

RELATIONSHIPS BETWEEN INCOME LEVEL AND WORK,  
SERVICE USE, AND INFORMAL RELATIONS AMONG  
PEOPLE LIVING WITH HIV/AIDS

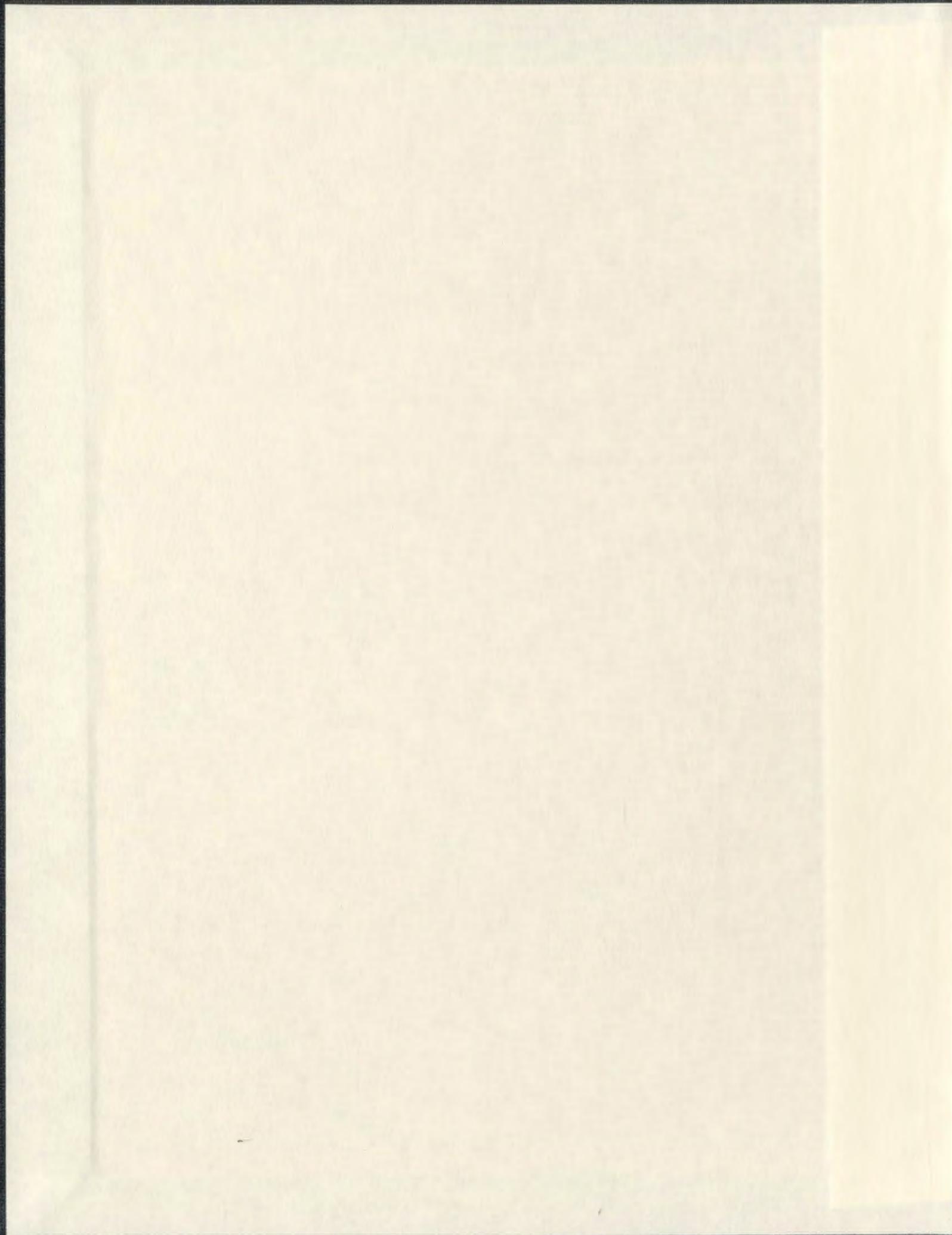
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RELATIONSHIPS BETWEEN INCOME LEVEL  
AND WORK, SERVICE USE, AND INFORMAL RELATIONS  
AMONG PEOPLE LIVING WITH HIV/AIDS

by

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## Abstract

The relationship between income and health is well established. However, we do not fully understand how various factors related to income lead to poor health. This study explores how people living with HIV/AIDS (PHAs) of various income levels experience paid and volunteer work, the use of private, government and non-profit services, and informal social relations. Through the use of semi-structured interviews, qualitative data was collected from 27 PHAs residing in the Maritime Provinces. Participants reported a number of psychosocial stressors linked to low income. This was evident in all three social domains explored. Low-income participants faced the greatest range of barriers to paid employment (e.g., lack of training and education). Those with long term low-income had fewer volunteer opportunities, likely related to not having acquired desirable skills through participation in the workforce. Participants had to rely on public income security programs that many found insufficient to their basic needs. Newly low-income participants described assertiveness and communication skills (likely acquired through paid work) that helped in obtaining maximum income assistance benefits. Participants with long term low-income may not have had opportunity to develop these skills. Low-income participants had less access to private services to help maintain their health (e.g., complementary therapies, psychosocial counselling and fitness centres). In this study, negative HIV-related interactions with family and community members were more common among low-income participants. Participants connected this to people's lack of knowledge about HIV/AIDS and discomfort or judgement regarding homosexuality. Furthermore, low-income participants did not always have the money to visit or call

family and friends, and to participate in community events. Overall, and in comparison to those with higher incomes, low-income participants experienced a greater range of stressors and had less control in addressing these stressors. This resulted in isolation and threats to self-worth; factors that are known to negatively impact upon health and well-being. For PHAs to meet their aspirations in paid or volunteer work, use of services, and informal social relations attention must be paid to oppression at individual, cultural and structural levels of society. Policy and program design must also focus on sources of stress, on factors that affect control over stressful life events, and on barriers to social engagement. Findings support the need for a population health approach to include an anti-oppressive analysis in exploring health inequities between population groups.

## Acknowledgments

I first want to thank the persons living with HIV/AIDS (PHAs) who participated in this study. I was continually impressed by their openness to share and their eagerness to discuss and try to make sense of the possible links between income and health. They shared for their own stories to be heard and also to try to make things better for others. The PHAs who made up the Research Advisory Team—John Arenburg, Troy Perrot and Jim B.—made essential contributions in the development of the project and in ensuring that the findings were presented in ways that made sense and would be helpful to the PHA community. On this same note, I want to acknowledge the financial contributions of the Canadian Strategy on HIV/AIDS, Health Canada<sup>1</sup>. I am very grateful for their support which both enabled and encouraged me to conduct the research in partnership with the PHA community. This community involvement and partnership was essential to the project's success.

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Last, but certainly not least, I want to thank my partner Bill. As in life, he accompanied me on this dissertation journey by providing steady support, timely encouragement and insightful comments. He truly demonstrated the significant impact social support can have on one's sense of well-being.

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<sup>1</sup> I also wish to point out that "the views expressed herein do not necessarily represent the official policy of Health Canada".

A modified version of Section 2.2 of this report (Population Health) was accepted for publication in the *Canadian Social Work Review*. It will appear entitled "Population Health: A Potential Approach for Progressive Social Work".

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## Chapter 1

### Introduction and Overview

An estimated 49,800 people in Canada were living with HIV/AIDS at the end of 1999 (Health Canada, 2002a) and 12,538 Canadians have died due to AIDS (Health Canada, 2002b). An estimated 4,190 Canadians became infected with HIV in 1999. This incidence rate has remained unchanged since 1996 (Health Canada, 2002a). Clearly, HIV/AIDS continues to threaten the health and well-being of many Canadians. In addition, epidemiological data suggest higher rates of HIV infection among those living in poverty than in the general population (Hankins et al., 1998; Hollander, 2000; Stockwell, Goza, & Luse, 1997). Given social work's long-standing involvement with people affected by poverty, social workers will be working with increasing numbers of low-income people living with HIV/AIDS (PHAs). Understanding the relationships between income level and health will be paramount in responding effectively to the needs of this population group.

National Population Health Surveys have shown that "Canadians with low incomes are more likely to have physical, social and mental health problems than Canadians with higher incomes" (Federal, Provincial and Territorial Advisory Committee on Population Health [FPTAC], 1999a, p. 184). Although income level and health are clearly linked, we do not fully understand how various factors associated with income lead to poor health (FPTAC, 1999a). This is also true for PHAs. Despite the significant influence of low income on health, and the higher rates of HIV infection among the poor,

our understanding of relationships involving income level in the lives of PHAs remains incomplete.

This study explored the experiences of twenty-seven PHAs of differing income levels in relation to paid and volunteer work, the use of private, government and non-profit services, and informal social relations. A qualitative research methodology, with potential to collect rich data, was well suited to this task. Participants, located through purposive sampling, resided in New Brunswick, Nova Scotia and Prince Edward Island (i.e., the Maritime Provinces) and included men and women, people of various sexual orientations, ages, income levels, and stages of illness, and new and longer-term low-income PHAs. Partnership with the PHA community was central to the design and implementation of the study. A research advisory team of PHAs provided community input on issues such as the relevance of the research question and the credibility of emerging themes. Study findings are intended to inform service delivery, health policy and community action agendas, with an ultimate goal of improving the quality of life for people living with HIV/AIDS.

Two theoretical frameworks informed the study's design and guided data analysis—Structural Social Work and Population Health. Structural social work holds that societal structures (i.e., social relations and institutions, and their supporting ideologies) have deterministic and often negative impact on people's lives (Mullaly, 1997). These structures are at the root of social problems, rather than any individual deficiencies. Population health “refers to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments,

personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services” (FPTAC, 1999a, p. 7). Put another way, many factors work at a population level to determine people’s health, and they are largely outside of individual control.

### 1.1 Living with HIV/AIDS, Income Level and Health

In reviewing the literature, I found a relatively small number of studies that compared aspects of the lives of PHAs of different income levels. These studies did suggest, however, that lower income PHAs experience more rapid disease progression and lower levels of psychological well-being than PHAs with higher income. Schechter et al. (1994), for example, found higher socio-economic status (SES) to be associated with slower disease progression independent of health care. These researchers suggested psychosocial factors as a possible explanation. Koopman et al. (2000) found that PHAs with lower income perceived the greatest stress in their daily lives. A second group of studies described the experiences of PHAs living in poverty, although no comparisons were made across different income levels (e.g., Ayala, 1996). These studies identified numerous stressors that low-income PHAs face in the areas of health care, income security and social support. A third group of studies included SES or income-related issues in a broad range of variables and underscored the importance of financial concerns in the lives of PHAs (e.g., Adam & Sears, 1996).

My recently published quantitative study (which I describe in greater detail in Chapter 3) revealed that PHAs in New Brunswick were quite satisfied with their medical care regardless of income level (Olivier, 2001). However, low-income participants were

more likely than higher-income participants to be unemployed, disabled and receiving provincial social assistance. In addition, the study found a strong link between a decline in health status and a decline in income. Low-income PHAs were also more likely to report experiencing increased distress and a number of problems, including inadequate housing, feelings of depression and helplessness, HIV-related discrimination, family tension because of HIV/AIDS, rejection by family or friends, and use of alcohol or drugs. These findings suggested that PHAs are like other Canadians, in that income level is associated with a broad range of indicators of health and well-being (FPTAC, 1999a).

National Population Health Surveys have shown that SES (using income as a proxy measure) is one of the most important determinants of health (FPTAC, 1999a). An extensive range of health factors is associated with level of income. Population Health Surveys indicate that low-income Canadians, in comparison to those with higher incomes, are more likely to report the following: fair or poor health, more frequent illness, lower levels of psychological well-being, higher rates of depression, greater activity limitations and disabilities, lower levels of social support, and higher rates of unmet health care needs (FPTAC, 1999a).

Although income as a determinant of health is well established, the means by which SES (inclusive of income) determines health status are not fully understood (FPTAC, 1999a). Some research suggests, however, increased susceptibility to poor health among those with low income is related to greater exposure to stressful life events and to people's lower coping skills and fewer resources (Kessler & Cleary, 1980). However, causation does not necessarily lie with the individual. Rather, "social class

largely determines the life experiences to which one is exposed, thus in large part shaping one's coping repertoire and determining access to social resources" (Kessler & Cleary, 1980, p. 466). In addition, factors that increase control over potential life stressors can prevent or mediate stress, in turn positively affecting health (Wilkinson, 1996). Money is one such factor.

Although my quantitative study identified numerous areas in the lives of PHAs that connect in some way to income level, an in-depth exploration of these areas was beyond the study's scope. Further investigation and comparison was needed to more fully understand the differences in lived experiences for low- versus higher-income PHAs, and how various factors associated with income might interact to support or challenge their health and well-being.

## 1.2 Research Question

The research question explored was "how do people of different income levels who are living with HIV/AIDS experience 1) paid and volunteer work; 2) private, government and non-profit services (e.g., income support, mental health counselling and complementary/alternative therapies but excluding medical care); and 3) informal social relations". The intent was to gain a comprehensive and in-depth understanding of 1) how factors related to the specified areas of social domains (e.g., challenges faced and strengths and supports used to cope with stressors) affect the health and well-being of PHAs, and of 2) differences related to income level.

This focus stemmed from my earlier quantitative study (Olivier, 2001) that had identified differences in experience of low-income versus higher-income PHAs in

relation to workforce/employment (e.g., level of unemployment), public services (e.g., reliance on income assistance, use of AIDS organizations and food banks), and informal social relations (e.g., rejection by family and friends). In addition, PHAs in the earlier study expressed high satisfaction with their medical care independent of income level. This finding provided the rationale for excluding medical services as a major focus in the proposed study. As a final check on the appropriateness of the research question and in keeping with a community-based approach to research, the relevance of the research question was reviewed with members of the PHA and AIDS communities prior to development of the full proposal.

### 1.3 Significance of Research

A Maritime Provinces study leading to greater understanding of factors that challenge or support the well-being of PHAs has significant implications for this region's PHA communities, as well as for others with an interest in the quality of life of PHAs (e.g., community-based AIDS organizations, government agencies, helping professionals). Specific to social work, a 1999 New Brunswick study found that 35% of social workers had at some time knowingly provided services to a PHA—up from 19% in 1992 (Olivier & Stanciu, 1999). This suggests that more social workers will have contact with PHAs. Study findings should help develop appropriate responses to the needs of PHAs (e.g., inform the delivery of direct services, health policy and advocacy agendas). The meaningful involvement of Maritime PHA communities—in deciding on the research focus and in data analysis—should enable these communities to gain greater control over their circumstances through critical analysis leading to social action.

Study findings, if applicable to other contexts, may prove useful to PHA stakeholders outside of the Maritime Provinces. Findings will add to the limited number of published studies of the lives of PHAs in relation to differing income levels. Others interested in the relationships between income level and health in general (e.g., population health theory) or in relation to other diseases may also find the study findings relevant. Finally, the study contributes to the social work literature concerning the impact of structural factors on people's lives.

#### 1.4 Overview of Study

This research report is organized under seven chapters: 1) Introduction and Overview, 2) Theoretical Frameworks, 3) Literature Review, 4) Research Design and Methodology, 5) Findings, 6) Discussion and Synthesis, and 7) Implications and Conclusions.

Chapter 2 reviews the two theoretical frameworks underpinning the study: Structural Social Work and Population Health. Each framework is discussed under the headings: definition and development, theory base, framework for action, limitations and opportunities, and application to the dissertation research focus. This chapter underscores the strengths of each framework, addresses inherent challenges or limitations, and makes the case for using the two frameworks in a complementary manner. Population health provided a useful framework for exploring the social domains of interest to the study in relation to their effect on health and well-being. Structural social work and related theories of oppression enabled a more critical analysis of determinants of health and well-being that emerged from the findings.

Chapter 3 reviews the literature specific to the substantive area being studied. It reviews the published literature on the experiences of living with HIV/AIDS in relation to income level and the three social domains explored. What is known about the relationships between income and health in general is also reviewed. The literature reinforces the importance of the need for knowing more about the impact of income on the lives of PHAs, and places the study in a broader context of income as a key determinant of health.

Chapter 4 details the research design and methodology under: (1) ontological and epistemological underpinnings, (2) research question, (3) methodology, (4) sampling and context, (5) data collection, (6) data analysis, (7) validation issues, (8) ethical considerations, and (9) limitations. Purposive sampling and semi-structured interviews allowed me to collect data from a diverse group of PHAs residing in the Maritime Provinces. While interviews focused on specified areas, the inherent flexibility of a qualitative design enabled me to pursue other areas that surfaced as critical to the well-being of PHAs. Once the interviews were transcribed, I coded and sorted the data into categories. I noted the relationships between categories, paying particular attention to similarities and differences between income groups. Member checks enabled participants to comment on how preliminary findings and analysis reflected their experiences.

The study's findings are presented in Chapter 5, organized under the categories: 1) paid and volunteer work, 2) private, government and non-profit services, and 3) informal social relations. In each section, I discuss the experiences of the participants as a

whole, and then point out differences for the various income groups. The broader description provides a context for reporting on differences related to income.

Chapter 6, Synthesis and Discussion, describes how participants experienced a number of stressors linked to lower income. Furthermore, inadequate income and forms of oppression limited the ability of some participants to cope with these stressors or challenges. Some participants were unable to benefit from the health-promoting aspects of paid work. Rather, they relied on income security programs that were stressful and inadequate to their basic needs. Some long-term low income participants faced difficulties in securing volunteer work. Higher income gave participants more options with respect to maintaining good health and managing illness through the use of private services (e.g., complementary therapies and psychosocial counselling). For some participants, negative interactions and inadequate income prevented desired involvement with family members and friends, leading to isolation and threats to self-esteem. All of these factors are known to impact upon health and well-being.

Chapter 7 concludes with implications. For PHAs to meet their aspirations in paid or volunteer work, use of services, and informal social relations attention must be paid to societal oppression at the individual, cultural and structural levels. Such a framework can support a comprehensive approach to addressing the root causes of people's problems. Specific areas for social work practice with people living with HIV/AIDS include a focus on sources of stress, on factors that affect control over stressful life events, and on barriers to social engagement. The findings also point to the need for a population health

approach to include an anti-oppressive analysis in exploring health inequities between population groups.

## Chapter 2

### Theoretical Frameworks

Two theoretical frameworks that underpin this study are: Structural Social Work and Population Health. In this chapter I discuss each framework under the headings: definition and development, theory base, framework for action, limitations and opportunities, and application to the research focus. I underscore the strengths of each framework, address inherent challenges or limitations, and make the case for the use of the two frameworks in a complementary manner to address the research question.

This presentation of the two frameworks makes my theoretical assumptions ‘transparent’ to the reader. A researcher always holds a set of values, beliefs and assumptions (Lincoln & Guba, 1985; Rubin & Rubin, 1995). A discussion of structural social work and population health can help the reader detect these influences in my work and to think critically about their validity and implications.

#### 2.1 Structural Social Work

##### 2.1.1 Definition and Development

Structural social work is an approach to social work that falls within the larger radical social work movement (Moreau & Leonard, 1989; Mullaly, 1997). While there is no consensus on a succinct definition of structural social work, in my view it can be best identified by its view of social problems, goals and methods of practice. Structural social work traces the causes of social problems to differential access to power and the resulting forms of oppression inherent in the prevailing social order (Moreau & Leonard, 1989;

Mullaly, 1997). The goal of structural social work, therefore, is “twofold: (1) to alleviate the negative effects on people of an exploitative and alienating social order; and (2) to transform the conditions and social structures that cause these negative effects” (Mullaly, 1997, p. 133). Alleviation of negative effects could be sought through such activities as helping clients obtain needed resources and “fostering an understanding of the client’s living/working conditions by linking these to primary structures of oppression” (Carniol, 1992, p. 7). Social transformation could be brought about through various forms of social action (Carniol, 1992; Moreau, 1979; Mullaly, 1997). This transformation would be directed towards a society reflective of socialism, with such attributes as participatory democracy, public control of the economy and an equitable distribution of wealth and opportunities (Mullaly, 1997). Strategies for working towards this twofold goal are examined in greater detail below under “framework for action”.

Structural social work was first developed in the mid-1970s by the School of Social Work at Carleton University, under the leadership of the late Maurice Moreau (Moreau, 1979; Moreau & Leonard, 1989). The social conditions that led to the development of this approach to social work date back to the 1960s with the flourishing of social and political movements aimed at addressing such issues as racial discrimination, pollution, and poverty. Reflecting these broader societal tensions, the social work profession at this time developed an increased interest in advocacy and social action (Ezell, 1994; Kutchins & Kutchins, 1978; McGowan, 1987; Mickelson, 1995; Sancier, 1984). Furthermore, social work thought and practice during this period was influenced by wider recognition that personal and social problems are not necessarily due

to people's deficiencies but rather due to the structure of society, and that welfare agencies serve a social control function (Kutchins & Kutchins, 1978; McGowan, 1987). Such were the dynamics that led the School of Social Work at Carleton University to examine its social work program and to begin a process of change that resulted in the development of structural social work (Moreau & Leonard, 1989). Before proceeding to discuss this development, I want to first point out some earlier influences. The roots of radical social work can be traced back to the progressive work of the Settlement House movement at the turn of the 20<sup>th</sup> century (Bombyk, 1995). Settlement house workers traced people's problems to societal structures and worked to bring about change in such areas as labour legislation, occupational safety, public health and women's rights (Bombyk, 1995). Continuing in this tradition, social workers (most notably Bertha Capen Reynolds in the U.S.) were active in organizing unemployed people and advancing socialism in the 1930s and 1940s (Bombyk, 1995; Mullaly, 1997). Furthermore, and as alluded to below, structural social work has been influenced by various critical social theories, including Marxism, those developed by the Frankfurt School, and more recently the work of Habermas (Mullaly, 1997). The commonality among critical theories is not only their criticism of existing social institutions and practices, but their attempts to effect change (Mullaly, 1997).

Moreau described the structural approach that developed at Carleton as having two discrete periods based on differing foundational theories (Moreau & Leonard, 1989). The first period covered 1974 to 1976 and drew from ecological systems theory and humanistic psychology. The second period, beginning in 1977 with a shift toward critical

and feminist theories, continues today. This shift was from the politically conservative and consensual view of society inherent in systems theories towards a conflict view of society more consistent with critical theories. Social problems were no longer viewed as “caused by deficits in communication between individuals and systems as both ecology and general systems theory posit. Differential access to power and conflict between systems are the problem not a lack of mutual fit, reciprocity, interdependence and balance between individuals and systems” (Moreau & Leonard, 1989, p. 23). The shift to a conflict perspective of society reflected the influence of Peter Leonard, a radical social work scholar from Britain (Moreau & Leonard, 1989). A number of radical social work publications of the time were also influential (in addition to Corrigan & Leonard’s *Social Work Practice Under Capitalism: A Marxist Approach*, 1978, were Bailey & Brake’s *Radical Social Work*, 1975, and Galper’s *The Politics of Social Services*, 1975). In 1979 Moreau published his foundational article on structural social work—*A Structural Approach to Social Work Practice*.

While structural social work has developed since the 1970s, it received less attention in the 1980s (Mullaly, 1997; Payne, 1997). Payne (1997), a British writer, attributed this decline to general neo-conservatism of this period and critical attacks within the social work profession. Others support this claim in relation to Britain, where economic recession and conservative government policies increased both workloads for social workers and their involvement in social control functions. Oppressed groups also complained that their interests were not adequately addressed within the radical social work movement (Langan & Lee, 1989). However, Payne (1997) also identified the

inequalities generated by conservative governments of the 1980s as one reason for renewed interest in radical social work in the 1990s. The number of radical and structural social work publications has increased since the early 1990s, including a large body of work from Australia. Among the structural social work publications is Bob Mullaly's *Structural Social Work: Ideology, Theory, and Practice* (1993, with a second edition in 1997), upon which much of the discussion below is based. Mullaly, a Canadian social work scholar, has a recognized leadership role in advancing structural social work.

### 2.1.2 Theory Base

As described above, structural social work is strongly influenced by socialist ideology and critical theories. Two aspects of this theory base are particularly relevant in informing structural social work practice: (1) an agency/structure dialectic; and (2) a conflict perspective on the nature of society and related views about the causes of social problems.

Structural social work theory holds that "social institutions and social relations of a particular society will be determined by the dominant ideology and, in turn, will operate in a manner consistent with and supportive of that ideology" (Mullaly, 1997, p. 134). These three structural components of society (i.e., dominant ideology, social institutions and social relations) are interdependent and mutually reinforcing. Inherent in this position is structural determinism. However, structural social work also leaves room for agency by incorporating radical humanism in addition to radical structuralism.

Radical humanism is a subjectivist orientation to social change and radical structuralism is an objectivist orientation. Each provides a different answer to the question, 'Are we creators of or created by our social reality?' Subjectivist radical humanism holds that knowledge and social reality are created in people's minds

through personal experience (Howe, 1987), and that no social facts exist because we create our own social reality. Conversely, objectivist radical structuralism holds that knowledge and social reality are external to the individual, that social reality is composed of concrete structures, and that this external social reality has a deterministic impact on an individual's development and circumstances (Burrell & Morgan, 1979; Howe, 1987). (Mullaly, 1997, p. 130)

At first glance, one might view radical humanism and radical structuralism as contradictory. However, Mullaly (1997) argues that these two perspectives do not represent a dichotomy but rather can be brought together in one coherent framework through a dialectical analysis. He concludes that "subjective reality and objective reality are irrevocably locked into a dialectical relationship. We are conscious creators of our surroundings, using thought, information, and emotion to act and to choose. At the same time, we are created by our surroundings" (Mullaly, 1997, p. 131). For radical humanism, the 'radical' aspect refers to freeing oneself from constraining social structures through changing one's subjective understandings of the social world; while the focus of radical structuralism is the recognition and transformation of actual oppressive social structures (Burrell & Morgan, 1979).

Structural social work also draws from conflict theory (e.g., Marxism) which sees "society as a continually contested struggle among groups with opposing views and interests" (Mullaly, 1997, p. 119). Consistent with this perspective, dominant groups are assumed to maintain social order through manipulation and control of subordinate groups (Ritzer, 1996). Due to their position of greater power, dominant groups can shape societal structures to serve their interests at the expense of the less powerful. Exploitative social relations can be organized around such differences as class, gender, race, age, sexual orientation and (dis)ability and a person may experience multiple forms of oppression

(Moreau & Leonard, 1989; Mullaly, 1997). For this reason, structural social work has as its ultimate goal the transformation of all forms of exploitative and alienating societal structures (Mullaly, 1997). This emphasis on conflict theory contrasts with other approaches to social work, such as general systems theory and ecological systems theory with their consensual view of society (Moreau & Leonard, 1989; Mullaly, 1997). Consensus theories (e.g., structural functionalism) maintain that society is characterized by shared norms and values, and that social order is based on agreement among social groups (Ritzer, 1996). A social work response to problems consistent with this more benevolent view of society and its structures would focus on individual adjustment and limited social reform (Mullaly, 1997).

Applying structural social work theory to the current Canadian context, Mullaly argues that individual and social problems can be traced to the societal structures of liberal/neo-conservative capitalism; and that inequality:

- (1) is a natural, inherent (i.e., structural) part of capitalism; (2) falls along lines of class, gender, race, sexual orientation, age, ability, and geographical region;
- (3) excludes these groups from opportunities, meaningful participation in society, and a satisfactory quality of life; and (4) is self-perpetuating. (1997, p. 133)

### 2.1.3 Framework for Action

A structural social work approach to practice requires the integration of its theory base in both problem assessment and intervention or action. The following are common themes found in the structural and radical social work literature and can be used to inform the analysis of problems and subsequent responses (Carniol, 1992; Fook, 1993; Healy, 1993; Moreau, 1979; Mullaly, 1997; Payne, 1997).

1. Analysis of causes of problems experienced by client groups and of barriers encountered in addressing problems:

- causes of problems traced to structural level of society, that is social institutions (e.g., schools, government, medical services) or oppressive social relations (e.g., class division, sexism, racism, ageism, heterosexism); and
- critique of dominant, underlying ideologies which determine social institutions and social relations.

2. Responses to problems experienced by client groups:

- protection of individuals against effects of oppression by more powerful groups and structures (e.g., addressing immediate needs for resources and advocacy);
- fostering client's understanding of the links between personal problems and oppression by societal structures;
- recognition of potential social control functions of responses to problems and acting to reduce worker-client power imbalances;
- fostering collective action to transform oppressive societal structures; and
- working toward goals of social transformation (i.e., removal of inequality and injustice, and replacement with structures that are more egalitarian and less exploitative).

Jan Fook (1993), an Australian social work scholar, has identified potentially radical elements of social casework or direct practice. She emphasises that assessment should identify how the inadequacies of socio-economic structures (e.g., power imbalances, ideological role restrictions and social labelling) cause personal problems. The goal of radical casework is then to assist individuals in changing their social situation through increased control (e.g., more power, decreased ideological restrictions and resistance to effects of social labelling) over the direct effects of these socio-economic structures. Suggested strategies to bring about change and increase control include social education (e.g., teaching new skills but in the context of an awareness of social factors and influences that necessitate such skills), active use of resources (i.e., teaching how to access services and resources), social empathy (i.e., empathy of feelings, experience and

perceptions of the social world), social support (e.g., in trying alternatives), developing critical awareness (e.g., through consciousness raising), empowerment, advocacy and the casework relationship (e.g., one based on equality and sharing).

Mullaly (1997) makes many of the same suggestions for carrying out social work practice with individuals and emphasizes consciousness raising through such means as critical questioning (e.g., about taken-for-granted assumptions concerning the causes of client problems), normalization (i.e., bringing attention to the fact that many others of the same social grouping share the same problem or concern) and redefining problem definitions to illuminate their structural origins. He also stresses the importance of collectivization (i.e., connecting people who share similar social challenges) not only as a means of consciousness raising, but also as a step towards collective social action. Overarching all of these social work practices is the goal of fostering client empowerment and a dialogical relationship (Mullaly, 1997). The latter refers to a relationship “wherein all participants in the dialogue are equals, each learning from the other and teaching the other” (Mullaly, 1997, p. 180). Mullaly (1997) also explains how alternative services and organizations (e.g., community-based AIDS organizations); social movements and coalition building; progressive unionism; professional associations; and electoral politics can bring about structural change—and all offer potential involvement for social workers. Carniol (1992) argues that although the average social worker may carry out many activities related to structural social work, full client empowerment and structural change cannot be attained without the fulfilment of a comprehensive set of activities.

#### 2.1.4 Limitations and Opportunities

A major criticism of structural social work is that it describes the social context in which people experience problems and in which social workers operate, but fails to provide comprehensive practice guidelines (Payne, 1997; Mullaly, 1997). Both Payne (1997) and Mullaly (1997) have pointed out, however, that the radical/structural social work literature of the 1990s has made progress in addressing this concern (e.g., Fook's 1993 book on radical casework; and Wachholz and Mullaly's 1997 article on a research model for structural social work).

In addition to developing its own applied literature, a related strength of structural social work is its willingness to be informed by other sociological and practice theories. Moreau (1979) cautioned, however, that the integration of other practice theories should not be done in a way that depoliticises clients' problems or mystifies the helping process. As an example, systems theory can be used to identify key people and organizations in an individual's life and to clarify the relationships among them, as long as a critical lens is then used to draw out causal explanations of problems (Mullaly, 1997). The use of population health in a manner consistent with structural social work, as described in the next section of this chapter, provides another example of extending structural social work's theory base by incorporating other theories. Fook (1993) has coined the term radical extension to describe the use of more conventional social work practices in a manner consistent with structural social work. This eclectic use of theory provides much opportunity to utilize and tap into theoretical frameworks that do not fall exclusively in the domain of structural social work. The integration of other practice theories also

addresses the limitation of structural social work theory that it “provides only a partial explanation for the behaviour and events which are met by social workers” (Payne, 1997, p. 234). Furthermore, structural social work’s twofold goal of helping individual clients and of working towards the transformation of societal structures suggests the potential for using practice methods associated with all levels of social work practice (i.e., from working with individual clients to macro levels of work).

I have found Mullaly’s work quite useful in my own social work practice by providing a framework for both micro and macro levels of practice, and for integrating the two. Lacking in the literature, however, are research reports and evaluations of actual structural social work practice. In many respects, the impact of structural social work has yet to be documented. Perhaps this limitation is not surprising given the relatively newness of this approach to social work; competition for space in the literature from more conventional views of social work; and the larger social arena in which structural social workers may be one group among many engaged in effecting social change.

#### 2.1.5 Application to Research Focus

Several aspects of structural social work theory and practice are particularly relevant to this research study: causal explanations of individual and social problems; the inclusion of various forms of oppression; and the agency/structure dialectic.

This study focuses on how people living with HIV/AIDS (PHAs) of various income levels experience: informal social relations; paid and volunteer work; and private, government and non-profit services. The exploration of these three social domains uncovered social relations and institutions, and their underlying ideologies that supported

the health and well-being of PHAs, and others that were harmful. The analysis of the research findings required an understanding of the dynamics of oppression. And consistent with a strength of structural social work—its willingness to be informed by other theories—I was able to locate literature that offered such an understanding. Three perspectives on oppression (brought to my attention in Mullaly, 2002) were particularly valuable to this study since they offered an understanding of: the various forms of oppression participants encountered; the intersecting and interacting of sources of oppression experienced by participants; and the locations where oppression occurs and where interventions can be directed.

Iris Young (1990) has identified five categories or forms of oppression (exploitation, marginalization, powerlessness, cultural imperialism and violence). By categorizing oppression in this way (rather than by a group attribute or characteristic such as class, race or gender), Young (1990) accommodates “the similarities and overlaps in the oppressions of different groups” and avoids falsely representing “the situation of all group members as the same” (p. 64). She argues that any of these five conditions is sufficient for identifying a group as oppressed, and that combinations of these forms may vary by group and by individual.

Exploitation occurs when the energies of subordinate groups are systematically transferred to the dominant group to maintain and augment the latter’s power, status and wealth (Young, 1990). Private ownership of the means of production and the capitalist labour market enable the systematic transfer of the powers of the working class to capitalists. Profit is derived from the difference between the value of the labour

performed (e.g., goods produced) and the lower price paid for the purchased labour. However, the loss to the worker can be greater than the difference between the true value of the labour and its purchased price. Young (1990) argues that “the powers of workers diminish by more than the amount of transfer, because workers suffer material deprivation and a loss of control, and hence are deprived of important elements of self-respect” (p. 49).

Young (1990) defines ‘marginals’ as “people the system of labor cannot or will not use” (p. 53) (e.g., old people, involuntarily unemployed, people with disabilities). She suggests that “marginalization is perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation” (Young, 1990, p. 53). Young acknowledges that the resulting material deprivation can be partially addressed through public income security programs. However, she explains that material deprivation is not the only harm caused by marginalization. First, needing to rely on income security may expose people to “patronizing, punitive, demeaning, and arbitrary treatment by the policies and people associated with welfare bureaucracies” (Young, 1990, p. 54). Secondly, marginalization “blocks the opportunity to exercise capacities in socially defined and recognized ways” (Young, 1990, p. 54). Young argues that even if marginalized people’s material needs were met, “injustices of marginality would remain in the form of uselessness, boredom, and lack of self-respect” (p. 55). Here Young is referring to exclusion from the labour market, but one could extend the concept of

marginalization to include other forms of social participation such as volunteer work and recreation activities.

Powerlessness is the final form of oppression that Young (1990) links directly to the social division of labour. She contends that people may have some level of power in relation to their work as measured by: degree of work autonomy; opportunities to develop and exercise skills; opportunities to exercise creativity and judgement; and the respect their work commands. In these aspects, non-professional workers tend to have less power than professionals and therefore suffer powerlessness. The more powerful status that professionals possess is derived from: required education and specialized knowledge; opportunity for professional advancement; day-to-day work autonomy and authority over others; and privileges that extend beyond the workplace. Young calls this latter aspect “respectability”. She argues that “the norms of respectability in our society are associated specifically with professional culture” (Young, 1990, p. 57). Professionals are more apt to expect and receive respect from others in all areas of life (e.g., from service providers). Non-professionals, on the other hand, are more vulnerable to disrespect.

Cultural imperialism “involves the universalization of a dominant group’s experience and culture and its establishment as the norm” (Young, 1990, p. 59). Young (1990) explains that “to experience 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 out as the Other” (pp. 58-59). The dominant culture, through various institutions (e.g., media, schools, churches), presents a worldview that includes prevailing views of oppressed groups. This

view characterizes many of these groups as deviant and inferior. These perceptions are held by members of society, shape institutions and become reinforced. Furthermore, “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). “When one’s personal identity matches the negative portrait or social identity provided by the social world, then we have a case of internalized oppression” (Mullaly, 2002, p. 59). However, as reflected in the concept of radical humanism, cultural imperialism is not absolute and people are able to resist negative social messages through formulating their own understandings of the social world.

Finally, Young (1990) points out that many oppressed groups suffer systematic violence. She argues that violence is a form of oppression when it is directed at a member of a group simply because of their group membership. She includes as violence “random, unprovoked attacks on their persons or property, which have no motive but to damage, humiliate, or destroy the person” as well as “less severe incidents of harassment, intimidation, or ridicule simply for the purpose of degrading, humiliating, or stigmatizing group members” (p. 61). Regardless of the actual experience of violence, “just living under such a threat of attack on oneself or family or friends deprives the oppressed of freedom and dignity, and needlessly expends their energy” (Young, 1990, p. 62).

I found Young’s (1990) approach to categorizing and understanding oppression useful in this study since participants described experience consistent with one or more forms of oppression. In addition, three of Young’s categories arise from the social

division of labour (i.e., exploitation, marginalization and powerlessness) while the remaining two categories (cultural imperialism and violence) are more broadly evident in society. Together the five categories lend themselves well to understanding the range of oppression participants experienced in the three social domains explored.

Although Young's conceptual framework accounts for forms of oppression, regardless of their source, participants' experiences of oppression can be more fully understood when linked to their respective bases of oppression (e.g., classism, sexism, heterosexism). For this purpose, Steven Wineman's (1984) model of intersecting and interacting sources of oppression proved helpful. Wineman uses the term 'forms of oppression' to refer to the group division upon which the oppression is based (e.g., class, sex, sexual orientation). However, like Young, he avoids representing the experiences of all groups as the same. Wineman argues for a "holistic analysis" of oppressions, with recognition that:

The different forms of oppression are distinct, each with its own unique sources and each affecting a particular oppressed group in a unique way—but they are not unrelated. Different oppressions intersect at innumerable points in everyday life and are mutually reinforcing, creating a total system of oppression in which one continuum of stratification cannot be addressed in isolation from all the others. Different forms of oppression are mutually reinforcing partly because they all embody an ethos of domination and subordination; partly because the experience of either superiority or inferiority on any one continuum of oppression can induce people to seek or maintain positions of superiority on other continua of oppression. Because of the intertwining of oppressions, oppressed groups overlap. Despite the existence of distinct categories of oppression, and despite the fact that many people have good reason to relate more deeply to one form of oppression than others, there is no kind of oppression that creates a distinct group which is unaffected, one way or another, by other forms of oppression. Many people, individually and in groups, are multiply oppressed; and almost everyone who is oppressed also has access to some form of superiority or domination.

(1984, pp. 169-170).

There are three key aspects to this holistic analysis of oppressions. First, people can experience multiple forms of oppression. Using this study as an example, some participants experienced discrimination and oppression related to their low socio-economic status, their sexual orientation and their living with HIV/AIDS. The second key aspect is the gradation of oppression (or advantage and privilege) that each person experiences depending on their location on a continuum. Wineman (1984) contends that “each person occupies some position on every continuum of oppression” (p. 168). This in part explains the third key aspect, that oppressions intersect and interact, affecting a person’s life in numerous ways. For example, a person’s advantage related to one form of oppression (e.g., a higher class status) may offset the negative consequences of an inferior status in another area of oppression (e.g., racism). Low status in relation to more than one form of oppression, however, may exacerbate the negative consequences for an individual. “Different forms of oppression intersect at many different points and in innumerable combinations, creating both multiple oppressions and mixtures of oppressor and oppressed status in various individual lives” (Wineman, 1984, p. 169).

The final perspective on oppression that I have drawn from to inform this study’s analysis concerns the locations of oppression. Neil Thompson (1998) and Mullaly (2002) argue that the picture of oppression is incomplete if one focuses solely on the dynamics of oppression at the personal or individual level. Rather, to understand “discrimination and the oppression that arises from it, it is important to recognize that it operates at three separate but interrelated levels: personal, cultural and structural” (Thompson, 1998, p. 12). The personal level is located within the other two levels, and the cultural level is

located within the structural context (Thompson, 1998; Mullaly, 2002). Furthermore, the three levels of oppression “are in dynamic interaction with one another, with each level supporting, reinforcing, and influencing oppression on the other two levels and, in turn, being supported, reinforced, and influenced by the other two levels” (Mullaly, 2002, p. 48). Locating oppression at the individual, cultural and structural levels of society also points to corresponding locations for anti-oppressive social work practice (Thompson, 1998; Mullaly, 2002).

Oppression at the personal level “comprises those thoughts, attitudes, and behaviours that depict a negative pre-judgement of a particular subordinate social group” (Mullaly, 2002, p. 49). Discriminatory social exchanges at the individual level, as well as people’s responses to such behaviour, were particularly relevant to understanding participants’ experiences. As alluded to above, thoughts, feelings and actions are significantly influenced by the cultural and structural levels of society. Thompson (1998) and Mullaly (2002) point out, however, that this influence does not preclude personal ‘agency’ impacting upon the cultural and structural levels.

“Oppression at the cultural level consists of those values, norms, and shared patterns of seeing, thinking, and acting, along with an assumed consensus about what is right and normal, that, taken together, endorse the belief in a superior culture” (Mullaly, 2002, p. 49). The earlier discussion of cultural imperialism (Young, 1990) illustrates how the dominant group imposes its culture as the norm and also promotes views of oppressed groups as deviant and inferior. Oppression “at the structural level refers to the means by which oppression is institutionalized in society. It consists of the ways that social

institutions, laws, policies, social processes and practices, the economic and political systems all work together primarily in favour of the dominant group at the expense of subordinate groups” (Mullaly, 2002, p. 49). The cultural and structural levels of oppression are closely linked. Cultural aspects of oppression are reflected in societal structures; the structural level of oppression, in turn, shapes prevailing culture (Thompson, 1998).

While the above discussion recognizes that cultural and structural levels of oppression have deterministic and negative impacts on people’s lives, there is also room for agency in the form of individual interpretation. This is consistent with the radical humanist aspect of structural social work’s subjective/objective dialectic (Mullaly, 1997). This concept of agency fits well with conducting member checks to ensure that participants see their perspectives reflected in the findings. Furthermore, radical structuralism is congruent with the principles of community-based research adopted in this research project, which call for community member involvement in all stages of the research process (Health Canada, n.d.). In this study a research advisory team of PHAs provided input in key areas such as the relevance of the research focus, data analysis and the final report. The team saw the research as a means of bringing about change and in effect, changing oppressive structures. An ultimate goal of the research was to foster empowerment, that is, for PHAs to gain greater control over their lives and social environment (Mullaly, 1997) through critical analysis leading to action.

## 2.2 Population Health

The presentation of population health outlines how it has been developed and applied in Canada. It relies on the work of the Federal, Provincial and Territorial Advisory Committee on Population Health (FPTAC) as an example of the application of a population health approach to policy and programming. In addition, only a limited number of review articles could be found to inform the discussion of limitations and opportunities.

### 2.2.1 Definition and Development

The definition of Population Health, as developed by the FPTAC, reads:

Population health refers to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services.

As an approach, population health focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systemic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well-being of those populations. (FPTAC, 1999a, p. 7)

Population health was first adopted as a policy approach by Federal, Provincial and Territorial Ministers of Health in 1994 with the publication of *Strategies for Population Health: Investing in the Health of Canadians*. However, the roots are much older. The Lalonde Report of 1974 (*A New Perspective on the Health of Canadians*) laid the groundwork for a population health approach by “establishing a framework for the key factors that seemed to determine health status: lifestyle, environment, human biology and health services” (FPTAC, 1994, p. 11). Of the four factors identified, however, initially lifestyle received the most attention (Hamilton & Bhatti, 1996; Marmor, Barer,

& Evans, 1994; Townson, 1999). In the 1970s a number of government and non-government programs promoted healthy lifestyles through the reduction of health-risk behaviours. Strategies included “the delivery of health education programs and public awareness campaigns combined with legislative changes to further discourage the identified risk behaviours” (Hamilton & Bhatti, 1996, p. 1). This approach is still prevalent today as exemplified by anti-smoking campaigns and legislation to curb smoking in public places.

During the 1980s, health policy discussion began to attend to other factors that determine health (Hamilton & Bhatti, 1996). For example, the World Health Organization introduced a broad definition of health which conceptualized health as “a complete state of physical, mental, social and emotional well-being” (FPTAC, 1999a, p. 3). *The Ottawa Charter on Health Promotion*, released at a World Health Organization Conference hosted by Canada, became a key document in informing population health (FPTAC, 1999a; Hamilton & Bhatti, 1996). The charter identified a broad range of prerequisites for health: peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity (World Health Organization, 1986). Attaining these prerequisites would require coordinated action “among all concerned, including governments (health and other social and economic sectors), non-government organizations, industry and the media” (Hamilton & Bhatti, 1996, p. 2). The charter called for action in five areas: building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services (World Health Organization, 1986).

While the *Ottawa Charter* was internationally influential (Hamilton & Bhatti, 1996; Trussler & Marchand, 1997), there were challenges to its implementation. Undoubtedly the charter surfaced differences (e.g., ideological and methodological) among health policy analysts and officials on how best to address the prerequisites for health. Hamilton and Bhatti (1996) suggest one barrier to sustained support for multi-sectoral action on the range of prerequisites was the need “to show how action directed at the underlying prerequisites or determinants can affect health” (p. 3). The Canadian Institute for Advanced Research (CIAR) began to address this gap through its Population Health Program (Frank, 1995; Hamilton & Bhatti, 1996).

Founded in the mid 1980s, the CIAR Population Health Program includes an interdisciplinary team of economists, health policy analysts, epidemiologists and social scientists (Frank, 1995). Information on key factors that determine health status was compiled and synthesized to develop a conceptual framework for thinking about why some groups of people are healthier than others (Frank, 1995). This research provided much of the empirical and theoretical foundation for current approaches to population health.

Since 1994, federal, provincial and territorial governments have followed a population health approach in two major reports on the health of Canadians (FPTAC, 1996; FPTAC, 1999a). Although these reports imply government support for a population health approach, policy analysts have observed little progress in tackling critical determinants of health such as income inequality (Townson, 1999). Furthermore, intergovernmental collaboration is complicated by provincial jurisdiction for health and

by provincial/federal disagreement over federal contributions and control in health matters. Health Canada's AIDS Community Action Program, exclusively funded by the federal government, however, provides an example of how population health is reflected in federal health policy. This program, which funds community-based AIDS organizations, requires the integration of population health principles within their work (i.e., community groups need to show how they will address key determinants of health).

### 2.2.2 Theory Base

The overarching goal of population health research is "to identify the group characteristics associated with good and bad health, in the hope of finding and then influencing the underlying causal factors" (Evans, Barer, & Marmor, 1994, p.4). A starting point in population health theory is the concept of heterogeneity. Heterogeneities refer to "differences in aggregate measures of health status between or among population groups, which appear to be consistently associated with some defining characteristics of those groups" (Hertzman, Frank, & Evans, 1994, pp. 67-68). As examples, "large gradients in life expectancy by income level, educational attainment, and social class have been repeatedly discovered in various parts of the developed world during the twentieth century" (Hertzman, Frank, & Evans, 1994, p. 67). Other characteristics used to subdivide a population (also associated with differing aggregate health measures) include sex, geography, and ethnicity/migration (Hertzman, Frank, & Evans, 1994). The detection of heterogeneities suggests that some factor or combination of factors is affecting the health of a population group as a whole. Therefore, heterogeneities serve as

entry points to studying the fundamental determinants of population health status (Hertzman, Frank, & Evans, 1994).

The identification of determinants of health associated with heterogeneities brings us closer to uncovering underlying causal factors of health status. Broadly defined, determinants of health can be viewed as factors that influence the health status of a population, either positively or negatively. The CIAR research pointed to key factors that determine population health, including physical and social environments, one's biological endowment, individual behavioural and immunological responses, individual and national productivity and wealth, and health care (Mustard & Frank, 1991).

Evans and Stoddart (1994) caution, however, that each category of determinants is inherently complex; "moreover, in specific contexts it may be the interactions between factors from different categories of determinants, and their timing, that are critical to the health of individuals and populations" (p. 32). They conclude that "the biological vulnerability or resilience of the individual, in response to external shocks, is dependent on the social and physical environment in interaction with the genetic endowment" (p. 52). This complexity is illustrated through National Population Health Surveys, which show that Canadians with low socio-economic status are more likely to report lower levels of psychological well-being, lower levels of social support, and higher rates of unmet health care needs (FPTAC, 1999a). All of these factors are in turn associated with poorer health outcomes (FPTAC, 1994; Mustard & Frank, 1991).

Researchers with the CIAR Population Health Program are also interested in uncovering the biological pathways that lead to poor health and through which causal

factors operate (Evans, 1994). Notably, these researchers define health in narrow terms, “as the absence of illness or injury, of distressing symptoms or impaired capacity” (Evans & Stoddart, 1994, p. 47). They also rely on morbidity and life expectancy statistics as measures of population health. Viewing health as the absence of physical illness and impairment, they argue that at some point biological processes must come into play with whatever factors are contributing to a population’s poor health (Evans, 1994). While some biological pathways to poor health are well-established (e.g., malnutrition, inadequate housing), the Population Health Program researchers acknowledge that they have only a beginning understanding of other pathways associated with social environment (Evans, Hodge, & Pless, 1994). By piecing together findings from a number of different disciplines, however, they conclude that external stresses, combined with inadequate resources to successfully respond to such stressors, evoke a cellular level response involving several physiological systems, including immune, endocrine and nervous system responses (Evans, Hodge, & Pless, 1994).

### 2.2.3 Framework for Action

To put population health theory into practice, the Federal, Provincial and Territorial Advisory Committee on Population Health published *Strategies for Population Health: Investing in the Health of Canadians* (1994). This document continues to inform population health strategies and health policy. *Strategies for Population Health* identified nine key determinants of health:

- income and social status;
- social support networks;
- education;
- employment and working conditions;

- physical environments;
- biology and genetic endowment;
- personal health practices and coping skills;
- healthy child development; and
- health services.

Since the publication of *Strategies for Population Health*, Health Canada has added gender, culture and social environments to the list of health determinants.

The authors of the report concluded that effective strategies to improve the health of Canadians “must address the broad range of health determinants in a comprehensive and interrelated way” (FPTAC, 1994, p. 28). They also advocated for continued research, sound evidence on factors that determine health, and supportive public policy in advancing a population health framework (FPTAC, 1994). Moving from policy to action, they stressed the importance of intersectoral collaboration. Since most of the determinants of health fall outside the auspices of health departments, a wide range of sectors need to be involved (e.g., economic, education, environmental, employment and social services sectors). The authors also argued for action across government, non-profit and private sectors, as well as at federal, provincial/territorial and local levels. In addition, they recognized the need to foster a greater understanding of the determinants of health and support for a population health approach among the general public and within sectors outside of traditional health fields.

The *Strategies for Population Health* document outlined requirements and implications of adopting a population health approach. These include less preoccupation with health care services and “a more balanced emphasis on and investment in all of the determinants of health” (FPTAC, 1994, p. 33). The implications underscored the need to

find effective responses to complex problems such as unemployment, environmental pollution, and social stress. In addition, responses require consensus for collaborative action among a diverse range of sectors. Long term commitment will be needed since most of the benefits of a population health approach will be realized in the mid to long term.

#### 2.2.4 Limitations and Opportunities

Population health presents both limitations and opportunities as a theoretical approach to understanding factors that affect the health of population groups, and for application congruent with structural social work. Four areas present particular challenges and opportunities. The first three relate to population health's theory base and the fourth to its application.

The first limitation is that the overarching sociological theory base of population health is ill defined and undeveloped. In addition, much of the population health literature implies a consensus view of society. This raises concerns about its congruence with structural social work. As already discussed, structural social work is based on conflict theory, with the recognition of dominant social groups maintaining social order through manipulation and control of subordinate groups. Consensus theories, on the other hand, hold that society is characterized by shared norms and values, and that social order is based on agreement among social groups (Ritzer, 1996).

Evidence for population health's congruence with consensus theory includes taking action on the many determinants of health through the collaborative efforts of a broad range of sectors, with little thought given to power imbalance between social

groups. For example, the FPTAC (1994), in its framework for action, argues for the involvement of “all key partners right from the start, to ensure that common priorities are being addressed and all key partners are on board” (p. 34). Inherent in this position is the assumption of shared norms and values among the various sectors. But tackling a determinant of health through a redistribution of wealth or power for example, would likely be resisted by those with more power who benefit from the current distribution.

Poland, Coburn, Robertson and Eakin (1998) are critical of population health (at least of the earlier approach advanced by the CIAR) for lacking an explicit theory of society and social change. Although early population health literature emphasized wealth as an important determinant of health, it was often done without analysis of the processes and structures that contribute to poverty and inequality. This approach, while appearing to be objective through the use of empiricist quantitative epidemiology, failed to situate itself in sociological theory, and in effect aligned itself with the dominant social order.

The use of scientific terminology provides another example of how societal inequalities, and the structures that support such inequity, are unexplored in population health theory. Hertzman, Frank, and Evans (1994) suggest that the term heterogeneity is more appropriate than inequalities or inequities in describing differences in health status among population groups since it is less value-laden and captures factors that are less dependent on societal influences (e.g., genetic diversity). But it is exactly these value-laden societal factors related to sex, race and social class that put segments of the population at greater risk of poor health. An aim of structural social work is to bring attention to these social divisions and oppressions. The use of the term heterogeneity,

couched in positivist science and neutrality, effectively masks social phenomena such as sexism, racism and class division.

Although the population health literature contains congruencies with consensus theory and the posturing of science as a neutral endeavour—two inherently conservative positions—it also has more progressive elements. One is the recognition of key factors or determinants of health external to the individual and over which the individual has little control. Furthermore, income and social status are considered among the most important determinants of health, calling attention to the more equitable distribution of wealth as a means of improving the health of a population (FPTAC, 1994). Reducing income inequality is prominent in population health approaches advocated by the FPTAC (1999a), the World Health Organization (Wilkinson & Marmot, 1998), and various non-profit research institutes (e.g., the Canadian Council on Social Development, 2001). Addressing poverty through reducing income inequality is certainly congruent with structural social work.

Social exclusion, a determinant of health that is beginning to gain prominence in Canadian social and health policy discourse, also has implications for a progressive policy agenda. This determinant recognizes that people's exclusion from various social dimensions (e.g., cultural, economic, political) leads to poor health. What is appealing about this concept is that it draws attention to the underlying reasons for exclusion (e.g., racism, sexism, classism) and points to solutions that promote inclusion (Canadian Council on Social Development, 2001; Guildford, 2000; Shookner, 2002). As such, social exclusion goes further than most population health positions in analyzing processes and

structures that maintain social and economic inequality. Social exclusion is a concept congruent with structural social work, which holds that structures (i.e., social relations, institutions and their underlying ideologies) are at the root of most of the problems people face (Mullaly, 1997).

Population health theory also recognizes that personal health practices such as smoking are largely determined by social and economic context rather than 'free choice', suggesting that efforts be directed at changing the context (Hertzman, Frank, & Evans, 1994; Marmor, Barer, & Evans, 1994). A related position in population health literature is that social, economic and physical environments influence an individual's ability to respond to stressors and to engage in health-promoting behaviours (FPTAC, 1994). However, as with earlier health promotion efforts focused on lifestyle choices, population health should not be used to justify a narrow focus on personal health practices blaming the individual for certain behaviours.

A second limitation of population health theory is its narrow definition of health. Population health theory (at least earlier writings) defines health as the absence of illness or injury, arguing that a broader definition of health (e.g., one that includes social well-being) would be too difficult to measure and would end up encompassing all human activity (and public policy) (Evans & Stoddart, 1994). Some critics have argued that the narrower definition neglects important issues relating to quality of life (Ryan & Chervin, 2001; Trussler & Marchand, 1997). The narrow definition of health, however, could be expanded. Differences in health status among population groups, where health is more broadly operationalized, could still be explored using a population health approach. There

is evidence of this shift in the literature. The most recent Canadian population health report (FPTAC, 1999a), for example, examined psychological well-being (i.e., self-esteem, sense of control over life chances, and sense that life is meaningful, events are comprehensible and challenges are manageable) as part of health and found a positive correlation between this health indicator and income level. Psychological well-being can be viewed as an endpoint health measure, without need to pursue how this factor, through a biological pathway, could lead to physiological illness or impairment.

Population health's focus on large population groups is the third limitation that relates to its theory base. This focus has led to a concern that smaller groups found within populations may be overlooked (Wong, 1997). For example, the authors of a report that examined gay men's health within a population health discourse pointed out that the last Canadian population health report (FPTAC, 1999a) made "just one fleeting reference to gay men and lesbians (not specifically as populations nor as population groups, but rather within a discussion of 'groups at high risk of suicide')" (Ryan & Chervin, 2001, p. 44). These authors ask if gay men were not taken into account because their smaller numbers do not warrant them being considered as a population, because of homophobia or heterosexism, or because gay men are not seen as a disadvantaged group with respect to health or life conditions (Ryan & Chervin, 2001). As a further example of exclusion, the FPTAC (1994) point out that health services designed to treat people who are already ill are "not really part of the population health approach, because they focus essentially on individual disease and clinical risk factors" (p. 25). This has serious implications for

people living with chronic illness, such as those living with HIV/AIDS, who attempt to use a population health approach to address the full range of their needs.

Clearly if population health is to become an overarching policy approach that does not exclude some members of a population, the needs of smaller and marginalized groups must be addressed. While smaller groups may gain from initiatives aimed at addressing key determinants of health on a large scale (e.g., redistribution of income through progressive social policy), their unique needs will not be addressed through this means alone. As an example, the extent of stigma towards people living with HIV/AIDS is likely a key determinant of health for this population group. Without the collective action of this group, this stigma and associated injustices would not have been reduced. This example also illustrates the importance of population group involvement in identifying their health needs and in formulating responses. Otherwise there is risk of their needs and input being lost in a top-down, macro-focus approach to health policy (Lippman, 1998; Poland et al. 1998). Vigilance will be required of small and marginalized groups, along with their allies, to ensure they are recognized in a population health approach. Once inclusion is established, population health can be used to identify and plan action aimed at addressing the health needs of these groups.

The fourth area that presents both limitations and opportunities relates to the application of population health theory. Trussler and Marchand (1997) have argued that population health's emphasis on multisectoral, macro-level intervention overshadows more local, community-development approaches to health issues. They conclude that population health "offers little for actual field practice, emphasizing instead large-scale

social and economic policy” (p. 19). Furthermore, bringing about macro-level change through the coordinated efforts of a broad range of sectors often presents with insurmountable challenges (Health Canada, 2002c). As with structural social work, however, these concerns may lessen as practice experience and subsequent evaluation evolve. The FPTAC report *Strategies for Population Health* (1994), for example, outlines numerous micro- and macro-level interventions.

Poland et al. (1998) argue that the lack of an explicit theory base makes population health’s application vulnerable to a conservative agenda. For example, proponents of deficit reduction could argue for lower taxes and reduced social spending as a means of producing greater wealth, with this supposedly leading to “trickle-down” wealth (and “trickle down” health). As another example, in the months leading to the ratification of the Kyoto Accord (on the reduction of green house gases), opponents argued that decreased wealth resulting from a slow down in the oil economy would threaten the health of Albertans. A further concern is expanding health policy responses to include sectors beyond health care could provide ideological justification for cost-cutting health services (Leonard, 1998; Ryan & Chervin, 2001). Cutting health care has serious implications for persons who due to illness or impairment rely on services to maintain their health and quality of life.

Despite its limitations in theory and application, a population health approach offers opportunities for social policy and programs potentially congruent with structural social work. By understanding and attending to the many factors that affect people’s health, population health both justifies and provides an approach to addressing a broad

range of social, economic and environmental issues. For example, reducing income disparities is now central to a population health approach. Addressing oppression and discrimination also fits within this health policy approach since both can be viewed as threats to social support—also an important determinant of health. These are critical issues to structural social work.

The recognition of how social, economic and physical environments interrelate to affect health is further reflected in a framework that calls for intersectoral action across government, non-profit and private sectors, as well as at various levels of society. While recognizing that consensus is not always attainable (or even desirable if it results in the continued oppression of population groups), greater opportunity for partnership, collaboration and collectivization does lend itself to garnering support for transformation of harmful social relations, institutions and underlying ideologies. Recognizing that interventions can be applied at various levels, also implies that population health theory can be integrated into social work practice at any level. As one example, social workers in direct practice can raise client awareness about external factors that affect health and well-being. This awareness in itself can be liberating, but can also support collectivization and social action aimed at changing social structures at a macro level.

#### 2.2.5 Application to Research Focus

The above discussion on limitations and opportunities points to how population health was applied in this study. The elements of theory that provide opportunity for radical extension, the expansion of the narrow definition of health, being vigilant that

smaller groups are not excluded and taking action on a range of health determinants all informed the research question, data analysis, and implications.

In this study, income level was used as the characteristic upon which participants were subdivided. And consistent with population health theory and research on income as a determinant of health, income level was found to be a factor in how participants experienced aspects of the three social domains explored. Furthermore, the three social domains overlap with other established determinants of health—social support networks, employment and working conditions, and health services.

Situating the study within a population health framework should also increase its applicability to population health theory and research. Population health already recognizes the strength of qualitative research in contributing both depth and detail to our understanding of human experience in complementarity to quantitative studies (Mustard & Frank, 1991). Corin (1994) explains how a population health research strategy can move between quantitative surveys and in-depth qualitative studies. “Fragments of life stories” and other forms of qualitative data can contribute meaning to quantitative data. Going the other way, qualitative data can suggest hypotheses to be tested in quantitative research.

Population health was a useful framework for exploring the areas of social domains of interest in this study. Structural social work and theories on oppression enabled a more critical analysis of the determinants of health. Socio-economic factors that determine the health and well-being of population groups can be reframed as forms and sources of oppression. Ultimately, the more knowledge we have about factors

associated with income and health, the better we will be able to intervene at individual, cultural, and structural levels of oppression.

## Chapter 3

### Literature Review

This chapter presents a literature review specific to the two substantive areas being studied: the experiences of living with HIV/AIDS and the relationships between income and health. The purpose for the literature review is to gain a detailed understanding of the published literature on the experiences of living with HIV/AIDS in relation to income level and to the three social domains explored (i.e., paid and volunteer work; private, government and non-profit services; and informal social relations). Secondly, the literature review provides a more general overview of what is known about the relationships between income and health, with a particular focus on how these relationships play out in the three social domains of interest.

#### 3.1 The Experiences of Living with HIV/AIDS

As discussed in Chapter 1, findings from a quantitative study (Olivier, 2001) helped identify the areas of social domains explored in the study. The identified areas provided a focus for the review of published literature on the experiences of PHAs. This review drew from: 1) research that made comparisons between PHAs of differing income levels; 2) literature on the experiences of PHAs who are living in poverty; and 3) studies that focused on the experiences of PHAs in general, including factors other than income (e.g., social support). I first review the studies that made comparisons between income groups and then discuss the literature under headings corresponding to the three areas of social domains explored in the study.

### 3.1.1 Comparisons of PHAs of Different Income Levels

I found eleven published studies that compared aspects of the lives of PHAs of differing income levels. Five of the studies dealt with physical health outcomes, while six examined psychosocial issues. The main focus of the studies on physical health was the association between socio-economic status (SES) and disease progression. Schechter et al. (1994), for example, found higher SES (measured by income, education and occupation) to be associated with slower disease progression among HIV positive gay men living in Vancouver. The researchers concluded that this relationship was independent of access to health care since study participants received a standardized approach to disease management by a select group of family physicians. Furthermore, they did not attribute the finding to disease advancement causing a downward SES drift because the SES differences were present early in the course of the disease. The researchers suggested psychosocial factors (e.g., social support) and nutrition as possible explanations for the finding. In a related Vancouver study, Hogg et al. (1994) found that lower SES (measured by income) resulted in shorter survival following HIV infection as compared to those with higher SES. Similar to the previous study, these researchers did not attribute their finding to income loss as a result of more rapid disease progression nor to a differential access to health care. In a more recent Italian study, Rapiti et al. (2000) found that people living in lower SES neighbourhoods had a shorter survival time after an AIDS diagnosis than those living in higher SES areas. The researchers speculated that the difference may be due to inequalities in health care or poor adherence to treatment. Although the above studies demonstrate a link between disease progression and SES, a

San Francisco study on survival with AIDS found no association between SES and length of survival time (Katz, Hsu, Lingo, Woelffer, & Schwarcz, 1998). These researchers suggested that the lack of association may be partly due to study participants having similar levels of access to care. They noted that San Francisco has an extensive range of services for poor people living with HIV/AIDS. In the fifth study on physical health and income, Daneault and Labadie (1999) found that PHAs living in extreme poverty in Montreal were more likely to complain of uncontrolled pain at time of death and were also more likely to die in hospital than persons with higher income. They speculated that health care professionals' inability to empathize and communicate with low-income patients interferes with pain management.

All of the six studies that examined income level and psychosocial issues found relationships that favoured PHAs with higher income. For example, Friedland, Renwick and McColl (1996) in a study of male PHAs living in Toronto found income to be positively related to quality of life. Quality of life was in part measured by access to material goods. A study of PHAs living in three U.S. states also found an association between higher income and better quality of life (Swindells et al., 1999). Richardson et al. (2001) in a nation-wide U.S. study found that HIV positive women with lower SES (measured by income and education) were more likely to suffer depressive symptoms than HIV positive women with higher SES. A fourth study, carried out with PHAs living in California, found that those with lower income perceived the greatest stress in their daily lives (Koopman et al., 2000). Several studies suggested reasons why PHAs with lower SES or income may experience lower levels of psychological well-being. For

example, Montoya, Trevino and Kreitz (1999) found that white low income PHAs living in Houston, Texas had more problems accessing housing, support groups and medical care than non-poor white PHAs. Further, African American low income PHAs had greater difficulty obtaining food assistance than non-poor African American PHAs. Similarly, an Australian study (Ezzy, De Visser, Grubb, & McConachy, 1998) found that lower income PHAs were more likely than those with higher income to go without health services, social and recreational activities, and basics such as food and transportation. Finally, Swindells et al. (1999) found that higher income PHAs made greater use of problem-focused coping (which was viewed as an effective coping style).

The above studies provide a beginning understanding of how people of differing income levels experience living with HIV/AIDS. However, there are many areas important to health and well-being that have not been explored, such as social support and employment. Furthermore, much of what has been published has limited transferability to the Maritime Provinces because the studies were typically conducted in other countries and/or in large urban centres.

The quantitative study that I carried out (Olivier, 2001) explored a wide range of issues in relation to income level. It was based on data gathered between December 1998 and March 1999 as part of a larger study of the needs of PHAs residing in New Brunswick (Olivier & Stanciu, 1999). The larger study used a non-random, purposive sampling strategy to distribute survey questionnaires through physician offices and community-based AIDS organizations. This resulted in 57 PHAs completing and returning questionnaires. The majority of participants were white (94%), male (92%) and

homosexual (63%). Nineteen participants (33% of total) were categorized as low-income (annual income of \$14,999 or less) and 30 participants (53%) were categorized as higher-income (annual income of \$15,000 or more). These income categories were based on Statistics Canada's 1998 low-income cut-offs (Statistics Canada, 1999). While I refer below to findings from this study, it has several limitations. Relying on a small, non-random sample decreases confidence that the sample represents the diverseness of PHAs living in New Brunswick. Since the participants were recruited through physicians' offices and AIDS organizations, PHAs not connected to such services (e.g., those with more transient lifestyles) are not likely included in the sample. In addition, the sample is primarily made up of white males, thus leaving out the experiences of women and people of colour. Having said this, findings with respect to income being associated with a broad range of indicators of health and well-being are consistent with National Population Health Surveys (FPTAC, 1999a), and this strengthens the likelihood of broader applicability.

### 3.1.2 Paid and Volunteer Work

The quantitative study (Olivier, 2001), based on data from the New Brunswick Needs Assessment (Olivier & Stanciu, 1999), revealed that low-income PHAs, in comparison to those with higher incomes, were more likely to be unemployed, disabled and receiving provincial income assistance (see Table 3.1). Low-income participants also tended to rely more on provincial social assistance and less on employment income when first diagnosed with HIV. This finding suggests that issues of low income and poverty may have preceded testing positive for HIV. Evidence also suggests, however, that

disability and illness contribute to a ‘downward spiral’ into poverty. Just under half of the low-income participants (47%), as compared to 27% of the higher-income participants, attributed a change in their income level to their HIV infection. For the majority of both groups (89% of low-income and 88% of higher-income), this change was a decrease in income.

Table 3.1: Current Employment Situation and Source of Annual Income

Variable	Low-Income (n = 18)	Higher-Income (n = 29-30)	p – Value
Employed	1 (6%)	18 (60%)	Fisher 0.002
Unemployed	4 (22%)	1 (3%)	
Disabled	10 (56%)	6 (20%)	0.008
Employed or Unemployed (i.e., able to work)	5 (28%)	19 (63%)	
Employment Income	1 (6%)	20 (69%)	< .0005
Provincial Social Assistance	12 (67%)	0	Fisher < .0005
Source: Olivier (2001)			

The literature on PHAs living in poverty provided limited information on the issue of employment. Ayala’s (1996) qualitative study of PHAs living in poverty in a large U.S. city found that PHAs lacked regular, gainful employment and were frustrated about being unemployed and the lack of economic opportunities. In a study on the needs of poor women living with HIV/AIDS, again in a U.S. city, Bunting, Bevier and Baker (1999) found that participants were frustrated at the lack of both job opportunities and inflexibility at the workplace. Some participants reported losing their jobs because of their HIV status.

The literature on the lives of PHAs in general and in relation to specific issues other than income level covered the topic of employment in considerable detail. For example, the New Brunswick Needs Assessment (Olivier & Stanciu, 1999) revealed HIV

had affected the work situation of nearly half of the participants (i.e., 48%). The ways in which HIV had affected participants' work situations are reported in Table 3.2, and include a decrease in job performance, stopping work altogether, and workplace discrimination.

**Table 3.2: How HIV Affected Work Situation**  
( $n = 24$ ; those who indicated HIV infection had affected their work)

How Work Affected	# of PHAs	% of Total
Job performance has suffered	11	46%
Had to stop working altogether	9	38%
Experienced or feared workplace discrimination	9	38%
Had to cut back on working hours	5	21%
Missed work days due to illness	4	17%
Was fired or asked to resign	2	8%
Have changed jobs	1	4%
Note: percentages total more than 100% due to some participants identifying more than one response category		
Source: Olivier & Stanciu (1999)		

**Table 3.3: Reasons for Not Being Able to Re-enter Workforce**  
( $n = 18$ ; those who indicated that they could not quickly re-enter workforce)

Reasons	# of PHAs	% of Total
Don't feel physically well enough to work	12	66.7%
Don't feel emotionally able to cope	11	61.1%
Too long out of the labour force	9	50%
Previous employment was too physically demanding for current health	7	38.9%
No jobs available in my area of work	6	33.3%
Would need retraining	5	27.8%
No resources to invest in training or education	5	27.8%
Previous employment was too stressful	5	27.8%
Inadequate education/skills	2	11.1%
Note: percentages total more than 100% due to some participants identifying more than one response category		
Source: Olivier & Stanciu (1999)		

The needs assessment also asked PHAs to assess their ability to re-enter the workforce. Thirty-six percent of participants said that they could not quickly re-enter the workforce; their reasons are reported in Table 3.3 (Olivier & Stanciu, 1999). Although the needs assessment did not look at differences in work experience between income groups, employment is clearly a potential area of difficulty and stress for many New Brunswick PHAs.

The Canadian AIDS Society (CAS) also carried out an extensive study related to PHAs returning to or remaining in the workforce (1998). They conducted consultation groups with PHAs in all regions of the country including Atlantic Canada (in total 102 PHAs participated), and conducted a nation-wide survey of PHAs (over 1,400 PHAs completed and returned questionnaires). Of the survey respondents, 38% were currently employed, 62% were unemployed and 36% were involved in volunteer work. Of the unemployed group, 20% were looking for paid work.

Survey participants, whether working or not, wanted to work. Their reasons included “earning an income”, “feelings of self-worth and confidence”, “making a contribution to society”, “interacting with others”, “being more sociable”, and “learning new things” (CAS, 1998, p. 42). Studies from the U.S. (Brooks & Klosinski, 1999) and Australia (Ezzy, De Visser, & Bartos, 1999) revealed similar reasons. These reasons suggest a link between working and a sense of well-being. This link is supported in a U.S. study that found an association between employment and better quality of life (Swindells et al., 1999).

Employment, however, was also associated with distress. Over half of the respondents in the CAS study who were working (54%) had not disclosed their HIV status to their employers. They had worries about negative attitudes from employers or co-workers, workplace discrimination, and loss of job or job security. In addition, 77% of employed PHAs worked in settings without support programs or policies for PHAs. Fifty-seven percent of PHAs in an Australian study (Ezzy et al., 1998) reported high levels of work stress. One in three participants (35%) had stopped paid employment at least once since testing HIV positive. Their reasons related to psychological well-being (e.g., stress and anxiety) and declining health. Of the participants in the CAS study who were no longer working, but had been employed, 38% had left their job due to stress, 11% due to scheduling conflicts with medical needs, 11% to prevent reductions in health or drug benefits, and 9% due to workplace discrimination.

Over half (57%) of the participants in the CAS study who were looking for work said they would not tell their future employers of their HIV status. Their reasons included fear of workplace discrimination and negative attitudes. The key concerns PHAs raised regarding returning to paid employment were “the loss of disability benefits and drug coverage”, “uncertainty over health status”, “fear of discrimination and stigma in the workplace”, “managing treatment schedules and side effects”, and “how to explain their absence from the paid workforce” (CAS, 1998, p. 8). In addition to these concerns, Brooks and Klosinski (1999) found that PHAs seeking employment worried about finding an employer who would accommodate their medical needs.

Adam and Sears (1996) in a qualitative study that looked at the experiences of PHAs living in Michigan and south-western Ontario found similar findings to those outlined above. Some participants in the Adam and Sears' study were actively looking for work or enrolled in job training as a step towards employment. Participants faced obstacles in finding work, including a limited job market, finding childcare, disclosing their HIV status, and gaps in their employment history (e.g., due to drug use).

Participants who were or had been working expressed concerns about the risks involved in disclosing their HIV status to employers and co-workers (Adam & Sears, 1996). Some had met negative attitudes and discrimination upon disclosing their status. These negative outcomes were sometimes associated with a participant's sexual orientation becoming known or being assumed. For those who were fired because of their HIV status, many felt that they lacked the time, energy or money to pursue legal recourses. Some participants who had disclosed, however, reported receiving support and compassion from supervisors and co-workers.

Some participants explained that it became more difficult to not disclose as their disease advanced and they began to experience symptoms (Adam & Sears, 1996). Needing to explain frequent washroom breaks due to diarrhea or a high number of doctor's appointments illustrates this difficulty. Participants also explained how symptoms (e.g., fatigue and memory loss) interfered with their work. Some participants left work altogether, while others coped by modifying their pace and type of work, and finding time during the workday for naps. Few workplaces had AIDS policies. Where these existed, some participants said that this provided a sense of security while others

expressed mistrust that the policies would be followed. Participants no longer working reported struggling with boredom and a sense of wasting time. For a number of participants, volunteering replaced some of the benefits derived from paid employment. Adam and Sears (1996) also found that being diagnosed with HIV sometimes represented more of a loss for PHAs of higher social class who might frame HIV as a threat to upward mobility and expectations. Those of lower social class, on the other hand, had a greater tendency to reframe HIV as another trouble or a chance for a new start.

Kirkham and Lobb (1998), who examined the experiences of HIV positive women living in British Columbia, found that 40% of participants had experienced a decrease in income since their HIV diagnosis and 23.6% feared losing their job. Two Australian studies (Ezzy et al., 1998; Ezzy, De Visser, & Bartos, 1999) showed that disease progression, by rendering a person unable to work, can lead to poverty. Similarly, Massagli, Weissman, Seage and Epstein (1994), who looked at job loss and the effect on income of PHAs living in Boston, found that two-thirds of the participants experienced a reduction or limitation in employment income due to their illness. And participants who left work experienced a considerable drop in income. Furthermore, work demands were not modified significantly for participants who remained employed (i.e., hours worked or demands), suggesting little workplace accommodation. Massagli et al. (1994) also found a connection between type of work and employment loss in that persons diagnosed with AIDS who had physically demanding jobs were more likely to leave their jobs than those with mentally demanding jobs. They speculated that jobs requiring higher mental effort might allow “more discretion over the pace of work or offer flexible work arrangements”

(p. 1980). These findings underscore the association between HIV/AIDS and loss of income and the economic benefit of remaining employed.

### 3.1.3 Private, Government and Non-Profit Services

As reported above under comparisons of PHAs of differing income levels, U.S. and Australian studies revealed that lower-income PHAs faced greater difficulty in accessing health services, food and housing assistance, and social and recreational activities (Ezzy et al., 1998; Montoya, Trevino, & Kreitz, 1999). The quantitative study of New Brunswick low- and higher-income PHAs (Olivier, 2001) showed that participants were quite satisfied with their medical treatment independent of income level (i.e., 94% of low-income and 96% of higher-income PHAs rated their medical care as generally or totally adequate). Participants of both income groups also reported similar patterns of drug treatment, physician usage and hospital stays. This is not unexpected, as all New Brunswick PHAs have free access to a wide range of services under a universal health care system. In addition, the majority of both groups obtained prescription drugs through the Provincial Prescription Drug Program. Higher-income PHAs, however, reported significantly greater access to prescription drugs through private insurance and indicated no use of food banks or community-based AIDS organizations' emergency fund programs (see Table 3.4). These last findings suggest an association between private/public service use and income level. With the exception of the three services noted, however, the study did not extensively explore low- and higher-income PHAs' use of services that fall outside of medical care.

Table 3.4: Use of Private/Public Services

Private/Public Services	Low-Income ( <u>n</u> = 16-19)	Higher-Income ( <u>n</u> = 28-30)	p - Value
Px Drugs through Private Insurance	2 (11%)	16 (53%)	0.002
AIDS Organizations' Emergency Funds	7 (37%)	0	Fisher 0.001
Food Banks	6 (32%)	0	Fisher 0.002
These findings are from the quantitative study, Olivier (2001); however they were not included in the final published article.			

The literature on PHAs living in poverty provided some additional understanding of their lives in relation to services used. Not surprisingly, Ayala (1996) found that poor PHAs relied extensively on public assistance. In addition, they often lacked both basic information about health care and access to a full range of health-related services—in part related to inexperience in negotiating health services and to a greater concern over day-to-day survival (e.g., income assistance, shelters). The nature of the health services received was strongly influenced by the quality of relationships with service providers. Notably, Ayala's research was with PHAs living in a large U.S. city, so some differences between the experiences of his study's participants and those of low-income PHAs living in the Maritime Provinces is expected (e.g., regarding access to health care). Bunting, Bevier and Baker's (1999) study of poor women living with HIV/AIDS identified participants' concerns with the provision of income assistance, but did not elaborate. However, another U.S. study (Crane, Quirk, & van der Straten, 2002) found that PHAs in receipt of income assistance worried that they could lose their benefits if their health improved and they returned to work. As a result some study participants worked 'under the table' to make ends meet.

Finally, studies that focused on the experiences of PHAs in general, including factors other than income, provided further insight into the use of services. The New Brunswick Needs Assessment (Olivier & Stanciu, 1999) found that 20% of PHAs were currently using alternative/complementary therapies (e.g., vitamins, special diet, massage) and that an additional 20% would have liked to use these services but could not afford to. Similarly, Gillett, Pawluch and Cain (2002) in a qualitative study of PHAs living in the greater Toronto area found that the greatest barrier to the use of complementary therapies was cost. Many in this study reported that their “experiences with complementary therapies were limited to those therapies that they could get for a minimal fee or free of charge through community service organizations” (Gillett, Pawluch, & Cain, 2002, p. 24). On a different matter, Adam and Sears (1996) found that some mothers living with HIV/AIDS (e.g., those with histories of injection drug use) feared losing their children to child protection agencies. Marcenko and Samost (1999) also found that child protection services were a source of both support and stress for HIV positive mothers.

#### 3.1.4 Informal Social Relations

The quantitative study (Olivier, 2001) showed that New Brunswick PHAs experience numerous problems and distressing feelings that relate to social support (see Table 3.5). The situation is most severe, however, for low-income PHAs who reported significantly greater rates of HIV-related discrimination, family tension, and rejection by family members and friends. In addition and as noted earlier, Ezzy et al. (1998) found

that low-income PHAs living in Australia had more restrictive social lives than those with higher income.

Table 3.5: Experiences Related to Social Support

Problems/Feelings Experienced (to any extent from 'a little' to 'a lot')	Low-Income ( <u>n</u> = 17-19)	Higher-Income ( <u>n</u> =28-29)	p - Value	
*Fear of being discriminated against because I am HIV+	17 (89%)	26 (90%)	0.037	
Wondering who to tell, what to tell my family/friends	15 (79%)	19 (66%)		
Feeling isolated/alone	16 (84%)	18 (62%)		
Concerns/worries about sexual relationships	13 (68%)	20 (69%)		
*Being discriminated against because I am HIV+	17 (89%)	18 (62%)		
Grief due to loss of family or friends to AIDS	9 (53%)	14 (48%)		
*Fear of being discriminated against because people think or know that I am gay	12 (67%)	12 (41%)		
Tension within my family because of HIV/AIDS	12 (63%)	9 (32%)		0.036
Fear of being rejected by family or friends	11 (58%)	12 (41%)		
*Being discriminated against because people think or know that I am gay	12 (63%)	11 (38%)		0.023
Being rejected by family or friends	11 (61%)	8 (28%)		
*since the nature of discrimination was not specified, these problems also have applicability to the workforce and the use of private/public services.				

The literature that explored the lives of PHAs living in poverty emphasized the importance of social support. Ayala (1996) found that strong family support among PHAs living in poverty improved their ability to comply with treatment, cope with illness and accept nearing death. In addition, he observed that health care staff were often more attentive if a patient's family was involved. Ayala (1996) also found that PHAs living in poverty often lacked family and community support. This was particularly true for some groups, such as those with a history of injection drug use. Bunting, Bevier and Baker's (1999) study of poor women living with HIV/AIDS found that the largest category of identified needs related to psychosocial issues. Among the psychosocial needs that the women most often cited was the need for a support group. The women expressed a desire

“to meet other HIV-positive women who shared similar feelings and experiences” (Bunting, Bevier, & Baker, 1999, p. 47). The women also mentioned the need for support from family and friends.

The literature that explored the lives of PHAs in general, but not limited to those living in poverty, provided additional insight into social support. The Kirkham and Lobb (1998) study of British Columbia women living with HIV/AIDS found that among the psychosocial problems experienced quite often by participants were a “lack of intimacy or satisfying sexual relationship” (53.6% of participants), “fear of rejection or discrimination” (51.8%), and “not having enough emotional support” (29.1%) (p. 322). A U.S. study on the experiences of HIV positive mothers revealed that participants had concerns about disclosing their HIV status to family members and friends. However, the participants did draw upon family and friends for support, as well as upon support groups (Marcenko & Samost, 1999). Bloom (1997), in a U.S. study on the experiences of gay men living with HIV, identified the importance of community support and the threat to social support posed by multiple bereavement due to HIV/AIDS.

Among numerous studies on barriers to and predictors of social support among PHAs, few suggested relationships between social support and SES or income level. Kadushin (1999), however, found that one of the greatest barriers to PHAs obtaining family support was the family’s lack of knowledge regarding HIV/AIDS. Lower-income PHAs’ social networks may have less access to accurate HIV/AIDS information. This speculation is supported by other research that found that persons with low income and those misinformed about the risk of HIV transmission had greater hostility and

stigmatizing views towards PHAs (Lentine et al., 2000; Mondragon, Kirkman-Liff, & Schneller, 1991).

Smith and Rapkin (1996) identified a number of barriers to family support including financial costs of accessing support, lack of access (e.g., due to distance), lack of acceptance, lack of intimacy, negative interactions, and avoidance of disclosure. Kadushin (2000) found that disclosure to family members facilitates receiving support. Additional studies linked social support satisfaction to being able to talk to family members about AIDS (Turner, Hays, & Coates, 1993), family members' acceptance of the PHAs' sexual orientation (Kadushin, 1996), and relationship satisfaction with family (Serovich, Brucker, & Kimberly, 2000).

Numerous studies have demonstrated the benefits of social support in the lives of PHAs in relation to: quality of life (Friedland, Renwick, & McColl, 1996; Swindells et al., 1999); meeting needs (Smith & Rapkin, 1995); adjustment to HIV/AIDS (Pakenham, Dadds, & Terry, 1994; Rodgers, 1995; Simoni & Cooperman, 2000); mental health and emotional well-being (Crystal & Kersting, 1998; Gant & Ostrow, 1995; Hays, Turner, & Coates, 1992; Ingram et al., 1999; Serovich, Brucker, & Kimberly, 2000; Simoni & Cooperman, 2000); stress mediation (Crystal & Kersting, 1998); and healthy coping strategies (Chidwick & Borrill, 1996; Leserman, Perkins, & Evans, 1992; Swindells et al., 1999). Siegel, Raveis and Karus (1994) and Ingram et al. (1999) found both an association between positive social support and lower levels of depression, and also an association between higher levels of depression and negative social interactions. Finally, Hays, Magee and Chauncey (1994) have identified helpful and unhelpful behaviours of

family members and friends. The helpful behaviours included: expressing concern, sharing feelings, allowing reciprocity in the relationship, interacting naturally, and providing encouragement, information, practical assistance, material aid and companionship. The unhelpful behaviours included: patronizing and overprotective manner, avoiding interaction and expression of feelings, criticizing the person's response to HIV/AIDS or to medical treatment, acting judgemental or ashamed, breaking confidentiality, making unreasonable demands, expressing pessimism, and making rude and insensitive comments.

As presented below, employment, health services and social support also interconnect with income to affect health and well-being.

### 3.2 Income and Health

The following section of the literature review demonstrates links between income level and a whole range of health indicators. This section also provides a current understanding of the causal links between income and health outcomes. In organizing the review, I used many of the same headings that the Federal, Provincial and Territorial Advisory Committee on Population Health (FPTAC; 1999a) used to organize data on the health of Canadians. These headings include: self-rated health, psychological well-being, chronic diseases, depression, disability and activity limitations, and life expectancy. In addition, two FPTAC reports on the health of Canadians provided much of the material for this review (*Toward a Healthy Future: Second Report on the Health of Canadians*,

FPTAC, 1999a; and *Statistical Report on the Health of Canadians*, FPTAC, 1999b)<sup>1</sup>.

Both reports made extensive use of data from the 1994-95 and 1996-97 National Population Health Surveys (NPHS).

### 3.2.1 Self-Rated Health

Self-rated health “describes how individual Canadians experience and assess their own physical and mental health” (FPTAC, 1999a, p. 12) and “has been shown to be a reliable predictor of health problems, health-care utilization and longevity” (FPTAC, 1999a, p. 14). Findings from the 1996-97 NPHS demonstrate a clear income-related gradient in self-rated health, with low-income Canadians reporting higher levels of poor health than those with higher incomes (FPTAC, 1999a) (see Table 3.6). Similarly Humphries and van Doorslaer (2000), in an extensive analysis of 1994 NPHS data, found that significant inequalities in self-reported ill-health exist across all income levels and are not just the result of differences between the lowest and highest income groups.

Table 3.6: Self-Rated Health by Income Level, age 12+

Income Level	Fair/Poor Rating	Excellent/Very Good Rating
Lowest	21%	47%
Middle	10%	61%
Highest	5%	73%

Source: FPTAC, 1999a, p. 15

### 3.2.2 Psychological Well-Being

The 1994-95 NPHS assessed the psychological well-being of Canadians based on three measures: coherence (“a perception that life is meaningful, challenges are

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<sup>1</sup> In these reports, income levels for a 1-2 person household are lowest income (<\$10,000), lower middle income (\$10,000-14,999), middle income (\$15,000-29,999), upper middle income (\$30,000-59,999), and highest income (≥\$60,000) (Statistics Canada, 1998) and are based on Statistics Canada’s 1992 low-income cut-offs (FPTAC, 1999b).

manageable and life events are comprehensible”), self-esteem (“sense of self-worth”), and mastery (“extent to which people believe that their life chances are under their control”) (FPTAC, 1999a, p. 12). As presented in Table 3.7, the survey found an income-related gradient, with low-income participants having lower levels of psychological well-being than those with higher incomes.

Table 3.7: Psychological Well-Being by Income Level, age 12+ for self-esteem and mastery and age 18+ for all three indicators

Income Level	Low Sense of Coherence	Low Self-Esteem	Low Sense of Mastery
Lowest	47%	18%	31%
Middle	33%	13%	22%
Highest	26%	10%	12%

Source: FPTAC, 1999a, p. 16

### 3.2.3 Chronic Diseases

Longitudinal findings for the 1994-95 and 1996-97 National Population Health Surveys showed that “for all major chronic diseases measured, estimated incidence rates were higher for people in the two lowest household income groups than for those in the upper three groups” (Statistics Canada, 1998, p. 4). The diseases and conditions examined included arthritis, high blood pressure, heart disease, diabetes and some cancers. U.S. studies also show that the prevalence of chronic diseases decreases as SES increases and the relationship follows a linear gradient (Adler & Ostrove, 1999).

### 3.2.4 Depression

As presented in Table 3.8, the 1996-97 NPHS found that the risk of depression was highest among Canadians with the lowest income (FPTAC, 1999b). In addition, for

those assessed to have been depressed, poorer Canadians reported being depressed for longer periods of time.

Table 3.8: Risk of Clinical Depression and Number of Weeks Depressed in Previous Year by Income Level, age 12+

Income Level	Possible Episode of Depression	Probable Episode of Depression	Average Number of Weeks Depressed
Lowest	3%	9%	8.3
Middle	1%	4%	7.5
Highest	1%	3%	6.8

Source: FPTAC, 1999b, pp. 294-295

### 3.2.5 Disability and Activity Limitations

The 1996-97 NPHS found that Canadians who reported any activity limitation or disability were more likely to have low incomes (FPTAC, 1999b) (see Table 3.9). This relationship held true whether the limitation was experienced at home, school or work.

Table 3.9: Long-Term Limitation or Disability by Income Level, age 12+

Income Level	Any Limitation or Disability	Limited at Home	Limited at School	Limited at Work
Lowest	29%	19%	6%	15%
Middle	18%	11%	3%	7%
Highest	14%	7%	3%	4%

Source: FPTAC, 1999b, p. 237

### 3.2.6 Life Expectancy

Higher income is also associated with longer life expectancy. Longitudinal NPHS data (1994-95 and 1996-97) showed that SES affected people’s survival time in that “being in the two lowest household income groups in 1994/95 was predictive of death before age 75, even after controlling for sex, chronic diseases, and smoking” (Statistics Canada, 1998, p. 5). In addition, Wolfson, Rowe, Gentleman and Tomiak (1993) in a large Canadian longitudinal study found that “higher earnings for males in late middle

age (age 45 to 64) are associated with significantly lower mortality at older age (age 65 to 74)” (p. S167). U.S. studies have demonstrated a gradient relationship between SES and mortality, with lower death rates associated with higher SES (Adler & Ostrove, 1999).

The extensive range of health factors associated with income level has led the FPTAC to conclude that socio-economic status (of which income is a component) is one of the most important determinants of health (FPTAC, 1999a).

### 3.3 Income Level, Paid and Volunteer Work, and Health and Well-Being

Employment can have significant effects on people’s physical, mental and social health (Canadian Public Health Association [CPHA], 1997; FPTAC, 1999a; Wilkinson, 1996). In addition to income, employment provides people with: a sense of identity and purpose; opportunities for personal growth; enhanced self-esteem; social status; and social support and interaction (CPHA, 1997; Wilkinson & Marmot, 1998). Health suffers in the absence of these benefits. The relationship between employment and health, however, is complex because some aspects of paid work can negatively affect health. In synthesizing the findings from a number of studies, Wilkinson (1996) concludes that “having little control over one’s work, low social support from managers and colleagues in the workplace, and a fast pace of work” (p. 181) can have deleterious effects on health. Other stress-inducing factors include: workload and unreasonable deadlines; monotony and boring, repetitive tasks; physical hazards; harassment; and lack of feedback (CPHA, 1997). High demand jobs that offer low control are especially threatening to health (Wilkinson & Marmot, 1998). Conversely, the amount of control people have at their workplace, the fewer stress-related demands, the ability to use their skills to enhance self-

esteem, and the social support they receive can contribute to better health (CPHA, 1997; Wilkinson, 1996).

The amount of control a person has over their work is partly related to socio-economic status (Wilkinson, 1996). Professional occupations, in addition to providing greater pay, generally provide more work autonomy than lower-paying non-professional and menial jobs (Young, 1990). Furthermore, people with higher education report the least amount of work stress (FPTAC, 1999b). There is also an association between income level and job satisfaction. The 1996-97 NPHS found that Canadians with the lowest incomes were more likely to report not being satisfied with their jobs (14%) compared to those with the highest incomes (8%) (FPTAC, 1999b).

People who are unemployed suffer significantly more physical and mental health problems and have shorter life expectancies than people who have jobs (CPHA, 1997; Evans, 1994; Wilkinson, 1996). The health effects of unemployment are linked to psychological consequences of lost benefits such as those listed above, and to financial problems and material deprivation (Wilkinson & Marmot, 1998). The link between unemployment and poorer health can also be traced back to job insecurity (Wilkinson, 1996). Anticipating job loss “has been shown to increase effects on mental health (particularly anxiety and depression), self-reported ill health, heart disease and risk factors for heart disease” (Wilkinson & Marmot, 1998, p. 18).

Lower-income Canadians are less likely than those with higher incomes to be involved in volunteer work. The rate of volunteering among those with incomes less than \$20,000 was found to be half that of wealthier Canadians (22% versus 44%; FPTAC,

1999a). The FPTAC (1999a) speculated that the inability to pay for transportation to a volunteer agency and clothing costs may be a barrier to volunteering. Lower income Canadians are also less likely to be involved in a community organization (e.g., sports and recreation, religious, school-related, cultural, educational and political groups; FPTAC, 1999a). Studies indicate that participation in community organizations is associated with lower mortality risk (Berkman, 1984; Kawachi & Kennedy, 1997). This likely relates to the health benefits of social support and integration, discussed below.

### 3.4 Income Level, Use of Services, and Health and Well-Being

National Population Health Surveys have shown that income is not generally a barrier to accessing universally insured medical services (e.g., general practitioner) (FPTAC, 1999a). However, these surveys have also shown that income does present a barrier to non-universal health-related goods and services such as dental procedures, eye care, non-physician mental health counselling, prescription drugs, and alternative or complementary therapies (e.g., massage therapy, homeopathy, acupuncture). For example, the 1996-97 NPHS found that 42% of the lowest-income group versus 81% of the highest-income group saw a dentist in the past year (FPTAC, 1999b). This survey also found that 6% of low-income Canadians had a recent visit to a chiropractor, compared to 12% of those with high incomes. Use of alternative or complementary therapies was also greatest among Canadians with higher incomes and among those with a university education. This finding suggests those with higher education may be more aware of different approaches to managing health and are better able to afford them (FPTAC, 1999a).

The FPTAC (1999a) noted that most income assistance programs provide some degree of vision care, dental and prescription drug coverage. This leaves low-waged Canadians and those without workplace health-insurance the least likely to have access to non-universally insured health services. It is not surprising that the 1996-97 NPHS found that Canadians with the lowest incomes (11% of women and 7% of men) were more likely to report an unmet health-care need than those with the highest incomes (7% of women and 3% of men) (FPTAC, 1999a).

### 3.5 Income Level, Social Support, and Health and Well-Being

Research has shown that social support and positive social relationships make important contributions to both mental and physical health (Berkman, 1984; Cohen & Wills, 1985; Wilkinson & Marmot, 1998). On the other hand, “lack of a confiding relationship with a close friend, relative or partner is associated with poorer health, but so also is less involvement with wider social networks, community activities, etc.” (Wilkinson, 1996, p. 182). Inadequate social support puts people at risk for depression, suicide, higher levels of disability from chronic conditions, physical health conditions and early death (Berkman, 1984; FPTAC, 1999b; Wilkinson, 1996; Wilkinson & Marmot, 1998). Socially isolated people die earlier than those with well functioning social networks (Kawachi & Kennedy, 1997; Wilkinson & Marmot, 1998). Furthermore, negative aspects of close relationships can contribute to poor mental and physical health (Wilkinson & Marmot, 1998).

Several possible mechanisms account for the potential health benefits of social support. Berkman (1984) proposed that social networks can: offer advice on accessing

and utilizing medical services; provide direct tangible or financial assistance; influence engagement in health-promoting behaviours; and mediate the negative effects of stress. All of these interactions, in turn, can influence health and well-being. Cohen and Wills (1985) cite evidence that social support contributes to well-being through a “main or direct effect” and also through protection from stressful events (a “buffering effect”). The main effect posits that “social networks provide persons with regular positive experiences and a set of stable, socially rewarded roles in the community. This kind of support could be related to overall well-being because it provides positive affect, a sense of predictability and stability in one’s life situation, and a recognition of self-worth” (Cohen & Wills, 1985, p. 311). The direct effect benefits health irrespective of stress level, while the buffering effect protects health in the presence of perceived stress. This protection operates in two ways: a person’s social network can both reduce the stress response to a stressful event and also provide resources to cope with stressors. Consistent with the buffering effect, Singer and Ryff (1999), in a longitudinal study that looked at income and social relationships, found that long-term low-income study participants with positive relationship histories had better health than those with negative relationship histories. They concluded that supportive relationships can compensate for some of the ill effects of low income. The HIV/AIDS literature also provides evidence of the benefits of positive social relationships. Studies reported above have shown associations between social support and both stress mediation (Crystal & Kersting, 1998) and healthy coping strategies (Leserman, Perkins, & Evans, 1992; Swindells et al., 1999).

Given the relationship between social support and health, lower-income Canadians may be disadvantaged. The 1996-97 NPHS found that income was positively associated with social support (FPTAC, 1999a). Canadians with the “lowest level of income had the lowest percentage of high support (74%), compared with those with the highest level of income (89%)” (FPTAC, 1999b, p. 131). Respondents were considered to have a high level of social support if they reported that they had someone they could “confide in”, “count on in a crisis” and “count on for advice”, and that “makes them feel loved and cared for” (FPTAC, 1999b, p. 132). Lower SES is also associated with higher levels of relationship conflict (Taylor & Seeman, 1999).

### 3.6 Explaining the Links Between Income and Health

As reported above, people with high incomes are usually healthier and live longer. Income (or lack of) can affect health directly through absolute material deprivation, and indirectly through conditions associated with poverty and/or income inequality (CCSD, 2001; CPHA, 1997; Lynch, Davey Smith, Kaplan, & House, 2000; Raphael, 2002; Marmot & Wilkinson, 2001).

The direct pathways between poverty and health are generally well understood. They include poor diet, substandard housing, unsafe or polluted neighbourhoods, and lack of access to services (CCSD, 2001; CPHA, 1997; Raphael, 2002). People on low income, for example, are least able to maintain a healthy diet. The 1996-97 NPHS found that “low-income households were the most likely to report running out of food (28%), receiving food from a food bank or other organization (10%) and not always having enough food to eat (21%)” (FPTAC, 1999a, p. 102). Low-income Canadians also “were

more likely to describe their eating habits as fair or poor than those in upper income brackets” (FPTAC, 1999a, p. 117). The 1996-97 NPHS also classified 57% of the lowest income group as inactive with respect to leisure, compared to 48% of the highest income group (FPTAC, 1999b). As with diet, barriers to leisure time activity relate to income, including the cost of equipment and recreational activity/centre user fees (FPTAC, 1999a).

It is well established, however, that the effect of income on health is not solely the direct result of material deprivation. The various findings from National Population Health Surveys demonstrate “an active gradient in health status from low to middle and upper levels of income can also be observed in virtually all measures of both mortality and morbidity” (FPTAC, 1999a, p. 43). Furthermore, “populations living in areas with greater income inequality have shorter life expectancies, independent of median levels of income” (Adler & Ostrove, 1999, p. 11). In other words, the impact of income as a determinant of health goes beyond the attainment of a minimal level of basic needs. Other factors are at play in people’s socio-economic environments that impact upon health and well-being. These indirect pathways between income and health are only beginning to be understood but appear to be linked to psychosocial responses to poverty or income inequality and/or to the material conditions associated with income inequality. Two main schools of thought have emerged relating to 1) stress and control, and 2) social cohesion (Raphael, 2002).

The first explains differences in health as stemming from social advantage and disadvantage, and length and level of exposure to potentially stressful events (Raphael,

2002). Kessler and Cleary (1980) found that increased susceptibility to poor health among those with lower income is related to greater exposure to stressful life events and to the coping skills people possess. Furthermore, they found that potentially stressful events evoke greater stress among persons of lower SES. People with low income may experience a greater number of stressors, react with greater distress to those stressors, and have fewer coping skills and resources to deal with stressors than those with higher income. Some of the stressors associated with low-SES environments include: discrimination, unemployment, underemployment, higher crime rates, residential crowding, and poorer living conditions (Baum, Garofalo, & Yali, 1999). Psychosocial resources associated with higher SES include: optimism, a sense of mastery or personal control, social support and effective coping styles (Taylor & Seeman, 1999). “Thus, enhanced risk of disease at lower levels of SES is due both to greater exposure to stress and reduced resources for buffering its impact” (Adler & Ostrove, 1999, p. 12).

Kessler and Cleary’s (1980) findings support that both early childhood experiences and upward mobility are related to less distress and better coping in the face of problematic life experiences. Childhood socialization is “important in shaping patterns of interpretation and coping that can magnify or reduce the influence of stress on emotional functioning” (Kessler & Cleary, 1980, p. 474) and “the experience of success associated with upward mobility creates the sort of assertive coping skills needed to avoid the psychological damage that can result from undesirable life events” (p. 472). This does not, however, necessarily suggest that causation lies with the individual. Rather, causation is inherently social in that “social class largely determines the life

experiences to which one is exposed, thus in large part shaping one's coping repertoire and determining access to social resources" (Kessler & Cleary, 1980, p. 466). Similarly, Taylor and Seeman (1999) argue that higher SES permits a wider range of life options and future planning which in turn provide more opportunities for skill development. Conversely, those of lower SES may be more pre-occupied with day-to-day struggles than future planning. This results in fewer opportunities for broad based learning and skill development.

Consistent with the above explanations, Lynch, Davey Smith, Kaplan, and House (2000) argue that it is not income inequality per se that affects health, but rather the material conditions associated with income inequality. These conditions not only include personal resources but also the way in which a society distributes resources and opportunities through its various institutions (e.g., schooling, workplace, social welfare, health care). They support their argument with a study (Ross et al., 2000) that found no significant associations between income inequality and mortality within Canada at both provincial and metropolitan area levels. Ross et al. (2000) did find, however, significant associations between income inequality and mortality in the United States. They concluded that "the lack of a significant association between income inequality and mortality in Canada may indicate that the effects of income inequality on health are not automatic and may be blunted by the different ways in which social and economic resources are distributed in Canada and in the United States" (Ross et al., 2000, p. 898).

The second explanation for the income-health gradient is that income inequality affects health through a breakdown of social cohesion (Kawachi & Kennedy, 1997;

Raphael, 2002; Wilkinson, 1996; Wilkinson & Marmot, 1998). In comparing health outcomes between different countries, Wilkinson (1996) found that in developed countries relative income is more important than absolute income. He contends that the level of income inequality in a society is a marker of social cohesion and that countries with greater income equity are both healthier and more cohesive. Notably, gradients between health and SES have been found in almost every industrialized country studied but they are shallower in more egalitarian countries (Adler & Ostrove, 1999).

Characteristics of strong social cohesion include people: having a strong sense of mutual trust and community, participating in social and voluntary activities outside the home, and contributing to the attainment of shared social goals (Wilkinson, 1996; Wilkinson & Marmot, 1998). Kawachi and Kennedy (1997) found the degree to which people trust others and participate in community organizations is correlated with both level of income equality and overall mortality. In other words, people who reside in regions characterized by high levels of civic trust, community participation and income equality live longer. Linking this back to the individual, Wilkinson (1999) argues that those with lower social status are more vulnerable to depression, disrespect, isolation, shame, poor social relations, and feelings of inferiority stemming from negative social comparisons. Perhaps those most marginalized are also the most vulnerable to the pressures of division, mistrust, and individualism characteristic of a society lacking cohesion. Furthermore, people living in poverty are not always aware of these unequal risk conditions. So in addition to feeling distressed over their situations, they may “internalize self-blame for their poverty, isolate themselves and set in motion a vicious

circle in which peer support declines, self-blame increases and isolation worsens” (CPHA, 1997, p.9).

In addition, socio-economic context largely determines personal health practices which in turn affect health. For example, the 1996-97 NPHS found that people with the lowest incomes (40% of men and 36% of women) were more likely to smoke than those with the highest incomes (16% of men and 13% of women) (FPTAC, 1999a). Wilkinson (1996) links smoking to greater stress, and concludes that smoking is a marker of socio-economic stress. This is supported by research indicating that social deprivation resulting from poor housing, homelessness or unemployment is “associated with high rates of smoking and very low rates of quitting” (Wilkinson & Marmot, 1998, p. 23). People who feel a greater sense of hope and control in their lives may find it easier to give up smoking (Wilkinson, 1996).

Consistent with research that links low income and stress, my own study found that low-income PHAs experience a number of stressors more frequently than those with higher incomes (Olivier, 2001). Koopman et al. (2000) also found that PHAs with lower income perceived the greatest stress in their daily lives.

Whether differences in exposure to stressful events and resources and/or social cohesion explain the health gradient, all likely affect health through physiological responses to stress. Stress, particularly when long-term, strongly impacts upon physical and mental health (Ader & Cohen, 1993; Brunner, 1997; McEwen & Seeman, 1999; Wilkinson, 1996; Wilkinson & Marmot, 1998). “The CNS [central nervous system] and endocrine responses associated with repeated exposures to stress may have long-term

effects on the immune and cardiovascular systems, leading to an increased risk of disease onset or more rapid progression of diseases once established” (Adler & Ostrove, 1999, p. 12). Turning on the biological response to stress too often and for too long results in: “depression, increased susceptibility to infection, diabetes, and a harmful pattern of cholesterol and fats in the blood, high blood pressure and the attendant risks of heart attack and stroke” (Wilkinson & Marmot, 1998, p. 11). So while chronic stress can be linked to biological pathways that contribute to negative health, it can also be traced back to societal structures that provide people with lower income fewer resources, less opportunity to develop coping skills, and ultimately less control over life circumstances.

The literature indicates that income is an important determinant of both mental and physical health. It can affect health directly through material deprivation and indirectly through relative deprivation. The direct pathways are well understood (e.g., poor diet, substandard housing). The indirect pathways are less clear, but may relate to social cohesion and to differences in social advantage and exposure to stressful life events. Other factors in a person’s socio-economic environment also affect health. Employment provides material and psychosocial benefits. Services can be used to help maintain health. Positive social relations have a direct benefit on health and well-being, as well as an indirect benefit through mediating stress. People with low incomes, however, may be disadvantaged in attaining benefits from all three of these social domains. The literature review reinforced the importance of knowing more about the impact of income on the lives of PHAs and also placed the study in a broader context of income as a key determinant of health. The importance of further study on the links

between income and health is shared by the FPTAC who concluded that “although there is a clear agreement that income is related to health, why this is so requires further study” (1999a, p. 39).

## Chapter 4

### Research Design and Methodology

This chapter presents my research design and methodology under nine topic headings: (1) ontological and epistemological underpinnings, (2) research question, (3) methodology, (4) sampling, context and participant descriptions, (5) data collection, (6) data analysis, (7) validation issues, (8) ethical considerations, and (9) limitations of the study.

#### 4.1 Ontological and Epistemological Underpinnings

A sound research study should demonstrate, either explicitly or implicitly, congruency between its ontology, epistemology and methodology. This was a challenge in this study, where one of the underlying theoretical frameworks, structural social work, maintains both objective and subjective views of knowledge and social reality. Chapter 2 presented Mullaly's (1997) argument for bringing subjective (radical humanism) and objective (radical structuralism) views of reality together through a dialectical analysis. Subjectivist radical humanism holds that people create their own understanding of social reality, while objectivist radical structuralism holds that there is an external social reality that has a deterministic impact on people's lives (Mullaly, 1997). I needed a research approach consistent with this theoretical perspective.

The challenge in establishing ontological, epistemological and methodological congruency stemmed in part from a lack of models or approaches in the research literature that hold, or at least make explicit, a view of reality with aspects that are

simultaneously independent and dependent of an individual's understanding of their experience. In fact, a frequent topic in the qualitative literature is the contrast between a positivist (and post-positivist) position with its realist ontology and an interpretive position (e.g., constructivism) with its relativist ontology (see for example, Guba, 1990; Rodwell, 1998). The two positions are generally presented as irreconcilable. For example, Rodwell (1998) argues that it is impossible to hold positivist assumptions of a single reality, while at the same time holding interpretive assumptions of multiple realities. The concept of a subjective/objective dialectic, however, suggests otherwise.

Since the subjective/objective dialectic shares some assumptions with the above two paradigms, it follows that research methods can be borrowed from either as long as they are used in a manner that does not exclude the possibility of objective or subjective views of reality. For example, some research methods (e.g., triangulation and negative case analysis) were used to detect suggested patterns and regularities in participants' experiences and thus informed the radical structural aspect of income as a determinant of health. Consistent with radical humanism, other methods (e.g., open-ended questions and member checks) served to uncover participants' subjective understandings. Before discussing methodology, however, I will first re-visit the research question.

#### 4.2 Research Question

This study's research question is "how do people of different income levels who are living with HIV/AIDS experience 1) paid and volunteer work; 2) private, government and non-profit services; and 3) informal social relations". I asked participants in interviews about their experiences and understandings of these areas, including

challenges faced and strengths and supports used to cope with stressors. Viewed collectively, these individual accounts help us understand how societal factors operate to support or challenge the health and well-being of PHAs. They form a picture of reality that is broader than any one person's perspective. However, individual participants' understandings are also reflected in the findings. In this way, aspects of both radical humanism and radical structuralism were brought into data gathering and analysis.

Having a clear research question informed by explicit theoretical frameworks helped keep the research focused. Otherwise, a researcher could easily become overwhelmed by the amount of data (Eisenhardt, 1999) or could omit data crucial to the phenomena being explored (Bloor, 1999). Wolfson (1994) has compared the theoretical framework (and I would add the research question) to a filter, "determining which observations must be attended to and which can safely, often unconsciously, be ignored" (p. 309). Having said this, I remained open to exploring unanticipated areas that emerged as important to the participants' health and well-being, and to shifting my understandings as suggested by the data.

Finally, the intent of this research was to gain a comprehensive and in-depth understanding of how factors related to the specified areas of social domains can affect the health and well-being of PHAs, and differences related to income level. As outlined in the next section, a qualitative research methodology was well suited to this task. Before proceeding to this discussion, however, I will first define the key concepts used in this study.

#### 4.2.1 Concepts

**Health:** I adhered to the broad definition of health developed by the World Health Organization and adopted by the Federal, Provincial and Territorial Advisory Committee on Population Health. This sees health as “a complete state of physical, mental, social and emotional well-being. Health is a resource for living that enables people of all ages to realize their hopes and needs, and to change or cope with the environments around them” (FPTAC, 1999a, p. 3). This definition proved well suited to the research question since a broad range of areas of social domains (or environments) was explored in order to better understand factors that challenge or support health and well-being. A key aspect of the definition of health is a person’s state of well-being.

**Well-Being:** I again drew from the work of the Federal, Provincial and Territorial Advisory Committee on Population Health in conceptualizing well-being. This committee defined psychological well-being in terms of a person’s sense of self-esteem, “the extent to which individuals feel that their life chances are under their own control” (i.e., mastery), and “a view of the world that life is meaningful, events are comprehensible and challenges are manageable” (i.e., sense of coherence) (FPTAC, 1999a, p. 15). Although this definition is specific to psychological well-being, I believe it can also be applied to a person’s general sense of well-being. The degree to which a person feels that they have control over life events and can manage challenges is pertinent to all areas of health—whether physical, mental, social or emotional. In addition, how a person views the world can influence their comprehension of matters relating to all facets of health. Relating this to self-esteem, the recognition of structural

causes of problems and/or challenges to addressing problems poses less of a threat to self-esteem than if these problems or challenges are attributed to deficiency on the part of the individual.

**Person living with HIV/AIDS (PHA):** This term refers to a person who has tested positive for HIV antibodies, whether symptomatic or not, and to a person who has been diagnosed with AIDS.

**Income Level:** Income levels were based on participants' annual pre-tax household incomes. The levels were categorized as low-income or higher-income based on Statistics Canada's 2000 low-income cut-offs (2001), which range from \$12,696 to \$15,757 for one-person family units and \$15,870 to \$19,696 for two-person family units living in areas similar in size to those indicated by the participants (i.e., rural communities to cities with populations between 100,000 and 499,999). [Note: the term higher income is only meant to differentiate from low income and is not meant to imply that participants of higher income necessarily have a high or adequate income.]

**Paid and volunteer work:** I operationalized paid and volunteer work to encompass employment and volunteer work itself, as well as efforts in finding work, experiences of being employed or volunteering, experiences of leaving work, and benefits received from paid and volunteer work.

**Private, government and non-profit services:** This grouping of services included private, government and non-profit services (other than medical services) that the participants had relied on, since their diagnoses with HIV infection, to assist them in meeting needs associated with their health and well-being.

Informal social support: Given the variety of relationships that could make up a person's support network, I encouraged participants themselves to name who they include in their support networks. I used an approach taken by Adam and Sears (1996), who asked study participants to tell them "whom they cared for and relied on most, and to discuss how HIV affected these relationships" (p. 92). In this way, participants could identify for themselves who they felt close to and/or who they relied on for support. In addition to identifying sources of support, I also distinguished the type of support received or desired. I relied on a four-type classification system developed by Kadushin (1999), who studied the support received from family of origin among gay men living with HIV/AIDS. These include: "emotional (for example, reassurance), instrumental (for example, providing goods), informational (for example, providing information/advice) and fun/relaxation support" (Kadushin, 1999, p. 200). (Kadushin acknowledges that with the exception of fun/relaxation, the types of support were adapted from the UCLA Social Support Inventory.)

#### 4.3 Methodology

A prevailing opinion in the social sciences research literature is that the research problem should determine the methodology chosen (Bloor, 1999; Hammersley, 1999; Neuman, 1997; Riessman, 1994). Riessman (1994) adds, however, that our ontological and epistemological beliefs also shape which methods we choose. Keeping this in mind, I contend that a qualitative methodology is best suited to the research question under exploration, and that such a methodology can be applied in a manner consistent with my

views of social reality and knowledge. So why is a qualitative methodology well suited to this research area?

First of all, the study's research question is primarily exploratory, focusing on how PHAs of different income levels experience specified areas of social domains. Qualitative methods lend themselves well to exploratory studies (Hammersley, 1999; Marshall & Rossman, 1995), where the concern is with generating theoretical ideas for further study (Eisenhardt, 1999; Hammersley, 1999), with investigating little-understood phenomena, and with identifying important variables (Marshall & Rossman, 1995). All of these facets of exploratory research relate to the purpose of the study.

Secondly, qualitative research methods can facilitate detailed and in-depth understandings of complex social phenomena (Lofland & Lofland, 1984; Marshall & Rossman, 1995; Rubin & Babbie, 2001; Rubin & Rubin, 1995). This is an aim of this study, where the purpose is to gain a comprehensive and in-depth understanding of how factors related to the areas under exploration can possibly affect health and well-being. In this respect, a qualitative design can address an explanatory concern, by identifying "plausible causal networks shaping the phenomenon" (Marshall & Rossman, 1995, p. 41). Qualitative data can help us understand the dynamics that underlie relationships, "that is, the 'why' of what is happening" (Eisenhardt, 1999, p. 150). Furthermore, participants will have developed their own subjective understandings of factors related to their health and well-being. Qualitative research methods using in-depth interviews provide participants with great latitude in sharing their understandings and are well suited to capturing these subjective understandings. As Bryman (1999) states "The qualitative

researcher is in a better position to view the linkages between events and activities and to explore people's interpretations of the factors which produce such connections. This stance affords the qualitative researcher a much greater opportunity to study processes in social life" (p. 43).

A third point in support of qualitative methodology is the potential for reciprocal interaction between participants and the researcher. This dynamic can permit the development of a dialogical relationship, where both participant and researcher are able to shape the direction, content and outcome (e.g., findings) of the interview process. This dynamic is illustrated in the following interchange between me and one of the participants:

John: *I put a shield around me, so that I don't know, so that...life doesn't...I don't know...it's just so bad I think so...*

Self: *There's lots of protection around you...*

John: *Too much...yeah.*

Self: *Yeah, cause if you protect yourself, it can also protect yourself from...prevent you from having close relationships...Those defense mechanisms can be helpful but also...problematic too.*

John: *Oh yeah, very much so. I mean...what you do you end up being alone, right? I can say...I was never this way before. Never. But it's just got so that I've gotten...I was going to say bitter, but I haven't gotten bitter. I haven't gotten hateful. It's just...I'm just protecting myself I think, which is stupid, which I shouldn't do. I should get over it, you know.*

Self: *Do you think that it is related to being HIV positive?*

John: *Oh, a great deal. Oh yes...*

'Member checks', discussed below under validation issues, also allow participants to influence the study through clarifying and expansion. A dialogical approach and member checks are consistent with structural social work's goal of involving people in defining their own issues and concerns, with a subsequent goal of social change.

Although qualitative methodology is well suited to this particular study, connections to quantitative research can also be made. Bryman (1999) claims few impediments to the integration of qualitative and quantitative methods as long as their differences are technical and not epistemological. Consistent with the former position, Hammersley (1996) has identified three forms of mixed methodology: 1) triangulation, using the findings from quantitative and qualitative methodologies to validate each other; 2) facilitation, using the findings from one methodology to inform another; and 3) complementarity, using both methodologies to gain different sorts of information about what is being studied. This study used elements of all three forms of mixed methodology.

An earlier quantitative study (presented in the literature review chapter; Olivier, 2001) provided a focus for the current study. Areas chosen for exploration stemmed from relationships detected in the quantitative study, but the dynamics of the relationships remained unknown. For example, the quantitative study revealed that lower-income PHAs experienced more family tension due to HIV/AIDS. However, it was not known if this tension was similar to what was reported by higher-income PHAs, only experienced more frequently, or if the nature of the tension was different for the two income groups. The current study revealed more about the nature of the family tension and showed that some sources of tension appeared linked to income level. In addition to the nature of relationships, Eisenhardt (1999) has pointed out that “qualitative data are useful for understanding the rationale or theory underlying relationships revealed in the quantitative data” (p. 142). For example, this study pointed to oppression as the root cause of some of participants’ problems. While the above discussion illustrates how the quantitative study

informed the direction of the current study and how findings from both studies proved to be complementary, the quantitative study and the current study also serve a triangulation function. Confidence in the validity of both studies' findings was strengthened by the congruency between the two sets of findings. For example, both studies showed that family tension due to HIV/AIDS appeared greatest among PHAs with low incomes. Viewed together, both studies form a larger body of research.

#### 4.4 Sampling, Context and Participant Descriptions

I have centred my research around the experiences of PHAs living in the Maritime Provinces. The choice of the Maritimes accommodated practical concerns about research resources and time-frame, while providing an adequate number of

Table 4.1: Description of Maritime Provinces

Characteristic	New Brunswick	Prince Edward Island	Nova Scotia
Geographic Size	72,908 km <sup>2</sup>	5,660 km <sup>2</sup>	55,284 km <sup>2</sup>
Population (2002)	756,700	139,900	944,800
Unemployment Rate (November 2002)	10.3%	11.4%	9.5%
Average Weekly Earnings (September 2002)	\$608.27	\$533.79	\$586.85
Main Employers (2001)	Service-producing sector (76% of jobs) - trade - health care and social assistance - accommodation and food services Goods-producing sector (24% of jobs) - manufacturing - construction - forestry, fishing, mining, oil and gas	Service-producing sector (73% of jobs) - trade - health care and social assistance - public administration Goods-producing sector (27% of jobs) - manufacturing - construction - agriculture	Service-producing sector (78% of jobs) - trade - health care and social assistance - educational services Goods-producing sector (22% of jobs) - manufacturing - construction - forestry, fishing, mining, oil and gas
Average Years of Schooling (1996)	11.6	11.9	12.1
Source: Statistics Canada (2002)			

participants and sufficient variation in experience for answering the research question. New Brunswick, Prince Edward Island and Nova Scotia make up the Maritime Provinces. As outlined in Table 4.1, New Brunswick is largest in area, while Nova Scotia has the largest population. Prince Edward Island is smallest on both counts. Overall, the three provinces have similar economic profiles. However, Prince Edward Island has a somewhat weaker economy measured by unemployment rate and average weekly earnings. The main employers for all three provinces are the service sector (e.g., trade and health/social services) and the goods-producing sector (e.g., manufacturing and construction). The average years of schooling in each province is slightly below the national average of 12.3 years (Statistics Canada, 2002). This contextual description and the participant descriptions that follow are intended to assist readers in assessing the transferability of the findings to other settings.

My background and familiarity with HIV/AIDS in the Maritime region facilitated access to the PHA community. (I worked for approximately 10 years with an AIDS organization in New Brunswick and have established a well-respected reputation.) Prior to finalizing the research question and with the consent of Memorial University of Newfoundland's Interdisciplinary Committee on Ethics in Human Research (ICEHR)<sup>1</sup>, I secured support for the research project from the region's community-based AIDS organizations and from a research advisory team comprised of PHAs. This support was critical to the sampling strategy, since I relied primarily on AIDS organizations to recruit study participants. All seven AIDS organizations in the Maritime Provinces agreed to

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<sup>1</sup> The full submission for ethical review is attached (Appendix 1) and is discussed under Section 4.8.

distribute notices to prospective participants. In addition, the two HIV clinics in New Brunswick agreed to hand out notices to patients or to leave notices in their waiting rooms. Using both AIDS organizations and clinics was intended to increase sample diversity.

Marshall and Rossman (1995) describe the ideal research site as one where: entry is possible; there is a rich mix of people and conditions of interest to the study; the researcher is likely to build trust with participants; and data credibility is reasonably assured. The Maritime Provinces, coupled with my experience and credibility in this region, enabled all of these criteria to be met.

The overall sampling strategy was purposive. Purposive sampling involves selecting participants based on decisions about whose experiences can provide information about the topic under investigation (Lincoln & Guba, 1985). In answering the study's research question, it was essential to include PHAs with a wide range of income levels. In addition, Lincoln and Guba (1985) have noted that purposive sampling is especially useful in attaining a maximum variation of conditions, thus increasing the "likelihood that the full array of multiple realities will be uncovered" (p. 40). Rodwell (1998) makes a similar point, arguing that purposive sampling "is needed to achieve the maximum variation of multiple perspectives in an emergent inquiry" (p. 56). I was able to sample for a wide range of experiences by including people from the three Maritime Provinces, men and women, people of various sexual orientations and diverse ages, rural and urban residents, newly and longer-term low-income PHAs, and people at various

stages of illness—from HIV positive without symptoms to having been diagnosed with AIDS.

Purposive sampling is also used to reach a state of ‘completeness’, a concept Rubin and Rubin (1995) define as the point where the researcher is satisfied that he or she understands the phenomenon being investigated. They state that evidence of reaching this point is when “each additional interviewee adds little to what you have already learned” (p. 72). They use Glasser and Strauss’ (1967) term ‘saturation’ to label this point in a research endeavour. While I did not have the resources to continue sampling until I reached the point of saturation for all of the factors explored, the sampling strategy did permit the attainment of a high degree of completeness relative to participant diversity as evident by the paucity of new themes emerging in later interviews.

The sampling strategy resulted in a total of 27 PHAs being interviewed. Twenty-six of the participants were recruited through Maritime AIDS organizations. The remaining participant heard about the study through word of mouth. Unfortunately, notices distributed through HIV clinics did not result in any additional participants. Participants were 23 males and 4 females ranging in age from 30 to 53 years, with a median age of 39 years. Twenty-one participants described their sexual orientation as gay, 5 as heterosexual and 1 as bisexual. Fourteen participants resided in New Brunswick, 9 in Nova Scotia and 4 in Prince Edward Island. Two participants lived in a small town or rural community. The remainder of the participants lived in cities ranging in population from 58,000 (Charlottetown, Prince Edward Island) to 359,000 (Halifax, Nova Scotia). A wide range of educational levels were represented with one participant

reporting grade 8 as his highest grade completed to several participants having completed undergraduate or post-graduate university degrees. Participants tested positive for HIV between the years 1985 and 2001, with the median year being 1993. Eleven participants described their current health status as HIV positive without symptoms, 10 as HIV positive with symptoms, and 6 as having been diagnosed with AIDS. One participant's health condition had reached the point where he required various home support services. Finally, participants' annual pre-tax household incomes ranged from \$5,550 to \$70,000, with \$10,258 being the median income level.

To facilitate data analysis, participants were divided into two income groups based on their annual pre-tax household income: low-income and higher-income. Fifteen participants were grouped as low-income and 12 participants as higher-income. Twenty-three of the participants reported one-person household incomes, while 4 participants combined their incomes with a partner or spouse. Demographic and descriptive information for the two income groups is presented in Table 4.2. Overall, both income groups contained a broad range of representation with respect to gender, age, sexual orientation and stage of illness. The low-income group had no representation from Prince Edward Island. However, several participants from this province had incomes at the lower end of the higher-income range and shared experiences common to those with low-incomes. The difference in median income level for the two groups was \$19,709. Consistent with the well-established positive association between income and education (Statistics Canada, 1998), the higher-income participants had higher levels of formal education. Sources of income also differed for the two groups, with low-income

participants' primary source of income being public income security programs (e.g., provincial income assistance and Canada Pension Plan disability benefits). In contrast,

Table 4.2: Participant Description: Low-Income and Higher-Income

Characteristic	Low-Income (n = 15)	Higher-Income (n = 12)
Income:		
Range	\$5,550 - \$10,320	\$17,218 - \$70,000
Median	\$7,264	\$26,970
Primary Source of Income:		
Provincial Income Assistance (PIA) Only	9	0
Canada Pension Plan (CPP) Only	1	0
Combination of PIA and CPP	5	3
Other Income Maintenance Program	0	3
Employment	0	6
Province of Residence:		
Prince Edward Island	0	4
New Brunswick	9	5
Nova Scotia	6	3
Gender:		
Female	3	1
Male	12	11
Age:		
Range	32 – 53 years	30 – 52 years
Median	40 years	39 years
Sexual Orientation:		
Gay	11	10
Heterosexual	4	1
Bisexual	0	1
Highest Education Level Attained:		
Middle School	1	1
Some High School	6	0
Completed High School	5	5
Some Post Secondary	2	2
Post Secondary Degree/Diploma	1	4
Area of Residence:		
City	15	10
Small Town/Rural	0	2
Year Tested HIV Positive:		
Range	1985 – 2000	1985 – 2001
Median	1990	1993
Health Status:		
HIV+ no symptoms	4	7
HIV+ with symptoms	8	2
AIDS diagnoses	3	3

participants with higher incomes generally had full-time employment income or access to more generous income maintenance programs such as a private disability/medical pension. Several in this group attained their higher-income status through a combined household income.

As data analysis proceeded, it became apparent that participants whose low incomes were long term had different experiences from those whose low incomes were more recent. For example, in reviewing people's accounts of accessing provincial income assistance, some participants appeared to have greater success in negotiating optimal services. In comparing participants, effective negotiation of services seemed linked to having had previous stable employment—a characteristic of the newly low-income. This observation led to a more systematic examination of differences between newly- and long-term low income participants. Participants with low incomes were therefore divided into two sub-categories: long term low-income and newly low-income. Participants in the first category had low incomes for many years. Most were receiving provincial income assistance only and had been at the time that they first tested HIV positive. The newly low-income group consisted of participants who were no longer able to work due to HIV symptoms and illness. When working, their incomes had been in the higher-income range. They now received their income from provincial income assistance and/or CPP. Demographic and descriptive information for the two low-income groups is presented in Table 4.3. Both groups included a range of diversities. The median income level for the long term low-income group was approximately \$3,000 less than that of the newly low-income group.

Table 4.3: Participant Description: Long Term Low-Income and Newly Low-Income

Characteristic	Long Term Low-Income (n = 9)	Newly Low-Income (n = 6)
Income:		
Range	\$5,550 - \$10,184	\$7,080 - \$10,320
Median	\$6,908	\$10,012
Primary Source of Income:		
Provincial Income Assistance (PIA) Only	8	1
Canada Pension Plan (CPP) Only	0	1
Combination of PIA and CPP	1	4
Other Income Maintenance Program	0	0
Employment	0	0
Province of Residence:		
Prince Edward Island	0	0
New Brunswick	7	2
Nova Scotia	2	4
Gender:		
Female	1	2
Male	8	4
Age:		
Range	32 – 53 years	33 – 52 years
Median	41 years	37 years
Sexual Orientation:		
Gay	8	3
Heterosexual	1	3
Bisexual	0	0
Highest Education Level Attained:		
Middle School	1	0
Some High School	4	2
Completed High School	3	2
Some Post Secondary	0	2
Post Secondary Degree/Diploma	1	0
Area of Residence:		
City	9	6
Small Town/Rural	0	0
Year Tested HIV Positive:		
Range	1985 – 2000	1987 – 2000
Median	1990	1993.5
Health Status:		
HIV+ no symptoms	3	1
HIV+ with symptoms	5	3
AIDS diagnoses	1	2

As indicated above, the overall sampling strategy resulted in 27 PHAs taking part in the interviews. While the literature does not provide definitive guidelines for the optimal sample size (other than sampling until one has reached saturation), Lincoln and Guba (1985) suggest that a dozen or so interviews is often sufficient. Luborsky and Rubinstein (1995) noted that “from 12 to 26 people in each study cell seems just about right to most authors” (p. 105). Interviewing 15 participants with low-incomes and 12 participants with higher-incomes fits with these general guidelines. This number of participants proved large enough to provide the necessary diversity for comparison and completeness, yet was still small enough to make the study feasible through the use of in-depth interviews.

#### 4.5 Data Collection

I collected all the data myself, through individual, face-to-face, semi-structured interviews that ran between one and three hours, with the median duration being 90 minutes. All of the participants opted to be interviewed in English (versus French) which made translating the description of the research and consent form unnecessary. A semi-structured interview format permits the researcher to guide the interview process through the use of a pre-determined series of questions or topics and associated probes, while still providing the participants with considerable latitude in how they answer (Bryman & Burgess, 1999; Rubin & Rubin, 1995). As an example of the latter, I made extensive use of open-ended questions to allow respondents to share their perspectives in their own words (Rubin & Babbie, 2001). The interviews proceeded from more general questions to more specific ones and probes for each of the areas explored, as I sought clarification,

details and examples stemming from the participants' initial responses (Lincoln & Guba, 1985; Rodwell, 1998; Rubin & Rubin, 1995). In this way, I could examine the accounts shared by respondents in the context of the overall discussion or conversation (Paget, 1999), as well as with rich detail and illustrations.

The semi-structured interview format proved to be particularly well suited to the study, where the research question had already been determined and areas of interest specified, and where the participants' perspectives were key to understanding the areas under exploration. Strengths of qualitative research, discussed earlier under methodology, also apply to the interview format (i.e., useful in exploration, facilitates detailed and in-depth understandings, and promotes an interactive, dialogical relationship between the researcher and the participants). Before choosing the semi-structured format, however, I had considered two other methods of data collection: focus groups and narrative inquiry.

I had thought of using focus groups in order to get input from a greater number of PHAs and to benefit from group interaction (e.g., participants building upon each other's ideas) (Kitzinger, 1994). In the end, I rejected this approach because I did not think it would give me an adequate understanding of individual participants' experiences (Kitzinger, 1994), which is essential to making comparisons between income groups. In addition, the highly personal nature of the areas explored (e.g., social supports, coping mechanisms) might have inhibited participation. Since confidentiality is less ensured in a group format, disclosure of personal and sensitive information also places participants at greater risk of harm than in individual interviews. I considered a narrative case study approach because of its potential to elicit in-depth and detailed descriptions of people's

lives. Such descriptions would facilitate a comparison between low- and higher-income participants. However, narrative inquiry is both time and labour intensive (Marshall & Rossman, 1995), so I would have had to reduce the number of interviews. A smaller number of participants would probably have reduced sample variation and the chance of detecting differences between income groups. In the end, I concluded that the semi-structured interview format provided the optimal balance of breadth (i.e., number of participants and variation) and depth (i.e., degree to which an individual PHA's experience could be explored).

'Tools' or aspects of the interview process that were particularly helpful in conducting the interviews and in managing the collected data included: the interview guide, attitude and skills of the interviewer, and recording and transcribing the interviews. In addition, ICEHR guidelines for ethical approval provided direction on planning and conducting the interviews. However, this latter discussion is contained in the upcoming section on ethical considerations.

An interview guide is used to provide structure to the interview, to help keep the interviewer focused on the main topics or themes and to prevent the interviewer from getting lost (Rubin & Rubin, 1995). The interview guide in this study was a checklist of main questions and topics to be covered with the participants (Rodwell, 1998). I organized the questions under five headings that covered background information, the three areas of social domains explored, and life in general (see Appendix 4). Although the interview guide provided structure and focus for the interview, as alluded to in earlier discussion, I took advantage of the flexibility of a qualitative design to pursue additional

questions or leads that arose during the course of a particular interview (Bryman, 1999; Lincoln & Guba, 1985; Rubin & Rubin, 1995). I also expanded the interview guide based on issues that emerged in earlier interviews. For example, several of the first participants interviewed spoke of the stress they experienced on cheque day (i.e., the day that they receive their income assistance benefits). This became a topic that I asked all subsequent participants about. The interview guide also served as a record of what was explored in each interview (Rodwell, 1998).

The attitude and skills of the interviewer are critical to establishing a relationship with participants that is conducive to open and in-depth communication (Andersen, 1999; Rodwell, 1998; Rubin & Rubin, 1995). Rubin and Rubin (1995) have found the following skills and approach useful in establishing such a relationship: conducting oneself in an ethical manner; being clear about study rationale and process; reassuring participants that they have something valuable to contribute to the study; demonstrating good listening skills; showing understanding, empathy, interest and respect; and establishing rapport before introducing more difficult and sensitive topics. This approach to relationship building has much in common with competent social work practice. And as a Master's trained social worker with 12 years of experience, I was able to demonstrate the necessary attitude and utilize the appropriate skills to carry out effective qualitative research interviews. This approach to interviewing, along with the use of open-ended questions, also likely reduced the degree of social desirability bias in participants' responses—that is “the tendency of people to say or do things that will make them or their reference group look good” (Rubin & Babbie, 2001).

Another consideration was my close association with PHAs and community-based AIDS organizations in the Maritime region. A close association with the research topic or population group presents both advantages and disadvantages. My familiarity with the research focus facilitated the development of trusting relationships with the participants and an ease in understanding their responses (Lofland & Lofland, 1984). On the other hand, I needed to be conscious of maintaining some distance so that my own ideas did not prevent me from understanding the participants' perspectives (Lincoln & Guba, 1985) or that due to 'over-rapport', I ignored perspectives other than those of the participants (Hammersley, 1999; Lofland & Lofland, 1984). I believe that I was able to establish a good balance between familiarity and detachment. I was in a fortunate position in that my ten years of experience with HIV/AIDS provided some closeness to the issue, but having recently left my employment in this field to pursue doctoral research gave me some distance. In addition, several means of ensuring that study findings reflect participant perspectives are discussed below under validation issues.

I audio taped the interviews with participants' consent. All participants agreed to the audio recording. Audio taping interviews provides a credible data source, assures accuracy and completeness, provides opportunity to review the interview, and enables the interviewer to focus on the interview with less worry about recording (Lincoln & Guba, 1985; Rubin & Rubin, 1995). These advantages outweighed the potential disadvantages associated with audio taping. The disadvantages include respondent distrust, mechanical failure and the amount of time to transcribe tapes (Lincoln & Guba, 1985; Rubin & Rubin, 1995). Furthermore, audio recordings do not capture all aspects and dynamics of

an interview (e.g., body language). For this reason, I wrote notes of the tone and context of each interview (Poland, 1999) and kept a reflexive journal of my ideas, insights and conjectures (Rubin & Rubin, 1995). These notes taken during data collection proved important since this stage of the research overlaps with data analysis (Eisenhardt, 1999). For example, the journal allowed me to track issues to pursue in subsequent interviews. This analysis was especially important because the interviews were conducted before the first interview tapes were transcribed. I discuss more about the use of a reflexive journal under validation issues.

Three people transcribed the interview tapes, which was invaluable since transcription was time-consuming. I used several strategies suggested by Poland (1999) to reduce transcription error and to maximize transcription quality. These included training the transcribers (e.g., supplying an example of a portion of a transcribed tape and providing instructions on how to note pauses, laughing, words that cannot be understood, and emphasis) and meeting regularly with the transcribers to review their work. In addition, I took steps to ensure that the transcribers complied with ethical principles of privacy and confidentiality (e.g., having them sign an oath of confidentiality, carrying out the transcribing in a private setting, and storing tapes and transcripts in a secure location). I also ensured that the interview settings and equipment facilitated good quality recordings (Poland, 1999).

#### 4.6 Data Analysis

While the research question and purpose determined the general areas to be explored, other salient issues emerged from the data—that is from the participants’

sharing of their experiences and understandings. This hints at two related characteristics of qualitative research: its emergent design and the overlap between data collection and data analysis (Corbin & Strauss, 1990; Eisenhardt, 1999; Lincoln & Guba, 1985; Marshall & Rossman, 1995; Rodwell, 1998). Emergent categories and themes identified through data analysis can lead the researcher to adjust his or her data collection strategy (Eisenhardt, 1999; Rodwell, 1998). As already mentioned, I modified the interview guide based on analysis of previously collected data. Eisenhardt (1999) cautions, however, that this “flexibility is not a license to be unsystematic” (p. 145) but rather is a planned process of taking advantage of the emergent information.

The following activities were carried out in the data analysis process. Although organized to reflect the overall order in which they were performed, the process was not linear but flexible and iterative.

#### 4.6.1 Coding

I began the analysis of each transcript by reading it for overall content. This allowed me to think about the data in the context of the entire interview and to start forming ideas about how the information could be categorized (Rubin & Rubin, 1995). The actual coding process involved “grouping interviewees’ responses into categories that bring together the similar ideas, concepts, or themes” (Rubin & Rubin, 1995, p. 238) by assigning a segment or unit of text to a particular coding category. I did not predetermine the size of the text segments but rather based their size on the amount of text that was required to describe the event or idea. Some of the coding categories were predetermined and reflected headings of the interview guide, while other coding

categories emerged from the data (Buston, 1999). I then used this combination of predetermined and emergent categories to code the subsequent interviews.

Rubin and Rubin (1995) suggest that the researcher work out the coding categories by first using a small sample of interviews. Furthermore, if the interviews are chosen to reflect maximum variation (e.g., low and higher income, rural and urban residence, male and female) the set of categories that emerges should be fairly complete and require minimal adjustment later. Following this advice, I developed a coding scheme based on the analysis of an initial set of six interviews that reflected a diverse range of participants. This resulted in a relatively stable set of categories that required little revision as subsequent analysis proceeded.

The coding scheme included two types of categories: descriptive and conceptual (Buston, 1999). I used descriptive categories to organize participants' accounts of activities and events for each social domain explored. I used conceptual categories to code segments of text that reflected abstract concepts, perhaps arrived at through some interpretation on my part (Buston, 1999). Some text was coded under both descriptive and conceptual categories. To illustrate, I placed one participant's account of having to leave work due to illness under the descriptive category 'leaving work' as well as under the conceptual category 'self-worth' since the participant described how leaving work resulted in a loss in self-esteem. Descriptive and conceptual categories assisted in analyzing specific areas of social domains as well as concepts that ran through several areas under investigation (Buston, 1999).

NUD\*IST Vivo (NVivo) software for qualitative analysis facilitated the coding process. I could code text segments of any size and once coded, the data was automatically stored under the assigned coding category. I could also easily retrieve the material in each category. Since the coded information could be linked back to the original interview, NVivo also enabled me to make comparisons of coded data with respect to specified demographic characteristics such as income level. After coding groups of five to ten interviews, I carried out within and across category analysis. I repeated this process until each of the 27 interviews were included in the analysis.

#### 4.6.2 Within and Across Category Analysis

The goal of within category analysis is to attain a thorough understanding of the descriptive area or concept that a category represents. To this end, I examined and compared the material within each of the categories in order to assess the uniformity of examples and experiences in each category (Rubin & Rubin, 1995). For example, of particular interest were similarities and differences for the various income groups. Being familiar with each of the categories on a stand-alone basis then helped in making comparisons across categories (Eisenhardt, 1999).

The goal of across category analysis is to detect patterns, and possible links or relationships between categories (Rubin & Rubin, 1995). As anticipated, some linkages were easily detected, since participants themselves raised several issues together, and pointed out their relationships (Rubin & Rubin, 1995). For example, participants made reference to low income causing stress. Analysis across coding categories also enabled me to see “linkages that are much less obvious by putting related ideas in proximity to

each other that were not raised at the same time or by the same interviewee” (Rubin & Rubin, 1995, p. 254). For example, I was able to detect how having had stable employment, which was the case for newly-low income participants, provided some advantage in securing volunteer work and in negotiating income assistance.

The within category analysis provided a range of well defined and described categories, and along with the linkages detected through across category analysis, resulted in a thorough understanding of the areas under investigation. I also used member checks, described more fully in the next section under credibility, to provide participants with opportunity to assess how well their perspectives were reflected in the findings. I was able to provide 18 participants with a preliminary report of the study findings. Of the seven participants who got back to me, all were satisfied with the report and two participants took the opportunity to make additional comments. Their comments did not contradict the report findings but rather expanded on them.

#### 4.6.3 When to Stop, Use of the Literature and Writing the Final Report

Confirmation by the participants that the findings accurately reflected their experiences and that the overall analysis ‘made sense’ provided indication that it was appropriate to move into the next phase of data analysis (Lincoln & Guba, 1985; Rodwell, 1998). The next phase involved writing the final report and examining the findings in relation to the literature (Charmaz, 1990; Eisenhardt, 1999; Rubin & Rubin, 1995). Charmaz (1990) points out: “through writing and rewriting, the researcher can bring out implicit arguments, provide a context for them, make links to the literature, critically examine the categories and concepts, and present the data cogently” (p. 1170).

In this final stage, my goal was to attain an integrated set of findings that described the phenomena under investigation, along with suggested explanations for the patterns and relationships observed (Rubin & Rubin, 1995). To this end, in Chapter 5, I describe the participants' experiences and in Chapter 6, I present a discussion and synthesis of the findings. The discussion and synthesis draws upon literature from the substantive area as well as from the theoretical frameworks that underpin the study. Finally, data analysis also ties in with the development of implications (Rubin & Rubin, 1995). My concluding chapter includes implications for social work practice.

#### 4.7 Validation Issues

How do we judge a research project to be of value? The research goal provides a starting point for this discussion. Hammersley (1990) argues that the goal of social research is “to produce knowledge that is of public relevance” (p. 56). Consistent with this goal, he suggests two criteria for assessing the value of research: validity and relevance. I agree with Hammersley's position, and will use the concepts of validity and relevance, supplemented by the overarching theme of transparency, to map out the handling of validation issues in the study. Table 4.4 summarizes the criteria used to establish validity and relevance.

##### 4.7.1 Validity

Hammersley (1990) sees validity as “the extent to which an account accurately represents the social phenomena to which it refers” (p. 57). Of course, judging the accuracy of how social phenomena are represented raises questions of ontological and epistemological congruency. As Lincoln and Guba (1985) point out, “different basic

beliefs lead to different knowledge claims and different criteria” (p. 294). Earlier in this chapter, I discussed my position that people form subjective understandings of social phenomena but that there is also a social reality independent of any one participant. As such, I will use criteria for ensuring validity in a manner consistent with this epistemology.

Table 4.4: Validity and Relevance Criteria

Criteria	Means Used to Attain
Credibility	<ul style="list-style-type: none"> <li>• prolonged engagement</li> <li>• triangulation</li> <li>• negative case analysis</li> <li>• member checks</li> </ul>
Dependability	<ul style="list-style-type: none"> <li>• description of the research methodology</li> </ul>
Confirmability	<ul style="list-style-type: none"> <li>• detail and illustration in reporting and analyzing the data</li> </ul>
Importance	<ul style="list-style-type: none"> <li>• literature review</li> <li>• consultation with community stakeholders</li> </ul>
Contribution	<ul style="list-style-type: none"> <li>• literature review</li> <li>• findings</li> </ul>
Transferability	<ul style="list-style-type: none"> <li>• provision of a description of the research context</li> </ul>

Lincoln and Guba (1985) have developed a framework for establishing the ‘trustworthiness’ of research that consists of four criteria: 1) credibility, 2) dependability, 3) confirmability, and 4) transferability. Although Lincoln and Guba come from a constructivist research approach, with a relativist ontology and subjective epistemology, aspects of their framework can be used in a manner consistent with this study’s epistemology. I contend that credibility, dependability and confirmability provide a sufficiently comprehensive set of criteria for both ensuring and assessing the validity of this research project. These are discussed below, with transferability reserved for the discussion of relevance.

#### 4.7.1.1 Credibility

Credibility refers to the degree to which the study's participants can see their accounts of the social phenomena being studied accurately reflected in the research findings (Lincoln & Guba, 1985). Lincoln and Guba (1985) propose a twofold task for implementing the credibility criterion: first, carrying out “the inquiry in such a way that the probability that the findings will be found to be credible is enhanced” (p. 296), and second, having the findings approved by the participants. I utilized prolonged engagement, triangulation, and negative case analysis to increase the likelihood of attaining credible findings (Lincoln & Guba, 1985). In addition, I conducted member checks to assess the degree to which credibility was attained (Lincoln & Guba, 1985).

Prolonged engagement entails spending sufficient time in the research process “to learn the context, to minimize distortions, and to build trust” (Lincoln & Guba, 1985, p. 307). Lincoln and Guba (1985) argue that it is not possible to understand any phenomenon without understanding its cultural context. Here I had the advantage of ten years of experience in the field of AIDS in the Maritime Provinces. This prolonged engagement has given me a good understanding of the contexts of the lives of PHAs. My long involvement and closeness to the issues allowed me to be readily accepted by the participants and to integrate easily into HIV-related discussion—cutting down on hesitancy and mistrust on the part of participants. Evidence of this was the participants' openness to discuss all of the interview topics.

With respect to triangulation, Lincoln and Guba (1985) have suggested that credibility can be enhanced through the use of different data sources, different data-

collection methods, and more than one investigator. To some extent, I have used all three of these methods. As already discussed, a quantitative study has been carried out with New Brunswick PHAs. The confidence in the validity of this study is enhanced by congruence between the two sets of findings (Hammersley, 1990). In a limited way, the Research Advisory Team fulfilled the criterion of multiple investigators since they were involved in some data analysis (e.g., reviewing the preliminary themes that emerged and draft chapters of the findings, discussion and synthesis). [Note: Guba and Lincoln (1989) have moved away from triangulation as a technique for establishing credibility, finding it too positivistic. However, I believe triangulation does not conflict with an epistemology that encompasses radical structuralism.]

I also used negative case analysis in establishing credibility (Lincoln & Guba, 1985). Lincoln and Guba (1985) describe negative case analysis as the process of revising a hypothesis based on the detection of cases that do not fit with the original hypothesis. In theory, revisions are done until the final hypothesis can account for all cases without exception. Along this same line, I took into account the minority perspectives of participants in formulating descriptions and suggested patterns and relationships. For example, I sought explanations for emergent relationships that did not hold true for all participants of a certain income group. This led to differentiating between the experiences of newly low-income and long term low-income participants.

According to Lincoln and Guba (1985), member checks are the most important criteria for assessing credibility. Through the use of member checks “analytic categories, interpretations, and conclusions are tested with members of those stakeholding groups

from whom the data were originally collected” (Lincoln & Guba, 1985, p. 314).

Confidence in the credibility of the findings is derived from the participants’ agreement that their accounts are adequately represented.

I performed member checks through three means. First, I obtained permission from participants to contact them if there was something in their respective interview transcript that required clarification or expansion. I contacted four participants for such reasons. A more formal phase of member checking occurred through providing participants with a copy of the preliminary findings. This allowed participants to ensure that their accounts were accurately reflected. As reported earlier, seven participants responded to the preliminary report. All seven participants approved of the report and two provided additional information that was subsequently incorporated. The final form of member checking relied on the involvement of the Research Advisory Team members who, as representatives of PHA communities, reviewed the preliminary analysis and the findings and discussion chapters.

#### 4.7.1.2 Dependability

Dependability is the second criterion that I used to establish validity.

Dependability is concerned with the soundness of the research process (Lincoln & Guba, 1985). In order to demonstrate dependability, this report contains a detailed description and justification of the research methodology. This should enable readers to judge for themselves the appropriateness of the data collection and analysis procedures.

Techniques used to establish credibility also contributed to the study’s soundness of design (Lincoln & Guba, 1985; Rodwell, 1998).

#### 4.7.1.3 Confirmability

Confirmability is the final criterion that I used to establish validity. This is concerned with a logical link between the data and the research findings (Lincoln & Guba, 1985). A researcher achieves confirmability by ensuring that findings “can be tracked to their sources” (Lincoln & Guba, 1989, p. 243) and that interpretations are supported by the data. This does not mean, however, that only one interpretation of data is possible. But rather, the logic between data and inference should always be evident. My attempt to demonstrate confirmability consists of clearly separating the findings (i.e., Chapter 5) from the discussion and synthesis of the findings (i.e., Chapter 6) to allow the reader to arrive at his or her own conclusions regarding the logic between data, findings and interpretations. Furthermore, the findings in Chapter 5 are illustrated and supported by actual interview data.

#### 4.7.2 Relevance

Relevance is the second concept that I used to assess the value of the proposed research. Hammersley (1990) contends that it is not sufficient for research findings to be valid; “equally important is that they make a contribution to knowledge that is relevant to some public concern” (p. 107). He proposes two criteria for determining relevance:

1. The importance of the topic. The research topic must relate (however remotely) to an issue of public importance.
2. The contribution of the conclusions to existing knowledge. The research findings must add something to our knowledge of the issue to which they relate. Research that merely confirms what is already beyond reasonable doubt makes no contribution. (Hammersley, 1990, p. 107)

I suggest that these two criteria, importance and contribution, along with Lincoln and Guba's (1985) transferability criterion for establishing trustworthiness, provide a framework for operationalizing the concept of relevance.

#### 4.7.2.1 Importance

My first chapter argues for the importance of this research. The well-being of people living with HIV/AIDS is an issue of public concern. Given the links between HIV infection and poverty and between income level and health, a more thorough understanding of the lives of PHAs in the context of income is critical to developing effective responses to the needs of this population group. Consistent with a community-based research design, consultation with community stakeholders was paramount in establishing the relevance of the research. A consultation that I carried out with the executive directors of Atlantic community-based AIDS organizations resulted in their full agreement on the importance of the research focus. In addition, members of the Research Advisory Team fully endorsed the importance of the study. The ongoing participation of PHAs through the Research Advisory Team also helped ensure that the research remained relevant to PHA community interests.

#### 4.7.2.2 Contribution

Hammersley (1990) offers several means through which research can contribute to the existing knowledge of a particular issue. These include filling gaps in the literature, testing previous findings, reformulating something taken for fact, checking to see if findings remain true, and testing theory. Filling gaps in knowledge fits with the purpose of this research project. As outlined in the introductory chapter, the study's findings

contribute to the understanding of the experiences of PHAs of differing income levels and to the development of population health theory by suggesting possible links between income and other factors that affect health and well-being. The significance of these contributions is heightened given that there are relatively few published studies that compare the experiences of PHAs of various income levels across a broad range of factors that influence health and well-being.

#### 4.7.2.3 Transferability

Transferability refers to the extent to which a study's findings have application in another site or context (Lincoln & Guba, 1985). Since transferability is about applying findings in other situations, it relates to the issue of relevance. The researcher, however, cannot be responsible for assessing the application of findings to another setting since he or she will not have knowledge of that site. Rather, the researcher needs to provide a thorough description of the research context in order to assist others in determining the transferability of findings (Lincoln & Guba, 1985). Ultimately, the research user must decide whether or not there is sufficient similarity between the research context and the new setting for transferability (Lincoln & Guba, 1985). My description of the study's setting, the participants, the research focus, and the findings will facilitate decisions about transferability (Rodwell, 1998). I also note considerations related to transferability in the limitations section of this chapter.

#### 4.7.3 Transparency

Transparency is the final concept that I used to address validation issues. Rubin and Rubin (1995) describe transparency as enabling the reader to follow the basic

processes of data collection and “to assess the intellectual strengths and weaknesses, the biases, and the conscientiousness of the interviewer” (p. 85). Rubin and Rubin’s (1995) concern is with the transparency of the research method, achieved through keeping good records of the process. However, I believe the concept of transparency applies to all aspects of the research project, from justification of focus to writing the final report.

I have attempted transparency by presenting the research question with clearly defined terms; a discussion of the theoretical frameworks where underlying assumptions are explicitly stated; a detailed description of the methodology; and a discussion of what I see as the study’s limitations. Specific to this section on validity and relevance, transparency strengthens the application of many of the criteria used. For example, demonstrating dependability requires that the reader has access to a detailed description of the research process. Similarly, for the reader to assess confirmability he or she needs to be provided with sufficient detail and illustration to see the logic between data and interpretations. Here clarity was particularly important since I came to my own understandings of participants’ experiences, in large part influenced by structural social work theory and related theories on oppression. However, and as reported above, I separated the findings from the discussion and synthesis of the findings in order to present the participants’ accounts as much as possible from their perspectives. My analysis of the findings was then reported in a separate chapter.

In addition to the final report, I kept a reflexive log to record salient aspects of the research process. I used Lincoln and Guba’s (1985) suggestion for organizing a reflexive journal around three headings: 1) the schedule of events, logistics of study and contacts,

2) the methodological log (i.e., research design decisions and accompanying rationale), and 3) personal diary (e.g., growing insights, and issues related to values and beliefs).

This log helped me track information needed to write a transparent report.

#### 4.8 Ethical Considerations

According to Rubin and Rubin (1995), “research ethics are about how to acquire and disseminate trustworthy information in ways that cause no harm to those being studied” (p. 93). I view ‘those being studied’ as the research participants as well as the PHA communities of the Maritime Provinces. As such, conducting the research in an ethical manner required that I paid attention to PHAs as individual participants and as a collective.

Adhering to the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS; 1998), as required by Memorial University of Newfoundland’s ethics review process safeguarded against unethical practice. Memorial University’s Interdisciplinary Committee on Ethics in Human Research (ICEHR) provided guidelines on what issues should be considered, including: 1) Harms and Benefits; 2) Scholarly Review; 3) Free and Informed Consent; 4) Privacy and Confidentiality; 5) Conflict of Interest; 6) Inclusiveness; and 7) Aboriginal Peoples. The full submission for ethics review is attached (Appendix 1), with some of the more critical considerations identified below.

A key principle of the TCPS document is protecting participants where any potential for harm is above the range of minimal risk, that is “greater than those encountered by the subject in those aspects of his or her everyday life that relate to the

research” (1998, p. 1.5). While I believe that the potential harm to participants in this study is within the range of minimal risk, I needed to pay particular attention to some concerns. The subject matter of the interviews was highly personal and sensitive, and for some participants discussing the topics being explored could evoke distressing feelings (Rubin & Rubin, 1995). As an experienced social worker, however, I felt confident that I possessed the necessary skills to assist a participant in acknowledging any painful feelings, and to make a referral to an appropriate agency if this were necessary. While discussion did evoke sad and angry feelings for some participants, at no time did this progress to a point where I felt a participant was at risk. No participant indicated that the interview was a negative experience and in fact, many reported that they enjoyed and appreciated the opportunity to discuss the issues explored. Being familiar with HIV and income-related services, I was able to answer questions that participants had about obtaining resources. This dual role of researcher and information provider did not appear to negatively affect the interviews.

Other safeguards against harm to participants were more typical of the ways ethical concerns are addressed in research. For example, I took measures to assure “that anyone who is a subject of research should participate in the research voluntarily and with full information about what the research involves” (ICEHR, 2000, p. 4). Furthermore, this ‘free and informed’ consent was maintained throughout the participant’s involvement in the research (TCPS, 1998). Activities and tools that I used to ensure this consent included providing the participants with a verbal and written description of the research (e.g., research purpose, nature of participation, and foreseeable

harms and benefits) and having them sign a consent form (copies of the research description and consent form are included as Appendices 2 and 3 respectively). I also left each participant with a copy of the consent form. This listed all the items that the participant was agreeing to (e.g., audio recording, transcribing and analyzing of interviews, member checks, right to withdraw consent to participate at any time and to not answer some questions, and the use of quotes in the final report).

The measures used to protect participants' privacy and confidentiality were also a part of the research description and of free and informed consent. For example, I informed participants about who would have access to the audio tapes and interview transcripts (e.g., the transcribers and me). In addition, I explained that information would not be presented in the final report in ways that could inadvertently disclose the identity of a participant (e.g., personal information would be presented with minimal demographic description in order to provide anonymity). Finally, emphasis on maximum variation fits well with a research design that does not arbitrarily exclude any population group from participating in the study (ICEHR, 2000).

In addition to safeguarding the interests of individual participants, I believe it is important to give thought to the interests of PHAs as a collective. Finch (1999), in doing research with women, found that one way of ensuring that her research findings would not be used to harm women was to provide a structural analysis of the issues explored. As one example, she linked women's seeming acceptance of subordinate roles to accommodating exploitative structures, in contrast with a superficial acceptance that women are satisfied with being restricted to such roles (Finch, 1999). I used structural

analysis in a similar manner. As an illustration, long term low-income participants appeared to have less effective communication skills in dealing with income assistance personnel in comparison to participants whose low-income levels were more recent. In the analysis of this finding, however, I was able to point out that through exclusion from the workforce, long term low-income participants were also denied opportunity to develop skills that could help in negotiating income assistance benefits. Another safeguard of the interests of PHAs as a collective was the Research Advisory Team. Having an advisory team made up of members from Maritime PHA communities assured that the data was analyzed in ways that would be useful to PHA communities.

#### 4.9 Limitations of the Study

The limitations of this study can be categorized as either being inherent in the research design or stemming from the implementation of the study. As discussed below, the sampling and data-collection strategies have limitations. In addition, several limitations emerged as the study proceeded.

While the sampling strategy was appropriate to the study's goal of attaining a rich description of the experiences of low to higher income PHAs, the relatively small number of PHAs that would be interviewed and the diversity of the sample was expected to place some limits on the completeness of the findings. I believed that the small sample size and diversity of participants would not permit areas of interest to be explored until no new information emerged (i.e., saturation). In a sense, the design reflected a trade off between maximum range of participant characteristics (in order to capture variation in experiences among PHAs) and the attainment of a more complete set of findings that could come

from interviewing a more similar group of PHAs. In my assessment, however, this trade off was warranted in order to be as inclusive as possible and to generate findings with potentially wide application. In the end, I was pleased with the degree of completeness that the study was able to attain relative to sample variation, as evident by few new themes emerging in the later interviews.

A limitation in the data-collection strategy stemmed from conducting interviews at one point in time. This reduced the likelihood of capturing changes in participants' understandings of their experiences, and so limited the depth of the radical humanist analysis. To a certain extent, this limitation was offset by participants' recall and sharing of how their perceptions changed over time (e.g., from feeling guilty about receiving income assistance to reframing it as entitlement). Social desirability bias likely contributed to a second inherent limitation in data collection. Even though a non-judgemental attitude was conveyed and open-ended questions utilized, it is likely that some participants provided answers consistent with expected social beliefs. For example, there is much social affirmation of those who are involved in work and condemnation of those perceived as able to work but not doing so. Such external pressure (which can also be internalized) may have contributed to a participant's reluctance to discuss a desired lifestyle that did not involve either paid or volunteer work.

The limitations associated with the implementation of the study related to the diversity of the sample and the low response rate to the formal member check. Although participants reflected a broad range of representation (e.g., people of various income levels, newly and longer-term low-income PHAs, men and women, people of various

sexual orientations and diverse ages, and people at various stages of illness), the experiences of certain demographic groups may not be completely reflected in the findings due to low participation from these groups. For example, only four women, six people with heterosexual sexual orientations and two residents of small towns/rural communities participated in the study. Other sources of variation were represented by only one PHA (i.e., Acadian and First Nations representation). Other diversities were missed altogether (e.g., visible minorities other than First Nations). Greater representation from these groups would have increased the completeness of the findings in relation to these diversities. In addition, all but one of the participants were recruited through community-based AIDS organizations and this may also have limited the diversity of experiences. PHAs who do not use AIDS organizations may be different from those who do (e.g., perhaps they are in less need of AIDS organization services, are more dissatisfied with the services, face access barriers, are more fearful of jeopardizing their anonymity, or perceive AIDS organizations as serving only gay men). The study also had no representation of lower-income PHAs from Prince Edward Island. However, this limitation was offset by participation of several people from this province whose incomes were just slightly above the low-income cut off. Their accounts often resembled the experiences of lower-income participants from other provinces. Any limitation to maximum variation of participants affects the overall completeness of the findings in relation to the phenomena being explored. The make-up of the participants and limitations in representation are important when making judgements about the transferability of findings.

Finally, the low response rate to the formal member check (7 responses out of 18 preliminary reports distributed to participants) raises concerns about the degree to which all participants' accounts were accurately reflected in the research findings (Lincoln & Guba, 1985). Furthermore, the member check met with only moderate success in terms of representation from all key participant groups. The seven member check participants included individuals from all three Maritime Provinces (1 from New Brunswick, 3 from P.E.I., and 3 from Nova Scotia) and main income groups (2 low-income and 5 higher-income participants). However, all seven participants were male and both low-income participants were from the newly low-income category. Although all seven of those responding approved the preliminary findings and analysis, the findings would be more credible if more participants and a greater diversity of participants had provided feedback.

## Chapter 5

### Findings: Work, Service Use and Informal Relations

By providing a focus and parameters for the study, the research question guides the analysis process. As previously presented, the central research question in this study is: How do people of different income levels who are living with HIV/AIDS experience 1) paid and volunteer work; 2) private, government and non-profit services; and 3) informal social relations. The intent of the research is to gain a comprehensive and in-depth understanding of 1) how factors related to the specified areas of social domains, such as challenges faced and strengths and supports used to cope with stressors, affect the health and well-being of PHAs; and 2) differences for PHAs of varying income levels. To attain this understanding, the analysis should include rich and detailed description, and discuss suggested patterns and possible relationships among the various factors explored. To this end, this chapter describes the experiences of the participants in the social domains explored with attention to the two perspectives inherent in structural social work—radical humanism and radical structuralism. In Chapter 6, I will present a discussion and synthesis of these findings through a more theoretical examination of factors that affect the attainment of social domain aspirations and by drawing upon emergent themes that overarch the three social domains explored. Thus Chapter 5 provides the basis for the more theoretical discussion in Chapter 6.

In keeping with the research question, the findings in this chapter are organized under the following categories: 1) paid and volunteer work, 2) private, government and

non-profit services, and 3) informal social relations. In each section, I discuss the experiences of the participants as a whole and point out differences for the various income groups. In this way, the broader description provides a context for reporting differences in relation to income. [Note: In order to protect the anonymity of participants, they chose fictitious names and occasionally I changed personal identifying information.]

## 5.1 Paid and Volunteer Work

### 5.1.1 Change in Employment Status due to HIV

Some participants reported that HIV has had little or no effect on their employment status, while others indicated that HIV has significantly affected their employment. Those who reported little or no effect, have either been able to remain fully employed since the time they tested HIV positive or had unsteady employment histories for reasons other than HIV. As an example of the former, Jack first learned that he was HIV positive two years ago. He continues to be employed with the same government department where he has worked for over ten years. Jack, like other participants who have continued to work full-time since their HIV diagnosis, has an income that falls within the higher-income range.

This stands in sharp contrast to participants who have struggled unsuccessfully for many years to attain stable employment and whose low incomes have generally been long term. For this group, barriers that impede obtaining employment often preceded their HIV infection and included: high unemployment rates, lack of employment opportunities, low education levels, physical health conditions unrelated to HIV, chronic mental health issues, learning disabilities, age discrimination and addictions. David, for

example, had physical and mental health conditions prior to HIV which prevented him from securing stable employment. He has concluded, however, that with the addition of symptoms from HIV, he will never be able to attain paid employment. So while symptoms related to HIV may add to a list of existing employment barriers, for some in this group HIV has reduced the likelihood of even periodic employment.

Other participants reported that HIV has played a primary and significant role in their change in employment status. For most in this group, the physical effects of HIV have rendered them unable to maintain paid employment. As Stephen, who left work two years after testing positive for HIV, explained:

*I started to get sick, and my doctor said I think you should quit work. Cause the work I was...was very physically as well as mentally demanding. And I just couldn't cut it anymore. (Stephen, higher-income)*

While most participants who left work due to illness cited physical health reasons, one participant said that he left work for emotional reasons. Vern explained that although he was physically able to work, he left work about ten years ago because he saw HIV inevitably leading to death:

*So...because I wasn't very informed of all about what HIV and AIDS was all about and all that kind of stuff and I just figured...I didn't want to work until the day I died type thing. (Vern, higher-income)*

Vern went on to say that after waiting several years and not becoming ill, he decided to return to work.

Other participants lost their jobs due to HIV discrimination or to a lack of accommodation of illness (e.g., employer's inflexibility around sick days) rather than from the direct effects of ill health. Clorise, who was working in a coffee shop, believes that her boss made up reasons for firing her once he found out her HIV status. Larry attributed being let go from his job as a maintenance worker to his employer thinking he would no longer be able to do strenuous work because of being HIV positive. Another participant who disclosed his HIV status to his employer in order to explain an absence from work was told by his employer that they needed dependable people. He was subsequently fired from his job with a restaurant. As a final example, Tyler shared the following about his experience working in a warehouse:

*I got sick while I was working, and then after I collapsed at work I didn't work for a couple of weeks until I was feeling better...and I got laid off after that...Well basically that job didn't want to hire me after that because you collapse in the middle of the warehouse that worries them. So I knew there was no job after that.*  
*(Tyler, higher-income)*

Participants who lost their jobs due to HIV discrimination often felt they had little protection or recourse, or that the cost of fighting the discrimination was too costly. This included the energy it might take to pursue a complaint. Alarming, these incidents did not all occur in the early years of AIDS where a lack of awareness was more common. All but one of the incidents of job loss took place within the last few years. Furthermore, the participants who experienced employment discrimination or lack of accommodation

worked in food industry and/or non-unionized labour jobs. This suggests that the type of work or employer may influence a person's vulnerability to workplace discrimination.

This is in marked contrast to the experiences of participants whose employers provide a greater sense of job security. Jack, a long-time government employee, expressed no fears of workplace discrimination:

*There are enough protections within government. It's really quite a supportive environment. In fact they're suppose to accommodate, like if I got to the point where I was, say unable to work as hard or needed to take a reduced workload, they're obliged to accommodate. (Jack, higher-income)*

Such a sense of security was not limited to government employment, several participants who worked for private businesses also reported similar levels of security.

### 5.1.2 The Experience of Leaving Work

Many of the participants who left work because HIV had affected their health described the decision to leave work as stressful, filled with fears and anticipated losses. Stephen expressed his concerns as follows:

*I was very apprehensive because at the time I thought how am I going to fill my days without work, and without my interaction with people...that I was going to be bored and I would have nothing to keep my mind sharp, and it was working with the public...and I was really going to miss that. I knew I was. I knew I was going to miss seeing all these people... (Stephen, higher-income)*

Terry emphasized the financial loss from being no longer able to work:

*Back then I was making \$36,000 a year ...so to go from that ...living by myself...to having to have a roommate ...and still barely surviving. Yeah, it was quite the transition. (Terry, newly low-income)*

For Terry, like others in the newly-low income category, leaving work and having to rely on government disability programs meant a significant decrease in annual income. Some participants also linked leaving work to a decrease in their sense of self-worth:

*Feeling of being a bum, living off of everybody that's paying into the unemployment system...into Canada Pension...yes there's a bit of a sense of loss there to one's esteem for sure. (Al, higher-income)*

For some participants, the stress of leaving work was compounded by learning at the same time that they were HIV positive (i.e., the reason for their illness) or having to disclose their HIV status to family members in order to provide an explanation for leaving work.

Several participants reported that their doctors played an important role in helping them decide when to leave work. Physician support and monitoring of health were especially valuable in the years leading to this decision. Participants also cited employers as a source of support. One participant, for example, took comfort in her employer telling her that she could return to the same job if her health improved. Another participant stated that his supervisor investigated benefit programs when it became apparent that he might have to leave work due to illness.

Several participants also spoke of seeking information on how to access income assistance programs. George decided to contact someone at a community-based AIDS

organization, who then referred him to the Canada Pension Plan (CPP) program.

Participants, who like George lacked private disability/pension benefits, described a fairly straight forward process in accessing income assistance programs. Typically, these participants went from employment to Employment Insurance to provincial income assistance to CPP disability benefits alone or in combination with provincial income assistance.

Jason, the lone participant accessing private disability benefits, however, described a more complicated process of moving from employment income to Employment Insurance benefits to long-term disability benefits and then finally to a medical pension:

*A lot of these things I wasn't really sure how they fit together and how they worked. So there'd be periods when I had absolutely nothing because I didn't have the knowledge to know when to apply for different things. So that made a lot of it very complicated and so I ended up leaving my job and really paring down my lifestyle because I didn't have the same financial basis anymore to live on and I was afraid. I didn't have a job. I didn't know if I was going to get a pension and for how long or any of these things. (Jason, higher-income)*

Jason stressed the usefulness of a service or counselling to assist in making decisions around leaving work and applying for various benefit programs (e.g., what programs are available, how they work and how they can be coordinated, when to apply, implications of various decisions). Such a service would have alleviated much of his stress and supported him when he was feeling tired and weak due to illness.

Participants who left work due to HIV-related discrimination reported feelings rooted in how they had lost their jobs. Clorise, who believes she was fired because of her HIV status, continues to carry hurt feelings:

*There was a lot of hurt feelings. Just stuff that I'm gonna, I'm probably going to carry around thinking, it angers me, but you can't prove anything...*

*(Clorise, newly low-income)*

These hurt and angry feelings, however, indicate that Clorise recognizes the unfairness of her firing rather than accepting as 'right' a social order that permits discrimination. This perspective is consistent with radical humanism, in that her thoughts about her dismissal freed her from self-blame and the further victimization of internalized oppression. Tyler who lost his job after becoming ill, went on to find another job. However, he still worries that he will become sick again and re-experience discrimination. He too was able to label his being fired as discrimination.

Although an upcoming section explores the benefits of volunteer work in detail, several participants spoke of the value of volunteer work in the context of leaving paid employment. Pierre cited volunteering with an AIDS organization immediately following leaving work as making the transition from paid employment much easier. The satisfaction he derived from volunteering offset any threat to self-worth from no longer being employed. Stephen, whose apprehensions about leaving work are reported at the beginning of this section, said that his fears did not materialize since volunteer work has kept him busy and engaged.

### 5.1.3 Paid Work Experiences

#### 5.1.3.1 Positive Aspects of Paid Work

Participants reported that employment income provided financial security and peace of mind. Adequate income reduced stress and worry about meeting basic needs of food, clothing and shelter. Glen, now employed full-time after not working for several years due to illness, can contrast his life now with when he was receiving provincial income assistance and CPP disability benefits:

*Paid employment...some of the benefits? Well I guess a better sense of security...financial security. When I was on you know social assistance or Canada Pension or disability...whatever you want to call it...I knew that I had a budget that would cover my rent...that kind of thing. Everything was paid you know or paid well enough so. You know phone and cable are a really big luxury. Food or quality food was certainly a luxury. So I think that from that perspective having that financial security (of being employed) allowed for things...allowed some flexibility...So if I think about it, I don't have to worry about you know accessing the food bank or can I access the food bank or have I accessed it too many times. (Glen, higher-income)*

Glen also found paid work less stressful and better for his health than relying on income assistance:

*It (employment income) makes a huge impact on your life...on your health and well-being...certainly alleviates stress...far more stressed-out or far more*

*stressful living on social assistance...than it is working you know and having a decent income. (Glen, higher-income)*

Some participants also argued that adequate income gave them control in managing their health. Jack described it as having more options:

*It (high income) gives me so many more options, whereas someone without that kind of income...I mean...I don't know how they deal with it you know...How they can cope...Having the financial stability that I do...I can buy some options for myself. (Jack, higher-income)*

Jack also noted that higher income enables purchases beyond basic needs, such as vacations, entertainment and gifts, and that these items contribute to his emotional sense of well-being.

The financial benefits of paid work were not limited to participants with full-time employment. Being able to earn money through work was important to low-income participants who supplemented their income by doing odd jobs. For example, Elvira said that she utilizes her provincial income assistance cheque to pay for rent and utilities, and that the money that she makes from a part-time job goes to buying groceries and personal items. She described her life before she found part-time work as much more stressful. As another example, Tim explained how important being able to do 'cash' jobs has been for him and his partner:

*I don't know if I can stress it enough. If I didn't have some of these other means of making some money...our life would be quite different. We wouldn't be able to do*

*a lot of the...just the everyday stuff that we do. You know we'd be kind of stuck in the house and getting depressed because we couldn't do anything.*

*(Tim, higher-income)*

The income Tim and his partner make from doing odd jobs placed them in the higher-income participant category, albeit at the lower end of the income range. They would have been categorized as newly low-income if they had to rely solely on what they receive from provincial income assistance and CPP. Several other participants, rather than working directly for pay, reported the benefit of working for their landlord in exchange for reduced rent.

In addition to direct income, several participants with full-time employment received health insurance through their workplaces. They used their health benefits to cover such items as prescription drugs, dental work, massage therapy and private counselling. Some of these participants have disability benefits through work which they can draw upon should HIV or another condition render them unable to work. Jack described how this provides a sense of security for the future should he ever become too ill to work.

In addition to financially-related benefits, participants identified other positive aspects of paid work. Many of their comments related to work enabling a person to keep active and engaged with others, providing a focus or purpose in life, and occupying time thus reducing the amount of worry about one's own health problems:

*Well it (working) ...it's a sense of purpose...a sense of reason...gives me a sense for being alive I suppose...gives me something to do because I get terribly bored when I'm not doing anything. (Glen, higher-income)*

*My job gives me very little time to ponder my health or worry about my health. And if I wasn't working I suspect I'd be...emotionally and mentally a lot worse off, because I just wouldn't have that kind of focus in my life...*

*(Jack, higher-income)*

Joseph linked the emotional sense of well-being he gets from working to countering depression and to taking better care of his physical health. Participants who were only involved in occasional paid work described similar benefits:

*The one thing (from doing odd jobs) is just out associating with 'Joe' general population. Just seeing and meeting and greeting people and...you're out of the house and it's something to do...it's somewheres to go. It gives you a little bit of a sense that you're still alive. It keeps the brain from going dead.*

*(Al, higher-income)*

Participants found that rewarding, interesting and satisfying aspects of paid work contributed to a better outlook on life, a better sense of self-esteem, and feelings of accomplishment. One participant, whose drug addiction had prevented her from working for many years, described how working part-time was helping her build her self-esteem. Another participant, who works as a human services counsellor, described his satisfaction from helping others.

Participants described their work colleagues as sources of friendship and support.

Jason, for example, disclosed his HIV status to some people at work:

*There were people that I was very close to...that I worked with, that I shared that with them because...well because I could trust them and they were good friends and I knew that if I ever needed to depend on people that I could turn to these people... (Jason, higher-income)*

One participant disclosed his HIV status to people at work through his supervisor when he became quite ill and was going to be off work for several weeks. He was appreciative of his co-workers' respect for how much he wanted to share. This participant's work colleagues followed his lead in conversations about his health and refrained from asking very personal questions.

Another area of benefit that participants discussed was the degree to which their work provides control and flexibility around pace of work and accommodation of illness. Larry, who works for his landlord, reported the following:

*My landlord is very easy going. He sort of lets me pick my own hours, when I want to do, when my work is done its okay as long as I do it. It's at my own discretion so that's actually a factor too, so if I don't feel up to it one day, I can always do it the next day. (Larry, higher-income)*

One participant described the accommodation his employer and co-workers provided during the time leading up to his leaving work due to illness:

*I'd go to the lunchroom at break and...lay down for a nap and like...you know I'd sleep for two or three hours...just pooped, and they would just let me sleep*

*all the time...nothing was ever said about that. Everybody...either picked up the slack...so they were very good like that.*

Participants also identified flexibility regarding attending medical appointments, which can be quite frequent. Jack, who works for a government department, said that he can use flex time, accumulated through working overtime, and sick days to travel to and attend medical appointments. Robert works in retail and described his employer as being very accommodating of his taking time off for medical appointments. Tyler, who works as a labourer, said that shift work provides a lot of flexibility when it comes to scheduling appointments. He can book an appointment for a day when he works nights. Failing this, he can switch a day shift for an evening one if he needs time off during the day.

A final area of accommodation is around absences due to illness. Some participants reported having had to take several weeks to several months off work due to illness. Their jobs were held until their return. They received income through sick day benefits and for longer periods of absence through Employment Insurance.

Inherent in the topic of workplace accommodation is security in knowing that one's job is not jeopardized by being HIV positive. Several participants noted that they felt secure in their jobs and had few worries about facing HIV-related workplace discrimination. One participant, for example, revealed that after he disclosed his HIV status to his employer, his employer demonstrated support by implementing HIV/AIDS education in the workplace. This sense of job security was reported by participants who worked in either the private, public or non-profit sectors.

As is explored below, many positive aspects of paid employment can also be attained through volunteer work. However, for some participants, paid work provided more rewards than possible through volunteer work alone. For Vern, it has to do with feeling like you have earned your income, as compared to being on income assistance:

*I feel good that I earn that paycheque compared to sitting home and just getting money. You know, I mean with Canada Pension, okay, I paid into it but you know it's still...I don't know it just bothered me that I didn't contribute anything back during that time. Even though I contributed into it while I was working, but still it did bother me. And now when I get my paycheque every two weeks it's like I've earned it. (Vern, higher-income)*

Tim, who is considering re-entering the workforce as a result of improvement in his health, also anticipates that paid work will provide a greater sense of accomplishment than volunteer work:

*It's important to me to be able to look back in a couple of years from now and say well I've actually done something, I've accomplished something. And you know I've been doing some of that with my volunteer work but it's still not the same as having paid employment. Nothing can compare to that. (Tim, higher-income)*

#### 5.1.3.2 Negative Aspects of Paid Work

As described in section 5.1.1, some participants faced workplace discrimination and lack of accommodation of illness that resulted in job loss. Furthermore, this may be related to the type of employment (e.g., food/service industry and non-unionized labour). Participants who anticipated job insecurity, or lack of accommodation if their HIV status

were to become known, reported fear and worry about their employer finding out and then losing their jobs. For some participants, a strategy of not disclosing to employers was used to prevent discrimination. Others found no particular need to inform their employer.

Working and worrying about others finding out about your HIV status can lead to a covert work lifestyle. Tyler, for example, described the challenges of trying to take medications throughout his work day when nobody is around to see him. He went on to say:

*I get busy at work and forget that I flew by the time that I was supposed to take them (medication) and...cause once you're on a machine you can't really just take off and go and take your pills cause...And you have to leave your machine cause I need water to be able to swallow them so. Sometimes it's impossible, it gets so busy sometimes it's tough...So far I've been lucky. Hasn't really done much harm but if I do that on a regular basis then eventually it's going to hurt me. (Tyler, higher-income)*

Given Tyler's experience, it is noteworthy that when asked if he thought there was more his employer could do to support his health and well-being, he replied:

*No...nothing they can do...It's all in my hands. It's up to me to be healthy.*

His reply suggests that some people may minimize the responsibility of the employer to provide a secure and accommodating work environment.

Another challenge is the difficulty of continuing to work while experiencing illness and symptoms, especially in the context of an unaccommodating workplace. Tyler shared the following:

*Well I couldn't keep up with the other workers...because I was always run down....it was like that three or four months before I collapsed. I was going in groggy and didn't have enough energy to go quick like they wanted me to and then my counts were way below all the other workers... You had to go at a good...really good pace and I didn't have the energy for it. And I spent more time in the bathroom than I did out on the floor. And I knew I didn't have a chance at that job. (Tyler, higher-income)*

Challenges to working while experiencing symptoms were not limited to physically demanding jobs or unsupportive workplaces. Jack, who works in an office setting which accommodates his illness, reported anxiety about his reduced capacity—and not knowing whether this was due to age, medication or the disease. He added that fatigue related to HIV contributes to workplace stress.

Some participants continue to work even though they know it jeopardizes their health. For Tony, the alternative to not working is greater struggle with poverty:

*You know like I can't really paint (apartments) because of my illness...because the smell of the paint and whatever, right. But I still do it because I save a little bit of money on my rent, and...well you pretty well have to these days because the welfare don't give you enough. After you finish paying your bills and whatever, I*

*mean...and then you still don't have enough money for groceries for the whole month. (Tony, long term low-income)*

A number of participants identified negative factors associated with paid work that are common to a lot of workplaces. Participants stated that work can be stressful and burdensome in general due to the types, amount and/or pace of work. Participants also cited negative factors related to unsupportive supervisors, lack of support and guidance, taking on too much work, time pressures and in the case of several participants in the human service field, being overwhelmed by client demands. Some participants saw these stressors as having direct impact upon their health. Tim said that a heavy workload, extensive overtime and an unsupportive employer resulted in 'mental burnout' and a decrease in his T-4 cell count (an indication of disease progression).

Finally, while being able to do paid work can contribute to a sense of emotional well-being, not being able to work can threaten emotional health. John, who has not had steady employment for over ten years, described his life as follows:

*I don't know how to really explain it but...when you're not working you know you've got nothing to get up for, you lay there and you go for a walk and say "no, I don't want to do that, go home, and watch TV" and...It's a waste of time...It's a waste of life. (John, long term low-income)*

One participant said that as a professional person, being unemployed was degrading. Another participant cited being unemployed among his main stressors and said that long-term unemployment was making it difficult for him to maintain a positive outlook on life.

### 5.1.3.3 Paid Work Goals

Participants who were working full-time hoped to maintain their current employment and/or advance their careers. Other participants appear to have accepted that their health will preclude their return to paid employment.

A number of participants were currently looking for work. For some, their health had improved to the point where they could work again. Two participants re-entered the workforce after successful recovery from drug and/or alcohol addictions. Some long term low-income participants never stopped looking for work. Participants in the job market identified numerous barriers to finding employment. Some barriers were not specific to HIV and included high unemployment rates, the lack of jobs, their lack of training, having a criminal record and age discrimination. Long term low-income participants mentioned the greatest range of barriers to employment.

Participants, of all income groups, identified a number of barriers to employment that were directly related to HIV. They mentioned the potential for HIV discrimination and for those wanting to work in the food industry, worry about how the general public might respond if they learned a restaurant has an HIV positive employee. Coupled with this was one participant's fear, however unfounded, that he could inadvertently infect someone else:

*Say if I wanted to even go wash dishes or something, and this is a small town, right. And the word spreads very rapidly here...and even if I wanted to go wash dishes. I mean I wouldn't myself. I wouldn't feel...you know comfortable doing that...because you would affect other people. You always have that thought*

*in the back of my mind, my gosh, you know what if I did cut myself. What if there is blood and it's not washed off properly...maybe it doesn't even mean anything.*

*But to me it... you know...it bothers me. (John, long term low-income)*

Terry noted the difficulty in trying to explain a long absence from the workforce, when one has been unable to work due to illness. Participants also mentioned the challenge in finding an employer who will be understanding and accommodating of periodic absences due to illness. Larry explained that some jobs may not accommodate reduced hours, and that an eight hour day coupled with travel time to and from work may be too tiring for some living with HIV/AIDS.

Several participants were attending or were planning to attend educational programs to increase their employability. Dontavia was trying to counter barriers to employment through starting his own business. He sees being self-employed as giving him more control and security with respect to disclosure of HIV, thus minimizing the chances of discrimination.

Some participants expressed hesitancy in attempting to return to work and losing the income security of CPP benefits and/or the secondary benefits that come from provincial income assistance such as prescription drug coverage:

*I think my biggest concern (in going back to work) would be whether I'd be able to afford the drugs that one has to continue taking. You know regular prescription drugs like we get from our doctors. You know cause some of those can be quite hefty in price. (Pierre, newly low-income)*

Even though CPP has allowances for making some money through part-time work and attempting to return to work<sup>1</sup>, participants said that they were still worried about working part-time and losing their benefits, or going back to work full-time and not being able to re-qualify for CPP if their health fails. Stephen believes it is now more difficult to qualify for CPP disability benefits:

*I wouldn't re-qualify. I would never go back into the workforce, cause I know I wouldn't qualify...Because when I got Canada Pension the doctor wrote this person has AIDS, and you got Canada Pension...Now I would not qualify. I am quote...too healthy...unquote, and I would be denied it. (Stephen, higher-income)*

Tim described how the stability he feels on CPP contributes to his hesitancy to jeopardize his income through an attempt at returning to work:

*I've really become so dependent on those things that I'm literally scared to do anything else...to actually try something full-time or to try going back to school or something like that. It's just been too frightening a prospect to consider because of what I'm going to lose. (Tim, higher-income)*

Tim explained that his decision on whether to return to work is further complicated by many fears and uncertainties, such as succeeding in school or re-training, being able to find a job afterwards, and how long his health will permit him to work.

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<sup>1</sup> A recipient of CPP Disability Benefits is allowed to earn up to \$3,900 a year from work without having to inform CPP and without losing benefits. A person can also continue to receive benefits for a three-month work trial period. Furthermore, if a person becomes unable to continue working due to the same medical condition anytime within a two-year period following the three-month trial period their reinstatement with CPP can be fast tracked. (Human Resources Development Canada, 2002).

For some participants from all income groups, treatment advances were tied in with work goals; either enabling them to remain employed or improving their health to the point where they felt able to seek employment. Others remain hopeful that treatment advances will one day enable them to return to work.

Some participants said that treatment advances allow for longer-term planning regarding employment and provide a sense of longer-term security:

*I can plan longer now just because I am on treatment so...I know that the treatment suggests that you know, I'm going to live a lot longer, and so I probably wouldn't go through a re-training if I thought these were the last two years of my life. I wouldn't bother re-training for a new career. So...yeah, treatment advances, you know to me, you know longevity that wasn't there before.*

*(Joseph, higher-income)*

Other participants, however, are hesitant to make plans not knowing how long the effects of the drugs will last. Glen expressed caution about people assuming that new treatments will enable a return to work:

*But you know...we're still at a point where a lot of these treatments are still new, that you can't generally say you should go back to work or none of you should go back to work. I mean it's an individual thing. We know that HIV acts differently in everybody's body. We know that the treatments will act differently in everybody's body...that kind of thing so...you know there are a number of questions I think that you might want to ask yourself...if you're thinking about going back to work... (Glen, higher-income)*

Finally, a number of participants from all income groups indicated that they do not see treatment advances enabling them to return to paid work. However, some of these participants attributed treatments to improving or stabilizing their health and permitting them to do volunteer work.

#### 5.1.4 Volunteer Work Experiences

##### 5.1.4.1 Positive Aspects of Volunteer Work

Participants from all income groups reported that volunteer work provides many benefits. They emphasized that volunteering gives them something positive to do, a reason to get out of the house, and/or something to look forward to. Clorise expressed it this way:

*It just makes me feel good helping other people and it's just a good feeling. It you know beats sitting home feeling useless, whining and complaining. It's like this gives me a pick-me-up, something that I can get up for one morning a week... (Clorise, newly low-income)*

Clorise's comment points to another benefit of volunteering: feeling like you are contributing to society by helping others. Jason, who volunteers for several community organizations, felt thus:

*I think it's really important for me to feel that I'm doing something that's valuable...and that I'm still contributing and that I'm productive, because I think that AIDS can create such a feeling of hopelessness and helplessness and if I was left to dwell on that all the time I wouldn't be here now. So it keeps me busy and it's a good kind of busy...you know to do for other people. (Jason, higher-income)*

Participants described a positive sense of accomplishment and satisfaction from volunteering. Some chose to volunteer in areas of importance to them, such as developing services for gay and lesbian youths and doing HIV-prevention education. Such work was integral to their maintaining a positive outlook on life. Participants also chose to volunteer at agencies as a way to repay the agency for help they had once received. For example, George volunteered at the hospital where he had received medical care in part to show his gratitude to hospital personnel. Larry described his relationship with a food bank as reciprocal; they provided groceries when he needed help and now he provides volunteer labour.

Some participants linked volunteering to maintaining or building their sense of self-worth. Al, for example, identified being able to contribute in some manner as integral to self-esteem:

*A lot of it boils down to the fact of your self-esteem. When you're contributing something, whether it's to a society or is in volunteering...it's definitely self-esteem and that there worthwhile feeling that's for sure. (Al, higher-income)*

Stephen said that doing volunteer work was very self-affirming, as was receiving appreciation from those you helped.

Several participants noted how volunteer work helps get their thoughts off their own health concerns and worries. John shared the following:

*I mean I forget about myself, right. And I have this thing "okay great, I'm sick, I'm going to get sicker tomorrow, I'm going to get sicker or weaker or what*

*happens if". And I find where I am helping other people my mind's being occupied". (John, long term low-income)*

For others, volunteer work puts them in contact with people who are experiencing personal and health problems. Such contact has enabled these participants to place their own problems in a broader human context. George, who volunteered in a long-term care facility, explained it this way:

*And I started feeding patients...getting involved in special programs and taking patients on outings and that was beneficial to me because it made me realize that I am not the only one that is in a hard situation. Or you know, like it made me feel less scared about my own situation because there's people far worse off than me. (George, newly low-income)*

Another benefit from volunteering is the opportunity to interact with others.

Several participants noted that the people with whom they volunteer are sources of friendships and support. Volunteering and interacting with others can also help counter isolation. Paul, for example, described how volunteering prevents both physical and mental withdrawal:

*For me, if I don't get out and do something in some positive way...I'll end up back in that hole...or that shell...and I'll probably die. By me going out and volunteer it helps my health. I know it does. I feel better about myself... And I couldn't see myself in a shell. You got to get...be active. You got to be productive. You got to communicate with people. (Paul, newly low-income)*

Another participant spoke of the rehabilitative effects of volunteer work. He recounted experiencing debilitating symptoms from mental illness, and attributed his recovery and being able to interact with people again to doing volunteer work. Jason noted how volunteering was a less expensive way to socialize and be with others than going out to events such as dances and movies.

Participants also pointed out the control and flexibility volunteer work offers. Al, for example, has control over the level and amount of involvement in volunteer work:

*I don't get myself bogged down and stressed out in it. And I'm not out there 14 hours a day volunteering either. I just do it on my own. The days that I feel like I can do something, I do. And the days that I don't, I don't. (Al, higher-income)*

Jason described how this flexibility works for him:

*I like volunteer work...because it does allow me the flexibility to come and go because I'm not a paid employee as such right...and it's really great because sometimes when my energy is great and things are going good, I have a lot of time and put a lot into those things. But when I'm not feeling so good or whatever, then I'm not feeling guilty and I'm not being harassed or you know singled out for missing a day here or a day there. (Jason, higher-income)*

Jason's comments allude to the flexibility of volunteer work in comparison to paid work. Participants noted that volunteer work can also offer the type of work one really enjoys, which is not always the case with paid employment. And as illustrated by the following comments, volunteer work can be less stressful and more rewarding.

*It's not a job that I find stressful (volunteering). So if I don't find it stressing then it doesn't affect my health. Working in the field that I was, as a waiter and everything I found very stressful. (Pierre, newly low-income)*

*I get more rewards and benefits from volunteering than I ever did out there. They appreciate me more than I ever was shown in paid work.*

*(Clorise, newly low-income)*

Clorise was also able to connect the emotional rewards of volunteering with her physical health:

*It's a good feeling (from volunteering) and that's just an immune booster for me.*

*It's done, I think it's done wonders for my health, my personal health. As opposed to when I was working (paid work), I was sick a lot more.*

*(Clorise, newly low-income)*

#### 5.1.4.2 Negative Aspects of Volunteer Work

Participants reported few negative aspects of volunteer work. Those who did identify concerns came from all income groups. Several participants mentioned that some volunteer positions carry heavy work demands, and that there is risk to health in trying to do too much. Tony shared the following about his volunteer work experience:

*I worked two years straight. You know just like I was always on the go but...that's how I burnt myself out...and then I kind ah...just slowed down on it.*

*(Tony, long term low-income)*

Participants identified other stresses from volunteer work, including the 'politics' of the agency (such as how decisions are made), the agency's lack of volunteer coordination

and utilization, the lack of volunteer recognition, and conflict and tension between people.

Although participants reported few negative aspects of volunteer work, not being able to participate in such activity was identified as a threat to one's sense of well-being. For example, Jason had for a time been unable to do any type of work because of ill health, described the following effects:

*And when I couldn't work any longer, and all I could do was basically lay around either in the hospital or at home...I began to feel like I didn't have any value, and that I was worthless. (Jason, higher-income)*

Finally, participants were able to challenge a potential negative aspect of volunteering—the belief that volunteer work is less important than paid work. Challenge to what is likely a societal belief was evident in several participants' comments:

*Well I feel rewarded because I'm doing something for people and I'm not doing it for money or for any really selfish kind of motive. (Jason, higher-income)*

Brad, who has never had steady paid employment, said that when he does something for someone—like shovel their driveway—he feels a greater sense of reward if he is not paid.

#### 5.1.4.3 Volunteer Work Goals

Some participants, particularly those unable to do paid work, hoped to continue their volunteer work:

*I've always been involved like with some sort of community work...And now where I don't have to work I have a whole lot more time to do that, and be available for that, and to do it freely. (Jason, higher-income)*

A few participants have had to cut down on the amount of volunteer work they do or have left volunteer work altogether due to deteriorating health.

Several participants in the long term low-income category reported difficulty in finding volunteer work. Some of the barriers to finding volunteer work included a lack of volunteer positions, mental and physical health conditions, learning disabilities, worry about people at the volunteer placement finding out they are HIV positive, and not meeting screening criteria. Ryan described the situation as follows:

*Right now...trying to find anything is really hard because even the volunteers are having a rough time at it here, trying to find something to do...Like I know that a lot of the nursing homes are looking for volunteers but...there's also a screening process and I got a criminal record for one...that wouldn't help and quite a few people know I'm HIV. (Ryan, long term low-income)*

One participant found it more difficult to find volunteer work when he was living in a rural community. Another participant expressed fear that even volunteer work could somehow jeopardize his income assistance and drug coverage.

Notably, several long term low-income participants who were facing difficulty in finding volunteer work were doing some volunteer work for a community-based AIDS organization. Furthermore, one of the participants who volunteers with an AIDS organization suggested that the agency provide training to increase his skill level.

Another participant from the long term low-income group stated that his local AIDS organization should do more to help him find volunteer work.

#### 5.1.5 Summary

Participants who were working full-time, which excludes all of the low-income participants, could potentially benefit from the many health-promoting aspects of paid work. The benefits that emerged in this study include financial security and peace of mind, less stress and worry about meeting basic needs, ability to purchase items that enhance quality of life, and more control in managing health through the purchase of goods and services. To a more limited extent, low-income participants who had some paid work experienced these same benefits (e.g., less stress).

In addition to financially-related benefits, participants reported that paid work enables a person to keep active and engaged with others, provides a focus or purpose in life, and keeps one's mind occupied. They also linked rewarding, interesting and satisfying aspects of work with contributing to a better outlook on life, a better sense of self-esteem, and feelings of accomplishment. For some participants, work colleagues were sources of friendship and support. Participants also linked control and flexibility at the workplace, and job security as positive aspects of paid work. Participants were able to link these aspects of paid work to their sense of well-being. Many of the above benefits were identified in other research that looked at the paid work experiences of PHAs (Brooks & Klosinski, 1999; Canadian AIDS Society, 1998; Ezzy, De Visser, & Bartos, 1999).

Except for financial benefits, participants identified many of the same rewards from volunteer work. Other research that examined the work experiences of PHAs supports this finding (Adam & Sears, 1996). Volunteer work gave participants something positive to do, a reason to get out of the house, something to look forward to, a sense that one is contributing to society by helping others, a sense of accomplishment and satisfaction, and opportunity to interact with others and receive support and friendship. Participants, in direct and indirect ways, connected these benefits to promoting emotional and mental health through reducing feelings of isolation, countering depression, reducing stress, maintaining or building self-esteem, and contributing to a positive outlook on life.

Participants also identified negative aspects of paid and volunteer work that could affect their health and sense of well-being. For paid work, these included the stress of job insecurity (e.g., fear of discrimination and a lack of accommodation), workload and time pressures, unhealthy work environments (e.g., exposure to paint fumes), working when experiencing symptoms and unsupportive supervisors. Other research on the paid work experiences of PHAs revealed similar findings (Adam & Sears, 1996; Canadian AIDS Society, 1998; Ezzy et al., 1998). Participants also mentioned stressors related to volunteering (e.g., interpersonal dynamics and taking on too much). However, they recognized that volunteering can offer much flexibility (e.g., choice of who you volunteer for, what days, what times, amount of involvement). Participants described not being able to do paid or volunteer work due to illness or exclusion as a threat to their well-being.

While the findings identified many structural barriers to attaining or maintaining paid and volunteer work (an area analyzed in depth in Chapter 6), they also provided

evidence of participants' abilities to counter imposed social constraints through their labelling of unfair treatment as discrimination and reframing volunteer work as no less valuable than paid employment.

## 5.2 Use of Private, Government and Non-Profit Services to Attain and/or Help Maintain Health and Well-Being

The services explored include those provided by community-based AIDS organizations, complementary therapies, peer support, income assistance/maintenance programs, other community-based or public services, and private services.

### 5.2.1 Community-Based AIDS Organizations

Participants with low incomes or with incomes at the lower end of the higher-income range reported that AIDS organizations provided direct financial support (e.g., through health maintenance and emergency funds) and/or services that related to low income (e.g., food banks and advocacy in getting subsidized housing and utilities hooked up). Certain programs, for example health maintenance funds, provided some participants with ongoing assistance (i.e., they received a set amount on a monthly to bimonthly basis depending on the specific organization). Some participants also sought services on an as-needed basis. For example, Patrick accesses an AIDS organization's food bank when he runs out of groceries. Some participants took comfort in knowing that an AIDS organization is there should a financial need arise.

Participants indicated that AIDS organizations provide many other helpful services, such as support counselling, referral to other agencies, information, peer support and massage therapy. The following comments illustrate this diversity of services:

*I come to the (names AIDS organization) a couple of times a month...for a haircut or health fund...or if I'm just...feel the walls closing in on me and I need ...an environment where I feel safe in...someplace where I can go and not be judged. (Terry, newly low-income)*

*I get more like... moral support. I get surveys...I get material sent to me from them. As they get it they send me updates for different things...updates on new medications that I read up on. (Paul, newly low-income)*

The pattern of use of these other services appears greatest among low-income participants with two exceptions. Participants from all income groups accessed services from AIDS organizations when they first tested HIV positive and also volunteered their time with these organizations.

Participants reported a high level of satisfaction with AIDS organization services. However, some also voiced complaints and concerns. These included people at the organization not always being welcoming, no place at the organization for clients to sit and socialize, the need for more support services, and the organization not doing enough to address their housing and financial needs.

Specific to direct financial assistance, participants raised concerns about emergency funds that are both needs and means tested. They described the funds as being difficult to access due to rigid criteria and differential treatment. Tony put it this way:

*I feel like some people can get what they want. But every time I ask for something I have a hard time getting it...I don't know. I find it very strange. I mean I know*

*some people comes in and no problem at all...they get this and that...And if I need...really need something, I have to fight for it. (Tony, long term low-income)*

John connected the concern to workers lacking empathy and an understanding of what it is like to be poor:

*I think one thing they have to know...how you feel inside...you know, what a person is going through...and maybe they should have to live on that amount for awhile, you know...and then they would know what it was like to go to the (second hand) depot, because you need winter boots, or a winter jacket, or a mattress to sleep on...(John, long term low-income)*

The concerns expressed about emergency funds stand in contrast to participants' descriptions of health maintenance funds. The latter may be income tested, but recipients are given much flexibility about how the money can be used:

*There's a health maintenance fund that I get a cheque...every month. That just goes into one of my chequing accounts and it gets used for whatever. My homeopathic treatments, my vitamins, my minerals...that kind of stuff.  
(Stephen, higher-income)*

Larry used the health maintenance fund to purchase winter clothes and extra things for Christmas.

Participants also recognized limitations AIDS organizations face in service delivery. These limitations included under funding and restrictive mandates imposed by funders. Joseph, for example, explained how a funding body can influence what services are delivered:

*Yeah, I find the organization really focused, and I know this is the mandate from their funding, is that it's about prevention and education. So I find it's a bit lacking as far as how they're able to help PHAs. (Joseph, higher-income)*

Finally, several participants were reluctant to come to an AIDS organization or use their services out of concern that their confidentiality could be broken. For some, the concern was heightened due to living in a small community and if gay, the overlap between AIDS organizations and the gay community.

### 5.2.2 Complementary Therapies

As identified above, AIDS organizations provide some access to complementary therapies such as massage therapy and vitamins through health maintenance funds and the delivery of services on site. For some lower income participants, AIDS organizations are their only means of access to complementary therapies. However, not all AIDS organizations in the Maritime region can facilitate such access.

Several low-income participants purchased vitamins on their own or could get them through social assistance. However, others from this income group reported that their low income precluded complementary therapies, with massage therapy often cited. Ryan, for example, wishes he could access massage therapy:

*But it's just that we...oh, anybody...doesn't matter if you're a PHA or not...we need a little bit of just the tension taken out or the pain...whatever it is and a lot of us can't afford forty or fifty dollars a week. (Ryan, long term low-income)*

Several participants had other reasons for not using complementary therapies. Some did not see the need and others lacked the time in a busy schedule. Several participants lacked knowledge of complementary therapies or where to find them.

Participants with higher incomes had greater access to various services. Private health insurance enabled the use of complementary therapies. Jason, for example, said that his insurance plan covers 80% of the cost of his massage and chiropractor treatments.

### 5.2.3 Peer Support Programs

Participants from all income groups pointed out the benefits of support from other PHAs. They benefit from sharing their stories, being with others who they feel really understand, learning from others, making friends, and receiving encouragement from other PHAs—especially from those who have lived with HIV for many years. Dontavia described the benefits he received:

*One of the things that I found useful here is meeting with someone who has been HIV positive for a number of years, cause I really felt when I first was diagnosed that it was the end. That death was near. Since then I met people who have 20 years with it so...that's been very helpful for me to know that there was life after HIV. (Dontavia, long term low-income)*

Participants also identified difficulties in accessing peer support. These included: no peer support programs where one lives, inadequate income to visit or call PHAs who live in other parts of the province, and not finding the desired diversity in peer support programs (e.g., women, heterosexual men and First Nation peoples). Participants also

worried about lack of confidentiality among other PHAs. Some found the Internet useful in accessing peer support in an anonymous manner.

Participants identified the important role community-based AIDS organizations can play in delivering peer support both through formal programs (e.g., one-to-one, support groups and weekend retreats) and informally (drop-in centres and opportunity to do volunteer work with other PHAs). Some participants living in smaller communities where local peer support is not attainable found that retreats and conferences allow them to access peer support. Drawing participants from large regions, these gatherings can also attract much diversity. Several participants explained that AIDS organizations also face barriers in delivering peer support, such as protection of confidentiality and encouraging participation in a society where stigma and shame are still attached to being HIV positive.

Some participants explained that they do not seek out formal peer support programs but rather obtain peer support informally through friendships with other PHAs. Although not limited to any one income group, such an approach to peer support did appear preferred by many higher-income participants. This difference is also consistent with the overall pattern of participants with higher incomes relying less on community-based AIDS organizations.

#### 5.2.4 Income Assistance/Maintenance Programs

All of the low-income participants relied on some type of public income security program<sup>2</sup>, as did several participants with incomes at the lower end of the higher-income range. Most long term low-income participants received provincial income assistance

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<sup>2</sup> I am using the term income security program to refer to both income assistance programs, such as provincial income assistance, and income maintenance programs, such as CPP disability benefits.

only and were receiving such assistance at the time they were first diagnosed. Some from this group explained how testing positive for HIV or becoming too sick to work resulted in an increase in their provincial income assistance monthly rates<sup>3</sup>. Many of the newly low-income participants received both provincial income assistance and Canada Pension Plan (CPP) disability benefits. This difference is related to their having more stable employment histories which provided opportunity to pay into CPP. All in this second group had paid employment when first diagnosed.

Regardless of the type of income security program being accessed, the income received by itself was inadequate to meet basic needs. For example, some participants could not procure sufficient healthy foods. Dontavia, who was only receiving provincial income assistance, described his concern about inadequate food affecting his health:

*I mean it's insufficient funds to survive. I mean we're not even surviving. It's starvation on just what I got...And having enough money to be able to supply the right kind of food to eat to maintain a healthy immune system, when...especially when you're...at a disadvantage with HIV...It's a major cause and a concern, cause I'm sure I'm not eating properly. And you get things that you have to eat that you don't want to eat. You don't have choices. You can't make your own choice anymore. You're at the mercy of the food bank and that's very stressful. So you know you're talking about medicines trying to keep you*

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<sup>3</sup> In New Brunswick for example, a single person deemed employable might receive \$264 a month in assistance. This can be increased to \$485 a month if the person is assessed low-employable due to illness. The income assistance rate can increase again to \$558 a month if the person is determined to be unable to work due to disability. In addition, a person diagnosed with HIV may be eligible for a \$30 a month special diet allowance.

*healthy, but you also have to talk about the proper kind of food. You can't go out and buy any fruit. You can't buy...I can't even afford to buy vitamins.*

*(Dontavia, long term low-income)*

Brad described having to make a difficult choice between following the recommendations of a dietician and being able to go out and socialize—since his income could not support both. Recognition that income assistance programs are inadequate illustrates the dynamic of radical humanism. People are able to make sense of their world in a way that assigns blame to the system (for not providing an adequate income) versus themselves (e.g., for not having the personal skill to make ends meet).

Participants dependent on income assistance also had insufficient money to purchase adequate housing, complementary therapies, prescription and over-the-counter medications, memberships to recreational/fitness centres, and transportation (e.g., to medical appointments and shopping). Securing transportation was particularly difficult for those who lived in areas without public transportation. A number of participants also stated that their insufficient income prevented them from going out with friends and from participating in community activities. Participants were able to link many of the above items to health and well-being. For example, Clorise made the connection:

*To be able to get out I think that's good for somebody's health you know. And it makes them feel good, but sitting home just gonna wear you down and depress you cause you have no money. So yeah, finances are big, play a big factor in maintaining good health all the way around. (Clorise, newly low-income)*

Participants in receipt of provincial income assistance often stressed the importance of non-monetary benefits (e.g., coverage of prescription drugs, dental and eye care, and travel to medical appointments). In fact, some participants who were on CPP and who also received a relatively small amount of money through the province, said that they were quite conscious about not doing anything that could jeopardize their eligibility for the secondary benefits received from provincial assistance. Tim, for example, said that he is careful about how much he makes from odd jobs so to ensure he stays eligible for provincial assistance. He described the importance of the additional benefits he gets from provincial assistance as follows:

*The social services doesn't give me a whole lot of actual money but it qualifies me for all my secondary drugs...it's all this secondary stuff that...the meds and all the supplement stuff that I get from the pharmacy and stuff that would be a huge loss you know. (Tim, higher-income)*

One person who was working full-time was able to get prescription drug coverage through provincial income assistance due to the cost of his medication being so high in relation to his employment income.

Participants found it very stressful trying to live on provincial income assistance and/or CPP. They described the day that they receive their income assistance/maintenance cheque as particularly stressful. Their expenses were greater than their income, and they had to decide which bills to pay and which ones can wait. They needed to run around to pay bills and wait in line-ups at banks. John described the heightened stress as follows:

*I find welfare day...I find it really almost too much...if I had my way I'd wait to the second or third but...you can't wait that long cause you don't have nothing... I find that the waiting at the bank...waiting to get your telephone bill paid...I mean everything's a lineup... And once you do pay your bills...you decide then...what if I spend this and this and this...I'll have this left. Right?...Do whatever is the most. Pay that off. Your most important...you gotta...pay it off. But you have to choose...you have to pick. (John, long term low-income)*

In contrast, participants with higher income described cheque day or pay day in either neutral or positive terms.

Participants noted that financial stress of low income also contributed to chronic day-to-day stress. Some were able to link financial stress to health and well-being. Elvira made the following point:

*If you don't have too much money it's definitely gonna affect your stress level and...if your stress level is high...it's gonna affect your health. (Elvira, long term low-income)*

Others described how the low level of provincial assistance negatively affects their outlook on life. Terry, for example, suggested PHAs would have more to look forward to in life if they received greater assistance:

*If people living with HIV and AIDS had more of an income...so that they had their independence...and guaranteed shelter...and guaranteed food... something more than just looking forward towards the basic struggles of life... that would make living with HIV a lot easier. (Terry, newly low-income)*

In addition to the stress from living on a low income, several participants felt stressed or embarrassed due to the dependency and stigma attached to income assistance.

Dontavia shared these feelings:

*It's the fact that you're dependent on someone else and it's not where I want to be...Social assistance itself has such negative connotations with it, and I just put more stress on myself by having to admit that I'm receiving it.*

*(Dontavia, long term low-income)*

Elvira sees herself as making less of a contribution to society by being on income assistance:

*I've been on welfare for so many years and...I just prefer to...you know...be a positive contribution to society instead of...always being a...always taking... (Elvira, long-term low income)*

Some participants said that they feel less stigma from receiving income assistance due to disability rather than unemployment.

Income program eligibility reviews, which could reduce assistance, are also stressful:

*The stress I'm putting myself under... in the fact that I know in the spring I will go for my annual review with the province, and I will probably have my provincial stipend cut. That's going to be hard, because I'm...just able now, barely able to meet...get ends to meet. (Stephen, higher-income)*

Participants also mentioned the stress, frustration and difficulty of trying to get things covered through income assistance, with the often time consuming process needed to argue your case. This stress accumulated and contributed to fatigue.

Participants also described factors that increase the likelihood of obtaining benefits from income assistance. Participants, primarily from the newly low-income and higher income groups, pointed out the need to be assertive and informed about policies and programs in order to maximize benefits. As Stephen explained:

*It's again being able to be intelligent enough to work the system to your advantage, and knowing that certain things are there. But you have to ask for them because of course they're not going to tell you. (Stephen, higher-income)*

A number of participants also noted the importance of a 'good' worker in helping them get as much as possible in terms of benefits and coverage. Al described his experience:

*I've had a couple of workers over the years that were very good...that literally went out of their way to see if there was something that they could get covered... if they could get it covered under...through being a disability requirement that you needed... (Al, higher-income)*

Another participant said that his worker would cover necessary items even though he believed that according to policy she was not supposed to.

Participants also identified factors that reduce the stress of cheque day and/or living on a low income. Some low-income participants reported that cheque day was actually unstressful, and even exciting because they had money. Two participants

described cheque day as a pleasant day because someone came by to drive them to pay bills, do grocery shopping and/or visit the food bank. This support came from a family member for one participant and an agency support worker for the other. Other factors that participants mentioned that help with income-related stress were earning some extra money through paid work, shared housing, rent-subsidized housing, making sure that the rent and utilities are paid so you have a secure place to live, rent that includes utilities, having some extra groceries in the house for times when you run out of money, not having any outstanding bills, and money management, budgeting and shopping skills.

Two long term low-income participants explained how provincial income assistance was helping them budget their money. One participant authorized income assistance to pay his rent directly so he always feels secure in knowing that he has a place to live. The other participant arranged for income assistance to pay him a portion of his income mid-month. In this way, he has money coming in when his food is running low.

As already reported under paid work goals (Section 5.1.3.3), participants receiving CPP disability benefits had some concern about engaging in limited to full-time employment and losing their benefits. Jason was receiving a private medical pension in combination with CPP benefits. He receives 70% of his regular base pay from employment plus a cost of living allowance and finds this adequate. He went on to say, however, that at one time he felt guilty about receiving a medical pension, especially on the days when he felt well enough to work. Jason described having to reframe feelings of guilt to feelings of entitlement. He said that he was able to do this, in part, by looking at

how he uses his income—to be productive and to maintain his health. Similarly, Paul was able to assert his entitlement to provincial income assistance:

*They're (income assistance workers) sitting there across the desk and they got this attitude...they're paying for the funding... "you've got to convince me why you need the support". I don't need to convince anybody...But sometimes they try to give me the run around... "you need another doctor's note". I said look "I don't need another doctor's note. Look on my file...it's already there...I'm classified as terminal disability". (Paul, newly low-income)*

Assertiveness and reframing appear to serve a radical humanist function, enabling participants to view receiving income security as a right of citizenship versus an income they do not deserve.

#### 5.2.5 Other Community or Public Services<sup>4</sup>

Participants with low incomes indicated using many community services related to meeting basic needs. For example, they used food banks which most described as helpful. Some participants, however, expressed dissatisfaction with the quantity and selection of healthy foods. Other services mentioned by participants included clothing banks, soup kitchens, Salvation Army for food vouchers, donations from churches, volunteer-transportation services, and subsidized housing. Those with rent-subsidized housing found it invaluable in helping them meet basic needs. Dontavia described the importance of such housing:

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<sup>4</sup> Note: medical services, which could fall within the community-based or public sectors, were not explored in this study. In addition, since only one participant's illness had progressed to the point of requiring homecare services, this area of service was also excluded.

*Luckily I'm with the city housing and they adjust it to your income. Just fortunate that I got it...otherwise I would not have been able to survive at all... So all these are really related to your health, whether you got a roof over your head or not, and food in your stomach. (Dontavia, long term low-income)*

Other participants said that rent-subsidized housing would greatly help with their financial concerns. However, there are long waiting lists for such programs where they live and some participants are given low priority because they are single without children.

Many of the newly low-income participants reported that accessing services to assist in meeting basic needs was new to them. One such participant was uncertain at first about the location of services, then reluctant to use them, but ultimately found the services helped in normalizing his situation:

*I mean there are resources that I have to use like the food banks, like the Churches, like the clothing banks and different things that are out there, I mean that are set up basically for the poor people. But I mean I had to find out where it is...where do I go...how do I use it? And that's kind of where I went and... it opened up a few doors I wasn't sure I wanted to go into but it...you know ultimately I find out that I'm not alone, and that people have to use these resources. (George, newly low-income)*

A number of participants from all income groups were using services related to mental and emotional health. With one exception, all of the low-income participants who were receiving mental/emotional health counselling did so through public and non-profit agencies. Higher-income participants, in comparison, were utilizing both public and

private counselling services (examined in the next section on private services). The public and non-profit agencies/services that participants were using included provincial mental health clinics, community counselling centres, a psychologist at one of the HIV clinics, and clergy. Several participants reported accessing provincial addictions services and Alcoholics Anonymous and/or Narcotics Anonymous. Participants described these services as quite helpful.

Some of the low-income participants who were using provincial mental health clinics, however, complained of long waits and the inability to see a counsellor as often as they would like. John, for example, described his desire to see his mental health counsellor at least once a month:

*I think just to know that I could go in, and once a month, just to say “Look, I’m doing great today. I’ve been doing good so far with, you know, within the last four weeks”. Just to...I think for five minutes even. Just to be able to do that, just for my own... for my own good I think. (John, long term low-income)*

Another participant had to wait two months for an appointment after being referred from a hospital emergency room due to a risk for suicide.

As a final area of public or non-profit services, some participants discussed accessing community programs for recreational and social purposes. One participant with low income described a program that subsidizes his YMCA membership so he pays only five dollars a month for full services. He also uses community computer access centres to keep his mind occupied, to correspond with people and to do research.

### 5.2.6 Private Services

Few participants with low incomes were using private services to help them attain and/or maintain good health. More would like to, but money was a barrier. For example, some would like to access private complementary therapies such as massage. In addition, participants said that more income would give them greater choice in mental health services, such as seeing a private counsellor or psychologist. Participants also said that inadequate income prevents them from purchasing a health or fitness centre membership. One participant said that he would like to take an art class but cannot afford the fee. John shared some of the things he would do with more money:

*Well you know, it's the craziest thing but...I love to swim...I like swimming...and I think if I had the money, I would go to...just to swim. I find that's really nice, really relaxing for me. I love it. And ah...I had a massage...I can't remember...I don't know what kind it was...I think that was a Swedish massage. But I think that's another thing I would do.*

*(John, long term low-income)*

Some participants with incomes in the lower end of the higher-income range also indicated that they would use private services if money was not a barrier. Joseph for example, recounted having to stop using a number of services when his income dropped:

*Just the alternative medicines if that's what you want to call it...like homeopathic remedies and massage therapy and that sort of thing becomes the first thing to go when your income drops a certain level, or at least for me they were. (Joseph, higher-income)*

In comparison to the experiences of participants with lower incomes, those with incomes at the mid to upper end of the higher-income range reported using a number of private services. Several were seeing a private counsellor. Higher-income participants also reported accessing private complementary therapies, housecleaning services, and private fitness centres. For some of these participants, workplace insurance facilitated access to private services.

#### 5.2.7 Disclosure of HIV Status to Service Providers

The issue of disclosing one's HIV status to service providers was included in the exploration of the various services. Participants from all income groups explained that they generally disclosed their HIV status to service providers if it seemed appropriate or relevant to the type of service (e.g., in seeking support services through an AIDS organization, in relation to mental/emotional health counselling, and in obtaining disability benefits through CPP or provincial income assistance). Ryan, for example, described the importance of letting his counsellor know he is HIV positive:

*Because they got to know certain details about me. And if I'm talking about a certain...like if ...my HIV is so low and I don't care no more if what happens...well at least they know what I'm talking about.*

*(Ryan, long term low-income)*

On the other hand, participants said that they did not disclose their HIV status where it seemed irrelevant to the service being requested or provided (e.g., accessing a food bank).

Many participants reported that service providers generally respond with acceptance and support to disclosure of their HIV status. One participant recounted how some of his income assistance workers tried to be more accommodating after learning that he is HIV positive:

*They've actually gone out of their way different times to accommodate me... A couple of their workers would come and do everything right here at the house...which was really you know confidential.*

No participant reported being discriminated against by a service provider as a result of disclosing their HIV status. One participant, however, wondered if income assistance workers were making less effort to assist him in finding work because he is HIV positive.

#### 5.2.8 Summary

Participants with low-income and those with incomes at the lower end of the higher-income range relied on community based AIDS organizations for direct and indirect financial support. With respect to financial assistance, preference was expressed for health maintenance funds which provided greater latitude in how funds could be spent versus emergency funds with narrower criteria. Participants reported that AIDS organizations provided a number of other helpful services such as counselling, referral, information, peer support and massage therapy. The pattern of use of AIDS organization services appeared greatest among lower-income participants. It is likely that many participants with higher incomes did not need financial support and have the means to access private sources of some services offered by AIDS organizations (e.g., counselling

and massage therapy). Participants worried about confidentiality not being maintained when accessing services, particularly in the context of peer support groups.

Participants with low incomes and some who had incomes in the lower end of the higher-income range relied on public income security programs (i.e., provincial income assistance and CPP disability benefits). Regardless of the income security program(s) being accessed, participants reported that their income did not allow them to meet all of their basic needs (e.g., food, housing, transportation). This caused day-to-day stress as well as heightened stress on cheque day. Some participants described financial stress as a threat to health and well-being. Being on income assistance itself was found stressful due to worries about periodic eligibility reviews and the difficulty in trying to get some items covered. Participants recognized the inadequacy of income security programs and did not blame themselves for not being able to make ends meet. Some countered guilt and stigma associated with income assistance through reframing such assistance as entitlement.

In addition to community-based AIDS organizations and income security programs, participants with low incomes utilized a number of other services related to meeting basic needs (e.g., food banks, clothing banks and rent subsidized housing). A shortage of rent subsidized housing emerged as an important concern.

Few low-income participants were using private services to help them attain/maintain their health. Some services that low-income participants would like to have been using included complementary therapies, private mental/emotional health counselling, and fitness/recreation centres. The literature also indicates that money is an important barrier to complementary therapies (Ezzy et al., 1998; Gillett, Pauluch, & Cain,

2002; Olivier & Stanciu, 1999). The option of private counselling is likely of particular importance in areas where public mental health resources are overburdened. For example, several low-income participants reported long waits to see a counsellor and being unable to see their counsellor as often as they would have liked.

In contrast, participants with incomes at the mid to upper end of the higher income range reported accessing private counselling, complementary therapies and fitness centres. This greater access to private services gave higher-income participants more control in maintaining their health and well-being, and in managing their illness through private means. This pattern of use of private health services is congruent with National Population Health Surveys (FPTAC, 1999a) which have also shown that income presents a barrier to non-universal health care services such as dental procedures, eye care, mental health counselling, prescription drugs, and alternative or complementary therapies.

### 5.3 Informal Social Relations

This section explores four categories of relationships: family of origin (parents, siblings and relatives); partner or spouse and children; friends; and community dynamics.

#### 5.3.1 Family of Origin

##### 5.3.1.1 Positive Interaction with Family of Origin

Participants from all income groups reported positive and supportive interactions with members of their family of origin. Emotional support, such as having someone to talk to when feeling down, was commonly noted. Ryan, for example, said that he visits one of his sisters when he wants some supportive company:

*If I need just to get out of the house...if I've had a rough day...I'll go over there and we'll sit there and talk... (Ryan, long term low-income)*

For Jason, having people who care for him and encourage him is paramount in his well-being:

*It's just the human thing... of having somebody else to care for you. I think that's totally the most valuable piece of anything with the AIDS... And people who encourage you to go on...people who give you strength. That's what I need when I'm living with this. People who believe in me that this isn't the end.*  
*(Jason, higher-income)*

Family members also provided participants with financial support, food and transportation. For example, some low-income participants said that they receive small amounts of money or groceries from their families to help them make it through the month. Others rely on their family for financial support during transitions or for more extraordinary expenses. Several participants live or have lived with their parents for financial reasons.

Having family to rely on sometimes alleviated some of the stress of low income. Pierre, for example, described how knowing that he could rely on his parents for money reduced the stress of the transition of leaving work due to illness. Patrick described how cheque day is no longer stressful in large part due to his mother's support. She comes to take him grocery shopping and to pay his rent. He said that he enjoys his mother's company and looks forward to these visits. Several participants said that being able to rely on family gave them a sense of security. Joseph put it this way:

*I just know they're there and that if I was ever in a jam, that they would be the ones that I would turn to first. In terms of like if I couldn't afford to pay for my own housing then I know any number of them are willing to have me stay at their place...There is security that I can't expect from anybody else other than my family. (Joseph, higher-income)*

Participants also shared that family members had provided care when they were sick (e.g., prepared meals), were people with whom they socialized (i.e., fun/relaxation support), and provided information. With respect to the latter, participants seemed to rely on family members for HIV-related information only if their family member had particular expertise (e.g., one participant's family member is a physician).

Participants from all income groups reported that HIV had not disrupted their family ties and that they had received acceptance and support upon disclosing their HIV status. Al shared his experience of disclosing to his mother:

*When I told my mother...I told her that I was gay and HIV positive in the same sentence...so she got a double whammy. And I didn't know how she was going to take it for she was quite religious, but she had a good cry...and told me that she still loved me...it didn't matter what it was as long as I was happy and that's the way she looked at it...and to look after myself. (Al, higher income)*

Robert disclosed to family soon after testing positive in order to have their support:

*There was no waiting for me, and the sole reason for that was to set up a support network, within my family and friends. (Robert, higher-income)*

Participants' accounts suggest that positive family responses are related to family members' acceptance of HIV, knowledge about HIV or willingness to become informed, and acceptance of the participant's sexual orientation. One participant, for example, described his family—parents, siblings, nieces and nephews—as being very accepting of his being both HIV positive and gay. He said both issues are discussed openly and are normalized within family interaction. This participant was particularly pleased with the acceptance of his nieces and nephews:

*When they were really little, they knew about Uncle... having something and they called it HIV LMNOP. So when I was sick they'd phone and they'd say "Uncle..., how's your HIV LMNOP?"*

And with respect to his older nephews:

*They never leave that I don't get a hug and a kiss. And these are grown young men who are very cool with displaying affection with their uncle, who happens to be queer and have AIDS.*

Another participant, George, linked support from his father to his father's openness to becoming informed about HIV/AIDS:

*My dad was the only one in my family that would sit down and read the information or the literature that I would give him. You know like I gave him an information sheet on what exactly HIV is and what can happen or what can't happen or you know like how it can be transmitted...how it can't be. And he was the only one in the whole family who was willing to sit down and read the whole thing. So that kind of showed me that he does care. (George, newly low-income)*

HIV had even brought some participants and their families closer together. Some attributed this to HIV being a catalyst for more open and honest communication. Others said that family members now demonstrate greater concern and put more effort into maintaining closer relationships. Jason provided additional insight on how HIV/AIDS can bring people together. He shared how experiencing a life-threatening illness made him more conscious of prioritizing people in his life and letting them know what they mean to him:

*There was a point when I just wanted a little bit more time so I could finish up a few things and say a few things to people, that I had never had the opportunity. And I think...after that and I started getting better and continued to get better...I really began to live with those things everyday... that it's important to tell people that you care for them while you're there and while you're with them right...So now those are the most important things in my life. That's why I prioritize my life. It's for people that are in it and being happy and being healthy and living every minute for all it's worth. (Jason, higher-income)*

In some cases HIV fostering closer relationships occurred even where they had been strained. Max had had frequent conflict with her sister, but HIV-related illness had brought them closer together:

*Well through my whole sickness... my sister was right by my bedside... the whole time. But before that we never got along, you know, we're always...something was always going on. But we kind of got closer as I ended up in hospital so many times and... I wake up and she'd be sitting there. (Max, newly low-income)*

Pierre's relationship with his mother had been strained by her lack of acceptance of his sexual orientation. They have become closer and communicate more openly since he disclosed his HIV status. Although not directly related to HIV, one participant reported improved relationships with her parents and sister after successful recovery from drug addiction.

Some participants who described their families as supportive also added that money was sometimes a barrier to reaching distant family. For example, Tony explained that calling his siblings always cheers him up when he is feeling down, but they all live away and he lacks money for long-distance calls. Another participant described how inadequate income prevents her from interacting with her family in ways that she would like. For example, she cannot buy birthday gifts for her family or go to movies with them.

#### 5.3.1.2 Negative Interaction with Family of Origin

Some participants from all income groups expressed worry and fear about disclosing their HIV status to family members. They may not disclose to protect themselves from emotional hurt. Although the decision to not disclose may provide emotional protection, it may also preclude support. Dontavia was afraid to tell his family that he is gay and HIV positive. He eventually did disclose to some family members and as he explained, received much valued support:

*Only recently I came out to my family, and so now that's been a great support for me as well. I never had that there really until two months ago...So that was very difficult for me and I had come out to them as a gay person first and then later on I mentioned that I was HIV, so that was difficult. And I spent about three years*

*in...suffered in silence with HIV. And I suppose that's the event of my whole life...suffering in silence and being gay, and it was a hard struggle.*

*(Dontavia, long term low-income)*

Incidents of negative HIV-related interactions with family members were more common among low-income participants in this study. For a number of participants, this negative interaction was intertwined with their family member's discomfort or judgement of homosexuality. Some participants who are gay, for example, felt blamed by family members for contracting HIV. David felt quite hurt by his mother's reaction:

*She said that "If you weren't gay, you would have never caught it" ...And I said "If you can't accept me, don't bother talking to me" and we never talked for about two or three months. (David, long term low-income)*

David's response also indicates his resistance to accepting being gay as something wrong, and is fitting with a radical humanist perspective of not internalizing negative social messages. Another participant, Jeff, explained that he cannot visit his mother because of the attitudes of other relatives towards homosexuality:

*I'm not welcome at my mother's house cause my brother and sister-in-law live there with her...I'm not welcome there...They think I chose this life...to be gay. (Jeff, long term low-income)*

Jeff went on to say that he is not sure if it's being gay or being HIV positive, or the combination of both, that is behind this rejection.

Higher-income participants also reported negativity towards their sexual orientation from family members when they first disclosed that they were HIV positive.

In these instances, however, the issues had been resolved to some degree. Joseph, for example, stated that his siblings were a bit homophobic and had more problem with his being gay than HIV positive. However, he described his family as having progressed to the point of being more accepting of his sexual orientation. Although this supports a possible link between income level and acceptance of homosexuality, it is important to point out that acceptance of homosexuality was not limited to participants with higher incomes. Participants from all income groups reported family member acceptance of their sexual orientation.

Some participants reported that their family's concern about what others in the community might think has caused negative tension. One participant, for example, has the impression that her mother and siblings are embarrassed that she has HIV. They have asked her not to talk openly about her disease.

Participants also attributed negative interaction to their family member's lack of knowledge about HIV/AIDS and/or resistance to becoming informed. George, who attributed his father's caring to a willingness to become informed, experienced a different dynamic with his mother. George believes that his mother's unrealistic fear that he might soon die, exacerbated by her lack of knowledge concerning HIV, has caused her to react angrily towards him and to limit their interaction.

A number of participants were dissatisfied with the amount or type of support received from family of origin. Several participants, for example, reported not receiving the financial support they wanted. Marilyn, who now has a higher income but was living

on income assistance at the time of her diagnosis, was not given the financial support she wanted from her family:

*When I first found out that I had HIV, I blocked it out of my mind for a whole year. Then all of a sudden it hit me. And when it hit, I needed help and I needed it bad. But no family...brothers and sisters...my mother and my father...nobody would help me in the family. And I was living in places...the cheapest I could get...250 dollars a month. (Marilyn, higher-income)*

Marilyn's comments also allude to not getting the emotional support hoped for from family members. Other participants echoed this disappointment.

Several participants reported that a family member who wants too much involvement in their life can cause relationship strain. One participant, for example, was living with her parents when she first became sick due to HIV:

*And it got to the point where I had to leave... I couldn't take my mother anymore, you know like... make sure I was taking my medications and don't do this, don't do that. I couldn't take it. It was too hard on the head. So I moved back to my own house.*

Some participants stated that certain family of origin problems were long-term and existed before they tested HIV positive. Participants linked these problems to family member attitudes towards homosexuality, giving and/or borrowing money from family members, participant's or family member's drug and/or alcohol use, lack of communication or closeness within the family, and a parent's controlling behaviour. Money as a factor in family tension was illustrated by one participant's recounts of

pleading with his family to give or lend him money. He went on to say that his family is reluctant to give him additional money until he quits drinking. HIV often exacerbated these long-term family conflicts. Terry for example, attributed not having a close relationship with his siblings to his being gay. He said things worsened when he was diagnosed with HIV:

*We didn't have a close relationship when I was growing up. But we started to and then I was infected...because it's such a social stigma...they just backed off...  
(Terry, newly low-income)*

Participants' descriptions of negative interactions also suggested how income can help address some types of family tension. The one participant's earlier comments about finding her mother too controlling illustrates this point. She had sufficient resources to be able to move out of her parents' home. Similarly, another participant said that he hopes that his relationship with his mother will improve now that he has the income to move out of his parents' home. Adequate income might also alleviate some problems around the expectations of financial support.

### 5.3.2 Partner/Spouse and Children

Four participants reported being in a current relationship with a partner or spouse. Three of these participants were men living with a partner of the same sex. One woman was living in a common law relationship with a man. In addition, three participants—two men and a woman—had recently started dating someone. Four participants, three men and one woman, discussed their relationships with their children.

### 5.3.2.1 Positive Interaction with Partner/Spouse and Children

The participants with a current partner/spouse or who had more recently started dating someone included representation from all income groups. They indicated that their partners were very important sources of support including: emotional, financial and fun/relaxation support; companionship; help with household chores such as cleaning and cooking; and help with personal care. Marilyn's comments illustrate the importance and range of supports:

*Well we do things together. We go grocery shopping together...He's good to me. He brings in my meal. He cooks. Right now I can't get out of bed so he has to do...for a bedpan...And he brings the basin in so I wash my face and then also when I brush my teeth. He does everything for me. That's how good he is to me. That's why I love him so much. (Marilyn, higher-income)*

Participants who lived with their partners received the widest range of support. In addition, for several participants being in a relationship and sharing living expenses meant the difference between having a low or higher household income, as well as less financial struggle.

Several participants had ex-partners who continue to provide various types of support. The types of positive interaction included emotional support, companionship, and care when the participant was sick. One participant continues to live with his ex-partner and benefits from sharing living expenses and household duties.

Participants from all income groups reported that their children were a source of support, typically emotional support and someone with whom they socialize. Their

children ranged in age from teens to young adults. Jack, for example, described his son as a source of emotional support:

*He lives outside the city... I talk to him regularly, in fact, virtually everyday we talk on the phone or by e-mail...we're in constant communication. So he's support...Works both ways...like you know he might call all upset over something that's going on in his life and...so you support him and then I can tell him what's going on in my life and he can support me... We're very close.*  
*(Jack, higher-income)*

#### 5.3.2.2 Negative Interaction with Partner/Spouse and Children

Two participants indicated that their HIV diagnosis precipitated a break-up with a partner or spouse. For one participant, the diagnosis meant disclosing to his wife that he was bisexual and that he had sexual relations with men during the course of their marriage. He reported that his wife felt betrayed and angry, in part for being put at risk of HIV infection. They struggled to maintain the marriage for about a year after his diagnosis, but eventually separated. The participant was pleased to recount, however, that he and his ex-wife continue to be very good friends. He also expressed pride at how well he and his family were able to handle this difficult period. He added, however, that some residual strain is evident as issues resurface.

The second participant had to deal with the revelation that his partner had unprotected sex outside of their relationship. He surmised that he became infected through his partner. Although they separated for a time, they are back together. The participant described his relationship with his partner as now much closer, but that they

are dealing with issues related to both of them being HIV positive. As an example, he and his partner have differing comfort levels about how out they want to be about their diagnosis. The participant said that he is much more open about disclosing his status and seeking outside resources. He feels that his partner is keeping a lot of his feelings bottled up, and would benefit from talking more about his diagnosis.

Two participants identified negative interactions with their children that related to HIV. One of the participants said that his son will no longer see him. He attributed this to his son's wife not being knowledgeable about HIV and fearing contagion. Max, the second participant, said that HIV has strained her relationships with her adult children in a number of ways. She believes that some tension comes from her children not really understanding HIV and the limitations it has placed on her. For example, she feels that her children cannot accept that she can no longer do many of the same activities with them. Max also said that she feels her children direct some of their anger at her. Anger that she believes comes from how she became infected and their fear of losing their mother.

In addition to HIV, Max described some family tension stemming from her daughter and three grandchildren living with her. At times she feels the financial strain of four other people living with her (e.g., the cost of extra groceries). Max added that she would like to live on her own. However, her daughter's low income prevents her from finding separate accommodation. In Max's case, she is affected by the inadequate financial resources of another family member.

### 5.3.2.3 Establishing Romantic/Sexual Relationships

Some participants said that they miss being in a relationship and see a partner as someone who can provide much support. Several participants said that not having a partner was one of their main stressors. Participants from all income groups, however, said that HIV poses difficulties or challenges to romantic/sexual relationships. The challenges related to how and when to disclose one's HIV status and to the other person not being accepting or wanting to become involved in a relationship with someone with HIV or AIDS. Joseph, for example, shared that he experiences anxiety about disclosing his status:

*When do you tell? You know you don't want to invest a whole lot of time and energy and then find out they're not interested. And for that reason you think well I should tell them fairly early on but if you tell them fairly early on they're not that invested in you and so why would they want to take that on? So you can't have a casual date cause there's...this big issue to face. (Joseph, higher-income)*

Robert shared similar concerns:

*Yeah, sometimes it can be very disappointing because, you know, you can get to know someone...you really like them and then, you know, you tell them and then they're out the door and that's it. (Robert, higher-income)*

George linked people's reluctance to date someone who is HIV positive to their fear of contracting the disease. He suggested more education could help in this matter. Others linked people's hesitancy to not wanting to become involved with someone who could

become sick and die. Several participants said that they fear transmitting HIV to someone else.

Participants with low incomes identified barriers to dating that related to their socio-economic status. Some said that being on a disability pension or not fully employed may make them less desirable to a potential partner. Terry put it this way:

*I mean how do you tell somebody that you meet that doesn't know you... "I live with my parents and I'm getting disability" and yet this person is living a productive normal life. (Terry, newly low-income)*

Dontavia shared that he felt hurt and that his self-esteem was damaged after someone he was dating ended their relationship because Dontavia did not have full-time employment. Other participants said that money prevented them from going out where they might meet someone.

Despite the various challenges, a number of participants from all income levels, of both genders, and both gay and heterosexual, established satisfying romantic/sexual relationships. George, for example, described the woman who he was dating:

*She's very empathetic... she doesn't understand everything about HIV/AIDS but she certainly just sort of sees me for the person that I am. And I've been very honest and straightforward with her from day one... And she's not afraid to get close to me... I mean that you can have a normal healthy sex life and still be HIV positive...and that you know people will still love you regardless of your illness. (George, newly low-income)*

Participants were eager to advise about dating. George, quoted above, said that you will develop more confidence in dating as you have some positive experiences. Fitting with radical humanism, participants stressed that it is important to not blame yourself if a person is not accepting of you as a PHA. Robert shared the following:

*The first couple of years...I always felt that it was me. And that their objections were understandable and that it was really me. And that was fine. However, at some point in time it changed, and it really has changed... is now at the point where, you know, if you can't deal with that then that's not my issue. Those are your issues. (Robert, higher-income)*

One participant shared his strategy for disclosing his HIV status:

*I wait a couple of days before having any sexual contact with anybody. If it comes down to it...like say we're dating and maybe the third date... I'll say to you well I'm HIV positive...does that bother you. (Ryan, long term low-income)*

Finally, another participant felt the need to see being single as no lesser a lifestyle as being in a relationship. This again illustrates how through reframing participants can free themselves from constraining societal messages.

### 5.3.3 Friends

#### 5.3.3.1 Positive Interaction with Friends

Participants of all income groups reported positive and supportive interactions with friends. Tony described the emotional support he receives from two friends:

*Especially emotional. I mean they've been always there for me and...doesn't matter what time of day or morning...I can remember calling them at four o'clock*

*in the morning because I'm depressed and we talked for hours and...they've always been there for me. (Tony, long term low-income)*

Jason shared that one of his best friends is very affirming, frequently reminding Jason of all of his positive qualities. Participants also noted that they benefit from socializing and doing things with friends (i.e., fun/relaxation support).

Some participants have friends who are also HIV positive, and can provide informal peer support. These friends help in problem solving and share information. In addition, participants reported that friends provide a sense of security. Jason, for example, said that he finds security in friends that he can rely on in periods of illness:

*I have friends... I've known for many, many years who know that I have AIDS and are always keen on how I'm feeling. And at times when I've been in crisis or at times when I needed things...they've always been there for me...always provided whatever I asked for...been supportive...cooked for me...stayed with me...done jobs and chores and things that I wasn't capable of doing...It's really good to know that if there's... if something happens you've got people... that you can fall back on. (Jason, higher-income)*

Jason also said that he finds comfort in sharing accommodations with a good friend, especially when he is feeling unwell or needs someone to talk to. Other participants reported deriving a number of benefits from living with a friend, including companionship and sharing household expenses, cooking and cleaning.

Some participants said that their friends provide financial support. Tony, for example, has several friends who help him in this way:

*Oh when I'm down and out, they'll...you know give me... money for groceries.*

*(Tony, long term low-income)*

Participants from all income groups reported that HIV had not affected their friendships in any negative way:

*No, my friends have never changed in any shape...form...even when I found out I was HIV. (Ryan, long term low-income)*

*All of my friends know I'm HIV positive. And none of them have a problem.*

*(Pierre, newly low-income)*

The acceptance Paul received upon disclosing his HIV status sustains his self-esteem:

*Just to be accepted for a human being helps a person's self-esteem...self-worth.*

*(Paul, newly low-income)*

Furthermore, some participants said that their relationships with certain friends have become closer following disclosing their HIV status. Al, for example, said:

*There was other people that I would say...are better friends now than before they find out that a person is HIV positive... They're more caring and they're more understanding and probably more concerned about your well-being and health... (Al, higher-income)*

Jason, as was the case with his family members, attributed becoming closer to friends since his diagnosis to his showing them greater appreciation.

For some participants with lower incomes or incomes at the lower end of the higher-income range, money emerged as a barrier to going out and interacting with friends. Pierre, for example, shared the following:

*A lot of my friends are into going to the theatre or out for dinner and I don't always feel that they should be paying, so I stop myself from going and being part of the group. (Pierre, newly low-income)*

When Vern had a low-income he would make up excuses when friends asked him to do things rather than admit to not having enough money:

*I've had people say "Oh, lets go out to go get a coffee" or "Let's go out to lunch" and it's like you know "I don't have the time right now". You know that wasn't the truth at all. I had lots of time. I just didn't have the money to do it.*

*(Vern, higher-income)*

One participant said that he does not feel comfortable going out when lacking clean or newer clothes.

#### 5.3.3.2 Negative Interaction with Friends

Some participants worried that disclosing their HIV status to friends would bring rejection or extended negative gossip. Jason said that he does not tell people in order to avoid their negative reactions. He described a number of such reactions, from being marginalized to being pitied to being judged:

*Sometimes I always get the feeling from some people...especially at the very first...that I wasn't going to be here that long anyway you know. So it's almost like you're kind of marginalized and that...it's like you're a person without a future. So you're kind of existing for the moment right? I don't feel like I want to tell people...cause I don't want people to feel sorry for me or I don't want it to set up barriers and obstacles because people feel or think that because*

*of my condition I'm not capable or less capable of doing things... And then people associate it with all kinds of things...with being a very promiscuous...you know it's kind of a disease or something that you pick up by using a dirty needle or being a slut... (Jason, higher-income)*

A number of participants reported that HIV has cost them some friends. Several participants found their friends just drifted away. One person said that her friends no longer visit and another said that people stopped calling. Al shared his experiences of losing relationships with people he considered friends:

*There was certainly a few so-called friends that I had from before that when I came out as being gay to them and told them that I was HIV positive too, either then or shortly after I never seen much more of them. I don't know if it was the fact to do that I was gay or if it was the fact to do with that I was HIV positive or a combination of the two. (Al, higher-income)*

Al's comments suggest that friends may distance themselves for reasons related to both HIV and homosexuality. George, who is heterosexual, believes that some people he thought of as friends "dropped" him because of their irrational fear of contagion and not for reasons related to homosexuality. He described his experience:

*Their fear was more in contracting it... I shouldn't even say friends because of the ones that were fearful of contracting it weren't...you know, they turned out really not to be that close of a...confidants or friends anyway... They had their little ideas and I figured well let them sit with that... (George, newly low-income)*

Max distanced herself from friends because they might ask intrusive questions about how she became infected:

*I don't see my friends anymore. I sort of stay away from them. You know because when I'm sitting with them I talk with them...just like going out for a social night. Have a few beers with them, you know, they start talking and asking me questions and how I got it. I say I don't know... (Max, newly low-income)*

For some participants, loss of friends led to isolation and loneliness. David described his loneliness from the loss of friends:

*Like they disappeared off the face of the earth. They don't even come near me...It don't hurt me in a way, but in a way it does because I like to have someone to talk to...without sitting here and watching TV or even go out...for a walk or go for a coffee or something like that...But now it's like there is no one around no more. (David long term low-income)*

#### 5.3.3.3 Establishing New Friendships

Participants from all income groups said that HIV had not been a barrier to establishing new friendships, except for romantic/sexual relationships. However, a number of participants did identify barriers to new friendships. Some barriers were the same issues to which participants attributed the loss of existing friends, including negative attitudes and fears related to HIV/AIDS and homosexuality. John, for example, described the stigma attached to associating with someone who is gay and/or HIV positive which deters potential new friends:

*You hang around with someone that's gay, you're automatically labeled as being gay. You hang around somebody that's HIV positive... "God, what are you doing with them? ...Don't you know he's got AIDS". (John, long term low-income)*

Both John and Vern connected people's lack of acceptance to their lack of education.

According to Vern:

*I just don't understand people's ignorance and their lack of knowledge on it, because if you don't go and get the information about it then you're not going to know about it, and I can accept that but you know the information is there to be accessed. So if they really wanted to be my friend, or get to know me, then they would you know try to get the information they need. (Vern, higher-income)*

Vern's comment is another illustration of resisting self-blame or responsibility for another person's non-accepting attitudes and behaviours.

Some participants protect themselves by avoiding contact with new people. John, for example, is aware of becoming more withdrawn since testing HIV positive, and of his resultant loneliness:

*I think I've come to a point where I put a shield around me... so I don't get hurt so much...I mean...what you do you end up being alone, right. I can say...I was never this way before... (John, long term low-income)*

Tony delays disclosing in order to minimize the risk of being hurt or rejected. He waits to make a decision to disclose or not until he gets a sense of the other person's attitude towards HIV/AIDS.

Finally, some participants linked low income with not being able to afford to go out and socialize, thus limiting the possibility of meeting new people. Clorise shared the following:

*I don't make enough to go out... You know you have enough for your rent, your bills, some food and I never spend money on myself because there's nothing left...It's in one hand and out the other. You know there's nothing left for movies or anything, bowling. (Clorise, newly low-income)*

#### 5.3.4 Community Dynamics

Participants spoke about informal social interactions that fell outside family and friends, such as interactions with neighbours and people encountered at social events.

##### 5.3.4.1 Positive Community Interaction

Participants from all income groups identified positive and supportive aspects of their communities. They also referred to several types of communities, including their immediate neighbourhoods and broader local communities, and the gay community. Ryan, for example, described the reciprocal relationships he has developed with others attending a local community bingo. He helps people out by going to get their coffee. In return, people give him the remaining change and also show concern that he might not have enough money to play bingo. Ryan feels pleased that he is able to help out others in this way. George said that he enjoys associating with people that he encounters at food banks and at a drop-in coffee house for 'street' people. He explained that he finds many of the people he meets at these services to be non-judgemental due to their own struggles with poverty. Tim reported receiving support within the gay community:

*The support that I found in the gay community from different members...it's been heart warming. I guess in some ways that the community is kind of there and they are more...you know a lot more supportive than I thought they ever would be... just emotionally and understanding. And most of the time when they react...when you tell them it's generally out of their fear for my well-being...it's their concerns over that than a fear of anything else... (Tim, higher-income)*

Some participants reported that they have observed their communities becoming more educated about HIV/AIDS, less fearful of HIV/AIDS, and more accepting and supportive of those living with the disease. Tim, for example, said that there is now greater awareness of HIV/AIDS in the gay community where he lives. He also noted that the gay community is becoming more involved in the delivery of support services. He believes that since his province added sexual orientation to its human rights legislation people are less fearful of getting involved in the gay community and risking their sexual orientation becoming known. Tim's experience may be related to the fact that he comes from a small urban centre. In contrast, Glen who resides in a larger city, said that he has always found the gay community very supportive of him and of others living with HIV/AIDS.

#### 5.3.4.2 Negative Community Interaction

Participants identified negative aspects of the communities in which they associate. Some participants were concerned that people in their community gossip and will tell others that they are HIV positive. They worry they will be judged or rejected if people find this out. This fear is not unfounded, as several participants have been

harassed in their local communities due to their HIV positive and/or gay status. In this study, incidents of harassment were more common among low-income participants. For example, one participant with low income described being verbally harassed and physically threatened by youths who recognized him from participating in an AIDS fundraising/awareness event. Another participant, David, said that when he goes for walks in his neighbourhood some people point him out as the person with AIDS. His landlord pressures him to stay in his apartment because she worries about other tenants being afraid to live in the same building with someone who is HIV positive. Another participant said that people at bingo will not sit beside her because they know she is HIV positive, and have said to her that they are now afraid to use the washroom there.

Some participants described a lack of acceptance and support within the gay community. Terry, for example, reported encountering the following dynamic at gay events and bars:

*“Oh... don't go around him... he's infected... you know... he's got the plague... you'll get sick” ... I just shut myself off from that.*

*(Terry, newly low-income)*

Robert believes that the gay community judges those who are HIV positive as irresponsible.

Participants also described the consequences of unsupportive communities. Notably, negative community dynamics can contribute to less going out and more loneliness. David, for example, said that he stays home more:

*I'm always in the house. I want to get out more. But when I do go out it just feels like everybody's pointing their fingers now. That's stressful for me.*

*(David, long term low-income)*

Community dynamics can also affect a person's comfort with respect to housing. Elvira lives in a boarding house with shared kitchen and bathroom facilities. She worries that the other residents will find out that she is HIV positive and judge or reject her, or out of ignorance, will not want to share dishes and the bathroom. Elvira wishes she could afford her own apartment. Her situation, along with the example of the participant who feels pressured by his landlord to stay indoors, illustrates how low income reduces housing options and makes one more vulnerable to discrimination. Patrick identified safety concerns in his neighbourhood related to it being known that he takes pain medication. He worries that his apartment will be broken into by people looking for drugs.

As with other types of informal social relations, participants attributed negative community interactions to people's lack of knowledge about HIV and/or homosexuality. George, for example, finds that HIV generally does not evoke a negative response from people with some knowledge of the issue:

*To most educated and mature people it's really not such a big deal. You know I mean it's the other people that really don't have the knowledge or the education about the whole thing... I find myself...ending up having to try to teach people or to explain to them...And it's difficult because if they have this narrow-minded*

*perspective of what HIV or what you know AIDS... they're not going to get off of that track. (George, newly low-income)*

### 5.3.5 Summary

Informal social relations, that is relationships with family, friends and community members, were a source of positive interaction for participants from all income groups. The types of support from family and friends were similar for participants of differing income levels and included: emotional support, money and other forms of instrumental support, fun/relaxation support such as people with whom to socialize, informational support, and help in problem solving. PHAs, in another study, reported similar helpful behaviours of family and friends (Hays, Magee, & Chauncey, 1994). Many participants, again representing all income groups, reported that HIV had not affecting their personal relationships in any negative way. They attributed this to their family and friends being accepting of them as a PHA, being knowledgeable about HIV or willing to become informed, and being accepting of their sexual orientation. Their speculations are consistent with other research (Kadushin 1996; 1999). Some participants noted that their communities (e.g., neighbourhoods and the gay community) were becoming better educated about HIV/AIDS, less fearful of the disease, and more accepting and supportive of people living with HIV/AIDS. Participants were also able to establish satisfying romantic/sexual relationships.

Participants were able to link the support that they received from family and friends to their health and well-being. Several participants noted that being able to rely on family and friends provides a sense of security. Some lower-income participants said that

emotional and instrumental supports alleviate some of the stress of low income.

Participants also linked socializing with others to good mental health. They attributed being able to sustain their self-esteem to the acceptance received from others. Earlier studies have also shown the benefits of social support in the lives of PHAs in relation to mental health and stress mediation (Crystal & Kersting, 1998; Gant & Ostrow, 1995; Hays, Turner, & Coates, 1992; Ingram et al., 1999; Serovich, Brucker, & Kimberly, 2000; Simoni & Cooperman, 2000). Conversely, participants described how the loss of support from family and friends can lead to isolation and loneliness.

Participants also identified interpersonal conflict and barriers to attaining desired social relations (explored in more depth in the next chapter). They reported experiencing judgement, distancing and rejection by family and friends related to their being HIV positive or gay. These experiences are similar to what PHAs have reported in other studies (Hays, Magee, & Chauncey, 1994; Smith & Rapkin, 1996). Some family of origin problems were long term (e.g., issues related to being gay, borrowing money, drug and alcohol use). However, HIV had often exacerbated these situations. Participants also experienced negative judgements, rejection and harassment in community interactions. Participants attributed negative social interactions to the other person's discomfort or judgement of HIV/AIDS and homosexuality, and to their lack of knowledge on these issues. In this study, negative HIV-related interactions with family and community members were more common among low-income participants.

For some participants, lack of money presented a barrier to interacting with family and friends as they would like (e.g., calling family long-distance and going out

with friends). The literature also identified lack of money as a barrier to social interaction (Ezzy et al., 1998; Smith & Rapkin, 1996). Some participants shared housing with family members. This sometimes resulted in relationship strain that could be reduced if the participant had sufficient income to live on their own. HIV posed difficulties or challenges to romantic/sexual relationships related to disclosure and to the other person's acceptance and willingness to date someone who is HIV positive. Furthermore, some low-income participants said that they lacked the money to date or to go out and socialize where they might meet someone. They also found that their low income or low SES made them less desirable to others.

Notably, participants were able to resist assuming self-blame and responsibility for other people's non-acceptance of them as HIV positive or gay—evidence of radical humanism. Through reframing, they were able to free themselves from oppressive social messages.

## Chapter 6

### Discussion and Synthesis

The goal of this chapter is to better understand how factors related to three social domains—paid and volunteer work; private, government and non-profit services; and informal social relations—affect the health and well-being of PHAs of varying income levels. Such an understanding will be informed both by a discussion and synthesis of the findings presented in Chapter 5, as well as by the literature.

The discussion first focuses on factors that appear related to income level and that contribute to or hinder the attainment of aspirations associated with the three social domains under investigation. The aspirations arose from the interview questions as well as from participants' comments and include attaining/maintaining: 1) desired paid or volunteer work; 2) health and well-being through the use of private, government and non-profit services; and 3) desired informal social relations. Notably, these aspirations overlap with already established determinants of health—employment and working conditions, health services, and social support networks (FPTAC, 1994). The discussion of the disjuncture between social domain aspirations and their attainment also serves as an entry to examining aspects of well-being, in particular stress, sense of control, isolation, and sense of self-worth. The literature was used to help link income-related factors to health and well-being as well as to elements of society which promote income-related differences.

## 6.1 Social Domain Aspirations and Their Attainment

### 6.1.1 Attaining/Maintaining Desired Paid or Volunteer Work

Given the benefits of paid and volunteer work identified in Chapter 5, it is not surprising that all participants in the study reported some type of work-related goal or aspiration. For example, those with paid employment wanted to sustain their employment. Those without paid employment, but feeling able to work, wanted to find a job. All without paid employment hoped to continue to do or find volunteer work. Although participants of varying income levels shared the desire to participate in paid or volunteer work, differences emerged among the income groups with respect to attaining and/or maintaining such participation. For some study participants, employment emerged as a location of structural or institutional oppression, as well as for discriminatory and oppressive interpersonal exchanges.

A quite evident difference between participants with higher incomes and those with lower incomes is that many participants with higher incomes had full-time employment. In comparison, none of the lower-income participants had full-time jobs. This finding reinforces an obvious link, but given the relationship between income and health, a link worth emphasizing—employment provides a higher income than is afforded by public income security programs. Aspects of participants' accounts about leaving work, however, point to group differences that preceded their current employment status.

Some participants reported job loss due to HIV-related discrimination and/or a lack of accommodation of illness. Those with non-unionized food/service industry and labour jobs appear most vulnerable to discrimination. Other research on the work

experiences of PHAs also reported workplace discrimination (Adam & Sears, 1996; Bevier & Baker, 1999; Canadian AIDS Society, 1998; Olivier & Stanciu, 1999), but did not link this to types of employment. Several participants who were fired when their employer found out they were HIV positive said that they did not feel they had the resources or energy to fight their dismissals. Adam and Sears (1996) also confirmed that people fired because of their HIV status also lacked the time, energy or money to pursue legal recourses. Such experiences point to limitations in human rights protection and the need for additional supports for people to challenge discrimination. Other participants, however, reported job security and accommodation of illness. One employer showed support by implementing AIDS education in the workplace when she suspected some employees might react negatively towards a work colleague with HIV. While some participants described challenges associated with continuing to work while experiencing symptoms, there is less pressure and stress with an employer who will provide accommodation (e.g., slower pace, shorter hours, flexible days, time off).

The contrast between supportive and discriminatory workplaces provides evidence that employment is structured in ways that place some groups of PHAs at greater risk. Low professional-work status, lack of union protection, and an overlap with a stigmatizing disease, exposed some participants to exploitation—one of three forms of oppression Iris Young (1990) associates with the division of labour. Exploitation occurs when the energies of subordinate groups are systematically transferred to the dominant group in an unfair exchange of labour for pay (Young, 1990). Exploitation is evident in this study where participants provide labour for little pay and/or no assurance of job

security and accommodation of illness. Furthermore, the range of compensation for labour, which includes minimum wage for some to health benefits and pensions for others, underscores the inequity inherent in exchanges of labour. Exploitation also characterizes the experience of the participant who continues to paint apartments in exchange for a reduction in rent even though he knows this work jeopardizes his health. In effect, this participant is trading off his health along with his labour. This example also illustrates the collusion of societal institutions in supporting oppression. Income assistance does not provide enough to live on, so people have to supplement their income through unsafe work. The desperation inadequate income assistance creates makes recipients of public assistance more vulnerable to exploitation. Young (1990) contends that the powers of workers diminish in an exploitative exchange of their labour since they suffer material deprivation and loss of control.

Another important aspect of participants' stories also preceded their current employment status. Nearly all of the newly low-income participants had been working until illness (and possibly until a lack of accommodation of illness) rendered them unable to continue their jobs. Yet the jobs they once held did not provide long-term disability benefits or a medical pension. So in effect these participants experienced exploitation in the workplace, and when they could no longer work due to illness or when accommodation was not provided, they became dispensable and impoverished. In contrast, one higher-income participant who is no longer able to work full-time remained in the higher-income category because his past employer did provide a medical pension.

The power differentials associated with different types of employment and rooted in class status, form the second type of oppression—powerlessness—that Young (1990) associates with the division of labour. As evident in this study, some participants experienced greater power at their places of work stemming from professional status and union protection. Such employment provided more control and flexibility around scheduling medical appointments and being away due to illness. And as discussed later in this chapter under stress and control, the ‘respectability’ derived from higher status employment extends privilege into other areas of social life, such as the way one is treated by service providers (Young, 1990).

Although being able to do paid or volunteer work can contribute to a sense of emotional well-being, findings show that not being able to work can threaten emotional health. Similarly, Adam and Sears (1996) found that some PHAs associated the inability to work with boredom and a sense of wasting time. Given these findings and the benefits of paid and volunteer work presented earlier, it is alarming that a number of participants, in particular those with long-term low incomes, identified barriers to attaining paid and volunteer work. Those related to paid work included: high unemployment rates, lack of jobs, lack of training, low education, age discrimination and criminal records. Barriers to volunteer work included: lack of positions, mental and physical health conditions, learning disabilities, and screening criteria. Furthermore, higher-income and newly low-income participants seem to have greater advantage in attaining volunteer work due to the skills they can bring in from their previous work experience, which make them highly desirable volunteers. In addition to the sets of barriers identified above, PHAs from all

income groups identified a number of barriers to employment that were directly linked to HIV (e.g., the potential for HIV discrimination, needing to explain long absences from the workforce, and worry about the loss of income security program benefits if one returns to work). Similar concerns were expressed by PHAs in other studies (Adam & Sears, 1996; Brooks & Klosinski, 1999; Canadian AIDS Society, 1998; Olivier & Stanciu, 1999). The greater exclusion from paid employment due to HIV/AIDS and the additional barriers that lower economic status participants faced in their attempts to secure paid or volunteer work constitutes 'marginalization', the third form of oppression Young (1990) links to the division of labour.

Marginalization occurs when whole groups of people are excluded from employment (Young, 1990). In this study, people living with HIV/AIDS who have lower economic status experienced the greatest marginalization. As alluded to in earlier discussion, not being able to participate in paid employment can result in material deprivation. Young (1990) contends, however, that there are two other negative consequences of marginalization. First, this form of oppression exposes people to negative effects of income security programs. This aspect of marginalization is explored in the next section under use of services. Second, marginalization deprives people of opportunities to participate in socially defined and affirmed ways (Young, 1990). This is consistent with the importance participants placed on being able to participate and contribute through paid and volunteer work. This consequence of marginalization is revisited in later discussion on the relationship between self-worth and isolation.

Finally, participants demonstrated understanding that the barriers they face in securing and in maintaining employment are rooted in societal structures and not in their own personal shortcomings. For example, participants who were fired from their jobs were able to label such action as discrimination. Others recognized group characteristics such as age and low education as barriers to employment. These participants were able to think critically and arrive at their own understandings of causes of problems. Such thinking is consistent with radical humanism. The full extent to which structural factors contribute to personal problems, however, was not always evident in participants' understandings. One participant, for example, appeared to accept his employer's lack of accommodation of illness as normal, and placed greater responsibility upon himself to not let his health affect his work.

#### 6.1.2 Attaining/Maintaining Health and Well-Being through the Use of Private, Government and Non-Profit Services

Whether by choice or circumstance, participants used a variety of services in attaining and/or maintaining their health and well-being. Lower-income participants made greater use of non-profit services and public income security programs in meeting basic needs (e.g., AIDS organization emergency funds, food banks and provincial income assistance). Although helpful, collectively these services and programs were insufficient to meet basic needs. Some, as explored below, also posed threats to psychosocial well-being. Higher-income participants, on the other hand, utilized more private services (e.g., private counselling and complementary therapies). This provided them with more options in managing their health.

Reliance on income security programs and services to offset low income marginalized some participants. Young (1990) contends that a consequence of marginalization or being excluded from paid work is exposure to “patronizing, punitive, demeaning, and arbitrary treatment by policies and people associated with welfare bureaucracies” (p. 54). Evidence of this form of oppression is present in participants’ descriptions of their use of public income security programs, as well as AIDS organization emergency funds.

Emergency fund programs, which are both needs and income tested, caused frustration and stress for some using them. The concerns related to rigid criteria, having to fight to receive benefits, differential treatment of clients, and workers who seemed to lack empathy and understanding about what it is like to be poor. In contrast, participants expressed much satisfaction with AIDS organization health maintenance funds, which although income tested, provided flexibility in spending money received. Participants expressed some of the same complaints and frustrations about accessing services through provincial income assistance as they did about emergency funds. They also reported stress from being subjected to periodic program eligibility reviews which could result in less income. Ken Battle, a Canadian policy analyst, contends that needs-tested welfare “involves an invasive test of the applicants’ income, needs and assets...and stigmatizes its recipients” (1999, p. 28). In contrast, income-tested social programs are not as intrusive and stigmatizing (Battle, 1999).

Several participants said that they felt stressed or embarrassed by the dependency and stigma attached to being on income assistance. Such findings suggest that

participants are influenced by prevailing negative images of persons on assistance. Such negative views are consistent with a form of oppression which Young (1990) calls cultural imperialism. This form of oppression involves the universalization of the dominant group's culture and experience as the norm, while also imparting negative views of oppressed groups.

The negative perspectives participants hold of being on income assistance come from the cultural level of oppression but are played out and reinforced by institutional and personal oppression (Thompson, 1998). For example, the distinction between the 'undeserving' poor (those perceived as able to work) and the 'deserving' poor (those perceived as unable to work due to no fault of their own) was reinforced by the awarding of marginal increases in income assistance to participants who moved from an employable to a disabled classification.

Internalized oppression occurs when members of oppressed groups believe the dominant portrayals of themselves (Mullaly, 2002). As noted above, some participants felt embarrassed about deriving their income from income assistance. One participant described being on income assistance as taking from society rather than making a positive contribution. Other participants said that they felt less shame from being on income assistance due to disability rather than unemployment. While this distinction may help some retain their sense of self-worth, it continues to blame those who are unable to work for other reasons. Such blame, when internalized as self-blame, poses a threat to a person's sense of self-worth. However, some participants were able to see through prevailing depictions of poor people. For example, many recognized that public income

assistance programs do not provide adequate income to meet basic needs and the fact that they are struggling to meet basic needs reflects systemic and not personal inadequacies.

In addition, some participants were able to reframe income security programs as entitlements and not income that they do not deserve. So while the findings show how income determines the services used and imposes restrictions on others (supporting the need for radical structuralism), participants' assessments of income assistance and reframing income security as entitlements illustrate the dynamic of radical humanism.

### 6.1.3 Attaining/Maintaining Desired Informal Social Relations

Given the benefits of social support described by participants in Chapter 5, it is troublesome that some participants experienced interpersonal conflict related to HIV/AIDS and barriers to attaining and/or maintaining desired informal social relations. Inadequate income emerged as a direct barrier to accessing support from family and friends, and to interacting with others in desired ways. For example, low-income participants did not always have the financial resources to visit or call family and friends, or to go out and do things with them. Not having enough money to go out also limited participants' opportunities for meeting new people and establishing friendships. The literature also identifies inadequate income as a barrier to accessing support (Smith & Rapkin, 1996) and to social and recreational activities (Ezzy et al., 1998). Furthermore, participants described barriers to establishing romantic/sexual relationships that related to their low socio-economic status. These included being less desirable to a potential partner due to being on income assistance or not fully employed. This undesirability is likely related, at least in part, to negative prevailing views of those who are unemployed and in

receipt of income assistance. Public discourse often depicts people who are not working and 'on welfare' as lazy and out to cheat the system, thus reinforcing their inferior position in society. Such beliefs illustrate the concept of cultural imperialism (Young, 1990), a form of oppression discussed earlier in this chapter.

Inadequate income also presented barriers to the resolution of some family problems. For example, the tension of living with a family member might be reduced if the participant (or in some cases their family member) had sufficient income to live on their own. Adequate income would also alleviate the need for financial support, thus eliminating another possible area of conflict. In addition, low-income families may lack the resources to provide instrumental support (e.g., the provision of money or food) to a family member with HIV/AIDS.

Participants reported negative interactions with family and friends related to HIV/AIDS (e.g., distancing, rejection, conflict). The loss of support and distancing of family and friends resulted in isolation and loneliness for some participants. Several participants, in anticipation of negative reactions or rejection by others, distanced themselves from family or friends and/or avoided meeting new people. Although this provided some protection from emotional hurt, it also increased isolation and reduced opportunity for social support.

Participants linked negative interactions related to HIV/AIDS to people's: lack of knowledge about HIV/AIDS and/or unwillingness to become informed; fear of contagion; worry about community reaction; and discomfort or judgement with respect to homosexuality. These issues also emerged as barriers to making new friends. Discomfort

or judgment of HIV/AIDS and homosexuality were frequently intertwined. Earlier research on predictors and barriers to social support for PHAs revealed similar findings. Studies indicate that being able to talk to family members about AIDS (Turner, Hays, & Coates, 1993), family members' acceptance of the PHAs' sexual orientation (Kadushin, 1996), and relationship satisfaction with family (Serovich, Brucker, & Kimberly, 2000) are linked to social support satisfaction. Conversely, Smith and Rapkin (1996) found that lack of acceptance and negative interaction were barriers to family support among PHAs.

Kadushin (1999) found that one of the greatest barriers to PHAs obtaining family support was the family's lack of knowledge regarding HIV/AIDS. Lentine et al. (2000) found that stigmatizing behaviours towards PHAs were more common among those misinformed about HIV transmission. Similarly, Mondragon, Kirkman-Liff, and Schneller (1991) found that persons with unrealistic perceptions of AIDS risk had greater hostility towards PHAs. Their study did not determine the direction of the relationship and they cautioned to not assume causality. In other words, inaccurate information about the risks of contracting HIV could lead to hostility, but hostility (e.g., negative attitudes towards PHAs) could lead to inaccurate risk perception. There is evidence in the findings for both possibilities. The family and friends that participants refer to in their accounts of negative interactions may lack accurate information about HIV/AIDS which results in fear and distancing. However, the finding that some family and friends were unwilling to become informed implies that they are resistant to learning about HIV/AIDS. This resistance could stem from pre-existing negative perceptions. The possibility of both dynamics points to directing efforts to influence cultural and structural levels of society

which through such processes as cultural imperialism, shape personal beliefs and attitudes. Of course, this does not preclude responding with educational services at the individual level.

Participants also expressed dissatisfaction with the amount or type of support received from family once they had disclosed their HIV status (e.g., some would like more financial support) and concern over family members wanting too much involvement in their lives. Participants also said that some family problems were long term and preceded their HIV diagnosis. Some long-standing problems, however, were exacerbated by issues related to HIV (e.g., heightening judgement around homosexuality and participants having greater financial need due to not being able to work).

Participants also described negative or unsupportive elements of their communities. They worried that they would be judged or rejected if people found out they were HIV positive. Several participants experienced harassment and physical threats related to being HIV positive and/or gay. Some were shunned by others at community events (e.g., people not wanting to sit beside them). As a result, some participants went out less which led to isolation and loneliness. Young (1990) contends that subjection to violence and harassment based on membership to a particular group is a form of oppression. As was the case of negative interactions with family and friends, several participants attributed negative community dynamics to people's lack of knowledge about HIV and/or homosexuality. Conversely, they associated more positive attitudes with people being better educated on these issues.

In this study, negative HIV-related interactions with family and community members were more common among low-income participants. In addition, negative attitudes, lack of awareness, and less tolerance emerged as common factors in these informal social relationships. This suggests possible relationships between income level and negative interactions. One possibility may be that the social networks in which low-income participants interact have had less exposure to accurate HIV information, or for that matter, to more progressive views of homosexuality. This would be consistent with participants' own observations. There is some support for this hypothesis in the literature. As already noted, two studies demonstrated a link between negative attitudes towards PHAs and misinformation about HIV transmission (Lentine et al., 2000; Mondragon, Kirkman-Liff, & Schneller, 1991). These studies also found an association between greater hostility and stigma towards PHAs and lower income. To apply this finding to the current study, one would need to assume that participants' social networks consist of people with low income. Should the above hypothesis prove correct, however, it is important to not lay blame at the individual level but to ask questions about what dynamics lead groups of people to hold uninformed and intolerant positions.

The literature on oppression offers a fuller explanation as to why lower-income participants may experience greater negative interaction. A dynamic of intersecting oppressions may be occurring, related to income, heterosexism and HIV, that makes lower-income participants more vulnerable to the effects of heterosexism and stigma associated with HIV/AIDS. Higher income, on the other hand, seems somehow to mediate the negative effects related to HIV/AIDS and homosexuality. Wineman (1984)

contends that people experience specific and often multiple forms of oppression on a continuum. In addition, a person may have limited higher status with respect to one source of oppression that may offset the negative consequences of lower status in relation to another form of oppression. The relatively higher economic status held by higher-income participants may offset some of the negative effects of an inferior status brought on by their sexual orientation or having a stigmatized disease. Evidence of this dynamic in this study is that overt discrimination or disdain relating to homosexuality and HIV/AIDS appeared more common among low-income participants. These participants did not have the possible mediating advantage of higher economic status. Other dynamics related to oppression may also be occurring in the socio-economic environments of low-income participants.

Wineman (1984) argues that people “at or near the bottom of one or more ladders of oppression are in turn led to act oppressively” (p. 174) due to: the need to compensate for their own oppression; a “socialization process, cultural conditioning, and ideological values which pervasively define success and self worth in terms of achieving and asserting superiority” (p. 174); “stressful and degrading social and economic conditions which can cultivate dehumanizing behaviors and attitudes” (p. 174); and “the internalization of oppression and a negative sense of self which can lead people who are treated badly to treat others just as badly” (p. 174). Evidence of oppressed groups acting in harmful ways emerged in two areas of the study. First, several participants who lived in ‘poorer’ neighbourhoods recounted being harshly judged and harassed by local residents. Secondly, the worry and experience that other PHAs do not respect

confidentiality was a recurring theme and barrier to participating in support groups. Wineman's (1984) explanation for the disharmony within oppressed groups complements the assertion that income inequality contributes to social disintegration (Kawachi & Kennedy, 1997; Wilkinson, 1996). Perhaps those most marginalized are also the most vulnerable to the pressures of division, mistrust and individualism characteristic of a society that lacks cohesion. Wineman (1984) strongly points out, however, that an examination of factors that contribute to subjugated groups oppressing others should not obscure identifying and challenging the primary sources of oppression from dominant groups. Similarly, others argue that an understanding of oppression requires moving beyond personal exchanges at the individual level and must include cultural and structural levels of oppression (Mullaly, 2002; Thompson, 1998).

As with the other two social domains explored, the oppressive effects of structures were not absolute and were offset by elements of radical humanism. Participants were able to resist assuming self-blame and responsibility for other people's non-acceptance of them as HIV positive or gay. Through reframing, they were able to free themselves from oppressive social messages.

## 6.2 Overarching Aspects of Well-Being

In chapter 4, well-being was defined as a person's sense of self-worth, "the extent to which individuals feel that their life chances are under their own control", and "a view of the world that life is meaningful, events are comprehensible and challenges are manageable" (FPTAC, 1999a, p. 15). This definition fits well with four themes that emerged across all three social domains examined. Two of the themes, control and self-

worth, are in and of themselves measures of well-being. The other two themes, stress and isolation, interconnect with control and self-worth. Specifically, an important interplay emerged with respect to the income-related stressors participants experienced and the control they had in responding to these stressors. Self-worth presented as being related to isolation in that many of the ways participants engaged with others, such as paid or volunteer work and relationships with family and friends, contributed to their sense of self-worth. Therefore, factors that contribute to isolation also limit opportunities for affirming social interaction.

#### 6.2.1 Stress and Control

The findings indicate that many of the stressors participants experience are linked to lower income. This conclusion is congruent with other research that found low-income PHAs experience greater amounts of stress (Koopman et al., 2000; Olivier, 2001). Furthermore, many factors emerged that limit the ability of lower-income participants to address the challenges that come their way. In contrast, higher-income participants identified few stressors unique to their economic status. They also had greater control or faced fewer barriers in attaining desired ends with respect to the social domains explored.

These findings are consistent with the literature that shows that low-income is associated with a greater number of stressors and fewer resources to address those stressors (Adler & Ostrove, 1999; Kessler & Cleary, 1980). Participants also indicated that stress had a negative impact on their health and well-being. Their observations are congruent with previous research that has established links between stress and physical and mental health (Alder & Cohen, 1993; Brunner, 1997; McEwen & Seeman, 1999;

Wilkinson, 1996; Wilkinson & Marmot, 1998). And both stress and lack of control are associated with poorer health outcomes (Wilkinson, 1996; Taylor & Seeman, 1999). So on a theoretical level, the overall patterns that emerged in the study are congruent with earlier research. What is new to the literature, however, are many of the manifestations of stress and control evident in the lives of people living with HIV/AIDS. Although the following discussion focuses on differences in relation to income level, it is important to note that participants from all income groups reported struggles with control in relation to HIV/AIDS itself posing threats to independence and self-sufficiency.

Stress associated with the struggles of trying to meet basic needs on a low income emerged as one of the main life stressors for low-income participants. Participants often spoke of being unable to procure sufficient healthy food and adequate housing. For some, income-related stress was heightened on cheque day due to expenses being greater than income, needing to decide which bills to pay and which ones to postpone, and running around and waiting in line-ups to pay bills. Participants also spoke of the day-to-day stress of not having an adequate income. In contrast, higher income (derived through employment or private pension) provided a sense of financial security and peace of mind. Higher income also gave participants control over their diet and choice of housing.

Lower-income participants did, however, identify various means that mediated the stress of low-income and increased their control over their financial circumstances. These means included social support on cheque day, earning some extra money through paid work, shared housing, rent that includes utilities, having some extra groceries in the house for times when money runs out, and money management skills such as making

sure that rent and utilities are paid so one has a secure place to live and not having any outstanding bills. The use of services specifically designed to meet the needs of people with low-income provided some participants with a greater sense of control (e.g., rent-subsidized housing, financial support through AIDS organizations, and food banks). In addition, relinquishing some control to income assistance program personnel may actually be desirable. One participant, for example, arranged for his income assistance benefits to be split into two payments so that he has a second cheque coming in mid-month. Another participant authorized income assistance to pay his rent directly. These options are only appropriate in limited circumstances, for example, with clients who have special needs such as cognitive challenges and ideally, who are in agreement.

As discussed earlier in this chapter, participants who derived their income through public income security programs reported a number of stresses associated with this source of income. They reported stress, frustration and difficulty in trying to get expenses covered. Some worried about program eligibility reviews which could result in a reduction of benefits. Participants also reported stress and embarrassment from being 'on welfare'. Several participants indicated that trying to get financial help from AIDS organizations could also be stressful and frustrating.

Newly low-income and higher-income participants pointed out that being assertive and informed about income assistance policies helps them maximize their benefits. Longer term low-income participants did not recount using assertive communication skills to the same extent, suggesting that they may be at a greater disadvantage in securing optimal treatment. The literature offers several explanations for

this finding. Perhaps newly low-income participants can apply skills learned from previous experiences to the new challenges associated with income assistance. Their time in the workforce may have offered opportunity to develop effective assertiveness and communication skills. Kessler and Cleary (1980) point out that “social class largely determines the life experiences to which one is exposed, thus in large part shaping one’s coping repertoire and determining access to social resources” (p. 466). Linking coping skills to class also suggests that the absence of certain skills may be a component of class disadvantage. In effect, long term low-income participants, through exclusion from stable employment, have also been denied opportunities for skill development. This connects to the concepts of marginalization and powerlessness, two forms of oppression (Young, 1990).

Young (1990) suggests that people with higher-status employment have greater power than those with lower-status employment. This power, in the form of ‘respectability’, extends beyond the workplace and contributes to expecting and receiving optimal services. Newly-low income participants may retain some of this respectability and advantage in negotiating for optimal income security benefits. Similarly, Hasenfeld (1987) argues that “clients with power resources, particularly income and education, are better able to obtain the services they want and are more likely to influence the social work process to suit their needs and interests. This is manifested, first and foremost, in the choices they have in selecting agencies and workers. The ability to choose and, particularly, the range of available choices are the core of power” (p. 476).

Another contributing factor may be that income security personnel are better able to communicate and empathize with those who were once employed and who may be closer to them in class status. This interaction, in turn, benefits the service user in the form of optimal service. This argument is supported in the literature on low-income PHAs and health care. Ayala (1996) found that the nature of the health care received by low-income PHAs related to the quality of communications and relationships with service providers. Similarly, Daneault and Labadie (1999) speculated that health care professionals' inability to empathize and communicate with low-income PHAs explained why some from this group were more likely to complain of uncontrolled pain at time of death (i.e., did not receive effective pain management).

The possibility that newly low-income participants retain some advantage or privilege from their previous employment status, and better relations with service providers, serves to illustrate a further dynamic of oppression—that specific sources of oppression operate on a continuum (Wineman, 1984). In this case, newly low-income participants continue to hold greater advantage, albeit limited, than participants who always found themselves at the bottom rung of economic status.

Newly-low income participants did, however, identify an area of income security programming where they found the negotiation more difficult. Some from this income group expressed confusion about how returning to work part- or full-time could affect their benefits. There are several possible explanations for this uncertainty: the hesitancy on the part of program recipients to even ask questions of agency officials for fear that it

will raise suspicion about their ability to work; and clear and comprehensive information not being available, complicated by periodic policy change or potential for change.

Higher income participants with private income were exempt from the stresses, hassles and insecurities associated with public income assistance programs. Their higher income also gave them greater control and choice in maintaining mental and physical health through private means such as complementary therapies, mental health services, and fitness and recreational facilities. Hasenfeld (1987) contends that the option of accessing a service from one of a number of providers gives consumers more power. Higher income participants also described feeling secure in knowing their finances permit access to services for current needs as well as for potential future needs. To a limited extent, AIDS organization health maintenance funds gave lower-income participants some access to private services in managing their health.

Participants reported stress associated with paid employment related to deteriorating health and episodic illness. This stress was heightened for those who did not anticipate job security or accommodation of illness if their HIV status became known or if they became ill. Some participants in service industry and non-unionized jobs reported such vulnerability. In contrast, some workplaces were very accommodating of absences due to illness, taking time off for medical appointments, taking medication at work, control over pace of work, and flexibility in schedule. This undoubtedly provides a sense of control in managing illness in the context of work and also over the decision about leaving work due to illness. One can envision this transition as less difficult in a work setting that accommodates illness. The more the accommodation, the more control a

person would conceivably have in deciding how long they can work and about the right time to leave. Nevertheless, the decision to leave work because of illness can still be distressing.

In this study, negative HIV-related interactions with family and community members emerged as more common among lower-income participants. This is alarming given that social support provides protection against the health effects of stress (Cohen & Wills, 1985). As was the case with the other areas examined, findings demonstrate that this group of participants has less control in addressing the challenges associated with informal social relations. Many of the types of stressors that lower-income participants experienced relate to their more limited ability to establish and maintain desired personal and physical boundaries with others. Higher income seems to permit more control in maintaining boundaries of choice.

Housing can provide an important physical boundary from pressures of the outside world. For some participants, inadequate income prevented acquisition of housing that provided such sanctuary. One participant living in a boarding house feared that other residents would find out that she is HIV positive and judge her or refuse to share the same kitchen or bathroom facilities. As a result, she would prefer to have her own apartment. In several cases, participants shared living accommodations with family members under circumstances where they felt living apart would ameliorate some interpersonal tension or conflict (e.g., from a controlling family member or intergenerational conflict). In such cases, the benefits of living with family did not outweigh the negative consequences. However, neither the participant nor his or her

family member could afford to live separately. One participant experienced pressure from his landlord to stay in his apartment so as not to alarm the other tenants, who might be concerned about living in the same building with a PHA. In this situation, the participant had a more rigid boundary imposed on him than he would have preferred. He did not have the resources to find another apartment. In contrast, those with higher income have greater control in securing accommodations that provide desired levels of separation and/or interaction with others.

Several lower-income participants also described stress resulting from others not respecting their personal boundaries. For one participant, this was evident through people in his neighbourhood pointing him out as a person with AIDS. Another low-income participant said that she is asked personally intrusive questions when participating in community events about how she became infected. Her experience contrasts with that of a higher-income participant, who reported that work colleagues respect how much he wants to share about his illness. This participant's work colleagues follow his lead in discussing his illness and avoid highly personal questions. One participant also described how higher income enabled him to seek private counselling when he found it awkward discussing issues with an AIDS organization counsellor known from outside the agency. For some participants, not being able to maintain desired personal boundaries in the community resulted in isolation, as they avoid unpleasant situations by staying at home.

### 6.2.2 Isolation and Self-Worth

The findings show how aspects of participants' engagement in informal social relations and in paid and volunteer work contribute to their sense of self-worth.

Conversely, isolation and disengagement from such interaction emerged as a threat to self-esteem. Furthermore, and as already evident from previous discussion, lower-income participants experienced a number of barriers to desired participation in paid and volunteer work and to desired interaction with family, friends and community. So in effect, income-level related factors that impose isolation also limit opportunities to maintain and/or to enhance one's sense of self-worth. Engagement enables supportive and affirming interactions with others, as well as provides a sense of belonging and opportunity to contribute. Although the following discussion focuses on differences in relation to income level, participants also reported threats to self-esteem that did not appear unique to any one income group. For example, participants reported that testing HIV positive, developing symptoms, and guilt and shame about becoming infected all threaten one's sense of self-worth.

Consistent with the literature (CPHA, 1997; Wilkinson & Marmot, 1998), participants linked rewarding, interesting and satisfying aspects of paid work with contributing to a better outlook on life, feelings of accomplishment, and a better sense of self-esteem. One participant whose drug addiction had prevented her from working for many years, attributed her current part-time job to helping her build her self-esteem. And while being able to do paid work can contribute to a sense of self-worth, not being able to work can threaten this aspect of well-being. This dynamic was particularly evident in the stories of newly and long term low-income participants. Some newly low-income participants linked leaving paid employment due to illness and having to rely on income assistance to a decrease in their sense of self-worth. For long term low-income

participants, the threat to self-esteem posed by not working parallels their long-term efforts to secure stable employment.

As introduced earlier in this chapter, marginalization is a form of oppression that deprives people of opportunities to participate in socially affirming ways (Young, 1990). The consequences that participants attributed to not being able to participate in the workforce supports Young's assertion that marginalization results in feelings of "uselessness, boredom, and lack of self-respect" (1990, p. 55). She explains that "most of our society's productive and recognized activities take place in contexts of organized social cooperation, and social structures and processes that close persons out of participation in such social cooperation are unjust" (Young, 1990, p. 55). Although Young is referring primarily to the paid labour system, one can see how marginalization could also apply to the exclusion from volunteer work.

Participants linked volunteering to maintaining and/or building their sense of self-worth. They attributed this to the self-affirmation derived from helping others and from contributing, as well as to the affirmation one receives from those helped. Several participants attributed the satisfaction derived from volunteering with offsetting the threat to self-esteem posed by being unable to engage in paid work due to illness. As with paid work, inability to participate in volunteer activity was identified as a threat to one's sense of well-being. In this respect, long term low-income participants appeared most vulnerable, since they reported a greater number of barriers to securing volunteer positions.

Relying on income assistance is a related factor in the relationship between paid work and self-worth. Several participants felt embarrassed by the dependency and stigma attached to income assistance. Others felt that they were taking and not contributing to society. As noted earlier in this chapter, the negative images participants hold of persons in receipt of income assistance can likely be traced to prevailing views in society. Some participants countered these negative views through reframing income assistance as entitlement. Furthermore, negative characterizations of people in receipt of income assistance as lazy or unmotivated stand in stark contrast to this study's findings in which participants were eager to find paid or volunteer work; an eagerness driven by their desire to contribute to society.

Earlier discussion noted how inadequate income can prevent some lower-income participants from interacting with family and friends as they would like. Limits imposed on desired interaction also limit opportunities to interact with loved ones in ways that would contribute to self-esteem (i.e., social support's direct benefit to well-being; Cohen & Wills, 1985). For example, some participants reported less reciprocity in relationships from being unable to purchase gifts for family members. Previous research has identified the importance of reciprocity in relationships in helping PHAs feel valuable and needed (Hays, Magee, & Chauncey, 1994). Another participant connected the acceptance that he receives upon disclosing his HIV status to his ongoing self-esteem. Conversely, negative interactions can cause emotional harm, including a direct threat to self-esteem by reinforcing internalized oppression. Studies have shown an association between higher

levels of depression and negative social interactions among PHAs (Ingram et al., 1999; Siegal, Raveis, & Karus, 1994).

These findings suggest barriers, external to the participant, which limit a person's ability to be involved with family and friends and in paid or volunteer work. The barriers deny participants opportunities to engage with others in ways that contribute to self-worth. In addition, exposure to negative social interaction rooted in negative images of PHAs, of people who are gay or of those with low income, can threaten one's sense of well-being. Again these are external influences. The literature, however, points to another dynamic—that low-self esteem can influence a person's ability to pursue social interactions. Nicholson and Long (1990) found that HIV positive gay men with low self-esteem were less likely to seek social support as a coping strategy. Similarly, Leserman, Perkins and Evans (1992) found that more helpless coping (i.e., greater feelings of helplessness) was related to poor self-esteem among a group of HIV positive gay men. These studies suggest that low self-esteem may hinder a person's ability or motivation to become more involved with others. Although this is important in working with PHAs who might have developed feelings of helplessness along with their low self-esteem, the structural, root causes of people's problems should not be ignored.

### 6.3 Conclusion

The findings indicate that participants experienced a number of stressors linked to lower income. Furthermore, inadequate income and forms of oppression limited the attainment of social domain aspirations. Some participants were unable to benefit from the health-promoting aspects of paid work. Rather, they relied on income security

programs that were stressful and inadequate to their basic needs. Some long-term low income participants faced difficulties in securing volunteer work. Higher income gave participants more options with respect to maintaining good health and managing illness through the use of private services. For some participants, negative interactions and inadequate income prevented desired involvement with family members and friends, leading to isolation and threats to self-esteem. All of these factors are known to impact upon health and well-being.

Figure 6.1 outlines the operation of various components of the discussion and synthesis. The socio-economic environment, which coincides with structural and cultural levels of oppression, influences the attainment of social domain aspirations. Imbedded within the socio-economic environment, the degree to which participants are able to attain their aspirations determines aspects of their health and well-being. It is at this level that personal oppression occurs. The depiction also indicates interactions between aspects of health and well-being. For example, distress can result from a lack of control over stressful aspects of one's life. Isolation can limit opportunities for supportive and affirming social interactions which in turn can impact upon one's sense of self-worth.

In order for PHAs to attain their aspirations in paid or volunteer work, use of services, and informal social relations, oppression at the individual, cultural and structural levels of society must be attended to. Such a framework can help ensure a comprehensive approach to addressing the root causes of people's problems. In addition, a focus on sources of stress, factors that affect control over stressful life events, and factors that

reduce barriers to isolation and provide opportunities for social engagement point to more specific areas for social work intervention in working with PHAs.

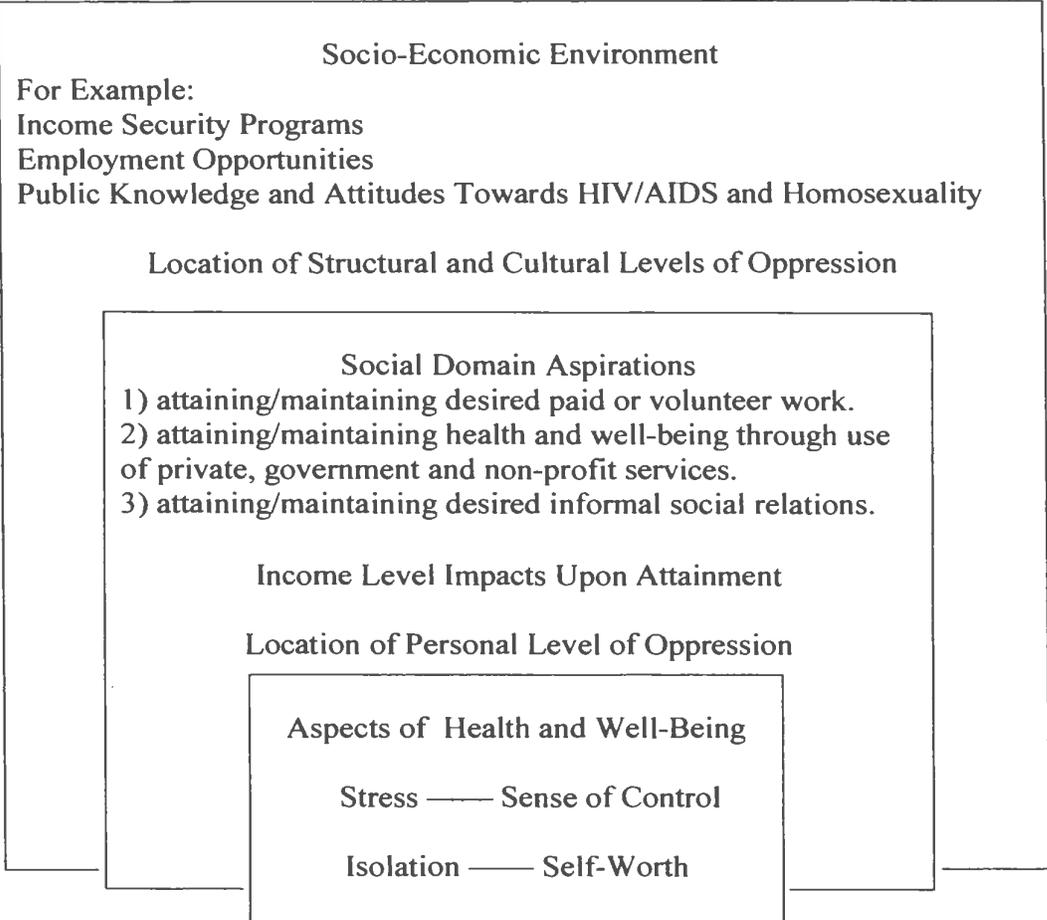


Figure 6.1: Socio-Economic Environment, Social Domain Aspirations and Health and Well-Being

## Chapter 7

### Implications and Conclusion

Empowerment is a process through which clients obtain resources—personal, organizational, and community—that enable them to gain greater control over their environment and to attain their aspirations. (Hasenfeld, 1987, pp. 478-479)

For people living with HIV/AIDS to fully attain their aspirations in relation to the social domains explored, oppression at the individual, cultural and structural levels of society must be addressed. Attention to these three levels of oppression can help guide the development of a comprehensive response to the challenges PHAs face in attaining and maintaining health and well-being. This approach also fits with the twofold goal of structural social work: “(1) to alleviate the negative effects on people of an exploitative and alienating social order; and (2) to transform the conditions and social structures that cause these negative effects” (Mullaly, 1997, p. 133). In addition, study findings on sources of stress, factors that affect control over life events, and elements that reduce isolation or provide opportunity for social engagement can inform social work approaches to working with PHAs. The findings also point to implications for the development of population health theory, in particular the need to integrate an anti-oppressive analysis in exploring the root causes of health outcomes experienced by different population groups.

#### 7.1 Social Work at the Personal Level

Empowerment is an important concept in informing social work with PHAs, as it is when working with other client groups. Mondros and Wilson (1994) define

empowerment as the psychological state of feeling a sense of competence, control and entitlement. This definition is particularly well suited to working with groups of people who through processes of oppression may lack the resources, knowledge and skill to feel competent and to exert control in their lives, and due to internalizing oppression, may not even feel entitled to equal and just treatment.

A second concept, and one that connects to empowerment, is consciousness raising. It is vital that people are able to think critically about the root causes of their problems and to identify elements in society that contribute to their oppression. Mullaly (1997, 2002) emphasizes consciousness raising through such means as critical questioning (e.g., about taken-for-granted assumptions concerning the causes of problems), normalization (i.e., bringing attention to the fact that many others of the same social grouping share the same problem or concern) and redefining problem definitions to illuminate their structural origins. I believe consciousness raising is critical in countering internalized oppression and fostering instead, a sense of entitlement.

Mullaly (1997) also emphasizes the importance of collectivization (i.e., connecting people who share similar social challenges) as a means of consciousness raising and as a step towards collective social action. He also stresses that worker and client interaction, including consciousness raising, must be done in the context of a dialogical relationship, “wherein all participants in the dialogue are equals, each learning from the other and teaching the other” (Mullaly, 1997, p. 180). The concepts of fostering client empowerment and critical analysis in the context of a dialogical relationship were key in my selection of the following intervention approaches.

### 7.1.1 Intervention Approaches

At the direct practice level, social workers and other service providers will need to be cognizant that low-income PHAs may experience numerous stressors related to their economic status (e.g., greater vulnerability to oppression based on having a stigmatized disease or from being gay). Despite the pervasiveness to which low income can compound the challenges faced by this client group, as a social worker I was encouraged by participants' descriptions of the benefits of having a 'good' worker. For example, several participants spoke highly of income assistance workers who went out of their way to get items covered. This finding shows that service providers can make a big difference even when working within inadequate social service systems. Coupled with this are other findings that point to areas of service that would be particularly valuable to PHAs.

#### 7.1.1.1 Individual Counselling

Participants reported a number of problems and challenges related to paid and volunteer work, service use, informal social relations and low income that lend themselves to social work practice with individuals.

Employment counselling would seem especially useful to PHAs attempting to remain in the workforce or trying to re-enter the workforce. In addition, those who were fired from their jobs due to being HIV positive may benefit from support in challenging such incidents of discrimination (e.g., through human rights or legal avenues). Discussion of volunteering could be helpful to those excluded from the workforce or unable to work due to their health. Such counselling could explore and raise awareness about the root causes of barriers to paid and volunteer work.

Exploration of the meanings of work and leaving work could stimulate discussion on how society assesses the value or worth of people based on their contributions to the workforce. PHAs might have internalized many of these same meanings and assigned values. Discussion might identify means, other than employment, through which people could attain or maintain their sense of contribution and self-worth. This could involve reframing volunteer work as equal to paid work. Such reframing could be done through sharing the many benefits that participants derived from volunteering (e.g., fosters a sense of well-being and self-worth, personal satisfaction from contributing to society, feeling engaged and connected with others). One could also emphasize how for many, volunteering provides a sense of control over type of work, hours, setting, issue, and level of involvement.

Importantly, one would need to help PHAs, especially those with long-term low incomes, address barriers to volunteer work. At the individual level, this could involve providing or finding opportunities for skills training. It might also mean ensuring that people have the resources to volunteer, such as travel money and suitable clothing. Skill development, coupled with volunteer experience, may even enable a person to eventually secure some level of paid work. This is important, since for some participants attaining even a small amount of paid work greatly reduced the stress of living on income assistance. Addressing barriers to paid and volunteer work are discussed further under social work at the structural level.

A second topic for direct practice is benefits counselling. Participants indicated a need for information and assistance in decision-making in accessing and utilizing income

security programs. This could involve providing information on program entitlements and on the optimal time to apply. Participants also identified the need for information on the implications of working while in receipt of program benefits. Full information would help PHAs assess the pros and cons of various options, ultimately leading to their better sense of control and empowerment.

Some participants, particularly those who have been excluded from the workforce, could benefit from learning additional communication and assertiveness skills. This stems from participants reporting that assertiveness enabled them to maximize their benefits from income security programs. However, it is important to explore the necessity of acquiring such skills in a way that does not blame the client for not already possessing certain skills. For example, the worker could share that many people learn ‘socially acceptable’ communication skills through work, and that these communication approaches may provide advantage or privilege in negotiating for services. Fook (1993) suggests teaching clients new skills to increase their control but in the context of an awareness of the social factors that necessitate such skills. Similarly, Mullaly (2002) argues that “personal development programs and courses should be framed within a social or critical analysis of oppression and social injustice” (p. 173).

Further related to the receipt of income assistance, it is important to explore the meanings people attach to their income source. This may entail discussing the various negative labels people attach to being on income assistance, which may have been internalized by the recipient. This exploration and discussion may lead to reframing guilt,

shame or embarrassment of receiving income assistance to entitlement and right of citizenship.

A third area of direct practice with individuals involves assisting clients in developing strategies to reduce stress and gain greater control with respect to living on a low and inadequate income. Here participants' suggestions on how to cope with 'cheque day' stress and low income in general can provide direction. But again, such strategies must be discussed in the context of the need to learn how to maximize available resources in relation to an inadequate social welfare system and not in a way that blames the individual for a lack of skill. The means lower-income participants used to help mediate the stress of low income included social support on cheque day, earning some extra money through paid work, shared housing, rent that includes utilities, having some extra groceries in the house for times when money runs out, and money management skills such as making sure that rent and utilities are paid so one has a secure place to live and not having any outstanding bills.

Finally, direct practice with individuals could involve identifying and addressing barriers to social support. This could entail finding new supports or ameliorating existing relationships with family members and friends. Factors contributing to relationship conflict or to barriers in meeting new people should be explored. Some factors may be traced to oppression and inadequate income. For example, low income excludes people from socializing with family and friends and from participating in community events and activities. A worker and client could also explore how low income makes maintaining desired boundaries more difficult. In addition to working on relationship issues with

PHAs, family members and friends themselves may seek individual counselling or counselling in a family or friend grouping.

#### 7.1.1.2 Group Work

Group work provides another means of addressing oppression at the personal level. Mullaly (2002) argues that bringing people together who are similarly oppressed is the most effective way for them to: “(1) develop political awareness; (2) self-define a more genuine identity than the one imposed on them by their oppressors; (3) develop the confidence to ‘come out’ and assert their more authentic identity; and (4) establish solidarity in order to take action against their oppression” (p. 175). In addition to the above, group members could gain from a range of benefits associated with group work in general (e.g., engagement with others, peer support, help in problem solving and the benefits of reciprocating such activities). Group work can counter isolation and provide a meaningful way for PHAs to contribute through helping others.

Many participants expressed hesitancy to join a support group out of fear that their confidentiality would not be maintained by other group members. Group workers will need to find ways to provide members with as much protection as possible in this regard. In reflecting on my own group work experience with PHAs, the importance of maintaining confidentiality was always discussed. However, study findings have given me new insight into how this discussion could be expanded. It may prove useful to explore within the group potential reasons for members not respecting confidentiality. In addition to reinforcing confidentiality, this could serve to raise awareness on how oppression leads to negative social interaction among groups that are oppressed

(Wineman, 1984). A group worker could also consider more traditional means of safeguarding confidentiality such as having members sign contracts in advance of attending meetings. I have also found that some PHAs prefer to join telephone support groups since this format provides a high level of anonymity.

Community-based AIDS organizations are a good candidate for sponsoring support groups since, based on this study, they are used by the most marginalized. In addition to support groups, participants suggested that AIDS organizations could provide ways for PHAs to socialize informally through drop-in centres or lounges. Given that many PHAs in this study felt isolated, AIDS organizations can play an important role in providing avenues for social interaction and engagement.

## 7.2 Social Work at the Cultural Level

In Chapter 2, oppression at the cultural level was described as the imposition of a dominant worldview about what is right and normal, and the promotion of negative views of oppressed groups (Mullaly, 2002; Thompson, 1998; Young, 1990). Cultural oppression was evident in the study's findings. For example, some participants said that they felt stressed or embarrassed due to dependency and stigma attached to being on income assistance; and as discussed above, this resulted in internalized oppression. Participants also described conflict or problems in social relations stemming from negative perceptions held by others (e.g., being judged because they are HIV positive and/or gay; and being less desirable to a potential partner due to their employment status or sources of income). As outlined above, internalized oppression can be countered through consciousness raising using individual and group interventions. However, it is

also important to challenge negative belief systems by transforming the cultural context in which they arise. This could counter oppressive beliefs that people already hold and prevent people from acquiring such beliefs to begin with.

Mullaly (2002) suggests several approaches to confronting oppression at the cultural level, including critiquing dominant discourses, developing and promoting alternative discourses, and confronting stereotypes. Furthermore, he proposes that such activity or 'resistance' can be carried out at both micro and macro levels of society. At the micro level, people can challenge classism, heterosexism and other forms of oppression wherever they are encountered in their day-to-day lives. For example, one female participant who became infected through a blood transfusion said that people often view her as an 'innocent victim' and are critical of gay men who are HIV positive. She uses such incidents to raise awareness about gay men being no less deserving of support or acceptance. Marginalized groups and their supporters can also challenge elements of oppression on a macro level through such means as public protest, the media, court challenges and public awareness campaigns. The finding that some family and friends were unwilling to become informed about HIV/AIDS implies that attitudes may need to be changed before people are open to education and information. Such attitudes may be changed through public awareness campaigns. The gains that lesbian and gay communities have made in recent years provide strong evidence that dominant belief systems can be altered. For example, over the past twenty years the public discourse on gay rights has shifted from whether or not people of minority sexual orientations are

entitled to human rights protection to such culturally embedded questions as the right to legal marriage.

In addition to indicating how dominant cultural beliefs lead to discrimination, study findings also directly challenge stereotypes about what it is like to be poor. For example, rather than a lack of motivation to find work, participants demonstrated just the opposite. Many participants recounted an eagerness to find paid work, driven by a desire to feel like contributing members of society. However, this finding also indicates a problematic cultural belief—that a person's value is often assessed by their participation in the workforce. Young (1990) argues that society needs to provide means for people to be engaged and contribute beyond the traditional workforce. This could involve valuing the contributions people make to society that fall outside of paid labour, such as volunteering. Anti-oppressive social workers need to challenge the belief that those who have paid employment are the most valuable members of society.

### 7.3 Social Work at the Structural Level

Oppression at the structural level consists of the ways social institutions (e.g., legal, educational, political, economic) operate to advantage the dominant group at the expense of marginal groups (Mullaly, 2002). Mullaly (2002) provides a number of strategies for confronting oppression at this level, including the use of alternative services and organizations; social movement theory and coalition-building; and critical social policy.

Mullaly (2002) argues that traditional, mainstream social service organizations are set up in accordance with dominant norms, values and expectations. As such, mainstream

organizations often exclude the experiences of marginalized groups and also can contribute to the further oppression of these groups. In contrast, alternative organizations are usually established by people affected by a particular issue and who envision a different approach to addressing community members' needs (Mullaly, 2002). These organizations often reflect values of community-control and participatory decision-making. It has been my experience that these values are reflected in Maritime AIDS organizations. As such, AIDS organizations can provide vehicles for citizen participation which in turn can foster social cohesion.

Community-based AIDS organizations are well placed to address oppression at a structural level. One way they can do this is by demonstrating alternative ways to deliver services, including the involvement of service-users (i.e., PHAs) in decisions about what services will be delivered. As evident in the findings, AIDS organizations already provide a number of services that enable PHAs to have greater control in meeting basic needs and in managing their health. For example, many participants utilize health-maintenance funds to purchase health-related goods and services. However, several participants expressed dissatisfaction with rigid criteria on how money received through some programs (e.g., emergency funds) can be spent. This suggests that AIDS organizations should design programs that maximize the control of the service user. Enhancing control is particularly important given that low-income PHAs face threats and limits to control in many areas of their lives.

The finding that PHAs, particularly those with low incomes, experience oppression stemming from several intersecting and interacting sources also needs to be

considered in policy and program design. The challenges of living with HIV/AIDS cannot be addressed in isolation from issues of classism, heterosexism and other sources of oppression. Wineman (1984) argues that a holistic understanding of oppression can prevent organizations “from ignoring the real diversity among its members and from developing superficial internal unity based on a single common characteristic” (p. 177). Put another way, AIDS organizations must resist any pressure to become single-issue organizations if this means neglecting the range of factors affecting the health and well-being of PHAs. As described under social work practice at the personal level, the impact of multiple oppressions needs to be considered in the delivery of direct services. A holistic analysis of oppression is also required to inform advocacy efforts aimed at transforming social structures such as public income security programs and the labour market. AIDS organizations are already utilized by PHAs who suffer multiple oppressions. As such, they are ideal locations from where PHAs and others can develop and implement social action strategies. Such involvement will likely foster empowerment for PHAs who feel they have little control in effecting change in their environment.

AIDS organizations can advance goals of macro-level change by tapping into social movements and by working in coalition with other groups (Mullaly, 2002). Wineman (1984) contends that a holistic understanding of oppression “provides a point of departure for overcoming divisions and building radical coalitions which can challenge all forms of oppression” (p. 176). Recognizing that people may identify more with a distinct category of oppression, Wineman (1984) argues that there is still a need for organizations that centre around particular forms of oppression, such as classism, racism

and sexism. However, the recognition that participants of these organizations experience multiple forms of oppression can be used to build coalitions around shared issues such as poverty, as well as around broader issues of social justice. For example, the study findings demonstrate that PHAs are affected by poverty and heterosexism. Undoubtedly other PHAs experience sexism, racism and other forms of oppression. Such recognition can be used to rationalize the involvement of AIDS organizations with other groups in forming broad-based social justice coalitions aimed at addressing all forms of oppression. Wineman (1984) envisions that “the emergence of a multiplicity of organizations and movements that are linked to one another around common demands for political/economic/social equality and cooperation, and mirror one another in their attention to internal diversity and power relations, can create a process of change which prefigures a society in which all forms of oppression are overturned” (pp. 176-177).

Implied in the above discussion on confronting oppression is the ultimate goal of social transformation. Mullaly (2002) contends that “anti-oppressive social work practice at the structural level attempts to change those institutional arrangements, social processes, and social practices that work together to benefit the dominant group at the expense of subordinate groups” (p. 193). He adds that “social reform is not a part of social transformation unless it represents one step in a long-range strategy for more fundamental change” (Mullaly, 2002, p. 193). In reality, however, it is not always easy to distinguish between policy changes whose intentions are reform versus those whose goals are strategic steps toward social transformation. The measures that I use to determine the congruency between recommended policy changes and anti-oppressive or structural

social work are: (1) will the change help “to alleviate the negative effects on people of an exploitative and alienating social order” (Mullaly, 1997, p. 133); and (2) will the desired change help surface the root causes of people’s problems (i.e., through applying an anti-oppressive or structural analysis). The following recommendations encompass structures related to paid and volunteer work, income security programs and other social programs. They stem from an anti-oppressive or structural analysis of the study findings.

### 7.3.1 Paid and Volunteer Work

There needs to be a review of labour legislation and policies, and employment and re-training programs with the goal of eliminating policy and program components that disadvantage PHAs. Such a review could also identify locations for policy changes that address the needs of PHAs with respect to employment. To this end, workplace policies that provide flexibility and accommodation around issues of chronic illness (e.g., accommodation of sick days and attending medical appointments, rest periods and flexible hours), prohibit discrimination, and ensure workplace education about HIV are needed. Programs aimed at helping people return to work (e.g., government sponsored training and work-experience programs) must also provide support and flexibility in meeting the needs of persons with chronic illness. Such programs also need to address the multiple barriers that long-term low-income PHAs face in their attempts to find work. Furthermore, the finding that some participants struggled with unemployment for many years points to the need to address earlier failures of the educational system to prepare some citizens for gainful employment. Given the inadequacy of public income security programs, attaining some level of paid employment may be the only route out of poverty

for many PHAs. It is also important that people receive a fair or living wage in exchange for their labour and that they are not forced to work under unsafe or unhealthy working conditions. Related to this policy area, the Canadian Council on Social Development (2001) recommend raising the minimum wage, pro-rating employment benefits for part-time workers and facilitating collective bargaining.

Volunteer bureaus and other community-based organizations need to identify and address the barriers people face in securing meaningful volunteer work. This could involve services for the prospective volunteer that address barriers to volunteer work (e.g., providing training opportunities). In addition, agencies that rely on the services of volunteers need to ensure that their policies and practices are fair and ethical, and that they provide accommodation and flexibility to those with chronic illness.

### 7.3.2 Public Income Security Programs

A policy area of paramount importance is the improvement of public income security programs that are found inadequate with respect to meeting the needs of lower-income PHAs. Inevitably many PHAs will be unable to maintain paid employment and will need to rely on such programs. Currently, provincial income assistance programs provide benefits far below the poverty line. A ‘single employable’ person on welfare in Nova Scotia, Prince Edward Island and New Brunswick receives an income equivalent to 30%, 36% and 21% of Statistics Canada’s Low Income Cut-offs (LICOs) respectively (Canadian Council on Social Development, 2002). For a single person classified as disabled, the percentages are 51%, 55% and 43% of the LICOs for Nova Scotia, Prince Edward Island and New Brunswick, respectively. Minimally, provincial income

assistance, alone or in combination with Canada Pension Plan, should ensure that recipients receive enough assistance to meet basic needs. An eventual goal should be to increase the amounts to equal LICOs. Income assistance programs should also fully inform recipients of various programs and policies in order to help recipients maximize their benefits. Finally, income security programs need to provide awareness and sensitivity training to their staff to enable them to communicate and empathize effectively with clients. Such training could focus on the complexity of oppression and include information on the full range of PHAs' needs.

In addition to direct income support, study findings show a gap in the availability of social housing. More social housing needs to be available. Participants who received rent subsidies underscored how important such programs are in enabling them to cope with limited income. Furthermore, any policy change that contributes to a more equitable distribution of income among Canadians (e.g., through progressive tax policies) should also contribute to better social and health outcomes for all (Wilkinson, 1996; Wilkinson & Marmot, 1998).

### 7.3.3 Other Social Programs

It is important to ensure that PHAs, regardless of income, have access to a full range of health-promoting services. Study findings suggest that higher-income PHAs have greater access to private complementary therapies and private mental health services. In this period of health care transformation, it is important to ensure that the universality of the health care system is not eroded but rather is enhanced through the coverage of additional services.

Several PHAs who experienced workplace discrimination felt that they did not have the resources to pursue any recourse. Human rights commissions require sufficient funding and effective policies to adequately support and respond to the needs of people who face discrimination. Human rights commissions could also play a more visible role in public education about discrimination, acceptance and tolerance.

Finally, there is a need for social programs that give low-income PHAs access to fitness and recreational facilities. Such programming would not only give people greater control in managing their health, but would also help counter the isolation many low-income PHAs experience.

In concluding this section on social work practice at the structural level, I have listed a number of strategies from the Federal, Provincial and Territorial Advisory Committee on Population Health's (1999a) most recent report on the health of Canadians.

“Improving health by reducing inequities in income distribution...” (p. 175).

“Continue to use tax and transfer/social policies to reduce inequities among different levels of wage earners” (p. 186).

“Increase earning capacities and employment opportunities among individuals and groups that have been left behind” (p. 186).

“Policies that promote full-time work for those who want it, fair wages, pay equity, access to employee health benefits, fair unemployment benefits and job diversification are all important strategies to consider” (p. 186).

“Review the effectiveness of current programs that provide a safety net for Canadians who require assistance at different times in their lives” (p. 186).

“Find ways to ensure that all Canadian individuals and families have their essential needs for shelter, privacy and security met” (p. 186).

“Develop long-term strategies to prevent hunger in Canada...” (p. 186).

“Recognize the importance of recreation and social services to health and find ways to provide equitable access to these services, regardless of an individual’s or family’s ability to pay” (p. 186).

These strategies fit closely with the study’s findings, and if acted upon, will provide relief to those suffering economic deprivation. However, the strategies are presented without an in-depth and structural analysis of the problems that they are meant to address. This illustrates how population health theory can be applied in a manner that does not surface the root causes of social problems.

#### 7.4 Implications for Population Health

As evident above, a population health approach can be applied in a manner that attempts to attain greater equity in the distribution of resources and opportunities. Although these are commendable goals, Mullaly (2002) argues that a distributive view of social justice is limited in that it does not identify or transform the social processes and structures that cause inequality to begin with. In contrast, structural social work, informed by anti-oppressive theory, has as its goal the identification and transformation of oppressive social processes and structures. “Social injustice from this perspective entails not only an unfair distribution of goods and resources, but includes any norm, social condition, social process, or social practice that interferes with or constrains one from fully participating in society, that is, from becoming a full citizen” (Mullaly, 2002, p. 35).

Structural social work and theories on oppression can provide this critical analysis of determinants of health. Through such analysis, some factors that determine health can be more accurately reframed as forms or sources of oppression. In this study, a radical structural analysis was used to explore how income-related factors (stemming from social

structures) can affect health and well-being. Furthermore, a number of suggested relationships to do with stress and control, and isolation and self-worth emerged. These could be followed up in further research, such as quantitative, longitudinal studies to determine causality. A radical humanist analysis was also applied in the study. It too addressed a limitation of population health—the potential for the voices of individuals to be lost in an aggregated approach to health policy and programming. The study also exemplified how a population health approach can adopt a broad definition of health and can be applied to relatively smaller population groups. With limitations addressed, population health can then be used in a manner congruent with structural social work. Population health also brings the added strategic advantage of being able to advance structural social work through an approach that already has mainstream currency. By bringing attention to the many factors that affect people’s health, population health can provide both a justification and an approach to addressing a broad range of social, economic and environmental issues.

### 7.5 Conclusion

The study findings suggest that Maritime PHAs have commonality with Canadians in general, in that income level is a powerful and pervasive determinant of health and well-being (FPTAC, 1999a). In this study, participants reported a number of psychosocial stressors linked to low income. This was evident in all three social domains explored. Low-income participants faced the greatest range of barriers to paid employment (e.g., lack of training and education). Those with long term low-income had fewer volunteer opportunities, likely related to not having acquired desirable skills

through participation in the workforce. Participants had to rely on public income security programs that many found insufficient to their basic needs. Newly low-income participants described assertiveness and communication skills (likely acquired through paid work) that helped in obtaining maximum income assistance benefits. Participants with long term low-income may not have had opportunity to develop these skills. Low-income participants had less access to private services to help maintain their health (e.g., complementary therapies, psychosocial counselling and fitness centres). In this study, negative HIV-related interactions with family and community members were more common among low-income participants. Participants connected this to people's lack of knowledge about HIV/AIDS and discomfort or judgement regarding homosexuality. Furthermore, low-income participants did not always have the money to visit or call family and friends, and to participate in community events. Overall, and in comparison to those with higher incomes, low-income participants experienced a greater range of stressors and had less control in addressing these stressors. This resulted in isolation and threats to self-worth; factors that are known to negatively impact upon health and well-being.

The study reinforces what social workers involved in AIDS work have learned from their practice—that HIV/AIDS issues are “intrinsically tied to issues of discrimination, poverty, unemployment, physical, mental and social well-being” (*Social Work Manifesto on HIV/AIDS*, 2000, p. 5). Addressing these issues will require interventions at both direct and policy levels of practice, as well as at personal, cultural

and structural levels of oppression. As individuals and as social workers we can choose to confront oppression.

There are two basic ways to react to having access to oppressor roles: to become identified with superiority, or to reject privilege and seek to dismantle systems of stratification in favor of equality. There are, similarly, two basic ways to react against oppression: to aspire to positions of superior status and power, or to reject stratification altogether in favor of equality.

(Wineman, 1984, p. 195)

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## Appendix 1

### Application for Ethics Review

#### Dissertation Proposal: “Relationships Between Income Level and the Well-Being of Persons Living with HIV/AIDS”

Claude Olivier, September 11, 2001

#### Re: compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)

What follows are the steps that I will take to comply with the TCPS for aspects of my dissertation research that involve human participants.

##### 1. Harms and Benefits

A key principle of the TCPS document is the need to provide greater protection to participants where any potential for harms is above the range of minimal risk, that is “greater than those encountered by the subject in those aspects of his or her everyday life that relate to the research” (1998, p. 1.5). I believe that the potential harm to prospective participants in this study is within the range of minimal risk. Having said this, there is one area of concern that I will need to pay particular attention to. The subject matter of the interviews is of a highly personal and sensitive nature (e.g., social support, HIV-related discrimination). For some participants, recalling and discussing issues related to the topics being explored may evoke distressing feelings. This may require some debriefing. As a Master’s trained social worker with 12 years of experience, I feel confident that I possess the necessary skills (i.e., empathy, assessment and referral) to assist a participant in acknowledging any painful feelings, and to make a referral to an appropriate agency if this were necessary. I am familiar with HIV-related resources in New Brunswick, Nova Scotia and Prince Edward Island—the three provinces where the study will take place. In addition, and given the isolation many people living with HIV/AIDS (PHAs) experience, some participants may find benefit in having an opportunity to discuss their HIV-related experiences.

##### 2. Scholarly Review

My dissertation advisory committee will fulfil the criteria of providing a scholarly review of the proposed study.

##### 3. Free and Informed Consent

A basic principle of ethical research is “that anyone who is a subject of research should participate in the research voluntarily and with full information about what the research involves” (ICEHR, 2000, p. 4). Furthermore, this ‘free and informed’ consent must be maintained throughout the participant’s involvement in the research (TCPS, 1998). I will use a description of the research and a consent form as the primary tools to ensure voluntary consent. Both of these documents, along with the Interview Guide, will be

translated into French should any of the prospective participants indicate that they wish to be interviewed in French.

I will provide participants with verbal and written descriptions of the research prior to the interview. The research description is attached (Appendix 2) and includes:

- Invitation to participate
- Research purpose
- Identity of researcher
- Expected duration and nature of participation
- Description of the research procedures
- Description of reasonably foreseeable harms and benefits that may arise from participating (TCPS, 1998)
- How results will be published and how participants will be informed of the results of the research

After verbally reviewing the consent form, I will ask participants to sign one copy of the form to indicate their consent and agreement with the conditions. I will keep the signed copy and leave an additional copy with the participants. The consent form that will be used is attached (Appendix 3) and includes:

- A list of all that the participant is agreeing to:
  - 1) To be interviewed (duration of 1-1.5 hours).
  - 2) To be contacted for ‘member checks’ (i.e., to clarify any information stemming from the interview and to review the preliminary categories that emerge from data analysis).
  - 3) To have the interviews audio recorded (only the researcher and the transcriber will have access to the interview tapes; the tapes will always be kept in a secure location, and will be erased once the study is completed).
  - 4) To have the interview tapes transcribed (only the researcher and the transcriber will have access to the interview transcripts; the transcripts will be stored in a secure location and will be kept by the researcher following the completion of the study).
  - 5) To have interview quotes included in the final report (in order to provide anonymity, no information that could identify the person quoted will be included in the final report or in any other published report).
  - 6) To retain the right to withdraw consent to participate at any time without repercussion, and the choice of not answering some questions.
- “A reference to a third party to whom the participant may go for further information if necessary” (ICEHR, 2000, p. 5).
- A description of reasonably foreseeable harms and benefits that may arise from participating (TCPS, 1998).
- An offer to conduct the interview in French if so desired.
- Indication that there will be no payment for participating in the study.

- A disclosure that the researcher is no longer employed by a community-based AIDS organization.
- The limits of confidentiality.

Voluntary consent means that it must be given “without manipulation, undue influence or coercion” (TCPS, 1998, p. 2.4). I will not be paying people to participate so this should eliminate one source of undue pressure to participate, in particular for those who are struggling with inadequate income. Secondly, I will disclose to participants that I am no longer employed with a community-based AIDS organization (I was employed with AIDS New Brunswick from 1989-1997 and 1999-March 2001). This should reduce any fear a participant may have that by not participating in the study access to AIDS organization services may be jeopardized. Furthermore, I have given consideration to prospective participants who might not be competent to provide their consent due to HIV-related symptoms. In my 12 years of experience in the field of AIDS, however, I have found that generally people remain competent to provide consent up until the very end stage of their illness. And I do not feel it necessary to interview PHAs at their end stage of life in order to meet the objectives of the study. Finally, prospective participants will be invited to participate through notices that I will ask community-based AIDS organizations and HIV-treatment specialists to distribute to their clients/patients (the research description serves as an invitation to participate, see Appendix 2). This method of recruitment provides a separation between the researcher and prospective participants, who will contact me of their own choice should they wish to participate. (Note: there are 3 AIDS organizations in New Brunswick, 3 in Nova Scotia and 1 in PEI; there is 1 HIV treatment clinic in each of New Brunswick and Nova Scotia, PHAs living in PEI generally travel to New Brunswick or Nova Scotia for specialized care).

#### **4. Privacy and Confidentiality**

Explicit in the consent form are steps that I will take to protect participants’ privacy and confidentiality. I will inform participants that in addition to me, a transcriber will have access to the audio tapes and the interview transcripts. The interviews are the only means that I will use to collect data. I will be the only person conducting the interviews and member checks. The transcriber will be asked to sign an oath of confidentiality and will be instructed to store any materials in a secure location. I will also keep materials in a secure location (i.e., my home office). For further protection of the participants’ privacy, I will not enter people’s names or initials on the audio tapes or transcripts; rather, I will use pseudonyms for each participant. I will keep personal information that could link the participants to their assigned pseudonym in a separate location from the audio tapes and transcripts. The interview transcripts will be analyzed for descriptions, and possible patterns and relationships pertaining to the areas under exploration (i.e., informal social support; workplace/employment; and use of private, government and non-profit services). The findings will be included in my dissertation report and likely will be published in scholarly journals. I will explain to participants, however, that information included in all such research reports will not be presented in ways that could inadvertently disclose their identity (e.g., I will present personal information with minimal demographic description

in order to provide anonymity). For example, individual participants' province of residence will not be identified. Following the completion of the study, I will erase the audio tapes but will retain copies of the interview transcripts. The consent form also describes the limits of confidentiality, including mandatory reporting laws. All three Maritime provinces require mandatory reporting of suspicion of child abuse or neglect and New Brunswick law requires reporting of suspicion that a health care provider has sexually abused a client. A social worker is also obligated to report unethical practices of another social worker. Another circumstance where confidentiality could be breached is where a person presents a threat of harm to self or others.

### **5. Conflict of Interest**

I do not believe that my research involves any real or apparent conflict of interest.

### **6. Inclusiveness**

The emphasis I place on maximum variation is congruent with not arbitrarily excluding any population group from participating in the study. While no quotas have been set, I will attempt to sample for a maximum range of experiences by including a broad range of representation (i.e., diversity of income levels, men and women, people of various sexual orientations and diverse ages—above the age of consent, rural and urban residents, newly and longer-term low-income PHAs, and people at various stages of illness—from HIV positive without symptoms to having been diagnosed with AIDS). I've restricted participation, however, to those above the age of 19 (i.e., the age of majority in Nova Scotia and New Brunswick, and the age of consent used for human subjects ethics review at the University of Prince Edward Island). My rationale for focusing on an adult population of PHAs is to provide some boundaries on the heterogeneity of the sample. Given the relatively small sample size that my resources permit (approximately 30 PHAs), I believe that to include children and youth would complicate the analysis and potential usefulness of findings by reducing the chances of detecting patterns and relationships among the issues explored.

### **7. Aboriginal Peoples**

This research study does not have an Aboriginal specific focus. However, it is possible that an Aboriginal PHA may volunteer to participate. Should this happen, he or she would certainly be welcome. Aboriginal participants, as is the case for all participants, will be able to use member checks to clarify or correct any information included in the preliminary findings. This provides one safeguard against interpreting an account without a full appreciation or understanding of Aboriginal culture or tradition. As a second safeguard, I plan to involve the organization Healing Our Nations: Atlantic First Nations AIDS Network in the event that emergent findings suggest the development of Aboriginal specific implications or recommendations. Such an activity should be facilitated by the fact that the executive director of Healing Our Nations has already endorsed the relevance of the research proposal.

Appendix 2  
Research Description/Invitation to Participate

**INVITATION TO PARTICIPATE IN RESEARCH PROJECT**

**Research Description: “Relationships Between Income Level  
and the Well-Being of Persons Living with HIV/AIDS”**

**Research Purpose**

My name is Claude Olivier and I am a PhD student in the Social Work Program at Memorial University of Newfoundland. My doctoral thesis involves research on how persons living with HIV/AIDS (PHAs) of differing income levels experience informal social support, the workforce/employment, and private, government and non-profit services. These are all areas that can have a tremendous impact upon a person's health and well-being. Yet, there are few studies that explore these areas in relation to income level. The results of this study should help address this gap and most importantly, inform service delivery, health policy and community action agendas, with an ultimate goal of improving the quality of life for PHAs. If you are a PHA living in New Brunswick, Nova Scotia or Prince Edward Island, and are 19 or older, you are eligible to participate in this study. Your consideration in deciding to participate is most appreciated.

**What's Involved In Participating**

Should you decide to participate, I will arrange to interview you sometime between October and December, 2001. The interviews can take place in a location that you find most comfortable such as a private office or your home and will take about 1 to 1.5 hours to complete. The interviews can be carried out in either English or French. During the interview, I will ask you a series of questions related to your thoughts and experiences around social support, employment and private/public services. For example, I will ask you how you see your income being related to your health and well-being. As another example, I will ask you to describe the types of support that you receive, or would like to

receive, from family and friends. I will also gather some 'demographic' information such as age, education level and household composition to see if these factors, in addition to income, seem to affect health and well-being. The interviews should feel like a conversation and you will be able to bring up ideas that you think are important to the research topic.

Because of the personal nature of the topics that will be discussed (for example, support from family and friends), you might find that some of the discussion causes you to have uncomfortable feelings. You may find it helpful to discuss these feelings, and if you would like, I can direct you to various community resources. Also remember that you can choose not to answer any question. In addition, you may find some benefit in discussing your HIV-related experiences.

The interviews will be audio taped (tape recorded), with your permission, and later transcribed and analyzed along with the interviews from the other participants. I will maintain your anonymity and the confidentiality of the information shared throughout all phases of the research project by such means as not writing your real name on the audio tapes or tape transcripts; keeping all research materials in a safe and secure location; and by not including in written reports any information that could identify you. Having many years of past experience working for an AIDS organization, I am very aware of and sensitive to issues of privacy and confidentiality.

I hope to interview about 30 PHAs from the 3 Maritime Provinces. I will examine the interview material in order to get descriptions of the experiences of PHAs. I will also be looking at differences and similarities in experience, challenges faced, and resources utilized. You will also be asked to review a summary of the findings in order to verify that your experiences and ideas are adequately represented. This 'checking back' will likely occur in early 2002.

### **What Will Happen To The Study Findings**

I plan to have a final report prepared by September 2002. I also hope to have the findings published in scholarly journals. If you want, I can also provide you with a summary of the findings.

### **How To Contact Me If You Are Interested In Participating**

If you are interested in participating in the study or if you have any questions, you can contact me by:

Telephone: (506) 454-5535, please call collect if you like

E-mail: [olivier@stthomasu.ca](mailto:olivier@stthomasu.ca)

Mail: 594 Hanson St., Fredericton, NB, E3B 3Z9

**Thanks again for your consideration,**

**Claude Olivier**

**Note: The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research (Memorial University of Newfoundland). If you have ethical concerns about the research that are not dealt with by the researcher, you may contact the Chairperson of ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at (709) 737-8368.**

## Appendix 3

### **Consent Form: “Relationships Between Income Level and the Well-Being of Persons Living with HIV/AIDS”**

**Thank you for considering to participate in this study. The research project is fully described on the attachment “Research Description”. What follows is a list of all the things that you will be agreeing to should you decide to participate in the study.**

1. To be interviewed (duration of 1-1.5 hours).
2. To be contacted for ‘member checks’ (i.e., to clarify any information stemming from the interview and to review the preliminary findings that emerge from the data analysis).
3. To have the interviews audio recorded (only the researcher, Claude Olivier, and the transcriber will have access to the interview tapes; the tapes will always be kept in a secure location, and will be erased once the study is completed).
4. To have the interview tapes transcribed (only the researcher, Claude Olivier, and the transcriber will have access to the interview transcripts; the transcripts will be stored in a secure location and will be kept by the researcher following the completion of the study).
5. To have interview quotes included in the final report (in order to provide anonymity, no information that could identify you will be included in the final report or in any other published report).
6. To retain the right to withdraw consent to participate at any time without repercussion, and the choice of not answering some questions.

#### **In addition:**

If you have any questions or comments about this study that you would like to discuss with someone other than the researcher, Claude Olivier, you may contact his dissertation supervisor, Dr. Leslie Bella, School of Social Work, Memorial University of Newfoundland (tel. 709-737-4512 or e-mail lbella@morgan.ucs.mun.ca).

Because of the personal nature of the topics that will be discussed (e.g., support from family and friends), you may find that some of the discussion causes you to have uncomfortable feelings. You might find it helpful to discuss these feelings with the researcher, who is trained to provide support. Also remember that you can choose not to answer any question.

You can choose to be interviewed in French.

No monetary compensation will be provided for participating in this study.

Although the researcher, Claude Olivier, once worked for AIDS New Brunswick, he no longer is employed by a community-based AIDS organization. Choosing to participate or not to participate in this study will in no way affect your eligibility to receive services from a community-based AIDS organization.

While your anonymity and the confidentiality of information shared will be preserved throughout the research process, there are some limits to the extent confidentiality can be guaranteed. These include: suspicion of child abuse or neglect; reports of unethical behaviour of a social worker; in New Brunswick, suspicion that a health care provider has sexually abused a client; and where a person presents a serious threat of harm to self or others.

**Your signature below indicates that you understand the intent of this consent as reviewed with you, the description of the research, and that your participation is fully voluntary.**

---

**Name**

---

**Date**

---

**Witnessed by Researcher**

**Note: The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research (Memorial University of Newfoundland). If you have ethical concerns about the research that are not dealt with by the researcher, you may contact the Chairperson of ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at (709) 737-8368.**

## Appendix 4

### **Interview Guide Relationships Between Income Level and the Well-Being of PHAs**

#### **1. Background and Demographics**

Sex:

Age:

Sexual orientation:

Area of residency (e.g., rural, town, city):

Annual family/household income:

Source(s) of income:

Household composition:

Education level:

Health status (i.e., HIV without symptoms, HIV with symptoms, AIDS diagnosis):

#### **2. Workforce/Employment (inclusive of employment benefits)**

Please describe your current employment situation (including volunteer work)?

Has this changed any from the time you first tested HIV+?

If yes, how? (ask for specific examples)

Has your income level been stable since you first tested HIV+?

If no, do you think this is related to being HIV+? Please explain?

Have your sources of income changed any from the time you tested HIV+?

If yes, how? (ask for specific examples)

Have you disclosed your HIV status to anyone at work?

If yes, what were the circumstances? How was the experience?

What concerns, if any, do you have about disclosing your HIV status at work?

Are there specific aspects about your work situation (including volunteer work) that make it easier or harder to maintain your health and well-being (e.g., employment benefits)?

(ask for specific examples)

Are there improvements that could be made to your work situation that would help you maintain your health and well-being? (if yes, ask for examples)

How have treatment advances (e.g., new medications), if at all, affected your work situation or outlook on work?

If you currently do not have paid employment, but feel able to work, how hopeful are you about finding paid employment?

Do you have any concerns about returning to work? (ask for specific examples)

Have you had to leave work due to your illness?

If so, what has this experience been like?

How are employment issues related, if at all, to your income?

### **3. Private, government and non-profit services (e.g., income support, mental health counselling and complementary/alternative therapies but excluding medical care)**

What services outside of family and friends do you use to help maintain your health and well-being?

Have the types of services you use changed since you first tested HIV+?

If yes, how? (ask for specific examples)

How have these services helped? Not helped? (ask for specific examples)

Do you have any needs that you think could be met, or be better met, through private or public services?

If yes, please explain?

Have you disclosed your HIV status to anyone at these services?

If yes, what were the circumstances? How was the experience?

What concerns, if any, do you have about disclosing your HIV status at these services?

How is your use of services affected, if at all, by your income?

### **4. Informal Social Support**

Who do you feel close to or care for in your personal relationships?

Who do you rely on for support, of any kind?

What types of support do you receive from these people in your life?  
(i.e., emotional, instrumental, informational or fun/relaxation)

Are there some people who you would like to receive more support from? (ask for examples)

Are there certain types of support you would like to receive? (ask for examples)

How has HIV affected your personal relationships?

Have you disclosed your HIV status to any family members or friends?

If yes, what were the circumstances? How was the experience?

What concerns, if any, do you have about disclosing your HIV status to family members or friends?

Are there any other types of disclosures that you are worried about (e.g., sexual orientation, drug use)?

How is your social support affected, if at all, by your income?

## **5. Life in General**

What are the main stressors or problems in your life right now?

How are you coping or trying to address these concerns?

How hopeful are you that you will be able to find a solution to these concerns?

How would you describe your outlook on life? Has this changed any from before you tested positive, or since?

How do you see income being related to your health and well being? (ask for examples)

Do you have other information or concerns that you would like to share that you think might help with this study?

Do you have any questions or comments?

## **6. About the Interview**

How did you find the interview?

Length of interview: \_\_\_\_\_

Language in which interview conducted: \_\_\_\_\_

Location of interview: \_\_\_\_\_

## **7. Additional areas to explore and questions added based on initial interviews**

Background:

Ethnicity and Race:

When did you first test HIV positive?

Employment:

Your assessment of stress/control at work?

Your thoughts on links between employment and health?

Services:

What about peer support (support groups, retreats)?

How would you describe the services of provincial income assistance?

Any worries about anticipated services?

Social Support:

Is support reciprocal?

Are there people to whom you provide support?

What communities do you see yourself belonging to? How are these communities supportive or unsupportive to your health and well-being?

Overall:

What's 'cheque day' like for you?

How would you describe your personal problem-solving and/or coping skills?

## Appendix 5

### Abbreviations

CAS: Canadian AIDS Society

CCSD: Canadian Council on Social Development

CIAR: Canadian Institute for Advanced Research

CPHA: Canadian Public Health Association

CPP: Canada Pension Plan

FPTAC: Federal, Provincial and Territorial Advisory Committee on Population Health

ICEHR: Interdisciplinary Committee on Ethics in Human Research

LICOs: Low Income Cut-offs

NPHS: National Population Health Survey

PHA: person living with HIV/AIDS

SES: socio-economic status

TCPS: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans



