experienced multiple marginalities yet were not permitted to share their experiences through language, and thus construct their own meaning or build their own chains of significance surrounding these realities (Treichler, 1999); a process most helpful in any help-seeking process, such as health and social service experiences.

Intersectionality Focus: Homelessness and Older PHAs

Older people living with HIV/AIDS who lack stable housing (or, the homeless) also experience a lack of recognition within services, as proposed by Young (1990, p. 55)¹⁰⁹. Sam, who is homeless, stated: “I’d feel a lot better if I did have housing; [I’m] tired of running around the streets looking for a place to stay”. I empathized: “That’s got to be hard when you are not feeling well all the time”. He replied: “Yeah, especially with my condition too, but, I don’t know, it doesn’t seem to be bothering them any”. This exchange suggests that Sam experiences challenges because of the way housing is distributed in Canada, and speaks of ‘them’ in his conceptualization of who is responsible for homelessness in the region. This finding again links to the idea of the role of structural arrangements (e.g. Moreau & Leonard, 1989) that either fails to acknowledge the severity of Sam’s situation, or function to keep Sam on the street.¹¹⁰

Jon also spoke to the injustice inherent in being older, living with HIV, and homeless by calling upon powerful social structures to “Give us some dignity for our last years”. The lack of felt ‘dignity’ experienced by Jon may be an example of ‘dehumanization’ proposed by Freire (1971/2007, p. 167) in the sense that denial of housing represents substandard human living conditions within the context of national wealth as is the case here in Canada. By evoking the idea of ‘dignity’, Jon reveals that he longs for respect in his old age, yet cannot attain it because of structural conditions that prevent him from accessing stable housing.

¹⁰⁹ Two of the participants reported being homeless. Also, some reported being near homelessness and other non-homeless participants expressed empathy and concern for homelessness among PHAs.

¹¹⁰ Invisibility in this sense seemed to occur in broader Canadian society, rather than within the PHA community. For instance, housed people living with HIV seemed to be well aware of homelessness among people in their age group. To this end, Timothy points to “a huge need especially with those socially ecologically depressed and homeless and [living with] HIV”.

During the interviews, I asked Sam: “Do you think you would be healthier if you had a... permanent place to live?” Sam replied that the mental health problems he experienced (as a result of the uncertainty involved in aging on the street while living with HIV/AIDS) would surely benefit from stable housing: “Well yeah. I would think so, you know, it’s been [a] strain on my head, you know. I worry a lot when I don’t have a place of my own.”

Together these participant stories are congruent with the popular notion that housing is a *social determinant of health* (e.g. Shapcott, 2004). For these participants, housing emerges as both necessary in fighting off mental strain and anxiety, as well as caring for one’s health. Therefore, these homeless PHAs, who face particularly significant health care challenges, experience a sort of double jeopardy as proposed by King, (1988) in that both their PHA and homeless statuses present barriers to their well-being and care. Here again, critical social theory drives the *social determinants of health* approach in that homelessness represents an exclusion from both material goods like stable housing and non-material benefits or opportunities such as the services that provide housing assistance.

The present study makes visible how some of these oPHAs feel they lack recognition and are excluded from mainstream society The finding of this study that exclusions may be based on HIV status, age, gender and homelessness, if generalizable, would present a challenge for social work. As such, the findings of this study suggest more research needs to be done on a broader scale to assess whether this is the case. This finding in particular supports the idea of compounded or multiple oppressions (King, 1988), and was supported by recent research indicating that multiple oppressions can be

constituted by any combination of concurrent identities (e.g. Petersen, 2006). Together, these examples challenge social work to better understand the idea of compounded (or, co-morbid) forms of oppression first proposed within the profession by the founder of structural social work, Maurice Moreau (with Leonard, 1989). Finally, although lack of recognition and uniqueness is a fact of life for these participants, oPHAs work toward social change by seeking out a community and engaging in proactive activities (see Chapter 7). For instance, during these interviews participants critically examined and resisted the idea of their marginality. As Jimmy put it, “I will not be an invisible faggot”. He is not alone in this spirit of resistance, and in fact the experience of being marginal may constitute a felt sense of community (as proposed by McMillan & Chavis, 1986; Young, 1990, p. 43) from which resistance can be launched.

Confusion in health and social services of oPHAs

The people interviewed in this study experience confusion. This confusion occurs through the lack of knowledge of both service users and their providers concerning issues like symptom ambiguity, life expectancy, transmission routes, HIV treatments and medication interactions. The lack of information available about the intersection of HIV and aging is argued to provide further evidence of oPHAs’ marginalization as proposed by Young (1990, p. 55).

Symptom Ambiguity

Lack of provider information concerning symptom ambiguity emerged within healthcare service experiences. This finding is supported by previous literature that suggested oPHAs experienced ambiguity in determining whether symptoms were caused by HIV, aging, the combination of aging *and* HIV or other factors (Segal, Schrimshaw &

Dean, 1999a; 1999b; Wooten-Bielski, 1999, p. 268). This finding was expressed by many participants, and expanded upon existing research in that chronic and psychological symptoms were discussed in relation to symptom ambiguity. In addition, symptom ambiguity as described by participants is informed by theories of the multiple forms of jeopardy (e.g. King, 1988).

Participants mentioned symptom ambiguity in reference to symptoms like physical pain, decreased sexual drive, low energy levels, diabetes, body appearance changes, forgetfulness and depression. For instance, Timothy questioned whether his energy levels were a result of aging or other factors: “Are energy levels affected because we’re just older...but is it also affected by my mood and depression, or is it also affected by my HIV status and general health?” He observed “I do find for whatever reason that it’s harder to come up with energy to get engaged in more things”. To better understand Timothy’s statement, we can again draw upon the idea of multiple jeopardy (King, 1988), which posits that people experience several liabilities that contribute to social problems. Although Timothy’s problem is symptom-related rather than social, he still identifies several liabilities that could explain his energy levels: age, depression, HIV status, and general health. Similarly, Violet expressed ambiguity over her diagnosis of diabetes:

I don’t know why I have become diabetic, is it because my mother was a diabetic? Is it because I’m 60, or is it because I take medication, or is it because I have suffered lipodystrophy and I have this excess fat here which for anybody creates a diabetic, so at one point it’s like, it doesn’t matter anymore why I’ve become diabetic, because there are 4 possibilities. (07/12/07)

Like Timothy, Violet describes her symptoms as based on a multitude of physical health liabilities, and also identifies that addition to HIV status, HIV medications may contribute to her symptoms.

Bette noted that she does not know whether her decreased sexual drive should be attributed to the aging process or her HIV medications. She expressed: “I don’t want my sex life to die anymore then it has”. She explained: “I don’t know if its age related, I don’t know if it’s related to the fact that I had a hysterectomy... Is it HIV meds related? ... I just don’t have, like I’m not in the mood, like ‘don’t bug me’. This response is particularly interesting because the symptom ambiguity Bette articulated did not seem to come from aging or HIV, but rather unknown side-effects of medical surgery and drug treatment.

In addition to physical ailments participants also noted the causes of their psychological symptoms are ambiguous. Bette reflected on her experience with memory loss: “I call it a senior moment when I forget things whether it’s HIV related or just the fact that I’m turning 62.” Bette’s comment suggests that she places more emphasis on her age than HIV status when considering memory loss. Likewise, the causes of emotional symptoms were also ambiguous. For example, Violet recounted a conversation with her psychologist about depression:

It was really weird because the psychologist would say “Look at the conversation that we’re having...are we talking about this because you are a woman? Are we talking about this because you are over 50? Or are we talking about this because you are HIV-positive?” and it wasn’t clear anymore. (07/12/07)

Violet’s recall of her therapy session suggests that her problems with depression stem from multiple, ambiguous sources, and that this is a cause for confusion for both her and her psychologist. This is particularly important to the present study of service because it indicates that healthcare providers are also challenged by the ambiguity inherent in the experience of aging with HIV.

Wesley offered some insight into the impact of HIV on the aging process. He suggested: “I think the aging syndrome is amplified because of other things the matter with you”. He elaborated: “I think it would be easier to get old, if you didn’t have anything the matter with you”. Wesley’s use of the word ‘amplified’ seemed to capture the physical health conditions of oPHAs in a manner congruent with the idea of intersecting or multiple forms of jeopardy. Specifically, King (1988, p. 47) proposed the ‘multiplicative’ rather than additive nature of concurrent oppressions. This seems to be the way oPHAs conceptualize their health outcomes.

This finding is supported by previous literature on the ambiguity of the symptoms accompanying aging with HIV disease. In essence, these participants echo previous interviews with oPHAs who asked whether symptoms should be attributed “H-I-V or A-G-E?” (Caffazo, 2004, p. D1, 4). These examples also build upon existing knowledge of symptom ambiguity among oPHAs in several ways. First, the present study made visible previously unexplored confounding factors impacting on health (i.e. mental health, medication use, non-HIV or age-related health outcomes). Also, the present study expands upon previous knowledge on acute medical symptom ambiguity to include problems of chronic (i.e. energy levels, diabetes, sexual drive) and psychological symptoms (i.e. memory loss and depression), and speaks to the idea of double jeopardy (King, 1998) and intersectionality (Hall Collins, 1998) to better understand the ‘amplification’ of the aging process in the presence of HIV.

In essence, just as previous writers theorized the existence of multiple forms of jeopardy within the social lives of people (e.g. King, 1988), some of these oPHAs seemed to have experienced multiple forms of jeopardy in their health outcomes. Specifically,

some oPHAs reported living with a great sense of ambiguity over which aspect of their concurrent health condition was the most problematic. This has important implications for the service experiences of oPHAs similar to those interviewed in the present study. Specifically, these people may present as patients with intersecting health issues which are impossible to attribute to aging, HIV status, or other health and social liabilities. As such, health and social service providers may wish to approach oPHAs in general with knowledge of the compounded nature of their health problems. Of course, this knowledge could also extend beyond issues of health to include an understanding of the compounded social problems of aging with HIV. This is the basis for an interesting parallel in conceptualizing (and bridging) health and social services for older adults living with HIV. Finally, this set of examples also points to the lack of knowledge among physicians and allied health professionals who, because they are not able to pinpoint what symptoms are caused by what, add additional confusion to the experience of aging with HIV.

Life expectancy

The idea of confusion in healthcare services is also present in participants' reactions to medical professionals' accounts of their prognoses and *life expectancies*. The stories of participants support existing literature that suggests life expectancy has increased for oPHAs since the early days of the AIDS epidemic (e.g. Scott & Constantine, 1999). For example, Timothy was told "You're going to be around a long time." In this statement, Timothy constructed his life expectancy as information that was relayed or told to him by a healthcare professional. Philippe recounted how physician prognoses have changed over time:

When I was diagnosed with HIV...the only thing that the doctor could say is that “you’re going to die in about 2 years”. So I started like that, and every 2 years all the doctors told me is that I have about 2 years to live...they [medical professionals] weren’t correct; they made me cry a lot. (06/12/07)

Together, these participants’ stories speak to the impact physicians’ prognoses have on the lives (and, outlook) of PHAs; in this case, professionals are constructed as governing time left in life. In essence, the authoritarian knowledge communicated to Philippe as ‘absolute’ changed as a result of advancement in the medical treatment of HIV/AIDS, and this had great psychological impact on the long-term survivors in this study. For Philippe, the changing meaning of HIV impacts Philippe’s sense of time left in life; he is subject to changing cultural meanings surrounding HIV (e.g. Treichler, 1999).

Also, these stories supported the idea of the *Lazarus* effect proposed by Scott & Constantine (1999) and affirmed by many others, which describes increased longevity for North American PHAs due to novel medical treatments¹¹¹. Although life expectancy has improved for the lives of these long term survivors of HIV/AIDS, they still face uncertainty as to how much time they have left, and this data suggests that they place trust in estimates provided by medical professionals. If physicians and allied health professionals are lagging in knowledge of these types of patients, as is suggested here, they have a responsibility to be knowledgeable of aging with HIV, inasmuch as this is a relatively new phenomenon patients in the post-HAART era will face.

HIV transmission

¹¹¹ Also emerging from the interviews was the idea of a differential in life expectancy, based on uncertainty. One participant said: “I just go with the flow there now, you know I’m 60 now so I might reach 65, who knows” and another said: “I love my age, I love 52, I love it and I would love it if I go to 60, love it even better”.

Bette felt that service providers “are not educated” in matters pertaining to her healthcare. Interestingly, when asked for a specific example of this, Bette elaborated on misinformation she received concerning HIV transmission over a decade ago:

I was given the wrong information about how you become infected...I was told by one doctor that I could never become infected because I had a hysterectomy when I was in my forties. So he said “You have nothing to worry about and don’t bother getting tested every 3 to 6 months”, which I did for 2 years. Until I met my husband and married him, I knew he was positive but I had no fear because the doctor told me that I would never get infected. So that was the first wrong message and that was back in ‘92. I met my husband in ‘93 and we got married in January 1994 and by September 1994 I was HIV positive. (15/11/07)

Bette’s powerful experience concerning misinformation regarding HIV transmission is a cause for concern. While this misinformation may be attributed to the fact that it occurred during the early days of the epidemic when we knew very little about HIV transmission, it is still surprising that she would be advised that she could not contract HIV through unprotected sex. In this case, following the ‘doctor’s orders’ cost Bette her HIV-negative status; a reality that speaks to the power of professionals in service experience as proposed by Young (1990, p. 56).

When considering Bette’s experience from an structural perspective, the physician may have been under the influence of several structural ideologies he shared with Bette concerning the ‘culture’ of HIV infection in Canada (Mullaly, 2007, p. 245). Specifically, the medical professional may have underestimated the risk of HIV infection among women, and also the risk of infection in heterosexual risk practices, mainly because infection rate during that time were predominantly diagnosed among gay men. In essence, the structural ideologies of patriarchal sexism and heterosexism influenced the institutional practices of the physician in assessing Bette’s risk for contracting HIV.

The fact that Bette was given inaccurate information about her risk as a woman suggests that at the time, the physician was operating under knowledge that disassociated women with HIV. Unfortunately, HIV was thought to have an intimate association with homosexuality (Treichler, 1999, p. 1, Weeks, 1990, p. 114), as evidenced by the marginalization and intersecting oppressions older women living with HIV face. This is consistent with Young's (1990, p. 60) concept of cultural imperialism, in which the visibilities of marginal groups are reduced in the context of a more dominant cultural group. In this case, Bette's risk as a woman having heterosexual sex was overlooked in context of HIV being thought of as predominantly transmitted through men having sex with men (or, MSM). While this finding should be viewed with caution since it occurred in the 1990s, because it is still fresh in Bette's narrative she still may distrust information provided by mainstream healthcare providers.

Misdiagnoses

Confusion was also evident in participants' stories relating to misdiagnoses by healthcare professionals. For instance, Wesley recalled being misdiagnosed with Alzheimer's disease instead of AIDS dementia complex:

I didn't have a rapidly advancing case of early onset Alzheimer's. I had one of the initial cases of what they now would call AIDS induced dementia, because over the years it has got better, I don't have it anymore...Alzheimer's...wouldn't have got better. (07/12/07)

Wesley's experience reveals that an HIV diagnosis was confused with a neuro-cognitive disorder often associated with older adulthood. Like Bette's experience, Wesley's misdiagnosis occurred several years ago (as indicated by his description of having an 'initial' case of AIDS-related dementia). However, Alzheimer's disease is still among the most common misdiagnoses for older adults living with HIV/AIDS (Emlet &

Poindexter, 2004, p. 89). Again, the professional who diagnosed Wesley may have operated under institutional practices based on ageist ideologies, informed by assumptions leading to a diagnosis of an age, rather than HIV-related disorder; the latter, an infection associated with unsafe sexual practices or shared injection-drug use, was not linked to old age. Similar to Bette's experience with sexism, for Wesley ageist ideologies may have constituted or contributed to institutional practices that placed the patient's life at risk.

It is important to note that Bette's experience of confusing information regarding HIV transmission and Wesley's misdiagnoses occurred a time when misinformation surrounding HIV was common. However, these experiences are significant to the present study of contemporary service experiences in that they emerged in participants narratives despite having occurred long ago, which suggest that they may still impact people's idea of healthcare services. While a historical account of confusion in healthcare services is now well-established, it appears that confusion is still present in healthcare experiences for these particular oPHAs, as described next.

Treatments

In addition to the experience of historic confusion in health and social services, participants also reported a lack of provider information and education about treatments for HIV infection in their recent healthcare service experiences. For instance, Caleb recalled taking an information sheet on novel drug therapies back from a conference to share with his GP and the clinic, and being asked: "Where did you get this, we don't even have them", leading Caleb to ask "What's wrong with the drug reps?". Caleb's experience is indicative of a lag in information in healthcare services for PHAs.

Specifically, Caleb's clinic did not have access to pertinent information concerning advancements in HIV treatment, suggesting that information is not being distributed quickly enough. Also, by asking Caleb where he got his information, the clinic staff seemed to express surprise that authoritarian medical knowledge was brokered by a PHA, whereas as traditionally this powerful knowledge has been reserved for professionals.

Caleb also reported a provider's lack of information regarding side effects:

I have been on 2 or 3 drugs and started them, say maybe on a Friday...I have to phone on a Saturday because I had such a reaction to it and my pharmacist said "Stop it, don't take anymore." I phoned [the infectious disease clinic] Monday morning and he said "Well, that's one of the side effects that's not listed, but try it again for another couple of days and see if you have the same reaction." So I tried it again, and of course I did and I stopped it. If you can't do anything for me, you know, just shove the whole thing up there [motions]. (16/11/07)

Caleb's sense of confusion, tinged with frustration, seems to stem directly from the clinic's lack of definitive information. In addition, to better understand Caleb's experience with side effects we can draw upon the idea of 'exploitation' as proposed by Young (1990, p. 49). Specifically, exploitation has been suggested to be the transference of labor of one group for the benefit another. In Caleb's case, being told to try the drug again to see if he has the same reaction implies a certain amount of uncertainty, experimentation, or even medical voyeurism, in which his health outcome is used to inform medical knowledge, which could be viewed as exploitive.

Caleb echoed this notion in his description of clinical drug trials: "There is not enough education given to people, or access to [professionals], before you go on the drug, because they are just brand new, and we're virtually the guinea pigs. I'm tired of being a guinea pig". Caleb's description of being treated as a 'guinea pig' suggests that he feels exploited within clinical drug trials. Exploitation, as a form of oppression, was described

by Young (1990, p. 49) as occurring when one group benefits from the labor of another group, also referred to as ‘transference of labor’. Specifically, Caleb describes himself as contributing quite a bit of physical and emotional labor as described by Hochschild (1979; 1983), but receiving little information in return. This frustration could be mitigated by sharing more information about the drug with Caleb, thus ‘demystifying’ (Moreau, 1979, p. 89) the situation for the patient. While these experiences speak to the collaborative nature of health services for oPHAs in the national capital region, there is also the felt sense of medical voyeurism, albeit justified by the potential wealth of knowledge developed from these early cases of older persons living with HIV. Although it is legitimate for Caleb to be frustrated with drug trials, it can also be argued that he volunteered for them, and thus contributed to his own sense of exploitation. In addition, it can be argued that Caleb is especially privileged to have access to experimental HIV medications, considering the many PHAs worldwide who do not.

The theme of confusion regarding treatments continued. Participants also described feeling confused over their healthcare providers’ limited knowledge of drug interactions. Violet recalled:

[My physician] has wanted me to take a medication, and I have to be really sharp because she’d say “We have this new medication for fibromyalgia, I want you to try this.” And my reaction was “Well what about that and my HIV medication?” So we would call the pharmacy and I [learned] am not ever, ever to take that medication. (07/12/07)

Violet’s experience suggests that she had to take an active role and be ‘really sharp’ in order to preempt her provider’s lack of knowledge concerning this particular drug interaction. This example suggests that physicians are not knowledgeable as pharmacists concerning possible interactions with antiretroviral

drug therapies. Violet's experiences with avoiding drug interactions suggest that she is proactive in her approach to medication regimens, but also points to a particularly dangerous lack of physician education, especially considering that the oPHAs in this study reported using more non-HIV than HIV-related medications.

Queer competence

Additionally, some oPHAs experienced a lack of provider knowledge (or confusion) concerning queer competence. Specifically, Jimmy noted that a GP "Sends you off to a psychologist who is almost totally homophobic". He elaborated: "In Ottawa, I think there is a lack of openly gay labeled...psychologists that say, you know, 'I, I cater to everybody', queer friendly, and knowledgeable about it. George revealed that his experience with queer incompetence and one provider's confusion presented a barrier for him to seek future service:

She [the psychologist] couldn't understand the fact that I was married and I had a child but I was still gay, she couldn't understand that, she kept asking questions about it. Well, it's quite common to have been married with children and still gay in Canada, but maybe not where she comes from. She just was overwhelmed with that, and couldn't understand that, so I didn't want to see her anymore, I didn't go back and talk to her.
(16/11/07)

In this case, the confusion was solely that of the allied healthcare provider. Based on Jimmy and George's stories, it is argued that heterosexism constitutes another ideology that may be shared by service providers, which manifests in institutional practices and presents real barriers to effective service experience for PHAs who identify as queer.

HIV Specificity

So far, I have argued that oPHAs experience confusion in healthcare services, and that this is due to the lack of providers' knowledge of HIV. This finding is important to

the present study in that it represents a good example of a how health and social service structures are subject to the time it takes for knowledge to develop, and identifies some forms of knowledge that that can easily be developed through education and training¹¹².

Jimmy criticized his healthcare provider: “I would figure as a GP...being his only guy [living with HIV], you know read up a little on things, you know, educate”. Violet noted that GPs’ lack of knowledge of HIV leads to increased work for her HIV-specialist:

[The GP] told me recently that she now has another person that is HIV positive, but it’s just 2 people in her career as a doctor...so, I always refer to my HIV doctor as my first doctor now and [my GP has] become my second doctor; my family doctor has dropped a position. So I’ll see her for different things, like I’ve got a twitch in my eye that I can’t seem to get rid of, I had the bronchitis and I can’t sleep, so those are the things I go and see my family doctor about, but I especially work with my HIV specialist.
(07/12/07)

In this statement, Violet implies that her GP lacks adequate experience in HIV/AIDS work, and she feels the need to seek out an increased level of care from her infectious disease specialist. This finding suggests that in the absence of sound knowledge at the community health level, PHAs are able to access specialty services that are more knowledgeable, and thus more responsive to their needs.

Together, these examples suggest that confusion is experienced by the oPHAs in this sample who use services in the NCR. Specifically, this confusion was attributed to lack of service provider knowledge, historically regarding transmission risk assessment, HIV diagnosis, and prognoses, and more recently through lack of insight into symptom ambiguity, knowledge of HIV treatments, their side effects, and possible medication interactions. Underpinning these experiences could be ageist, sexist and heterosexist ideologies that assert structural influence upon institutional practices (Mullaly, 2007, p.

¹¹² Education and training is a key component of competency that should be expected from medical professionals, and is the responsibility of the medical professional, not the patient.

245), which in turn translates into lack of knowledge among healthcare providers, and confusion among patients.

In sum, participants provide examples indicating that they feel a lack of recognition (which led to a sense of isolation), uniqueness and confusion. These experiences reveal a general lack of knowledge among healthcare professionals surrounding the emerging field of HIV and aging. Together, these themes represent marginalization, proposed by Young (1990, p. 55) to be a form of oppression. Therefore, I argue that at least in this sense, oPHAs in our region are oppressed in health and social services. Also emerging from the data is the sense that marginalization is particularly pronounced for oPHAs who are female or homeless. This tends to support the idea of intersecting or multiple oppressions (e.g. Hall Collins, 1998; King, 1988). It is questionable whether oPHAs experience other 'faces' of oppression, and this will be explored in the Chapter 6, which addresses discrimination and stigma, and Chapter 7, which addresses power.

CHAPTER 6: DISCRIMINATION IN HEALTH AND SOCIAL SERVICES OF OPHAS

Introduction

This section provides several examples of discriminatory treatment in health and social services experienced by older adults living with HIV/AIDS in our region. An argument is made herein that discriminatory practices are based on institutional practices of HIV exceptionalism (Bayer, 1999; 1991) and HIV-related stigma (Herek & Capitano, 1993; 1999), at least to the extent that participants perceive ‘enacted’ stigma through sanctions applied to them, and ‘felt’ stigma through the processes of shame (or, internalization) and oppressive fear (or, anticipated stigma), as well as lowered expectations of service (Green & Platt, 1997, p. 72; Freire, 1970/2007; Emler, 2006).

Examples of Discrimination & Exceptionalism in Services for oPHAs

Surgical Procedures

Several participants experienced discrimination in health and social services. For instance, Bette described particularly discriminating experiences at a hospital. Bette reported that “I went in to have my surgery, one of the nurses commented “Oh, I don’t want to change *her*.” Surprised by this explicit instance of discrimination, I asked Bette to elaborate:

They were like in the same room, and the one [of the nurses] [said]: “I just don’t want to.”, and I said: “You don’t have to change me at all; I can go change myself, if that’s how you feel.” I was really upset. You’re wearing gloves, what more do you need? Put a mask on if that’s how scared you feel, I don’t care, put an extra coat on; I really don’t give a shit. But I’m a patient here, you took an oath to look after us and not discriminate.
(15/11/07)

In explaining Bette's experience, a link can be made between the nurses' discrimination and the fear of transmission that constitutes a large part of HIV-related stigma as proposed by Green & Platt (1997). Bette's use of the words 'mask' and 'gloves' imply that she believed the nurses was fearful of potential transmission. Specifically, the nurse may have been operating under the faulty assumption that she was at risk of contracting HIV by changing Bette, a phenomenon referred to as fear of 'contagion' among healthcare providers (Green and Platt, 1997, p. 79). It is likely that in this instance the human fear of the infection is stronger than advanced medical knowledge. In addition, the nurse's blatant resistance to changing an HIV-positive patient may imply a certain degree of cultural imperialism. To understand this experience as culturally imperialistic, we can draw upon Young's (1990, p. 143) explanation of cultural imperialism as the belief in the superiority of a dominant culture compared to another, rooted in fear or disgust. Specifically, these may have very much a component of this service experience, as changing usually involves proximity and exposure to human bodily fluids, which could have activated a feeling of 'disgust' in the nurse as described by Young (1990 p. 144). Bette's nurse may have been functioning under a psychological mechanism that is rooted in the human psyche to avoid a threatening 'Other' as described by Young (1990, p. 59). Bette's experience suggests that stigma may have influenced poor treatment toward the oPHAs in this sample in healthcare services in the NCR.

A particularly interesting form of poor treatment discussed by participants was differential treatment, or HIV-exceptionalism, as proposed by Bayer (1999). HIV-exceptionalism has been described as discrepancy between the treatments of HIV compared to other, similar, diseases (Bayer, 1999, 1991). In the present study, HIV

exceptionalism was experienced by participants accessing health and social services like surgical procedures and parole services. The first instance involved the perception of discrimination from a nurse after learning Bette's HIV status:

She [the nurse] said, "Oh what are these medications?" and I said "They're my HIV meds." And she backed away and gave me a strange look and left the room. I sat there for 45 minutes waiting for someone to come and tell me when the surgery was, what they were going to do, and nobody came back. So I got fed up and I left. (15/11/07)

Bette's description of her poor treatment is indicative of her belief that she was excluded on the basis of her HIV-status. In order to better explain her experience, we can draw from the idea of HIV exceptionalism in healthcare services (Bayer, 1999). Specifically, had Bette's medications been for another type of disease, the nurse may not have fled the room. Whether the nurses' reaction was because of lack of knowledge, fear, or stigma is unknown. However, Bette frames this experience in response to the nurse learning of her HIV status, and thus this experience can be viewed as being based on the presence of HIV. To better understand how stigma may have been experienced by Bette, we can draw upon Young's (1990) idea of cultural imperialism, particularly her description of the 'semiotic', which was defined as part of an aspect of interaction that exists outside of language, and displayed through imperialist or stigmatizing gestures, like a 'shadow' (Young, 1990, p. 143). In Bette's case, being abandoned by the nurse felt just as stigmatizing as being verbally refused service.

Timothy believes that he was refused surgery based on his HIV status in the past: "I...had seen a surgeon for a procedure that needed to be done and well, I didn't get those services, and those services weren't provided. The response, the 'No' was because of my HIV status". Timothy clarified "This was in the early days [of the epidemic], my immune

system wasn't very strong, and I may not [have] heal[ed] well from the procedure", but insisted the "perception for me was that, this person was homophobic and AIDS phobic". Timothy's response suggests that while there were real health risks involved in his case of withheld service, he perceived the situation as socially stigmatizing. Timothy's experience can be better understood through the idea of HIV exceptionalism as proposed by Bayer (1999) based on sound medical reasons. Specifically, Timothy's immune system was not strong enough at the time for a surgical procedure. However, despite evidence of a medically valid barrier, Timothy was critical of the surgeon's decision to forgo surgery, and sensed that he was being denied based on 'homophobic' and 'AIDS phobic' ideologies. From a structural perspective (Moreau & Leonard, 1989; Mullaly, 2007), these ideologies are viewed by Timothy as influencing institutional practices that impacted his level of care. As mentioned earlier, this is another example of an historical experience, but it is important to the present study of services in that this previously experienced sense of discrimination may leave long term survivors like Timothy uneasy and distrustful of healthcare providers here in the present. Therefore, it is important to compare Timothy's experience from the early days of the AIDS epidemic to contemporary service experiences, where HIV is presumably viewed as a more manageable disease, and thus should not be subject to the same exceptionality concerning surgery. This, however, is not the case.

Similar to Timothy's historical discrimination based on HIV status, Bette reported that she experienced another instance of HIV exceptionalism in the availability of a minor medical procedure during a very recent visit to her podiatrist. She explains:

I have an ingrown corn that goes inside, so I showed it to him and he said "Oh" he said, "That's not a problem, we can fix that up, we can do it on

your next visit.” Then he looked at me, and he said “Oh...” then he looked at the chart, then he said “Oh, you’re HIV positive?” I said “Yes.” So I thought, ‘Well is this going to make a difference?’, And it did. Cause he never did anything. He just used an electric sander to sand down the corns that I have...Nothing; no surgery. (15/11/07)

While the physician in Timothy’s previous situation may have had reasonably valid medical concerns over a major surgery, it is questionable why Bette was denied a seemingly risk-free, minor medical procedure. Likewise, it is very clear in this experience that the physician, who planned the surgery for Bette’s next visit, changed his medical opinion after learning of her HIV status. However, regardless of why she was refused surgery, it is clear that Bette felt a sense of discrimination and exclusion based on her HIV status, as indicated by her statement “Is this [HIV] going to make a difference? And it did.” In essence, Bette experienced discrimination and assumed it was because she is HIV-positive, and this assumption may have deterred her from following up with the physician as to why she was denied elective surgery. This is important in that participants may attribute the denial of services to stigma, and it seems that this assumption is left unchallenged, as providers do not take the time to clarify this confusion. Therefore, Timothy and Bette’s experiences being denied surgeries can be linked to an earlier theme of this thesis, namely oPHA’s confusion in health and social services. Also, the idea of HIV exceptionalism as applied to withholding services is particularly important for older adults living with HIV. Specifically, since the human immune system declines with age, these participants may find themselves refused for surgeries just like in the past, although now for different reasons. Nonetheless, since these participants attribute these medical decisions to HIV-related stigma, they may continue to do so as they continue to age.

Social goods and services

Several participants also alluded to differential treatment when they tried to obtain social goods and social services. For instance, Timothy and Violet revealed a barrier to accessing stable housing in that they are not able to get mortgage insurance coverage: “On that medical questionnaire, your HIV status is red lighted; you’re denied mortgage insurance if you are HIV-positive”. Timothy’s belief that HIV is ‘red-lighted’ is suggestive of HIV being treated as exceptional by private service institutions as well as in healthcare (Bayer, 1999). Timothy suggests that this is unfair, considering that other chronic conditions are permissible for this type of insurance coverage. This fits with Bayer’s (1999) work that when compared to other illnesses, HIV is deemed to be exceptional. Further, Violet reported knowing by not revealing her condition when asking for mortgage insurance coverage from her private financial institution because “I know I am going to be refused”. The concept of anticipated stigma will be discussed at length in the next section. We can better understand how this represents sanctioning of social opportunities when we view mortgage insurance as a component of securing stable housing (e.g. Shapcott, 2004).

Jon also experienced HIV exceptionalism within the law enforcement system, noting that while health conditions like asthma are not reported in his criminal record, his HIV status is. He elaborated:

They [parole officers] pulled me up in the computer, it says that I’m HIV-positive and it’s usually in bold letters, like you know, ‘watch out’.... and in detox: ‘HIV positive’ [was recorded], right on my ID card in big letters, like wow. (15/11/07)

He noted “Not ‘asthmatic’ written, you know, like bold letters, it makes you think, look out, you know, watch him”. This statement is also congruent with the definition of HIV

exceptionalism (Bayer, 1999) that sets HIV apart from other illnesses¹¹³. Specifically, Jon's reference to HIV-status identified in 'bold letters' suggests that, for him, HIV is treated as different, or exceptional. In order to better understand Jon's frustration, we can draw upon structural social work theory (Moreau, 1979; Mullaly, 2007) which posits that the institutional practices in law enforcement services are influenced by ideologies that treat HIV as dangerous (e.g. "watch out") or different. Specifically, asthma is not a contagious disease, but HIV is, and therefore law enforcement service providers identify it in bold letters to underline its infectious nature. In addition, the police approach in this case is oppressive, in that it relies on a myth that HIV is easy to catch through casual contact. This leaves Jon feeling as if he is being singled out and discriminated against by these service providers. This could have especially negative implications in law enforcement, which tends to view clients as potential threats regardless of HIV status. In Jon's case, he may be considered particularly dangerous, and treated as such.

These experiences also link to previous work on HIV-related stigma within healthcare services conducted by Green & Platt (1997). Specifically, the poor treatments these participants experienced are interpreted as examples of 'enacted' stigma or "sanctions applied to people with a condition" (Green & Platt, 1997, p. 72). Specifically, these participants experience sanctions or withheld services on the basis of their condition, which is thought to be exceptional. Whether these experiences are intentional instances of enacted stigma is questionable, however it is clear that participants' sensed or felt discriminated against. Green & Platt (1997) explained this, stating "Whilst

¹¹³ Several participants compared HIV to other diseases in articulating the social injustice of HIV discrimination. Jimmy and Caleb constructed their experiences of HIV exceptionalism in relation to cancer. Jimmy said "It shouldn't be any more different than people who have cancer", and Caleb suggested that some illnesses are more socially accepted by stating "We got to live with it [HIV/AIDS] and we're not open like breast cancer and everything else".

attitudes to[ward] seropositives may have softened in the last few years, such a change has yet to be perceived by people with HIV” (Green & Platt, 1997, p. 89). This is a particularly important point to consider in developing our understanding of the present stories. In essence, it is questionable whether stigma was enacted in the health and social services of oPHAs, however it is without question, that for the older PHAs interviewed in this study it was perceived and felt. In this sense, merely the perceived sense of stigma in service experiences suggests that discriminatory institutional practices are somehow anticipated by oPHAs in our region.

Anticipated Stigma in Services of oPHAs

Based on the lingering perception of stigma that participants expressed in the previous section, I argue that oPHAs in the present study experience ‘anticipated stigma’, much in the same manner oPHAs did in Emlert’s (2005; 2006; 2007) recent work. Specifically, participants’ disclosure of HIV status is identified as producing or instigating potential sanctions. For instance, Caleb reported that he anticipates stigma from people in general: “I’m in a redneck community; you don’t dare say it [HIV-positive status] or you’ll be run out of town”. We can better understand the seriousness of anticipated stigma through Caleb’s fear that he will be sanctioned or displaced as a result of disclosing his HIV status.

Timothy refers to a felt sense of discrepancy between the benefits and disadvantages of disclosing his HIV status: “I feel more sensitive to tell somebody on an individual basis, because...I might be setting myself up to feel stigma and discrimination”, pointing once again to the idea that discrimination is ‘felt’ (Green &

Platt, 1997) and ‘anticipated’ (Emlet, 2006). Similarly, Philippe described a dichotomy that existed for him in disclosing:

That’s a real burden, you know; if you walk the street without saying that you’re HIV to your fellow; but at the same time...you give them a blade to cut you whenever they want. (06/12/07)

Philippe’s statement speaks to the discrepancy in which he weighs the benefits of disclosing, and chooses not to for fear of being ‘cut’ by people’s stigmatized beliefs and actions. Together, Timothy and Philippe’s stories support the idea of ‘anticipated stigma’ as described in previous research with oPHAs (e.g. Elmet, 2006), and expands this concept by describing the ‘split’ people may experience concerning disclosure because they anticipate being subject to stigma (Emlet, 2006). Specifically, disclosure emerges here as a pre-cursor to anticipated discrimination and poor, stigmatized treatment. It seems that because of this, some participants have chosen not to disclose their HIV status, and remain marginalized.

When asked “Have you ever experienced a negative event in which someone knowing your HIV status has caused you stigma or discrimination?” Violet responded: “No, no, just the fear, the fear of somebody knowing.” While Violet did not report enacted stigma, her comments can be understood as relating to the fear, or anticipation of stigma in response to disclosure her HIV status as described by Green & Platt (1997) and Emlet (2006). Her comment supports Freire’s (1971/2007) idea that “The oppressed...are fearful of freedom (Freire, 1971/2007, p. 47). Specifically, Violet’s fear of stating she is a PHA means that ‘fears the freedom’ of putting into words her experience of living with HIV. This could impact service experience in several ways. For instance, it could deny Violet and others the possibility of freely participating in social services aimed at PHAs.

Several participants reported that paranoia and fear (or, worry) concerning HIV-related stigma impacts their service experiences. Specifically, anticipated stigma played a role in health and social services in that some participants feared that healthcare providers would reveal their HIV status to the general public. Violet described a recent experience in an infectious disease clinic waiting room:

I'm sitting in the waiting room and I'm waiting and I don't dare look at anyone else in the waiting room, because they might recognize me or I might recognize them, or you know, the uncomfortable feeling that you have when you are at the waiting room, and then the nurse would cry out "Violet Foster, room 4." And I'm going "Oh, how she could do that, she just told everybody my name." So for the first 2 years I was, I kept telling them "Don't use my name, just say Violet" (07/12/07)

In this case, anticipated stigma was so severe that Violet requested her name not be used in the waiting room for fear of identifying herself publically as HIV-positive. Here, Violet refers to an 'uncomfortable feeling' that implies anticipated stigma.

Likewise, disclosure to public housing services like shelters is viewed as problematic for some oPHAs. For instance, Sam suggests that disclosure leads to problems him in the public shelters:

I: Have you ever told someone at a shelter that you are living with HIV?

P: Oh yeah.

I: How were the people's reactions? How was the community?

P: They don't seem to like you; there are quite a few people with HIV that's in there. (07/12/07)¹¹⁴

Sam perceives a lack of regard for PHAs within the shelter system of the NCR. This speaks to the unjust structural arrangements that exist in his situation. Specifically, even though 'there are quite a few' PHAs who access shelters in the region, they are perceived as disliked, at least by Sam.

¹¹⁴ I: Interviewer; P: Participant

I also argue herein that anticipated stigma (e.g. Emlet, 2006) plays a role in expectations of positive experiences with health and social services. This particular theme emerged time and again from several examples in which participants' attributed their satisfaction with services to sheer luck. For instance, Timothy talked about his continuum of care: "I've been followed for a long period of time and I've been lucky... so lucky to be able to get to this point in time without as much heartache, stigma and discrimination". Likewise, Jon reported: "I've got lucky; I mean I'm lucky with the doctor". Also, Jimmy mused: "I must have had a horse shoe up my ass!", and elaborated: "Unlike most people that experience HIV, I've been really, really lucky with health providers". Thus, adequate health service is framed as somewhat of an anomaly from what people expect or anticipate from the healthcare system, and this anticipated discrimination may be connected to the idea of anticipated stigma (e.g. Emlet, 2006). Specifically, oPHAs may have developed lower expectations, and anticipate inadequate services because of their HIV status.

In this sense, the present study differs from Fritsch's (2005) study that found oPHAs reported mostly positive experiences with medical services, whereas this was only partially true for participants in the present study. Specifically, the present study informs this idea of reported satisfaction among oPHAs in Ontario as possibly attributed to luck and lowered expectations in health and social services. While anticipated stigma and lowered expectations are associated with health and social services, what is unclear is how these beliefs come to be. One possible explanation is that these participants have internalized discriminatory beliefs.

In order to better understand these participants' experienced and anticipated stigma, we can draw upon the idea of internalization of oppression (Freire, 1970/2007, p. 47). In essence, internalization is the mechanism that drives anticipated stigma. Participants reported internalizing discriminatory beliefs which characterize PHAs as abnormal, or falling outside of the dominant cultural norm. For instance, Violet described herself in relation to "Some of the normal folks who don't have HIV". We can better understand Violet's comparison by drawing upon Bishop's (1994) idea of internalization. According to Bishop (1994, p. 55) "we carry within us a blueprint of the culture's oppressive patterns to be reproduced". This seems to be the case with Violet, who has internalized the dominant world view that to be HIV unsure is better than HIV-positive. In this sense, Violet's line of thinking also fits in with Young's (1990, p. 59) idea of cultural imperialism, in which groups are compared to one another. Specifically, Violet compares to herself, a PHA, to people living without HIV/AIDS. This is important to the study in that if Violet's experience of internalized stigma was generalizable to oPHAs in general, this would present a problem for social worker challenging stigma.

How this internalization of stigma in these participants came to be is questionable, although I argue next that this could be partially attributed to health and social service experiences. For instance, Philippe described how stigma was internalized through his interactions with the providers of healthcare services:

Doctors and nurses are, were unsympathetic with people. How could I describe that? They were afraid of us, and that put my brain into that mould, that people are afraid of us, so I pushed [away] everybody around me. (06/12/07)

Philippe's statement further supports the earlier finding that people frame their present feelings in relation to prior service experiences. Specifically, by stating that

providers 'are', and 'were' unsympathetic, Philippe is suggesting that this poor treatment has occurred in the past, but persists. Philippe notes that healthcare providers 'put into my brain that mould'. In trying to make sense of this idea, we can draw upon Freire's (1970/2007) idea that oppressed people adopt the cultural knowledge that "the dominant group fears or loathes them" (Freire, 2007, p. 148). Specifically, the cultural response to HIV has been loathing and fear (Green & Platt, 1997), and this has made its way into Philippe's thinking that "people are afraid" of him. In this sense, Philippe internalizes stigma in that he expects to be loathed and feared, and then isolates himself, which marginalizes him further from health and social services. Such mechanisms are understood as adopting the guidelines of the oppressor (Freire, 1970/2007, p., 167). This is an example structural oppression, in that stigmatizing ideologies are enacted, felt, internalized and again enacted, except in the latter circumstance Philippe plays a role in oppressing himself by 'hosting' the dominant beliefs (Freire, 1970/2007).

When asked "Do you feel that the experience that you had in the past contribute to you not being open now, to physicians, nurses, social workers, people like that?", Philippe replied: "Yes, yes. Rejection was so hard". Here, Philippe notes that the fear he experienced in service relationships resulted in him pushing away other service providers. To understand this movement from being feared, to fearing/rejecting others, we can draw upon the work of Bishop (1994, p. 55), who noted "the ways of power-over follow their cycle from macrocosm to microcosm and back again". In this sense, fear from institutional practices in the macrocosm is internalized by Philippe, who came to view himself as feared, only to then avoid relationships with others in the macrocosm.

Together, these examples suggest that stigma is not only anticipated, but deeply internalized in some of these participants.

Assumptions associated with HIV-related stigma

Participants' stories surrounding discrimination and anticipated stigma allowed for an examination of the nature of HIV-related stigma (Herek & Capitanio, 1993; 1999). Specifically, HIV-related stigma seems to focus on themes like sexual and drug behaviors, bodily contamination, and death. This concept of stigma expands previous work done by American feminist (Young, 1990), Canadian feminist (Bishop, 1994), queer (Weeks, 1991), African American (West, 1982) and PHA scholars (Silversides, 2003), all of whom provided support for the idea that socially constructed group differences are based on our bodies' abilities and appearance¹¹⁵.

Sexual practices and drug use

Stigma is based on behaviors, or things we do with our bodies, namely sexual practices and drug use. For example, sexual practices were brought up by several participants. Jon reported: "A lot of [people think] it's a gay disease". Wesley, a two-spirited aboriginal stated: "I've had all sorts of problems related to my different sexuality or living style". Timothy accounted for homophobia specifically by healthcare providers:

This person [the service provider] was homophobic and AIDS phobic and I thought it was sort of inappropriate assumptions to make, just because, that you are gay, that you are involved in this certain [sexual] practice, and that sort of practice. (15/11/07)

¹¹⁵ These participants' experiences of stigma could have been based on a fear of the 'Other' and the abject (e.g. Young, 1990). For instance, participants' descriptions of stigma based on homophobia, drug use and body appearance tended to suggest that stigma emerged as a result of a judgment directed toward a threatening 'Other' positioned just beyond the self. In this sense, the 'Other' was framed by Young (1990, p.129) as being particularly threatening when the possibility of becoming the other existed (in this case, either through engaging in homosexual sex, using drugs, and contracting HIV). Likewise, Young's (1990) exploration of the fear of the abject was well-represented by Bette's experience with the nurse who refused to change her, presumably in response to an innate fear of becoming infected by the abject body fluids that may have been involved in 'changing' Bette.

Timothy's statement can be understood by drawing upon the idea that stigmatizing assumptions are indeed based on how we behave, and particularly formed in response to sexual orientation, specifically sexual practices outside of the heterosexual norm (e.g. Weeks, 1991). In this case, the service provider in this situation operated on hetero-normative assumptions of penetration as constituting sex for gay men, and this insulted Timothy.

Similarly, Jimmy reported: "Even in the medical profession, there still is a stigma...the doctors in Ottawa always...report... if...I still practice safe sex, you know, I can't suck dick with a condom..." Jimmy refers to the stigma here implied in the surveillance of his sexual life that has become the norm in national healthcare practices (as evidenced by PHAC, 2006; McDonald & Wong, 2006). Jimmy's experience is also supports previous work suggesting that older gay men experience condom fatigue (Murray & Adam, 2001, p. 75).

This experience can be better understood by drawing upon work on HIV-related stigma (Herek & Capitano, 1999, p. 1137) which cites sexual prejudice surrounding transmission routes of HIV as contributing to this form of stigma. Specifically, Jimmy does not have as good an experience sucking dick with a condom as without. However, physicians in the region report Jimmy when he discloses engaging in this practice. The stigma here relates to dated beliefs over how HIV is transmitted. Specifically, Jimmy is discouraged from oral sex, or sucking dick, without a condom, while this has actually been reclassified as an activity that is a 'low risk' for HIV transmission by the Canadian AIDS Society (2004, p. 22). Thus, Jimmy is sanctioned for an invalid reason based on a false assumption. Once again, this provides an example of people, even healthcare

professionals, having a hard time breaking the signification of oral sex in HIV. This belief shows up in contemporary institutional practices of surveillance and reporting (Treichler, 1999, p. 2).

Also, the idea of drug-related stigma among providers was mentioned. For instance, Caleb reported drug stigma within a support group he attended: “Don’t mention anything about alcohol or drugs or you’re blackballed”. Likewise, Jon recounted an experience of drug stigma at a local shelter that could have cost him his life:

[I was] on the verge of being hospitalized... I was actually shivering, shivering at the front desk, book me into a shelter and the lady said to me “This isn’t the neighborhood detox.” And I said “What for?” and she said “Well, obviously you’re high.” I said “I’m not high. I’m really sick.”
(06/12/07)

In this case, Jon was believed by the shelter worker to have used drugs, was stigmatized and discriminated against when he was actually sick and needed shelter most.

HIV and death, cleanliness and appearance

Stigma was constructed by participants as based on other assumptions, namely that HIV meant certain death, was dirty, and that the bodies of PHAs are physically undesirable and highly identifiable. Several participants recalled service providers as operating under the assumption that HIV equaled death¹¹⁶. For instance, Violet confirmed that service providers operated under the belief that “because you have this [HIV], you are eventually going to die.” George recounted an experience in which his healthcare provider phoned a local health unit in his presence:

The health unit asked him who it was for and he mentioned my name, and...the response from the health unit was “Is that guy still alive?” And I

¹¹⁶ Caleb constructed his survivorship in relation to the association of HIV and death: “Some of my friends say ‘How come you’re still around than everybody else your age and so on, you associate with, [are] mostly dead?’ Well I said ‘Hey, I haven’t finished raising hell yet.’”.

could hear the doctor say “Yes, he is sitting right in front of me, doing quite well”. (16/11/07)

George’s experience underlines the assumptions oPHAs may be up against, even in healthcare services. Viewed from structural perspective, the ideologies associating HIV with certain death influenced the institutional practices of the public health unit. No doubt George found this demoralizing. Thus, a structural ideology fed into practices that impacted the well-being of a patient. If this practice was generalizable, it would have specific implications for oPHAs: people are only getting used to the idea of the possibility of increased longevity with HIV, and may find it difficult to believe that people develop into old age with HIV. Thus, people are surprised when presented with a ‘guy’ like George. In essence, this suggests that service providers may need to improve their sensitivity in discussing the long term survival of PHAs in Canada. An additional assumption mentioned was the uncleanliness associated with HIV. Bette recounted that an experience with a discriminating healthcare provider “made me feel really unclean”. She elaborated:

[After what] the doctor said I really considered myself dirty. What I had was a dirty stain and I couldn’t get rid of it for the longest, longest time, until I met my partner that I have today. That makes me feel a lot better. I have realized now that I am not dirty. (15/11/07)

This finding supports Goffman’s (1953) original contention that stigma involves a social spoilage, or staining, a phenomenon particularly experienced within the PHA community (e.g. Chapman, 2000). Bette’s use of language also confirms the existence of cognitive binaries of clean/dirty, often associated with discourse and popular slang surrounding HIV (i.e. referring to HIV-negative status as being ‘clean’).

HIV-related stigma is based on the appearance of the infected body, often

characterized by signs of lipodistrophy and wasting. Jimmy observed: “I can spot someone who is HIV positive now, especially the old timers, just like back in the old days you could tell someone who was living with AIDS back then”, but cautioned “that should not be a discriminatory factor amongst ourselves; we should be able to go out.” Jimmy also mentioned that assumptions made within the gay community regarding the likelihood of someone’s HIV status has been based on appearance: “He’s too cute or he’s well built, he can’t be infected”. Here, Jimmy refers to the assumption that HIV is easily identified and that good looks and physiques mean that someone is unlikely to have HIV.

In sum, the present study expands its anti-oppressive lens to the experience of discrimination in the health and social service experiences of oPHAs in our region. Specifically, discrimination is linked to the concepts of HIV exceptionalism (Bayer, 1999) and classic stigma (Goffman, 1953), HIV-related stigma, (Herek & Capitanio, 1993; Green & Platt, 1997). These concepts have recently been investigated among older PHAs specifically (Elmet, 2006; 2007a; 2007b). Emerging is the idea that anticipated stigma deters the disclosure of HIV-status, is internalized, leads to lowered expectations, and operates on several faulty assumptions. Together, these examples are congruent with recent stigma research conducted with oPHAs. Emler (2006) reported the common experiences of rejection, stereotyping, fear of contagion, violations of confidentiality, and internalized [stigma], all of which have been documented in the present thesis. Finally, the idea of stigma was linked to Young’s (1990) concept of cultural imperialism, which in itself is proposed to be a ‘face’ of oppression. Thus, the examples from this chapter further support the argument that the oPHAs interviewed in this study felt they are in

some ways oppressed in health and social services. This argument for the theme of oppression is further explored through an examination of power, in the next chapter.

CHAPTER 7: POWER IN HEALTH AND SOCIAL SERVICES OF OPHAS

Introduction

Power is an important theme that emerged from the present study. Power, as conceptualized by Young (1990) and Bishop (1994) is evident in the participants' experiences. Participants experienced traumatizing violation, non-compassion, and power struggles between service providers and users, leading to a sense of futility or powerlessness. There appears to be several forms of power at play in the health and social experiences of oPHAs in the region. These include power held by the professional as well as institutional power enacted through bureaucracy, mode of service delivery, and wait times. In addition, PHA power was demonstrated through self-advocacy, volunteerism, and peer networking.

Violations

The most blatant example of power enacted in healthcare services were traumatic references to violence. Violence is important to include in this study since it relates to stigma inherent across social systems, which could potentially include systems of care. Also, older adults living with HIV in our region are part of several marginalized groups (queer, women, and seniors), all of which have historically experienced violence, and therefore it is interesting to see whether this emerged in their narratives on service experiences.

Philippe described his experience of being mistreated in society using a violent metaphor: "I have been judged...slapped...hurt because I'm HIV". Wesley recounted the violence he experienced related to homophobia:

I've gone through a lot of trauma and a lot of gay bashing by outing myself, and I was too out. I've been beaten up, I've been robbed, I've had my place burned down, I've had all sorts of problems related to my different sexuality or living style. So I just now choose not to be particularly visible. (07/12/07)

Wesley's discussion of becoming invisible reflects the idea of the felt sense of futility that accompanies powerlessness as proposed by Young's (1990, p. 50) work. This is relevant and important to service experience in that he suggested that invisibility may act as a deterrent or barrier to service use.

Finally, Bette's experienced traumatic violation in the diagnostic room that is indicative of the dominant cultural norm of violence against women was reinforced through a violating medical procedure. Bette recalled reporting to the hospital and experiencing a demeaning and violating diagnostic procedure that was horrifyingly inappropriate considering her vulnerable situation:

They put me in an examining room and he told me to lie on this table and showed the probe that he was going to insert. I had reminded him, told him that I had been raped by my ex, and could he be very gentle. Well he wasn't.... I just felt, more attacked you know and it was extremely painful and it was a steel probe, I don't know what it was for, I didn't ask, I just want[ed] to leave that hospital...[After the procedure] I was just shaking and sobbing and nobody stayed with me, they just left me in the room crying and lying on the table. (15/11/07)

These examples suggest that Bette was 'dehumanized' (Freire, 1971/2007, p. 167) by her service provider during a diagnostic process. Specifically, she was abandoned in a time of trauma in a manner that lacks human compassion. Bette likened her experience of being left alone after such a violating medical procedure to her experience of childhood sexual trauma: "It was like I was a child again and being used, you know, for their own purposes, because I was left alone". Further, the traumatic violation of her body brought

back memories of her rape. Bette was so traumatized from her ordeal that she wanted to 'leave', or escape.

Using Moreau's (1979, p. 89) idea of how demystifying services delivery for clients is a socially just professional practice, Bette's confusion here is an example of hospital staff not making an effort to explain the details of the situation for the patient. It is also indicative of the insensitivity of the physician to women's experiences, since it did not seem to be acknowledged that the procedure could be traumatic, even though Bette mentioned that she had been abused in the past.

Finally, Bette discussed how this service experience impacted her personal relationship with her partner: "When he [Bette's partner] picked me up I was just trembling, I couldn't look him in the face, I felt violated again and I wouldn't let him come near me because it was like my father molesting me again and my husband raping me, all these things came to, like a flashback". Bette was re-traumatized. While it has been suggested that HIV diagnoses and HIV disease are associated with traumatic stress (e.g. Olley, Zeier, Seedat & Stein, 2005; Delahanty, Bogart & Figler, 2004; New York State Department of Health, 2001), there has been limited evidence to date to suggest that health and social service experiences have, in themselves, been traumatic (Green & Platt, 1997, p. 71). Bette's comments suggest this is the case. In summary, insensitivity, lack of positive regard and information, and dehumanizing behavior by medical professionals reactivated memories of sexual abuse. Therefore, I argue that health and social service experiences can be not only negative, but in extreme cases traumatic.

Power Struggles

Several participants reported power struggles in the interpersonal communication between service provider and user (or, professional and non-professionals; Young, 1990, p. 56). Several participants referred to a struggle for power in decision-making processes. For instance, Jon reported that “sometimes we [physician-patient] argue”. Jacques described his physician getting angry about his medication adherence: “I threw some medication into the garbage. It’s my life, not his, I have the right. So I told him a few times, he turned red! Wow. Are you a doctor?” Jacques’ experience can be better understood by drawing upon Young’s (1990, p. 56) idea of power differential between professionals and non-professionals in service provision. In essence, Jacques’s physician challenged him on his adherence to medication, and Jacques knew of his right to refuse treatment. This created a struggle for power, which caused the medical professional to ‘turn red’ in a manner Jacques deemed disrespectful and unbecoming a healthcare provider.

Similarly, several participants reported challenges in discussing sexual practices asserting their sexual rights with their healthcare providers. The present study views sexual practices as activities subject to human rights, and thus power seems to have been enacted in these instances through a blockage of these rights, that is, a block of oPHAs’ ability to control and self-regulate their sexual lives. Bette identified how she was confronted by her physician about sex:

He asked me if I had a partner, and I said well I sort of do and I sort of don’t. He said to me, “Did you inform him of your status?” I said “No, I don’t have to, unless it’s going to be a long term relationship, I don’t feel that I have to. I’m very protective; I made sure at that time that all the men used condoms.” At that time, he said, “Do you realize that I could report you to the health department?” All I said to that was “You go right ahead

'cause I'll deny everything I said to you. ...this is between a doctor and a patient. I'm not doing anything wrong. I'm still using condoms, to whereas before I never did because it just wasn't how I grew up. Condoms used to prevent pregnancies and at my age I didn't even know how to put a condom on or what they looked like and if you're not used to having something, then you're not used to using it. (15/11/07)

Bette outlined how she challenged her physician's concern over her sexual practices, and the threat of being reported to public health. Bette knew of her right to physician-patient confidentiality. Finally, Bette also described how her age fit into this discussion of safe sex. This identifies how Bette experienced the institutional practices that governed her service experience as oppressive, controlling and threatening.

This experience can be better understood through a structural analysis of what occurred. Specifically, Bette's provider, in bringing into question her sexual practices and threatening to report her, created a struggle based on two conflicting ideologies: one of state control, surveillance and regulation of the HIV-positive person for public health purposes and one of individual rights. In this situation, Bette was cognizant of her rights, and asserted them when confronted by her physician. Undoubtedly, having to do this during a service experience evoked a sense of discomfort for both Bette and her physician. Bette's experience identifies the challenge healthcare providers' face in balancing the right to confidentiality with the duty to inform a public health risk. Thus, again this can be understood as yet another example of ideologies influencing institutional practices (e.g. Mullan, 2007, p. 245), which in turn impact the feelings of the people sharing the service experience. Bette's experience is particularly important to our understanding of counseling older adults on safer sex practices. Specifically, older adults may not be knowledgeable of condom use, which only became popular in the last couple of decades.

Similarly, Jimmy reported that when he discusses his sexual practices with his healthcare provider:

I would get a lecture. It's like someone slapping my hand saying you know you should have used a condom...condoms break too and a lot of people use[d] condoms and got infected because condoms break... I would go the [hospital] before I'd go to him, 'cause I don't want a fucking lecture. (15/11/07)

This authoritarian, prescriptive and condescending lecturing style of the physician deterred Jimmy from seeking advice from his regular provider. In the case of sexual practices, communication between healthcare providers and oPHAs are sometimes condescending, intimidating, and prescriptive, characterized by authority and power differentials that challenge the sexual rights of service users. Interestingly, these examples are congruent with other forms of condescension described in studies of provider-client communication, namely 'elderspeak' directed at older adults (Ashburn & Gordon, 1981; Kemper, 1992; 1994; Gould et al., 2002).

Together, Jacques, Bette and Jimmy's experiences can be better understood by drawing upon Young's (1990) idea of powerlessness, particularly in regard to the professional/non-professional split. Specifically, Young pointed out the unjust structural arrangement in which professionals attempt to enact power-over service users suggesting "the powerless... must take orders and rarely have the right to give them" (Young, 1990, p. 56). Similarly, Young (1990, p. 56) suggested that powerlessness involved the blockage of decision making opportunities of oppressed groups. In the cases of Jacques, Bette and Jimmy, their decisions to adhere to medication or assert their sexual rights were blocked; however this did not go unchallenged. In short, these examples provide examples of power struggles in health service experiences and suggest that power is

enacted by both the service provider and user. The injustice inherent here is that since the service provider operates from an advantageous position of slightly more authority considering the clinical environment in which the discussion occurs. In this sense, the clinical environment and medical institution supports the power of the medical professional, very much in the same way Young (1990, p. 32) re-conceptualized Foucault's understanding of power as a supportive 'netlike' organization. This web of power holders constitutes professional power.

Professional power

I argue that professional power is experienced by some participants through the perceived lack of acknowledgement of participants as human beings worthy of respect when receiving health services. For instance, Philippe reported "Last time I saw the doctor he pushed his chair, stood up and walked away when I was talking to him". Philippe's experience represents a lack of respect, and lack of control over the service experience, which led him to feel frustrated. Lack of acknowledgement was also reported through lack of eye contact and face to face interactions in health and social care experiences. Specifically, Jacques talked about how the lack of eye contact led to him feeling a sense of invisibility:

Some doctors there they have their own way to talk to the patient... look at the computer? Look in my eyes... That's the way he is. I need eye contact. Him it's like 'comme ça' [typing motions]. It's like I don't exist. He's typing and I'm like "Whoo-hoo! I'm here!" (06/12/07)

Power, as proposed by Young (1990) was enacted in this situation though the healthcare professional not acknowledging the patient, thus rendering him marginal to his service experience and without decision-making capacity. These experiences can be better understood by drawing upon structural social work theory (Moreau, 1979; Mullaly, 2007)

that posits institutional practices are influenced by oppressive ideologies (Mullaly, 2007, p. 245). In these cases, Philippe and Jacques experienced. For instance, the ideology of impersonality played out in Philippe and Jacques experiences of being abandoned or ignored.

Related to professional power in health services was the idea of futility, or relinquishing power to the professional. Specifically, the feeling of powerlessness manifests itself in a sense of futility felt by participants to report these situations, adding to a sense of the service provider's, or professional's power. Bette expressed a sense of futility following mistreatment from a medical professional: "I cannot remember his name, and I wish I could so I could report him, but I'm just too tired to go through all that shit." Similarly, Jacques shared this sense of futility following an argument with his physician: "I almost complained; I almost switched doctors. I was so depressed; I went 'fuck it'". These examples further support the idea of felt powerlessness in health service experiences, and highlighted the role of futility in powerlessness. In these situations, ideologies influenced institutional practices, which in turn led to patients feeling frustrated and marginal in their own healthcare.

Finally, the experiences of being abandoned and ignored during service experiences could be viewed as a blockage of respect or the denial of personhood not unlike Freire's (1970/2007, p. 44) concept of dehumanization. Specifically, Freire (1970/2007, p. 44) conceptualized dehumanization as "a distortion of the vocation of becoming more fully human". In these situations, patients were not given the time or opportunity to become fully humanized (Freire, 1970/2007, p. 43) in the eyes of their service providers. This is undoubtedly influenced by dominant structural ideologies like

capitalism for profit, which influences the amount of time spent with the patient and prevents collaborative decision-making in healthcare. In addition, these experiences can be further understood through Freire's (1970/2007, p. 44) idea that dehumanization "marks not only those whose humanity has been stolen, but also...those who have stolen it". In essence, just as oPHA service users are dehumanized, so too are the healthcare providers who operate under the institutional guidelines that enact these ideologies.

Professionals can use their power to make service experiences more positive. For instance, while dehumanization (Freire, 1970/2007) of human services was experienced by several participants, several participants reported that they had positive experiences in which they were acknowledged, attended to, or humanized. Specifically, there were several instances in which participants reported positive provider-user communication, suggesting an additional form of 'professional power' in that service providers have the power to break away from cold institutional practices and illuminate service experiences with warmth. For instance, Jon reported "my family physician, he welcomes me with open arms, I mean, he's a doctor and treats me as such- as a patient, he doesn't [prejudge]". Also, Caleb also reported that he was given more solicitous attention from a healthcare provider than he anticipated:

[The HIV specialist] said to me one day "You know, we're only allowed 15 minutes with each patient now." Well, I said "Your 15 minutes is up." Well, he says "I'm not finished so I'm going to stay until I am finished." So that's where all the ones get behind. (16/11/07)

Caleb's response suggests that in some instances physicians take more time to spend with the patient; however this was not without instilling in the patient a sense that there were institutional rules in place, and for the physician to ignore them meant running 'behind'. This experience can be better understood by referring to ideological primary

structures (Moreau & Leonard, 1989) like capitalism which fuel a capital-driven healthcare economy in which patient care is ultimately compromised. In essence, this dominant ideology makes physicians feel as if they were failing to follow institutional policies if they offered their patients more solicitous attention. In other words, under the current neo-liberal system of governance, compassion in service experience is treated as a liability that compromises hospital efficiency.

Philippe recounted his recent experience of being ‘humanized’ by a social worker:

The social worker at the welfare office was a doll...she was about 3 or 4 years older than I, she really connected with me, she saw in my eyes, she saw in my behavior that I need to be talked to slowly, gently, with a lot of heat, you know a lot of warmth, and she did it. I don't know if she could figure that out that I needed that. I remember I was so happy, because she filled out most of the papers for the ODSP; she gave me everything that I had the right to receive, she really did help me. (06/12/07)

Philippe's positive experience can be better understood by contrasting it with Freire's (1970/2007) idea of dehumanization. In this situation, the service provider helped Philippe to be viewed as fully human in the eyes of the service institution. Here again, just as Freire (1970/2007, p. 44) suggests that dehumanization impacts both the oppressor and oppressed, in this case the reverse process of humanization (Freire, 1970/2007, p. 43) impacted Philippe through the social workers display of human qualities of positive regard and warmth. Philippe's experience is a good example of an approach to social work practice that both minimizes power differentials (e.g. Reisch, 2002, p. 351), and is ‘warm’ (e.g. Philippe). For Philippe ‘warmth’ is constituted by elements of eye contact, slow and gentle speech, and being cognizant of client (and human) rights. Given a structural analysis, these moments reflect the social worker's resistance to institutional policies that may be cold and impersonal; in Philippe's situation, the social worker went

beyond her requirements to create a warm environment for her client. This is particularly meaningful to this study in that it suggests a different kind of professional power than previously described, namely one that supports the client. This has implications for interactions between service users and providers, in that professionals can also resist the dehumanizing institutional practices (and ideologies) that alienate people from participating in health and social services.

It is particularly interesting to note that in articulating their experiences with professional power within healthcare, participants were mostly negative, but in articulating their communication with social services, participants were positive. This suggests that there may have been a difference in the power differentials produced by service provider type, and that perhaps more research should be conducted to see if this is in fact the case with oPHAs, or society in general. Such research could identify areas for potential improvement, and assist the argument that healthcare providers could adopt approaches of positive regard and the non-authoritarian style displayed by the social worker described by Philippe. As emerged here, power emerged as occurring not only through the service professional, but seemed to be rooted in organizational power, or institutional practices.

Institutional Power in Service Experiences of oPHAs

The way institutional services are organized is important to the present study because this accounts in part for the sense of ‘power-over’ oPHAs experience in their health and social services, and thus provides a good example of structural power. Specifically, participants feel that have little input into the arrangement of their health and social services, just as Young (1990, p. 54) criticized. For instance, participants

found service institutions to be based upon ideologies of bureaucracy; programmatic, overly ridged non-compassionate approaches to services, and this structural organization fails to meet the needs of this vulnerable population. Second, integration of services is viewed as based on capitalist ideologies focused on cost-cutting presented barriers to the services oPHAs needed (e.g. alternative therapies, transport, etc.), and thus do not encompass the comprehensive care that oPHAs need. Finally, participants reported difficulty with wait times. This is important in that reduced time spent with patient, delayed processing times for vital services, and poor management of patient expectations indicate a lack of respect that further supports the idea of powerful ideologies in health and social services. Together, these institutional practices constituted institutional power which influence health and social service experiences of oPHAs in this region

Bureaucracy

The idea that health and social services are bureaucratic emerged as a problem for oPHAs. Bureaucracy was articulated by participants' perception of profit-driven health services economy, and by the idea of 'paperwork'. For instance, oPHAs described institutional power as enacted by social structures that draw profits from PHAs. Among these are pharmaceutical industries. Bette predicted: "There will never be a cure for this [HIV], are you kidding? The pharmaceutical companies are sitting back and drawing in the money and filling their pockets". Once again, if examined using structural social work theory (Moreau, 1979) and Young's (1990) idea of exploitation this comment is an example that participants were aware of the structural underpinnings of their social reality and how they may feel a sense of being exploited by these structures.

Jon reported social service organizations “are very red tape, I mean, and very, very firm.” Jon’s use of the word ‘firm’ implies that he perceives institutional practices as powerful. Bette wished that the Ontario Disability Support Program (or, ODSP) would not: “force the doctor to make more paperwork”. Bette explained that was a barrier for her healthcare: “My first HIV specialist, used to be pissed off at ODSP because he had to fill out these section 8¹¹⁷ that meant more work for him and less time with a patient”. Bette felt that if “it’s in your file at ODSP, they [provincial drug plan] should automatically put that, so that the pharmacist can see that it’s covered”. Bette identifies that the system ‘forces’ her physician to do paperwork comprising time available for interaction with the patient, thus implying institutional power over both service users and providers.

Philippe referred to the paperwork involved in getting his needs met: “I remember I was so happy, because she filled out most of the papers for the ODSP, she gave me everything that I had the right to receive; she really did help me”. Jon described bureaucratic paperwork as an often inflexible process of prescribed activities in which institutional practices enact power or control over service providers and users. He likened participating in the paper bureaucracy to being told:

 this is what you have to do if you want this, and as long as you do it, it doesn’t matter...you can lie to them, it doesn’t matter, and you’ll get it. Put it in paper, you’ll get it. (06/12/07)

Thus, Jon suggests that the only way around barriers like paperwork is to lie to his ODSP worker. Jon also alluded to some workers who have ‘bent’ the rules, however he emphasized that this was not common. When read through the lens of Young (1990, p.

¹¹⁷ According to the MOHLTC (2008): A physician may request coverage for drugs that are not listed in the [drug] formulary. MOHLTC has a process (known as “Section 8”) where a committee of experts reviews these requests and recommends to MOHLTC whether the ODB should pay for these drugs.

56), this supports the popular idea of decision-making inequities between service providers and users. However, when viewed as a manifestation of institutional power, the emphasis on paperwork can be seen as oppressive to the provider's autonomy as well. From a structural social work perspective, the ideology that ODSP is a residual service within a neoliberal state fits in with the idea that services are not constructed for easy access. Therefore, Bette, Jon and Philippe, and their service providers, experience a blockage of decision-making opportunity that stems from institutional guidelines based on structural ideologies of neoliberalism through bureaucracy, residualism, and retrenchment suggested here through the processing of paperwork.

Integration of Services

Another way institutional power is experienced is through the integrated nature of health and social services in the NCR. This is reflective of recent shifts in Ontario healthcare services, including hospitals that practice models of program management (Globerman & Bogo, 1995) and the creation of local health integrated networks (or, LHINs; Sinclair, Rochon & Leatt, 2005). Participants differed regarding whether services should be better integrated. While centralized or 'umbrella' social services were viewed by some participants as desirable and cost-effective, others suggested this mode of service delivery leads to a lack of focus if applied to healthcare services that are HIV-specific. In addition, PHA services in Ottawa were compared to other urban centers in terms of their integration. Participants outlined several problems with the integration of services for oPHAs, including lack of inter-governmental program communication (ODSP, OHIP, etc.), inadequate inclusion of alternative/holistic therapies and lack of transportation.

Jimmy reported positive experiences with the integrated services he received at an infectious disease unit of a hospital in the NCR: “[the hospital] has been right on the ball, and it’s like a one stop service...I used to go in with a list and I said and I’d go boom, boom, boom”. Similarly, Wesley reported his experience with integrated healthcare services at another local hospital, but seemed less enthusiastic:

P: I have a care team now which consists of a physician...a nephrologist, a social worker, a dietician and a pharmacist, I see them once a month at [the hospital], or once every 2, whatever they tell me... to do.

I: You see them all at once as a team or...?

P: They come in one after another.

I: Excellent, is that how you prefer it?

P: That’s how they do it. (07/12/07)

We can draw upon Young’s (1990, p. 56) idea of decision-making to better understand Wesley’s experience. Specifically, he suggests that within integrated services at the hospital he lacks decision-making power. First, Wesley reports doing ‘whatever they tell me... to do’, implying that he lacks control over how often he accesses his care team. He also noted that the integrated service he receives is “how they do it”, but not how he necessarily prefers them to be delivered. Together, this is suggestive of a lack of decision-making power in the description of his healthcare services.

Violet reported that she did not support the further integration of general healthcare services into her HIV-specialty visits to the hospital. She suggests instead that HIV specialists should download some of their patients’ health issues onto family physicians and general practitioners (or, GPs). Following an appointment with her HIV specialist, Violet reported:

I thought that it was quite natural that she sent me back to my family doctor...I really feel that at [the infectious disease unit at the hospital] the doctors have to focus, have to focus on the main issues of the people with HIV and I think at one point general doctors should be, should be

knowledgeable on HIV and should be able to absorb some of the stresses and some of the responsibilities so that the specialist can focus exactly on the HIV only. (07/12/07)

Violet's statement concerning the needs for non-integrated services speaks to the importance of specificity. When viewed in relation to Wesley's experiences with care teams, it is questionable whether integrated services delivered 'one after the other' are as preferable as they are efficient. Viewing this from a structural lens, we can see that once again, the dominant ideology of cost-effectiveness is enacted in the institutional practices of integrating services of the hospitals, and that oPHAs are critical of these developments. While there seems to be ambivalence (as was the case with Wesley) or criticism (by Violet) toward the integration in healthcare services, it remains to be seen whether similar opinions emerge for social services in the national capital region.

In terms of social service agencies, Jimmy provides a financial rationale for the further integration of social services for PHAs. He observed:

[It] seems like very simple math if you put everything in one fucking house, you would pay one goddamn tax, one goddamn heat bill, and all that...[In] big cities like Vancouver, Montreal, Toronto, the social care services are held in one big house type of thing, one big umbrella. Here in Ottawa you have to go through twelve agencies for the pecking order, for the cash. People that are really sick with HIV and AIDS, that can't travel around...and it's difficult...whereas in Toronto, you can literally go [to] one building. (17/11/07)

Jimmy supported his case for the increased integration of services by describing PHA services in the national capital as not as well integrated compared to other cities. Jimmy's comments can be better understood by drawing upon a structural lens. Specifically, Jimmy is receiving services from multiple providers who espouse the ideology of separateness and independent services, whereas this ideology, expressed in institutional practices, creates barriers for Jimmy (and

others) to access transport between service organizations. Thus, while services are available, they may not best serve clients, as transport is required from one service center to another. Finally, while Jimmy is referring to a gap in service, he is also asserting power in that he is critical of the ways in which his services are rendered, and offers constructive suggestions, based on his experiences in other cities, to remedy the service gap.

Similarly, Jacques, Jon, and Caleb suggested that transportation should be better integrated into the delivery of their health and social services: One participant reported that “sometimes you’re not feeling well and can’t take that long bus ride, you don’t feel like taking that long bus ride, but you know, although we are not considered a disability but we should have access to the *Paratranspo* [service]¹¹⁸”. This is particularly important to the study of older PHAs, mainly in that several participants report mobility issues which present problems to accessing services. As these people and others in their cohort grow older, mobility may emerge as a issue requiring increased attention.

Jimmy also suggests that there needs to better integration of alternative therapies into conventional health and social services: “There is not...funding to have and house people who can do massage therapy and alternative therapies. If you don’t have health insurance, or you don’t have the cash, you don’t get it”. This was further exemplified by one participant reporting they provided volunteer Reiki services for people at their local ASO because the service was otherwise unavailable. Jimmy seems to relate his access to service to financial resources, insurance and cash, and this can be understood using a structural lens. Specifically, the dominant ideology of capitalism and looming threat of

¹¹⁸ *Paratranspo* is Ottawa’s public transport system which serves people living with disability in the national capital region (http://www.octranspo.com/acc_menuue.htm)

increased privatization of care services in Canada influence the institutional practices of service organizations in that they do not offer certain services used by oPHAs.

Together, these examples suggest the need for further integration of social services for the oPHAs in this sample. Specifically, these citizens may have specialized needs that have not been met in regards to subsidized access to public transit or access to *Paratraspo*, and availability of services like alternative therapies. This discussion of integrated services is important to understanding health and social care in Ontario, especially considering the recent shift to integrative program management styles of hospital care and the local health integration network (LHIN) approach to community health. These experiences of service gaps can be viewed from a structural lens in that institutions function assuming that some services are essential to the health and well-being of oPHAs, while others, like alternative services and transportation, are more peripheral. This undoubtedly relates to the neo-liberal/capitalist ideology which posits that the privatization of peripheral services and cost-effectiveness are key to the provision of public services. In sum, these bureaucratic decisions represent a type of institutional ‘power over’ mentality in service provision that limits the ability of people to customize their health and social care to fit their specific needs.

Wait Times

An additional way institutional power is enacted in health and social services is through wait times (for a Canadian review, see Sanmartin, 2000), which emerged as a major concern in participants’ stories. Participants reported problems with wait times for reimbursements for out-of-pocket medical expenses, time spent with patients during appointments, times between appointments, wait times for medical referrals, time spent in

waiting rooms, disability and housing program eligibility wait times, response times from health information services. Interestingly, participants had several suggestions for improvement of this problem. Bette stressed the urgency around the time she waits for ODSP coverage to reimburse her for medical equipment. She explained:

Every year we have to fill out a section 8 and that takes anywhere from 6 weeks to 4 months for ODSP to complete it so I can get it. We did the section 8 in July, and the cut off date for use was September of this year, I just got my epi pen at the beginning of November. So if anything would have happened between September and November 1st would that [old] epi pen have worked? How long would I have to wait for ODSP to pay me back? I can't afford to wait. (15/11/07)

In Bette's case, structural ideologies that espouse the importance of bureaucratic paperwork causes a time delay for her provincial disability insurance provider and this has a financial impact on her.

Caleb reported concern for the amount of time per visit a physician spends with a patient living with HIV/AIDS nowadays compared to earlier days of the AIDS epidemic:

They used to spend a half an hour with you and they used to weigh you and look at your body, look in your mouth, look in your ears, eyes and everything else, now it's just "wham bam thank you ma'am" sort of thing. It's really gone downhill. (16/11/07)

Caleb suggests that the quality of the relationship between patient and physician declines as a result of Caleb's perception that the physician was less thorough. In essence, as diagnostic abilities of the medical response to HIV/AIDS improved, physician-patient relationships became more alienated. Caleb continued: "it's getting [to be] like take-out service, you're in, you're seen for a few minutes, do you need any meds, "here", see you in 6 months...and I said 'No, that's too long a stretch, let's make it 3' [months]". In this instance, Caleb enacted his power by slowing the pace of the meeting in order to meet his

need for more frequent consultations. Caleb also identified long wait times for getting a access to a physician through medical appointments:

[the physician] said “Well what were the symptoms?” and I told him, and “Oh, we’ll book you an appointment.” Can’t get an appointment until June 1st. This is the health care system. I don’t know, not very well. (16/11/07)

With this response, Caleb suggests anxiety over the presence of symptoms, as well as the frustration that accompanies having to wait months for an appointment to address them. In this sense, power is enacted over Caleb’s mental well-being through the institutional practice of establishing wait times. Undoubtedly, this is influenced by an ideology of conservatism in healthcare expenditures, which creates an inadequate supply of physicians to meet patient demand, resulting in a six month wait to see a professional¹¹⁹ Ironically, Caleb referred to a healthcare system that suffers from such glitches as ‘not well’, and perhaps itself in need of care, changing or healing.

During appointments, Caleb recounted problems with healthcare provider punctuality, stating he “had to wait as long as an hour and a half”. Wesley reported: “You end up sitting around a lot, they consume time”, which seems to suggest that he values his time spent waiting.¹²⁰ George reported the same experience:

I’ve seen myself wait in one room for over an hour and a half to see a physician and that’s one thing I didn’t like, waiting time to see a doctor. They put you in a room and say that he will be right in, well an hour and a half later and no one has come in. That didn’t make me happy. (16/11/07)

George’s experience is important to the present analysis, since it suggests that the problem he experienced with wait times was not (only) the time it took to see someone, but also the healthcare provider’s failure to better manage his expectations by relaying an

¹¹⁹ Caleb refers to waiting until June, 2008 for an appointment, and this interview was in November, 2007.

¹²⁰ In hindsight, this seemed be a reasonable observation for a older adult living with HIV/AIDS whose time left in life was at one time suggested by powerful medical authorities to be limited.

accurate estimate of how long he would have to wait. Also, George implied being ‘put’ in a room, and this could be viewed as an example of enacted power. This failure to relay accurate information to patients was exemplified in other sections of this thesis (see the description of participant confusion in Chapter 5), and may provide further evidence of ‘elderspeak’ (e.g. Ashburn & Gordon, 1981; Kemper, 1992; 1994; Gould et al., 2002). From a structural perspective, this may represent a genuine lack of hospital resources to estimate wait times for physician availability, based on the ideologies of fiscal cutbacks that cause inadequate supply to meet patient demand. George had the following recommendation for addressing patient wait times:

I think the nurse should be able to inform a patient that it is going to be a long waiting list, so if you want to go, have to do something else and come back in an hour and a half or two hours instead of just putting you in a room, waiting, having you wait, and wait and wait. (16/11/07)

George speaks to the important of power-sharing. In this case, information or knowledge is the commodity which is seen as propping up institutional power. By sharing information with George concerning realistic expectations, providers would be able to manage expectations while giving patients a sense of respect, control, or power. Viewed from a perspective of structural social work (Moreau, 1979, p. 89), this sharing of information would be an example of ‘demystifying’ the situation for the service user.

Philippe brought up the topic of wait times for social care services when he recalled his application to the Ontario Disability Support Program (ODSP):

I was sick when I applied, I had a big belly, I had a problem to walk, a problem with my lungs, they took care of me and they really wanted to fill out the paper in order for me to receive it as fast as possible”. He continued: “So after two months I was accepted. (06/12/07)

This finding suggested that, even though workers at ODSF facilitated his application, Philippe's wait time for social services was still quite lengthy. Finally, several participants reported that they had experienced wait times in accessing public housing. For instance, Sam articulated:

You think that, you think that they would take that into consideration that I have HIV, and I am much older, you would think that they would help you get a place a long time ago, you know, instead of playing head games. They don't give you no reason why, they don't even try to contact you, you know. (07/12/07)

Sam's experience is interesting in that the institutional practices of this particular housing service were framed as elusive, secretive, and unaccountable. When viewed from a structural social work perspective that espouses the importance of demystifying service processes to clients ((Moreau, 1979, p. 89), this experience of lacking explanation as to the status of his place on the wait list clearly diverges from the preferred practice of structural social workers. When probed if he had tried to contact the housing service, Sam replied: "Oh yeah, I've phoned, and they say they are still waiting, [I'm] still on the waiting list...there is nothing more I can do". This supports the previous finding that power enacts itself with these participants through a sense of frustration, or futility. This can better be understood through Young's (1990) concept of powerlessness. Specifically, Sam, having made attempts to secure stable housing, with little feedback, felt like he was powerless to do anything further to help himself. Wesley also reported his waiting time for public housing assistance and the role his age and income play in his access to public housing:

I put myself on a list for subsidized housing and I think because of my age I got interviewed quite quickly I think within about a year I had my interview, and then I found out that I wasn't eligible for subsidized housing anyways because of my income level. (07/12/07)

In Wesley's situation, it would have been helpful for a worker to have 'demystified' the process by informing Wesley that he was not eligible due to income before waiting a year to secure an interview.

Some participants identified that the oppression accompanying homelessness compounded the experience of wait times for other types of service. For instance, Jon spoke of his particular dislike of wait times and how they impact him: "All I need is a warm bed right now. I don't need to go to all these places, and get stressed out, and wait 6 hours to be seen". Jon's comment suggests that homelessness was 'stressful' enough without having to endure the uncertainty of wait times.

Further highlighting the urgency that should be placed into better addressing wait times is a suggestion that Wesley makes: "I tend to leave everything until it becomes an emergency; so when I do see somebody for services, I'm usually very far past and I usually get fairly fast service". This strategy, while clever, also has the potential to be dangerous for Wesley and expensive for the health care system. However, Wesley's strategy provides an extreme example of a creative response to structural arrangements in healthcare. Specifically, Wesley employs his knowledge of an ideology influencing institutional practices, in this case the idea of 'worst comes first', or triage, in order to get his healthcare needs met. In this case, Wesley used his knowledge of the healthcare system to ensure that his needs were met. This is one of the many ways in which oPHAs 'do it for themselves' in health and social services. I argue that this constitutes a sort of PHA power. Other examples of this are discussed in detail next.

PHA Power in Health and Social Services

In addition to professional and institutional power, there are examples of PHA power in that participants advocate for their own needs and rights *with* their service providers, engage in volunteerism to mitigate service gaps, and access peer networks to reduce isolation and confusion. This section is important as it highlights the several ways older adults' living with HIV/AIDS enact power and respond to structural service deficiencies, and thus negotiate a better reality in terms of their health and social service experiences in the national capital region.

In my previous discussion of power struggles, I included Bette's experience with a physician threatening to report her sexual practices. In this scenario, Bette's advocated for her right to physician-patient confidentiality. This idea of self-advocacy emerged as a common theme among these participants. For instance, Jimmy noted: "My own GP, I give him credit, he's a cool guy, but I had to put him in his place one time", suggesting that he advocates for himself while engaging healthcare services. Bette reported making a DVD on stigma and outlines that "My plan and my wish is to bring it to intern classes, nursing staff classes to show it". She also notes "I've done a lot of speeches with nurses, with the healthcare profession". Therefore, Bette's comment indicated that she is actively challenging the lack of service provider information/education that she experiences in her healthcare. Caleb's proactive role in directing his own healthcare helps to reduce the power differential between patients and their providers. He describes "The doctor comes in and...I usually ask him "What's the BP and what's the pulse...how's my B12 and how's my testosterone and my liver function, my kidney and so on, my diabetes?" This suggests a sharing of power between the professional and non-professional as proposed

by Young (1990, p. 56). However, when professional power becomes too much for Caleb, he refuses his physician's advice, as was the case concerning HIV treatments:

He [the physician] used to come in and push drugs "You got to go on this drug; you do this, you got to do that." And I said "No, I'm not. It's my body I want to know what I am putting into it, give me the drug trials so I can read." [The response was:] "Well, we don't have them right now." [I asked] "Oh, how come?" I said "If you keep this up, I'm going to take you out." So he kept it up and I let him out. (16/11/07)

Caleb's ability to 'let out' his physician suggested he too has power in his service experiences. In the same vein, Jimmy encourages people who are dissatisfied with their service experience to speak up: "A lot of people have bad things to say about [the hospital], but hey, you know, as a patient you have input, a lot of people feel that they don't." In this sense, input is power, in that it can change circumstances to better suit the needs of these participants.

In addition, oPHAs possess power in that they help inform the knowledge base of their healthcare providers. Specifically, since there is little knowledge surrounding the intersection of HIV and aging, several participants collaborate with their healthcare providers to better inform the medical institution's response to this new medical phenomenon. For instance, relating to the previously explored theme of marginalization and lack of recognition, several participants referred to being the 'first' patient their physicians have served to enter old age with HIV. Violet reported that her GP was "not tuned in to HIV and it's a learning process for her, because I'm her first [patient aging with HIV/AIDS]". This suggests that Violet helps her provider 'tune in' to the needs of aging PHAs. Jacques, in describing his experience with a physician recalled "He asked for my assistance sometimes, like [a] student finishing their degree". Thus, Jacques implied that there an exchange of knowledge that the professional benefits from.

In addition, Caleb and Wesley reported viewing the PHA community as a source of HIV-related information that mitigated confusion over the lack of provider education and information and challenged the monopoly of power by service providers and institutions. When asked “Where do you get most of your health information?” Caleb replied “Pamphlets I pick up here and there, from the support group, networking”. Caleb further demonstrated an example of how people within the community help each other:

One that was in our group...he was [HIV] negative for the longest time and he started to get symptoms and so on, so he phoned me up and he said “Where should I go to get tested?” I said, “Go to the anonymous clinic.” And he went and he tested [HIV] positive, “What doctor should I go and see?” So I told him to go to [physician, name withheld], so he’s going to [physician, name withheld]. (16/11/07)

These examples suggest that the PHA community was a valid source of support and treatment information in the absence of better public services. This is also suggested to be strength of people of this age group (e.g. Chou & Wister 2005). From a structural perspective, the ideology of community influences the practices of PHAs to gather and distribute health information themselves.

Similarly, oPHAs enact power by engaging in volunteerism to mitigate shortages within social service organizations, especially at the ASO level. Bette indicated “I do a lot of community work and a lot of volunteer work”. Caleb also reported “volunteering most of the time”¹²¹, and Violet reported: “I’ve done things as a volunteer as well, so I’ve put myself out quite a lot here”. Examples of PHA volunteerism at ASOs in the NCR are consistent with previous research on the movement toward peer, or ‘consumer’-driven models of social services (e.g. Yamada, 2001; Cain, 2001; Poindexter, 1999). These examples are particularly interesting in that PHAs report high levels of volunteerism in

¹²¹ He rationalized this by stating “I would rather be busy than sitting at home in front of either idiot tubes”

ASOs, yet no one reported volunteering in healthcare service locations. This suggests that oPHAs may feel more comfortable volunteering in ASO environments, which they may perceive as less threatening or less oppressive than medical institutions. Presumably, volunteerism by participants at the ASO would be much more controlled and oppressive in health care settings.

Some of these oPHAs enacted power and 'did it for themselves' through the development of peer support networks in the NCR. Timothy experienced great need in the past for community peer support: "There was a whole area that wasn't being answered for me, and that's just peer, mostly peer support for other people also affected by AIDS. [The ASO; name withheld] has provided that". Jimmy outlined the need for support beyond the scope of what conventional mental health service providers can provide: "Sometimes people just need somebody to talk to, it doesn't have to be a trained psychologist, or a registered psychologist". Rather, he suggests "sometimes people just need someone to bitch [to], like a friend, you know, who they can just sound off to, and then they feel better...without doctors". Undoubtedly, this gap is filled through peer support programming.

Timothy outlined the recent history of peer support within ASOs, and the transition from traditional, professional-led programming to peer-driven programming of support services in Ottawa. Timothy recalled the role PHAs in the national capital region played in instigating a peer-driven model of service, and traced the development of peer driven services from theory to action: "We were receiving information, we were receiving you know, theory, and it did take a while before we actually got those [support groups] going with our peers." This suggests that PHAs in this sample engaged in a

'banking of knowledge' similar to what Freire (1970/2007, p. 71) described. However, the community moved beyond this educational model, and managed to establish peer-driven programming that is now the norm at the local ASO. George described his powerful experiences within an ASO peer support group specifically for long term survivors. He explained that his satisfaction stems from the shared age of the group members. George reported:

[People in the group were] very close people [to] my age or a little younger. It wasn't a lot of real young people in it. I think the group started with that intention for middle age people to older people, the long time survivors, and I fit right in there, because I have been living with this since [the 1980s]. (16/11/07)

However, George later expressed that the long term survivor's group did not meet all of his peer support needs as an older adult living with HIV. Rather, he reported:

I'd like to have a seniors' group, a seniors' peer group that we could go to, and that I could go to. That would be very beneficial. Share and hear other people's stories with aging and growing old, I know the [long term survivor's group; name withheld] is partially that, but I mean I am still the oldest on in that group. They say that they are all growing old, but no they are not, they're still younger than I am. (16/11/07)

This finding suggests that, while the long term survivors' group serves older PHAs in the region, some participants feel that they would benefit from a group directly aimed at seniors.

While George expressed interest in engaging more older adults in peer programming, Violet identified the potential for enacting PHA power through peer mentorship within the ASO community, and specifically how oPHAs can engage younger PHAs: "I think it's an asset for [the ASO] to have older people mixed...with the younger people". She recalled hearing a speaker recently that was particularly inspirational:

He was 65 years old and I went up to him and said “You are an inspiration, and you need to be there, because you are an inspiration some young people would look at you and say well, you know if I do the right thing, if I make the right decisions, if I find the right resources I could be there someday, look at him and look at her and look at him.” (07/12/07)

Violet therefore posits that older adults in the PHA community provide a good example of positive healthcare behaviors. Similarly, Violet spoke of oPHAs’ power as peer role models: “I think once again we are role models; as parents we were role models, as aging adults we are role models, and now as HIV people of a certain age we are again role models”. These examples are particularly interesting because they suggest that oPHAs are concerned for younger PHAs and view their lived history of healthcare experiences as valuable to others.

Philippe expressed criticism of younger PHAs: “When I see kids around here do their shit and the way they behave, and I know the way it goes, I know from where it started and when it’s going to finish if it don’t stop”. Bette explained:

I hear that people still come in and say ‘I’m newly diagnosed’ I have to wonder, you know that, do you people do not see what we go through?...Some of my friends have just tested positive last year... I’m so angry with them, because they have known what I’ve gone through, like, not all the pills work...and the side effects [are] phenomenal Do you really want to go through that, you know? I tell you what a shitty life I have, and you don’t protect yourself. You’d rather do your drugs, you’d rather get so drunk, that you don’t know who you’re screwing, you know, in a bathhouse, in the corner of a bar, you know...you don’t give a shit about yourself. That still irritates me to this day. (15/11/07)

Bette’s feelings about the lack of recognition of her suffering suggest that she feels exploited (Young, 1990, p. 49-50). Specifically, she feels that her learning experience living with HIV, and her emotional labor (Hochschild, 1979; 1983) go unnoticed by new PHAs, are somehow in vain, and this frustrates her to the point of acting out in a powerful way. This may be an example of Bette feeling that she experiences a more

difficult time than other members of the PHA community; a common occurrence among oppressed people. However, at the root of Bette's anger is genuine concern. She says: "I get go pissed off at them, it takes me a long time to walk up to them and say I'm sorry that I feel the way I did, and I'm sorry that I yelled at you, but you know that I love you, and I never want you to go through that".

Considering the preceding examples of power at play in health and social services, it appears that the oPHAs are mostly overpowered by provider and institutional power, and that their situation is grim. However, in response to these forms of power, oPHAs constructed themselves as proactive service users. The idea of oPHAs as proactive in their health and social service experiences emerged from participants stories of self-advocacy in healthcare service experiences, the PHA community as a source of HIV-treatment information, volunteerism by PHAs within ASOs, and the development of peer support networks in the national capital region. This finding is congruent with Fritsch (2005), who concluded that although they accessed certain services less than their younger counterparts, oPHAs were no less able to access specialized services and in fact were more directive and 'proactive' in seeking care (Fritsch, 2005, p. 44). I argue herein for an additional source of power in health and social service experiences in the region: PHA, (oPHA) power. PHA power supports the idea of resistance, or the rejection of oppression as described by Mullaly (2007, p. 276-282) in health and social services. Specifically, using the criteria outlined by Young (1990), the initiatives oPHAs engage in mitigate the impact of lack of recognition, confusion, discrimination, and power struggle that have been argued here to constitute oppression. This level of resistance is unsurprising, considering the considerable history of advocacy in both the aging and

PHA communities (e.g. Hyduk & Moxley, 2000; Freeman, 2005; Shepard & Hyduk, 2002). Also, conceptualizing oPHAs as active agents in their health and social service experiences brings into question popular notions of service user passivity, dependency and vulnerability proposed by Young (1990, p. 55) and Gordon & Fraser (1994). It would appear that, in the absence of adequate health and social services; oPHAs did it for themselves.

CHAPTER 8: CONCLUSION & DISCUSSION

Putting It All together: Barriers to Services

The present study attempts to determine what kind of barriers to health and social service experience these participants encounter. This section is necessary in order to parse negative experiences from true barriers meriting a social work response. For instance, many of the negative aspects of service experience (i.e. lack of recognition, confusion, and discrimination, professional and institutional power) are mitigated by the idea of PHA power, and thus may not represent real barriers, per se. Conversely, many of these oppressive experiences remain problematic despite resistance. To this end, several measures were employed to capture what participants felt produced barriers for them. First, I asked participants to indicate services that they needed but could not get. Second, participants were asked to complete the *Barriers to Care Scale* (BACS; Heckman et al., 1998). Finally, participants were asked about services experiences in qualitative interviews. In essence, I felt that together, these different tools would allow me to parse my subjective qualitative interpretations of what presents barriers with more objective measures, thereby strengthening the participants' voices.

One way to measure barriers to services is to tally the number of times participants ($n=11$) selected that they 'needed but could not get' services. Out of twenty-six services, seven people (64%) indicated that there were no services that they could not access. Two people (18 %) indicated that they could not get access to one service; one participant indicated that they could not access two services, and one participant

indicated that they could not access six services¹²². In sum, housing, homecare, mental health, holistic therapies, and transportation were inaccessible for some participants. Data from this sample suggests that these oPHAs are mostly able to access the services they needed, with a few exceptions. However, this information does not tell the whole story.

A second way to determine barriers was to use data from the BACS (Heckman et al., 1998). Global BACS scores were tallied by adding all of the numerical responses and dividing by the total number of potential barriers (Heckman, 1998, p. 371). Participants could have scored between 1 and 4, with higher scores meaning more difficulty accessing services. For this group, the BACS scores ranged from 1.00 to 3.40, with a mean score of 2.16 ($n = 11$). A complete description of this data can be found in Table 2. However, these score do not tell us much. To this end, any of the potential barriers contained in BACS that were reported by three or more participants as a ‘major problem’ were noted and tallied. These included: (a) lack of health care professionals who are adequately trained and competent in AIDS care, (b) shortage of psychologists, social workers and mental health counselors, (c) lack of psychological support groups for persons with HIV/AIDS, (d) level of knowledge about HIV/AIDS among residents in the community, (e) community residents’ stigma against persons living with HIV/AIDS, (f) lack of adequate and affordable housing, and (g) lack of employment opportunities for people living with HIV/AIDS. Together, these data from the OOPS questionnaire and BACS measures were used to achieve trustworthiness in assessing with the barriers participants identified in the qualitative interviews. Most of these barriers were discussed throughout

¹²² Specifically, George indicated he could not get access to pastoral counseling, Sam indicated he could not access transportation vouchers, Jon indicated he could not access housing services or internet use, and Philippe reported having difficulty accessing homecare, counseling, chiropractic/occupational therapy, social work, psychological, and alternative therapy services.

previous sections of this thesis, for example inadequate and up-to-date knowledge about HIV/AIDS among medical professionals and the shortage of housing and mental health services (see Chapter 4).

Finally, participants discussed their experiences of barriers to optimal service experience throughout the sharing of their stories. Participants reported having experienced several barriers to optimal health and social service experiences. These included lack of recognition, uniqueness (and confusion); discriminatory practices; based on HIV-exceptionalism and stigma provider and institutional *power* characterized by bureaucracy (e.g. “They are very red tape”), integration of services (e.g. I: “Is that how you prefer it?”; P: “That’s how they do it.”) and wait times (e.g. “I can’t afford to wait”). Together, these barriers are examples of marginalization, powerlessness, and cultural imperialism, as proposed by Young (1990, p. 42), and there is even some evidence of exploitation, and in some cases violence. Additional barriers to health and social services include tangible shortages of specific services, including long-term care housing and mental health services (e.g. “We used to have a counseling service which worked very, very, very well...but everything depends on the almighty book”). These are general service problems inherent in the present neoliberal state, and extend to older adults living with HIV.

In addition to barriers, participants also discussed several important facilitators to service experience. For example, PHA power is enacted through peer support groups for long-term survivors in this sample through proactive approaches to service user-ship and positive provider-user communication). Also facilitating services are ASOs, community volunteerism, as well as use of housing and social support, and HIV specialties within

healthcare. Interestingly, several topics were seen as facilitators to some participants and barriers to others (e.g. as organization of services, HIV-exceptionalism). Interestingly, Fritsch (2005, p. 44) categorized barriers to medical and social services as organizational, individual, societal, and informational. Likewise, the barriers articulated by the participants of the present study seemed to support this idea¹²³. Specifically, barriers described by oPHAs included those relating to organization (bureaucracy, integrated services, wait times), individual (internalized oppression, anticipated stigma, depression, etc.), societal (marginalization of gay, female, homeless and PHAs), and information (confusion, lack of information, provider education, etc.). Based on previous research, it is not surprising that oPHAs in the region experience these barriers (Heckman et al., 1998). In addition to several of the barriers suggested to exist, these people also experience marginality that mainstream PHAs may not. This has direct implications for social work outreach and practice.

In Summary

In the present study, participants' stories were examined for examples of their experiences with health and social services. Participants' stories revealed that they used a variety of health and social services, and these services varied in their HIV-specificity. Participants reported more positive experiences with PHA services than mainstream services. This not surprising considering that participants were recruited through a PHA service site. They also reported gaps in several specific services (i.e. long term care, housing, and mental health services).

¹²³ However, Fritsch (2005) found that older adults living with HIV/AIDS experienced fewer barriers to care than did younger adults living with HIV/AIDS, whereas the present study did not make this comparison.

The participants of this exploratory study experienced health and social services as oppressive. They provided examples of *marginalization* via lack of recognition, uniqueness and isolation; provider and institutional *power* characterized by bureaucracy, the integration of services and wait times and discriminatory practices based on *cultural imperialism*. Within these experiences there were also examples of exploitation, and in some cases even violence. Young (1990) proposed that to experience any one ‘face’ of oppression was to be considered oppressed. Since these participants’ stories provide examples of several forms, it can be argued that they experience services as oppressive. This may be true for other oPHAs living in the region and beyond. Throughout this thesis, an argument I make is that the oppression experienced by these participants is structural, in that primary structures or ideologies (xenophobia, HIV/AIDS-phobia, ageism, sexism, capitalism) influence institutional practices, which in turn impact the relations between service providers and users (Moreau, 1979, Mullaly, 1997/2007).

Despite these challenges, the oPHAs in this study resisted oppressive service experiences by doing it for themselves through personal advocacy, community information exchange and peer networking. Overall, these themes may represent barriers and facilitators to service experiences among this group. The main research questions I put forth were ‘What were the health and social service experiences of oPHAs in the NCR?’ and ‘Do these people experience barriers to services?’ During the analysis, several secondary questions emerged. First, as the interviews occurred it became increasingly important to ask ‘Were oPHAs treated *well* in their health and social service experiences?’ the answer to which, for whatever reason, is mixed, and somewhat more problematic in mainstream versus HIV-specific services. Second, I asked ‘Are these

experiences characterized by social injustice and oppression?’ In brief, this appeared to be the case for some of these participants. At this juncture, it is important to reiterate that qualitative studies must address the issue of transferability as a component of trustworthiness (Tutty, Rothery & Grinnell, 1996, p. 126). Specifically, these conclusions are only applicable, or transferable, to other oPHAs in an urban setting with a spectrum of available services.

The next logical question that emerged was if this is indeed the case, ‘What can social workers do to attempt to change this reality? Some suggestions are provided in the section on relevance to social work practice that follows.

Discussion

Summary of Main Themes

The main theme that emerges from this study is that some of the older PHAs in the study experienced oppressive services, particularly within the health and mainstream service organizations. This oppression is framed as being propped up by the structural organization of services in the national capital region. In addition, participants spoke to general social problems like issues with housing, including homelessness and lack of long-term care options. Participants also reported a lack of mental health services. Other major themes that emerged from the data were the idea of some of these oPHAs resisting instances of oppressive service structures, mainly by ‘doing it for themselves’ through self advocacy, volunteerism and building peer support networks within local ASOs. Together, these themes have several important implications for social work at the practical and policy levels.

The present study attempted to fill a critical gap in national social work literature. The present study is helpful because it was the only exploratory study in Canada to focus solely on the service experiences of *older adults* living with HIV. The closest work to date was a Canadian study by Fritsch (2005), who compared the service use of younger and older PHAs, and literature reviews on HIV and aging by Canadian social workers (Maclean & Clapp, 2001a; 2001b) and nursing professionals (Eldred & West, 2005; Johnson, Haight & Benedict, 1998). In contrast, there has been ample research conducted on the service experiences of oPHAs in the United States, (e.g. Emlet & Frakes, 2002; Emlet & Berghuis, 2002; London, LaBlanc & Aneshensel, 1998; Emlet, 2004; Nokes, Chew & Altman, 2003), particularly in the field of social work by Charles Emlet (2004) and Cynthia Poindexter (2004). Overall, examples from the stories of the present thesis mapped onto many of the findings of these previous authors.

The present study also tried to make sense of people's stories using a previously unused theoretical lens. Specifically, participants' stories were interpreted using a lens structural social work (Moreau, 1979; Moreau & Leonard, 1989; Mullaly 1997/2007) focusing on social justice and anti-oppression, with a particular emphasis on the kinds of oppression experienced by oPHAs (e.g. Young, 1990; Bayer, 1999; Green & Platt, 1997; Emlet, 2006). In addition, some theoretical links were made, namely connecting this segment of the PHA community with the idea intersectionality and compounded oppressions (Hall Collins, 1998; King, 1988), as well as how these ideas fit into a *social determinants of health* approach (Raphael, 2004; Wilkinson & Marmot, 2003). These theoretical conceptualizations helped form an understanding of services for these participants, and lead to several practice and policy recommendations.

Strengths and Limitations

The study has several limitations. The major limitation of the study is the small sample ($n = 11$) size, which impacts the transferability (Tutty, Rothery & Grinnell, 1996;p. 126), or ability to generalize the examples provided by this sample (Heppner & Heppner, 2004, p. 340). However, this sample size was similar to the number of oPHAs interviewed by Fritsch (2005)¹²⁴. In addition, the participant recruitment strategy resulted in homogeneity of the sample along lines of race and gender (for example, there were no black or transgendered participants interviewed)¹²⁵. In addition, the sampling technique resulted in an overrepresentation of participants that accessed services through local ASOs. In other words, this study did not manage to reach people who have been alienated from ASOs in the national capital region. Further, it is possible that, because the interviews took place at a local ASO, participants were reluctant to discuss negative service experiences with ASOs. This may account for the positive experiences alluded to in relation to social, but not health care, services in the present study.

In addition to limitations, several challenges emerged from the study. For instance, the process of member checking (Lincoln & Guba, 1985, p. 314) to verify the content of interviews was not completed due to timelines and some participants refusing the opportunity to follow up. In addition, during the analysis phase, too many themes emerged from the qualitative data, some not having to do with health and service experience, which in hindsight could have been indicative that interviews were perhaps too long (or, too broad). Also, I decided to engage in manual analysis rather than use a qualitative analysis software (e.g. NVivo) and this introduced several challenges to

¹²⁴ This study's sample was comparable to the twelve older PHAs Fritsch (2005) interviewed.

¹²⁵ This has been suggested to be the case in many situations, including research with transgendered communities. For a discussion on *erasure* of transgendered experiences, see Namaste (2000).

maintaining a timeline and organizing themes. Also, a challenge of the present project was the inability to conduct a pure community-based research project (i.e. *Positive Spaces, Healthily Places* project). Specifically, time in graduate school simply does not lend well to community-based research, and as time went on this project began to look more and more like the “helicopter researcher” the researcher had been cautioned about when engaging the PHA community (OHTN Summer Learning Institute, 2008). In addition, participants may have engaged in other studies, therefore limiting the amount of forthcoming and new information available for the present study of their service experiences; a condition referred to as being “researched to death”. Finally, it was particularly challenging to balance gaps in literature with gaps in community need; however it was the hope that HIV and aging will be increasingly ‘looked upon’ as a result of this project and participants’ willingness to share their experiences.

The study also has several strengths. First, several methods were incorporated to better assure the trustworthiness, credibility and transferability of the findings. For instance, the credibility of the study was strengthened by the use of ‘peer debriefing’ (Erlandson et al., 1993, p. 140), a process by which I engaged the thesis Supervisor and ASO case manager regularly concerning the methodology and interpretation of themes. Finally, the study can be considered dependable mainly through the auditing process the researcher engaged in through journaling and memo taking (Tutty, Rothery & Grinnell, 1996, p. 98; Heppner & Heppner, 2004, pp. 8, 152-54)¹²⁶.

The study engaged in a process referred to as triangulation (Denzin, 1970; Jick, 1979). Specifically, the present study made use of both qualitative and quantitative

¹²⁶ Heppner & Heppner (2004, p. 8) notes that journal reflection is a good way of overcoming psychological and emotional barriers to qualitative interviewing, and this was certainly the case for me.

research strategies to get a better picture of the health and social experiences of these oPHAs, although the sample size did not lend to traditional statistical quantitative analysis. Given the small sample size, quantitative scales (e.g., BASC, GDS) were used to inform the qualitative interviews and thus improve credibility. For example, if a participant noted on the BACS that healthcare provider information was a major problem, the researcher would ask the participant to elaborate on that in qualitative interviews. It is interesting to note that quantitative measures of service barriers (i.e. BACS barrier reported as problematic) mapped well onto the qualitative comments made by participants in terms of problems with service experience (e.g. lack of training, shortage of mental health services, lack of support, community stigma, etc.). While this could be viewed as a potential bias in the research interviews, this was particularly helpful in conducting first time qualitative interviews. In essence, this gave me a sense that I was going in the right direction with my analysis. Together, this further supports the idea that mixed methods, or the triangulation of methods create a sense of ‘convergence’ (Campbell & Frisk, 1959) that adds to the credibility of qualitative research.

Relevance to Social Work Practice

After reviewing what the participants said in their interviews, I reflected upon how these stories will impact my practice, and how they could inform social work practice in general. The following extrapolations maybe important things social workers should consider. The stories of these participants corroborated previous research and this underscored several important implications for social work practice. First, the lack of recognition experienced by some of the oPHAs in this study, may lead to members of this vulnerable group being ‘unserved’ by social workers and other health and social care

providers (Emlet & Poindexter, 2004). Considering this invisibility, social workers may wish to improve and better incorporate their knowledge of HIV and aging into their practice¹²⁷, and encourage clients, co-workers and broader society to do the same. For instance, classic clinical HIV/AIDS social work methods of dispelling myths and biases associated with HIV (e.g. Beauger, Dupuy-Godin and Jumelle, 1989; CASW, 1997; Ryan, 1999) could be expanded to include HIV and aging and directed at seniors in the community. To this end, community HIV outreach could be more inclusive of older adults, through strategies ranging from renewed dialogue with seniors regarding the sex and drug scenes in the region, to more proactive measures like the distribution of condoms and safe injection kits in seniors' communities. This type of programming has been introduced in the United States (Kaiser Daily HIV/AIDS Report, 2008), but there is no known evidence that such an initiative exists in Canada.

The stories of service experiences of these oPHAs pointed to several strategies that may be useful when working with these types of clients. For instance, participants felt that their best service experiences were ones where power differentials were minimized (especially in the case of medical providers,), had transparency (lack of information from providers), had reasonably managed their expectations¹²⁸, and were characterized by a communication style that included eye contact, slow, clear speech, such as in Philippe's description of 'warmth' from a social worker.

¹²⁷ In light our quickly aging population, social workers would be wise to improve their knowledge of aging and geriatric competencies (Wilson, 2006; Damron-Rodriguez, 2006) regardless of the fields in which they currently work.

¹²⁸ George suggested: "I think the nurse should be able to inform a patient that it is going to be a long waiting list, so if you want to go, have to do something else and come back in an hour and a half or 2 hours instead of just putting you in a room, waiting, having you wait, and wait and wait".

The participants' stories suggest that they may have experienced oppression in a multiple or compounded fashion (e.g. intersections of class, age, HIV status, gender and sexual orientation). Thus, these themes support the popular notion that integrated assessment is essential for social work with oPHAs (Emler, Scott Gusz & Dumont, 2002). Interestingly, competence in complex case work is required to address previously established discourse of interlocking, multiple oppressions (Moreau & Leonard, 1989; King, 1988) based on intersecting identities (Hall Collins, 1998). In particular, the examples from the present study revealed particularly marginalized realities may be experienced by women and homeless oPHAs. While there is limited social work literature on the intersection of HIV and gender (e.g. Gallego, 1998), there is even less on homelessness among this segment of our population. Therefore, I suggest that social workers in this niche field should engage in *interdisciplinary* work with other professionals, as well as act *transdisciplinary* with PHA community members to mitigate these additional forms of structural oppressions.

Social workers in the health field are part of interdisciplinary health care teams. Considering this, I suggest that social workers, traditionally liaisons between clients and health and social services, can optimize their role by using their professional voices to talk to health and social care providers regarding the needs for effective medical practice with oPHAs that is mindful of client (and human) rights and avoids condescension (particularly around medication adherence and sexual practices, issues raised in the Chapter of this thesis describing participant's stories of power). In the case of the latter, I suggest that practitioners be encouraged to adopt a stance of sex positivity

which extends beyond mere acknowledgement of sex among older adults living with HIV, but to the encouragement and celebration of sexuality among this group.

Finally, despite the sampling bias that exists in that all of this study's participants were recruited from an ASO, many experienced peer support services, and felt that this was an important service. This reflects previous research on oPHAs and group processes (Heckman et al., 2001; Lavick, 1994), and thus I suggest that social work practice with older PHAs encourage clients to engage peer-support networks. In addition, social workers could encourage peer support initiatives in their agencies, along with PHA volunteerism and mentorship that have constituted the Greater Involvement of People Living with HIV/AIDS; or GIPA principles (UNAIDS, 1999). Specifically, based on the stories of participants who experienced the long term survivor's group in the national capital suggest it may be beneficial to implement this program in other areas of the country. Together, these participants' stories support previous ideas that health and social services for older adults living with HIV are complex and required highly skilled service providers across social work, nursing care, and medicine (e.g. Poindexter & Elmet, 2006; Petrovic, 2006; Nokes & Emler, 2006). Thus, many of the practice suggestions I make for social work practice in this thesis may be applicable to other helping professions.

Relevance to Social Policy

In addition to clinical and case work, social workers have been in a position of participating in the PHA advocacy movement in Canada¹²⁹. Based on the stories of these participants, and identified service and policy gaps, I suggest several ways to assist oPHAs would in developing advocacy in several areas of health and social policy. These

¹²⁹ Often social workers work interdisciplinary and transdisciplinary in the area of PHA advocacy in Ontario.

include applying political pressure on existing HIV/AIDS strategies concerning policies addressing long term care and housing, mental health, ASO funding and peer support programming, equality of benefits from private insurance providers, transportation, alternative therapies, healthcare practices, and improved research networks.

The stories of the participants reinforced the need to increase the visibility of older adults living with HIV/AIDS within the Federal Initiative to Address HIV/AIDS in Canada (PHAC, 2008) and Ontario's response to HIV/AIDS (MOHLTC, 2008) to better address long term care for oPHAs. A long term care strategy for this particular segment of the population was described, to some degree, by participants as lacking at best. Undoubtedly, a solution to this potential social crisis needs to involve a national dialogue between federal and provincial policymakers on HIV/AIDS, as well as those trusted with developing long term care policies for the aging population.

Concerning housing, the examples from the present study of the national shortage of housing should be viewed as a rationale for age-based exploration of the *Positive Spaces, Healthily Places* (Tucker & Koornstra, 2008) and *ACRIA* (Karpaick, 2006) datasets to see how older PHAs across Ontario and North America have experienced the national housing crisis. Regardless, housing has been a major point of advocacy by social workers, and this type of assistance needs to be extended to this particularly vulnerable segment of the homeless population in the national capital and its surrounding regions. In addition, social workers have a history of advocating for improved health and social services of marginalized populations. Many of these participants spoke to the lack of competent mental health services for clients, which reflect previous findings on mental

health services in Canada and abroad (e.g. Everett, 2000; Tew, 2005). As such, social workers should help clients engage in advocacy to meet this reported service gap.

The examples from these participants' stories spoke to a need for increased HIV/AIDS funding in general, with a new emphasis on long term survivorship, and with particular attention paid to increased base funding for local ASOs. This need was framed as essential in maintaining peer support programming, which was constructed as effective by the participants in this study. In addition, I suggest that based on some of the participants' concerns with mortgage insurance, social workers should engage global financial institutions and encourage insurance providers to update their eligibility criteria to include people living with HIV so that they can receive equitable home coverage and financial security. In addition, based on Caleb and Violet's comments, I believe that advocacy is required for the inclusion of alternative therapies under provincial drug plans and in PHA services like ASOs. I suggest that this could be accomplished through advocacy coalitions with professional associations of alternative therapies (Canadian Interdisciplinary Network for Complimentary and Alternative Medicine Research, Holistic Health Research Foundation of Canada, etc.) Other advocacy efforts could focus on obtaining *Paratranspo* coverage for our national capital's most vulnerable (and, in some cases disabled) seniors, some of which in this study indicated transportation was a barrier. I suggest that this need of these oPHAs (and others in the national capital) needs to be addressed through subsidized transportation programming enacted at the municipal level.

In addition to social advocacy, I suggest that social workers can engage in medical advocacy for changes in the health practices with oPHAs. For instance, one

particularly effective strategy that could easily be enacted to avoid missed HIV diagnoses among older adults in Ontario may be to incorporate the option of HIV screening during regularly scheduled check-ups that come with ageing (i.e. “Get your prostate test, Get your STD/HIV test”; “Get a mammogram, Get an STD/HIV test”). Physicians and other health professionals may just find that seniors are both open to HIV testing, or never considered it; either reaction merits improved HIV-related information for this age group. Additionally, I suggest that social workers can work with university and college health science programs and students to push for an increased number of hours of training regarding HIV (and aging). In terms of the healthcare system, advocacy can be launched to better address wait times at the policy level. Finally, based on Caleb’s experience with clinical HIV drug trials, I suggest that social workers are able to advocate for participant rights in medical research and help older clients living with HIV/AIDS influence medical research efforts. For instance, this study’s data supports mounting evidence that older adults use HIV medication regimens in combination with a plethora of other medications, although virtually no research has investigated the status and cost of drug coverage and healthcare¹³⁰ for oPHAs or how HIV medications interact with other popular medications (e.g. HARRT and heart medications, hormones and menopause).

In terms of research networks, I suggest that social workers can advocate for a directed research strategy for oPHAs. This could be established in several ways, including the establishment of a special subcommittee of the Ontario AIDS Network (OAN) or the Ontario HIV Treatment Network (OHTN) representing oPHAs (roughly equivalent to U.S.-based National Association of HIV over 50 (NAHOF)). Alternatively, I

¹³⁰ Krentz, Auld & Gill (2003) did a study of the changing health costs of HIV treatments, 1995-2001; however this did not account for age-related increases in medication regimens.

suggest that coalitions between research networks can dedicate resources for older adults (e.g. the OHTN, OAN, and the Canadian Working Group on HIV and Rehabilitation¹³¹). In addition, I suggest that it would be beneficial for larger, national tri-council research bodies, such as Canadian Institutes of Health Research (CIHR), to achieve increased interconnectivity between their well-established aging institute/pillar with all other research institutes/pillar, particularly with infectious diseases in the case of oPHAs. After all, Canadians have and continue to age in unprecedented numbers, suggesting that all fields of research will eventually have to incorporate population aging in the near future. Social workers can use their liaison skills to facilitate these connections. Finally, I believe that social workers have been particularly poised to conduct community based research (CBR), engage in creative dissemination, and advocate with PHAs for improved research capacity within communities¹³². Together, these policy suggestions challenge social workers to play a role beyond the practice level for the betterment of society for older adults living with HIV.

Future directions

In the present study I echo the call for further research into the lived experiences of older people living with HIV (e.g. Zaboltsky & Kennedy 2004; Ory, Zaboltsky & Crystal, 2003) and the need for a new cohort study of people aging with and without HIV (Justice et al., 2001). I suggest that future research could either want err on the side of a quantitative examination of a larger sample, or maintain a small sample size to better articulate the multiple realities of participants in qualitative research and incorporate participatory action research concepts (Brown & Strega, 2005). Specifically, I suggest

¹³¹ <http://www.hivandrehab.ca>

¹³² At the 2008 OHTN research conference, I commented that “older people are fucking and sharing injection drugs” during a presentation.

that future research into this area encourages inclusiveness through an expansion of the inter-disciplinary to *transdisciplinarity* (Klein, Grossenbacher-Mansuy & Häberli, 2001) research with PHA community members. For instance, by acknowledging the input of multiple fields of scholarship, practice, as well as sources of knowledge outside these traditional systems (e.g. PHA community members), I believe that future research will be more credible.

Future research should be conducted in areas outside the NCR to see what impact, if any, living in the national capital has on service experience, and also what services look like in rural and urban communities. Ideally, a larger, cross-Canada sample (i.e. Halifax, , Toronto, Vancouver, etc.) would be appropriate, similar to the recent study on LGBT elders being conducted out of McGill University (Brotman, Ryan & Cormier, 2003). In addition, the present study should be explored in relation to the findings of the *Positive Spaces, Healthy Places* project (e.g. Tucker & Koornstra, 2008) , which, to date, has collected the most data pertaining to housing and PHAs in Ontario. Specifically, I suggest that it would be interesting to see how the national housing crisis plays into aging with HIV/AIDS at a provincial level and if the experiences documented in the present study are reflected at a macro-level. In addition, since social opportunities/benefits that formed *social determinants of health* emerged from participant stories as areas of injustice, I suggest that further research should be conducted on other social goods identified by the SDOH approach (i.e. education, food, etc.).

In addition, I suggest that other large scale PHA studies (e.g. the AICRA project; Kirkpatrick, 2006) should incorporate measures to address aging. Finally, it remains unclear what role age exactly plays in the human drama that is the HIV epidemic.

Therefore, more comparative studies of younger and older adults, as conducted by Frisch (2005), should be continued, along with well-funded, longitudinal studies that will give us a better picture of how this drama unfolds in the future. Luckily, aging researchers have been particularly well-poised at longitudinal and comparative research methods (e.g. Schaie, 1996).

In this study I acknowledge that the development of effective medications have stabilized the danger of HIV for many in the affluent, western world. It remains essential for research to continue comparing PHAs in the pre and post HAART eras (Manton & Stallard, 1998, p. 848). In particular, biomedical research on medication interactions (i.e. tolerability and safety) in the age of HAART need to be further examined (Casau, 2005, pp. 856-57), as does menopause for female oPHAs (Casau, 2005, p. 856-57, pp. 859). In addition, I suggest that further research is needed concerning the cognitive and emotional outcomes of older adults living with HIV and what impact, if any, an expanded life expectancy has upon the psychosocial adjustment of these people¹³³. Also, given the mental health needs that emerged from this study, a particularly appropriate follow up to the present study would examine the mental health, resiliency and coping mechanisms of this group of oPHAs. Finally, the impact of HIV extends beyond the person hosting the virus and these affected parties are also aging and merit inclusion in aging PHA research¹³⁴.

Finally, the stories of the older adults presented here, at best, are relevant only to the experiences of those living in the privileged western world, and I acknowledge that

¹³³ In many ways, this future research question stems from the author's previous work on *socioemotional selectivity theory* (Carstensen, 2006) and perceived time left in life. In this research, seniors are often asked to "Imagine a medical miracle has extended your life" and report their social, cognitive and emotional preferences. oPHAs represent a ecologically superior version of this method, and this should be examined.

¹³⁴ Interesting work is being done with AIDS grandmothers in Africa (e.g. Wilson & Adamchak, 2001).

aging with HIV has not been the reality of many people living the epidemic worldwide.

Therefore, while acknowledging the importance of increased research and practice attention to aging with HIV in Canada, it remains equally critical to expand research beyond our borders toward areas of the world where HIV has become endemic, specifically the African continent. It is my hope that this thesis prompts readers to ask why some people are aging with HIV and others are not.

REFERENCES

- Adler, W.H. et al. (1997). HIV infection and aging: Mechanisms to explain the accelerated rate of progression in the older patient. *Mechanics of Ageing and Development, 96*, 137-155.
- Ahmadi, F. & Tornstam, L. (1996). The old flying Dutchmen: Shuttling immigrants with double assets, *Journal of Aging and Identity, 1*(3), 191–210.
- Andersen, R. & Newman, J.F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly, 51*, 95-124.
- Anderson, R. (1968). *A behavioral model of families' use of health services*. Research Series No. 25 Chicago: Center for Health Administration Studies. University of Chicago.
- Andersen, R. et al. (2000). Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the United States. *HRS: Health Services Research, 35*(2), 390-416.
- Antiretroviral Therapy Cohort Collaboration. (2008). Life expectancy of individuals on combination antiretroviral therapy in high-income countries: A collaborative analysis of 14 cohort studies, *The Lancet*, 372, 293-299.
- Ashburn, G., & Gordon, A. (1981). Features of a simplified register in speech to elderly conversationalists. *International Journal of Psycholinguistics, 7*, 31-43.
- Avis, N.E. & Smith, K.W. (1998). Quality of life in older adults with HIV disease. *Research on Aging, 20*(6), 822-845.

- Badger, T. A. (1998). Depression, physical health impairment and service use among older adults. *Public Health Nursing, 15*(2), 136-145.
- Baltes, P.B. & Baltes, M.M. (1998). *Successful aging: Perspectives from the behavioural sciences*. Cambridge, England: Cambridge University Press.
- Barclay, T.R. et al. (2007). Age-associated predictors of medication adherence in HIV-positive adults: Health beliefs, self-efficacy, and neurocognitive status. *Health Psychology, 26*(1), 40-49.
- Bayer, R. (1999). Clinical progress and the future of HIV exceptionalism. *Archives of Internal Medicine, 159*(10), 1042-1048.
- Bayer, R. (1991). Public health policy and the AIDS epidemic. An end to HIV exceptionalism? *The New England Journal of Medicine, 324*, 1500-1504.
- Bazeley, P. (2007). *Qualitative data analysis with NVivo*. Thousand Oaks, CA: Sage Publications.
- Beauger, M., Dupuy-Godin, M. & Jumelle, Y. (1989). AIDS: A clinical approach. *The Social Worker, 5-7*(1), 23-27.
- Berger, P.L. & Berger, B. (1975). "Becoming a member of society: Socialization". In Berger (Ed.). *Sociology: A biographical approach*. New York: Basic Books Inc. pp. 48-71.
- Berkman, B. (Ed). (2006). *Handbook of social work in health and aging*. New York: Oxford University Press.
- Bernard, E.J. (2005). *Aging HIV population cause for concern*. Retrieved online on September 5th, 2005 from: <http://www.aidsmap.com/en/news/67AD7FA8-3504-4006-9B1C-87BBAFC81939.asp>

- Bishop, A. (1994). *Becoming an Alley: Breaking the cycle of oppression*. Halifax: Fernwood.
- Bradley, E.H. et al (2000). Expanding the Andersen model: The role of psychosocial factors in long-term care use. *HSR: Health Services Research*, 37(5), 1221-1242.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brotman, S., Ryan, B. & Cormier, R. (2003). The health and social service needs of gay and lesbian elders and their families in Canada. *The Gerontologist*, 43(2), 192-202.
- Brown, L. & Strega, S. (Eds.). *Research as resistance: Critical, indigenous & anti-oppressive approaches*. Toronto: Canadian Scholar's Press.
- Bryant, T. (2003) "Housing and health". In D. Raphael, (Ed.) *Social determinants of health: A Canadian perspective*. Toronto: Canadian Scholar's Press. pp. 217-232.
- Bytheway, B. & Johnson, J. (1990). On defining ageism. *Critical Social Policy*, 10, 27-39.
- Caffazo, D. (2004, June 7) "Aging with AIDS". *News Tribune (Tacoma, WA)*. D1, D4.
- Cain, R. (1993). Community-based AIDS services: Formalization and depoliticization. *International Journal of Health Sciences*, 23(4), 665-684.
- Cain, R. (2001). The involvement of people living with HIV/AIDS in community-based organizations: Contributions and constraints. *AIDS Care*, 13(4), 421-432.
- Cain, R. & Todd, S. (2001). *Shifting sands: The changing context of HIV/AIDS services in Ontario*. McMaster University and Ontario HIV/AIDS Treatment Network.
- Campbell, D.T. & Fiske, D.W. (1959). Convergent and discriminant validation by

- the multitrait-multimethod matrix. *Psychological Bulletin*, 56, 81-105.
- Canada. Public Health Agency of Canada. (2004). *HIV among older Canadians*. [Ottawa:Health Canada, 2004] < http://www.phac-aspc.gc.ca/publicat/epiu-ae/pi/epi_update_may_04/6_e.html> (Accessed March 1st, 2007).
- Canada. Public Health Agency of Canada (PHAC) (2005). *AIDS community action program*. Retrieved online on July 23rd, 2008 from: http://www.phac-aspc.gc.ca/aids-sida/funding/actionprog_e.html
- Canada. Public Health Agency of Canada (PHAC). (2006). *Canadian guidelines on sexually transmitted infections, 2006 edition*.
- Canada. Public Health Agency of Canada (PHAC). (2008a). *HIV/AIDS research and surveillance*. Retrieved April 17th, 2008 from: <http://www.phac-aspc.gc.ca/aids-sida/research/index-eng.php>
- Canada. Public Health Agency of Canada (PHAC). (2008b). Federal initiative to address HIV/AIDS in Canada. Retrieved October 1st, 2008 from: <http://www.phac-aspc.gc.ca/aids-sida/fi-if/index-eng.php>.
- Canada. Public Health Agency of Canada (PHAC; 2008c). *Letter to AIDS service organizations from Regional Director, Ontario-Nunavut Region, Public Health Agency of Canada*, July 14th, 2008.
- Canadian Association of Social Workers (CASW). (1997). *Comprehensive guide for the care of persons with HIV disease*. Toronto: CASW.
- Canadian AIDS Society. (2004). *HIV transmission: Guidelines for assessing risk (5th ed)*. Toronto: Canadian AIDS Society.
- Canadian Television (CTV). (2008) "UN report says fewer people dying of AIDS".

Accessed July 31st, 2008 from:

http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20080730/UN_AIDS_080730/20080730?hub=TopStories

Canadian Television (CTV). (2007). "Senior numbers to soar as boomers come knocking". Accessed February 27th, 2007 from:

http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20070227/statscan_seniors.

Carinol, B. (1992). Structural social work: Maurice Moreau's challenge to social work practice. *Journal of Progressive Human Services*, 3(1), 1-20.

Carstensen, L.L. (2006). The influence of a sense of time on human development. *Science*, 312, 1913-1915.

Centers for Disease Control. (2002). *HIV/AIDS surveillance report*, 13(2), 1-44.

Chapman, E. (2000). Conceptualization of the body for people living with HIV: Issues of touch and Contamination, *Sociology of Health & Illness*, 22(6), 840-857.

Chiao, E., Ries, K., & Sande, M. (1999). AIDS and the elderly. *Clinical Infectious Diseases*, 28, 740-745.

Chou, P.H.B. & Wister, A. (2005). From cues to action: Information seeking and exercise self-care among older adults managing chronic illness. *Canadian Journal on Aging*, 24(4), 395-408.

City of Ottawa. Ottawa Public Health. (2006). *Health status report: Measuring health in Ottawa to build a stronger and healthier community (2006)* Ottawa, Ontario.

City of Ottawa. (2009). AIDS and HIV. Retrieved from:

http://www.ottawa.ca/residents/health/conditions/cd/sti/28_2_1_en.html

- Coates, J. (1992). Ideology and education for social work practice. *Journal of Progressive Human Services, 3*(2), 15-30.
- Coates, T.J. (1997). What are HIV prevention needs of adults over 50? In T.J. Coates, (Ed). *HIV prevention: Looking back, looking ahead*. Center for AIDS Prevention Studies and the AIDS Research Institute, University of California, San Francisco.
- Coleman, C.L. (2003). Transmission of HIV infection among older adults: A population at risk. *Journal of the Association of Nurses in AIDS Care, 14*(1), 82-85.
- Comfort, A. (1977). *The good age*, London: Mitchell Beazley
- Crawford, A.M. (1996). Stigma associated with AIDS: A meta-analysis. *Journal of Applied Social Psychology, 26*, 398-416.
- Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.
- Crothers K. et al. (2006). Increased COPD Among HIV-Positive Compared to HIV-negative veterans' *Chest, 130*, 1326-1333.
- Crystal, S., LoSasso, A.T. & Sambamoorthi, U. (1999). Incidence and duration of hospitalizations among persons with AIDS: An event history approach. *Health Services Research, 33*, 1611-1638.
- Crystal, S. & Sambamoorthi, U. (1998). Health care needs and services delivery for older persons with HIV/AIDS: Issues for service and delivery. *Research on Aging, 20*(6), 739-759.
- Cyrstal, S. et al. (2003). The diverse older HIV population: A national profile of economic circumstances, social support, and quality of life. *JAIDS: Journal of Acquired Immune Deficiency Syndromes, 33*, S76-S83.

- Daley, A. (2005). Lesbian and gay health issues: OUTside of the health policy arena. In J. Cohen & J. Keelan (Eds.) *Comparative program on health and society, Lupina Foundation working paper series, 2004-2005*. pp. 45-59. Munk Centre: University of Toronto. Accessed October 13th, 2007 from: www.utoronto.ca/cphs/WorkingPapers_2004-5.shtml.
- Damron-Rodriguez, J. (2006). "Moving forward: Developing geriatric social work competencies. In B. Berkman (Ed). *Handbook of social work in health and aging*. New York: Oxford University Press. pp. 1051-1064.
- Delahanty, D.L., Bogart, L.M. & Figler, J.L. (2004). Posttraumatic stress disorder symptoms, salivary cortisol, medication adherence, and CD4 levels in HIV-positive individuals. *AIDS Care, 16 (2)*, 247-260.
- Denis, A.B. (2001). Multiple identities ... multiple marginalities: Franco-Ontarian feminism. *Gender and Society, 15(3)*, 453-467.
- Denzin, N. K. (1970). *The research act in sociology*. Chicago: Aldine.
- Dougan, S., Payne, L.J.C., Brown, A.E., Evans, B.G., & Gill, O.N. (2004). Past it? HIV and older people in England, Wales and Northern Ireland. *Epidemiological Infections, 132*, 1151-1160.
- Dowd, J. J. & Bengtson, V. L. (1978) Aging and minority populations: An examination of the double jeopardy hypothesis, *Journal of Gerontology* 30: 584-94.
- Draaisma, M. (2008). *Drugs increase life expectancy of HIV patients by 13 years: Study*. Retrieved online August 1st, 2008 from: <http://www.cbc.ca/canada/story/2008/07/31/f-hiv-life-expectancy.html>
- Durkheim, E. (1895/1982). *The rules of sociological method*. Tr. by W.D. Halls.

New York: The Free Press.

Edmonds-Crewe, S. (2004). Ehtnogerontology: Preparing culturally competent social workers for the diverse field of aging. *Journal of Gerontological Social Work, 43(4)*, 45-58.

El-Sadr, W. & Gettler J. (1995). Unrecognized human immunodeficiency virus infection in the elderly. *Archives of Internal Medicine, 155*, 184-186.

Eldred, S. & West, L. (2005). HIV prevalence in older adults. *Canadian Nurse, 101(9)*, 20-23.

Emlet, C.A. (1993) Service utilization among older people with AIDS: Implications for case management. *Journal of Case Management, 2*, 119-124.

Emlet, C.A. (1997). HIV/AIDS in the elderly: A hidden population. *Home Care Provider, 2(2)*, 69-75.

Emlet, C.A. (2004). "Knowledge and use of AIDS and aging services by older, HIV-infected adults". In C. Poindexter (Ed.). *Midlife and older adults and HIV: implications for social services research, practice, and policy*. New York: Haworth Press. pp. 9-24.

Emlet, C.A. (Ed.) (2004). *HIV and older adults: Challenges for individuals, families and communities*. New York: Springer Publishing Company.

Emlet, C.A. (2005). Measuring stigma in older and younger adults with HIV/AIDS: An analysis of an HIV stigma scale and initial exploration of subscales. *Research on Social Work Practice, 15(4)*, 291-300.

Emlet, C.A. (2006). "You're awfully old to have *this* disease": Experiences of stigma and

- ageism in adults 50 years and older living with HIV/AIDS. *The Gerontologist*, 46(8), 781-790.
- Emllet, C. A. (2007). Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis. *AIDS Patient Care and STDs*, 21, 740-752.
- Emllet, C.A & Berghuis, J.P. (2002). Service priorities use and needs: Views of older and younger consumers living with HIV/AIDS. *Journal of Mental Health and Aging*, 8(4), 307-318.
- Emllet, C.A. & Berghuis, J.P. (2002). Service priorities use and needs: Views of older and younger consumers living with HIV/AIDS. In C.A. Emllet (Ed). *HIV and older adults: Challenges for individuals, families and communities*. New York: Springer Publishing Company. pp. 93-110.
- Emllet, C.A. & Farkes, K.J. (2002). Correlates of service utilization among midlife and older adults with HIV/AIDS: The role of age in the equation. *Journal of Aging and Health*, 14(3), 315-335.
- Emllet, C.A., Gusz, S.S., & Dumont, J. (2002). Older adults with HIV disease: Challenges for integrated assessment. *Journal of Gerontological Social Work*, 20(1/2), 41-62.
- Emllet, C.A. & Nokes, K.M. (2006). "Health issues of older adults with HIV/AIDS". In P. Burbank (Ed.). *Vulnerable older adults: Health care needs and interventions*. New York: Springer Publishing. pp. 209-234.
- Emllet, C.A. & Poindexter, C.C. (2004). Unserved, unseen, and unheard: Integrating programs for HIV-infected and HIV-affected older adults. *Health & Social Work*, 29(2), 86-96.
- Emllet, C. & Poindexter, C.C. (2006). Services for HIV-infected and HIV-affected older

- Adults. In B. Berkman (Ed). *Handbook of social work in health and aging*. New York: Oxford University Press. pp. 577-585.
- Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, CA: Sage.
- European Coalition of Positive People (1994). *Paris Declaration, Paris AIDS Summit: 1 December 1994*. Retrieved July 21st, 2007, from: www.ecpp.co.uk
- Evans, R. & Stoddert, G. (1990). Producing health, consuming health care. *Social Science and Medicine*, 31(12), 1347-1363.
- Foucault, M (1975). *Birth of the clinic: An archaeology of medical perception* (Translated by A. M. Sheridan Smith). New York: Vintage Books.
- Fraser, N. & Gordon, L. (1994). A genealogy of dependency: Tracing a keyword of the U.S. welfare state. *Signs*, 19(2), 309-336.
- Freeman, I.C. (2005). Advocacy in aging: Notes for the next generation. *Families in Society: The Journal of Contemporary Social Services*, 86(3), 419-423.
- Fritsch, T. (2005). HIV/AIDS and the older adult: An exploratory study of the age-related differences in access to medical and social services. *The Journal of Applied Gerontology*, 24(1), 35-54.
- Freire, P. (1970/2007). *Pedagogy of the oppressed (30th Anniversary edition)*. New York: Continuum Publishing.
- Galabuzi, G. (2003) "Social exclusion" in D. Raphael (Ed.) *Social determinants of health: A Canadian perspective*. Toronto: Canadian Scholar's Press. pp. 235-251.
- Gallego, S.M. (1998). "Providing services to HIV-positive women". In D.M. Aronstein &

- B.J. Thompson (Eds.) *HIV and social work: A practitioner guide*. New York: The Haworth Press, Inc. pp. 431-442.
- Genke, J. (2000). HIV/AIDS and older adults: The invisible ten percent. *Care Management Journals*, 2(3), 196-205.
- Globerman, J. (1995). Social work and the new integrative hospital. *Social Work in Health Care*, 21(3), 1-21.
- Goldman, C. (2006). "The graying of AIDS". *Time*. Accessed on November 21st, 2006 from: <http://www.time.com/time/magazine/article/0,9171,1223367,00.html>.
- Gott, C.M. (2001). Sexual activity and risk-taking in later life. *Health and Social Care in the Community*, 9(2), 72-78.
- Green, G. & Platt, S. (1997). Fear and loathing in health care settings reported by people with HIV. *Sociology of Health and Illness*, 19(1), 70-92.
- Gussow, Z & Tracy, G.S. (1970). Stigma and the leprosy phenomenon: The social history of a disease in the nineteenth and twentieth centuries. *Bulletin of the History of Medicine*, 44(5), 425-49.
- Hall Collins, P. (1998). Intersections of race, class, gender, and the nation: Some implications for black family studies. *Journal of Comparative Family Studies*, 29(1), 27-36.
- Hall Gueldner, S. (1995). The elderly: The silent population. *Journal of the Association of Nurses in AIDS Care*, 6(5), 9-10.
- Hammer, S.M. et al. (2008). Recommendations of the International AIDS Society USA Panel: Antiretroviral treatment of Adult HIV infection, 2008. *Journal of the American Medical Association*, 300(5), 555-570.

- Hays, R.D. et al. (2000). Health-related quality of life in patients with human immunodeficiency virus infection in the United States: Results from the HIV Cost and Services Utilization Study. *The American Journal of Medicine*, 108, 714-722.
- Heckman, T.G. et al. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*, 10(3), 365-375.
- Heckman, T.G., Kochman, A.K. & Sikkema, K.J. (2002). Depressive symptoms in older adults living with HIV disease: Application of the chronic illness quality of life model. *Journal of Mental Health and Aging*, 8(4), 267-279.
- Heckman, T.G., Kochman, A.K. & Sikkema, K.J. (2004). "Depressive symptoms in older adults living with HIV disease: Application of the chronic illness quality of life model". In C.A. Emlet (Ed). *HIV and older adults: Challenges for individuals, families and communities*. New York: Springer Publishing Company. pp. 37-54.
- Heckman, T.G., Kochman, A.K. & Sikkema, K.J., Kalichman, S.C., Masten, J., Bergholte, J. & Catz, S. (2001). A pilot coping improvement intervention for late middle-aged and older adults living with HIV/AIDS in the USA. *AIDS Care*, 13(1), 129-139.
- Heckman, T.G., Kichman, A., Sikkema, K.J. & Kalichman, S.C. (1999). Depressive symptomatology, daily stressors, and ways of coping among middle-age and older adults living with HIV disease. *Journal of Mental Health and Aging*, 5(4), 311-322.
- Heijnders, M. L. (2004). The dynamics of stigma in leprosy. *International Journal of Leprosy and Other Mycobacterial Diseases*, 72(4), 437-447.
- Heppner, P.P. & Heppner, M.J. (2004). *Writing and publishing your thesis, dissertation*

- & research: A guide for students in the helping professions.* Toronto: Thompson.
- Herdt, G. & Lindebaum, S. (1992). *The time of AIDS: Social analysis, theory and method.* London: Sage Publications.
- Herek, T.G. (1999). AIDS and stigma. *American Behavioral Scientist*, 42(7), 1102-1112.
- Herek, G.M. & Capitanio, J.P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health*, 83(4), 574-577.
- Herek, G.M. & Capitanio, J.P. (1999). AIDS stigma and sexual prejudice. *American Behavioural Scientist*, 42(7), 1126-1143.
- Herek, G.M., Mitnick, L. & Burris, S. (1998). AIDS and stigma: A conceptual framework and research agenda. *AIDS Public Policy Journal*, 13(1), 36-47.
- Hesselgrave, B. (2008). Challenges of a new frontier: Aging with HIV. Retrieved online on April 1st, 2008 from: <http://www.miller-mccune.com/article/271>
- Highleyman, L. (2007). Young at heart. *Poz Focus*, pp. 2-5.
- Hinkin, C.H., Castellon, S.A., Atkinson, K. & Goodkin, K. (2001). Neuropsychiatric aspects of HIV infection among older adults. *Journal of Clinical Epidemiology*, 54, 44-52.
- Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. *American Journal of Sociology*, 85(3), 551-575.
- Hochschild, A. R. (1983). *The managed heart: Commercialization of human feeling.* Berkeley: University of California Press.
- Hyduk, C.A. & Moxiey, D.P. (2000). Challenges to the implementation of personal advocacy for older adults. *Families in Society*, 81(5), 455-565.

- Inungu, J.N., Mokotoff, E.D., & Kent, J.B. (2001). Characteristics of HIV infection in patients fifty year or older in Michigan. *AIDS Patient Care and STDs*, 15, 567-573.
- Jick, T.D. (1979). Mixing qualitative and quantitative methods: Triangulation in action *Administrative Science Quarterly*, 24 (4), 602-611.
- Johnson, M., Haight, B.K. & Benedict, S. (1998). AIDS and older people: A literature review for clinical nursing research and practice. *Journal of Gerontological Nursing*, 24(4), 8-13.
- Joyce, G.F., Goldman, D.P., Leibowitz, A.A., Alpert, A. & Bao, Y. (2005). A socioeconomic profile of older adults with HIV. *Journal of Health Care for the Poor and Underserved*, 16(1), 19-28.
- Justice, A.C. et al. (2001). Justification for a new cohort study of people aging with and without HIV infection. *Journal of Clinical Epidemiology*, 54, 3-8.
- Kahana, E. & Kahana, B. (2001). Successful aging among people with HIV/AIDS. *Journal of Clinical Epidemiology*, 54, 53-56.
- Kalichman, S.C., Heckman, T., Kochman, A., Sikkema, K., Bergholte, J. (1996). Depression and thoughts of suicide among middle-aged and older persons living with HIV-AIDS. *Psychiatric Services*, 51, 903-907.
- Kaiser Daily HIV/AIDS Report. (2008). "AIDS project New Haven launches program to educate older women about HIV". Accessed April 4th, 2008 from:
http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=51346
- Karpiak, S.E., Shippy, R.A. & Cantor, M.H. (2006). *Research on older adults with HIV*. New York: AIDS Community Research Initiative of America, 2006.

- Kemper, S. (1994). "Elderspeak": Speech accommodations to older adults. *Aging and Cognition, 1*, 1-10.
- Kemper, S. and Harden, T. (1999). Experimentally disentangling what's beneficial about elderspeak from what's not. *Psychology and Aging, 14*(4), 656-670.
- King, D.K. (1988). Multiple jeopardy, multiple consciousness: The context of a black feminist ideology. *Signs, 14*, 42-72.
- Klein, J.W., Grossenbacher-Mansuy, W. & Häberli, R. (2001) *Transdisciplinarity: joint problem solving among science, technology, and society: An effective way for managing complexity*. Basel ; Boston: Birkhäuser.
- Kolb, P.J. (2004). Theories of aging and social work practice with sensitivity to diversity: Are there useful theories? *Journal of Human Behavior in the Social Environment, 9*(4), 3-24.
- Kohli, R. et al. (2006). Aging and HIV infection. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 83*(1), 31-42.
- Krekula, C (2007). The Intersection of age and gender: Reworking gender theory and social gerontology. *Current Sociology 55*(2), 155-171.
- Krentz, H.B., Auld, M.C. & Gill, M.J. (2003). The changing direct costs of medical care for patients with HIV/AIDS, 1995-2001. *Journal of the Canadian Medical Association, 169*(2), 106-110.
- Labonte, R. (2004). Social inclusion/exclusion and health: Dancing the dialectic. In D. Raphael (Ed.) *Social determinants of health: A Canadian perspective*. Toronto: Canadian Scholar's Press. pp. 253-266.
- Landman, C. (2008). A theology for the older, female, Hiv-infected body. *Exchange, 37*,

52-67.

Larkin, M. (2006). HIV/AIDS and adults over 50: A call to action. *The Journal on Active Aging*, September/October 2006, p.??

Lavick, J. (1994). Psychosocial considerations of HIV infection in the older adult. *AIDS Patient Care*, 127-129.

LeBlanc, J. (2005). Area native is longtime HIV survivor. *Sackville Tribute Post*, February 22nd, 2005.

Levy, J.A., Ory, M.G., & Crystal, S. (2003). HIV/AIDS interventions for midlife and older adults: Current status and challenges. *Journal of Acquired Immune Deficiency Syndromes*, 33 (Supp. 2), S59-S67.

Lightman, E. (2003). *Social policy in Canada*. Toronto: Oxford University Press.

Lieberman, R. (2000). HIV in older Americans: An epidemiological perspective. *Journal of Midwifery & Women's Health*, 45(2), 176-182.

Linsk, N.L. (2004). Resource information: HIV over fifty. In C. Poindexter (Ed). *Midlife and older adults and HIV: Implications for social services research, practice, and policy*. New York: Haworth Press. pp. 119-122.

Linsk, N.L. (2000). HIV among older adults: Age-specific issues in prevention and treatment. *The AIDS Reader*, 10(7), 430-440.

London, A.S., LaBlanc, A.J. & Aneshensel, C.S. (1998). The integration of informal care, case management and community-based services for persons with HIV/AIDS. *AIDS Care*, 10(4), 481-503.

Lubben, J. & Damron-Rodriguez, J. (2006). World population aging. In B. Berkman,

- (Ed). *Handbook of social work in health and aging*. New York: Oxford University Press. pp. 939-944.
- Lundy, C. (2004) *Social work and social justice*. Peterborough, ON: Broadview Press.
- Mack, K.A. & Ory, M.G. (2003). AIDS and older Americans at the end of the twentieth century. *Journal of Acquired Immune Deficiency Syndromes*, 33 (Suppl. 2), S68-S75.
- Mackie, I. (2008). *The greying of HIV: Aging in the era of HAART*. Presentation at Vancouver Hospital & Health Sciences Center. Retrieved online on October 21st, 2008 from: <http://www.cfenet.Ubc.ca/vIde o.p hp?id=23&sid=33&cat=1>.
- MacLean, M.J. & Clapp, C. (2001). HIV/AIDS and aging. *Geriatrics Today: Journal of the Canadian Geriatric Society*, 4(2), 75-78.
- Maclean, M.J. & Clapp, C. (2001). HIV/AIDS and aging: Implications for social work with older caregivers. *Canadian Social Work*, 3(10), 67-74.
- McMillan, D.W. (1996). Sense of community. *Journal of Community Psychology*, 24(4). 315-325.
- McMillan, D.W. and Chavis George, D.M. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, 14, 6-23. pp. 6-23
- Mahalingam, R. & Trotman-Reid, P. (2007). Dialogue at the margins: Women's self-stories and the intersection of identifies. *Women's Studies International Forum*, 30, 254-263.
- Manfred, R. (2004). HIV infection and advanced age: Emerging epidemiological, clinical and management issues. *Ageing Research Reviews*, 3, 31-54.
- Manton, K. & Stallard, E. (1998). Forecasting methods for HIV/AIDS and aging.

- Research on Aging*, 20(6), 846-864.
- Marshall, Gordon. (1998). *The Oxford dictionary of sociology*. Oxford University Press: Toronto.
- Marx, K. (1974). Introduction to a critique of political economy. In K. Marx & F. Engels (Eds.). *The German ideology*. New York: International Publishers.
- Marx, K. & Engels, F. (2004). *The communist manifesto*. (edited by L.M. Findlay). Peterborough, Ontario: Broadview.
- McDonald, N. & Wong, T. (2006). Canadian guidelines on sexually transmitted infections, 2006. *Canadian Medical Association Journal*, 176(2), 175-176.
- Meadows, J., Le Marechal, K. & Catalan, J. (1998). Mental health problems in older adults with HIV referred to a psychological medicine unit. *AIDS Care*, 10, 105-112.
- Mills, C. (1959). *The sociological imagination*. New York: Oxford University Press.
- Ministry of Health and Long Term Care (MOHLTC). (2008). *Ontario HIV/AIDS infection rates*. Retrieved online on October 21st, 2008 from: http://www.health.gov.on.ca/english/providers/program/hivaid/s/general/charact_epidemic.html
- Mooney, A. (2005). Some body wants to be normal: An account of an HIV narrative. *Journal of Medical Ethics*, 31, 72-80.
- Moore, L.W. & Amburgey, L.B. (2000). Older adults and HIV. *Association of Operating Room Nurses (AORN) Journal*, 71(4), 873-876.
- Moreau, M. (1979). A structural approach to social work practice. *Canadian Journal of Social Work Education*, 5(1), 78-94.

- Moreau, M. (1990). Empowerment through advocacy and consciousness-raising: Implications of a structural approach to social work practice. *Journal of Sociology and Social Welfare*, 17(2), 53-67.
- Moreau, M. & Leonard, L. (1989). *Empowerment through a structural approach to social work: A report from practice*. Unpublished thesis: Université de Montréal/Carleton University.
- Morgan, D.L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Quantitative Health Research*, 8, 362-376.
- Mullaly, R. (2007). *The new structural social work*. (3rd ed). Don Mills: Oxford University Press.
- Mullaly, B. (1997). *Structural social work: Ideology, theory, and practice*. (2nd ed). Toronto: Oxford University Press.
- Mullaly, R.P. & Keating, E.F. (1991). Similarities, differences and dialectics of radical social work. *Journal of Progressive Human Services*, 2(2), 49-78.
- Murray, J. & Adam, B.D. (2001). Aging, sexuality, and HIV issues among older gay men. *The Canadian Journal of Human Sexuality*, 10 (3/4), 75.
- Namaste, V. (2000). *Invisible lives: The erasure of transsexual and transgendered people*. Chicago: University of Chicago Press.
- National Association of HIV Over Fifty (2006a). *HIV and aging issues bibliography*. Accessed on November 3rd, 2006 from:
<http://www.hivoverfifty.org/bibliography.html>.
- National Association of HIV Over Fifty (2006b). *Resource information*. Accessed on

November 3rd, 2006 from:

http://www.hivoverfifty.org/nahof_resources.html

- Nelson, T.D. (2005). Ageism: Prejudice against our feared future self. *Journal of Social Issues, 61(2)*, 207-221.
- Novak, M. (1993). *Aging & society: A Canadian perspective*. Scarborough: Nelson Canada.
- Neuman, W.L. (1997). *Social research methods*. Boston, MA: Allyn and Bacon.
- Neuman W.L. & Kreuger, L.W. (2006). *Social work research methods: Qualitative and quantitative approaches*. Toronto: Pearson Education Inc.
- New York State Department of Health. (2001). Trauma and post-traumatic stress disorder in patients with HIV/AIDS (updated online September 2004). In: *Mental health care for people with HIV infection: HIV clinical guidelines for the primary care practitioner*. New York (NY): New York State Department of Health, pp. 69-75.
- Nichols, J.E. et al. (2002). *Aging with HIV: Psychological, social and health issues*. San Diego: Academic Press.
- Nokes, K.M. & Emler, C.A. (2006). Health care strategies for older adults with HIV/AIDS. In P. Burbank (Ed). *Vulnerable older adults: Health care needs and interventions*. New York: Springer Publishing. pp. 235-250.
- Nokes, K.M., Chew, L. & Altman, C. (2003). Using a telephone support group for HIV-positive persons aged 50+ to increase social support and health-related knowledge. *AIDS Patient Care and STDs, 17(7)*, 345-351.
- Olley, B.O., Zeier, M.D., Seedat, S. & Stein, D.J. (2005). Post-traumatic stress disorder

- among recently diagnosed patients with HIV/AIDS in South Africa. *AIDS Care*, 17(5), 550-557.
- Orsulie-Jeras, S., Shepard, J.B., & Britton, P.J. (2003). Counseling older adults with HIV/AIDS: A strength-based model of treatment. *Journal of Mental Health and Counseling*, 25(3), 233-244.
- Ontario AIDS Network (OAN; 2008). *Letter to the Honorable Tony Clement from Ontario AIDS Network*, July 15th, 2008.
- Ory, M.G., Zablotsky, D.L. & Crystal, S. (1998). HIV/AIDS and aging: Identifying a prevention research and care agenda. *Research on Aging*, 20, 637-652.
- Patton, C. (2002). *Globalizing AIDS*. Minneapolis: of Minnesota Press.
- Patton, C. (1990). *Inventing AIDS*. Routledge: New York.
- Patton, C. (1986). *Sex and germs: The politics of AIDS*. Black Rose Books: Montreal.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods (2nd ed.)*. Newbury Park, CA: Sage Publications.
- Pearlin, L. I. (1989). The sociological study of stress. *Journal of Health and Social Behavior*, 30(3), 241-256.
- Persson, A. (2005). Facing HIV: Body shape change and the (in)visibility of illness. *Medical Anthropology*, 24, 237-264.
- Petersen, A. (2006). An African-American woman with disabilities: The intersection of gender, race, and disability. *Disability & Society*, 21(7), 721-734.
- Ontario. Ministry of Health and Long Term Care (MOHLTC). (2008). *HIV/AIDS strategy*. Retrieved online December 1st, 2008 from:
http://www.health.gov.on.ca/english/public/pub/aids/hiv_ontario.html.

- Poindexter, C. (Ed) (2004). *Midlife and older adults and HIV: Implications for social services research, practice, and policy*. New York: Haworth Press.
- Poindexter, C. (2004). Six champions speak about being over 50 and living with HIV. In C. Poindexter (Ed). *Midlife and older adults and HIV: Implications for social services research, practice, and policy*. New York: Haworth Press. pp. 99-118.
- Poindexter, C. & Emler, C. (2006). HIV-infected and HIV-affected older adults. In B. Berkman (Ed). *Handbook of social work in health and aging*. New York: Oxford University Press. pp. 91-99.
- Rachlis, M. (2004). Health care and health. In D. Raphael (Ed.) *Social determinants of health: A Canadian perspective*. Toronto: Canadian Scholar's Press. pp. 297-310.
- Raphael, D. (2004). *Social determinants of health: A Canadian perspective*. Canadian Scholar's Press: Toronto.
- Rawls, J. (1971, 1999). *A theory of justice*. Cambridge, MA: Harvard University Press.
- Reisch, M. (2002). Defining social justice in a socially unjust world. *Families in Society: The Journal of Contemporary Human Services*, 83(4), 343-354.
- Riley, M.W. (1989). AIDS and older people: The overlooked segment of the population. In M.W. Riley, M.G. Ory, and D. Zablotsky (Eds.) *AIDS in an aging society: What we need to know* (p. 3-26). New York: Springer.
- Ryan, B. & Rowe, W. (1999). *Social work and HIV: The Canadian experience*. Toronto: Oxford University Press.
- Sankar, A., Luborsky, M., Rwabuhemba, T. & Songwathana, P. (1998). Comparative perspectives on living with HIV in late life. *Research on Aging*, 20(6), 885-911.
- Sanmartin, C. et al. (2000). Waiting for medical services in Canada: Lots of heat, but

- little light. *CMAJ*, 162(9), 1305-10.
- Savasta, A.M. (2004). HIV associated transmission risks in older adults: An integrative review of the literature. *Journal of the Association of Nurses in AIDS Care*, 15(1), 50-59.
- Shah, S. & Mildvan, D. (2006). HIV and aging. *Current Infectious Diseases Reports*, 8(3), 241-247.
- Schaie, K.W. (1996). *Intellectual development in adults: The Seattle longitudinal study*. New York: Cambridge University Press.
- Schneider, H. (1992). *The social context of AIDS*. London: Sage Publications.
- Scott, S. & Constantine, L.M. (1999). The Lazarus syndrome: A second chance for life with HIV infection. *Journal of the American Pharmaceutical Association*, 39(4), 462-466.
- Senterfitt, W. (1988). The Denver Principles: The Original Manifesto of the PWA Self-Empowerment Movement. *Being Alive*, May, 1998: Los Angeles.
- Sharples, T. (2008). More midlife (and older) STDs. In *Time Magazine*. Accessed July 2nd, 2008 from: <http://www.time.com/time/health/article/0,8599,1819633,00.html>
- Shapcott, M. (2004), Housing. In D. Raphael (Ed.) *Social determinants of health: A Canadian perspective*. Toronto: Canadian Scholar's Press. pp. 201-216.
- Shepard, B. & Hayduk, R. (2002). *From ACT UP to the WTO: Urban protest and community building in an era of globalization*. Brooklyn: Verso.
- Siegel, K., Bradley, C. & Lekas, H. (2004). Causal attributions for fatigue among late middle-aged and older adults with HIV infection. *Journal of Pain Symptoms and Management*, 28(3), 211-224.

- Siegel, K. & Schrimshaw, E.W. (2003). Reasons for the adoption of celibacy among older men and women living with HIV/AIDS. *The Journal of Sex Research*, 40(2), 189-200.
- Siegel, K. & Schrimshaw, E.W. (2002). The perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS. *Journal for the Scientific Study of Religion*, 41(1), 91-102.
- Siegel, K., Schrimshaw, E.W. & Dean, L. (1999a). Symptom interpretation and medication adherence among late middle-age and older HIV-infected adults. *Journal of Health Psychology*, 4(2), 247-257.
- Siegel, K., Schrimshaw, E.W. & Dean, L. (1999b). Symptom interpretation: Implications for delay in HIV testing and care among HIV-infected late and middle-aged and older adults. *AIDS Care*, 11(5), 525-535.
- Siegel, K., Raveis, V. & Karus, D. (1998). Perceived advantages and disadvantages of age among older HIV-infected individuals. *Research on Aging*, 20(6), 686-711.
- Silversides, A. (2003). *AIDS Activist: Michael Lynch and the politics of community*. Toronto: Between the Lines Books.
- Sinclair, D., Rochon, M. & Leatt, P. (2005). *Riding the third rail: The story of Ontario's Health Services Restructuring Commission, 1996-2000*. Montreal: The Institute for Research on Public Policy.
- Skiest, D.J., Rubinstien, E., Carley, N., Gioiella, L. & Lyons, R. (1996). The importance of comorbidity in HIV-infected patients over 55: A retrospective case-control study. *American Journal of Medicine*, 101, 605-611.
- Smith, G. (2006). *Erving Goffman*. New York: Routlage.

- Solomon D.J., Hogan, A.J., Bouknight, R.R., Solomon, C.T. (1989). Analysis of Michigan Medicaid costs to treat HIV infection. *Public Health Report*, 104(5),416–424.
- Solomon, L, Frank, R., Vlahov, D. & Astemborski, J. (1991). Utilization of health services in a cohort of intravenous drug users with known HIV-1 serostatus. *American Journal of Public Health*, 81, 1285-1290.
- Sowell, R.L. et al. (1997). Resources, stigma, and patterns of disclosure in rural women with HIV Infection. *Public Health Nursing*, 14 (5), 302-312.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research*. Thousands Oaks, CA: Sage Publications.
- Tashima, K.T. & Carpenter, C.C. (2003). Fusion inhibitors: A major but costly step forward in the treatment of HIV-1. *New England Journal of Medicine*, 348(22), 2249-2250.
- Tew, J. (2005). *Social perspectives in mental health*. Philadelphia: Jessica Kingsley Publishers.
- Titmuss, R. (1958). *Essays on the welfare state*. London: Alen & Unwin.
- Topolski, J.M. (2002). Older adults, substance use, and HIV/AIDS: Preparing for a future crisis. *Journal of Mental Health and Aging*, 8(4), 349-363.
- Travers, R. et al. (2008). The greater involvement of people living with AIDS principle: Theory versus practice in Ontario's HIV/AIDS community-based research sector, *AIDS Care*, 20(6), 615-624.
- Treichler, P.A. (1999). *How to have theory in an epidemic: Cultural chronicles of AIDS*. Durham & London: Duke University Press.

- Tucker, R. & Koornstra, J. (2008). *Positive Spaces, Healthy Places: Methods; baseline findings; health outcomes at 6 months*. Ruthann Tucker, Ontario HIV Treatment Network, and Jay Koornstra, Bruce House, Ottawa. Paper presented at the Third National Housing and HIV/AIDS Research Summit, Baltimore, Maryland.
- Turner, B.J., Kelly, J.V. & Ball, J.K. (1989). A severity of classification system for AIDS hospitalizations. *Medical Care*, 27, 423-37.
- Tutty, L.M., Rothery, M.A. & Grinnell, R.M. (1996). *Qualitative research for social workers*. Toronto: Allyn & Bacon.
- United Nations Joint Program on HIV/AIDS & World Health Organization (UNAIDS, 2007). *AIDS epidemic update: December 2007*. United Nations.
- UNAIDS (1999). *From principle to practice: Greater involvement of people living with or affected by HIV/AIDS (GIPA)*. Geneva: UNAIDS.
- United States of America. (2005). *HIV over fifty: Exploring the new threat*. Hearing before the Special Committee on Aging, United States Senate, One Hundred Ninth Congress, First session, Washington, D.C. May 12th, 2005. Serial No. 109-7. Washington, D.C.: U.S. Government Printing Office.
- Uranga, R. (2005, November). Drugs help AIDS patients live well into senior years. *Los Angeles Daily News*, paragraph 5. Retrieved December 7, 2005 from <http://www.dailynews.com>
- Valcour, V.G. & Sacktor, N. (2002). HIV-associated dementia and aging. *Journal of Mental Health and Aging*, 8(4), 295-306.
- Vaillant, G.E. & Mukamal, K. (2001). Successful aging. *American Journal of Psychiatry*, 158, 839-847.

- Vance, D.E. & Robinson, F.P. (2004). Reconciling successful aging with HIV: A biopsychosocial overview. In C. Poindexter (Ed). *Midlife and older adults and HIV: Implications for social services research, practice, and policy*. New York: Haworth Press. pp. 59-78.
- Vance, D.E. & Roybal, E.R. (2006). Spirituality of living and aging with HIV: A pilot study. *Journal of Religion, Spirituality & Aging, 19(1)*, 57-74.
- Wan, T.T.H. (1989). The behavioral model of health care utilization by older people. In M.G. Ory and K. Bond (Eds.). *Aging and health care: Social science and policy perspectives* (pp. 52-77). New York: Routledge.
- Ward, J. (2004). Not all differences are created equal: Multiple jeopardy in a gendered organization. *Gender & Society 18(1)*, 82-102.
- Warner, T. (2002). *Never going back: A history of queer activism in Canada*. University of Toronto Press: Toronto.
- Weaver, L. & Amburgey, L.B. (2000). Older adults and HIV. *Association of Operating Room Nurses Journal, 71(4)*, 873-876.
- Weber, M. (2000). "Class, Status Party". In J. Farganis (Ed.). *Readings in social theory: The class tradition to post-modernism*. McGraw-Hill: Toronto. pp. 136-146.
- Weeks, J. (1991). *Against nature: Essays on history, sexuality, and identity*. London: Rivers Oram Press.
- Wellons, M.F. et al. (2002). HIV infection: Treatment outcomes in older and younger adults. *Journal of the American Geriatrics Society, 50*, 603-607.
- West, C. (1982). *Prophesy deliverance! An Afro-American revolutionary Christianity*. Philadelphia: Westminster.

- Whipple, B., & Scura, K. W. (1996). The overlooked epidemic: HIV in older adults .
American Journal of Nursing, 96, 123-126.
- Wilkie, F. et al. (2003). Cognitive functioning in younger and older HIV-1 infected adults. *Journal of Acquired Immune Deficiency Syndromes, 33* (Suppl. 2), S93-S105.
- Wilkinson, R. & Marmot, M. (2003). *Social determinants of health: The solid facts*. World Health Organization Regional Office for Europe: World Health Organization.
- Wilson, N.L. (2006). Educating social workers for an aging society: Needs and approaches. In B. Berkman (Ed). *Handbook of social work in health and aging*. New York: Oxford University Press. pp. 1041-1050.
- Wilson, A.O. & Adamchak, D.J. (2001). The grandmothers' disease: The impact of AIDS on Africa's older women. *Age & Aging, 30*, 8-10.
- Winningham, A., Ritcher, D., Corwin, S. & Gore-Felton, C. (2004). Perceptions of vulnerability to HIV among older African American women: The role of intimate partners. In C. Poindexter (Ed). *Midlife and older adults and HIV: Implications for social services research, practice, and policy*. New York: Haworth Press. pp. 25-42.
- Winningham, A. et al. (2004). The changing age of HIV: Sexual risk among older African American women living in rural communities. *Preventative Medicine, 39*, 809-814.
- Wooten-Bielski.(1999). HIV & older adults. *Geriatric Nursing, 20*(5), 268.272.
- Wutoh, A.K. et al. (2005). Treatment perceptions and attitudes of older human

immunodeficiency virus-infected adults. *Research in Social & Administrative Pharmacy, 1*, 60-76.

Yamada, Y. (2001). Consumer direction in community-based long term care: Implications for different stakeholders. *Journal of Gerontological Social Work, 35(3)*, 83-97.

Yesavage et al. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research, 17(1)*, 37-49.

Young, I.M. (1990). *Justice and the politics of difference*. Princeton, NJ: Princeton University Press.

Zaboltsky, D. & Kennedy, M. (2004). Assessing the progress and promise of research on midlife and older adults with HIV/AIDS. In C.A. Emlet (Ed). *HIV and older adults: Challenges for individuals, families and communities*. New York: Springer Publishing Company. pp. 37-54.

Zingmond, D.S. (2001). Circumstances at HIV diagnosis and progression of disease in older HIV-infected Americans. *American Journal of Public Health, 91(7)*, 1117-1120.

APPENDIX I: PHA SERVICE IN ONTARIO (AND THEIR NEOLIBERAL CONTEXT)

In this section, the current state of affairs of PHA services in Ontario is discussed. Next, the Canadian global-capitalist state is examined, with an emphasis on the impact that neo-liberal governance and social policies (e.g. government cutbacks to social welfare) has on PHA services in Ontario. Specifically, oPHAs in Ontario are subject to a system of inequality under regional, provincial, and national structures that espouse ideologies of neo-liberal global capitalism and ever-retrenching systems of social welfare. In addition, the forms of welfare system in place are inequitable in their scope and lead to further barriers to accessing optimal health and social services for Canada's most vulnerable groups, including older PHAs.

PHA Services in Ontario

The current state of HIV services in Ontario is best described as precarious and unstable. Ontario has several national and provincial bodies that serve PHAs, including the Ontario HIV Treatment Network (OTHN), Canadian AIDS Treatment Information Exchange (CATIE), the, Canadian Aboriginal AIDS Network (CAAN), and the Canadian AIDS society (CAS), etc., as well as many various local AIDS service organizations which make up a coalition Ontario AIDS Network (OAN). Many of these organizations have experienced a transition from grassroots community agencies to increased medicalization and professionalism (for a review of Ontario ASOs, see Cain, 1993; for an American perspective, see Patton, 1990, p. 13), however it is argued that many PHA service organizations have returned to their grassroots approach, and most espouse PHA-driven services created for, with and by community stakeholders (Travers et al., 2008).

While many communities in Ontario have ASOs, these agencies exist under the constant restraint of limited funding and threat of fluctuating public interest in the well-being of PHAs. Recently, in response to pressure from a Coalition of ASOs¹³⁵, the Public Health Agency of Canada (PHAC, July 16th, 2008a) publicized a funding decision benefiting ASOs and PHAs in Ontario. Specifically, the PHAC (2008a) announced it would invest “\$24 million in the (national) AIDS Community Action Program”¹³⁶ (ACAP; PHAC, 2005). Of the \$12.1 million allocated for fiscal year 2008/09, \$9.5 million has already been committed, and the remaining \$2.6 million will be made available in British Columbia, Ontario, Quebec and the Atlantic regions. The announcement was meant to “provide community organizations with more time and resources to implement their projects...and make a difference in the lives of those living with or affected by HIV and AIDS” (PHAC, 2008a). Finally, the announcement reiterated the government’s emphasis on funding for programs “based on sound goals, planned outcomes and *value for money*” (PHAC, 2008a; italics added). Shamefully, this funding commitment still falls short of a 2005 promise (by the same politician responsible for this announcement; OAN, 2008a).

While governments remain hesitant to increase spending on social welfare for PHAs, commitments that have been made can be undoubtedly attributed to the political and social activism of the Canadian AIDS movement. In the last two decades, there was

¹³⁵ On July 16th, 2008, the Board of Directors of the Ontario AIDS Network cancelled a well-publicized planned die-in for action event that was scheduled for Thursday, July 24, 2008. This was the response of the Ontario AIDS movement to an announcement made earlier that day by the Regional Director of the Ontario-Nunavut Region, Public Health Agency of Canada regarding an increase in funding for the AIDS Community Action Program (ACAP) (Personal communication, Rick Kennedy, Executive Director, OAN).

¹³⁶ The AIDS Community Action Program (ACAP) is a component of the *Canadian Strategy on HIV/AIDS*, the federal government’s framework to respond to AIDS in Canada. ACAP aims at: “preventing the spread of HIV; ensuring treatment, care and support for people living with HIV and AIDS, their caregivers, families and friends; minimizing the adverse impact of HIV/AIDS on individuals and communities; and minimizing the impact of social and economic factors that increase individual and collective risk for HIV infection” (PHAC, 2005).

much community organizing among members of PHA communities, resulting in a strong and seemingly unified AIDS movement (e.g. Shepard & Hyduk, 2002; Silversides, 2003; Warner, 2002). One achievement of the movement was the acknowledgement of the implementation of the United Nations' *Greater Involvement of People Living with AIDS* (GIPA; UNAIDS, 1994) principle into national and provincial AIDS service organizations, and community-based research practices (for a review, see Travers et al., 2008). Interestingly, these positive developments occurred within an ever growing national climate of globalization, capitalism, government retrenchment, and limited availability of services.

The neoliberal context

Ontario exists within a Canadian system of global, neo-liberal capitalism that increasingly neglects the maintenance of the welfare state (Lightman, 2003; Lundy, 2004, p. 1-2; Mullaly, 2007, p. 2; Raphael, 2003, p. 17)¹³⁷. Mullaly (1997/2007) refers to this shift in welfare state intervention to free-market or economic *determinism* (Mullaly, 2007, p. 8-9). This government retrenchment has left aspects of the Canadian welfare system vulnerable.

Mullaly (2007) characterized conditions under the Canadian global-capitalist state with a particular focus on the condition of social welfare:

pension benefits for the elderly are under threat, health services face continuous crisis of under funding, homelessness continues to increase and is now a massive problem, social workers are required to act in punitive ways and to handle ever-growing caseloads...privatization of social

¹³⁷ Lundy (2004) suggests that the new global Canadian economy is reflective of classic socialist fears of a universal interdependence of nations (Marx & Engels, 1948/2004). In contrast to earlier models of social welfare, which attempted to create a 'harmonious relationship...between capitalism and the...welfare sector' (e.g. Keynesian welfare state, 'mixed economy', or 'welfare capitalism'), our global capitalist economy downplays the centrality of the nation state, and instead espouses the principles and demands of global markets.

services, along with deleterious consequences, continues to increase” (p. 12).

Indeed, the changing nature of the Canadian welfare state has left the role of social work in the global capitalist economy in question. Similarly, Young (1990, p. 54) states:

because they depend on bureaucratic institutions for support or services, the old, the poor, and the mentally and physically disabled are subject to patronizing, punitive, demeaning and arbitrary treatment by the policies and people associated with welfare bureaucracies. (p. 54)

Michel Foucault further supported this idea in a roundtable discussion on social work (in Chambon, Irving & Epstein, 1999, pp. 91-93) and suggested social workers have taken on new dimensions of ‘surveillance and correction’ and that the profession has become ‘programmatically’ and ‘institutionalized’.

Canada’s foray into the global market, coupled with the conservative cuts of recent federal governments (in attempt reduce expenditures and eliminate national deficits), has resulted in cuts to social programs. This is evidenced by the termination of the Canada Assistance Plan and subsequent implementation of the *Canada Health and Social Transfer* (CHST; 1996), as well as the introduction of the *Social Union Framework Agreement* (SUFA), which essentially limits the responsibility of our federal government to intervene unilaterally in respect to social welfare (Lightman, 2003, p. 20). These policies result in visible and harsh impacts for people residing in Canada. For instance, between 1980 and 1995 poverty rates increased from 15.3% to 17.4% (National Council on Welfare, cited in Mullay, 2007, p. 17). Interestingly, in the last decade Canada has managed to produce a fiscal surplus (Mullaly, 2007, p. 32). This leads social workers to ask: ‘but at what cost?’

In addition to government retrenchment via conservative policy shifts, there is evidence that Canada's limited social welfare system is an inequitable system with differential impact based on vulnerable group status. For instance, Titmuss (1963) suggested that there is a social division of welfare in which certain groups benefit from social welfare more than others, but ironically this differential favors people of higher status as opposed to those in greatest need. For instance, Canada's social welfare system consists of three forms of social welfare: (a) income *tax breaks*, also known as 'Canada's hidden welfare system' (b) *occupational* welfare (e.g. employment insurance), and (c) *social* welfare (e.g. modest universal transfers, means-tested programs, minimal social insurance initiatives). In examining this system for accessibility, it becomes obvious that the severely disadvantaged only benefit from one of these types of welfare, and those who do manage to access social welfare services often experience stigma for doing so (Young, 1990, pp. 54-55; Mullaly, 2007, pp. 18-19). Thus, severely marginalized people, including some older PHAs, are alienated from the very system of national welfare proposed for the benefit of all citizens. This is blatantly inconsistent with ideas of equity and social justice (Reisch, 2002; Young, 1990).

Despite the current state of affairs, there have been several developments that indicate resistance to globalization and neo-liberal capitalism. Mullaly's (2007) account of structural social work theory posits that globalization outside of North America seems to be increasingly shifting to serve national concerns as opposed to fully realizing global market governance (e.g. India, China, Asia, etc.). Interestingly, Mullaly (2007) cites the collapse of the globalization thesis, stating that "globalization as it was originally conceived is now dead" (Mullaly, 2007, p. 29). Further, recent world events, such as the

U.S. decision to act unilaterally on the 2003 invasion of Iraq and the now infamous economic bail-outs of 2008-09, provide evidence that the nation state is stronger than ever, or that “nation states rule; economies do not” (Mullaly, 2007, p. 29). What remains to be seen is whether new emphasis on the nation state will usher in a new era of spending in social welfare and thus improved services for vulnerable and marginalized groups, including older PHAs.

Further resistance to global-capitalism has been demonstrated through social movements. These include broad social movements against oppressive ideologies and more nuanced movements against specific Canadian health and social policies. For instance, broad demonstrations by social movements at the G8 summit in Cologne (1999) and World Trade Organization in Seattle have been suggested to represent a new era of community organizing (for review, see Shepard & Hayduk, 2002). Additionally, there has and continues to be much grassroots organizing surrounding HIV/AIDS in Canada, from the early days of the AIDS Coalition to Unleash Power (ACT UP!) to work currently being done on behalf of PHAs in Ontario. While it remains unknown what impact resistance will have on powerful social structures, the current thesis took an emancipatory approach to oppression in health and social services.

APPENDIX II: THE RESEARCH ENTERPRISE AND OLDER ADULTS LIVING WITH HIV/AIDS

Recently, there has been increased global interest in aging in response to the quickly shifting demographics of society. This trend inevitably contributes to increased public interest into HIV and aging. For instance, HIV and aging are featured in widely circulated PHA media (e.g. Highleyman, 2007; Kaiser Daily HIV/AIDS Report, 2008) and is gaining increased exposure in the popular media like *Time* magazine¹³⁸ (Goldman, 2006) and local newspapers and websites (e.g. LeBlanc, 2006¹³⁹; Caffazo, 2004; Bernard, 2005; Uranga, 2005; Hesselgrave, 2008; Sharples, 2008; CTV News, 2008; Draaisma, 2008), as well as in public service announcements aimed directly at the PHA and aging communities (e.g. Larkin, 2006; NAHOF 2006a;b). Encouragingly, in 2005 the Special Committee on Aging of the United States Senate¹⁴⁰ conducted a hearing called ‘HIV over 50: Exploring the New Threat’ in which testimonials of oPHAs and their service providers were communicated to national leaders. Despite this spike in public attention, oPHAs remain on the margins of popular HIV/AIDS and aging discourses. Also, this increased public awareness was assisted by much advocacy, capacity building, and ‘back-burner’ research conducted on HIV and aging since the late 1980s up to present day.

Research and capacity building with oPHAs has a rich and shared history.

Unsurprisingly, it appears that as empowerment among this segment of PHA communities grew, so too did scholarly research focus. Poindexter (2004) outlines the

¹³⁸ Goldman (2006) contributed an article to *Time* magazine titled ‘the Graying of AIDS’. *Time*’s website (www.time.com) features a video gallery dedicated to graying with HIV.

¹³⁹ The story of Sally Richard was reported in the *Sackville Tribune Post* while I was an undergraduate at Mount Allison University, sparking my interest in this topic.

¹⁴⁰ The hearing was high profile, co-chaired by Sen. Hillary Rodham Clinton of New York (the state in which the landmark ACRIA study of 1,000 oPHAs was conducted and where much academic research has emerged on HIV and aging).

development of HIV and aging advocacy and research in a recent review. According to Poindexter (2004), much of the early agenda setting with oPHAs was carried out with the assistance of American social workers in the mid 1980s. During this time, the New York AIDS and Aging Task Force was developed, and later came to be known as The New York Association of HIV over 50 (NAHOF). In 1989, Riley, Ory and Zablotsky's seminal work *AIDS in an Aging Society* was released, the first publication of its kind. This was followed by a special issue of the journal *Families in Society* in 1994, which focused on oPHAs. In 1996, the first annual conference devoted solely to HIV and aging was held at Hunter College in New York City, which led to the official establishment of the NAHOF, as well as an HIV interest group of the Gerontological Society of America.

In 2001, social work professor Michael Maclean and gerontologist Chris Claap published the first Canadian articles on HIV/AIDS and aging in *Geriatrics Today* and *Canadian Social Work Review*. This would be the only Canadian work done until 2005, when Tara Fritsch conducted a landmark study of service use among younger and older PHAs in the Toronto-Hamilton area. In 2002-03, special issues of *Journal of Mental Health and Aging*, the *Journal of Acquired Immune Deficiency Syndromes*, and the *Journal of HIV/AIDS & Social Services: Research, Practice and Policy* were dedicated to the topic; the latter was co-published as a book edited by Cynthia Poindexter, *Midlife and Older Adults in HIV: Implications for Social Service, Research, Practice and Policy* (2004). Also in 2004, Charles Emlet edited a second HIV-focused issue of the *Journal of Mental Health and Aging*, which was later released as a book, *HIV/AIDS and Older Adults* (2004). At the same time, the findings of the comprehensive 'West Central Florida

survey of middle aged and older adults with HIV disease' ($n = 172$) was released as a book edited by Nichols (2003).

In 2006, the AIDS Community Research Initiative of America (ACRIA; Karpiak, Shippy & Cantor, 2006) released a landmark study of oPHAs ($n = 1,000$) in New York City. Currently, the National Association of HIV over 50 (NAHOF) maintains a comprehensive, interdisciplinary bibliography of HIV and aging publications online, and produces quarterly newsletters for its members and interested parties (Poindexter, 2004, pp. 4-5; NAHOF 2006a). What is remarkable about the development of capacity and research with the oPHA community was that they occurred hand in hand, reflective of the PHA-driven nature of PHA-centered research. The idea of incorporating the voices of oPHAs fits in with the Denver (ACPHA, 1983; Senterfitt, 1988) and GIPA principles (UNAIDS, 1999), and continues to be espoused by research communities in Ontario (Travers et al., 2008).

Poindexter (2004) reviewed research into oPHAs and reported that contributions are “sprinkled throughout scholarly journals of widely disparate disciplines and professions” (Poindexter, 2004, p. 5). The multiple fields relevant to this group- ranging from epidemiology to social work, as well as knowledge indigenous to the PHA community- means that research in this area must take a *transdisciplinary* approach (Klein, Grossenbacher-Mansuy & Häberli, 2001; for description of this concept, see Chapter 2).

A challenge faced by the research community is agreement upon who is considered to be an older adult. That is, what age groups does this population include? The vast majority of HIV and aging research operationally defines older adults as people aged 50 and over (Poindexter & Elmet, 2006, p. 97-98; Eldred & West, 2005, p. 20).

Governmental agencies also use this 50 and over criteria (Public Health Agency of Canada, 2008; 2004). The trend of using '50+' is largely attributed to the initial 1982 practice of the U.S. Center for Disease Control (CDC; in Poindexter, 2004). In the early stages of the HIV/AIDS epidemic, it was deemed appropriate to report statistics in interval age groups only up to age 50 years (i.e. 25 and under, 25-44, 44-49, and 50 and over). At the time, this was perfectly acceptable, as the prevalence of HIV in older adults, and subsequently their survival rates, was practically non-existent. This practice was maintained by the CDC until 2002, when this highly heterogeneous 'over 50' age group was finally broken down for statistical purposes to reflect the 45-54, 55-64, 65-plus age groups (Poindexter, 2004, p. 7). While this criterion works for the time being, further subdivisions of the older adult age group will undoubtedly need to be investigated in the coming decades (i.e. 65-74; 75 and over). Also, like most aging research, studies fail to acknowledge the incredible amount of variability among people in these age groups, which could potentially confound research findings. In addition, the use of 50+ as indicative of older adulthood is not typical of aging research, which traditionally defines older adulthood as occurring much later in life. This could pose problems for integration of HIV into mainstream aging research.

Despite marked efforts to produce research into the experiences of oPHAs, the consensus of the scientific and social science communities is that research remains scarce, and most of it was conducted over a decade ago (Emlet & Poindexter, 2004, p. 93; Eldred & West, 2005, p. 22). As such, literature on HIV and aging produced before 1995 must be reviewed with caution as the nature of HIV changed drastically when antiretroviral and protease inhibitor therapies became available for PHAs in affluent

countries. In addition, the vast majority of this research has been conducted in the United States, leaving a gap in Canadian (and international) perspectives.

The past research enterprise with oPHAs has several important implications for the present project. First, a solid framework for examining HIV and aging has been established, particularly within the field of social work (e.g. Emlet, 1993-2007; Maclean & Clapp, 2001a, 2001b; Poindexter, 2004; Geneke, 2000, etc). Second, there has been much work done addressing the experiences of oPHAs, which has revealed several factors the present study will address (e.g. health and social demographics, health and social service use, barriers to care, stigma, etc.). A challenge presented by the current body of literature surrounding HIV and aging is the lack of Canadian content.

Specifically, there has been little research produced examining service experiences and barriers of older PHAs in the context of a national public healthcare system under threat by neoliberal trends in governance, as is the reality of older PHAs living in the national capital region. Finally, there is a lack of emphasis on structural relations and factors experienced by oPHAs, a gap the present study aims to fill.

APPENDIX III: LETTER OF INFORMATION (INFORMED CONSENT)

Informed Consent -Community Members

Outline of project

You are invited to participate in a research project investigating the health and social service needs, experiences and barriers of older adults living with HIV. This study is being carried out by Charles Furlotte, School of Social Work at Carleton University under the supervision of Dr. Karen Schwartz. This research has been approved by Carleton University Research Ethics Committee.

In this study, you will be asked to answer three short questionnaires taking approximately 20 minutes. You will be asked to answer questions about your age, educational background, health, language abilities, work experience and services accessed. You will also be asked to answer some questions about your thoughts and feelings about problems you may face to accessing services. Finally, you will be asked to discuss your experiences living with HIV, and the services you receive. This part of the study will be videotaped. Participation will take approximately 1 hour.

Consent:

Your involvement in this project is very much appreciated. Your responses will remain *confidential*. You should note that while efforts have been made to protect the anonymity of your participation in this study, staff and others at the AIDS Committee of Ottawa may be aware that you are participating. All the answers that you give will be held *anonymously*. You will remain anonymous in the final thesis, and any publications that follow. Your name will not be used for any part of this project. Your answers will be labeled with a code number, not your name. No one except the researcher will be allowed to see any of your responses. Your answer sheets will be kept under lock and key and will eventually be destroyed.

Your participation in this study is *voluntary*. You are free to discontinue participation at any time during the study. Your participation in the current study *will not* affect the services you receive from AIDS Committee of Ottawa, your physician, or any other care provider. If you agree to participate in this research project, please sign and print your name below. Your signature indicates that you have read this information provided above and that you have decided to participate.

There are no known risks associated with participating in this research. However, we will be asking you questions about your experiences, and recalling negative experiences may be upsetting. Should any of the questions upset you please do not answer them, or take a break before continuing. If you wish to withdraw your participation you may do so. You may decide at that time if we may use any of the information you have provided or have it destroyed. If your participation is in any way traumatic please let us know and the ACO staff will provide supportive listening and if you want they will provide referral services to a counselor. Responses of all the people that participate in the study will be combined, and the general results will be presented at scientific conferences, community events and published in scientific journals and books.

I, _____ (Your name: please print) have read the above letter and understand my participation is voluntary and I agree to participate.

Interviewee: _____ Date: _____

Researcher: _____ Date: _____

If you have questions about this study, please contact:

Charles Furlotte,
School of Social Work,
Carleton University, Ottawa, ON,
509 Dunton Tower,

APPENDIX IV: DEBRIEFING FORM

Thank You!

Dear Volunteer Participant:

First, I would like to express my gratitude to you for participating in this project. It is through the help of people like you that researchers all around the world can learn more about how to improve health and social services for people living with HIV.

This project is the basis of a Master's thesis project conducted by Charles Furlotte, a student in the School of Social Work at Carleton University. The project is being done under the supervision of Dr. Karen Schwartz.

There were several goals with this project. The first goal was to see what types of services people over the age of 50 living with HIV/AIDS accessed. Second, we wanted to determine what types of barriers to care exist for this group of people. Finally, we wanted to hear your suggestions for what health and social service providers can do to better serve you in the future.

We hope you enjoyed your participation today. If you have any questions or concerns about the study, please contact Charles Furlotte by calling (613) 321-2162 or emailing cfurlott@connect.carleton.ca. If you have any concerns about this study, you can also contact Prof. Antonio Gualtieri, Chair of the Carleton Research Ethics Board, at (613) 520-2517 or ethics@carleton.ca. If any of the information we discussed in this study has bothered you, we encourage you to speak with Mr. Khaled Salam, Case Manager/Support Worker at *The Living Room* at 613 563 0851, or 238 5014 ext. 234. The results of this study will be available for viewing sometime next year. I will be giving a series of presentations at *The Living Room* to update people of his progress. If you would like to receive news of when these presentations will be held, please leave us your name and address on the attached sheet, or refer to the AIDS Committee of Ottawa's monthly calendar.

We thank you most sincerely for your generous assistance; projects like this one could not be carried out without you!

Sincerely,

Charles Furlotte

APPENDIX V: COPY OF RESEARCH INSTRUMENTS

Demographics Questionnaire

Background Information

In order to better understand the results of this study, we need to know a few things about you and your educational and health background. This information will be kept strictly confidential. Please note that we do not ask for your name on this form.

1. My birth date is:
(month) (year)

2. I am:
 - a. male
 - b. female
 - c. transgender
 - d. intersex

3. I am:
 - a. married/co-habiting
 - b. single
 - c. widowed/divorced/separated
 - d. other

4. Which of the following do you identify most with?
 - a. gay/lesbian
 - b. bisexual
 - c. straight
 - d. queer
 - e. other

5. Which of the following do you most identify with?
 - a. European
 - b. Aboriginal
 - c. Asian
 - d. African
 - e. Latino
 - f. other

6. How many grades did you complete in school? (grades 1 to 12): ____

7. How many years of college, university or training school did you complete? ____

8. The language I speak the most frequently in day to day life is:
 - a. English
 - b. French
 - c. Other (please specify):

9. Currently, I am (please circle all that apply):

- a. Employed full-time
- b. Employed part-time
- c. Retired
- d. A full-time homemaker
- e. A full-time student
- f. A part-time student
- g. Doing volunteer work
- h. Receiving ODSP benefits
- i. Receiving CPP/QPP benefits
- j. Receiving OAS benefits
- h. Other

10. If you are retired:

When did you retire from full-time employment? ___

11. What is your primary occupation? (If you are retired, what *was* your primary occupation?):

12. What is your annual income?

- a. less than \$10,000
- b. \$10-25,000
- c. \$25,000-40,000
- d. \$40-60,000
- e. \$60,000 +

13. About how many times have you seen a doctor in the past year?

- a. None
- b. Once
- c. 2-6 times
- d. 7-12 times
- e. Over 12 times

14. How many prescribed HIV medications are you presently taking? __

14b. Please indicate what type of HIV medications you are currently prescribed:

14c. How many prescribed medications not related to HIV are you presently taking? __

14d. Please indicate what type of medications not related to HIV you are currently prescribed:

15. Please identify your HIV status:

- a. HIV-positive (symptomatic)
- b. HIV-positive (asymptomatic)
- c. AIDS
- d. don't know/prefer not to say

16. Have you experienced any co-infections, either currently or in the past? (circle one):
Yes/No

16b. If so, please identify which types of co-infections you have experienced.

17. How long have you known you are HIV positive?

- a. less than 1 year
- b. 1-5 years
- c. 5-10 years
- d. 10 years or more

18. How old were you when you first learned of your HIV status?

- a. 15-24
- b. 25-35
- c. 35-45
- d. 45-55
- e. 55-65
- f. 65 or over

19. Please indicate which of the following services you have accessed in the last six months by checking off whether you **use**, **don't use**, or **need, but can't get**. Also, please indicate how **important** each service is for someone like you, using a rating scale from 1 to 10, where 1 means the service is not very important to you, and 10 means the service is very important to you.

<u>Type of Service</u>	<u>Use</u>	<u>Don't</u>		<u>Importance</u>
		<u>Use</u>	<u>Need, but can't get</u>	
case management				
open-drop in				
Spiritual/religious/pastoral counseling				
foodbank				
meals				
clothing				
laundry facilities				
internet/computer use				
transportation vouchers				
housing assistance				
legal assistance (e.g. legal clinics)				
home care				
counseling services				
peer support				
chiropractic/occupational therapist				
social worker				
psychologist/psychiatrist				
HIV specialist physician				
nurse/ nurse practitioner				
holistic medicine				
alternative therapies (e.g. reiki, massage, acupuncture, etc.)				
HIV support groups (e.g. peer groups)				
HIV phone hotline or referral line				
HIV-related internet sites				
HIV clinical drug trials				
seniors groups				

Thank-you!

APPENDIX VI: COPY OF ADVERTISEMENT



HIV & Aging Study

Are you **over 50**, living with HIV/AIDS, and would like to share your views, experiences and suggestions for health and social services in the Ottawa region? We need your help!

Charles Furlotte, School of Social Work, Carleton University, is conducting research on the health and social services needs of older adults in our community.

The study will take place at The Living Room, located at 270 Bank St. Suite 700, Ottawa, ON. The study consists of a survey, and an interview, and should take about 1.5 hours.

If you are interested, please contact Charles Furlotte at crfrlft@mta.ca, or Khaled Salam at support@aco-cso.ca, (613) 563-0851 or (613) 238-5014 ext. 234.



Let your voices be heard!

*This research project has been approved by the Carleton University Research Ethics Committee
613-520-2517 ethics@carleton.ca*

APPENDIX VII: COPY OF THEME LIST

Color	Theme(s)		
<input type="checkbox"/>	Aging	<input type="checkbox"/>	Family/social support
<input type="checkbox"/>	Stigma	<input type="checkbox"/>	Mental health
<input type="checkbox"/>	Disclosure	<input type="checkbox"/>	Hospital experience
<input type="checkbox"/>	Disease/Chronic Illness	<input type="checkbox"/>	Integrated services
Management		<input type="checkbox"/>	Initial misdiagnoses
<input type="checkbox"/>	Co-morbidity	<input type="checkbox"/>	Community
<input type="checkbox"/>	Housing	<input type="checkbox"/>	Gender

TABLE 1: GERIATRIC SCALE SUMMARY TABLE

Table 1: Geriatric Depression Scale Summary Table

<i>Participant</i>	<i>GDS Score</i>
Bette	10
Jimmy	2
Timothy	7
Caleb	8
George	10
Philippe	10
Jacques	3
Jon	8
Violet	0
Wesley	4
Sam	7

TABLE 1: Geriatric Depression Scale Summary Table

TABLE 2: BARRIERS TO CARE SCALE (BACS) SUMMARY

TABLE

Table 2: BACS Summary Table

<i>Participant</i>	<i>BACS Score</i>
Bette	3.40*
Jimmy	3.25*
Timothy	2.08
Caleb	3.08*
George	1.75
Philippe	1.16
Jacques	1.75
Jon	2.67*
Violet	1.00
Wesley	1.92
Sam	1.75

M: 2.16 (*n* = 11)

TABLE 2: Barrier to Care Scale Summary Table

*Note: scores with asterisks indicate moderate to high level of experienced barriers to care