THE FOOD AND NUTRITION CONCERNS OF A SAMPLE OF NONIMMIGRANT LOW-INCOME WOMEN LIVING WITH HIV

by

Mary Pilipenko

B.Sc. (Hon. H.Ec.), The University of Western Ontario, 1995

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Abstract:

The number of women living with poverty, HIV, and substance use is increasing in British Columbia and in Canada. Women living in poverty lack sufficient money to buy food. HIV and substance use have been shown to increase the risk for weight loss but women are also exposed to cultural weight norms that valorize thinness. Local funding is available for complementary therapies but little is known about the meanings of these therapies for women living with HIV. The purpose of this qualitative study was to explore the effect of these potentially conflicting issues on the food and nutrition concerns of a sample of low-income nonimmigrant women living with HIV and to compare their concerns to the assumptions made in a sample of food and nutrition documents.

Thirteen nonimmigrant participants receiving income assistance, most of whom had a history of substance use, were recruited through an HIV clinic and an HIV support organization. Fifteen semi-structured, in-depth interviews were conducted; two of the participants were interviewed twice. Interviews were transcribed verbatim and analyzed for relevant themes. Documents were analyzed for assumptions about the reader.

The participants lacked money to buy appropriate foods because income assistance was inadequate and they spent food money on drugs. Substance use negatively affected their food intakes and weights. Societal pressures to be thin, HIV concerns, and poverty were associated with positive and negative perceptions of weight and body shape changes. Through analysis of the data, different eating patterns became apparent: eating, not eating, healthy/unhealthy eating, and eating for HIV. Most of the women were striving for healthy eating when trying to eat for their HIV. Although most of the participants were using complementary therapies, they did not have a keen interest in them. Assumptions made in
food and nutrition documents did not reflect the concerns of the participants.

Because of the profound effects of poverty, substance use, and dominant weight norms for women on food, nutrition, and weight concerns, dietitians need to assess their clients’ circumstances to provide relevant advice. To be successful, nutritional goals will have to take the clients’ own priorities into account.
# Table of Contents

Abstract .................................................................................................................. ii

Table of Contents ................................................................................................... iv

List of Tables .......................................................................................................... vii

Acknowledgements ................................................................................................. viii

1. Introduction .......................................................................................................... 1

2. Literature Review ................................................................................................. 7
   2.1 Nutrition Therapy for Persons Living with HIV ............................................ 7
   2.2 Body Weight, Body Shape, and Body Image .................................................. 9
      2.2.1 Changes in Weight and Body Shape ...................................................... 10
         2.2.1.1 HIV-Related Factors ...................................................................... 10
         2.2.1.2 Substance Use .............................................................................. 17
      2.2.2 Perceptions of Weight and Body Shape Changes ................................... 19
          2.2.2.1 The Social Context of Weight Preoccupation ............................... 19
          2.2.2.2 Factors That May Modify Dominant Weight Norms .................... 25
      2.2.3 Summary ............................................................................................... 29
   2.3 Poverty ............................................................................................................ 30
      2.3.1 Poverty, Food, and Nutrition ................................................................. 32
      2.3.2 Poverty-Related Factors Affecting Food and Nutrition ......................... 37
      2.3.3 Summary ............................................................................................... 39
   2.4 Complementary Therapies .............................................................................. 40
      2.4.1 Prevalence and Use of Complementary Therapies ................................. 41
      2.4.2 Sources of Information About Complementary Therapies .................. 42
      2.4.3 Reasons for Using Complementary Therapies ..................................... 43
      2.4.4 Difficulties in Accessing Complementary Therapies ............................. 44
      2.4.5 Perceived Efficacy of Complementary Therapies ................................ 45
      2.4.6 Summary ............................................................................................... 46
   2.5 Summary of Literature Review ....................................................................... 46

3. Study Design and Methods ................................................................................... 48
   3.1 Study Objectives ............................................................................................ 48
   3.2 Theoretical Framework .................................................................................. 48
   3.3 Research Design ............................................................................................ 50
      3.3.1 Data Collection ..................................................................................... 50
         3.3.1.1 Interviews ..................................................................................... 51
            3.3.1.1.1 Sample Size .......................................................................... 51
            3.3.1.1.2 Inclusion/Exclusion Criteria .................................................. 51
            3.3.1.1.3 Recruitment .......................................................................... 52
            3.3.1.1.4 Interviews ............................................................................ 53
            3.3.1.1.5 Interview Guide .................................................................... 54
### Table of Contents

3.3.1.2 Document Collection ................................................................. 54
3.3.2 Analysis of Interviews and Documents ............................................. 55
3.3.3 Strategies to Enhance Rigor ............................................................ 57

4. Participant Interviews ............................................................................. 61
4.1 Description of Study Participants ......................................................... 61
4.2 Poverty-Related Food Problems ........................................................... 67
   4.2.1 Not Having Enough Money .......................................................... 67
   4.2.1.1 Reasons For Not Having Enough Money ................................... 67
   4.2.1.2 Effects of Poverty on Eating .................................................. 70
   4.2.1.3 Strategies to Cope With Low Income ..................................... 72
   4.2.2 Other Problems Associated With Poverty ..................................... 77
   4.2.2.1 Lack of Cooking and Storage Facilities and Vermin ............... 78
   4.2.2.2 Lack of Transportation ......................................................... 79
   4.2.2.3 Dental Concerns ................................................................. 82
   4.2.3 Summary of Poverty-Related Food Problems ............................... 83
4.3 Body Weight and Other Body Image Concerns ...................................... 83
   4.3.1 Weight Loss .............................................................................. 84
   4.3.2 Weight Gain ............................................................................. 86
   4.3.3 Body Shape Changes ............................................................... 88
   4.3.4 Participants’ Feelings About Weight and Body Shape Changes .... 88
   4.3.4.1 Dominant Weight Discourse ............................................... 89
   4.3.4.2 Rejection of Dominant Discourse ....................................... 93
   4.3.4.3 HIV Concerns .................................................................. 95
   4.3.4.4 Poverty and other discourses .............................................. 99
   4.3.5 Summary of Body Weight and Other Body Image Concerns ......... 101
4.4 Eating Patterns .................................................................................... 102
   4.4.1 Emergence of Different Eating Patterns .................................... 102
   4.4.2 Not “Eating” ............................................................................ 103
   4.4.3 “Eating” ................................................................................... 106
   4.4.4 “Healthy Eating”/“Unhealthy Eating” ...................................... 109
   4.4.5 “Eating For HIV” ................................................................... 118
   4.4.6 “Alternative Eating” ............................................................... 126
   4.4.7 Summary of Eating Patterns .................................................... 127
4.5 Complementary Therapies .................................................................. 129
   4.5.1 Use of Complementary Therapies .............................................. 129
   4.5.2 Sources of Information About Complementary Therapies ....... 131
   4.5.3 Reasons for Using Complementary Therapies ............................ 133
   4.5.4 Barriers to Complementary Therapy Use .................................. 136
   4.5.5 Perceived Efficacy of Complementary Therapies ..................... 138
   4.5.6 Summary of Complementary Therapies ................................... 140
4.6 Summary of Participant Interviews ...................................................... 140

5. Food and Nutrition Documents ............................................................ 142
   5.1 General Characteristics of the Documents ..................................... 142
   5.2 Perspective .................................................................................... 147
# Table of Contents

5.2.1 “Healthy Eating” Perspective ................................................................. 149  
5.2.2 “Alternative” Perspective ................................................................. 150  
5.2.3 “Scientific” Perspective ........................................................................... 152  
5.2.4 “Feminist” Perspective ........................................................................... 152  
5.3 Substance Use ......................................................................................... 153  
5.4 Low Income ............................................................................................... 154  
5.4.1 Transportation ...................................................................................... 159  
5.4.2 Dental Concerns ................................................................................... 159  
5.5 Weight Concerns ...................................................................................... 160  
5.6 HIV ........................................................................................................... 161  
5.7 Complementary Therapies ....................................................................... 163  
5.8 Summary of Documents ........................................................................... 163  

6. Discussion ..................................................................................................... 165  
6.1 Living on a Low Income ........................................................................... 165  
6.2 Weight and Body Shape Changes and Perceptions .................................. 172  
6.3 Eating Patterns .......................................................................................... 176  
6.4 Complementary Therapies ....................................................................... 181  
6.5 Food and Nutrition Documents ................................................................. 184  
6.6 Study Limitations ...................................................................................... 188  
6.7 Implications for Future Research ............................................................... 190  
6.8 Conclusions ............................................................................................... 191  

7. References .................................................................................................... 193  

8. Appendices .................................................................................................... 219  
8.1 Appendix A: Recruitment Letters ............................................................. 219  
8.2 Appendix B: Informed Consent ................................................................. 223  
8.3 Appendix C: Semi-Structured Interview Guide ......................................... 227  
8.4 Appendix D: Food and Nutrition Documents ............................................ 231  
8.5 Appendix E: Demographic Questionnaire ............................................... 234
List of Tables:

Table 4.1: Health Information ................................................................. 63
Table 4.2: Demographic Information ...................................................... 64
Table 5.1: Producer of Documents ......................................................... 143
Table 5.2: Author and Credentials ......................................................... 144
Table 5.3: Perspective ........................................................................... 148
Table 5.4: Cooking and Storage Facilities .............................................. 158
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1. Introduction

The human immunodeficiency virus (HIV) attacks the immune system and leaves the host more susceptible to infection (Schoub, 1994, p. 19). The acquired immunodeficiency syndrome (AIDS) is the last manifestation of HIV infection in its natural progression (Schoub, 1994, p. 19). In Canada, AIDS is diagnosed by the presence of one or more defined diseases such as viral infections (e.g. cytomegalovirus) and parasitic infections (e.g. *P. Carinii pneumonia*), and fungal infections (invasive candidiasis) (Health Canada, 1998). The presence of one of these diseases or infections and seropositivity for HIV or the lack of any other illness explicating the symptoms defines the AIDS diagnosis (Health Canada, 1998). AIDS development from the time of HIV infection is on average 8 to 11 years (Health Canada, 1998). The advent of new protease inhibitor drugs has substantially increased life expectancy and delayed disease progression, however, development of resistance to these drugs remains a problem and adherence is a challenge when basic necessities of life such as food and housing are inadequate (Deeks, Smith, Holodniy, & Kahn, 1997; Provincial HIV/AIDS Strategy Advisory Committee, 1998; Sherer, 1998).

Worldwide, the number of women living with HIV/AIDS was estimated in 1997 as 12.2 million, representing 41% of the total number of adults living with HIV/AIDS (UNAIDS/WHO Global HIV/AIDS and STC Surveillance, 1998). HIV and AIDS are reported in Canada and British Columbia through the number of AIDS cases and the number of HIV-positive test results. In Canada, as of December 31, 1998, 1,218 reported AIDS cases were in adult women representing 7.5% of total reported cases, however, the proportion of new AIDS cases in women has increased from 6.3% before 1990 to 13% of incident AIDS cases in 1996-1998 (Bureau of HIV/AIDS, STD and TB, 1999d). The
number of AIDS cases in women in Canada is probably under-estimated due to under-reporting and reporting delays (Health Canada, 1999). In British Columbia, the number of new AIDS cases in women has actually decreased from a peak in 1995 although there are still more AIDS cases reported in women in 1998 than in 1985 (Wong, MacDougall, Patrick, Rekart, & Barnett, 1998). Women in Canada are increasingly making up a larger proportion of positive HIV tests (Bureau of HIV/AIDS, STD and TB, 1999d). Although the number of new HIV-positive test results has also actually declined in British Columbia in 1997-1998, more women are testing positive for HIV in 1998 than in 1985 (Wong, MacDougall, Patrick, Rekart, & Barnett, 1998). Therefore, HIV and AIDS in women in Canada and British Columbia continues to be of concern.

Demographically, women between the ages of 20 and 40 years are most affected by HIV/AIDS in Canada and British Columbia (Bureau of HIV/AIDS, STD and TB, 1999b; Wong, MacDougall, Patrick, Rekart, & Barnett, 1998). Caucasian and Aboriginal women are the two groups of women most affected by HIV/AIDS in Canada and British Columbia (Bureau of HIV/AIDS, STD and TB, 1999a; Wong, MacDougall, Patrick, Rekart, & Barnett, 1998). The two most common methods of transmission of HIV for women in Canada and British Columbia are heterosexual contact and increasingly, intravenous drug use (Bureau of HIV/AIDS, STD and TB, 1999b; Wong, MacDougall, Patrick, Rekart, & Barnett, 1998). The number of AIDS cases in women in Canada purportedly due to injection drug use has increased from 6.4% before 1990 to 28% of all AIDS cases in 1996-1998 (Bureau of HIV/AIDS, STD and TB, 1999d). Injection drug use is the major risk factor of female Aboriginal AIDS cases in Canada (Bureau of HIV/AIDS, STD and TB, 1999c).

Poverty has been identified as a risk factor for HIV (Health and Welfare Canada,
1990; Krueger, Wood, Diehr, & Maxwell, 1990) and poverty has been associated with reduced survival in men living with HIV (Hogg et al., 1994). In British Columbia, the proportion of women living on a low-income has increased among the newly positive HIV test results (Provincial HIV/AIDS Strategy Advisory Committee, 1998). According to a survey of women living with HIV in British Columbia, 43% of the women were receiving income assistance and more than one third had not finished high school (Kirkham & Lobb, 1998). Many of these women have children: of the total number of women surveyed, 52% had children and 12% of these women had children who were HIV-positive (Kirkham & Lobb, 1998).

Despite the growing number of women living with HIV, most HIV research has focused on men, particularly gay males (Hankins & Handley, 1992). Therefore the nutritional advice given to men is similar to that given men. Women living with HIV are often advised to choose a high-protein, high-energy diet to prevent malnutrition (Fields-Gardner, Thomson, Rhodes, 1997, p. 47). However, the joint contexts of HIV, substance use, poverty, and living in a society that encourages women to be thin may mean that this advice is difficult for many clients to accept and/or to implement. For example, women living with HIV may be struggling with weight or body shape changes that are involuntary. Persons living with HIV are at risk for weight loss and loss of lean body mass (Chlebowski, Grosvenor, Bernhard, Morales, & Bulcavage, 1989; Kotler, Tierney, Wang & Pierson, 1989). Weight gain may occur due to HIV-related medications (Carbonnel et al., 1998; Stricker & Goldberg, 1998) and treatment of secondary infections (Kotler, Tierney, Altilio, Wang, & Pierson, 1989; Macallan et al., 1993). Body shape changes may be effected through the use of certain HIV medications or the virus itself (Dong et al., 1998; Kotler,
Rosenbaum, Wang, & Pierson, 1999; Shaw, McLean, & Evans, 1998; Viraben & Aquilina, 1998). Women who are involved in substance use are also at risk for weight loss because of decreased appetite and intake when using drugs (McCulloch, Howard, & Ivan, 1999; Smit et al., 1996). Weight gain may also occur with the discontinuation of drug use (Aylett, 1978; Gambera & Clarke, 1976; Hoy & Flanigan, 1994; Varela et al., 1990; Varela, Marcos, Santacruz, Ripoll, & Requejo, 1997; Zador, Lyons Wall, & Webster, 1996). As well, women who are living with HIV and women who are living on a low-income may not be able to procure appropriate foods (Campbell & Horton, 1991; McCulloch, Howard, & Ivan, 1999; Tarasuk & Maclean, 1990; Travers, 1996).

Advice about weight maintenance may also be difficult for clients because women living with HIV, like other women in our society, are encouraged by the media and societal norms to pursue a slim and toned body (Hesse-Biber, 1996, p. 10). Attempting to attain this ideal can prompt women to resort to strict dieting and exercise which necessarily conflicts with nutritional advice of HIV and other health professionals who encourage an adequate intake to maintain a healthy weight and generous stores of lean body mass (Fields-Gardner, Thomson, & Rhodes, 1997, p. 43). Little is known about how women living with HIV negotiate between the advice of health professionals regarding weight maintenance and the prevailing discourse for women regarding a thin, perfect body shape at the same time that they may be experiencing weight and/or body shape changes.

As well as receiving nutritional advice from health professionals, women living with HIV may also be obtaining advice from practitioners and advocates of complementary-based therapies such as homeopaths and AIDS service organizations (Bandy, Guyer, Perkin, Probart, & Rodrick, 1993). Women in British Columbia have access to funding for such
therapies from the Complementary Health Fund which has been set up by the British
Columbia Persons With AIDS Society, a support organization for persons living with HIV.
It is unclear what food and nutrition advice women receive from “alternative” practitioners,
how they decide which therapies (if any) to use because of the availability of funding, and
how they see the relationships between these therapies and their nutritional well-being.

Low-income women also have access to written materials that are food- or nutrition-
based to help them address their various food and nutrition concerns. Little is known,
however, about what inherent assumptions exist about the readers of these documents or
how these assumptions compare with the actual experiences of these women.

Based on the concerns of health professionals, the societal discourse on women and
weight, the constraints of poverty, and the ability to choose complementary therapies, it
appears that women living with HIV must negotiate between a variety of conflicting needs
as they try to manage their health and nutritional well-being. However, little information is
available about how these conflicting needs play out in women’s lives. Given the chronic
nature of HIV and as more women become HIV-positive, there is an increased need for
dietetic services. Information regarding the issues of women and weight, poverty, and
complementary therapies would help health professionals and other persons working with
this population in providing relevant advice. The following study is therefore proposed to
discover, describe and explain the food and nutrition concerns of low-income women living
with HIV.

The main objective of this study was to explore the food and nutrition concerns
experienced by a sample of low-income women living with HIV. Based on a review of the
literature and discussions with Diana Peabody, registered dietitian at the Oak Tree Clinic
(providing medical and support services to women, youth and children living with HIV),
issues that were expected to be pertinent to the food and nutrition concerns of low-income
women living with HIV included poverty, weight loss and body image, and use of food- and
nutrient-based complementary therapies. As well, because current print materials providing
nutrition advice to this population were prepared in the absence of research into these
clients' specific food problems, the suitability of these materials is not known. Therefore,
secondary objectives of the study were to:
a) explore the meanings of weight and body shape changes occurring within the context of
HIV,
b) examine the relationships of those meanings in (a) to the current discourse on women
and body image,
c) explore the relationships between poverty, HIV and food,
d) examine the meanings of food- and/or nutrient-based complementary therapies for poor
women living with HIV, and
e) examine the advice and underlying assumptions found in a selection of food- and/or
nutrition-based documents available to the participants and compare these assumptions to
the women's experiences.

The remainder of this thesis will focus on a review of pertinent literature, study
design, results from participant interviews, results from the analysis of food- and nutrition-
oriented documents, and discussion of the results.
2. Literature Review

Due to the lack of direct data available about the food and nutrition concerns of low-income women living with HIV, this literature review will focus on the areas identified in the secondary objectives of the study. The section begins with an overview of nutritional advice for persons living with HIV from the dietitian's perspective. Next, a review of the reasons for weight and body shape changes within the contexts of HIV, substance use, and societal pressures on women to have a thin body will be discussed. Potential reasons for weight loss and weight gain within the context of HIV will be explored on a macro level because details regarding the molecular reasons for weight changes are not pertinent to the present study. The effects of poverty on food and nutrition-related issues will be explored. The chapter will conclude with a discussion of the use of complementary therapies by women living with HIV.

2.1 Nutrition Therapy for Persons Living with HIV

Nutrition therapy for HIV-positive persons centres on recommendations of what foods to eat (based on healthy eating principles), food safety guidelines, management of symptoms that may interfere with food intake, and guidelines regarding the use of complementary therapies (Fields-Gardner, 1994). Persons living with HIV are commonly recommended a high-protein, high-calorie diet to meet their increased nutritional needs (Fields-Gardner, Thomson, & Rhodes, 1997, p. 47). Because preservation of lean body mass is one of the primary goals of nutrition therapy, extra protein is recommended to maintain or rebuild lean body mass (Fields-Gardner, Thomson, & Rhodes, 1997, p. 47, Selberg et al., 1995). A high-protein, high-energy diet includes foods that are high in
calories and protein to meet the extra need for energy and protein that is demanded with infection and increased metabolism (Fields-Gardner, Thomson, & Rhodes, 1997, p. 47). Commercial nutritional supplements are also included within the realm of high-protein, high energy foods and are used when the client lacks appetite or is unable to eat a normal diet (Fields-Gardner, Thomson, & Rhodes, 1997, p. 54).

Because persons living with HIV have a compromised immune system, food safety guidelines are especially important to prevent food-borne illness (Fields-Gardner, 1994; Fields-Gardner, Thomson, & Rhodes, 1997, p. 44). Guidelines include drinking sterilized water, maintenance of appropriate temperatures when cooking or storing foods, discarding out-of-date foods, avoidance of foods that are insufficiently cooked, maintaining a clean cooking environment, and avoidance of unpasteurized foods or eggs with cracked shells (Fields-Gardner, Thomson, & Rhodes, 1997, pp. 46-47).

Symptoms related to HIV may interfere with food intake and include lack of appetite, dry mouth, difficulties in swallowing or mouth pain, taste changes, nausea/vomiting, and diarrhea/constipation (Fields-Gardner, Thomson, & Rhodes, 1997, pp. 48-53). Lack of appetite might be alleviated through consumption of small, frequent meals including favourite foods (Fields-Gardner, Thomson, & Rhodes, 1997, p. 48). Moist foods and liquids are helpful for problems with dry mouth (Fields-Gardner, Thomson, & Rhodes, 1997, p. 51). Foods that are suitable for mouth sores include cold foods and soft foods (Fields-Gardner, Thomson, & Rhodes, 1997, p. 50). Soft foods and room-temperature foods are suitable for painful swallowing (Fields-Gardner, Thomson, & Rhodes, 1997, p. 50). Taste changes may be masked by sour or acidic foods, different seasonings, cold foods, marinating foods, and changing food textures (Fields-Gardner, Thomson, & Rhodes, 1997, p. 51).
Chapter 2: Literature Review

p. 50). Nausea and vomiting may be treated by eating slowly, eating small frequent meals, separating food and fluid intake, drinking an adequate amount of fluids, selecting cold foods, avoiding strong smelling foods, and trying foods with different textures or flavours such as bland, salty, or dry foods (Fields-Gardner, Thomson, & Rhodes, 1997, p. 49).

Diarrhea may be prevented by avoiding high-fat foods, dairy products with lactose, coffee and alcohol, gas-forming foods, and high-fiber foods (Fields-Gardner, Thomson, & Rhodes, 1997, pp. 52-53). Other recommendations for diarrhea include choosing foods that are high in soluble fiber and potassium and obtaining enough fluids that are preferably high in calories to prevent the loss of fluids and electrolytes (Fields-Gardner, Thomson, & Rhodes, 1997, pp. 52-53). Constipation may be treated with foods high in insoluble fibre such as whole grains, fruits, and vegetables or use of cathartics such as prunes or laxatives (Fields-Gardner, Thomson, & Rhodes, 1997, p. 53).

Complementary therapies may be used by persons living with HIV. Vitamin and mineral supplementation is recommended to supplement the micronutrients that are often depleted in HIV infection (Fields-Gardner, Thomson, & Rhodes, 1997, p. 53). A single multivitamin providing 100% of the RDA for micronutrients is recommended (Fields-Gardner, Thomson, & Rhodes, 1997, p. 54). Other complementary therapies that are chosen by persons living with HIV should be evaluated in terms of their potential for harm (Fields-Gardner, Thomson, & Rhodes, 1997, p. 56). Therapies which are benign and which the client believes in should not be discouraged (Fields-Gardner, Thomson, & Rhodes, 1997, p. 56)

2.2 Body Weight, Body Shape, and Body Image

Involuntary weight and body shape changes may occur for HIV-related factors and
substance use-related factors. Women living with HIV are at risk for weight loss for HIV-related reasons but may also experience weight gain or body shape changes due to HIV medications. Substance use, specifically intravenous use of cocaine and/or heroin, may also affect intake so that weight loss occurs with drug use and weight gain occurs with cessation of drug use. As a result, women who are living with both HIV and substance use may be at higher risk for weight and body shape changes. Because of North American societal pressures on women to have thin bodies, weight and body shape changes may be interpreted as positive or negative by some women, possibly conflicting with nutritionists' concerns about the consequences of those weight changes. The following section explores possible reasons for weight and body shape changes experienced by low-income women living with HIV and continues with a discussion of how societal pressures to be thin and the context of HIV may influence the meaning of weight and body shape changes for these women.

2.2.1 Changes in Weight and Body Shape

Given the current demographics of HIV infection in Canada, it is likely that many women living with HIV will experience weight loss and weight gain related to HIV and cocaine and/or heroin use. Body shape changes may also occur for HIV-related reasons. The following section will explore in detail the reasons and consequences for weight and body shape changes in HIV and substance use.

2.2.1.1 HIV-Related Factors

HIV nutritional research has focussed on reasons for weight loss, wasting, and body shape changes. HIV infection results in weight loss, wasting and malnutrition (Kotler, Wang, & Pierson, 1985). Malnutrition and wasting have been found in clinically stable or
early HIV infection (Ott et al., 1993; Risser, Rabeneck, & Foote, 1995), acutely ill HIV-positive persons (Trujillo et al., 1992), and in persons at more advanced stages of HIV infection (Suttmann et al., 1995; Ysseldyke, 1991). There is a higher risk of wasting as HIV infection progresses (Risser, Rabeneck, & Foote, 1995). Kravcik et al. (1997) noted in an Ottawa study that wasting illnesses were more common causes of death in HIV+ persons between 1984-1995.

Several studies, mostly of men, have shown that weight loss and loss of lean body mass can predict survival time (Kotler, Tierney, Wang, & Pierson, 1989; Palenicek et al., 1995; Semba, Caiaffa, Graham, Cohn, & Vlahov, 1995; Suttmann et al., 1995) and are associated with a greater risk of death (Guenter et al., 1993; Semba, Caiaffa, Graham, Cohn, & Vlahov, 1995; Sorkin et al., 1995; Wheeler et al., 1998). Small weight losses of as little as 5% of baseline weight have been found to increase the risk of death (Wheeler et al., 1998). Maintaining a healthy body weight is therefore an important goal in HIV therapy (Fields-Gardner, Thomson, & Rhodes, 1997, p. 43).

Since loss of lean body mass is implicated in predicting survival time, body composition studies in persons living with HIV have been the focus of intense research interest. However, most studies have looked only at men. The few studies of body composition in women with HIV-related weight loss have found proportionately more fat than lean body mass loss (Grinspoon et al., 1997; Kotler, Wang, & Pierson, 1985; Mulligan, Tai, Greenblatt, & Schambelan, 1996; Raghavan et al., 1996), however, loss of lean body mass is also evident in later stages of wasting in women (Grinspoon et al., 1997). Kotler et al. (1999) noted that HIV+ women weighed less than HIV-negative women in cohorts of American and African subjects and the difference in weight between HIV-positive and HIV-
negative women was predominantly fat.

Different patterns of weight loss exist in HIV infection. Weight stability interspersed with periods of rapid weight loss due to secondary infection may occur (Macallan, 1999). Grunfeld, et al. (1992) observed a 5% loss in body weight in a 28-day period in AIDS patients with secondary infection. Other types of weight loss due to gastrointestinal infection, malabsorption (Macallan et al., 1993), and HIV viral replication (Rivera, Briggs, Qian, & Sattler, 1998) tend to be more chronic and slower (Macallan et al., 1993).

Periods of stable weight may be due to a decrease in activity because of the fatigue and malaise which frequently accompanies HIV infection (Grunfeld & Feingold, 1992). If weight gain does occur, it may not be of the same magnitude as the previous weight lost, resulting in progressive weight loss over time (Rivera, Briggs, Qian, & Sattler, 1998).

Weight loss and wasting in persons living with HIV occur through a variety of one or more of the following mechanisms: decreased intake, altered metabolism, malabsorption, and immune activation.

Decreased Intake: Decreased intake is thought to be the predominant factor in weight loss etiology in HIV (Grunfeld et al., 1992; Macallan et al., 1995; Macallan, 1999). Macallan et al. (1995) have shown that energy balance becomes negative during rapid weight loss due to a reduction in food intake (Macallan et al., 1995).

Decreased intakes can result from depression (Fields-Gardner, 1994) and disturbances in the central nervous system resulting in changes in mental processes (Babameto & Kotler, 1997; Fields-Gardner, 1994; Moldawer & Sattler, 1998). Other related factors include lethargy (Strawford & Hellerstein, 1998), fatigue (Babameto & Kotler, 1997; McCulloch, Howard, & Ivan, 1999), taste changes (Heald, Pieper, & Schiffman, 1998;
McCulloch, Howard, & Ivan, 1999, Moldawer & Sattler, 1998; Strawford & Hellerstein, 1998; Wanke, 1998), nausea (Moldawer & Sattler, 1998; Strawford & Hellerstein, 1998; Wanke, 1998), or lack of appetite (Babameto & Kotler, 1997; McCulloch, Howard, & Ivan, 1999; Strawford & Hellerstein, 1998; Wanke, 1998) from medications or the HIV virus itself. Secondary infections or acute HIV infection can also cause lack of appetite (Babameto & Kotler, 1997; Beaugerie et al., 1998; Grunfeld et al., 1992; Moldawer & Sattler, 1998), mouth or throat pain (Babameto & Kotler, 1997; Graham et al., 1993; Moldawer & Sattler, 1998; Rabeneck et al., 1990; Strawford & Hellerstein, 1998; Wanke, 1998), and diarrhea (Macallan et al., 1993). Persons experiencing diarrhea may consciously restrict their intakes to reduce the amount of diarrhea they experience (Babameto & Kotler, 1997; Grunfeld & Feingold, 1992). Eating regimens that are associated with HIV-related medications such as protease inhibitors may further exacerbate intakes because the medication may need to be taken without food or with special foods that are not calorically dense (Deeks, Smith, Holodniy, & Kahn, 1997).

Altered Metabolism: Although decreased intake may be the primary factor in weight loss, increases in resting energy expenditure (REE) may exacerbate the risk for weight loss (Macallan, 1999). Although most studies have been done with men, there are some data on changes in REE in women. As in men, findings of increased REE have also been inconsistent. Increased REE has been found in some (Grinspoon et al., 1998; Mulligan, Tai, Greenblatt, & Schambelan, 1996) but not all studies with women (Sharpstone et al., 1997). REE has been found to be significantly correlated with fat-free mass and free testosterone levels but not weight (Grinspoon et al., 1998). In men, increased REE has also been found to be significantly correlated with an increase in plasma HIV RNA (Mulligan, Tai,
Schambelan, 1997). Although a similar study has not been done in women, it has been suggested that differences in REE may be related to changes in viral load (Mulligan & Bloch, 1998).

**Malabsorption**: In addition to deceased oral intake and alterations in REE, secondary infections can cause malabsorption and weight loss (Carbonnel et al., 1997; Gillin et al., 1985; Jimenez-Exposito et al., 1998; Kotler, Francisco, Clayton, Scholes, & Orenstein, 1990; Kotler & Orenstein, 1994; Lambl, Federman, Pleskow, & Wanke, 1996).

Malabsorption due to secondary infective agents such as cryptosporidiosis (Carbonnel et al., 1997, Clayton, Heller, & Kotler, 1994), isosporiasis (Babameto & Kotler, 1997; Restrepo, Macher, & Radany, 1987), microsporidia (Carbonnel et al., 1997; Kotler & Orenstein, 1994), and *Mycobacterium avium complex* (Roth, Owen, Keren, & Volberding, 1985) occurs through intestinal injury (Kotler, Francisco, Clayton, Scholes, & Orenstein, 1990; Kotler, Reka, Chow, & Orenstein, 1993). Ileal dysfunction may also derive from long-term bacterial enteropathy from *Escherichia coli* (Kotler et al., 1995). AIDS enteropathy, defined as enteropathy without evidence of pathogen(s), may also exist and result in malabsorption (Harriman et al., 1989; Kotler, Gaetz, Lange, Klein, & Holt, 1984; Ullrich et al., 1989) but this is controversial (Kotler, Reka, Chow, & Orenstein, 1993). Other reasons for malabsorption are medication side effects (Moldawer & Sattler, 1998), malignancy, GI obstruction (Strawford & Hellerstein, 1998; Wanke 1998), and possibly bacterial overgrowth (Budhraja, Levendoglu, Kocka, Mangkornkanok, & Sherer, 1987; Kotler, et al., 1995) due to hypochlorhydria or reduced gastric acid secretion (Lake-Bakaar, et al., 1988).

**Immune Activation**: Weight loss has also been associated with immune activation (Hoover, Graham, Palenicek, Bacellar, & Saah, 1992; Zangerle, Reibnegger, Wachter, & Fuchs,
1993), particularly in injection drug users (Marmor et al., 1996). Urinary neopterin, a product of an activated immune system, was found to correlate with BMI and to significantly predict weight loss prior to AIDS-defining illness (Zangerle, Reibnegger, Wachter, & Fuchs, 1993). HIV primary infection was significantly associated with weight loss in injection drug users and homosexual men (Hoover, Graham, Palenicek, Bacellar, & Saah, 1992; Marmor et al., 1996). Weight loss may accompany the HIV seroconversion or circumstances associated with weight loss may be associated with increased risk of HIV infection (Marmor et al., 1996). Weight loss and malnutrition in HIV are therefore multifactorial: decreased intake, altered resting energy expenditure, malabsorption, and immune activation all contribute to weight loss and generalized malnutrition.

Although studies have primarily focussed on reasons for weight loss, reports of weight gain have also been found in the literature. Use of HIV medications and treatment of secondary infections results in weight gain. Zidovudine (AZT), an antiretroviral HIV medication, has been available since 1987 (Fields-Gardner, Thomson, & Rhodes, 1997, p. 3) and has been associated with weight gain (Collier et al., 1990; Fischl et al., 1987). The first of several protease inhibitors was introduced in 1995 (Fields-Gardner, Thomson, & Rhodes, 1997, p. 3). Protease inhibitors have also been shown to be associated with weight gain in some (Carbonnel et al., 1998; Stricker & Goldberg, 1998) but not all studies (Schwenk et al., 1999). Treatment of secondary infections has been shown to result in weight gain (Kotler, Tierney, Altilio, Wang, & Pierson, 1989; Macallan et al., 1993).

Peripheral lipodystrophy or "peripheral fat wasting" is a syndrome which has been linked to the use of HIV medications such as protease inhibitors (Carr et al., 1998). Protease inhibitors have also been associated with metabolic changes such as hyperlipidemia and
insulin resistance (Carr et al., 1998) but, for the purposes of this study, metabolic changes in HIV+ women using protease inhibitors will not be discussed. Body shape changes due to changes in fat distribution have been associated with the use of protease inhibitors and nucleoside reverse transcriptase inhibitors (both HIV medications) in women (Dong et al., 1998; Polo et al., 1999). Clinical reports and retrospective cross-sectional studies have shown changes in fat distribution in men and women in a variety of body areas including reduced fat in the face, arms, and/or legs (Dong et al., 1998; Ho, Chan, Wong, & Lee, 1998; Shaw, McLean, & Evans, 1998; Viraben & Aquilina, 1998; Wurtz, 1998), smaller breasts (Shaw, McLean, & Evans, 1998), larger breasts (Dong et al., 1998; Hengel et al., 1998), increased abdomen (Dong et al., 1998; Hengel et al., 1998; Rosenberg, Mulder, Sepkowitz, & Giordano, 1998; Shaw, McLean, & Evans, 1998; Wurtz, 1998), and buffalo hump (Dong et al., 1998). Buffalo hump is the appearance of extra fat at the base of the neck above the back (Carr, Samaras, Chisholm, & Cooper, 1998). These changes in fat distribution in women have been found in conjunction with overall fat gain (Dong et al., 1998), fat loss (Shaw, McLean, & Evans, 1998), weight gain (Wurtz, 1998), and weight loss (Shaw, McLean, & Evans, 1998). In other studies, changes in fat distribution have been found to be independent of weight changes (Rosenberg, Mulder, Sepkowitz, & Giordano, 1998; Viraben & Aquilina, 1998; Wurtz, 1998). Decreased subcutaneous fat and increased visceral fat has been observed (Kotler, Rosenbaum, Wang, & Pierson, 1999). Discontinuation of the medications may not reverse the changes in body fat distribution (Viraben & Aquilina, 1998). Changes in fat distribution have resulted in self-perceptions of looking like an HIV patient and have resulted in the discontinuation of HIV drug therapy for some patients (Carr, Samaras, Chisholm, & Cooper, 1998).
As well as protease inhibitors, other types of HIV medications (e.g. nucleoside reverse transcriptase inhibitors) (Polo et al., 1999) and viral load (Kotler, Rosenbaum, Wang, & Pierson, 1999) may be implicated in the redistribution of fat although the mechanisms are not clear. In a retrospective cross-sectional study, Kotler, Rosenbaum, Wang, and Pierson (1999) noted that body shape changes were observed before protease inhibitors were in use and may be attributable to the HIV virus itself. Therefore, studies of fat metabolism and re-distribution among HIV+ persons receiving and not receiving HIV therapies is currently an area of intensive research.

2.2.1.2 Substance Use

In this section, substance use refers specifically to the use of cocaine and/or heroin unless otherwise specified. Substance use has been shown to result in weight loss (Hoy & Flanigan, 1994; Santolaria-Fernandez et al., 1995; Varela et al., 1990; Varela, Marcos, Santacruz, Ripoll, & Requejo, 1997) and substance users with and without HIV have been shown to be thinner than the rest of the population (McCombie et al., 1995; Santolaria-Fernandez et al., 1995). Female drug users have been shown to have smaller BMI’s than male drug users but there was no significant difference in weight loss between females and males (Santolaria-Fernandez et al., 1995). One study of predominantly heroin users, 50% of whom were employed, found no significant differences in weight or BMI between female drug users and non-drug users because of an increased consumption of carbohydrates (Morabia et al., 1989). Involuntary weight losses of 10 lbs. in 6 months have been reported in seropositive and seronegative injection drug users, however, weight loss was more common in users who were also HIV-positive (Smit et al., 1996). Injection drug users tend to eat very little and less frequently when they are using drugs (Gambera & Clarke, 1976;
McCulloch, Howard, & Ivan, 1999; Santolario-Fernandez et al., 1995; Smit et al., 1996; Worden & Rosellini, 1979) and weight loss has been associated with poor intake for substance users (Santolario-Fernandez et al., 1995). Food intakes are decreased when injection drug users are using drugs due to a lack of appetite, forgetting to eat, or concerns about achieving a drug “high” (Gambera & Clarke, 1976; McCulloch, Howard, & Ivan, 1999; Santolario-Fernandez et al., 1995). Weight loss may also be related to the more active lifestyle that substance users engage in when they are seeking drugs to satisfy their habits (Noble & McCombie, 1997). Weight gain, with an increase in appetite, or normal body weight has been shown with detoxification and with methadone maintenance (Aylett, 1978; Gambera & Clarke, 1976; Hoy & Flanigan, 1994; Varela et al., 1990; Varela, Marcos, Santacruz, Ripoll, & Requejo, 1997; Zador, Lyons Wall, & Webster, 1996).

Alcohol use has also been related to weight loss and weight gain but the results have not been conclusive. Isocaloric substitution of ethanol has been shown to result in weight loss (Pirola & Lieber, 1972; Reinus, Heymsfield, Wiskind, Casper, & Galambos, 1989), weight gain (Foltin, Kelly, & Fischman, 1993), and no weight changes (Contaldo et al., 1989) but addition of ethanol to a control diet has been shown to result in weight gain (Pirola & Lieber, 1972) in experimental studies. In cross-sectional surveys, alcohol intake in women has been associated with lower body weight than that for nondrinkers (Gruchow, Sobocinski, Barboriak, & Scheller, 1985; Williamson et al., 1987). In longitudinal studies, increased alcohol intake in women was associated with a lower weight or BMI (Colditz et al., 1991; Gordon & Kannel, 1983), however, women ingesting the most amounts of alcohol had a higher BMI (Colditz et al., 1991). In another longitudinal study, female drinkers were not found to be at risk for weight changes after a 10-year follow-up (Liu, Serdula,
Studies of marijuana use by smoking or ingestion have shown that marijuana or its active ingredient increases hunger (Abel, 1971; Noyes, Brunk, Avery, & Canter, 1976), food intake (Abel, 1971; Foltin, Brady, & Fischman, 1986; Greenberg, Kuehnle, Mendelson, & Bernstein, 1976; Hollister, 1971), and weight (Greenberg, Kuehnle, Mendelson, & Bernstein, 1976).

### 2.2.2 Perceptions of Weight and Body Shape Changes

The previous section focussed on reasons why low-income women living with HIV might be experiencing weight and/or body shape changes. Most of these changes are unintentional. It is likely that women’s perceptions of weight and body shape changes will be influenced by the dominant norms or discourse for women and weight that valorizes thinness and stigmatizes obesity. This dominant discourse will be described in this section. Other contextual or social factors that influence or oppose these dominant norms will also be discussed.

#### 2.2.2.1 The Social Context of Weight Preoccupation

Although there is a prodigious amount of literature on the subject of women and body weight preoccupation, it must be noted that most of studies that have examined weight preoccupation in women have focussed on women who are primarily college-educated, college-aged, white, and middle-class. Several terms have been commonly used in this literature. In describing weight preoccupation, studies often refer to the term “body image”. Body image may be defined as “an individual’s subjective experience with his or her body and the way he or she organizes this experience” (Rodin, 1993, p. 644). The term “obesity”
is usually defined in different studies, however, the definition has not been standardized between studies (Sobal & Stunkard, 1989).

The dominant weight discourse for women in North America valorizes thinness. As a result, many women are preoccupied with their weights and are intentionally dieting to become thinner to achieve the normative body ideal. Ideal body images have been shown to be promulgated through the media and may increase women's body dissatisfaction (Heinberg & Thompson, 1995; Ogden & Mundray, 1996; Stormer & Thompson, 1996). Media ideals such as Miss America Pageant winners and contestants and Playboy centrefolds have been becoming increasingly thinner between 1959 and 1988 (Garner, Garfinkel, Schwartz, & Thompson, 1980; Wiseman, Gray, Mosimann, & Ahrens, 1992). Retrospective analyses of Playboy centrefolds, photographs of models in popular magazines, and photographs of popular movie actresses revealed that the ideal body shape has become less curvy and more tubular between 1901 and 1988 (Garner, Garfinkel, Schwartz, & Thompson, 1980; Silverstein, Perdue, Peterson, & Kelly, 1986; Wiseman, Gray, Mosimann, & Ahrens, 1992). More women than men have been shown to be thin in television programs in 1980 (Silverstein, Perdue, Peterson, & Kelly, 1986). The number of diet articles in women’s magazines has increased significantly between 1959 and 1988 (Garner, Garfinkel, Schwartz, & Thompson, 1980; Wiseman, Gray, Mosimann, & Ahrens, 1992) and more messages to be thin and in shape were found in women’s than in men’s magazines in 1980 (Silverstein, Perdue, Peterson, & Kelly, 1986).

Not only does the dominant weight discourse for women emphasize thinness, but overweight persons are also stigmatized (Barker & Cooke, 1992; Rodin, Silberstein, & Striegel-Moore, 1985). Obese persons are believed to be responsible for their own obesity
(Bowen, Tomoyasu, & Cauce, 1991) and are thought to have negative personality characteristics such as lack of intelligence, reduced self-control, and emotional and psychological problems (Barker & Cooke, 1992; Robinson, Bacon, & O'Reilly, 1993). Women who were overweight were more likely to have experienced criticism about their weight from parents or peers than normal weight women and overweight men (Stake & Lauer, 1987). Not only are obese persons viewed negatively by other persons, but obese persons see themselves as less attractive and are more anxious and unhappy about their weights than normal weight persons (Cash, Counts, & Huffine, 1990; Sarwer, Wadden, & Foster, 1998; Stake & Lauer, 1987). Increasing BMI has been also correlated with increasing body dissatisfaction and body discomfort (Sciacca, Melby, Hyner, Brown, & Femea, 1991; Thompson & Psaltis, 1988). Negative body image and anxiousness about one’s weight continued even with weight loss in formerly overweight females (Cash, Counts, & Huffine, 1990).

Given the promotion of a thin ideal and the stigmatization of obesity, concerns about weight and dieting have become almost “normative” for women in our society (Rodin, Silberstein, & Striegel-Moore, 1985). Women have been shown to be unhappy with their current weights (Cash & Henry, 1995; Demarest & Langer, 1996; Garner, 1997), their bodies (Monteath & McCabe, 1997), and their body image (Stowers & Durm, 1996). Studies have shown that women feel “fatter” than they actually are (Thompson & Dolce, 1989; Thompson & Psaltis, 1988; Tiggemann, 1996). Even normal or underweight women may perceive that they are heavier than they really are (Galgan & Mable, 1986; Mintz & Betz, 1986; Sciacca, Melby, Hyner, Brown, & Femea, 1991; Statistics Canada, Housing, Family and Social Statistics Division, 1994; Thompson & Psaltis, 1988, Tiggemann,
Winefield, Winefield, & Goldney, 1994). Striegel-Moore, McAvay, and Rodin (1986) noted that feeling fat was significantly correlated with numerous dieting endeavours, perceived societal pressures to be thin, and with actual overweight.

Women may be unsatisfied with certain body parts as well as their weights. The most commonly mentioned areas are the hips (Cash & Henry, 1995; Dolan, Birtchnell, & Lacey, 1987; Galgan & Mable, 1986; Gattellari & Huon, 1997; Mintz & Betz, 1986; Monteath & McCabe, 1997), chest or breasts (Dolan, Birtchnell, & Lacey, 1987; Gattellari & Huon, 1997; Mintz & Betz, 1986), legs (Cash & Henry, 1995; Dolan, Birtchnell, & Lacey, 1987; Monteath & McCabe, 1997; Silberstein, Striegel-Moore, Timko, & Rodin, 1988), buttocks (Cash & Henry, 1995; Monteath & McCabe, 1997; Silberstein, Striegel-Moore, Timko, & Rodin, 1988), thighs (Cash & Henry, 1995; Galgan & Mable, 1986; Gattellari & Huon, 1997; Mintz & Betz, 1986; Monteath & McCabe, 1997; Silberstein, Striegel-Moore, Timko, & Rodin, 1988), calves (Mintz & Betz, 1986), waist (Cash & Henry, 1995; Dolan, Birtchnell, & Lacey, 1987; Galgan & Mable, 1986; Gattellari & Huon, 1997; Monteath & McCabe, 1997), and stomach (Cash & Henry, 1995; Gattellari & Huon, 1997; Monteath & McCabe, 1997). Obese women may rate the same body parts more negatively than normal weight women: overweight women rated their thighs, chest, hips, and waists less attractively than did women of normal weight (Pearlson, Flournoy, Simonson, & Slavney, 1981; Stake & Lauer, 1987). More obese than normal weight women rated their waists and abdomens negatively (Sarwer, Wadden, & Foster, 1998).

The end result of women's dissatisfaction with their weights and certain aspects of their bodies is a desire for a slimmer body. Although women in studies have been shown to want to be slimmer (Fallon & Rozin, 1985; Monteath & McCabe, 1997; Silberstein,
Striegel-Moore, Timko, & Rodin, 1988; Stevens & Tiggemann, 1998), women in different weight categories have also been shown to desire a thinner body. Forty-five to 93% of overweight women (Connor-Greene, 1988; Demarest & Langer, 1996; Dolan, Birtchnell, & Lacey, 1987; Green et al., 1997; Kunkel, 1987; Nielsen, 1988), 22 to 70% of normal weight women (Connor-Greene, 1988; Demarest & Langer, 1996; Dolan, Birtchnell, & Lacey, 1987; Green et al., 1997; Kunkel, 1987; Mintz & Betz, 1986; Nielsen, 1988; Tiggemann, 1996), and 5 to 23% of underweight women (Connor-Greene, 1988; Nielsen, 1988) want to be thinner or prefer an ideal weight that is thinner than their current weight. Not only do women want to be thinner but women who are thinner are more satisfied with their bodies than women who are heavier (Gray, 1993; Mintz & Betz, 1986).

This desire for thinness has translated into an epidemic of dieting among women in North America. Weight loss has become a prized goal. The prevalence of dieting has been shown to range from 33 to 62% in women in the general population (Craig, 1993; Green et al., 1997; Horm & Anderson, 1993; Kunkel, 1987; Levy & Heaton, 1993; Serdula et al., 1993; Williamson, Serdula, Anda, Levy, & Byers, 1992). In studies of women where weight status has been described, prevalence of dieting in overweight women ranged from 53 to 71% (Biener & Heaton, 1995; Craig, 1993; Green et al., 1997; Kunkel, 1987). Even normal and underweight women have been shown to be dieting: the prevalence of dieting in normal weight women ranged from 32 to 47% (Biener & Heaton, 1995; Craig, 1993; Green et al., 1997; Kunkel, 1987) and in underweight women the prevalence of dieting ranged from 8 to 9% (Craig, 1993; Green et al., 1997; Kunkel, 1987).

Despite dieting attempts, women typically regain the weight that they lose when they diet (Grodstein et al., 1996; Haus, Hoerr, Mavis, & Robison, 1994; Wadden et al., 1992).
For example, although obese women have been shown to lose 9 to 22 kg by dieting, weight gains ranging from 10 to 25 kg have also been shown following dieting (Bartlett, Wadden, & Vogt, 1996; Blackburn et al., 1989; Foster, Wadden, Kendall, Stunkard, & Vogt, 1996; Grodstein et al., 1996; Wadden et al., 1992). As well, normal weight women have been shown to have weight fluctuations of 15 kg (Biener & Heaton, 1995).

Reasons for dieting include improving attractiveness or appearance (Biener & Heaton, 1995; Green et al., 1997, Levy & Heaton, 1993) and improving health (Biener, Heaton, 1995; Green et al., 1997). Losing weight to improve attractiveness or appearance was favoured by younger and slimmer persons (Green et al., 1997; Levy & Heaton, 1993). Losing weight for health reasons was more common in older or heavier persons (Green et al., 1997; Levy & Heaton, 1993). Number of dieting attempts and the number of women dieting increased as women’s BMIs increased (Craig, 1993; Green et al., 1997; Serdula et al., 1993).

Cited methods of dieting in descending order of popularity have included exercise (Biener & Heaton, 1995; Craig, 1993; Levy & Heaton, 1993; Neumark-Sztainer, French, & Jeffery, 1996; Neumark-Sztainer, Sherwood, French, & Jeffery, 1999), reducing fat intake (Neumark-Sztainer, French, & Jeffery, 1996; Neumark-Sztainer, Sherwood, French, & Jeffery, 1999), eating less (Craig, 1993; Neumark-Sztainer, French, & Jeffery, 1996; Neumark-Sztainer, Sherwood, French, & Jeffery, 1999), using diet foods (Levy & Heaton, 1993), decreasing intake of junk food and sweet foods (Neumark-Sztainer, French, & Jeffery, 1996), increasing intake of fruits and vegetables (Neumark-Sztainer, French, & Jeffery, 1996), eating a balanced diet (Craig, 1993), taking vitamin/mineral supplements (Levy & Heaton, 1993), counting calories (Levy & Heaton, 1993), and skipping meals.
(Levy & Heaton, 1993). Skipping meals as a weight loss method was significantly more popular in persons of a lower socioeconomic status than in persons of a higher socioeconomic status (Jeffery & French, 1996).

Because obesity is also stigmatized, many women are also concerned about becoming fat and gaining weight has negative connotations. A national survey in the United States showed that almost half of the 803 female subjects were concerned with being or becoming obese (Cash & Henry, 1995). Normal weight female college students expressed significantly more concern about becoming fat than their male counterparts (Cash & Brown, 1989). In a study of food and nutrition beliefs among a population of HIV+ persons, about 1/3 noted that they were trying to avoid weight gain (Henseler, Curry, & Johnson, 1992).

Despite efforts to lose weight and prevent weight gain, a thin ideal is often unachievable because the female body is not programmed to be very thin biologically (Rodin, Silberstein, & Striegel-Moore, 1985). In trying to achieve a thin ideal and falling short of it, women become frustrated and critical of their own body size (Rodin, Silberstein, & Striegel-Moore, 1985).

2.2.2.2 Factors That May Modify Dominant Weight Norms

Different factors have been found to interact and modify the dominant weight discourse on women and weight. The influence of substance use, living on a low income, ethnicity, and age on dominant weight norms will be described.

Substance Use: Normative weight concerns may be intensified with substance use and may result in eating disorders. Eating disorders have been seen as being at the extreme end of a continuum of women's preoccupation with weight (Rodin, Silberstein, Striegel-Moore, 1985). Women who are substance users are also prone to eating disorders which may be
caused by or predate the onset of substance use (Beckley-Barrett & Mutch, 1990). In a
study comparing women with bulimia versus women with anorexia nervosa, a diagnosis of
bulimia and purging predicted cocaine and alcohol use (Wiederman & Pryor, 1996).
Twenty-two percent of the callers to a National Cocaine Hotline were diagnosed with
bulimia, 7% were diagnosed with both bulimia and anorexia and 2% were diagnosed with
anorexia (Jonas, Gold, Sweeney, & Pottash, 1987). The study, however, lacked a control
population (Jonas, Gold, Sweeney, & Pottash, 1987). Female psychiatric patients with
substance use disorders were shown to have a higher frequency of eating disorders than
male psychiatric patients (Grilo et al., 1997).

Living on a Low Income: Most studies on weight and body image have been conducted
with female college students and little is known about the influence of the dominant weight
discourse on women living in poverty. Available data on lower socioeconomic status and
weight concerns have either supported or not supported dominant weight concerns. In
contrast with dominant weight norms, data have shown that women who are living in
poverty tend be heavier (Badun, Evers, & Hooper, 1995; Craig, 1993; Jeffery & French,
1996; Rand & Kulda, 1990; Ross & Mirowsky, 1983; Starkey, Kuhnlein, & Gray-Donald,
1998; Tarasuk, Geduld, & Hilditch, 1998). The greater incidence of obesity in lower class
women may stem from a reduced emphasis on restrained eating in order to be thin,
difficulties in acquiring healthy foods and having to settle for cheaper foods which are high
in fats and sugars, lack of nutritional knowledge, and/or a perceived lack of control over
weight issues (Bowen, Tomoyasu, & Cauce, 1991). Furthermore, persons with a lower
socioeconomic status have also been shown to consider themselves underweight, unlike
most women (Horn & Anderson, 1993) and a lower proportion of low-income women were
dieting compared to persons of a higher socioeconomic status (Biener & Heaton, 1995; Horm & Anderson, 1993; Levy & Heaton, 1993). Women in the lower socioeconomic classes were also shown to be less sensitive to weight gain before noticing and attempting to lose the weight (Jeffery & French, 1996).

On the other hand, other studies have shown that the dominant weight discourse does influence women of lower socioeconomic status. Women living in poverty, like women of a higher socioeconomic status, have been found to have a thin weight ideal (Abell & Richards, 1996; Jeffery & French, 1996), to be similarly dissatisfied with their bodies (Stevens & Tiggemann, 1998), to want to lose weight (Craig, 1993), and to be dieting as much as women of a higher socioeconomic status (Jeffery & French, 1996; Serdula et al., 1993).

**Ethnicity:** In this section, ethnicity refers specifically to Aboriginal persons. Aboriginal populations appear to be influenced by the dominant weight discourse for women. In studies of Aboriginals in Canada and the United States which support dominant weight norms, girls had more body dissatisfaction than boys (Neumark-Sztainer, Story, Resnick, & Blum, 1997), women had a slimmer ideal shape than men (Gittelsohn et al., 1996), more women than men desired a slimmer shape (Gittelsohn et al., 1996), and a larger body image was associated with more body dissatisfaction in women (Gittelsohn et al., 1996; Neumark-Sztainer, Story, Resnick, & Blum, 1997).

The effects of normative weight concerns also appears to be reduced for this population. Compared to other studies of white college-aged females, the ideal body image has been found to be larger in the Aboriginal population than that of Caucasian women even though both Aboriginal and Caucasian women want to be thinner (Gittelsohn et al., 1996). The authors attributed the larger body image ideal among the women of the community as
Chapter 2: Literature Review

evidence that the women had not fully tapped into the dominant North American culture (Gittelsohn et al., 1996). Despite concerns with weight and body image, Aboriginals also have a greater degree of overweight than Caucasians (Bowen, Tomoyasu, & Cauce, 1991) suggesting less adherence to normative weight concerns. The greater degree of overweight in Aboriginal persons may also be influenced by a higher prevalence of poverty among Aboriginal persons as compared to the Canadian population (Statistics Canada, 1993).

Aging: Like ethnicity, aging also appears to blunt the effects of dominant weight concerns. Although women are still concerned with weight and body image as they age (Altabe & Thompson, 1993; Franzoi & Koehler, 1998; Lamb, Jackson, Cassiday, & Priest, 1993; Pliner, Chaiken, & Flett, 1990; Stevens & Tiggemann, 1998), women’s weight concerns have also been shown to decrease with age (Green et al., 1997). Older women have been found to regard their weight and body parts more positively than younger women (Franzoi & Koehler, 1998), and more older women had a heavier weight ideal than younger women (Green et al., 1997; Lamb, Jackson, Cassiday, & Priest, 1993). Fewer older than younger women were found to be dieting (Green et al., 1997).

Increasing age also affects the dominant weight discourse in the Aboriginal population. Women between the ages of 30 and 50 were more likely to desire a slimmer shape than women over the age of 60 years (Gittelsohn et al., 1996). Women in their 40’s felt a slimmer body was healthier whereas women over 50 believed a larger body shape was healthier (Gittelsohn et al., 1996).

Because of the influences of the dominant weight discourse on women in North America, it is probable that low-income women living with HIV are influenced in their perceptions of weight and body shape changes. However, no information is available
describing how poor women living with HIV rationalize advice to maintain a healthy weight by health care providers with cultural pressures to be thin.

2.2.3 Summary

Living with HIV and substance use may induce weight and/or body shape changes in low-income women living with HIV. HIV may result in weight loss through decreased intake, altered metabolism, malabsorption, and immune activation. HIV-related factors influencing weight gain include use of HIV medications and treatment of secondary infections. Body shape changes have been noted with the use of certain HIV medications and possibly through the HIV virus itself. Cocaine and/or heroin use may induce weight loss and their cessation may induce weight gain primarily through decreases or increases in intake respectively. Increasing alcohol use appears to be associated with a lower BMI in women and marijuana has been associated with weight gain.

Perceptions of involuntary weight and body shape changes may be influenced by dominant weight norms for women in North America and other factors. Within the dominant discourse, thinness is promulgated by the media and obesity is stigmatized. Women are unhappy with their weights and concerned over the appearance of certain body parts. They tend to feel fat, and want to be thinner by dieting to lose weight. Although women may be successful at losing weight intentionally, they also tend to gain most of it back when they stop dieting. Women also fear becoming fat and avoid weight gain because obesity is stigmatized. Because women are unable to achieve the thin ideal, they become preoccupied with their weight and body image. Substance use may increase body preoccupation because of its relationship with eating disorders. Women living on a low income or women of an Aboriginal background may partially tap into dominant weight
norms. Aging appears to reduce weight preoccupation. Given these influences and the concerns of health professionals, it is unclear how low-income women living with HIV interpret weight and body shape changes.

2.3 Poverty

Literature on poverty, food, and nutrition is scarce but information on the food-related problems of women living both with HIV and on a low income is even scarcer. However, poverty may be expected to interfere with the ability of these women to follow health professionals’ advice because low-income women living with HIV face the same obstacles as other poor women: increased risk of poor health and mortality (Adams, 1988; Adams, 1993; Adler, et al., 1994; Cadman et al., 1986; Health and Welfare Canada & Statistics Canada, 1981; House et al., 1990; Manga, 1993; Marmot, Shipley, & Rose, 1984; Maxwell & Simkins, 1985; Millar & Wigle, 1986; Norman, 1986; Pappas, Queen, Hadden, & Fisher, 1993; Statistics Canada, Housing, Family and Social Statistics Division, 1994; Wigle & Mao, 1980; Wilkins & Adams, 1983, p. xxviii, p. 95; Wilkins, Adams, & Brancker, 1989), lack of financial resources (Baxter, 1995, p. 150; Kirkham & Lobb, 1998), stress (Maxwell & Simkins, 1985), inadequate housing (Charles & Kerr, 1988, p.171), and lack of education (Ross, Shillington, & Lochhead, 1994, p.121). Women living with HIV, already stigmatized by the disease (Moneyham et al., 1996), face increased stigma due to poverty (Hobbs Leenerts, 1998; National Council of Welfare, 1979) and ethnic status if they are Aboriginal (National Council of Welfare, 1990). These issues may interfere with the ability of low-income women living with HIV to follow nutritional advice.

In Canada, poverty is most commonly defined as those persons below the "low-income cut-off" (National Council of Welfare, 1987). This cut-off is based on the

Unattached women under the age of 65 had a poverty rate of 39.5% in 1996 (National Council of Welfare, 1998). Single mothers with young children fared even worse: 61.4% of these women lived in poverty in 1996 (National Council of Welfare, 1998). The number of Aboriginal women living in poverty is not known (National Council of Welfare, 1990) but a greater proportion of Aboriginal persons are poor compared to the Canadian population (Statistics Canada, 1993).

The foremost concern for persons living on a low income is lack of money (Badun, Evers, & Hooper, 1995). Two reasons for lack of money include the inadequacy of income assistance and, within the context of substance use, spending food money on drugs. Women living with HIV may be on income assistance (Levy, Foley, & Forer, 1994) which is designed to provide for the basic necessities of life when all other sources of income are exhausted (National Council of Welfare, 1987; National Council of Welfare, 1997). Women living with HIV in British Columbia as well as other low-income women have noted that income assistance is inadequate (Baxter, 1995, p. 150; Kirkham & Lobb, 1998). In British Columbia, disability incomes in 1996 were only 60% of the poverty line and made up 35% of an average income for a single employable person (National Council of Welfare, 1997-1998). Compounding the inadequacy of income assistance, women who are also injection drug users spend their money on drugs and have little leftover for other necessities.
Factors that may augment income assistance payments include an HIV diagnosis, children, and special earnings exemptions. For example, persons qualify for increased benefits under B.C. Benefits if they are living with HIV (Feindel, Gibson, & Reid, 1998). The federal government provides an allowance for each child the low-income recipient has to support. For example, a single parent with one child received an extra $1,233 a year in 1996 (National Council of Welfare, 1997-1998). Low-income persons are also entitled to keep $200 plus 25% of miscellaneous monthly earnings in addition to their monthly income assistance cheques (Feindel, Gibson, & Reid, 1998).

2.3.1 Poverty, Food, and Nutrition

Living on a low income compromises nutrition levels because other expenses take precedence over food expenditures and food expenses are seen to be flexible (Baxter, 1995, p. 22, 38,194; Charles & Kerr, 1988, p.175; Davis, Katamay, Desjardins, Sterken, & Pattillo, 1991; Fitchen, 1988; Hargrove, Dewolfe, & Thompson, 1994; Levens & Clague, 1986; McKenzie, 1974; National Council of Welfare, 1990; Tarasuk & Maclean, 1990). Not having enough money for food has been shown to be a concern to low-income persons and persons living with HIV (Badun, Evers, & Hooper, 1995; Baxter, 1995, p. 117; Core Women Care, 1995; Hargrove, Dewolfe, & Thompson, 1994; Hobbs Leenerts, 1998; McCulloch, Howard, & Ivan, 1999; Tarasuk, Geduld, & Hilditch, 1998). Twenty-four percent of food bank users noted that increasing welfare payments would reduce hunger (Levens & Clague, 1986).

Lack of money for food is not related to poor spending practices because low income persons have been shown to spend their food dollars wisely. Low-income persons may
spend proportionately more of their money on food than higher income persons (Badun, Evers, & Hooper, 1995; Fitchen, 1988; Levens & Clague, 1986; Robbins & Zafiriou, 1987) but they may not spend more money per se than higher income persons. Horton and Campbell (1989) found that low-income persons chose cheaper brands in the smaller more expensive local stores and therefore did not pay more than higher income persons for food. Conversely, DeVault noted that low-income women chose more expensive name brands because they wanted to be sure that the food would be acceptable and not wasted (DeVault, 1991, p.179).

Because money allocated to food is frequently compromised for the sake of other fixed expenses, nutrient intakes are influenced by income. Persons living on a low income have been found to eat diets that are high in fats, sugars, and starches and lacking in meat, dairy products and fruits and vegetables (Fitchen, 1988). Starchy foods are seen to be filling by low income persons (Fitchen, 1988). McKenzie (1974) has suggested that when money is scarce, less money is spent on nutritious food and less nutritious foods or foods that are "comforting" are selectively eaten. Some studies have shown that various nutrients have been found to be decreased and/or below the RNI in low-income Canadians: energy (Badun, Evers, & Hooper, 1995; Campbell & Horton, 1991), protein (Campbell & Horton, 1991; Maxwell & Simkins, 1985; Richard, Sevigny, & Roberge, 1984), vitamin A (Badun, Evers, & Hooper, 1995), vitamin C (Maxwell & Simkins, 1985; Myres & Kroetsch, 1978; Richard, Sevigny, & Roberge, 1984), folate (Badun, Evers, & Hooper, 1995; Campbell & Horton, 1991; Maxwell & Simkins, 1985; Myres & Kroetsch, 1978), calcium (Badun, Evers, & Hooper, 1995; Campbell & Horton, 1991; Maxwell & Simkins, 1985; Richard, Sevigny, & Roberge, 1984), iron (Badun, Evers, & Hooper, 1995; Campbell & Horton, 1991;
Maxwell & Simkins, 1985), and zinc (Badun, Evers, & Hooper, 1995). However, one American study showed that low-income households spent their food dollars more wisely and obtained more nutrient-dense diet per food dollar than high-income households (Morgan, Peterkin, Johnson, & Goungetas, 1986).

Persons on income assistance tend to have a characteristic eating pattern over the course of the month. Low-income women have money for food when they get their income assistance cheque but cannot afford foods they like to eat just before they receive their next cheque (Baxter, 1995, p. 39; Fitchen, 1988). A good diet was especially difficult for women on a low income to achieve before cheque day (Baxter, 1995, p. 200). A report by the B.C. Nutrition Council also documented that income assistance was inadequate to support a healthy diet (Marquis, 1990).

Because low-income women may have difficulty maintaining their diets over the course of the month, skills on making their food dollar stretch may be lacking. One study of low-income persons showed that skills were needed to purchase nutritious cheap foods and to cook creatively (Hargrove, Dewolfe, & Thompson, 1994). However, Badun, Evers, and Hooper (1995) noted that their low-income subjects did not want nutrition education to learn how to stretch their food dollar but rather needed more money to survive (Badun, Evers, & Hooper, 1995).

Because of the difficulties of having enough to eat, many persons living on a low income utilize several strategies to cope. One of the primary strategies is using food charity, primarily food banks (Badun, Evers, & Hooper, 1995; Baxter, 1995, p. 39, 102; Campbell & Desjardins, 1989; Canadian Association of Food Banks, 1998; Canadian Association of Food Banks & Hungerwatch, 1989; Fitchen, 1988; Hobbs, MacEachern, McIvor, & Turner, 1989).
Chapter 2: Literature Review

1992; Levens & Clague, 1986; Riches, 1997; Starkey, Kuhnlein, & Gray-Donald, 1998; Tarasuk, Geduld, & Hilditch, 1998; Travers, 1996). Food charity tends to be used at the end of the month when people have run out of money for food (Emmons, 1986; Hobbs, MacEachern, McIvor, & Turner, 1992). Using food charity is seen to be a last resort when no other options are available (Tarasuk, Geduld, & Hilditch, 1998).

Two studies have examined the food charity experience from the point of view of the user. Hobbs, MacEachern, McIvor, and Turner (1992) invited low-income persons in Vancouver to share their thoughts and feelings about food charity and to suggest ideas for improvement. Respondents found the food at food charity organizations was not very nutritious, of poor quality, and not consistently available. Participants found the lineups frustrating, humiliating, and unhealthy when the weather was bad. Volunteers at food charities were perceived to believe that they were better than the people they served. People with food allergies found it hard to find the foods that they could eat or they resorted to eating whatever was available. Despite the participants’ need for food charity, they had difficulty accepting it. Food charity was perceived to exist because of the greed of other people (Hobbs, MacEachern, McIvor, & Turner, 1992).

A second qualitative study conducted in Vancouver’s Downtown Eastside by McCulloch, Howard, and Ivan (1999) explored HIV-positive injection drug users’ experiences of accessing food in an attempt to pinpoint how food providers could better accommodate the needs of this population. The participants in this study typically used more than one type of food charity because they spent their food money on drugs and food charity was free to them. Access to different food charities increased with each “label” that the user had. For example, living with HIV enabled low-income persons to access not only
regular food charities but food charities expressly for persons living with HIV. Food quality was a matter of concern for the participants. Participants noted problems accessing food charity if they had children because food charities were more geared to individual use. Food charity was also difficult to access because the services were unavailable when injection drug users needed them (i.e. late at night) or the participants were unaware when the services were available. Problems were encountered when standing in line such as concerns for personal safety, poor health, bad weather, time spent waiting for service, and stigma when accessing food charity. Concerns were also expressed regarding the discriminatory attitudes of the volunteers towards the persons using food charity.

Other studies on food charity use have also noted the sense of stigma experienced by the users (Baxter, 1995, p. 123; Tarasuk & Maclean, 1990). This sense of stigma is seen to be additive to the stigma incurred from living with HIV (Creed, 1995). Concerns about opening hours in food banks are echoed by the fact that most food banks are only open part-time (Canadian Association of Food Banks, 1998). Twelve percent of respondents on food bank use noted that they did not use the food bank regularly because they received help from family and friends (Levens & Clague, 1986).

Using multiple strategies to alleviate the effects of poverty helps women to cope when they are short of money for food (Tarasuk, Geduld, & Hilditch, 1998). In addition to the use of food charity, other strategies to cope with low income include receiving food from family (Baxter, 1995, pp. 70-71; Campbell & Desjardins, 1989; Levens & Clague, 1986), friends (Campbell & Desjardins, 1989; Levens & Clague, 1986), daycares (Campbell & Desjardins, 1989), buying food on credit (Tarasuk, Geduld, & Hilditch, 1998), and receiving food in return for services or other goods (Fitchen, 1988). However, some strategies such as
buying in bulk may not be easily utilized if money is not readily available, storage facilities are inadequate, or transportation is lacking (Charles & Kerr, 1988, pp. 170-171; Fitchen, 1988; Maxwell & Simkins, 1985).

2.3.2 Poverty-Related Factors Affecting Food and Nutrition

Other poverty-related problems that are associated with food and nutrition include inadequate housing, lack of transportation, and dental concerns. Inadequate housing has been associated with lack of cooking and storage facilities and vermin such as mice and cockroaches. Studies on persons living with HIV have shown that finding affordable housing is difficult (Creed, 1995; Piette, Fleishman, Stein, Mor, & Mayer, 1993). Because income assistance payments are inadequate, available housing may lack adequate cooking and storage facilities (Core Women Care, 1995; McCulloch, Howard, & Ivan, 1999; Maxwell & Simkins, 1985; National Council of Welfare, 1990). Cooking utensils may also be in short supply (McCulloch, Howard, & Ivan, 1999). In a study of low-income families in the United States, lack of adequate cooking and storage facilities interfered with obtaining food (Emmons, 1986). Food may also be spoiled when storage facilities are inadequate, contributing to increased cost (Maxwell & Simkins, 1985). Women who lack adequate storage facilities may therefore resort to shopping more often and spending more money for smaller purchases (Fitchen, 1988) and may not be able to take advantage of foods available through food charity (McCulloch, Howard, & Ivan, 1999). The lack of adequate facilities may have more of a negative impact on poor women than men because women are primarily responsible for domestic labour (Payne, 1991, p. 134-135). Vermin have also been noted to be a concern for low-income women living with HIV (Core Women Care, 1995).

With regards to transportation, low-income persons have been shown to rely on
public transit (National Council of Welfare, 1998-1999). Transportation to large supermarkets may be a problem for women living on a low income or living with HIV because they cannot afford it or they may not have anyone to drive them (Baxter, 1995, p. 103-105; Charles & Kerr, 1988, pp. 170-171; DeVault, 1991, p.178-179; Hobbs Leenerts, 1998, Kirkham & Lobb, 1998; Piete, Fleishman, Stein, Mor, & Mayer, 1993). Women living with HIV who experience fatigue may find that even if they can afford public transport, they may be too tired to use it (Levy, Foley, & Forer, 1994). Carrying heavy groceries by walking or taking public transit has been noted to be an effort for persons living in poverty (Hargrove, Dewolfe, & Thompson, 1994; Travers, 1996). HIV may further compromise a person’s ability to get groceries if they are not feeling well or have experienced wasting due to HIV (McCulloch, Howard, & Ivan, 1999; Testa & Lenderking, 1999).

Persons on a low income may therefore prefer to shop close to home. However, prices may be higher in low-income neighbourhood chain supermarkets and in local, smaller stores (Fitchen, 1988; Maxwell & Simkins, 1985; Travers, 1996). Smaller stores that are more expensive may also entice low-income shoppers because they extend credit (Maxwell & Simkins, 1985; Roberts, 1982). In a survey of the priorities surrounding health care for women in the Downtown Eastside, a low-income area of Vancouver, some respondents felt that lack of nearby grocery stores was of concern (Core Women Care, 1995).

Dental health may be deteriorated through poverty, living with HIV, and substance use (Capilouto, Piette, White, & Fleishman, 1991; Charette, 1993; Greene, Chu, Diaz, & Schable, 1997; Kuthy, Odom, Salsberry, Nickel, & Polivka, 1998; McCarthy, Haji, & Mackie, 1996; Maxwell & Simkins, 1985; Nikias, Fink, & Shapiro, 1975; Picozzi, Dworkin,
Leeds, & Nash, 1972; Schuman et al., 1998; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999; Zador, Lyons Wall, & Webster, 1996). Barriers to seeking dental care among persons living in poverty or living with HIV include lack of money, lack of dental coverage, lack of transportation, lack of time, lack of knowledge of where to get dental care, and fear of dentists (Charette, 1993; Greene, Chu, Diaz, & Schable, 1997; Kuthy, Odom, Salsberry, Nickel, & Polivka, 1998; McCarthy, Haji, & Mackie, 1996; Manski & Magder, 1998; Nikias, Fink, & Shapiro, 1975; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999). Low-income women who had primary concerns other than HIV were more likely to have unmet dental needs (Shiboski, Palacio, Neuhaus, & Greenblatt, 1999). Persons living with HIV may have poor dental health because of decreased immunity, secondary infections, and more aggressive periodontal disease (McCarthy, Haji, & Mackie, 1996). They may also be reluctant to seek appropriate dental care due to concerns that treatment would be refused if HIV status was revealed, concerns about having to disclose HIV status, and concerns about transmitting the virus to other patients (Greene, Chu, Diaz, & Schable, 1997; McCarthy, Haji, & Mackie, 1996; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999). Tooth decay and periodontal disease have also been noted in substance users due to their high intake of very sweet foods and reduced dental care (Picozzi, Dworkin, Leeds, & Nash, 1972; Zador, Lyons Wall, & Webster, 1996). Persons living with HIV with untreated oral disease may have difficulty chewing and swallowing which may lead to reduced intake and weight loss (Weinert, Grimes, Lynch, 1996).

2.3.3 Summary

Many women in British Columbia who are living with HIV are also living in poverty. Low income persons do not have adequate financial resources because income
assistance is inadequate and, for those living within the context of substance use, money that might be allocated to food is preferentially spent on drugs. Inadequate money for food compromises food expenditures and has a negative impact on nutritional status. Eating patterns have been shown to be unstable as money for food becomes scarce over the course of the month. Low income persons have been shown to use various coping strategies to obtain more food, primarily food banks. Studies of food charity use have shown that low income persons have negative experiences with food charity because of personally unacceptable food, lineups, friction with the volunteers, having children, lack of availability, and stigma. Low income persons tend to cope by using multiple strategies such as food charity and free food from other sources such as families, friends, and other organizations. Other problems associated with poverty that impact food and nutrition concerns include inadequate housing, lack of transportation, and dental concerns. Due to the ways in which poverty limits women’s food selection choices, it is likely that poverty will interfere with the ability of women living with HIV to implement nutritional advice.

2.4 Complementary Therapies

As there is no cure for AIDS (Hogg et al., 1996), many persons living with HIV have resorted to the use of complementary therapies (Fairfield, Eisenberg, Davis, Libman, & Phillips, 1998). Various monikers have been used to describe unconventional therapies used by HIV patients. “Alternative therapies” refer to non-Western approaches vs. conventional Western therapies. This term implies that Western therapies are superior to non-Western therapies. The term “complementary therapies”, which is preferred by HIV patients, encompasses all Western and non-Western therapies and does not imply any hierarchy based on respectability (Pawluch, Cain, & Gillett, 1994). For the purposes of this study, the term
"complementary therapies" will be used and designated as those therapies which are food-and/or nutrient-based and include any therapy that is ingested by the participant.

With the recent success of HIV combination therapy, especially protease inhibitors, there has been a reduced demand for complementary therapies (Elion & Cohen, 1997), however, as persons living with HIV have been shown to develop resistance to various HIV medications, the demand for complementary therapies is expected to continue (Elion & Cohen, 1997). The following section will explore the prevalence and use of complementary therapies, sources of information about complementary therapies, reasons for use, difficulties in using complementary therapies, and the perceived efficacy of complementary therapies by women living with HIV.

2.4.1 Prevalence and Use of Complementary Therapies

Studies have been done primarily with mixed samples of men and women and only a few women have been included in the samples. Few studies have focused on women specifically. This review will include only those studies done with women only or those studies including men and women for which there is separate data for women in the sample.

The prevalence of complementary therapy use in studies including HIV+ women varies from 0 to 52% (Anderson, O'Connor, MacGregor, & Schwartz, 1993; Bates, Kissinger, & Bessinger, 1996; Berrier et al., 1996; Creed, 1995; Meneilly, Carr, & Brown, 1996). Therapies that have been used include a variety of vitamins and minerals such as multivitamins (Levy, Foley, & Forer, 1994), beta-carotene (Levy, Foley, & Forer, 1994), vitamin A (Levy, Foley, & Forer, 1994), vitamin C (Levy, Foley, & Forer, 1994), vitamin E (Levy, Foley, & Forer, 1994), B vitamins (Levy, Foley, & Forer, 1994), zinc (Levy, Foley, & Forer, 1994), iron (Levy, Foley, & Forer, 1994), calcium (Levy, Foley, & Forer, 1994),
magnesium (Levy, Foley, & Forer, 1994), and unspecified vitamins or minerals (Bates, Kissinger, & Bessinger, 1996; Creed, 1995; Meneilly, Carr, & Brown, 1996). Plant-based therapies included evening primrose oil (Levy, Foley, & Forer, 1994), Chinese medicine (Berrier et al., 1996), and herbal remedies (Bates, Kissinger, & Bessinger, 1996; Berrier et al., 1996; Meneilly, Carr, & Brown, 1996). Animal extracts included bee pollen (Levy, Foley, & Forer, 1994) and acidophilus (Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996). Food-based therapies included special diets (Bates, Kissinger, & Bessinger, 1996). In studies which noted the most common therapies, vitamins/minerals, herbal remedies, Chinese medicine, food-based therapies, and animal extracts were the most popular in that order (Bates, Kissinger, & Bessinger, 1996; Berrier et al., 1996; Meneilly, Carr, & Brown, 1996). In a Vancouver study of HIV+ women and complementary therapy use, 75% of respondents spent more than $100 per month on therapies (Meneilly, Carr, & Brown, 1996). Compared to HIV+ women who did not use complementary therapies, HIV+ women using complementary therapies have been found to be more likely to be high school graduates (Bates, Kissinger, & Bessinger, 1996) with higher incomes (Berrier et al., 1996). However, little is known about the use of complementary therapies by low-income women living with HIV.

2.4.2 Sources of Information About Complementary Therapies

Information regarding complementary therapies is obtained from a variety of sources by women living with HIV including other people such as friends (Bates, Kissinger, & Bessinger, 1996; Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996; Pawluch, Cain, & Gillett, 1994), relatives (Bates, Kissinger, & Bessinger, 1996; Levy, Foley, & Forer, 1994), persons living with HIV (Levy, Foley, & Forer, 1994), and health care workers...
(Bates, Kissinger, & Bessinger, 1996; Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996), stores and organizations such as health food stores (Levy, Foley, & Forer, 1994), bookstores (Levy, Foley, & Forer, 1994), libraries (Levy, Foley, & Forer, 1994), and support networks for persons living with HIV (Bates, Kissinger, & Bessinger, 1996; Levy, Foley, & Forer, 1994); and other miscellaneous sources such as the media (Bates, Kissinger, & Bessinger, 1996). In studies which noted the most popular sources of information about complementary therapies, health care workers, friends, relatives, support organizations for persons living with HIV, and the media were the most popular in that order (Bates, Kissinger, & Bessinger, 1996; Meneilly, Carr, & Brown, 1996; Pawluch, Cain, & Gillett, 1994).

2.4.3 Reasons for Using Complementary Therapies

Women living with HIV use complementary therapies for HIV-related factors and personal factors. HIV-related reasons included obtaining adequate calories (McCulloch, Howard, & Ivan, 1999), obtaining adequate vitamins/minerals (McCulloch, Howard, & Ivan, 1999), maintaining health (Creed, 1995), alleviating symptoms (Levy, Foley, & Forer, 1994; Pawluch, Cain, & Gillett, 1994), depression (Levy, Foley, & Forer, 1994), or stress (Levy, Foley, & Forer, 1994), increasing appetite (McCulloch, Howard, & Ivan, 1999), maintaining weight (McCulloch, Howard, & Ivan, 1999), and increasing energy (Levy, Foley, & Forer, 1994). The most commonly cited reasons for choosing complementary therapies were getting enough calories, vitamins/minerals, and maintaining health (Creed, 1995; McCulloch, Howard, & Ivan, 1999).

Maintaining health with the use of vitamin/mineral supplements is related to micronutrient deficiencies that occur with HIV. Micronutrient deficiencies in HIV can
occur due to ileal dysfunction, fat malabsorption, and reduced intake (Babameto & Kotler, 1997; Friis & Michaelsen, 1998). Women living with HIV have been found to be deficient in selenium (Baum et al., 1997), zinc (Baum et al., 1997; Coodley, Coodley, & Nelson, 1995), β-carotene (Coodley, Coodley, & Nelson, 1995), vitamin A (Baum et al., 1997; Coodley, Coodley, & Nelson, 1995; Semba, Park, Royal, & Griffin, 1996; Semba, Farzadegan, & Vlahov, 1997), vitamin E (Baum et al., 1997; Coodley, Coodley, & Nelson, 1995), vitamin B12 (Baum et al., 1997), and vitamin B6 (Baum et al., 1997; Coodley, Coodley, & Nelson, 1995). Deficiencies have been found to increase as HIV progresses and to occur despite adequate intakes of micronutrients (Baum et al., 1997; Coodley, Coodley, & Nelson, 1995). Compared to HIV+ men, HIV+ women suffered more widespread and more severe deficiencies of micronutrients especially at advanced disease stages (Baum et al., 1997; Rousseau, Molines, Metidji, & Moreau, 1998).

Personal reasons for using complementary therapies included doing something positive for their own health even if the therapies were not perceived to be particularly efficacious (Levy, Foley, & Forer, 1994), fighting other illnesses (Levy, Foley, & Forer, 1994), using therapies based on past or others' experiences (Levy, Foley, & Forer, 1994), and choosing affordable therapies (Levy, Foley, & Forer, 1994; McCulloch, Howard, & Ivan, 1999).

2.4.4 Difficulties in Accessing Complementary Therapies

Several difficulties in accessing complementary therapies have been noted by HIV+ women in the literature. Difficulties included inability to afford complementary therapies (Creed, 1995; Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996; Paterson, Carwein, & Sabo, 1996), problems in accessing complementary therapies (Core Women...
problems remembering names and reasons for taking therapies (Levy, Foley, & Forer, 1994), bad side effects (Meneilly, Carr, & Brown, 1996), general perceived harm (Meneilly, Carr, & Brown, 1996), and difficulties in obtaining and understanding information about complementary therapies (Creed, 1995; Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996). Some pamphlets on complementary therapies were difficult to understand by the women in one study because the language was difficult to read and information was inconclusive (Levy, Foley, & Forer, 1994). The participants also found it difficult to put all the information they may have gathered into a coherent “whole” (Levy, Foley, & Forer, 1994). Women living with HIV in this study obtained their information about complementary therapies in different ways but the authors noted that the women needed time and money to gather the information (Levy, Foley, & Forer, 1994). Confusion surrounding the use of complementary therapies is also experienced by the general population (Dwyer, 1992).

2.4.5 Perceived Efficacy of Complementary Therapies

The perceived efficacy of complementary therapies varied from efficacious (Creed, 1995), to no benefit (Meneilly, Carr, & Brown, 1996), to harmful (Creed, 1995; Meneilly, Carr, & Brown, 1996). Most of the participants in one study found that complementary therapies were useful in their efforts to maintain their health (Creed, 1995). About one third of women in another study noted that the therapies were of no benefit (Meneilly, Carr, & Brown, 1996). Between 10-13% of women in both studies experienced side effects (Creed, 1995; Meneilly, Carr, & Brown, 1996).
2.4.6 Summary

Complementary therapy use by women living with HIV has not been extensively studied. In the few studies that have been conducted, prevalence of use ranged from 0 to 52%, and the most common therapies included vitamins/minerals, herbal remedies, Chinese medicine, food-based therapies, and animal extracts. The most popular sources of information about complementary therapies were friends, health care workers, relatives, support organizations for persons living with HIV, and the media. Complementary therapies were used for HIV-related and personal reasons. Difficulties in accessing complementary therapies included poverty, problems with access, difficulty in remembering what was taken, adverse effects, and problems in obtaining and understanding information about complementary therapies. Perceived efficacy was variable.

2.5 Summary of Literature Review

Little is known specifically about the food and nutrition concerns of low-income women living with HIV, however general problems related to poverty, substance use, and HIV are presumed to affect this population. HIV-related factors and substance use may result in weight and body shape changes. Interpretations of these changes may be affected by dominant weight concerns resulting in favourable impressions of weight loss and negative impressions of weight gain. These interpretations may conflict with weight-related advice from health professionals. Poverty may interfere with food intake because low-income persons cannot afford the foods that would optimize their nutritional status. Complementary therapy use in women living with HIV is highly variable. Although these therapies are used for a variety of reasons, difficulties exist to their use. Discovering the
meanings of food and nutrition concerns for women living with HIV, and gaining an understanding of how these influences translate into coping behaviors will be of use to nutritionists working with this group and other low-income women living with HIV in allowing appropriate nutrition strategies to be planned.
3. Study Design and Methods

3.1 Study Objectives

The main objective of this study was to explore the food and nutrition concerns of a sample of low-income women living with HIV. Secondary objectives were to:

a) explore the meanings of weight and body shape changes occurring within the context of HIV,
b) examine the relationships of those meanings in (a) to the current discourse on women and body image,
c) explore the relationships between poverty, HIV and food,
d) examine the meanings of food- and/or nutrient-based complementary therapies for poor women living with HIV, and
e) examine the advice and underlying assumptions found in a selection of food- and/or nutrition-based documents available to the participants and compare these assumptions to the women’s experiences.

3.2 Theoretical Framework

Based on the objectives, a qualitative research design predicated on the tenets of constructivism and utilizing ethnographic methods was used in this study of the food and nutrition concerns of low-income women living with HIV. Constructivism represents a paradigm for conducting research that differs from the positivist tradition. Guba and Lincoln defined paradigm as a “worldview that defines, for its holder, the nature of the ‘world’, the individual’s place in it, and the range of possible relationships to that world and its [parts.]” (Guba & Lincoln, 1994, p. 107). Constructivism may be understood by its basic
assumptions about reality and how is it perceived (ontology), the relationship between the researcher and knowledge (epistemology), and the relationship of the researcher to the research process (Guba & Lincoln, 1994). The ontological assumptions of constructivism are rooted in the belief that multiple realities or "constructions" exist which are specific to subjects and their social world (Guba & Lincoln, 1994). These constructions are shaped and defined by the individual's experience and social setting (Rubin & Rubin, 1995, p. 35; Schwandt, 1994). Epistemologically, constructivism acknowledges that there is no one reality and that knowledge is defined and influenced by interaction between the researcher and the participants. In constructivism, the researcher is acknowledged to have values that shape the research process. Such values are not to be hidden but should be clearly exposed so that it is clear how the researcher's own belief system has influenced the research process (Guba & Lincoln, 1994). Such beliefs are not framed as hypotheses because the qualitative process is inductive. An inductive research process means that the ideas are generated from the data (Creswell, 1994, p. 7). Therefore, in this study, food and nutrition concerns were solicited from the participants and clarified through further interviews with the participants. This contrasts with quantitative research which is deductive (Creswell, 1994, p. 7). In a deductive research process hypotheses are set before the study and the aim is to prove or disprove the hypotheses (Creswell, 1994, p. 7).

A constructivist paradigm was appropriate because my primary interest was in learning how the study participants defined and explained their food and nutrition issues rather than exploring their feelings about a pre-determined set of issues that I felt would be pertinent to them. For this reason, I did not use hypotheses to test their veracity. The constructivist paradigm also allowed me to explore how the social contexts of poverty, HIV,
and women's preoccupation with weight interacted or shaped the food and nutrition issues of the study participants.

Ethnographic methods were also utilized in the study. An ethnographic perspective means understanding and describing a culture from "the native point of view" (Spradley, 1979, p. 3), and understanding the meaning of the participants' words through direct contact with them. Meanings ascribed to experienced phenomena often predispose behaviour (Spradley, 1979, p. 5). Ethnographic methods were appropriate because I was interested in the meanings the participants ascribed to weight changes, to complementary therapy use, and how they perceived food and nutrition concerns. Ethnographic interviewing techniques and analysis were used to understand the different concepts that emerged from the data and to develop themes that described and explained the food and nutrition concerns of the participants (Spradley, 1979, pp. 12-13).

Because it was expected that low-income women living with HIV would face many barriers in making decisions about food and nutrition, food- and nutrition-related documents available to these women were collected to explore the assumptions made about the reader and to compare these assumptions with the experiences of the participants. This information would be useful for persons working with this population in making their nutritional advice more relevant.

3.3 Research Design

3.3.1 Data Collection

To develop a thorough understanding of the meaning of food-related issues in the lives of women living with HIV and to explore the assumptions made about these issues,
two types of data collection were used: individual interviews and collection of food-related written documents which were available to low-income women living with HIV.

### 3.3.1.1 Interviews

#### 3.3.1.1.1 Sample Size

In qualitative studies, sample size is determined on the basis of theoretical saturation whereby further investigation reveals no new information (Patton, 1990, p.185-186). Although achieving theoretical saturation is the ideal, in reality the constraints of time and money limited the number of women I interviewed to 13. This number of participants was enough to gain a good understanding of the main themes while the minor categories were less fully explored. Factors such as length of poverty, reason for poverty, reason for HIV diagnosis, number of children, presence/lack of partner, current risk behaviours, age, and time of diagnosis were perceived to possibly influence food and nutrition concerns. The sample was therefore purposive (Creswell, 1994, p.148) rather than random. Women were chosen at first without concern about their demographic characteristics, however, subsequent recruitment focussed on women who had diverse characteristics in order to compare and contrast factors of potential influence. The sample was also a volunteer convenience sample because participants volunteered to become involved in the study and were chosen from among women who attended the HIV clinic and the support organization for women living with HIV.

#### 3.3.1.1.2 Inclusion/Exclusion Criteria

Inclusion criteria specified that the participants must be able to speak English, be receiving income assistance, have been diagnosed with HIV at least 3 months prior to
recruitment, and have experienced a minimum weight change of 5 lbs. Because I speak
English, English-speaking women were selected and recruitment, obtaining informed
consent, and all interviews occurred in English. Women on income assistance from BC
Benefits were selected because poverty has been recognized as a risk factor for HIV
(Krueger, Wood, Diehr, & Maxwell, 1990). Due to the devastating effects of learning of a
diagnosis of HIV, women who had been diagnosed at least 3 months prior to recruitment
were selected so that they could freely consider and discuss their food and nutrition concerns
without being overwhelmed by the newness of the HIV diagnosis. Women having
experienced weight changes of a minimum of 5 lbs. were also included in the study to
explore their feelings about weight changes vs. nutritional advice.

Exclusion criteria included immigration to Canada within that last 4 years and
inability to participate due to mental incompetency. To consider the impact of the North
American discourse on women, weight, and body image, women immigrating to Canada
within the last 4 years from a country outside North America were excluded. Women who
were mentally incompetent to participate, for whatever reason, were also excluded from the
study. The study received ethical approval from the Behavioral Research Ethics Board at
UBC and from the Research Coordinating Committee at the Children’s and Women’s
Health Centre of British Columbia, formerly BC Women’s Hospital.

3.3.1.1.3 Recruitment

Recruitment occurred in two different ways: direct contact with the women and
solicitation through flyers and newsletter notice. Contact with the women occurred through
screening and recommendation by Diana Peabody, Registered Dietitian at the Oak Tree
Clinic. The Oak Tree Clinic provides medical and other support services for women, youth,
and children living with HIV and their families. Permission was obtained from the clinic to conduct the interviews on site and to enable clients to be approached for recruitment.

Recruitment letters (Appendix A) detailing the study were presented by Diana Peabody to potential participants who, if interested, allowed the release of their name (and phone number if available) to me and I, in turn, contacted the potential participant. If no phone was available, Diana Peabody arranged an interview time for the participant to meet with me. Study participants gave informed consent prior to the interview (Appendix B).

Recruitment also occurred through solicitation by flyer and newsletter notice. Permission was obtained from the Positive Women’s Network, a support organization for women living with HIV, and the Oak Tree Clinic to post flyers describing the study. Women were also informed of the study through an advertisement in the “Positive Women’s Network Newsletter”, a newsletter prepared by the Positive Women’s Network. Interested women in turn contacted Diana Peabody or myself by phone for further information.

3.3.1.1.4 Interviews

Thirteen women were interviewed between June 1997 to June 1998. Two women were interviewed twice because they had more to discuss than what could be covered in one interview. All other participants were interviewed once. Interviews ranged from approximately 40 minutes to 1½ hours. All interviews were conducted at the Oak Tree Clinic with the exception of one which took place at the participant’s home. The location of the interviews was mutually acceptable to all parties. To increase rapport and with the permission of the participant, the Oak Tree dietitian was present for three of the interviews. Permission was obtained from each participant to audio-tape the interview for further analysis. Each participant was paid an honorarium of $25.00 for each interview.
Interviewing proceeded until saturation of the data occurred and no new information was revealed from further data collection (Rubin & Rubin, 1995, p.72).

3.3.1.5 Interview Guide

Interviews were conducted using a semi-structured interview guide (Appendix C). Questions were developed for the interview but I was free to pose other pertinent questions to pursue developing themes (Rubin & Rubin, 1995, p. 45). In giving their responses, participants were encouraged to focus on the time period between the date of their HIV diagnosis and the present. Pilot testing of the interview guide occurred with the first two interviews. Ethnographic questions such as descriptive, structural, and contrast questions were used to shape the interview guide (Spradley, 1979, p. 60). Descriptive questions were used to enable the participants to describe their food and nutrition concerns. Structural questions were used to further the completeness of the data. Contrast questions were also used to clarify emerging issues (Spradley, 1979, p. 60). Questions about the participants' food and nutrition concerns were used to focus the interviews around pertinent issues, however women were also able to initiate discussion on related issues. Probing questions were used to obtain more information if necessary (Rubin & Rubin, 1995, p.148). The design of the interview guide was flexible and changed over time to explore and clarify emerging themes (Rubin & Rubin, 1995, p. 44).

3.3.1.2 Document Collection

Data collection also included a review of food- and nutrition-related materials to which low-income women living with HIV had access. Collection and analysis of documents followed the interviews. Documents fit under the general categories of “nutrition
and HIV”; “nutrition and poverty”; and “general nutrition”. Documents were chosen from three different locations:

1. Food and nutrition documents were collected through contact with dietitians from an HIV Practice Group of which I was a member. Each dietitian in the group was asked to choose 5-10 documents that were used regularly in counseling with low-income women living with HIV. Documents chosen from dietitians were analyzed in their original format. Diana Peabody, a dietitian at the Oak Tree Clinic, noted that she often “personalized” the documents that she used depending on the needs of the client.

2. Newsletters from the Positive Women’s Network (Feb. 1997 to July/Aug. 1998) were also searched for relevant articles.

3. Information materials on food and nutrition that were on display at the Pacific AIDS Resource Centre Library and the Oak Tree Clinic were collected. These materials were chosen because they could be accessed without assistance.

A total of 45 documents were chosen for analysis. Documents were chosen so that a variety of messages and topics could be considered (Altheide, 1996, p. 33). Based on the audience for each of the documents, 41 documents were included in the final discussion (see Chapter 5). See Appendix D for the list of documents.

3.3.2 Analysis of Interviews and Documents

As is typical of qualitative studies, data collection and data analysis of interviews occurred simultaneously (Bogdan & Biklen, 1992, p. 154; Spradley, 1979, p. 94). Verbatim transcripts from the interviews were produced through the use of computer software (Microsoft Word 6.0, 1993-1994). Data were compressed by identifying topics in the transcripts (Tesch, 1990, p. 116) which were coded (Tesch, 1990, p. 121) using computer
software, “Atlas/ti” (Muhr, 1993-1994). Some examples of topics or codes were “appetite”, “cooking and storage facilities”, “healthy eating”, “fat fear”, and “complementary therapy use”. Coded transcript segments were then grouped together into larger code families (Tesch, 1990, p. 122) such as “food and eating”, “poverty”, “weight and body image”, “complementary therapies”, “substance use”, “HIV”, and “demographics”. Transcript segments within each code family were reviewed to identify similarities and differences in responses between the participants (Creswell, 1994, p.154; Tesch, 1990, pp. 144-145). Ethnographic analysis was used to determine the semantic relationships between the codes thereby facilitating the formulation of larger themes (Spradley, 1979, pp. 107-108). For example, if the participant noted her lack of desire to eat when actively using street drugs such as heroin and cocaine, a semantic relationship was identified between substance use and eating: substance use was a barrier to eating. By noting that other ways of eating were discussed by the participants in the transcripts, the larger theme of eating patterns was derived from the data.

Not all the data collected from the interviews were included in the final analysis. During the interview process, the HIV status of one of the participants was questioned. Confirmation of the participants’ HIV status was not sought through official documentation because trust was believed to be an issue that could further the rapport in the interviews and HIV status had never come into question. I was, however, reluctant to interview this participant because there was suspicion about her HIV status. After consultation with the dietitian and the co-director of the Oak Tree Clinic, the participant was interviewed for the study because it was felt that challenging her HIV status with her at that time might have an adverse effect. After further reflection, it was decided that most of the information collected
would be included in the study and only that information that did not change the results of the study would be excluded. Examples of excluded information were being embarrassed to use meal tickets, not being able to eat red meat because it was “too heavy”, and taking Ensure® because she automatically regurgitated her food after eating.

Documents were analyzed to determine audience, author and credentials, producer of the document, form, location, reading difficulty, presence of disclaimer, purpose, and perspective. Assumptions contained within the documents about pertinent factors as substance use, poverty, weight issues, HIV, and complementary therapies were also explored. Perspective refers to what Altheide (1996) called “frames” or viewpoints that underlie what is written in a text (p. 30). He defined “frames” as “the focus, a parameter or boundary, for discussing a particular event. Frames focus on what will be discussed, how it will be discussed, and above all, how it will not be discussed.” (Altheide, 1996, p. 31). The perspective of each document was studied to make clearer the assumptions that drive the production of each document and to contrast those assumptions with the food and nutrition concerns that were expressed by the women.

3.3.3 Strategies to Enhance Rigor

In the quantitative paradigm, criteria for evaluating outcomes are validity and reliability. Conversely, in the qualitative paradigm, a study is evaluated in terms of its trustworthiness (i.e. credibility) and its transferability (i.e. external validity) (Guba & Lincoln, 1994). Member checks are one way in which credibility can be enhanced. Member checks involve sharing the themes that develop from the study with the participants and with peers. In this study, themes derived from earlier interviews were verbally shared with the participants in later interviews. A verbal report was chosen given the difficulty for
the participants in understanding a written report and the need to clarify the themes as necessary. The participants also changed mailing addresses with relative frequency which made receipt of a written report more uncertain. Themes from the interviews and document collection were also shared with the Oak Tree Clinic dietitian and my advisor for feedback (Creswell, 1994, p. 158).

Transferability was enhanced by documenting the demographics of the study participants and by making transparent study biases. Demographic information (Appendix E) was also obtained from each participant to better characterize the sample and to allow other researchers to determine how the results might compare with another group of women living with HIV elsewhere (Creswell, 1994, pp. 158-159).

Within qualitative research, it is generally accepted that the researcher will have an influence on the study through her own values and beliefs (Paterson, 1994, Rubin & Rubin, 1995, p. 12). Such biases within the qualitative paradigm are not regarded as study limitations but must be noted and addressed (Paterson, 1994, Rubin & Rubin, 1994, p. 14). Researchers must therefore acknowledge that they have an influence on the research process and document their influence by recording their thoughts and feelings during the research process (Spradley, 1979, p. 76). For this reason, I kept a field-work journal of experiences, thoughts, perceptions and feelings as the study proceeded to reveal any potential biases. I had several beliefs before the study started. One of the driving forces for the study was the belief that women living with HIV would be strongly influenced by the dominant discourse on women and body weight. This belief stemmed from my experience of weight gain before the study started and my keen interest in issues of weight and dieting. I believed that the women in my study would be influenced by normative weight concerns that affect women in
the North American culture and, as a result, I expected that these women would be resistant to recommendations of weight gain by dietitians. After initial consultation with Diana Peabody, I anticipated that weight loss would be a huge concern for women living with HIV because of concurrent concerns about the HIV virus. I assumed that poverty would overwhelmingly influence food and nutrition concerns partly because of my own experience in dietetic internship when counselling persons living on a low-income. I felt that complementary therapies would not be of huge interest to this group of women because of their poverty status and educational level. Having learned that the many of the women at the Oak Tree Clinic were injection drug users, I originally felt that this subgroup would not be suitable for interviewing as they would not be able to think about the questions or give coherent responses. However, after consultation with my thesis committee, it was decided that interviewing injection drug users would be salient to the study given the explosion of HIV infection in that population in the Downtown Eastside (Strathdee et al., 1997). It was concluded that, provided the study participants were not “high” or inebriated for the interview, there would not be a problem interviewing them. I was also concerned about the differences in lifestyle between myself and the study participants and I anticipated some personal discomfort and, based on that, difficulties in conducting the interviews.

Based on my thoughts and feelings before I began data collection, I took several steps to minimize my biases in the interviews. I completed a course in basic interviewing skills which helped me to use open-ended questions and avoid leading questions. An example of an open-ended question is, “what food or nutrition concerns do you have?”. Open-ended questions encourage the participant to provide her own response without influence from the interviewer (Patton, 1990, p. 295). Similarly, leading questions such as
“how does poverty shape your food and nutrition concerns?” were avoided to encourage the participant’s response from her own perspective (Patton, 1990, p. 301). Transcripts of early interviews were read by Dr. Chapman and Diana Peabody to review my interviewing techniques and to provide suggestions for improvements which I incorporated in later interviews (Creswell, 1994, p.158). An interview guide was used to structure the interview so that I would address not only the objectives in which I had a keen personal interest, but all my study objectives (Patton, 1990, p. 280). I verbally discussed the emerging themes with my participants in later interviews to solicit feedback and determine whether I was “on track” (Creswell, 1994, p. 158). I explored the different community resources that were available to persons living with HIV so that I could increase rapport by having a common understanding of what was available to the participants (Paterson, 1994). To further increase the participants’ comfort level, I used plain language and dressed simply for the interviews (Rubin & Rubin, 1995, p. 102).
4. **Participant Interviews**

This chapter, describing the findings from participant interviews, is divided into 5 main sections. The first section includes a description of the study participants. The next two sections focus on the two major food and nutrition problems identified by the study participants: poverty and weight changes. The fourth section in this chapter describes the different eating patterns that the women discussed. The final section in the chapter deals with complementary therapies.

4.1 **Description of Study Participants**

Health and demographic information about the 13 women who participated in the study is summarized in Tables 4.1 and 4.2, respectively. All of the women were born in Canada. The majority of the participants were in their 30's with the ages ranging from 25 to 48 years. Four women were overweight (BMI>27) and three were underweight (BMI<20) according to the Canadian Guidelines for Healthy Weights (Expert Group, Health Promotion Directorate, Health Services and Promotion Branch, 1988). Six of the 13 women were taking HIV medications, most commonly 3TC and AZT. Time since HIV diagnosis ranged from less than a year to 16 years. CD4 counts represent the number of certain types of T-lymphocytes that induce the cellular immune response. The CD4 count is a common measure of immune function in HIV (Gimenez-Lambert, L’Homme, Johnson, & Flannery, 1996, p. 13). An increase in CD4 count is reflective of increased immunity which is beneficial and a decrease in CD4 count is reflective of decreased immunity which makes the host more susceptible to infection (Gimenez-Lambert, L’Homme, Johnson, & Flannery, 1996, p. 13). Three of the women had a CD4 count less than 200; five women had a CD4...
count between 201 and 500; and five had a CD4 count greater than 500.

As shown in Table 4.2, the participants generally had limited education, ranging from Grade 9 to some university courses. Five women had no children. Of the eight women with children, only two had children living with them at the time of the interview. Cheryl\(^1\), Karen, and Peggy had children who had been put into care either permanently or temporarily. Three women did not have any of their children with them because the children were grown or were staying with another person. Five women were living with a partner or a friend. Information was not collected on the participants’ sexual orientation, however, four of the participants had male partners. Three partners or roommates were also on income assistance and two were working full-time or were self-employed. Eleven participants had a history of substance use and one of them was still using drugs at the time of her interview. Two women had no history of substance use. Nine women were Caucasian and four were Native or First Nations\(^2\). The participants had been receiving income assistance for up to 9 years. Most of the women had lived on a low-income before being diagnosed. All but one of the study participants lived in Vancouver and the lower Mainland. Information was not collected from the participants on possible histories of eating disorders. In summary, the participants were a sample of nonimmigrant women living with HIV, most of whom had a history of substance use, and all of whom were receiving income assistance.

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\(^1\) Pseudonyms have been used to preserve the participants’ anonymity.

\(^2\) The terms Native or First Nations are used here because these terms were used by the participants to describe themselves. In the rest of the thesis and for the sake of clarity, the term Aboriginal will be used to refer to the Native and First Nations participants.
### Table 4.1: Health Information

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Country of Birth</th>
<th>Age (y)</th>
<th>BMI (kg/m²)</th>
<th>Medications</th>
<th>Years Since HIV Diagnosis</th>
<th>CD4 Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>Canada</td>
<td>34</td>
<td>18</td>
<td>1st interview: AZT, 3TC, Septra, fluconazole, sometimes acyclovir 2nd interview: indinavir, D4T, DDi</td>
<td>5.5</td>
<td>101-200</td>
</tr>
<tr>
<td>Cheryl</td>
<td>Canada</td>
<td>31</td>
<td>21</td>
<td>AZT, 3TC</td>
<td>2</td>
<td>201-500</td>
</tr>
<tr>
<td>Chris</td>
<td>Canada</td>
<td>47</td>
<td>26.6</td>
<td>none</td>
<td>16</td>
<td>0-50</td>
</tr>
<tr>
<td>Dayna</td>
<td>Canada</td>
<td>25</td>
<td>23.5</td>
<td>none</td>
<td>3</td>
<td>501-999</td>
</tr>
<tr>
<td>Gail</td>
<td>Canada</td>
<td>29</td>
<td>16.2</td>
<td>none currently, past: nelfinavir, D4T, 3TC</td>
<td>3</td>
<td>201-500</td>
</tr>
<tr>
<td>Janice</td>
<td>Canada</td>
<td>35</td>
<td>17.6</td>
<td>none</td>
<td>10</td>
<td>501-999</td>
</tr>
<tr>
<td>Karen</td>
<td>Canada</td>
<td>26</td>
<td>27.5</td>
<td>AZT, 3TC, Septra</td>
<td>2.5</td>
<td>201-500</td>
</tr>
<tr>
<td>Linda</td>
<td>Canada</td>
<td>37</td>
<td>24.3</td>
<td>none</td>
<td>&lt;1</td>
<td>201-500</td>
</tr>
<tr>
<td>Nancy</td>
<td>Canada</td>
<td>48</td>
<td>30</td>
<td>none</td>
<td>1</td>
<td>&gt;1000</td>
</tr>
<tr>
<td>Peggy</td>
<td>Canada</td>
<td>35</td>
<td>30</td>
<td>AZT, 3TC</td>
<td>3</td>
<td>201-500</td>
</tr>
<tr>
<td>Rain</td>
<td>Canada</td>
<td>32</td>
<td>25.4</td>
<td>none</td>
<td>2</td>
<td>501-999</td>
</tr>
<tr>
<td>Shirley</td>
<td>Canada</td>
<td>38</td>
<td>23</td>
<td>AZT</td>
<td>4</td>
<td>101-200</td>
</tr>
<tr>
<td>Sylvia</td>
<td>Canada</td>
<td>34</td>
<td>36.5</td>
<td>AZT, 3TC</td>
<td>2.5</td>
<td>&gt;1000</td>
</tr>
<tr>
<td>Pseudonym</td>
<td>Highest Level of Education</td>
<td>Children (Age in years)</td>
<td>Partner or Housemate</td>
<td>Partner or Housemate on Income Assistance</td>
<td>History of Substance Use</td>
<td>Ethnicity</td>
</tr>
<tr>
<td>-----------</td>
<td>---------------------------</td>
<td>-------------------------</td>
<td>----------------------</td>
<td>------------------------------------------</td>
<td>--------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Alice</td>
<td>Grade 11</td>
<td>none</td>
<td>none</td>
<td>no</td>
<td>yes</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Cheryl</td>
<td>Gr. 12</td>
<td>HIV+ boy (4), girl (7), both in care</td>
<td>none</td>
<td>no</td>
<td>yes</td>
<td>First Nations</td>
</tr>
<tr>
<td>Chris</td>
<td>some university courses</td>
<td>none</td>
<td>none</td>
<td>no</td>
<td>yes (casual user)</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Dayna</td>
<td>Gr. 9</td>
<td>boy (6), boy (9), boys with partner girl (2)-with Dayna</td>
<td>none</td>
<td>no</td>
<td>yes</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Gail</td>
<td>Gr. 10</td>
<td>none</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Janice</td>
<td>Gr. 11</td>
<td>daughter (18), son (20), both not living with her</td>
<td>none</td>
<td>no</td>
<td>yes</td>
<td>Caucasian</td>
</tr>
</tbody>
</table>
Table 4.2: Demographic Information (continued)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Highest Level of Education</th>
<th>Children</th>
<th>Partner or Housemate</th>
<th>Partner or Housemate on Income Assistance</th>
<th>History of Substance Use</th>
<th>Ethnicity</th>
<th>Years on Income Assistance</th>
<th>Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karen</td>
<td>Grade 12</td>
<td>children in permanent care (since before diagnosis)</td>
<td>yes</td>
<td>no (works full-time)</td>
<td>yes</td>
<td>Caucasian</td>
<td>6</td>
<td>Burnaby</td>
</tr>
<tr>
<td>Linda</td>
<td>one year of nursing (VGH)</td>
<td>girl (8), girl (9), living with mother</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>Caucasian</td>
<td>&lt;1</td>
<td>Vancouver</td>
</tr>
<tr>
<td>Nancy</td>
<td>Gr. 11</td>
<td>2 grown children (28 and 26), not living with her</td>
<td>none</td>
<td>no</td>
<td>yes</td>
<td>Caucasian</td>
<td>1</td>
<td>Gibsons, BC</td>
</tr>
<tr>
<td>Peggy</td>
<td>high school</td>
<td>4 children in permanent care</td>
<td>none</td>
<td>no</td>
<td>yes</td>
<td>First Nations</td>
<td>5</td>
<td>Downtown Eastside</td>
</tr>
<tr>
<td>Pseudonym</td>
<td>Highest Level of Education</td>
<td>Children</td>
<td>Partner or Housemate</td>
<td>Partner or Housemate on Income Assistance</td>
<td>History of Substance Use</td>
<td>Ethnicity</td>
<td>Years on Income Assistance</td>
<td>Residence</td>
</tr>
<tr>
<td>-----------</td>
<td>---------------------------</td>
<td>----------</td>
<td>----------------------</td>
<td>----------------------------------------</td>
<td>--------------------------</td>
<td>----------</td>
<td>-----------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Rain</td>
<td>Grade 11</td>
<td>son (11), daughter (9), both with Rain</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>First Nations</td>
<td>2</td>
<td>Burnaby</td>
</tr>
<tr>
<td>Shirley</td>
<td>Grade 10</td>
<td>none</td>
<td>yes</td>
<td>no (self-employed)</td>
<td>yes</td>
<td>Native</td>
<td>6</td>
<td>Burnaby</td>
</tr>
<tr>
<td>Sylvia</td>
<td>college courses</td>
<td>none</td>
<td>none</td>
<td>no</td>
<td>no</td>
<td>Caucasian</td>
<td>&lt;1</td>
<td>East Vancouver</td>
</tr>
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4.2 Poverty-Related Food Problems

4.2.1 Not Having Enough Money

When the study participants were asked if they had any food or nutrition problems, the two major concerns they discussed were not having enough money to eat and concerns about weight changes. Six participants noted that not having enough money for food was their primary food and nutrition concern. All the other respondents also noted problems with poverty and food in the interviews. Rain said,

"We don't get a whole lot of money for like vegetables and stuff like that. We always end up with lots of dry stuff. When you're living on social assistance, it's like you gotta really budget and stuff."

Participants' comments about money problems included discussion of why they lacked money, the effects of poverty on how they ate, and strategies they used to increase their access to food.

4.2.1.1 Reasons For Not Having Enough Money

Linda: I'm not good at [budgeting my money], but I'm getting better....[My money] used to be gone in two days...I wouldn't buy anything except dope and now 10 days after welfare day, I've still got a little bit of change in my pocket.

Participants’ money shortages related to the amount of financial aid provided by income assistance and, at times, to the use of money for street drugs instead of food. Dayna

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3 Quotations in this document have been modified slightly from the verbatim transcripts in order to preserve the participants’ anonymity or increase readability. Modifications include deletion of repeated or extraneous words such as “um” and “you know”, ellipses (...) to indicate that several words or phrases have been omitted, and words in [square brackets] that have been inserted to clarify comments that may not be clear in the
described living on BC Benefits this way:

> Single people are even worse off than people with families. They get even less. They only get $325 for rent and then $200 to live off of...and that's not a lot to live off of especially when you're trying to eat and pay bills and stuff. It doesn't pay your bills. You have $50 and...that's not having a life or anything either. [You] can't do anything, go anywhere...kinda...sit at home and...look at the food you don't have.

Because of their HIV status, many of the participants were receiving “disability” payments under BC Benefits and about half of the participants were also receiving a special high-protein diet allowance of $40 per month (Martin, 1997). However, 10 women noted that the payments were insufficient. Because the amount of money was insufficient for their needs, budgeting was not always an option. When Dayna was asked how she budgeted her money, she said, “Well I don't really. There's no way to budget how much money you get. It's not enough money to make a budget with.” Her sense of the inadequacy of the benefits is supported by other documentation. At the time she was interviewed in 1998, income assistance provided $596.00 and $771.00 per month for level 1 and level 2 disability, respectively (Feindel, Gibson, & Reid, 1998). In British Columbia, disability incomes were only 60% of the poverty line and 35% of an average income for a single employable person in 1996 (National Council of Welfare, 1997-1998).

The bureaucracy involved in the poverty system was also restrictive. Linda, for example, needed to get a letter from her doctor for a hot plate, and she needed to pay $50 to get a microwave oven to reheat meals from a meal delivery service for people living with HIV. She was told to talk to her financial aid worker about the need for a microwave oven, but Linda perceived that her worker was “tough” and would not be responsive to her
Substance use also resulted in not having enough money for food because the participants spent their food money on drugs. Alice said that, for her, substance use made her poverty worse because she spent all her money on drugs within a day or two of receiving it and had no money left for the rest of the month. And Linda said, “I'd go days without eating food really. Just drink a lot of fluids when I was doing the heroin and stuff. Cause any money you [spent] on food took away from your drugs. Can't have that!”

Conversely, substance use also freed the participant from the need to worry about food. When using hard drugs such as cocaine and heroine, participants would often not eat. When they did want to eat, there were no worries about finding food, because they could, like Peggy, rely almost exclusively on food charity. Peggy’s food cravings and the food available at food charities shaped her diet. Substance use also became an escape from the normal work of living in poverty. As Linda said,

> You forget. You know, everything goes away. It's just procrastinating...but everything goes away.....You become TOTALLY irresponsible. As long as you get coke, doesn't matter. What if your rent [goes], so what? I'll live on the streets as long as I can get that fix. It's really a sick way to live.

Certain living and family situations and lack of cooking skills increased the perception of poverty. Alice often found herself in a relationship with a man who controlled all the money. Alice commented, “So it's like I never even have a penny. It becomes all part and parcel of that entire thing. He'll see to it we've got food but it's just a nightmare. That whole HORRIBLE pattern. I just HATE it.” Karen had lived in a drug treatment centre and received very little money each month. Cheryl found that her poverty was
affected by the presence/absence of her children. If she had fewer children with her, if the children were younger, or if the child had special needs, her sense of poverty was increased. Chris lacked the cooking skills necessary to prepare cheaper cuts of meat.

The HIV diagnosis, children, and casual work were factors perceived to lessen poverty. For example, Nancy spent her money more wisely as a result of the diagnosis and Linda found she had increased access to resources that were previously unavailable to her such as a food bank and a meal delivery service, both for persons living with HIV. Having her children with her meant that Cheryl received more money each month. Cheryl was asked about having enough money for food now that her children were in care:\(^4\):

\begin{verbatim}
I: So now do you find that...you ever run short of food?
C: Now I do, yeah.
I: And what's the difference between [then and now]?
C: I don't have income for them. I don't have the income.
I: So the extra income for the kids allowed you to have that extra money?
C: Lots more groceries yeah.
\end{verbatim}

Sylvia obtained casual work which supplemented her income assistance cheque but did not interfere with her eligibility to receive it.

4.2.1.2 Effects of Poverty on Eating

When the participants received their cheques, those participants who were not using drugs would first pay for fixed expenses such as rent and bills and then allocate leftover money to food. Dayna said, "I pay my rent. I pay my bills and I take so much for groceries
with the rest.” As a result, food expenditures were often compromised. Participants complained of not being able to afford fruits and vegetables, juice, meat, chicken, fish, dairy products, diet foods, low-fat foods, convenience foods, organic foods, and foods that they craved.

Four participants experienced changes in their eating habits over the course of the month because they could not afford the foods they regularly ate. When they received their income assistance cheques, they had enough money to buy the foods that they craved and liked to eat. However, when they ran out of money before the next cheque had arrived, the women would resort to dry staple foods that were left in their cupboards such as noodles, soup, toast, and cereal. These foods were not necessarily their favourites and some of the women felt that they lacked creative cooking skills to make meals interesting. As Sylvia said,

> Every meal is like your favourite stuff for the first 2-3 weeks sometimes and then all the favourite stuff’s gone....So what's left? So it's usually like soups and pastas [with] some kind of pasta sauce and all your staple stuff that is always in the cupboard. That's kind of the last week [that] you get those kind of things. That's when your creative cooking comes in.

Some of the participants did not believe in wasting food so ate what was available even though they did not like it. However, some of the participants still had “cravings” for favourite foods which they tried unsuccessfully to satisfy with staple foods or “homemade substitutes”. Sylvia explained, “Yesterday I baked apple squares ‘cause I didn't have enough eggs to make any of the chocolate stuff. So I figured, ok, well sugar is sugar. So I got the sweet [craving] out with that.” However, cravings for favourite foods were not completely satisfied until the next cheque day when the participants could afford to buy exactly what

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4 “I” represents the dialogue of the interviewer.
they craved.

Nine of the participants did not change their eating habits over the course of the month. Reasons for a steady diet were living situation, help from other people, complete reliance on food charity, incremental cheque payments, and conscious budgeting. Several of the women were living with partners or family members, or had friends who helped out with the expenses. Peggy ate the same way because she was totally reliant on food charity for her food. Cheryl received her income assistance cheque in increments so that she was unable to spend all her money at one time. Gail rationed her more expensive foods over the course of the week. Gail explained,

I try to eat a lot of meat. I'll eat meat four days out of the week and then a pasta three days out of the week...stuff like that...or perogies or...you know just macaroni and cheese that night or something. I try to [get] variety so that I'm not dwindling away my food...so that it lasts, right?

4.2.1.3 Strategies to Cope With Low Income

The strategies participants employed to increase their access to food included use of food charity, help from family and friends, and money-saving techniques. The term “food charity” included use of food banks, free communal meals, meal service for persons living with HIV, and any free food or groceries available from community service organizations or churches. Food charity had been used by all the participants to obtain food when they had no money, to help in their budgeting attempts, to avoid adverse consequences when forced by the participant’s partner, and to increase the variety in their diets. For example, Karen said, “When I don’t have any money, I’ll go down [to the food bank] and we’ll get milk and eggs and [a] few little things.” Alice used the food bank with her boyfriend because she was
afraid of violent repercussions if she refused to go with him. Currently two participants were not using food charity. Shirley was reluctant to use food charity because she had stopped using drugs and felt she should be able to budget her money. Shirley described her previous experience of using the food bank and her hesitation to use it now:

When I went to this food bank and I was living with a person who was also into drugs, it seemed kind of like a low kind of thing to do. There were people that hung around Hastings [street] that I felt very uncomfortable [with]. I felt uncomfortable with my addictions [because] I didn't have a choice at that time. I would feel even worse now because I'm in recovery and I don't spend that money on drugs or alcohol anymore. I'm trying you know as best as I can. I don't spend money on anything. I'll go to Value Village [second-hand clothing store] or whatever. And if I had to [go to the food bank] it would just be really bad.

Alice did not need food charity because she was living with her parents.

Organizational factors, children, and substance use resulted in an increased amount of food from food charity, increased food charity use, or a more enjoyable food charity experience. Organizational factors included receiving extra or special foods during holidays or receiving other perceived benefits while accessing food charity. During Christmas and Easter, the organizations often gave away more food or special foods which the participants appreciated. Gail noted, “Once in while [the food bank will] have a little surprise, you know if it’s Easter or something. [They’ll have] a little chocolate bunny or something.” Linda and Janice were able to enjoy other benefits, such as advocacy and social contact if the food bank was located close to other services for persons living with HIV. Food charity use increased when children were put into care. For example, Cheryl attended free lunches put on by a local support organization for women living with HIV because her income assistance payments were reduced when her children were put into care. Participants were
able to get more food if they had children living with them because food was allotted per person in the household. Peggy used her children's identification documents to obtain extra food although her children were in permanent care. Peggy said, "There's two food banks I go to right now but I only get [food] for myself. But like places like the Salvation Army or something like that, I use my kids' [identification documents] [to get extra food]." When the participants were using drugs, they relied exclusively on food charity when they did eat. Other minor reasons for increased food charity use, increased food, or an enjoyable food charity experience were close proximity to the food charity organization, lack of money, the HIV diagnosis, and respect for the organization.

The major factors that hampered or decreased the use of food charity or resulted in a negative food charity experience were organizational factors and poverty. Prominent organizational factors included perceived poor food quality, lineups, and availability. Some participants chose not to take certain foods because of concerns about pesticides, vermin, and food quality. Dayna and Nancy refused to use the food bank or the food line because of poor food quality. For example, Nancy was asked,

I: What's your experience with [food lines]?


I: How many times have you used a food line?

N: As few times as possible. Enough. Enough to know I don't wanna do it anymore.

Participants hated to lineup for service at food charity organizations because of
discomfort, boredom, bad weather, standing in line, and the time involved in accessing the 
services. Sylvia, Janice, and Cheryl were uncomfortable with the other persons in the 
lineups because they felt no kinship with them, were afraid of them, or saw other sicker 
persons who reminded them of their own HIV status. For example, Sylvia explained,

I mean I know everybody that's there [at the food bank] is in 
the same situation that you are but it's still a bit humiliating. 
And it's kind of annoying cause you have to stand in line for 
so long. It's not things that I would probably, normally buy 
anyway, but if it's an option between starving and having this 
stuff, I'll take that stuff. So it's ok, but sometimes I don't feel 
all that safe because a lot of the people that go are street drug 
users and stuff and I'm always a little leery that someone's 
going to try to roll me outside of the door or something to take 
your money or take your groceries or something. I never feel 
completely safe when I'm there. So I usually hang out at [the 
support network for women living with HIV] until it's over 
and then go home. Cause I always feel safe there. But as 
soon as I get into that lineup and see [the other people], it's 
also a big reminder of how sick you can get.

Nancy and Janice found the lineups boring and had no patience to wait. Cheryl found it 
uncomfortable to stand in line when the weather was bad. Linda had trouble waiting in line 
because she was fatigued from the HIV and not eating well. Lineups were also time-
consuming because of the number of people accessing services. Two of the participants 
either left the lineup before they could access services or chose to use food charity when 
there was no lineup. If the participant chose to access food charity on an alternative day, 
less food was available to them.

The third major organizational factor negatively affecting food charity use was 
availability in terms of hours of service and proximity. Linda and Cheryl were limited in 
their use of food charity because of limited hours of service. Nancy noted that there were no 
food lines where she lived. Other minor organizational factors were not liking the available
foods, resentment of the volunteers that worked there, and inability to get extra food if the organization was aware that the participant’s children were in care.

While lack of money for food was a strong motivator for food charity use, other aspects of poverty also reduced food charity use, resulted in a negative food charity experience, or limited the amount of food a participant received. Stigma, transportation difficulties, and lack of cooking facilities were the main factors negatively affecting food charity use. Because of the associated stigma, participants felt uncomfortable and embarrassed when they had to use food charity. Shirley noted, “It’s just sad knowing that you have to do that, that you have to go and line up at a food bank.” Participants would avoid using food charity or consciously reduce the amount of groceries that they carried home due to transportation difficulties in handling heavy groceries. As Sylvia explained,

S: It's pretty heavy a lot of the time. Like sometimes they have big things like boxes of cereal and things like that and that can get quite heavy....Lots of canned things and stuff...So I can barely get it off the ground sometimes but I always manage to get it home, somehow or other. One arm might be a little longer than the other one by the time I get home but I usually get a seat on the bus...THAT time of day.

I: Do you ever consciously like restrict how much you take so that you can carry it....if you're tired?

S: Sometimes.

Lack of cooking facilities reduced the amount of food that was used by one of the participants. Linda was unable to cook the eggs and potatoes she got from food charity so she sold them to buy other foods that were soft to chew and did not require cooking. Linda said,

I get all the milk and eggs and stuff [from the food bank]. There’s guys in the building that [will] buy the eggs and then I can go buy a muffin or cereal. But I’d rather cook the eggs
Other minor factors negatively affecting food charity use or experience were personal and interpersonal factors. Personal factors included lack of need, weighing the pros and cons of using food charity, having to volunteer the use of a car so other women could get to the food bank, food allergies which restricted available foods, and lack of knowledge about food bank eligibility. Interpersonal factors included social contact at the food charity and family conflict which barred family members from using the food charity.

The second major strategy used by the participants to cope with low income was help from friends, relatives, or partners in the form of money for food or food. Sylvia said, "When I was first diagnosed and couldn't go back to work, there just was no money. So my cupboard was a lot emptier then and I relied a lot on the food bank. Friends that would have me over for dinner and bring over little care packages and stuff like that so that's what kind of got me through that time."

Other money-saving strategies were shopping strategies such as buying in season or in bulk, checking sales flyers, using sales coupons, making foods from scratch, and running a tab.

Although most participants were using food charity and other money-saving techniques, employing these strategies to cope was still ineffective in ensuring an adequate and personally-acceptable food supply. Linda noted that she did not have enough to eat over the course of the month even with the food she got from the HIV food bank.

### 4.2.2 Other Problems Associated With Poverty

In addition to lacking sufficient money to purchase personally-acceptable foods,
some participants were unable to afford or keep adequate housing. Related to inadequate housing were insufficient cooking facilities, inadequate food storage, and vermin.

4.2.2.1 Lack of Cooking and Storage Facilities and Vermin

Three of the participants lacked adequate cooking or storage facilities. Linda was perhaps the most extreme example of lack of cooking facilities. Linda noted that her major food and nutrition concern was,

Just being able to cook. I just got on the Ensure® and I've put on weight but they only did it for 3 months. So I know as soon as it stops I'll lose weight again 'cause I have bad teeth from the drug abuse? But if I could cook, I know I could maintain my weight. So my most frustrating issue is lack of cooking facilities.

Linda lived in a hotel room with a toaster as her only appliance. She did not eat meals but survived on foods that were quick to prepare and not necessarily healthful. She frequently did not have enough to eat because she could not cook the foods she obtained from the food bank. Ironically, she had a can opener, but no cooking facilities to reheat canned food.

Nancy lacked adequate cooking utensils because they were stolen while she was incarcerated. Nancy said,

N: I'm having quite a difficult time because this is the first time that I've lived on my own. I don't have household items.

I: What do you mean by household items?

N: You know, dishes, pots, pans? Tea towels, linens, household essentials.

I: [Why] don't [you] have those?

N: I've lost them. I was incarcerated for a while. All my stuff was stolen out of my storage locker. Just shit happens. Life happens.
Sylvia tended to waste food because she lacked adequate freezer storage.

Some living situations improved the participants’ access to cooking and storage facilities. Linda practiced her cooking skills when she visited her mother and children. Likewise, Janice found that she had access to cooking and storage facilities while living in a transition house. However, she worried about having adequate cooking and storage facilities when she moved out. Nancy shared utensils with her landlady and with her uncle when she visited him.

Finally, five participants talked about having problems with vermin and three had had to waste food. Peggy, for example, had discarded a box of crackers that were infested with insects. Three factors alleviated the problem of vermin: sealing foods well, maintaining cleanliness, and living in a co-op where pest-related costs were covered such as wasted food costs.

4.2.2.2 Lack of Transportation

Transportation was the second source of poverty-related food problems for the participants. Eleven of the participants relied on public transit which limited the amount of groceries that could be carried home. Karen described how she shopped more frequently and spent more money when she used the bus, however, shopping less frequently by cab was still burdensome.

When I [use the bus], I'll go and then wind up spending more than I should cause I'll go and just buy a few things. [I buy] as much as I can carry...go back and buy a few more things the next day and [I found that] that didn't work. So the last time I went, I guess I picked a really bad day to go. It was cheque issue day so I was gonna take a cab because I bought the whole two weeks worth [of groceries]. Cause [the next time,
my roommate] buys again. So there was quite a bit and I was waiting outside the store for half an hour for the cab to show up. Then I had to get the cab driver to help me bring [the groceries] upstairs to my apartment because there was too much. I couldn't carry it all. Well it was just lovely.

Major strategies that the participants used to alleviate the burden of public transit included reducing reliance on public transit or facilitating the grocery shopping experience when using transit. Five participants used other forms of transportation to reduce their dependence on public transit: bike, car, sharing a car, and walking. Minor factors that reduced the need for public transit were shopping at closer stores and scheduling more than one appointment on the same day so that transit was used less frequently. Three of the participants facilitated an easier transit experience by soliciting help from friends, roommates, or significant others in carrying the groceries. Karen said,

When I was going with my friend before she started having all these problems, I was going [to the food bank] just about every week. Even if I had to go somewhere after, she'd just take the stuff home in her car and then drop it off at my place the next time she picked me up. So that worked out ok.

Reducing the cost of transit was a minor factor improving access to transportation. Three participants shared the cost of a cab, retrieved discarded bus transfers, or had applied for and received a cheaper yearly bus pass.

Major barriers or factors providing a negative transit experience or reduced use of public transit were poverty, substance use, and chaotic lifestyle. Three of the participants were unable to afford bus fare and one of the participants had difficulty getting a bus pass. Sylvia did not have enough money for transportation. Sylvia said,

I mean it really got to a point where [I] was choosing whether I was going to go to all my appointments or whether I was
gonna eat. Because you've only got 60 dollars to work with and if you have to pay 54 [dollars] for a bus pass, that doesn't really leave you with much for food.

Linda had had to wait for a letter from her doctor recommending that she get a bus pass because she was not eligible for one on her level of income assistance. Substance use was also a barrier to transportation if money allocated to transportation was spent on drugs. Janice was asked,

I: Is that a monthly [bus] pass you get?

J: I don't get the bus pass though.

I: So you take that money and spend it on something else?

J: Well I was spending it on dope.

Associated with poverty and substance use were the chaotic lifestyles of the participants. Two of the participants had lost their bus pass application forms because they were stolen or misplaced. Gail wanted to ensure the safety of her new accommodations before the application form could be sent to her. Gail said,

G: When I lived on Wall Street, my place was broken into and my bus pass was stolen. So I have to phone today about that. Had to wait until I got some cash, then I can get it back. So I've been just spending [my own] money [for] the bus which is really not a good thing. Which is really gonna cut me short...

I: So in terms of even waiting to ask about that bus pass for you, what's been the delay there? I'm thinking since you've been clean this past month?

G: No money. It costs like $5 to get it done. No address to get it sent to. I had to make sure that I had a safe place and that I REALLY wanted [my address] to be there.....I have to have my own sense of "I live here". This is MY place.
Other minor factors contributing to reduced public transit use or a negative transportation experience were logistical factors, personal factors, and HIV-related factors. Logistical factors included carrying heavy groceries by bus, the time involved in using public transit, and waiting for the bus in bad weather. Personal factors comprised lack of awareness of the availability of free transit tickets, physical disability, fear of sickness while using public transit, and multiple connections when commuting. HIV-related factors included nausea experienced on transit after taking HIV medications.

4.2.2.3 Dental Concerns

For four participants, poverty, substance use, use of HIV medications, violence, and personal factors had resulted in dental problems that limited the intakes of hard foods such as fresh fruits and vegetables, meat, and nuts. Dental problems were exacerbated in poverty because of insufficient dental care and lack of cooking facilities. Chris said,

I have no teeth on the bottom. I had oral surgery and they couldn't fit a denture in. I had an infection and then they took some more bone out to try to fit a denture. Then the Ministry decided to say "oh you can't have another denture now". So for 2 years now I've been without bottom teeth.

Linda’s eligibility for dental care was related to the time she spent on income assistance. Lack of cooking facilities exacerbated Linda’s dental problems because she could not cook the eggs she obtained from the food bank. She sold the eggs instead, and used the money to buy less healthy but softer, sweet foods, such as muffins.

I think that's why I'm so wired on those muffins because I CAN chew without my teeth hurting...cause they're so soft....But if I had eggs or if I had a pot and a hotplate that I could boil soft-boiled eggs and make a sandwich...[I could eat that.]
Substance use produced strong cravings in the participants for sweet foods and further deteriorated dental health. Some of the HIV medications made the teeth more brittle and prone to breakage. Violence resulted in loss of teeth. Sylvia ground her teeth at night which contributed to her tooth problems. Strategies used to improve intake included cooking foods, shredding foods, or choosing softer foods to eat.

4.2.3 Summary of Poverty-Related Food Problems

In summary, participants did not have enough money to eat because their income assistance payments were insufficient and, with drug use, money was spent on drugs, not food. The participants' sense of poverty was increased by certain living and family situations and lack of cooking skills. Conversely, sense of poverty was decreased by the HIV diagnosis, presence of children, and casual work. For some participants, eating habits changed over the course of the month from favourite foods at cheque time to more personally unacceptable foods just before the monthly cheque was received. Most of the participants were able to maintain their eating habits throughout the month because of living situation, help from other people, complete reliance on food charity, incremental cheque payments, and attempts to budget. The participants tried to cope with their circumstances by using food charity, getting food or money for food from other people, and other money-saving strategies. Other poverty-related food issues were housing problems such as lack of cooking and storage facilities, vermin, lack of transportation, and dental problems.

4.3 Body Weight and Other Body Image Concerns

Weight changes and body image concerns, the second major food and nutrition concern, were specifically identified by five participants. Most of the other participants also
discussed weight-related issues. Concerns were expressed about weight loss, weight gain, and body shape changes. Most participants had experienced at least one cycle of weight loss and weight gain with weight changes up to 100 lbs. Alice explained her weight loss/weight gain cycle with drugs, “It all just seemed to be drug related. If I was on the drugs, I would totally lose weight and then I'd gain in recovery.” Weight changes resulted from lifestyle or health changes. The women’s feelings about these weight and body shape changes were both shaped by and contradicted the dominant discourse about women and body weight. Concurrently, participants were influenced by concerns about their HIV and poverty.

4.3.1 Weight Loss

Major reasons for weight loss were substance use, HIV-related factors, dieting, and living situation. Substances used included cocaine, heroin, and/or alcohol. Substance use from heroin and/or cocaine was the main reason for weight loss in eight participants. When these drugs were used, participants had no appetite, did not eat, and lost weight. Weight losses tended to be rapid and large (from 7 to approximately 100 lbs.) and in most cases, left the participants severely underweight. Cheryl described her weight loss with drug use, “I was smoking the coke and that was making me not eat....I was just losing lots of weight.” Two participants that had used drugs did not lose weight. Linda’s drug use, however, did allow her to maintain her low weight of 107 lbs. Chris only used drugs recreationally and they did not affect her weight.

Although seven participants either did not note or report weight changes due to HIV, six participants discussed HIV-related causes for weight loss including weight loss due to the virus, depression and stress due to the HIV diagnosis, and the HIV medications. Weight losses ranged from 2-78 lbs. Weight loss due to the virus resulted from contracting the
virus, secondary infections, and unexplained weight loss attributed to the HIV. When Sylvia contracted the virus, she lost weight. Sylvia said, “When I was originally exposed, I dropped about 30 lbs. in about a month.” Depression and stress from the diagnosis caused a lack of appetite which led to lower food intake and weight loss. Rain increased her activity level and lost a couple of pounds when she chose to become more involved with group activities as a result of her stress in dealing with her diagnosis. Because she had other people who were counting on her, she could not afford to stay depressed. Alice had had her HIV medications changed and was having difficulty adjusting her eating to them.

For the longest time I've just...been maintaining [my weight] at 105 [lbs.]....Then since starting this medication [with]....all these eating guidelines, I was 98 [lbs.]

Alice and Janice also found that they had difficulty gaining weight so that their usual body weights decreased over time.

Three of the participants had limited their intakes in order to lose weight. Weight loss ranged from 4-12 lbs. They were concerned about weight gain because they were normally thinner or were worried about the stigma of obesity.

Living situation compounded Alice’s difficulty in eating for her HIV medications and resulted in a weight loss of 9 lbs. Alice had moved back home with her parents. Meal times were determined by Alice’s mother but Alice found that the meal times were not suited to her HIV medications. As well as maintaining a low-fat diet for her husband, Alice’s mother was also very weight-conscious herself. Alice’s mother’s thinness was a reminder to Alice to watch her own figure. Alice felt uncomfortable eating the higher fat foods she needed in front of her mother because her mother discouraged them. Alice explained,
I admit if I was to get up and to start frying myself bacon and eggs, there would be a thought: what must my mom think that I'm having bacon and eggs? I mean it would be there. So there you go! Or [if] I'm having two eggs, she's gonna think, you know, you don't have two eggs!

Although she was eager to buy low-fat foods for Alice, Alice’s mother was reluctant to buy the higher fat foods that Alice needed.

Other minor reasons for weight loss included loss of children into care and personal factors such as eating healthier, menstrual period fluctuations, not liking the food in hospital, stress, and being busy with school.

### 4.3.2 Weight Gain

The main reasons for weight gain were substance use-related reasons, HIV-related reasons, taking nutritional supplements such as Ensure® or Boost®, and personal factors such as healthy eating. Substance use-related reasons for weight gain included cessation of cocaine, heroin, alcohol, or tobacco, or using marijuana or alcohol. Eight participants regained the weight that they had lost when they were using drugs. Participants experienced increases in appetite, intake, and moderate and rapid weight gains (from 8 to 26 lbs.) which may or may not have resulted in obesity. Alice talked about her weight gain in the recovery house:

I basically went from not eating at all [when I was using drugs], you know to eating. Especially in the recovery house. I remember I gained weight rather rapidly there 'cause we ate a lot at the recovery house. Probably the most I ever ate in my life was at that time.

Weight gain was facilitated by residential drug rehabilitation because of structured mealtimes and an abundance of food. Cessation of alcohol and tobacco also resulted in
weight gain. Karen gained 40 lbs. when she stopped using alcohol and gained 15 lbs. when she quit smoking. As with weight loss, Chris used drugs only rarely and they did not affect her weight.

Contrary to cessation of substance use, using alcohol or marijuana also resulted in weight gain. Peggy said, "On booze, I weighed a lot. I weighed about 250-260 lbs."

Alcohol seemed to offset weight loss that resulted from hard drug use. For example, Peggy and Cheryl both gained weight using alcohol, up to 100 lbs., but Peggy was also using hard drugs at the same time. Cheryl also found that she gained weight when she used marijuana.

Six participants experienced weight gain ranging from 8 to 70 lbs. for HIV-related reasons including anticipated wasting or concerns about thinness in future, depression, starting new HIV medications, recovery from illness, and the HIV infection. For example, Nancy gained about 60 lbs. to prepare for anticipated wasting in future.

I always did have a very nice figure and now I'm overweight, I don't like [it]. I also over-reacted when I found out that I had gone through all that body wasting and thought well I'll just pack on a bunch of extra [lbs.] for the next time.

Rain was extremely depressed over her diagnosis, ate more to comfort herself, and gained 30 lbs. When Alice started her HIV medications, she was able to gain about 25-35 lbs. Sylvia gained weight after recovering from her initial flu-like symptoms from acute HIV infection. Chris gained 70 lbs. when she was diagnosed because she felt her body was in shock and she was holding onto the weight.

Four participants gained weight in a range of 10 to 40 lbs. when using a nutritional supplement such as Ensure® or Boost®. Linda spoke of her weight gain with Ensure®:

"Yeah I've only been on the Ensure® [for] two months and I've gained. I weighed 107 [lbs.]

87
for a long, long, long time and now I'm 124 [lbs.]...So I gained 17 lbs. in two months.”

Weight gain tended to be easy and quick.

Healthy eating allowed three participants to gain 5 to 20 lbs. by eating regularly and reducing intake of junk food. Other minor reasons for weight gain included other personal factors such as liking the food when out of hospital, unhealthy eating, aging, menstrual period fluctuations, wanting to gain weight to be healthier, being immobilized in hospital, poverty, and living with children.

### 4.3.3 Body Shape Changes

Five of the women noted body shape changes due to the HIV (medications or virus) or due to weight changes. Body shape changes that were HIV-related included thinner arms, thinner face, thinner thighs, bigger thighs, and smaller chest. Changes resulting from weight loss included smaller chest and thinner arms. Body shape changes due to weight gain included bigger breasts, rounder face, and bigger stomach. Alice noted, “it seems that I always gain weight in my stomach. That’s where it goes.”

### 4.3.4 Participants’ Feelings About Weight and Body Shape Changes

Participants viewed weight and body shape changes as negative or positive. Many of these perceptions were reflective of the dominant cultural discourse regarding ideal female bodies, although some perceptions were in opposition to this discourse. HIV and poverty-related concerns also shaped some participants’ feelings about weight and body shape changes.
4.3.4.1 Dominant Weight Discourse

Nine of 13 participants were influenced by the “dominant weight discourse”. The dominant weight discourse that promotes a thin body for women through dieting and exercise is promulgated through the media and social interactions (Hesse-Biber, 1996, p. 10). This discourse was manifested in the participants’ comments about weight such as having an ideal body weight, wanting to be thinner, not wanting to gain weight, being unhappy if overweight, wanting to have a certain body shape, feeling “fat”, and being stereotyped if heavier. Three participants had a thinner ideal weight than recommended to them by their health professionals. Nancy described her ideal body shape:

N: You know I don't think that I'm really obese or really ugly but I prefer to be thinner and more proportioned and more balanced in my appearance.

I: What does proportion or balance mean for you?

N: [Having] a good figure.

I: How would you define that?

N: Barbie-doll figure..... To look good. To look like I don't have excess fat. To be in good firm muscle tone.

The dominant discourse was also seen in responses to questions about hypothetical weight changes such as “how would you feel if you lost or gained 10 lbs.?”. Perceptions of hypothetical weight loss were positive if the reason for the weight loss was known. For example, Karen was asked how she would feel if she lost 10 lbs.: “Well, if I just lost [the pounds] out of nowhere, I’d be kinda worried. But if I knew that I was dieting and exercising and trying to lose it in a healthy way, then that would be ok.” Perceptions of hypothetical weight gain were negative because the participants felt they would be less
attractive, less comfortable with the extra weight, and stigmatized if heavier. Stigma from excess weight was seen to be additive to the stigma of living with HIV. Sylvia explained,

The biggest thing that happened to me when I was diagnosed is I felt very undesirable all of a sudden. Like nobody was going to find you attractive anymore and nobody was going to think that you’re sexy or anything like that. So to add some weight on to that sort of helps to make you think that way. More because the bigger you get, the less attractive that you usually feel. So I’m ok with how I am now but I wouldn’t want to all of sudden put on 50 lbs. or something. ‘Cause then you’d start to go "oh oh!" I don't think I want THAT!

Hypothetical weight gain was acceptable if exercise was combined with the weight gain.

From the perspective of the dominant discourse, actual weight loss was viewed positively and actual weight gain was viewed negatively regardless of the reason for the weight change. Seven participants were pleased with weight loss or with body shape changes that resulted in thinner body parts. Positive perceptions of weight loss that fit the dominant discourse were associated with the context of substance use, low or high usual body weight, and family influence. As mentioned previously, when the participants lost weight from hard drug use, they lost large amounts of weight and became underweight. Within the context of substance use, some participants felt that they looked better than when their weight was normal. For example, Alice was very thin when she was using drugs and felt she looked good. Despite comments from her friends on her extreme thinness, she was unable to “see” herself as being too thin. This body image distortion seemed to be fostered by the substance use environment. For example, Linda was asked how she felt she looked when she was using cocaine:

I thought I looked fine but then I was around other coke addicts. We all looked the same. Gaunt, you know, deathly pale. So I thought I just looked normal….Then I got myself
out of that environment and people [said] "hey you’re kinda thin." And I realized they were right.

For participants who were normally thin and had experienced weight gain, weight loss was a positive experience because they were uncomfortable with the extra weight. For example, Nancy lost weight when she was using drugs and felt great about it because she didn’t like being overweight:

N: I was living in the Downtown Eastside but I was not eating that well. And I thought, “oh great! I’m losing weight. FINALLY!”

I: Why did you feel good about that weight loss?

N: Cause I don’t like being overweight. I don’t like it at all. I feel more comfortable around 120, 125 lbs.

Weight loss and thinner body shape changes were positive if the participant was heavier. Sylvia who was heavier liked the thinner arms, legs, and face that she was experiencing. Sylvia said, “I have no problem with [the changes]. If I could just get rid of some of my stomach, I’d be happy.” Alice’s perception of her weight loss was influenced by her mother’s own weight preoccupation and Alice became accepting of her lower usual body weight over time. Alice said,

When I was around the recovery house, I got used to seeing a lot of people heavier whereas [now] I seem to be surrounded more by my mom or that thinness thinking. So you sorta get into that mentality again [of being thin].

Numerous negative comments about weight gain and larger body shape changes also reflected the dominant body weight discourse and were influenced by low usual body weight and the stigma of obesity. Seven participants experienced weight gain negatively because
they were normally thinner and were uncomfortable with the extra weight. For example,
Dayna said, “[I] just don’t like the way I look at that weight. I’m not happy with the way I
look. And I’ve never weighed that much so it’s just something I’m not used to.” Likewise,
body parts that became bigger with weight gain were perceived negatively. Linda was
unhappy that her face was rounder than she was used to when she was thinner. Some of the
participants experienced panic and fear that they would not be able to control weight gain.
For example, Alice experienced panic when she gained weight and was close to her “ideal”
body weight.

A: I’m back to wanting to be 110 [lbs.] but I’m also aware that as I get up there I’ll start getting into fear again as well.

I: What’s that fear about?

A: Fear that maybe I will just keep gaining and keep gaining or you know...maybe I'll lose control of it and you know get too big...and then have a weight problem the other way.

Shirley had limited her food intake to prevent further weight gain when she stopped using
drugs because of the stigma of obesity and her concerns about the impact of extra weight on
her low self-esteem.

Because of the discomfort with weight gain, five participants wanted to lose weight.
Strategies for losing weight included healthy eating with or without exercise, avoiding
unhealthy foods such as junk food, and eating less food. Although Janice was not trying to
lose weight, she acknowledged that using drugs would be one method of losing weight, “if I
gain [a] few pounds, then in my mind I think I should go on a bender so I’ll lose it.....Expensive diet, though, I might add.” Barriers to losing weight were poverty because of the inability to purchase expensive diet foods and the availability of cheaper fattening
4.3.4.2 Rejection of Dominant Discourse

In contrast to perceptions of weight and body shape changes that reflected the dominant discourse regarding women's bodies, most participants made general comments about weight or had reactions to weight or body shape changes that either did not support or were in opposition to this discourse. Participants were either unaware of the dominant discourse and tapped into other minor discourses or were aware of and opposed the dominant discourse on women and body weight. For example, three participants who were Aboriginal and not a part of the dominant culture made general comments about weight such as being accepting of a higher weight, wanting to gain weight, or being resistant to weight loss. For example, Peggy would never have gone on a diet because she "[liked] her food too much now". Sylvia and Chris, conversely, were aware of the dominant discourse but rejected it in general comments about weight because of age, family weight concerns, or time. Shirley was more accepting of her heavier weight now because of her age. Family weight concerns drove Sylvia to reject the cultural weight discourse when she refused to diet and accepted her own larger size. Sylvia said,

I'd watched my mom diet her whole life and I just thought that is not for me. She's not happy whether she's skinny or fat so it doesn't make any difference. That's not what the problem is. So I figured well, I can't do anything about [it] today. This is something that I'll have to happen over the long run...I've always just thought well you can't please everyone all the time so if you're not going to like me because I weigh more than you do, the hell with you. Who needs you, you know? So, I just kinda figured well, there's no point in sitting here crying because I can't fit in this skirt anymore. I'll just find one that I do fit in and go. But it took a long time to come to terms with that and it took going and buying some clothes that fit and actually admitting to myself "Ok you're not a size 12 anymore."
Quit trying to squeeze into that. You're just making it worse for yourself." So...I bought some clothes and then it was better.

Like the general comments on weight, most perceptions of actual weight and body shape changes that opposed the dominant discourse were from participants who were unaware of the dominant discourse or who tapped into other discourses. Rejection of the dominant cultural weight discourse stemmed from substance use-related factors, medical concerns, ethnicity, time, and changes in specific body parts. Unlike the positive perceptions of weight loss and the negative perceptions of weight gain with dominant weight norms, five of the participants did not have a positive reaction to weight loss with drug use and/or had a positive reaction to weight gain when drug use was discontinued because they felt unhealthy, did not want anyone to see them, were unconcerned about their weight, did not feel that they looked better when thin, or they felt good about their weight gain in drug rehabilitation. For example, Dayna said, "Well it's just unhealthy. Doesn't look nice being 100 lbs. and being 5'6". It's gross. It's like being anorexic." Four participants were influenced by a medical perspective on weight changes and believed it was unhealthy to be too skinny and healthier to be a heavier weight. Alice felt she looked unhealthy now and had "flashes" where she felt she looked healthier when she was heavier. Three Aboriginal participants were less attuned to the dominant discourse and accepted a higher usual body weight and/or refused to diet after weight gain. For example, Cheryl was asked,

I: [What] is the weight you would be the most healthy at?

C: 'Bout a 143. I was like that over the summer. When I came up here for my appointments, I was pretty happy with the weight.

I: So right now you're not at that weight. You're a little bit
Some participants subscribed less to the dominant body weight discourse over time. Sylvia noted that she had come to terms with her larger size because she had been bigger for years. Changes in feminine shape such as smaller breasts from weight loss were perceived negatively whereas larger breasts from weight gain were positive for some participants. Alice and Gail were unhappy that weight loss has resulted in the loss of their feminine busts whereas Linda was pleased that she had “breasts again” after her current weight gain. Using Ensure® to gain weight was a minor factor that resulted in a positive perception of weight gain. Only one participant was aware of the effects of the dominant discourse on her perceptions of weight gain and rejected it when she was in drug rehabilitation. Alice said,

It was interesting cause that's [in rehab] when I first became aware of that whole “mother” influence on my eating....I was eating a lot and thinking, I wouldn't have given myself permission to eat like this before. For the first time in my life, I felt really good with the weight gain. I had a whole new perspective on my weight [and] my body image when I went into that recovery house.

4.3.4.3 HIV Concerns

HIV concerns were another reason why participants' reactions were sometimes in opposition to dominant cultural norms. Some participants were fearful of hypothetical weight loss (i.e. “how would you feel if you lost 10 lbs.?”) if it was unintentional or if they attributed it to the HIV. Peggy felt that if she lost weight now, it would remind her of the movie, “Philadelphia”, and she would think she was getting sick.

Six participants also exhibited concerns about actual weight changes that were linked with their HIV. HIV concerns were manifested when weight loss or thinner body shape
Chapter 4: Participant Interviews

changes were viewed negatively and weight gain was viewed positively. Actual weight loss or thinner body shape changes were perceived negatively when unintentional or unexpected, when associated with HIV, and when comments from others were received. Three participants worried about unintentional weight loss if they could not tie it to substance use or to normal weight loss mechanisms such as dieting and exercise. Sylvia described her feelings when she lost 30 lbs. on contracting the HIV virus,

"It's normal to [go] up [or down] 5 or 10 lbs. throughout a year kind of thing but to drop 30 [lbs.] in a month is not normal. Not to be able to hold any food in at all was not normal for me so that made me a little nervous. You're thinking "oh oh I've got who knows what, cancer or something."

Unexpected weight loss was a concern if the participants were expecting weight gain from methods they had successfully used in the past such as new HIV medications, Ensure®, or increased food intake. For example, Janice wanted to know why she could not gain weight even though she was eating more high-fat foods:

I am losing and I just can't seem to gain [the weight]. I mean that's why I've gone on this ice cream kick to try to gain weight and I can't gain ANYTHING. The weight's just dropping off me now.

Weight loss was also a worry because it was associated with HIV in some of the participants' minds. For example, Peggy was worried about any weight loss she experienced because she attributed it to the HIV. Other people's comments made Alice feel self-conscious about her weight and she increased her intake of food and Ensure®. Thinness was associated with HIV, AIDS, bodily damage, and death. For instance, Gail was asked about her feelings if she lost weight:

I: If...you were to lose 10 lb. without trying, how would you
feel?

G: Devastated...Devastated....Because I don't want to waste or to lose weight. I wanna GAIN....

I: What would be going through your mind in terms of that?

G: I'm dying? I'm going to die? Something's wrong here?

I: You would immediately think of the HIV?

G: Or AIDS.

Weight gain was positive for two of the participants when it was successful and when health professionals were pleased. For example, Alice felt that the AZT (HIV medication) she had used in the past allowed her to gain weight. She felt good about the weight gain at that time because the HIV medication allowed her body to function properly. Alice said,

When I started the AZT and that which was some years ago, I thought that it had really contributed to my weight gain...I felt better about my body cause I was at that real thin state...I had wanted to gain and it just seemed that I was gaining better. I thought, ah! my body's working.

For Gail, gaining weight was positive because she was following advice. Gail commented,

The [most] obvious reason [that I'm happy at a higher weight] is cause [the dietitian] was very happy with me. It matters to me that when I come here I'm not in bad shape. It matters to me that I'm in good shape...and that I've been listening to people...and that they haven't been wasting their breath on me....because I know that [the dietitian and the doctor and the pharmacist].....all care. They wanna see that we're doing well as people...not a dying breed.

Contrary to the meanings of thinness within the context of HIV, being heavier and living with HIV had the opposite meaning. Sylvia who had a larger body size found that she
did not have the expected “wasted” appearance of a person living with HIV. Sylvia said,

The biggest thing that I have is people don't want to believe me about being HIV+, because they look at me and think, “well you're not looking like skeletor or anything. You can't be sick. It must be wrong. There's a mistake somewhere. You're not a drug user, you know, you aren't promiscuous and everything so there's no way. It can't be right.”

Because of their fears of weight loss and attendant HIV concerns, three participants wanted to gain weight. Strategies of gaining weight included nutritional supplements, increased intake of certain foods such as high fat foods and meat, and eating regularly. Participants turned to Ensure® as the major strategy to try and gain weight because they had been successful using it in the past. Janice said, “I was on Ensure® I think it was about a year ago and that's the only time that I've felt really good and gained weight.” Major barriers to gaining weight included poverty and the HIV virus. As mentioned in the section on poverty, some participants lacked adequate cooking and storage facilities, sufficient food at times, or were unable to get Ensure®, and ironically had access to low-calorie foods through food charity. Some participants found it harder to gain weight which they attributed to the HIV. Janice said,

J: I would like to know why I'm not gaining any weight anymore. I thought I knew everything about HIV but this part I don't understand. ‘Cause I'm not really sick yet so I'm not going through the wasting period. So I don't understand why I'm [not] gaining [weight].

I: But you think it has something to do with the HIV?

J: Oh yeah, ‘cause I'm not doing drugs anymore either.

Other minor barriers in the participants’ attempts to gain weight were the dominant body weight discourse, substance use, and physical disability.
As mentioned previously, the participants did not tap into dominant body weight discourse to the exclusion of the other discourses. Participants were sometimes influenced by conflicting discourses and had ambivalent feelings about body weight or body shape changes. For example, Nancy described her feelings about extra weight,

I always did have a very nice figure and now I'm overweight, I don't like [it]. But I also over-reacted when I found out that I had gone through all that body wasting and thought, well, I'll just pack on a bunch of extra [pounds] for the next time [of wasting].

Sylvia also had mixed feelings about the body shape changes that she was experiencing,

My face isn't as round, I don't have as much chin, and my arms are way smaller. That's the biggest place I noticed it...and my legs. So I don't know what that's from but, as long as it keeps going, I don't care. As long as it stops at some point. I don't want to turn into that "Thinner" movie or something.

HIV concerns were rejected with time or supplanted by the dominant body weight discourse in only two participants. For example, Alice found that she became more lax in her desire to gain weight over time. Dayna, who tapped into the cultural weight discourse primarily, would have been happy to lose 10 lbs. even if the weight loss was unintentional.

4.3.4.4 Poverty and other discourses

Not only were the participants affected by the cultural weight discourse and HIV concerns, but they also interpreted weight changes through clothing fit and poverty which affected their ability to afford new clothes. Hypothetical questions about weight changes revealed concerns about clothing fit. For example, Janice and Gail would have been pleased to gain weight because they would fit into their clothes again. Similarly, Dayna would have been happy with weight loss because her clothes would have fit her once more.
Similar concerns were expressed regarding actual weight loss and weight gain. Participants interpreted weight loss positively or negatively depending on clothing fit and the ability to afford new clothes. For example, weight loss was positive when it resulted in a better clothing fit for Rain. However, Sylvia was angry at first about her weight loss because her clothes no longer fit her and it was expensive to replace the items she needed. Sylvia said,

I never gained back all the weight that I lost so I've had to find things. I had to buy all new underwear. There [are] some things like winter coats and things that you can get by with and shoes and everything but my bra size changed and those are ridiculously expensive... so I've been sort of picking things up as I go so it wouldn't be quite the shock now that it was then [when I lost weight before].

Alice had received an inheritance and had splurged on expensive clothing. She was upset that she had lost weight, that the clothes did not fit her as well, and that she had not worn them regularly. Weight gain was also perceived negatively and positively according to clothing fit and the ability to afford new clothes. When Gail gained weight, one of the reasons she was happy was better clothing fit. Gail said, "[At that weight], I looked really great, I felt really healthy, and [my clothes] didn't hang off my body. Those were the three main reasons [I felt good at that weight]." Three of the participants were unhappy with their weight gain because they could not fit into their clothing and could not afford to buy new clothes. Karen said, "I'm really uncomfortable [because] I've gained. I want to lose 10 lbs. because my pants don't fit me properly anymore and stuff. I can't afford to go out and keep buying new clothes." To rectify the lack of clothing resulting from weight gain, Chris was able to borrow clothing from a relative.

Medical concerns also affected Shirley's interpretation of weight gain. Her step-
parents were obese and had diabetes and Shirley feared weight gain because of the complications associated with the diabetes and the obesity. Thinness also had other meanings for the participants that were not associated with the dominant body weight discourse or with HIV concerns such as looking like a man, an injection drug user, or looking unhealthy or anorexic.

4.3.5 Summary of Body Weight and Other Body Image Concerns

Weight changes and body shape changes were the second main food and nutrition concern of the participants. Weight loss was attributed primarily to substance use, HIV-related factors, dieting, and living situation. Major reasons for weight gain included substance use-related factors, HIV-related reasons, nutritional supplements, and personal factors. Body shape changes were attributed to HIV or weight changes.

Perceptions of weight loss, weight gain, and body shape changes were influenced by the dominant body weight discourse for women. However other comments by the participants were in opposition to the same discourse, and reflected HIV, poverty, and other concerns. Within the cultural weight discourse, weight loss and thinner body shape changes were generally viewed positively and weight gain and larger body shape changes were viewed negatively. Weight loss or thinner body shape changes were viewed positively when the participant was using hard drugs, had a low or high usual body weight, or a family weight preoccupation. Negative perceptions of weight gain and larger body shape changes were influenced by low usual body weight and the stigma of obesity. Some of the participants wanted to lose weight because of their discomfort with the extra weight they had gained. Many participants who tapped into the cultural weight discourse at times rejected it when they perceived weight loss negatively and weight gain positively. Other
participants were less aware of the dominant discourse and/or tapped into other discourses. Factors affecting the rejection of the dominant body weight discourse included substance use-related factors, medical concerns, ethnicity, time to get used to weight changes, and change in specific body parts.

HIV concerns were expressed by many participants who also tapped into the cultural weight discourse. With HIV concerns, actual weight loss or thinner body shape changes were viewed negatively when unintentional or unexpected, when associated in the participant’s mind with HIV, and when comments from others were received. Actual weight gain was viewed positively when successful and when health professionals were pleased.

Participants were also affected by poverty when they gained or lost weight. Weight gain or weight loss was positive or negative depending on the fit of the participant’s clothing and her ability to afford new clothes if she needed them. Other minor issues such as medical concerns affected perceptions of weight changes.

4.4 Eating Patterns

4.4.1 Emergence of Different Eating Patterns

When the participants were interviewed, they described what, when, and why they ate. As data analysis was occurring, different patterns of eating and meal planning concerns emerged from the data: “not eating”, “eating”, “healthy/unhealthy eating”, and “eating for HIV”. These eating patterns can be seen to form a continuum ranging at one end from “not eating” to “eating for HIV”. Participants tended not to eat when they were using cocaine and heroin, to start eating when they stopped drug use, to struggle between eating healthy and eating unhealthy when they were off the drugs for some time, and to eat for HIV when
they had absorbed the dietary advice they were given. Some of the participants rejected "eating healthy" or followed an "alternative eating pattern". Each category of eating will be described in more detail below.

4.4.2 Not "Eating"

Not "eating" can be defined as reduced or no food intake. Substance use and being too busy to eat resulted in no food intake whereas poverty, HIV-related factors, children, and substance use also resulted in reduced food intake.

Hard drugs such as cocaine and heroin prevented food intake because of a lack of appetite. Alcohol use also prevented food intake in order to maintain the drinking-related "high". Cheryl’s primary food and nutrition concern was not being able to eat when she was using cocaine.

C: I got no appetite. A lot of people are like that when they’re using cocaine.

I: If I was to be with you on a day when you’re free-basing cocaine, can you describe to me how you would eat?

C: [Nothing]. Sometimes up to 3 days.

The participants ate no food for several days because they had no appetite when they were using drugs and, as mentioned in the poverty section, money that would normally have been spent on food was spent on drugs. Karen did not eat when she was drinking alcohol. Karen said, “For a while I was drinking [heavily]. [Didn’t] want to eat [because] that [would] kill the effects of the alcohol.” Contrary to most of the participants, three of the participants noted that they could eat when using drugs or alcohol. For example, Gail still drank Ensure® while she was using drugs because she liked the taste of it. Cheryl found that if
she was injecting cocaine, she was still able to eat after she had been injecting for a period of
time. Chris used drugs recreationally and found that they did not affect her appetite.

Participants would skip meals when they were too busy to eat, or to prepare food in
advance, or could not afford to buy foods away from home. Chris noted that she sometimes
did not eat anything for 2 days when she was busy. For the participants, being busy entailed
medical appointments, volunteer work, and personal commitments. Sylvia found that she
lacked the organizational skills to plan to eat breakfast. Sylvia said,

It's my own fault for not being more organized and getting
[my breakfast] set up in the morning or the night before or
whatever. You always think, oh no, I'll get up. I'll have lots
of time and then the next thing you know it's like, oh my god!
I've got to go!! But I'm not a real morning person at all. Like
to me morning starts about 10 o'clock so I don't usually even
get hungry til about 11. So if I have to be somewhere at 9, the
thought of getting up and cooking you know some toast or
whatever is just not something that even crosses my mind that
early in the day. Glass of water, some pills, [and] out the door
I go.

Other minor reasons for not eating anything were HIV-related factors, loneliness,
living situation, and eating habits. HIV-related factors included lack of appetite and
depression and stress over the diagnosis.

Food intake was decreased because of poverty, HIV-related factors, children and
substance use. Some of the participants did not have enough money for food and had to
reduce their intake. Janice described how she did not have enough to eat when she lived
with her son:

J: We just didn't have enough money to eat cause my rent was
so high.

I: What would you eat?
As described in the previous section on poverty-related food problems, some participants’ food intake was compromised at the end of the month just before the next income assistance cheque was received because the amount of the cheque was insufficient to meet their needs. The HIV diagnosis precipitated poverty for Chris and Sylvia. Sylvia relied on the help of friends in the form of money for food or food to be able to eat.

Living with HIV also resulted in reduced food intakes. Participants ate less due to taste alterations, lack of appetite, and fatigue from their HIV medications. Shirley described her lack of appetite and taste alterations with the HIV medications:

Now that I'm HIV and I'm taking the medication, I still don't feel like eating. If anything, I think I'm a little more fussy. [It’s] suppertime when [partner] is here and he made me a hamburger and I lost my appetite. You know it's once in a blue moon that he'll cook something and that happened to be a hamburger. I [ate] it and I just kinda [got] an awful taste in my mouth. I [figured] if I [had] another bite I [was] gonna be sick. So I think [with] the pills I lose my appetite.

Both the presence and lack of children reduced food intake in some situations. When children were present, the participants preferentially gave up their own food for the sake of their children out of concern for their children’s health. Janice said, “Well I would give [my son] more food because he’s a growing boy.” Lack of children also affected intake through a direct effect on finances and through depression when children were put into care. The amount of income assistance was calculated based on the number of children living with the participant. For example, Cheryl had less money for food when her children were put into care but was also depressed which contributed to her decreased intake.
Not only did substance use prevent food intake but it also reduced food intake. When using hard drugs such as cocaine and heroin, participants would not eat for days at a time. After the participants came down from the drug “high”, they became hungry again but the size of their stomachs would decrease the amount of food they could consume. For example, when Cheryl did try to eat, she noted she “[could] only put a little bit in my stomach. My stomach had shrunk.”

Other minor factors that decreased food intake were depression when eating alone, lack of appetite, idiosyncratic eating practices, being too busy to eat much, the dominant body weight discourse for women, and family weight history. Idiosyncratic eating practices included personal food beliefs such as not believing in eating lunch and not liking a particular food. The dominant weight discourse decreased intake because of concerns about gaining too much weight. Family weight history was related to concerns about health problems associated with obesity and restricting intake to avoid weight gain. Consequences of “not eating” were HIV-related nausea and fatigue, constipation, weight loss or prevention of weight gain, guilt at not being able to eat prepared food, food waste, and discontinuation of HIV medications because they were supposed to be taken with food.

4.4.3 “Eating”

Contrary to the participants’ descriptions of not eating and not eating enough food, there were times when they simply “ate” or ate more of any available food. “Eating” was motivated by substance use-related factors, idiosyncratic eating patterns, HIV-related factors, family or social responsibilities, and social contact. Cessation of hard drugs such as heroin and cocaine was the primary reason for “eating”. When the participants stopped using hard drugs, their appetites returned and they ate because they were hungry. Shirley
noted that when she “came out of detox, [she] was eating like crazy.” In residential drug detoxification programs, food was abundantly available which facilitated large intakes of food. As the participants began to eat regularly, their stomachs stretched allowing consumption of more food. One of the participants spoke of forcing herself to eat, presumably to adjust to eating normally once more. As discussed in weight changes, during this period, they often gained large amounts of weight. Although cessation of substance use triggered “eating”, using drugs also precipitated “eating” for some of the women. Eating was initiated with substance use to prevent an overdose from using intravenous drugs, from using marijuana or from wanting just to have something to eat when drinking alcohol. For example, Cheryl noted, “I only [ate] because I knew you could overdose if you [didn’t] eat.”

For several of the participants who were currently not using drugs, “eating” was triggered by hunger or appreciation of the taste of the food. Five participants noted eating when they were hungry. Dayna noted that she did not decide what she ate, she just got “hungry and [looked] in the cupboard [for whatever was] there.” Peggy ate more food when she was released from hospital because she did not like the food while she was in the hospital.

HIV-related factors motivated “eating” due to symptoms and the HIV diagnosis. “Eating” was precipitated in response to symptoms or “eating” was initiated to prevent symptoms as a result of personal experience. Sylvia ate to prevent symptoms whereas Shirley ate in response to symptoms she experienced. Sylvia said,

> I have to listen to [my body] a lot more closely now. If I feel hungry, I have to eat something. Before I could sort of put it off until I got around to it or until I got home or until I found a store or whatever. Now if I don't [eat], I start feeling nauseous.
Rain increased her food intake when she was diagnosed because she felt it would enable her to stay healthy and to comfort herself. When Sylvia accessed services at an AIDS service organization, she saw other people living with HIV and it reminded her to “keep her shit together” so that she could remain healthy. Sylvia said,

I know whenever I've had dealings with [AIDS service organization], when I leave there, it's just totally depressing. Cause most of the people up there are really sick. It's really an eye opener and you kinda go "oh, that could be me if I'm not careful and don't keep my shit together."

For Sylvia, “keeping the shit together” meant taking her medications and eating in response to symptoms. Sylvia said,

It's like I'm startin’ to feel [a] little weak, now, I gotta go and get something. I think like that. It's really, really easy to fall into a depression when you have this kind of illness. So I have to really keep on top of that.

“Eating” was also facilitated by family or social responsibilities. Several of the participants were prompted to eat when they prepared food for their families or other people. Setting an example at the dinner table for the children was also a prompt to eat. Dayna said, “I sit at the dinner table and even if I’m not hungry, I try to sit there and eat a little bit of something [that] they’re eating just so [my children] can’t say, ‘well you’re not eating so why should we?’”

Social contact decreased feelings of loneliness and isolation and facilitated “eating”. Cheryl noted that her appetite was much better when her children were with her than when they were put into care. Shirley ate more when her partner talked to her at the table than when he did not interact with her:

He's sittin there he's reading his paper and I'm kind of sitting
here and I'll have a bit of my coffee or something like this. So my food will sit there...[But] if we're talking back and forth or something like this, then I [eat] like we do on Saturday mornings.

Other minor cues for “eating” included reminders to eat from other household members, eating to ensure vitamins were absorbed or to prevent bad reactions from taking vitamins on an empty stomach, not wanting to waste food, and wanting to gain weight. Consequences of “eating” were weight gain, prevention or alleviation of HIV-related symptoms, comfort, staying healthy, social education, reduction in food waste, and facilitation of the efficacy of complementary therapies.

4.4.4 “Healthy Eating”/“Unhealthy Eating”

The third main pattern of eating was what I will call “healthy eating/unhealthy eating”. When asked how they ate with their HIV diagnosis in mind, many of the women described their attempts to eat more healthfully. They spoke of eating a diet that followed Canada’s Food Guide, eating a low-fat diet, or eating regularly. Although “healthy eating” was the goal for many of the participants, some participants characterized their actual diets as being “unhealthy”. More than half the participants were trying to eat healthier. For example, Sylvia was trying to eat more vegetables because,

They're good for you. They give you energy [and] lots of vitamins that I would be getting normally instead out of a pill. [They’re] good for your hair, your nails, your teeth, all those things. They're just better for you than some of the things I eat.

“Healthy eating” and “unhealthy eating” were closely related. Characteristics of “healthy eating” included eating the requisite number of servings from the four food groups
in Canada’s Food Guide, eating a balanced diet, eating in moderation, eating to prevent chronic disease or to alleviate health problems, drinking a lot of water, following a heart-smart diet, eating regularly, watching what you ate, and eating a variety of foods. Healthy foods included fruits and vegetables especially fresh ones, dairy products, diet foods, juice, fish, chicken, liverwurst, and turkey. In contrast, snacking, eating out, overcooking foods, skipping meals, and foods eaten when money was scarce were also considered to be a part of “unhealthy eating”. Unhealthy foods were foods that were to be avoided in a “healthy diet” such as chocolate, junk foods such as pop and chips, high-sugar foods, high-fat foods, high-cholesterol foods, comfort foods, convenience foods, leftover substitute foods made to satisfy cravings, caffeine, red meat, desserts, and favourite foods. Red meat was described as both “healthy” and “unhealthy”. For example, Rain and Sylvia felt that an increased intake of meat would be healthier but Karen felt that red meat should be avoided. For example, when talking about red meat Sylvia said, “It helps with the iron. My iron gets really low around my period and stuff. I hate green vegetables so [red meat is] the biggest source of iron.” Whereas Karen said, “Doctors say generally that red meat has high cholesterol or something or it’s too rich or something like that.” Healthy food was felt to be tasteless, boring, filling, expensive, and slimming. Unhealthy food was thought to be tasty, cheap, filling, and fattening.

Because “healthy eating” and “unhealthy eating” were closely related, motivations for “healthy eating” were often barriers for “unhealthy eating”. For example, if the participant was motivated to eat healthfully, she often did not eat unhealthfully. Motivations for “healthy eating” included HIV-related factors, general concerns about eating more healthfully, comments or actions of other persons, cessation of drug use, and living situation.
HIV-related factors included eating healthfully for the HIV and having another HIV+ family member. As mentioned previously, one of the primary reasons for “healthy eating” was the desire to eat well for the HIV. When asked how they ate for their HIV, the majority of the participants described their efforts to eat more “healthfully” or noted one or more of the characteristics of “healthy eating”. Linda described her attempts to eat healthier for her HIV:

I: How do you feel you should be eating for your HIV?
L: Well balanced.
I: Can you tell me what that means to you?
L: Your basic food groups and...a lot more fresh vegetables and fruit.

The HIV diagnosis was also a trigger for Nancy to eat more healthfully:

I: How different would you say your eating is now compared to before your diagnosis?
N: Well, it's more consistent. I always have my cereal and vitamins first thing in the morning to start the day. I eat at more regular intervals, like regular hours.
I: Why is [it] that you're eating more consistently now?
N: Because I would really like to stay healthy. Because I'm taking responsibility for my healthcare. I feel that I am, as much responsibility as I can. I want to feel good and I want to feel healthy as long as possible and I wanna feel young as long as possible.

Because Cheryl’s son was HIV+, Cheryl tried to ensure that the rest of the family ate healthfully. Cheryl said, “I have a son that’s [HIV]-positive so we made sure the eating habits were pretty good. So everybody would eat what he ate.”
Not only were the participants concerned about eating healthfully for their HIV but efforts to eat healthfully also appeared in general discussions about food. For example, Nancy described how she decided what to eat, “I try and eat a balanced diet. Like there's [the] Canadian Food Guide. You know, five vegetables and fruits and seven servings of grains and three ounces of protein [a] couple of times a day.” Awareness of healthy eating guidelines tended to be unconscious as Dayna noted, “It's just knowledge and stuff. You hear it on TV and that. It's just common knowledge to eat vegetables and fruit and stuff that are good for you than to eat junk.”

“Healthy eating” was also facilitated by the comments and actions of family members and friends. Comments were either suggestive of what to eat or critical of current diet. Family members helped introduce variety into the meals by preparing food for the participant or the participant got positive feedback for her cooking skills. This encouragement prompted a concern about food and nutrition. Karen was encouraged by her roommate to buy foods that were healthy for her. Karen said,

K: I find I'm having a lot more freedom of my choices like what I want I mean. Before when I was in a relationship with this guy, it was all what he wanted which was stuff like meat [and] potatoes. Bunch of stuff I don't even like, night after night. No vegetables, no fruit, no tuna, no fish, nothing like that so....

I: How does your current roommate influence what you eat?

K: He doesn't eat fish either but he tells me buy it, right?....[He says to me], buy it for yourself, buy whatever you [want]. Just cause I don't eat it.....

Cessation of substance use was another factor in promotion of a healthy diet and a barrier to “unhealthy eating”. Participants quit their drug habits, often with the HIV diagnosis, and became committed to living a healthier lifestyle. For example, Karen said,
I don't have a hard time eating but I just don't think I eat very healthy. Like right now, I'm really conscious of my health. I don't want cholesterol, I don't want yeast, I don't want anything with fat or anything. This is my focus right now. You know I've given up everything: I don't drink, I don't smoke, I don't do drugs. So I'm basically trying to lead a healthy lifestyle.

Cheryl noted that she decreased her intake of junk foods when she stopped using drugs.

Living situation facilitated “healthy eating” if the participant was living in a transition house, at her parents’ home, or with a partner who had other health concerns. Living in a transition house supported a healthier diet because food costs were shared communally and unhealthier foods were often not purchased. Janice found that healthy foods like salads and vegetables were always purchased in the transition house. Living with parents allowed for a healthier diet because food was prepared for the participants. For example, Alice lived with her parents and felt that her mother cooked healthy meals which Alice ate. Shirley’s concerns with her partner’s health rather than her own, was the prompt for her to learn and practice a “heart-smart diet”. By taking care of her partner, Shirley felt that she was “ok”. Shirley said,

I guess I get the feeling that long as I have [partner] that everything's ok. And that [as] long as I take care of him and things are ok with us, that I really don't need to go down [to the Positive Women's Network].

Other minor factors that motivated “healthy eating” were the desire to lose weight or prevent weight gain, getting information on healthy eating through reading or taking a food course, rejection of unhealthy family eating habits, lack of money for junk foods, trading leftover unhealthy foods, personal factors, children, eating regularly which prevented snacking, and avoiding unhealthy foods such as caffeine because of bad side effects.
Chapter 4: Participant Interviews

Personal factors included liking the taste of healthy foods, listening to what the body needed, responding to general symptoms, and preventing health problems. Consequences of "healthy eating" were better prognosis, better health, and prevention of weight gain as well as weight gain.

Barriers that existed to "healthy eating" were often motivations for "unhealthy eating". The primary barriers to "healthy eating" were HIV-related factors, poverty, substance use-related factors, children, and personal factors. HIV-related factors included fatigue, being too busy to eat well, effects of the HIV medications, fears about weight loss due to HIV, and depression when thinking about eating for HIV. Several of the participants were too fatigued to cook meals for themselves and, as a result, chose convenience foods that required minimal preparation or chose to eat out if they could afford it. Sylvia found that she didn’t have the energy to pre-prepare meals for the times she was fatigued. Sylvia said, "If I'm really burnt out, I don't feel like cooking anything. So I'll eat things like bananas, toast, stuff that takes minimal effort to cook, a can of soup, whatever. That kind of stuff.” Participants were often too busy because of medical appointments to eat meals. They relied on fast foods, junk foods or skipped meals to save time. Chris said,

When I get up, if I have meetings right away or if I have appointments, I won't eat. If I'm at home and I can't figure out something that I want, I have a tendency to do a lot of junk food because it's convenient.

The HIV medications either interfered with the tolerance for certain foods or the scheduling of the HIV medications precluded the ability to eat in a healthy way. Alice questioned her ability to eat healthfully when she had so many eating guidelines to follow for the HIV medications. One participant was eating ice cream to try and gain weight because she was
worried about her weight loss which she attributed to the HIV. Thinking about eating healthy for the diagnosis was depressing for Dayna so she did not attempt to eat well for her HIV. Dayna said,

D: I'm supposed to eat better [for the HIV]. That's what they say. You're supposed to eat a bit more nutritiously and regular and take certain vitamins and stuff...but I don't really think about it. I guess I don't remind myself daily that I'm HIV so I don't really think about "well I better eat this because I'm sick". I just eat.

I: ...Why is that?

D: It's just something that I don't wake up and [say] "oh today I'm HIV. I'm gonna make sure I eat proper." It's just not very happy to think about everyday.

Poverty also interfered with "healthy eating" and promoted "unhealthy eating" because healthy foods were not affordable but unhealthy foods were. Karen said,

When I go shopping, it's like I have a certain amount of money to spend and the fat-free stuff and the diet products and anything that's good for me seems to cost twice as much as the stuff packed with chemicals and preservatives and fat and stuff that I don't want.

Dental concerns that were related to poverty precluded the consumption of healthy foods such as fresh fruits and vegetables. For example, as mentioned in the poverty section, Linda was unable to chew raw vegetables and could not cook them because she lacked cooking facilities. She ate softer foods such as chocolate chip muffins. Lack of cooking facilities prevented Linda from eating healthy foods such as eggs. Food charity offered foods that Nancy considered were unhealthy such as desserts and candy at holiday times.

Substance use-related factors also motivated "unhealthy eating" and were barriers to "healthy eating" when participants were in detoxification programs as well as when they
were using drugs. Many of the participants noted strong cravings for chocolate and sweet foods when they were detoxing and when they were using drugs. For example, Linda was asked if she experienced food cravings:

Chocolate. Big time. Always. And I guess [it’s] the "junky sweet tooth" as they call it. I don’t know if that’ll ever leave me. I crave sugar a lot...I guess because of the methadone. Cause [with] heroin you crave sugar all the time and methadone’s synthetic heroin basically. I used to take those sugar packets and open up three and just [swallow them] right down. Like [it] makes people sick. I couldn’t do it so much now but I used to.

Nancy noted that her craving for sugar was like a replacement addiction for her previous drug addiction. Unhealthy eating was also facilitated in drug detoxification: Nancy noted that in the 12-step programs she attended, there was an abundance of cakes and other sweet foods.

At times, children were a barrier to eating more healthfully and prompted unhealthy eating. Participants with children received less income assistance when their children were in care and could not afford healthy foods. The dietary needs of the children were put before those of the participants. For example, Dayna tried to ensure that her children’s diets were varied:

I: How do you decide what to cook for your daughter or your son?

D: It depends on what they’ve eaten. I just balance it out. They get...meat, vegetables, and something, like potatoes or pasta. Depends on what they had the day before. If they had cereal for breakfast, they get porridge. If they had porridge, they get eggs. If they had eggs, they get pancakes. I rotate. I have egg day, pancake day, porridge day, that kind of stuff.

I: When they come to visit you, do you make a point of asking them what they’ve had to eat?
D: Yeah.

When children were present, participants were tempted to eat unhealthy foods which were there for the benefit of the children. Nancy said, “When I stayed at the transition house, there were always a lot of ice cream and cookies because of [the] kids and things.”

Major personal factors which were barriers to “healthy eating” and prompted “unhealthy eating” included cravings for unhealthy foods and disliking the taste of healthy foods. Premenstrual syndrome, stress, and fatigue resulted in cravings for unhealthy foods such as chocolate and sugar. For example, Sylvia noted, “Right before [my period] I can always tell when it's coming cause I have an insatiable chocolate craving. The rest of the month, I could take it or leave it. It's always been that way, my whole life.” Several of the participants did not like the taste of such healthy foods as water, yogurt, and vegetables and avoided them. Other minor personal factors that encouraged “unhealthy eating” and discouraged “healthy eating” included eating convenience foods due to insomnia, snacking when eating alone, physical disability which precluded cooking and encouraged consumption of convenience foods or prevented intake of healthy foods, family eating habits, lacking the cooking skills to make an interesting diet, being too lazy to cook, eating junk foods when bored, quitting smoking, eating comfort foods for comfort, choosing unhealthy foods because they were available, allowing consumption of unhealthy foods if the participant exercised, and living situation.

There were positive and negative outcomes from “unhealthy eating”. Positive outcomes were the ability to sleep, comfort, saving time and effort when using convenience foods, facilitating eating when dental concerns were present, and a sense of satiety. Negative outcomes included decreased perception of health, guilt, weight gain or inability to
lose weight, addiction to sweets, exacerbation of dental concerns due to intake of sugary foods, insomnia when eating too much caffeine, and increased poverty when buying fast foods. As mentioned previously, weight gain from intake of unhealthy foods resulted in the need for new clothes which the participants could not afford.

Some of the participants ate in ways that rejected the framework for “healthy eating”. For example, Chris drank regular soda and coffee and had chocolate everyday. Chris said,

Give me sugar. Give me caffeine. I’m not really a coffee drinker but I mean if I’m out, I’ll have coffee and if I have company, I’ll have coffee. I drink tea. I drink at least a pot of tea a day.

She seemed to be aware of “healthy eating” but consciously rejected it and believed in eating foods that may be advocated by alternative practitioners. Peggy was unconcerned about the quality of the foods that she ate from food charity. Her lack of concern about the quality of her diet may have been related to her ongoing substance use. When Peggy was asked how her eating had changed with her HIV diagnosis, she noted that she was eating more food. Peggy can therefore be seen to fit at the “eating/not eating” end of the continuum of eating patterns in her understanding of how to eat for the HIV.

4.4.5 “Eating For HIV”

As mentioned previously, various eating patterns could be determined from the participants’ comments on what, when, and why they ate. When the participants were asked specifically how they ate for their HIV, almost all of the eating patterns on the continuum were considered to be appropriate. As described above, most participants described “healthy eating” when they were asked about eating for their HIV. Some participants,
however, described eating more nutritiously but did not specify what that meant. For example, Karen said,

   Well I think now more than at any time it's important to eat nutritious food, nutritious meals. Not just [to have] something for the sake of eating a meal but to actually think more about what it is...More for my immune system. To have the nutrition and the energy from the food and the vitamins that [that] gives.

Other participants spoke of eating more food, eating in response to symptoms, or eating something. Fewer women, however, were striving to eat more protein and/or more calories for their HIV.

Descriptions of what to eat for the HIV were not consistent. Some of the participants who had espoused the need to eat more nutritiously for their HIV also described how they were just trying to eat, eat more or had made no changes in their eating habits with the diagnosis. For example, Karen, who had described the need to eat more nutritiously, also noted how she was eating since the diagnosis, “Well [my eating is] better ‘cause [before the diagnosis] I'd go all day and then realize, oh yeah [I] forgot something. I didn't eat! Now at least I try to have something.”

As mentioned, a few participants were trying to eat more protein and/or more calories for their HIV. The participants did not use the term “eating for HIV” in their descriptions of what they ate. These participants were following guidelines for an eating pattern that I have categorized as “eating for HIV” which included eating more protein and/or eating more calories, drinking enough water, following food safety guidelines, and/or eating special foods for HIV medications. Eating more protein and/or calories meant eating foods that were foods that were naturally high in protein or energy as well as high-protein,
high-energy nutritional supplements such as Ensure®, Boost®, and CitriSource®. Drinking water was important to prevent some of the side effects of the HIV medications such as kidney stones. Principles of food safety included washing hands, keeping the cooking area clean, cooking foods until well done, boiling water before drinking it, avoiding raw foods, drinking bottled water, refrigerating foods promptly, throwing out food that was outdated, and checking expiry dates. Eating special foods such as low-protein, low-fat foods was sometimes required when taking the HIV medications.

Interestingly, although ten participants were following some food safety guidelines, only six participants were trying to eat more protein and/or more calories. For example, Sylvia said, “I’m supposed to be on a high-protein diet so I should be having some sort of protein everyday.” Nine of the participants had tried or were using nutritional supplements such as Ensure® and Boost®.

The participants were motivated to eat in ways that were congruent with HIV nutrition guidelines for a variety of reasons some of which were not related to their HIV. Factors which motivated “eating for HIV” included personal factors, HIV-related factors, and external factors. Personal factors included liking the taste of foods advocated for HIV, wanting to gain weight, eating habits, and deciding that certain advice made sense motivated “eating for HIV”. Several participants liked the taste of bottled water and Ensure® or other nutritional supplements which facilitated their intake. Gail described how she had Ensure® when she was using drugs, “Those were the first thing I had in the morning. I usually gulped two down in the morning. I just loved those things in the morning. I liked my berry [flavour]. Berry, gotta have ‘em!” Cheryl had used nutritional supplements to gain weight because she was happier and healthier at a heavier weight. Cheryl said,
I try not to drink too much of [Ensure®]. Three a day. I definitely drink one in the morning and sometimes after I've had dinner and there's no dessert, I'll have one. I do that [to try] to gain the weight.

Chris tended to eat the same foods meal after meal and had no worries about food safety because she never had leftovers. Karen followed food safety information because it made sense to her.

HIV-related factors were the primary motivation for “eating for HIV” and included concerns about weight loss, fear of food-borne illness, comments from other persons, the HIV diagnosis, being busy, and secondary infection. Some participants worried about weight loss because of their HIV. For example, Alice was concerned about weight loss and she tried to increase her caloric intake by focussing on high-fat foods. Food safety was followed by some participants because they could not afford to get sick. For example, Linda said,

I check [the expiry dates] a lot because...[at the] food banks a lot of the stuff is JUST expired. I still can't bring myself to eat it so I give it to somebody else like my boyfriend. He'll eat anything...but to me it's very important....I can't afford to get sick.

Linda started taking Ensure® when she received comments on her thinness. Linda said, “Someone said, oh you’re so thin you know if you got really sick you’d have nothing to fight [the infection]. So that was the thing [that got me started on the Ensure®].” The HIV diagnosis triggered food safety concerns and practices for Alice. Cheryl used Ensure® because she found it was convenient when she busy. When Alice developed a yeast infection in her ankle, her fear over her health inspired a desire to comply in the HIV nutrition guidelines. Alice said,
I guess cause all through my life, I've sorta had healthy eating [in] mind. Other than when I did sorta really let go of it and when I started using AZT and they really wanted me to gain [weight]. I went up to 115 [lbs.] I let go and that was one time that I did strive to, you know, really eat for the HIV.

External factors also facilitated "eating for HIV" and included recommendations or prompts to eat for HIV, advocacy from AIDS service organizations, observations of how other persons living with HIV managed on nutritional supplements, and the desire to try a new product. Sylvia described how she learned about how to supplement her diet and get bottled water for her HIV:

My friend who hooked me up with that doctor, gave me the list of all the different places I should go to and one of them was the [HIV] grocery. So that sort of helped to supplement the extra things that I was supposed to be having and then the water as well.

Linda was able to get bottled water through the local AIDS service organization. She also saw how well her brother had gained weight with Ensure® and believed it would be beneficial for herself. Sylvia tried new nutritional supplements when they became available commercially.

Other minor motivators for "eating for HIV" were factors related to substance use, poverty, and the Complementary Health Fund. When using drugs, the participants did not buy food because they did not eat and therefore, did not concern themselves with food safety. Stopping drug use allowed one of the participants to eat more of the foods she needed for her HIV. Poverty-related factors included the availability of nutritional supplements through food charity and the attainment of stable housing which facilitated "eating for HIV". Funding from the Complementary Health Fund, a fund for persons living with HIV to purchase complementary therapies, could be used to purchase bottled water.
Consequences of “eating for HIV” were weight gain, prevention of kidney stones when drinking enough water, and weight loss when trying to eat on a schedule for the HIV medications.

Barriers to “eating for HIV” included, ironically, HIV-related factors, poverty, and living situation. HIV-related factors included lack of information on how to “eat for HIV”, strict HIV medication eating schedules, perception of illness, perceived ability to “eat for HIV”, being busy, and decreased vigilance in “eating for HIV” over time. Although 6 participants encountered barriers to “eating for HIV” due to HIV-related factors, Alice appeared to be most affected because of her stringent eating guidelines for her HIV medications. Several participants lacked information on how to “eat for HIV” because they had lost the information, couldn’t recall what they had been told or read about it, or were unclear on the exact guidelines. Alice said,

I haven't looked at that [HIV nutrition guidelines] thing in ages. I remember getting that guide. Yeah it was symptomatic and asymptomatic. I think a lot of it too is since I moved to my parents, everything is packed, so I don't really know where all that stuff is.

She found it difficult to eat for her HIV medications because of the schedule which was impractical and prevented her goal of weight gain. For example, Alice could not eat any food between two hours before and one hour after taking one of her medications and had to eat low-fat foods with another medication. Alice said,

This medication now has gotten me on such a tight schedule....I feel like my body would like to have a meal at that time, not a low-fat yogurt. Like maybe a slice of pizza or whatever. I don't always feel like I'm doing my health [any good], and yet, I hafta to do that for the medications. But sometimes I wonder what's more necessary for my system, getting the food or feeling really hungry just so I can get the
Alice also found it difficult to eat when she was with friends because they were on “alternative” eating regimes for their HIV medications. She relied more on her sense of illness as an impetus for “eating for HIV”; if she didn’t feel “sick”, she was less concerned about following the guidelines stringently. Alice also found that “eating for HIV” was unrealistic and simply tried to follow Canada’s Food Guide. Gail found it difficult to eat the required number of calories because she was too busy to eat due to medical appointments related to her HIV. Finally, although Alice may have been keen to follow food safety guidelines when she was diagnosed, over time, she became less vigilant. Alice said,

You see I used to boil the water. I went through that really extreme phase and you know now I've sort of eased off. Now and again if I want a rare steak, I'll just go and have it. But it definitely changed with the diagnosis.

Poverty was also a barrier to “eating for HIV” because of the red tape in obtaining nutritional supplements, lack of money, and lack of transportation. The participants also encountered difficulties in obtaining nutritional supplements because they could not afford them and there were complex procedures in obtaining them. Cheryl could not afford Ensure® and had trouble getting it through the dietitian. Cheryl said,

The last [visit with dietitian] they were concerned about my weight so they were trying to get Ensure®. I haven't gotten it yet cause I don't think the social worker got the letter. So I'm gonna bring her a letter up after I leave here. Make sure, hand it right to her face, saying, "I need it".

The participants could not afford high protein foods. Sylvia said,

The only thing that I find is that I usually don’t have enough
money to get things like cheese and meats which is something that I'm supposed to be getting. So I get em when I can and watch for the sales. It's about all you can do......I'm supposed to be having a high-protein diet so I should be having some sort of protein everyday. But I don't necessarily get it everyday.

Lack of transportation prevented Linda from accessing the resources on eating for HIV that she knew were available.

Living situation proved to be a formidable barrier for Alice in her attempts to “eat for HIV”. Alice felt compelled to live with her stepfather and mother because of her guilt over her substance use and her perception that that had worried them in the past. Living with them would ensure that they knew she was all right. She also felt guilty living with them because she was not charged rent. Her stepfather was aging and Alice was concerned about his reaction if she moved out. Alice’s mother did most of the cooking and food shopping. Alice’s stepfather had a heart condition and her mother prepared low-fat foods for him which Alice considered were healthy. Alice needed to eat low-fat foods for her HIV medications but found that the foods that her mother prepared were not low-fat enough for her medications. At the same time as her mother prepared low-fat foods for her stepfather, Alice’s mother also prepared many baked goods but Alice did not eat them because she was not fond of them. Her mother was very concerned about diet, body weight and maintained a slim figure for herself. Alice’s mother was unwilling to buy the higher fat foods that Alice needed to eat when she was not taking her HIV medications. Alice felt uncomfortable eating higher fat foods in front of her mother because of her mother’s concerns about diet and weight. Mealtimes were also not consistent with the times that Alice needed to eat for her HIV medications. To try and eat at the times she needed to for her HIV medications,
Alice resorted to eating the supper meal away from home. Alice felt that she had no control over her eating habits and was a “child” once again living with her parents. Alice said,

Yeah living with one's parent can get to you at the best of times because now I'm having to change my schedule. I'm not really even quite hungry yet at dinner time. I'd rather really have [dinner] a little bit later and I would probably even make [it] a more rich dinner...so I've been going out for dinner and things like that to friends...I do find sometimes dinner's a little bit too early....I just look forward to living on my own. Just eating when I feel like it. I do have control but I wouldn't feel I could say "Oh you guys go ahead with dinner and I'll make something later." I would feel like I should eat dinner with them or whatever. What are you gonna do, say no?.....I guess I feel like a little kid a lot of the time. Plus because I have put them through worry in the past, I always sorta want them to know that I'm doing ok or whatever.

Other minor barriers to “eating for HIV” were personal factors, dominant weight norms for women, and substance use. Personal factors included not liking the taste of the water, lack of need, and physical disability. Some of the participants did not like the taste of water and did not drink enough of it. Karen did not use nutritional supplements because she did not feel that she needed them. Chris had a problem with her leg and was unable to stand by the stove to cook the high-protein foods that were suitable for “eating for HIV”. Two of the women were resistant to “eating for HIV” because they had gained enough weight or were not sure that gaining weight was necessarily healthy. Nutritional supplements were generally stopped when the participants were using drugs because the participants did not eat. Consequences of not “eating for HIV” were weight loss, symptoms such as fatigue and nausea, and kidney stones.

4.4.6 “Alternative Eating”

Several participants followed eating guidelines similar to those advocated by
alternative practitioners. These guidelines included advocating a vegetarian diet, raw or fresh foods, organic foods, certain vegetables such as onions and garlic because they were beneficial to health, and eating yogurt for intestinal health. Foods to be avoided included yeast, sugar due to yeast infections, pesticides, processed foods, additives, certain vegetables, and meat.

Interest in this alternative eating pattern was triggered by various factors such as an interest in nutrition, fear of yeast infections, and food service work. For example, Karen avoided yeast and sugar because she was afraid of getting a yeast infection. Janice’s concern about processed meats stemmed from her previous work in a nursing home. She was aware that clients had special dietary needs and interpreted that processed meats were bad for her. Alternative eating was facilitated for Chris when she was allowed to carry a tab at a local restaurant that served the foods she preferred. Poverty was a barrier to “eating alternatively” because the participants could not afford foods and/or were unable to chew foods that they felt were beneficial. For example, Chris could not chew the raw foods that she preferred because of dental problems and could not afford the organic foods she needed. Chris said, “If you want to eat healthy, you’ve got to eat organic. These [foods] are all more expensive. You know, real food is more expensive and we can’t buy boxed food on what we make, let alone real food.” “Alternative eating” reduced the variety of personally acceptable foods for the participants.

4.4.7 Summary of Eating Patterns

The eating patterns that the participants followed could be seen to be on a continuum from “not eating” to “eating for HIV”. “Not eating” can be characterized as eating no food or eating less. Eating no food resulted from hard drug use and being busy. Eating less food
occurred with poverty, HIV-related factors, and children. “Eating” occurred when the goal was to eat something or to eat more of any food. Motivations for “eating” were substance use-related factors, idiosyncratic eating patterns, and HIV-related factors.

“Healthy/unhealthy eating” was the third pattern of eating. Many participants spoke of eating more “healthfully” or described one or more of the characteristics of “healthy eating”. “Healthy eating” included following the four food groups and getting the right number of servings from each group, eating fruits and vegetables, and eating regularly. “Eating unhealthy” meant eating foods that were to be avoided with “healthy eating” such as junk foods (chocolate), high-fat and high-sugar foods, convenience foods, and skipping meals. Motivations for “healthy eating” tended to be barriers for “unhealthy eating” and included HIV-related factors such as wanting to eat well for the HIV, general concerns about eating more healthfully, and prompts from other persons. Barriers to “healthy eating” which were also motivations for “unhealthy eating” and included HIV-related factors, poverty, substance use-related factors, children, and personal factors.

The fourth eating pattern was “eating for HIV”. This eating pattern included eating more protein and/or eating more calories, drinking enough water, following food safety guidelines, and/or eating special foods for the HIV medications. Interestingly, most of the participants were aware of food safety guidelines but few of the women were attempting to eat more protein and/or more calories. Motivations for “eating for HIV” included personal factors, HIV-related factors, and external factors. Barriers to “eating for HIV” were also HIV-related factors, poverty, and living situation.

Some of the participants ate “alternatively” and espoused the benefits of vegetarianism, raw and organic foods, and certain vegetables, and yogurt. Foods to be
avoided were pesticides, processed foods, sugar, yeast, certain vegetables, and meat. Poverty was a barrier to “alternative eating” because of perceived cost and poor dental health.

4.5 Complementary Therapies

Complementary therapies included any food- or nutrient-based therapy that was taken orally including vitamins/minerals, herbs or preparations derived from herbs, animal extracts, special diets, and alternative treatments. One objective of the study was to examine the meanings of food- and/or nutrient-based complementary therapies for low-income women living with HIV. The interviews were conducted when funding was available for complementary therapies through the “Complementary Health Fund” (CHF). The fund was set up by the British Columbia Persons With AIDS Society, an AIDS service organization, so that persons living with HIV could be reimbursed for purchased therapies up to a maximum of $100 per month. One of the goals of the study was to learn how low-income women living with HIV chose to use the available funding and how they interpreted the relationship between their health and the use of these therapies.

During the interview process, information was collected about what therapies were used, how information was obtained about complementary therapies, reasons for use of complementary therapies, barriers to using complementary therapies, and efficacy of complementary therapies.

4.5.1 Use of Complementary Therapies

Generally, there was a lack of keen interest in complementary therapies. The participants only discussed their therapy use when asked about it specifically in the
interviews. Three participants were unfamiliar with the term, "complementary therapies". They were familiar with individual therapies such as Chinese herbs, acupuncture, or vitamins but were unfamiliar with the encompassing term for them. For example, Rain was asked,

I: Have you had any experience with complementary therapies?
R: No.
I: Did you ever use them before you were diagnosed?
R: No. I don't even know what it is.
I: Usually complementary therapies are things like, some people try Chinese herbs or they use vitamins?
R: Oh!

Although some participants were unfamiliar with the term, eleven women (85%) were currently using some type of complementary therapy. Types of therapies used ranged widely including vitamins/minerals, plant-based therapies, animal extracts, food-based therapies, and other miscellaneous therapies. The following therapies have been listed in descending popularity of use. Vitamins and minerals used included multivitamins, vitamin C, B vitamins, vitamin E, calcium or calcium plus vitamin D, multiminerals, unspecified vitamins, and zinc. Plant-based therapies that were used included garlic pills, echinacea, Chinese herbs, ginseng, goldenseal, ginkgo biloba, astragalus, comfrey, St. John’s Wort, milk thistle, cayenne pepper, and marijuana. Animal extracts included fish oil, acidophilus, yogurt capsules, and royal jelly. Food-based therapies included the no-yeast diet and the BRAT (bananas, rice, applesauce, toast) diet (Lalari & Cheng, 1992). Other therapies used included alternative therapies that were orally administered such as naturopathic drops and
coenzyme Q10. The amount of money spent per month was variable and ranged from less than $10 to $200 per month.

4.5.2 Sources of Information About Complementary Therapies

The women got information about complementary therapies from the following sources, listed in descending order of popularity: health professionals such as doctors, dietitians, and pharmacists; media such as books, magazines, journals, television, newspapers, pamphlets, and photocopied information; other persons such as friends, family, health food store staff, other persons living with HIV, and grief counsellors; alternative health professionals such as naturopaths, reflexologists, iridologists, and acupuncturists; and other miscellaneous sources such as participation in a clinical trial, the internet, and conferences.

The participants obtained and processed information available to them in different ways. The majority of the women tended to be “receivers” of information about complementary therapies. They would “receive” and follow without question the advice given to them from various sources such as health professionals, friends or family, media, alternative practitioners, AIDS service organizations, health food store staff, and vitamin trial. Dayna, for example, took advice from her fiancé:

My fiancé told me what I should take. The “enchina” [echinacea] or whatever that stuff is called, I was told that was good for colds and flu or something and the vitamin E’s good for your skin and hair and my vitamin C, you’re supposed to have I guess a certain amount a day.

In contrast to these women who simply followed the advice of trusted sources, other participants were active “seekers” of complementary therapy information. They sought out information about complementary therapies on their own by reading books, asking questions
Chapter 4: Participant Interviews

about therapies, and using more than one source of information to make their selection. For example, Nancy described her reasons for using multivitamins:

I’ve been studying nutrition since I was sixteen. From 48 [my age], that’s 32 years. I [have] no formal education in it but anything I could get my hands on related to nutrition, I’ve read and I’ve adjusted and applied it if it made sense.

Some of the participants used “experiential” knowledge to find out what therapies to use by trusting their “bodytalk” or observing the experiences of other persons. For example, Chris said, “I do take different [vitamins] because I’m deficient in different things and I watch my body very very closely.” A few of the participants “processed” the information that they received before they decided to adopt the therapies. They tended to apply what they had learned only if it made sense to them. As Nancy said:

I’m skeptical. I mean it has to make sense. It has to be logical and it has to come from more than one source. Like [if] some hare-brain comes up to me and says that if I eat that calendar I’m gonna be healed from HIV, I’m [probably] gonna do a little research before I eat the calendar.

The manner in which complementary therapies were chosen was not always consistent because some therapies may have been recommended and accepted without question while other therapies were researched before use. For example, Chris took Chinese herbs on her acupuncturist’s recommendation but had no idea what she was taking. Conversely, she made decisions about other therapies after reading, discussing them with health professionals, and judging her personal experience with them. Chris said,

They’ll make a recommendation [for a therapy] and I’ll try it. If I feel better, fine and if I don’t, I say, "ok I’ve tried it long enough, I can't afford it, drop that one." And so, in order for me to start taking it I will have read all the literature. In order for me to continue taking it, means that it was working and I
don't remember what it was for.

4.5.3 Reasons for Using Complementary Therapies

The participants were taking complementary therapies, not only with their HIV status in mind, but for other reasons as well. Major factors influencing the use of complementary therapies were advice from other persons, personal factors, HIV-related factors, and “frameworks” or perspectives including the “good health”, the “alternative”, and the “folk medicine” frameworks. Participants often had multiple reasons for choosing a therapy.

Many participants chose to take complementary therapies based on the advice of health professionals, friends or family, the media, alternative practitioners, persons at AIDS service organizations or health food stores, or followed what was recommended in a vitamin trial. Nancy described why she was taking echinacea: “I have talked to the pharmacist here and she says that [echinacea is] a good thing to use but not to overuse it because it can interfere with the immune system.”

Although recommendations for taking complementary therapies may have been related to living with HIV, many of the women were influenced by personal factors in choosing their therapies. Several of the participants were also interested in taking therapies to prevent minor illnesses such as colds and influenza. Cheryl described why she took vitamin C, “I don’t want to catch everybody’s cold plus [because] of the areas I hang around in. People [are] exposed to TB and stuff.” If the participant had taken therapies before the diagnosis or had grown up taking them, therapies were continued or resumed. For example, Sylvia described how she started taking a multivitamin, “I've always taken one...since I was a kid taking Flintstones...[My mother] always harped on me cause [she] knew I never ate
enough vegetables so [she] figured I better have some vitamins." Chris, Cheryl, and Rain took therapies to increase energy levels. Some participants took certain therapies to improve the quality of their skin or hair or favoured garlic pills over raw garlic to avoid bad breath. Other minor personal factors included preference for familiar therapies that were perceived to be less exotic, availability, enjoying the taste, preferred form of the therapy, physical complaints, body prompts, stress or exhaustion, concerns about memory, and efficacy.

Most of the participants were also taking complementary therapies for HIV-related reasons. The HIV diagnosis prompted four participants to start using therapies or to use different therapies. For example, Chris took different vitamins after she was diagnosed because her doctor said she was deficient in different nutrients. Complementary therapies such as co-enzyme Q10, garlic oil, and astragalus were taken to boost the immune system. Other minor HIV-related reasons for therapy use were concerns about yeast infections, HIV medication-related side effects, and taking vitamins to maintain health or to replenish nutrients that were depleted because of the HIV.

Through data analysis, three different frameworks emerged that guided the choice of complementary therapies for seven of the participants: the “good health”, “alternative”, and “folk medicine” frameworks. About half of the participants were influenced by the “good health” framework which was prompted by concerns about preventing chronic diseases such as osteoporosis, lung cancer, and heart disease, taking vitamins as an insurance for not eating well, and maintaining health. Linda’s desire for calcium supplements was due to her unconscious acceptance of the healthy eating framework. She said,

L: I’ve heard that the methadone....makes your bones brittle and being a woman you have to be more concerned about that - the calcium.
I: ....Where would you have learned about that?

L: I don't know. Just common knowledge and I've got a very deep interest in medical things.

The "alternative" framework, used by approximately one quarter of the participants, was based on the premise that food did not provide all the necessary nutrients for good health, that illness was caused by toxins, and that natural therapies were superior to conventional medical treatments. The participants that followed this framework therefore chose supplemental vitamins, detoxing therapies, and "natural" remedies. Nancy believed in taking vitamin E because it was an "anti-toxant" to "chemicals that [were] processed with [her] foods, hormones in the beef, hormones in the chicken, different steroids that [were] injected into foods, and chemicals that [were] used for pest control and vegetables." Gail preferred to use the BRAT (bananas, rice, applesauce, toast) (Lalari & Cheng, 1992) diet to stop her diarrhea rather than taking medication because the diet was natural.

Only Nancy tapped into the "folk medicine" framework. She believed in the power of traditional foods such as garlic for the immune system and the use of marijuana as an herbal remedy. Nancy said, "I find [the marijuana] relaxing and I find it a meditation tool. I sleep on it. It's a very good herb." Use of the different frameworks was not mutually exclusive for the participants. For example, Nancy took calcium because of her concerns about osteoporosis, milk thistle to detoxify her body, and garlic because she believed in its immunological benefits.

Other minor reasons for choosing complementary therapies were substance use, complementary therapy funding, and poverty. Substance use resulted in complementary therapy use because of concerns about nutritional status and self-control. Taking vitamins was also a way to take control and be responsible. For example, Linda said,
Chapter 4: Participant Interviews

L: It's up to me whether I take that damn vitamin or not! It's helped me get a sense of structure....I've been almost on the bus and run back to my room to get [the multivitamin]....I'm afraid [of letting] go of that one thing that I have to do....I want to be in control now....All day I didn't have to do anything, if I didn't want to. Whereas now, my body needs that multivitamin so I have to take that.

I: It’s you taking responsibility...for yourself?

L: Yeah.

Funding was also available for complementary therapies through the Complementary Health Fund. Five of the participants were currently accessing the funding. Like the frameworks just discussed, poverty also influenced the choice of complementary therapies because participants found cheaper therapies or chose therapies on the basis of cost. Linda chose to get her vitamins from a downtown clinic because she could get them for free instead of paying for them and getting reimbursed.

4.5.4 Barriers to Complementary Therapy Use

Barriers to using complementary therapies included barriers to accessing the Complementary Health Fund, personal factors, and poverty. The majority of the participants were not using the Complementary Health Fund because of lack of need, substance use-related factors, poverty, and organizational factors. Some of the participants did not need to access the funding because they got free vitamins from friends or downtown clinics, they were using simple therapies and did not need the funding, or they received their therapies in a clinical trial. For example, Cheryl said, "If I needed something exotic, then I would use [the Complementary Health Fund] I guess.” As mentioned previously for food, a few of the participants were unable to access the funding while they were involved in substance use.
because they spent their money on drugs. Janice felt that she would start using the
Complementary Health Fund now because in the past she spent that money on drugs.
Poverty interfered with the access to the Complementary Health Fund because the
participants did not have enough money to buy the therapies first before they were
reimbursed. Karen said,

I didn't buy any vitamins for the first while cause I didn't have
any money to spare. I was living in a treatment place and you
only get like 60 bucks or something for yourself and I smoked
so there was no money. Now I have a certain amount of
money allotted and that money just goes back to the same
thing. It's like 50 bucks [is] vitamin money and water money.
When I get it back, I put it back out and get something
different.

The complexity of the CHF system was also a barrier to its own use because some of the
participants were confused by the system of reimbursement or were encountering “red tape”
in using the funding. For example, Nancy said, “Yeah I haven't known how to use [the
Complementary Health Fund] really. Being in a transition house and then moving, I don't
know where my receipts are. So I have to find them all and get refunded.” Peggy was
unaware that the funding existed.

Personal factors that were barriers to complementary therapy use were lack of
memory and lack of need. Some of the participants were not taking certain therapies
because they could not remember what they wanted to try. Karen said, “There’s actually
[therapies] I’d like to try. I still haven’t tried [them] yet. I don’t know, I just keep forgetting
about them every time I’m [in the store].” Gail forgot to take her therapies if there was a
change in her routine. Participants did not take certain therapies if they felt they did not
need them. Perception of need was influenced by the participants’ sense of being “ill”; if
they “felt” healthy, they perceived that they did not need the therapies. For example, Dayna said,

Because I'm healthy right now, I guess it's not like a worry for me..... I think too that's why I keep buying vitamins and the ones that I don't open, I put them away. I know there probably will be a time where I'll start to worry a little bit more about it but right now I guess I worry more about my kids..... Cause I'm not sick right now. So I try to worry and spend as much time as I can doing stuff like that before I do ever get sick or whatever.

Shirley also related her need for therapies to her care of her partner. She believed that taking care of partner allowed her to be “ok” herself. Other minor personal barriers were what to take or confusion due to contradictory information, lack of perceived efficacy, and experience with bad side effects.

Poverty was the third major barrier to complementary therapy use. Participants were unable to afford the vitamins they normally took or wanted to take. Linda was unable to get the multivitamin that she preferred because she was not receiving enough money on income assistance. Karen felt a responsibility to spend the funding she received wisely: “I look at it this way, even though [the therapies are] free, the money's gotta come from some place. I'm not gonna waste their money on stuff that I'm never gonna use.”

Other minor barriers to complementary therapy use were substance use and interpersonal factors such as family conflict and lack of support from partners.

4.5.5 Perceived Efficacy of Complementary Therapies

The perceived efficacy of the therapies ranged from no benefit to beneficial. Participants who felt that the therapies were beneficial noted that complementary therapies provided energy, maintained good health, helped with iron count, allowed them to relax or
sleep, and had aesthetic effects such as shinier hair. For example, Linda noted a benefit from taking her multivitamin, “I know my hair’s a lot shinier and stuff. I know my iron level has gone up although it’s not good yet. So yeah, it has helped.” Karen noted that while the therapies were beneficial, they were not curative. Three participants did not perceive a benefit from taking the therapies for the HIV. For example, Shirley was not sure about the physical benefits of taking her multivitamin:

> Actually I really don't notice a difference. It must be good. I mean I feel ok. I guess I'm gettin to be a little undecided because I have aches and pains and numbness but I think that's probably because of the AZT. So, when I do run out of the Centrum, you know, I start panicking a little bit.

These participants did, however, continue to take the therapies for other reasons, among them influence from the “good health” and “alternative” frameworks previously discussed and recommendations from other persons. Complementary therapies that were taken in moderation were not thought to be harmful. For example, Alice felt that taking complementary therapies in moderation was not harmful but taking them in excess would be problematic:

> I don't know it just seems like after a while you start taking so much darn stuff. I used to fear sometimes [that] maybe your body then sort of [becomes] dependent on a really rich supply. Then if that was removed, [your body] would suffer. I don't know maybe causing sort of a deficiency in the body.

Only two of the participants had noted any bad reactions. Sylvia had trouble swallowing her vitamin pill because it was so large and would often throw up. Sylvia said,

> The main [reason] that [I threw] up was my vitamins for a while there cause they were just so big. They would stick in my throat then I'd throw up. [This] was causing me some concern because when I would throw up, I'd throw up my [HIV] medication too and you only have enough for so many
days. So I wasn't sure if I was getting as much [as I should have been]. You don't know how much [is] dissolved before it [comes] out or if you're even getting anything.

Participants avoided bad reactions by varying the time when the therapies were taken or taking them with food. For example Sylvia took her vitamins with juice and Dayna took her vitamins at night.

4.5.6 Summary of Complementary Therapies

Although most of the participants used complementary therapies, they were not keenly interested in them. The most commonly used types of therapies were vitamins/minerals and plant-based therapies. Most information about complementary therapies was obtained from health professionals, media, and other persons. Participants obtained information in different ways: receiving, seeking, experiencing, and processing. Therapies were used for a variety of reasons including advice from others, personal factors, HIV-related factors, and "frameworks" which influenced choice and included the "good health", the "alternative", and the "folk medicine" frameworks. Barriers to complementary therapy use were barriers to accessing the Complementary Health Fund, personal factors, and poverty. Perceived efficacy of complementary therapies ranged from no benefit to beneficial.

4.6 Summary of Participant Interviews

The two major food and nutrition problems that were raised by the participants were not having enough money for food and weight concerns. Poverty and substance use were the overriding factors in not having enough money for food. Substance use was the major influence in weight gain (not using drugs) and weight loss (using drugs). In their
perceptions of weight changes and body shape changes, various meanings emerged. Participants showed both a concern for achieving a culturally acceptable weight and a concern for unintentional weight loss which they perceived to be HIV-related. However, their perception of weight changes was also influenced by poverty. Participants were unconscious of different eating patterns they described such as “not eating”, “eating”, “healthy/unhealthy eating”, and “eating for HIV”. Substance use-related factors primarily determined whether participants did “not eat” or “ate”. Most of the participants were trying to eat healthfully for their HIV. Complementary therapy use encompassed a variety of therapies. However, the participants were generally uninterested in complementary therapies, did not understand them, and preferred to stick to simple regimens.
5. Food and Nutrition Documents

To explore the assumptions that health professionals and service providers make about the food and nutrition concerns of low-income women living with HIV, document analysis was conducted of food and nutrition literature available to this population. Because it was expected that the participants would have many conflicting food and nutrition issues, the underlying goal of this part of the study was to explore the assumptions made in food and nutrition documents about the reader and to compare them with the experiences of the participants. I hoped that this information would prove useful for the writers of these documents in making their discussion of nutritional issues more relevant to this population. With that in mind, 45 documents were collected for final analysis from a total of 69 food and nutrition documents that were obtained using the procedures described in Chapter 3.

5.1 General Characteristics of the Documents

The documents analyzed in this study included pamphlets, articles from periodicals, photocopies taken from books, and printed information from the internet. The documents were analyzed for general characteristics such as the intended audience, producer of the document, author and credentials, purpose, reading difficulty, presence of disclaimer, and location of the document. The assumed audience of the documents included HIV+ persons (n=24), HIV+ women (n=10), persons living in poverty (n=7), persons concerned with weight loss (n=3), and Canadians in general (n=1). Because the three largest groups of documents were directed towards HIV+ persons, HIV+ women, and low-income persons, further discussion will focus on these three groups of documents (total n=41). (See Appendix D for a list of the documents. Numbers in round brackets at the end of quotations...
refer to the identifying document number in Appendix D.)

As shown in Table 5.1, documents that were geared to HIV+ persons were largely produced by AIDS service organizations with the second largest producer being a clinic or hospital. In contrast, the documents geared to HIV+ women were produced largely by HIV support agencies. The majority of documents geared to low-income persons were produced in a clinic/hospital setting.

Table 5.1: Producer of Documents

<table>
<thead>
<tr>
<th>Producer of Documents</th>
<th>HIV+ Persons No. (% of 24)</th>
<th>HIV+ Women No. (% of 10)</th>
<th>Low-Income No. (% of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic, hospital</td>
<td>7 (29)</td>
<td></td>
<td>4 (57)</td>
</tr>
<tr>
<td>National, provincial organization, government agency</td>
<td>1 (4)</td>
<td></td>
<td>1 (14)</td>
</tr>
<tr>
<td>HIV Support Group</td>
<td>13 (54)</td>
<td>9 (90)</td>
<td></td>
</tr>
<tr>
<td>Miscellaneous Books</td>
<td>1 (4)</td>
<td></td>
<td>1 (14)</td>
</tr>
<tr>
<td>Self-Produced by Writer</td>
<td>2 (8)</td>
<td>1 (10)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td>1 (14)</td>
</tr>
</tbody>
</table>
Several documents had multiple authors with various credentials (see Table 5.2). Approximately half of the documents that addressed HIV+ persons were written by dietitians, however, 38% did not note the author or had authors without credentials. Conversely, 90% of the documents geared for HIV+ women noted no author or were written by authors with no credentials. Only 20% of the documents that addressed women living with HIV were written by dietitians. Of the documents that were geared to persons living in poverty, 85% were written by dietitians or dietetic interns. Twenty-eight percent of these documents did not note the author.

Table 5.2: Author and Credentials

<table>
<thead>
<tr>
<th>Author Listed and/or Credentials</th>
<th>HIV+ Persons No. (% of 24)</th>
<th>HIV+ Women No. (% of 10)</th>
<th>Low-Income No. (% of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author unknown</td>
<td>5 (21)</td>
<td>3 (30)</td>
<td>2 (28)</td>
</tr>
<tr>
<td>Author but no credentials</td>
<td>4 (17)</td>
<td>6 (60)</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td>12 (50)</td>
<td>2 (20)</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Doctor (MD)</td>
<td>2 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ph.D.</td>
<td>1 (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietetic Intern</td>
<td></td>
<td></td>
<td>1 (14)</td>
</tr>
<tr>
<td>Herbalist</td>
<td></td>
<td></td>
<td>1 (10)</td>
</tr>
<tr>
<td>Naturopath</td>
<td>1 (4)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Most of the materials geared to HIV+ persons and HIV+ women were made to inform and empower the reader. Information was provided to readers to expand their knowledge and facilitate their decisions about food and nutrition concerns. Conversely, the documents geared to low-income persons all provided specific direction in what to do and/or what to eat. It seemed to be assumed that low-income readers needed specific directions about what to do and would not be interested in general background information on recommended actions.

Materials geared to HIV+ persons and HIV+ women were generally written at a higher level of reading difficulty. For instance, an article on N-acetylcysteine defined and described the role of glutathione in the body:

Glutathione is a key antioxidant compound required for the smooth functioning of all cells. It is composed of three amino acids: cysteine, glutamine and glycine. Besides acting as an antioxidant, glutathione is involved in protein synthesis, amino acid transport, and the recycling of other antioxidants, such as vitamin C. Test tube studies have noted that lowering intracellular glutathione levels decreases cell survival and limits T-cell response to foreign antigens. At the same time, the cells become more easily activated and more liable to improper programmed cell death ("apoptosis") in response to inflammatory cytokines such as tumor necrosis factor alpha (TNFα) (32).

Most of the documents that were more difficult to read were freely available to the participants and not explained by a dietitian. The documents geared to low-income persons had a lower level of reading difficulty. Documents geared for low-income persons tended to use words or phrases instead of complete sentences. For example, a document on ways to save money gave a list of low-cost foods to buy and provided the following money-saving hints: "watch portion size, cut up meat, fish and poultry yourself, use bones and leftover bits
for soup, enjoy meals without meat, fish, or poultry sometimes, plain rice is cheaper than seasoned rice" (10). All the documents geared to low-income persons were available directly from a dietitian who would adjust them to meet the individual’s needs.

Disclaimers were sometimes used in the documents. The disclaimer noted that the material was provided for informative purposes so that readers could make educated decisions. The material was not endorsed in any way and the reader used the material at her/his own discretion. For example, in a pamphlet about foods to eat for a healthy immune system, the disclaimer read that the mandate was to “make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health” (30). Using the material at one’s own discretion was further emphasized by the following statements:

The project does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the PWA Society of B.C. do not accept the risk of, nor responsibility for, any damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this project. Persons using the information provided through this project do so by their own decision and hold the Society’s Board, staff, and volunteers harmless (30).

About half the documents geared to HIV+ persons had a disclaimer as did half of the documents geared specifically to women. None of the documents addressing low-income persons had a disclaimer.

About half of the documents for HIV+ persons were found at an AIDS service organization and one third were accessed through a dietitian. The majority of the documents for HIV+ women were found at the Pacific AIDS Resource Centre library (PARC). These documents were freely available and not personalized to the needs of the reader.
Conversely, all the resources for low-income persons could only be accessed through a dietitian and were personalized according to the needs of the client.

5.2 Perspective

Perspectives may be defined as viewpoints that frame a document’s content (Altheide, 1996, p. 30). They are not explicitly described in the document but implicitly mold what information is included and how the information will be discussed (Altheide, 1996, p. 31). Perspectives in turn define what themes or motif ideas appear in a document (Altheide, 1996, p. 31). The analyzed documents generally fell into one or more of four different perspectives that I have labelled the “healthy eating”, “alternative”, “scientific”, and “feminist” perspectives.

As shown in Table 5.3, the majority of the documents geared to HIV+ persons and low-income persons followed a “healthy eating” perspective. Only 40% of the documents for HIV+ women followed this perspective. The alternative perspective influenced 33% and 40% of the documents for HIV+ persons and HIV+ women respectively. Thirteen percent of documents for HIV+ persons and 30% of documents for HIV+ women followed the scientific perspective. The “feminist” perspective was the most prevalent in the documents for HIV+ women. Some documents were influenced by more than one perspective.
<table>
<thead>
<tr>
<th>Perspective</th>
<th>HIV+ Persons No. (% of 24)</th>
<th>HIV+ Women No. (% of 10)</th>
<th>Low-Income No. (% of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy Eating</td>
<td>17 (71)</td>
<td>4 (40)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Alternative</td>
<td>8 (33)</td>
<td>4 (40)</td>
<td></td>
</tr>
<tr>
<td>Scientific</td>
<td>3 (13)</td>
<td>3 (30)</td>
<td></td>
</tr>
<tr>
<td>Feminist</td>
<td>1 (4)</td>
<td>5 (50)</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 5: Food and Nutrition Documents

Each perspective will be described in more detail below.

5.2.1 “Healthy Eating” Perspective

Documents following this perspective were written to give the reader general information on what to eat. The major theme was the importance of nutrition. For instance, a pamphlet on nutrition for HIV-related wasting syndrome noted, “[the] importance of proper nutrition cannot be emphasized enough” (38). Nutrition was emphasized so that the reader, by following document advice, could be healthier. Feeling good about yourself was also a theme in documents reflecting the “healthy eating” perspective. For example, an internet guide to healthful living with HIV advised, “Don’t be afraid to do things you like for yourself. Spend some time everyday doing things that you enjoy” (34).

Within the “healthy eating” perspective, recommended foods and diets included high-fibre foods such as dried beans and whole grains, red meat, a well-balanced diet, and a high-energy high-protein diet. Recommended actions included eating regularly, eating a variety of foods, drinking a lot of fluids, taking vitamins with food, and using nutritional supplements only when necessary. For example, the pamphlet, Positive Nutrition, advised the reader to “[try] to get the most of your vitamins and minerals from the foods you eat” (1). Foods to be avoided or taken in moderation were fat, sugar, junk food, coffee, tea, alcohol, and natural therapies such as vitamins and minerals. The palatability of recommended foods was not commented on and the reader was assumed to be able to eat nutritiously without spending a lot of money. For example, in a pamphlet on low-cost foods and tips on how to save money, the author advised, “store brands or no-name canned or frozen products are usually cheaper than name brands and just as nutritious” (10).

The documents which followed a “healthy eating” perspective were characteristic in
terms of their structure and inclusion of information on food safety. The information was grouped according to Canada’s Food Guide food groups: grain products, vegetables and fruit, milk products, and meat and alternates. The document, Positive Nutrition, recommended that the reader “[use] the food groups as a guide to be sure you’re getting all the nutrients you need each day” (1). Serving sizes and numbers of servings in each food group were recommended. Nutritional breakdowns for recipes were sometimes given or the recommendation to follow the Recommended Daily Allowance was advised. The documents included some description of metabolic processes to aid in the understanding of the material. For instance, a document on taste alterations explained,

[our] mouths have a number of taste receptors located strategically to enhance taste perception. These receptors turn over, or are replaced, every 10 days. Malnutrition blunts the body’s ability to replace the receptors which, over time, leads to a decrease in the overall number of receptors with a subsequent loss of taste sensation (11).

Food safety concerns were addressed. The document, Positive Nutrition, recommended the reader “[be] clean. Wash your hands before preparing foods and before eating” (1). Most of the documents promoting the healthy eating perspective were written by dietitians and referrals to a dietitian were commonly recommended.

5.2.2 “Alternative” Perspective

The “alternative” perspective condoned a “natural” approach. Documents with an “alternative perspective” focussed primarily on complementary therapies and noted that “complementary therapies can be used in many ways for many different reasons” (2). According to this perspective, disease occurred because of toxins in the body and the body
had the capacity to heal itself. A pamphlet on basic vitamin therapy noted that,

[blue-green] algae contains beta carotene, chlorophyll, amino acids, and high levels of B-12. Because this cleanses your system, Siano recommends that you start slowly and build up your dosage, or else you may develop a skin rash (as your body flushes toxins out of your system). (19)

Natural therapies were emphasized. An article described “natural therapeutic methods [such as] diet, nutrition and herbs” (20) as treatments for vaginal infections. In many cases the therapies were to be used for HIV symptom relief. Fresh, unprocessed, and organic foods were recommended as were high doses of vitamins. The “alternative” perspective was similar to the “healthy eating” perspective in some of the foods that were to be avoided. Like the “healthy eating” perspective, foods to be avoided in the “alternative” perspective included junk food and sugar. Other foods to be avoided included meat, yeast, and some of the food groups like the dairy group.

Some of the documents contained statements that were disparaging of conventional Western medicine. For example, in an article on traditional Chinese medicine (TCM), it was noted, “[conventional] western medicine is based on theories, and is supported by absolute laws, where there is little room for individual differences and needs. Due to it’s supposed lack of scientific methodology, many people have a hard time understanding TCM” (16).

Many of these documents were written by uncredentialled writers. The purpose of these documents was to inform and to empower the reader to make decisions around their health. Readers were encouraged to do their own research:

[if] you’re interested in using alternative or complementary therapies, the first place to start is to decide what you want to use them for. From there, you can research what kinds of things you can use.....It’s important to try out different things and decide what works for you (2).
5.2.3 “Scientific” Perspective

Documents written from the “scientific” perspective included scientific information in the document to inform and empower the reader. Data from studies were included: “fat-free mass accounted for 51% of the difference in weight between the HIV-positive and the control men compared to only 18% of the difference between HIV-positive and HIV-negative women” (26). Some documents reported on side effects or interactions of HIV medications. In many cases, the study results were inconclusive and there was a lack of clear recommendations. For example, an article on nutrition and HIV noted that “as with the above vitamins, there is no specific recommendation for supplementing in HIV-positive people; the studies just haven’t been done” (31). Characteristically, these documents were the most difficult to read because they assumed that the reader was very familiar with the “lingo” used in scientific reports. In an article on N-acetylcysteine, the author noted,

just this month, Leonore and Leonard Herzenberg and colleagues at Stanford University published the findings from two analyses - one an investigation of the correlation of glutathione level in CD4 cells with CD4 count and the other a trial designed to determine whether orally administered NAC replenishes low glutathione levels (32).

Most of the writers of these documents were uncredentialled.

5.2.4 “Feminist” Perspective

Documents that were framed by a “feminist” perspective focussed on women’s special nutritional needs, psychosocial issues affecting women, and the lack of studies involving women. Many documents addressed specific nutritional concerns in women such as pre-menstrual syndrome, menstrual irregularities, pregnancy, menopause, and
osteoporosis. For example, in an article on nutritional considerations for women living with HIV, "Ms. Ploss [recommended] adding 300 calories and 10 grams of protein daily to estimated pre-pregnancy needs, and taking prenatal vitamins" (21). Psychosocial issues unique to women such as body image and woman's role as caregiver were addressed. An article on the nutritional needs of women living with HIV noted,

psychosocial and environmental factors are also influential, e.g., body image, caretaking and access to food. Women living with HIV, especially those who care for children and/or other family members, may require special encouragement to take the initiative to care for their bodies (21).

A lack of data was noted from scientific studies on women living with HIV because research was acknowledged to have been conducted primarily on men. For example, the article on nutritional needs of women living with HIV noted, "little is currently known about the gender-specific needs of HIV-infected persons" (21). Women were seen to be at a disadvantage when living with HIV in terms of overall outcome. An article on women living with HIV and nutrition noted, "compared to HIV-infected men, women with HIV are at an increased risk of death, although their disease progression accelerates at the same time as men" (22). Most of the documents written from a feminist perspective were written by uncredentialled writers.

5.3 Substance Use

Substance use was rarely mentioned in the documents. Only three (8%) documents for HIV+ persons and three (30%) documents for HIV+ women made mention of substance use. For example, an article on nutrition and weight loss noted that certain "appetite stimulants may not be appropriate for people in recovery from alcohol or substance abuse"
Chapter 5: Food and Nutrition Documents

(23). Alcohol was also not recommended to the reader in seven (29%) of the documents for HIV+ persons and in one (14%) of the documents for low-income persons.

Because substance use was rarely mentioned, it was assumed that the reader was eating regularly, had no food cravings, had good organizational skills, and was using complementary therapies. As noted in Chapter 4, substance use affected food intake, food cravings, and complementary therapy use. Most of the documents in each of the three groups assumed that the reader was eating. Eight (33%) documents for HIV+ persons and three (30%) documents for HIV+ women recommended that the reader eat small, frequent meals. Less than one third of all the documents recommended avoiding such foods as chocolate, coffee/tea, and sugar. Five (21%) of the documents for HIV+ persons and four (57%) of the documents for low-income persons assumed that the reader had good organizational skills such as making lists of tolerated foods. For example, an article on poor appetite advised the reader to “keep a list of foods that you enjoy and tolerate on hand. It’s easier to think of something to eat” (3). One (4%) of the documents for HIV+ persons noted self-injecting vitamin B12 as a way receiving sufficient amounts of that vitamin: “either injections (self-administered) or sub-lingual B-12 (dissolves under the tongue) is recommended” (7).

5.4 Low Income

Few of the HIV-related documents acknowledged that lack of money could influence food choices and/or that access to food was difficult. One (4%) document for HIV+ persons and one (10%) document for HIV+ women stated that lack of money could influence the choices made by the reader and/or noted that access to food was difficult. For example, the pamphlet entitled Nutrition for Life, noted “economics, emotions, physical strength, support
systems, knowledge, and beliefs, are among the factors that may influence the choices and actions you make and take” (34). Later in the same pamphlet, however, the author made further assumptions about the reader’s ability to afford foods and extra items by noting, “this means caring about yourself to take the measures you can in your daily life to make it better, whether that means snacking on salted nuts for extra protein or having fresh flowers on your table” (34). All of the documents for low-income persons, however, assumed that living on a low income would affect food choices.

Assumptions were made in the documents about foods that could be afforded and shopping styles. High-cost foods were also assumed to be affordable in the majority of the documents directed to HIV+ persons, HIV+ women, and low-income persons. High-cost foods included a high-protein, high-calorie diet, low-fat foods or a low-fat diet, a varied diet, and individual high-cost foods such as real fruit juice, fresh fruits and vegetables, cheese, organic foods, and convenience foods such as deli meats. For example, an article on nutrition and HIV noted that,

if fat is not an option for you (e.g., pancreatitis, liver disease, malabsorption), the best bet is eating a lot of low- or non-fat, high calorie foods. These are surprisingly easy to find. As an example, notice the very low- and non-fat pastries at your healthfood store or supermarket (7).

Six (86%) of the seven pamphlets directed to low-income persons assumed that a healthy diet was affordable. It was assumed that money was available for restaurants and for having food delivered from the grocery store in four (17%) of the pamphlets directed to HIV+ persons. Shopping in a store was assumed in 63%, 50% and 86% of the documents geared to HIV+ persons, HIV+ women, and low-income persons respectively.

Although it was assumed that high-cost foods were affordable, documents did refer
to low-cost foods as well. Most low-income documents made reference to low-cost foods and did not assume access to a varied diet. The majority of documents geared to persons and women living with HIV+ and low-income persons also referred to foods that were obtainable at a food bank such as canned foods, dairy products, potatoes, and peanut butter.

Foods that were to be avoided in a few of the documents were foods that were readily accessible on a low-income. For example, bulk purchases were discouraged in one (4%) document for HIV+ individuals. Canned foods were to be avoided in two (20%) documents for HIV+ women even though they are a staple at food banks. Foods that were said to suppress the immune system in one (4%) document for HIV+ individuals were also foods that were generally available to low-income persons such as boxed macaroni and peanut butter. One (4%) document for HIV+ persons assumed that the reader never had restricted access to food.

Money-saving tips were presumed to be helpful to the reader. Two (27%) documents geared to persons on a low-income assumed that by following the directions therein, the reader could save money if they tried: “it is possible to meet the challenge of eating well on a limited budget if you are flexible and willing to work at it” (18).

The vast majority of the documents assumed basic cooking and storage facilities as indicated in Table 5.4. A review of cooking and storage facilities revealed that most of the readers were assumed to have more than one appliance or utensil. For all the documents, the two most commonly assumed appliances were a stove and a fridge. Freezer space was assumed in about one third and one half of documents for HIV+ persons and low-income persons respectively. A can opener was assumed in the majority of low-income documents. Very few of the documents for HIV+ persons assumed that storage space was available for
food but more than half of the low-income documents made that assumption.

Even if cooking facilities were not explicitly assumed, the assumption was still implicit. For example, one low-income document (4) on “eating well with no stove or fridge” was noteworthy in that it provided a list of foods that could be eaten without cooking but one third of the foods needed refrigeration and another list of foods that did not need refrigeration but one third of them needed cooking. Only one document, geared to HIV+ women, questioned access to cooking and storage facilities: “does she have access to equipment for preparing and storing food, and to food itself?” (21). However, foods that needed cooking and refrigeration were later recommended in the same document.
Table 5.4: Cooking and Storage Facilities

<table>
<thead>
<tr>
<th>Assumed Facility</th>
<th>HIV+ Persons No. (% of 24)</th>
<th>HIV+ Women No. (% of 10)</th>
<th>Low-Income No. (% of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stove</td>
<td>15 (62.5)</td>
<td>5 (50)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Fridge</td>
<td>16 (67)</td>
<td>5 (50)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Freezer section or freezer</td>
<td>9 (37.5)</td>
<td>1 (10)</td>
<td>4 (57)</td>
</tr>
<tr>
<td>Microwave</td>
<td>3 (12.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toaster</td>
<td>3 (12.5)</td>
<td>1 (10)</td>
<td></td>
</tr>
<tr>
<td>Broiler or oven</td>
<td>1 (4)</td>
<td></td>
<td>2 (29)</td>
</tr>
<tr>
<td>Blender</td>
<td>3 (12.5)</td>
<td>2 (20)</td>
<td></td>
</tr>
<tr>
<td>Mixmaster</td>
<td></td>
<td></td>
<td>2 (29)</td>
</tr>
<tr>
<td>Popcorn popper</td>
<td>1 (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can opener</td>
<td>3 (12.5)</td>
<td>2 (20)</td>
<td>5 (71)</td>
</tr>
<tr>
<td>Other utensils</td>
<td>6 (25)</td>
<td>2 (20)</td>
<td>4 (57)</td>
</tr>
<tr>
<td>Storage space</td>
<td>4 (17)</td>
<td></td>
<td>4 (57)</td>
</tr>
</tbody>
</table>
5.4.1 Transportation

The majority of documents geared to HIV+ persons, HIV+ women and low-income persons assumed that the reader had access to transportation. Less than half of the documents geared to HIV+ persons and HIV+ women assumed that the reader could manage heavy food items. Conversely, all of the documents geared to low-income persons assumed the use of heavier items such as canned and bulk items. For example, a pamphlet on shopping on a limited budget advised the reader to, “figure out how much you need [of dried beans, peas or lentils] for the month and buy a variety to prevent boredom” (18). Only one (14%) of these documents advised the reader to avoid shopping around for bargains because money spent on transportation would negate any savings made on food purchases.

5.4.2 Dental Concerns

The majority of documents geared to HIV+ persons, HIV+ women, and low-income persons assumed no dental problems. Only one (4%) document geared to HIV+ persons mentioned periodontal problems. Two (8%) documents for persons living with HIV and one (10%) document for women living with HIV recommended the addition of sugar to foods which may have exacerbated dental problems.

Other recommendations were more conducive to dental health but were not made for that reason. Sugar was not recommended in 20% of all the documents because of concerns about the immune system and secondary infections. Soft moist foods were recommended in 3 (13%) documents for HIV+ persons for poor appetite or sore mouth.
5.5 Weight Concerns

About half of the documents for HIV+ persons and HIV+ women assumed that weight loss or the need to gain weight was the reader's foremost concern: "...this article will...suggest ways to prevent weight loss/wasting" (24). This assumption was not made in any of the low-income documents.

Recommendations were directed towards gaining weight or preventing weight loss. High-calorie items such as peanut butter, homo milk, ice cream, pudding, cheese, powerbars, and granola bars were recommended in eight (33%) of the documents geared to HIV+ persons, four (40%) of the documents for HIV+ women, and one (14%) of the documents for low-income persons. Similarly, one (4%) of the documents for HIV+ persons recommended avoiding low-calorie items: "...since salads do take time to eat, energy could be wasted doing unnecessary work" (37). Three (13%) of the documents for HIV+ persons and one (10%) document for HIV+ women recommended therapies to stimulate the appetite such as marijuana, Chinese herbs, and zinc.

Five of the total number of documents reflected concerns that were consistent with the dominant body weight discourse for women such as exercising for weight control, monitoring weight, knowing ideal body weight, avoiding foods that could lead to weight gain, and showing concerns for body shape changes. Only one (4%) document geared to HIV+ persons and one (14%) document for low-income persons discussed exercise for body weight or body shape control. For example, comments interspersed in a collection of recipes for low-income persons included the following statement: "daily exercise can help you firm up your muscles, use up extra calories and lose weight" (41). Two (20%) documents geared to HIV+ women assumed that the reader monitored her weight. One
(10%) document for HIV+ women assumed knowledge of an ideal weight range. For example, an article on weight loss and wasting noted,

> In order to prevent weight loss, the intake of nutrients must be equal to or exceed the energy used by the body. This is the reason why it is crucial to practice the principles of good nutrition and to always aim at achieving ideal body weight (24).

Three (13%) documents for HIV+ persons, one (10%) document for HIV+ women, and four (57%) low-income documents recommended avoiding high-fat foods or using low-fat items. One (4%) document for HIV+ persons was devoted entirely to body shape changes that may be linked to the use of certain types of HIV medications.

Few documents acknowledged that women may have unique perceptions of weight changes due to influence from the dominant body weight discourse for women. Only three (30%) documents for HIV+ women and one (4%) document for HIV+ persons openly acknowledged cultural weight concerns with women’s weight and body shape changes. For example, in an article on nutritional considerations for women living with HIV, the author noted, “body image, which changes greatly with weight loss and illness in general, may be a particular concern for women” (21).

### 5.6 HIV

Assumptions were made about knowledge of recommended diets and time availability in some of the documents. In discussing HIV and nutrition, a healthy, well-balanced or a high-protein, high-calorie diet was recommended. About one third of documents geared to HIV+ women assumed the reader had knowledge of a healthy diet but none of the documents geared to HIV+ persons or low-income persons made that assumption. Knowledge of a high-protein high-calorie diet was assumed in three (13%) of
documents for HIV+ persons and in one (10%) of documents for HIV+ women. However, none of the low-income documents made that assumption.

Because the participants often spoke of being busy (Chapter 4), the amount of time assumed to be available to the reader was analyzed. Various amounts of time were assumed to be available to read the documents and in the recommendation of time-consuming and time-saving activities. The length of the documents ranged from 1-20 pages. The documents for HIV+ persons and women tended to take the most time to read.

Time-consuming activities which concerned ways to eat, food safety, and saving money were recommended in the documents. More than half of the documents for HIV+ persons and women and all of documents for low-income persons recommended time-consuming activities such as eating small frequent meals, monitoring one’s intake, making a list of enjoyed foods, cooking from scratch, eating slowly, resting after eating, and avoiding of convenience items such as “fried foods, fast food, boxed macaroni, and peanut butter” (30). Four (17%) of the documents for HIV+ persons recommended time-consuming activities concerning food safety such as rotating foods in one’s freezer, labelling food packages, boiling one’s water, and holding food at a certain temperature for 10 minutes after reheating. Three (43%) documents for low-income persons made time-consuming suggestions to save money such as checking flyers, comparing costs, and making a shopping list.

Recommendations for saving time included getting help with meal preparation and using convenience foods but were rarely mentioned in the documents. Help with meals was assumed in two (8%) documents for HIV+ persons. For example, in a document on poor appetite, the reader was advised to, “take advantage of offers from family and friends” (3).
Seven (29%) of the documents for HIV+ persons and four (57%) of the documents for low-income persons recommended using convenience foods.

Only one (10%) document for HIV+ women acknowledged the time needed to care for others that is most commonly “women’s” work. An article on nutrition and women living with HIV asked, “is she responsible for caring for and feeding others, such as children, parents or other family members?” (21).

5.7 Complementary Therapies

For the most part, it was assumed that the reader had an interest in complementary therapies and that the therapies were affordable. Up to 60% of the documents for HIV+ persons and women assumed that the reader had an interest in complementary therapies. The documents directed to low-income persons did not address complementary therapies. About half of the documents for HIV+ persons and HIV+ women assumed that the reader could afford complementary therapies. Vitamins were assumed to be expensive in only one (4%) document for HIV+ persons and one (10%) document for HIV+ women. Access to free or cheaper vitamins was described in 3 (13%) documents for HIV+ persons and one (10%) document for HIV+ women. Less than 40% of the documents for HIV+ persons and HIV+ women assumed that the reader would take the recommended vitamins regularly.

5.8 Summary of Documents

The largest audiences for the documents were HIV+ persons, HIV+ women, and low-income persons. Most documents for HIV+ persons and low-income persons followed a healthy eating perspective, however, most materials geared to HIV+ women followed a feminist perspective. The “healthy eating” perspective emphasized the importance of
nutrition and feeling good about yourself and recommended a healthy diet as per Canada’s Food Guide. The “alternative perspective” involved advocating natural therapies to help the body cure itself. Documents written from the “scientific” perspective provided data from scientific studies which were often not conclusive. The “feminist” perspective focussed on the unique nutritional needs of women and the lack of studies involving women.

Very few of the documents assumed that the reader was a substance user: the majority of all the documents assumed that the reader was eating regularly. Although the majority of documents for persons living with HIV did not acknowledge that economics could affect food choices, low-income documents did assume that living on a low income would affect food choices and made recommendations of cheaper foods. Cooking and storage facilities, access to transportation, and good dental health were assumed in most of the documents. The main weight concern was assumed to be weight loss rather than weight gain. Very few of the documents acknowledged the dominant body weight discourse that influences women. A healthy, well-balanced or a high-protein, high-calorie diet was recommended for HIV in some of the documents. Most of the documents assumed that the reader had an abundance of time to follow time-consuming suggestions and few of the documents offered time-saving suggestions. Many of the documents assumed that the reader had an interest in complementary therapies and could afford them.
6. **Discussion**

The main objective of this study was to explore the food and nutrition concerns identified by low-income women living with HIV. The two major food and nutrition problems from the perspective of the participants were the inability to afford food and/or appropriate foods on a low income and weight changes. Substance use was the predominant factor affecting the eating patterns of the participants and, in turn, their weights. Although the predominant influence on perceptions of weight and body shape changes was the dominant weight discourse, HIV-related factors and poverty also had an influence. With regards to their HIV, participants were more concerned with aspects of healthy eating than with eating more protein and/or more calories. Complementary therapies were a minor concern for the participants and substance use and poverty were major barriers to their use. Assumptions made in food and nutrition documents available to the participants were generally not reflective of their concerns. The following discussion will cover each of these points including implications for practice, followed by a discussion of the study limitations, implications for future research, and conclusions.

**6.1 Living on a Low Income**

As evidenced by the number of women who noted that poverty was their main food and nutrition concern, poverty was the overriding factor influencing participants' decisions around food and nutrition. This is not surprising, given that being on income assistance was one of the criteria for participation in the study. Others have noted that current levels of income assistance are inadequate (National Council of Welfare, 1997-1998) and insufficient to meet the specific needs of persons living with HIV (Core Women Care, 1995; Kirkham &
Lobb, 1998; McCulloch, Howard, & Ivan, 1999). Substance use was pervasive among the participants and, when they spent money for drugs such as cocaine and/or heroin, they did not have enough money for food. The finding that substance use was another major contributor to participants’ poverty was also noted in another study of the food problems of a similar population in Vancouver (McCulloch, Howard, & Ivan, 1999).

Most of the participants in this study were able to maintain their eating habits over the course of the month because they received help from family, friends, and roommates either in the form of food gifts or money for food or they lived in a communal situation where the food was purchased for them. Receiving food or money for food has also been noted by low-income persons in other studies (Baxter, 1995, pp. 70-71; Campbell & Desjardins, 1989; Levens & Clague, 1986). For persons living in the Downtown Eastside of Vancouver, the community is especially “tight-knit” and sharing or trading between neighbours occurs regularly (D. Peabody, personal communication). Other ways that a stable diet was ensured included relying exclusively on food charity when using drugs, receiving the income assistance cheque in incremental payments, and consciously rationing more expensive foods over the course of the month. Four of the participants, however, were unable to maintain the same intake over the course of the month and experienced food insecurity. Food insecurity may be defined as “a condition in which all people at all times [are unable to] acquire safe, nutritionally adequate and personally acceptable foods that are accessible in a manner that maintains human dignity” (Cyr, 1991). This inability to maintain eating habits over the course of the month is supported by studies of other low-income persons (Baxter, 1995, p. 39; Fitchen, 1988). Two of the participants lived alone and had no children for which they may have received extra money for food (National
Council of Welfare, 1997-1998). One of the participants was living with her partner but he was also on income assistance. The fourth participant had children but they were living with her mother and she had yet to receive the extra benefits entitled to her as a person living with HIV (Feindel, Gibson, & Reid, 1998).

The participants used food charity extensively as a way to cope with food insecurity and their experience of food charity was very similar to that noted in other studies. The use of food charity by low income persons and persons living with HIV is also supported in other studies (Badun, Evers, & Hooper, 1995; Baxter, 1995, p. 39, 102; Campbell & Desjardins, 1989; Hobbs, MacEachern, McIvor, & Turner, 1992; Levens & Clague, 1986; McCulloch, Howard, & Ivan, 1999; Starkey, Kuhnlein, & Gray-Donald, 1998; Tarasuk, Geduld, & Hilditch, 1998; Travers, 1996). Like this study, other studies have shown that food charity is used by low-income persons when money is scarce (Emmons, 1986; Hobbs, MacEachern, McIvor, & Turner, 1992), by persons living with HIV when using drugs (McCulloch, Howard, & Ivan, 1999), and by persons living with HIV because food charity geared for persons living with HIV was accessible to them (McCulloch, Howard, & Ivan, 1999). The participants in this study, however, had a wider variety of other reasons for using food charity such as extra foods at holiday time, social contact, advocacy, having children which allotted more food per household, and close proximity to food charity. Because the participants did not have enough money to ensure variety in their diets, they were especially pleased with the extra and different foods at holiday time. In Vancouver, some of the food charity organizations for persons living with HIV are housed together with AIDS service organizations. Advocacy which is a mandate for support organizations working with persons living with HIV would also be important to the participants. Women
living with HIV also tend to feel isolated (Campbell, 1990; Lea, 1994; Shayne & Kaplan, 1991) therefore social contact would alleviate their sense of isolation. Because of the pervasiveness of substance use among the participants, it was not surprising that food charity was relied on when the participants used drugs. It was also not uncommon for the participants with children to lose the care of their children if it was deemed that the women were unfit due to substance use. Because having the care of the children was not guaranteed, the participants probably were more aware that having their children with them increased their food charity allotment. Services that were located in the downtown core were especially accessible to the participants that lived in the vicinity.

Factors negatively affecting food charity in this study were also noted in other studies: poor food quality (Hobbs, MacEachern, McIvor, & Turner, 1992; McCulloch, Howard, & Ivan, 1999), lineups (Hobbs, MacEachern, McIvor, & Turner, 1992), availability (Canadian Association of Food Banks, 1998; McCulloch, Howard, & Ivan, 1999), and stigma (Baxter, 1995, p. 123; Hobbs, MacEachern, McIvor, & Turner, 1992; McCulloch, Howard, & Ivan, 1999; Tarasuk & Maclean, 1990). The results from this study were very similar to those in other studies presumably because the subjects were also low-income and in some cases, living with HIV. Although the participants in this study also noted that they had problems with the lineups, HIV-related concerns such as fatigue from the HIV virus and a sense of discomfort concerning the other food charity users in the lineups were also evident. It is noteworthy that although the HIV label may be applied to a group of persons, within that group heterogeneity still exists and can be a source of discomfort between the group members. For instance, women living with HIV may feel they have little in common with gay men living with HIV (Littlewood, 1994). Participants in this study also noted
transportation difficulties presumably because they came from different parts of Vancouver and the lower Mainland and most of the services were only available downtown. Lack of cooking facilities was also a prominent factor for one of the participants because she was experiencing a greater depth of poverty than the other participants.

Other poverty-related factors of concerns were lack of cooking and storage facilities, vermin, lack of transportation, and dental concerns. Other studies with persons living on a low income, living with HIV, and/or living with substance use have shown lack of cooking and storage facilities (Core Women Care, 1995; McCulloch, Howard, & Ivan, 1999) and vermin (Core Women Care, 1995) are a problem. Similarly, participants in one study were unable to take advantage of foods from food charity due to lack of cooking and storage facilities (McCulloch, Howard, & Ivan, 1999). The participants in this study were quite resourceful in finding other alternatives to a lack of cooking facilities, either by cooking at a family member’s home or sharing utensils and appliances with the apartment manager. Because of the chaotic backgrounds of the participants, cooking facilities were also available to participants living in a transition house with communal cooking facilities.

As noted in other studies (Baxter, 1995, p. 103-105; Charles & Kerr, 1988, p.170; DeVault, 1991, p.178-179; Hobbs Leenerts, 1998, Kirkham & Lobb, 1998; Piette, Fleishman, Stein, Mor, & Mayer, 1993), participants in this study noted the lack of transportation. Problems with illness as well as the difficulty in handling heavy groceries were also noted in this and in other studies of low-income persons and persons living with HIV (Hargrove, Dewolfe, & Thompson, 1994; McCulloch, Howard, & Ivan, 1999). However, the participants also had strategies for reducing their use of public transit and for improving their grocery shopping experiences. For those persons who were in close proximity to the grocery stores, they used walking or bicycling to save on transportation costs.
proximity, walking and riding a bike were alternatives. Sharing transportation and getting help with groceries was also common and may have reflected the sense of community and sharing by low-income persons. In this study, substance use also interfered with access to transportation. Participants who were using drugs spent their transportation money on drugs or the chaotic lifestyle resulted in lost or stolen passes.

Dental concerns were also noted in this study and other studies of low-income persons, persons living with HIV, and persons living with substance use (Capilouto, Piette, White, & Fleishman, 1991; Charette, 1993; Greene, Chu, Diaz, & Schable, 1997; Kuthy, Odom, Salsberry, Nickel, & Polivka, 1998; McCarthy, Haji, & Mackie, 1996; Maxwell & Simkins, 1985; Nikias, Fink, & Shapiro, 1975; Picozzi, Dworkin, Leeds, & Nash, 1972; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999; Schuman et al., 1998; Zador, Lyons Wall, & Webster, 1996). Participants in this study noted the lack of sufficient dental coverage which contributed to their inability to receive appropriate dental care and this has been noted in other studies of persons living with HIV (Greene, Chu, Diaz, & Schable, 1997; McCarthy, Haji, & Mackie, 1996; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999). Although it has been shown that persons living with HIV may be reluctant to seek dental care due to fears about their HIV status (McCarthy, Haji, & Mackie, 1996; Shiboski, Palacio, Neuhaus, & Greenblatt, 1999), the participants did not express the same concerns in this study presumably because they had restricted access to dental care with the income assistance system or they were using drugs and uninterested in dental care. Violence also affected dental health for some of the participants which may have been reflective of the influence of substance use and the participants' chaotic lifestyles.

Despite the contexts of substance use and HIV, living on a low income took
precedence over all other concerns. Dietitians working with this vulnerable population need to be aware that inadequate resources have a profound effect on the ability of low-income women living with HIV to follow nutritional advice. Therefore, dietitians working with this population need to assess the depth of poverty that is affecting the client and need to adjust recommendations so that they are relevant to the client's needs. Because so many of the participants relied on food charity, dietitians need to have a good understanding of what services are available as well as what is offered in their community. Recommendations regarding foods to eat should coincide with what is available in food banks. Based on the concerns of the participants, advocacy for better quality food and longer hours at food charities would be helpful. Because some of the participants had problems with cooking and storage facilities, it would be useful to establish what resources were available to the client. Foods that do not require cooking nor storage facilities should also be recommended for those clients lacking both. Clients that lack cooking and storage facilities may be more vulnerable to vermin and recommendations on how to protect food from vermin would also be useful. Clients could be encouraged to share the chore of grocery shopping to make it easier for them. Dental concerns affected several of the participants, and as with cooking and storage facilities, dietitians need to establish what foods the client can manage. Advocacy for increased dental coverage for this population would also improve dental health. All recommended foods should take potential dental barriers into account.

Given Dietitians of Canada's commitment to food security for all Canadians (Cyr, 1991), consideration must be given for the special dietary needs of low-income women living with HIV. As noted previously, dietary recommendations for persons living with HIV may require the use of a high-protein, high-energy diet (Fields-Gardner, Thomson, &
Rhodes, 1997, p. 47). Advocacy to increase the amount of money these women receive would help them to follow nutritional advice.

6.2 Weight and Body Shape Changes and Perceptions

The second most predominant food and nutrition concern from the perspective of the participants was weight changes. This related to one of the secondary objectives of the study which was to explore the meanings of weight and body shape changes occurring within the context of HIV and to examine the relationships of those meanings to the dominant discourse on women, weight, and body image. Substance use, not HIV, was the predominant factor affecting eating habits and weight changes. When the participants were using drugs, they had no appetite, ate nothing for days, and consequently lost weight. Conversely, cessation of substance use increased appetite, intake, and weight. Perceptions of weight and body shape changes were related to the dominant weight norms for women, HIV, and poverty.

In some ways, these findings are not unique. The effects of substance use on weight have been reported by others (Hoy & Flanigan, 1994; Santolaria-Fernandez et al., 1995; Varela et al., 1990; Varela, Marcos, Santacruz, Ripoll, & Requejo, 1997). Weight loss for HIV-related reasons is associated with the duration of HIV infection with persons more likely to experience weight loss at advanced stages of the HIV (Fields-Gardner, Thomson, & Rhodes, 1997, p. 9). Eight of the participants were considered to be immunocompromised (Fields-Gardner, Thomson, & Rhodes, 1997, p. 7) and six participants discussed weight loss that they attributed to the HIV. The exact cause of weight loss in the participants is not known from the results of this study. However, some of the participants who were immunocompromised may have attributed their weight loss to substance use instead of HIV
because they knew from past experience that they lost weight when they used street drugs.

Weight preoccupation of women in our society has also been well documented (Fallon & Rozin, 1985; Garner, 1997; Green et al., 1997; Mintz & Betz, 1986; Nielsen, 1988; Rodin, Silberstein, & Striegel-Moore, 1985; Statistics Canada, Housing, Family and Social Statistics Division, 1994) and the weight concerns of persons living with HIV have been noted elsewhere (Testa & Lenderking, 1999). What is novel about the current findings, however, is that the participants in this study were affected by all of these issues: substance use, the dominant weight discourse for women, HIV concerns, and poverty.

Perceptions of weight and body shape changes for the participants were context-dependent and conflicted. From the perspective of dominant weight norms, the participants were happy with weight loss and unhappy with weight gain. These perceptions were context-based. Weight loss was positive for some of the participants within the context of using drugs. Drug use seemed to intensify the influence of the dominant weight discourse on weight perceptions such that the participants appeared “anorexic” in terms of their perceptions of their weight. They seemed to delight in their emaciated bodies. The link between eating disorders and substance use is also supported by others (Grilo et al., 1997; Jonas, Gold, Sweeney, & Pottash, 1987; Wiederman & Pryor, 1996). Weight loss was also seen to be positive within the contexts of previous weight gain or obesity and, similarly, weight gain was negative if the participant was normally thinner. These perceptions can be seen to relate to the stigma of obesity. Family weight concerns also influenced the participants if the family member was preoccupied with their own weight. One study has shown that women’s body attitudes shape those of their children (Rieves & Cash, 1996).

Within the context of HIV, perceptions of weight and body shape changes were in
Chapter 6: Discussion
direct contrast to those influenced by the dominant weight discourse. The contexts for a negative perception of weight loss were unintentional weight loss, comments from others, and a perceived connection between the weight loss and HIV. Weight gain was positive if successful and if health professionals were pleased. Trying to please health professionals was a unique context in this study and may have resulted from the power imbalance between the participants and their health care providers and from the need to do as advised (D. Peabody, personal communication). Stigma may have also played a part. Although other persons may shun the participants for being HIV-positive, the health care team was seen as caring. That expression of caring may have prompted a need to please health professionals because they did not shun the participants. In order not to disappoint the health care team, one participant gained weight and was pleased in being able to follow recommendations.

The influence of the dominant weight discourse and HIV concerns on perceptions of weight and body shape changes were sometimes conflicted. For example, Nancy had gained extra weight in fear of future wasting but was also unhappy about the extra pounds because she did not like to be heavy. Similarly, Sylvia was happy and uncomfortable about the thinner body shape changes she was experiencing because she did not know why they were happening or when they would stop. This contradicts the results of one study with persons living with HIV in which HIV concerns were the only influence on perceptions of weight and body shape changes (Testa & Lenderking, 1999). However, in that study, most of the participants were male and only 8 women were included in the focus groups. Because the current study focussed specifically on women, the influence of the dominant weight discourse was more apparent. Although the participants were affected by both dominant weight norms and HIV fears, it was not clear in what contexts the influence of the dominant
Another unique finding from this study was the effect of poverty on perceptions of weight changes. When weight changes occurred, clothing fit was affected and participants lacked money to buy new clothes due to inadequate income assistance. Given the strong influence of poverty on other food and nutrition concerns, it is not surprising that poverty also influenced perceptions of weight changes. The participants were unable to afford other clothes if they experienced weight gain or weight loss because, under income assistance at the time of the interviews, money for work clothing was the only clothing allowance available (Martin, 1997). Therefore, weight changes were particularly stressful.

Because the weight goals of health professionals may conflict with those of women who are influenced by the dominant weight discourse, recommendations of weight gain may be ignored by the client. Poverty may also impact the receptiveness of clients to weight recommendations if the clients are unable to afford new clothes to accommodate weight changes. Substance use which results in dramatic weight changes may further complicate weight counselling issues. Because of these various and often conflicting influences, perceptions of previous weight and body shape changes should be explored with the client to make visible and acknowledge these influences. This is especially important in the case of body shape changes that may be due to HIV medications which are a cornerstone of HIV therapy. Weight goals of dietitians and health professionals may have to be negotiated with the client in order to be successful. Like food security, dietitians need to lobby for extra money for clothing to accommodate recommended weight changes so that negotiated weight goals may be successful. Considering that weight gain was associated with the treatment of substance use and that six of the participants were worried about weight loss due to HIV
fears, more treatment programs for substance use would be of benefit to this population.

### 6.3 Eating Patterns

Although there was no specific objective to explore eating patterns within the context of HIV, different styles of eating became apparent through data analysis. As mentioned previously, substance use had an overriding influence on food intake: using drugs prevented food intake and cessation of drug use stimulated food intake. Although it is not clear what HIV dietary advice was received by the participants, six women were trying to eat more protein and/or more calories and the majority of the participants were trying to eat more healthfully with their HIV in mind. Many of the participants had tried nutritional supplements. Principles of healthy eating were not followed as a package but rather certain principles such as eating more fruits and vegetables were cited as ways to eat with the HIV in mind. Most of the participants were also aware of and trying to follow food safety guidelines.

Studies have shown that substance use has a negative effect on food intake (Gambera & Clarke, 1976; McCulloch, Howard, & Ivan, 1999; Santolaria-Fernandez et al., 1995; Smit et al., 1996; Worden & Rosellini, 1979). Some studies have shown that persons living with HIV believed in or were trying to eat more healthfully for their HIV (Heathcock et al., 1998; Henseler, Curry, & Johnson, 1992; Levy, Foley, & Forer, 1994; McCulloch, Howard, & Ivan, 1999) while other studies have shown that some persons living with HIV were trying to eat more calories (McCulloch, Howard, & Ivan, 1999) or were using nutritional supplements because of a lack of appetite (van Servellen, Sarna, & Jablonski, 1998). Although the women in this study were motivated to follow food safety guidelines because of concerns of food-borne illness and because of their HIV diagnosis, one study on food
safety awareness in British persons living with HIV showed that they lacked food safety information and few followed food safety guidelines (Heathcock et al., 1998). Because most of the subjects in that study were male, food safety advice may have been overlooked because the subjects were not cooking for themselves. The majority of the women in this study cooked for themselves and were more concerned with food safety.

As noted previously, substance use was found to have a profound effect on eating patterns. Substance use itself may be seen, not as a dichotomy of "using drugs" and "not using drugs", but as a continuum with constant or frequent drug use at one end and never using drugs at the other end. Persons affected by substance use tended to "slide" back and forth between frequent drug use and temporary periods of no drug use because of the refractory nature of the problem (Diana Peabody, personal communication). Because of the influence of substance use on eating patterns, participants who were using drugs frequently may not have been eating nor interested in improving their diets at the time they were interviewed. For these participants eating more food may have been the goal in eating for their HIV because they were not eating regularly when using drugs. Other participants may have temporarily stopped their drug use and were interesting in eating food once again. Still other participants may have been able to discontinue their drug habits and were attempting to eat more healthfully, sometimes with their HIV in mind. Other women who were not using drugs and were aware of healthy eating may have been trying to eat more protein and/or more calories for their HIV if recommended by the dietitian. Therefore, depending on the placement of the individual on the substance use continuum, different ways of eating for the HIV were observed.

In this study, the participants may have been trying to follow healthy eating
principles because of dietary advice based on their placement on the substance use continuum. It is not known what dietary advice the participants received regarding their HIV. The majority of the participants in this study may also have been trying to follow healthy eating principles for their HIV because of general concerns about healthy eating. Canadian consumers have been found to be concerned with eating a healthy diet and the majority of Canadian consumers are getting nutrition information from different media such as radio, television, magazines, and books (The Canadian Foundation for Dietetic Research, Dietitians of Canada, & Kraft Canada Inc., 1997). Healthy eating messages have translated into efforts by Canadian consumers to eat more healthfully by decreasing fat intake, increasing variety, eating more fruits and vegetables, and decreasing intake of sweets (The Canadian Foundation for Dietetic Research, Dietitians of Canada, & Kraft Canada Inc., 1997). It is presumable that the participants would also be affected by healthy eating concerns and by the information about healthy eating that affect other Canadians. In trying to eat better for their HIV, the participants would adopt the same behaviors that other Canadians are pursuing for reasons of general health.

Few of the participants followed a high-protein, high-energy diet for their HIV. Poverty was a major factor in trying to eat more healthfully and in trying to eat a high-protein, high-energy diet, however, the participants may have found healthy foods more affordable than high-protein, high-energy foods. Therefore, more participants concentrated on “healthy eating” because it was a diet they were more able to afford.

Messages about “eating for HIV” are also not as pervasive as those for healthy eating and would only be gained through interacting with a dietitian or through reading materials for persons living with HIV. It is likely that much information is received in a counselling
session with a dietitian making the receipt of the high-protein, high-energy diet message by a person living with HIV more difficult. Several of the participants noted that they were not aware of or could not remember what they had been told by the dietitian in terms of what to eat. Therefore, it is not surprising that more participants were trying to follow “healthy eating” rather than “eating for HIV”. Concentrating on healthy eating may also have been easier for the participants than trying to “eat for HIV” because of intermittent substance use. As Alice noted, she was unable to eat for HIV because the amount of recommended food was perceived to be excessive whereas Canada’s Food Guide guidelines were more acceptable because they were potentially achievable.

“Eating for HIV” may also be seen as contradictory with “healthy eating” because the focus is on weight gain whereas weight gain is not inherent in “healthy eating”. The goal of weight gain was not shared by every participant further making the adoption of “eating for HIV” more difficult. Furthermore, 20 to 31% of women between the ages of 18 and 65 have been found to be restrained eaters (Rand & Kulda, 1991). Restrained eating may be defined as dieting (Rand & Kulda, 1991). Therefore, eating a high-protein, high-energy diet for the purposes of weight gain would be contrary to the participants’ tendency to diet.

Most of the participants had tried nutritional supplements such as Ensure® and Boost®. It is well known that in the Vancouver community, nutritional supplements are highly prized by substance users and persons living with HIV. Supplements are thought to be more beneficial for the purposes of weight gain than other regular high-protein, high-calorie foods. Most of the participants may have tried nutritional supplements and believed in them because of the positive “mystique” surrounding their efficacy.
Aspects of "healthy eating" tended to be followed by the participants rather than taking a holistic approach. Participants also may not have had a holistic view of healthy eating because their eating patterns were so extremely different when they were using drugs or not using drugs. Simply eating regularly may have been the ideal they focussed on if they were not eating anything previously. As noted previously, many of the participants could not afford the healthy foods that they thought they needed which would further prevent them from following all healthy eating principles.

An interesting finding in this study was that most of the participants were trying to follow food safety guidelines for persons living with HIV. Following food safety guidelines may have been easy because, although they are a part of eating for HIV, they are also part of the message of healthy eating which is ubiquitous (The Canadian Foundation for Dietetic Research, Dietitians of Canada, & Kraft Canada Inc., 1997). The high-protein, high-energy message was more in conflict with cultural weight norms and the desire for a slimmer shape and therefore was not followed. Food safety guidelines may also have been followed because following them was less expensive than following a high-protein, high-energy or healthy diet. The participants were probably also motivated to follow food safety guidelines because if they did not, they became ill, whereas there was no perceived negative outcome from not eating a high-protein, high-energy diet.

Each client that visits a nutritionist may have different nutritional concerns. For a client living with HIV, a nutritionist may focus on the HIV in making dietary recommendations even though the HIV may not be paramount to the client. In this study, the participants had various difficulties in eating appropriately such as living on a low income, living with HIV, and living with substance use. Recognition of the ways in which
these different contexts affect eating patterns would allow nutritionists to tailor their advice to the client’s circumstances. For example, for a woman who is struggling with substance use, recommendations to eat regularly and to maintain intake may still be appropriate. However, for a woman who is not using drugs or alcohol and may be more interested in nutrition, recommendations to follow healthy eating guidelines as a package or to increase protein and/or energy intakes (if needed) may be germane. Awareness of the refractory nature of substance use would prompt nutritionists to monitor the circumstances of the client and assist in providing relevant advice. The context of poverty must also be taken into account and recommendations geared to the client’s access to resources. Given the difficulties that were expressed by some of the participants in obtaining commercial nutritional supplements, the process to obtain them should be streamlined so that persons in need of these supplements can access them in a timely manner. By identifying inappropriate eating patterns, the nutritionist can facilitate the adoption of more appropriate eating strategies.

6.4 Complementary Therapies

Another secondary objective of the study was to examine the meanings of food- and/or nutrient-based complementary therapies for poor women living with HIV. Because funding was available to the participants to purchase complementary therapies but little was known as to why or if they accessed it, exploration of the use of complementary therapies was included in the study. Complementary therapies were not important to most of the participants although most were using them. Some of the participants were unfamiliar with the term, “complementary therapies”, and I had to define the term in the interview. Complementary therapies were used for a variety of reasons. Some of the barriers to
accessing complementary therapies were substance use and poverty.

Complementary therapy use has been shown to be variable in other studies including women living with HIV (Anderson, O'Connor, MacGregor, & Schwartz, 1993; Bates, Kissinger, & Bessinger, 1996; Berrier et al., 1996; Creed, 1995; Meneilly, Carr, & Brown, 1996). Although women living with HIV who are more educated and have higher incomes appear to be more common users of complementary therapies (Bates, Kissinger, & Bessinger, 1996; Berrier et al., 1996), most of the women in this study were using therapies. They were able to access complementary therapies because the participants tapped into the funding, got free therapies, or paid for the therapies themselves. None of the other studies on complementary therapies use in women living with HIV noted a lack of familiarity with the term “complementary therapies”. This may have been due to the low educational level of the participants in this study: more than half of the participants had not completed high school.

The participants tended to use a variety of therapies such as vitamins/minerals, plant-based therapies, animal extracts, food-based therapies, and other miscellaneous therapies. These types of therapies have been noted in other studies (Bates, Kissinger, & Bessinger, 1996; Berrier et al., 1996; Creed, 1995; Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996). The participants had various reasons for using different complementary therapies, some of which were not related to the HIV. Studies have also shown that women living with HIV choose therapies for HIV-related (Creed, 1995; Levy, Foley, & Forer, 1994; McCulloch, Howard, & Ivan, 1999; Pawluch, Cain, & Gillett, 1994) and other reasons (Levy, Foley, & Forer, 1994; McCulloch, Howard, & Ivan, 1999). In this study, unlike other studies, the participants used different frameworks for choosing what therapies to take:
"good health", the "alternative", and the "folk medicine" frameworks. The "good health" framework could have been influenced by the general interest by Canadians in healthy eating (The Canadian Foundation for Dietetic Research, Dietitians of Canada, & Kraft Canada Inc., 1997) as noted by the participants attempts to eat more healthfully. The "alternative" framework may have influenced some of the participants because of a general interest in complementary therapies in the general population (Eisenberg et al., 1993) and especially in persons living with HIV (Fairfield, Eisenberg, Davis, Libman, & Phillips, 1998). Nancy was the only participant who was influenced by the "folk medicine" framework and this may have been due to her older age.

None of the studies in the literature noted that substance use was a barrier to complementary therapy use but some studies, like this study, have noted that poverty was a barrier to complementary therapy use (Creed, 1995; Levy, Foley, & Forer, 1994; Meneilly, Carr, & Brown, 1996; Paterson, Carwein, & Sabo, 1996). In the present study, substance use was a barrier to complementary therapy use because the participants were obligated to purchase the therapies with their own money first, collect receipts for their purchases, and then present the receipts for reimbursement. Those participants with histories of substance use noted that they preferred to spend their money on drugs. The chaotic lifestyle that accompanied substance use also meant that the participants had difficulty in keeping track of their receipts. Another reason why the participants may not have been interested in complementary therapies was because they lacked time and money to seek out the information. These barriers to complementary therapy use have also been noted in another study of women living with HIV (Levy, Foley, & Forer, 1994).

Because complementary therapies were not of keen interest to the participants, it
would be useful for nutritionists to determine each client’s interest and approach to complementary therapies. The participants in this study were using complementary therapies for many reasons, not just for the HIV. Dietitians need to be supportive of the client’s wish to use complementary therapies, if applicable, while ensuring that the use of complementary therapies is not harmful to the client (Fields-Gardner, Thomson, & Rhodes, 1997, p. 56). Even though funding was available to the participants to purchase complementary therapies, some of the women were unable to access it. The reimbursement system for purchasing complementary therapies through the Complementary Health Fund is in place presumably to prevent the funding from being used fraudulently. However, the same system is preventing low-income women living with HIV, who have the most need for funding, from benefitting from it. This system needs to be changed so that persons living on a low income can access it if they wish to purchase complementary therapies.

6.5 Food and Nutrition Documents

Food and nutrition documents available to the participants were analyzed to uncover some of the assumptions about persons living with HIV made by health professionals and other service workers. Because persons living with HIV are not homogeneous, it was hoped that this analysis would result in recommendations that would make nutritional advice for this population more relevant. The appropriateness of documents geared to HIV-positive persons, documents geared to HIV-positive women, and documents geared to low-income persons for this population will be considered, followed by recommendations.

Out of the 3 types of documents, documents specifically aimed at people living on a low income were most appropriate because one of the study entry criteria was receiving income assistance. Low-income documents were easy to read and appropriate for the
participants who had limited education. The low income documents were also available only through a dietitian and six participants got their information about healthy eating, eating for HIV, and/or complementary therapies from a dietitian. Low-income foods were suggested and poverty was assumed to affect food choices. As mentioned previously, poverty was the number one food and nutrition concern of the participants.

However, the low-income documents had some weaknesses. Most of these documents also assumed participants shopped in a store, had cooking and storage facilities and utensils, and could afford a healthy diet. As noted previously, many of the participants accessed food charity organizations extensively. Three of the participants experienced inadequate cooking and/or storage facilities and about half of the participants complained of not being able to afford a healthy diet. Access to transportation and recommendation of heavy items were also assumed in low-income documents despite the fact that the participants expressed difficulties accessing public transit and grocery shopping when using public transit. The low-income documents also assumed that the reader had no dental problems although some of the participants did have problems with their teeth. Time-consuming activities were also recommended in these documents even though the participants often complained of being busy. Finally, the low-income documents assumed that the reader had no problems with substance use despite the fact that the substance use was pervasive among the participants.

Documents geared to HIV-positive persons seemed to be particularly unsuitable for the participants. These documents were difficult to read and were not explained by a dietitian. Some of the participants noted that they had difficulty in understanding and/or obtaining information about complementary therapies and about eating for HIV. About half
of these documents were accessible from an AIDS service organization, however, only four participants obtained information from AIDS service organizations. These documents did not assume that the reader was living on a low income. Access to transportation and lack of dental concerns were also assumed. Time-consuming activities were recommended. Regarding matters of weight, weight loss was assumed to be the problem and suggestions were given on how to gain weight. These concerns were reflective of the HIV concerns that affected many of the participants. Most of the participants, however, were affected by the dominant weight discourse in their perceptions of weight and body shape changes. An interest in complementary therapies was assumed as was the ability to afford them. The participants were not keenly interested in complementary therapies and, despite the funding available to them, had problems affording them due to poverty and substance use. Finally the reader was assumed not to have problems with substance use.

Documents that were geared for HIV-positive women were somewhat more suitable for persons living with HIV because they noted or addressed concerns that were specific to women such as weight issues and special health care issues for women (i.e. osteoporosis). Most of these documents were available from an AIDS service organization although some women were accessing information from a dietitian. Documents for HIV+ women were written at a high reading difficulty but were not explained by a dietitian. It was assumed that the reader was not living on a low-income. Access to transportation and no dental concerns were assumed. Weight loss was assumed to be the concern in most of these documents. Like the documents for HIV-positive persons, documents for women living with HIV recommended time-consuming activities and assumed that the reader could afford complementary therapies. Finally, documents geared to HIV+ women assumed that the
reader had no problems with substance use.

One reason why documents geared to HIV+ persons and HIV+ women may not have addressed low-income concerns and substance use may be the changing demographics of the persons being infected. In the 1980's, the majority of infected individuals were white homosexual males (Strebel, 1995) whereas currently women living in poverty (Provincial HIV/AIDS Strategy Advisory Committee, 1998), injection drug users (Bureau of HIV/AIDS, STD and TB, 1999b; Wong, MacDougall, Patrick, Rekart, & Barnett, 1998), and Aboriginal women (Bureau of HIV/AIDS, STD and TB, 1999c) are being increasingly affected by HIV. Men at the beginning of the epidemic were interested in complementary therapies and nutrition because the number of conventional treatment choices was limited (Abrams, 1990; Dwyer, Bye, Holt, & Lauze, 1988). Like the interests of those persons early in the epidemic, many of the documents geared for HIV+ persons are focused on informing and empowering the reader as to what choices they had for self-therapy. Other concerns that reflect the needs of those who are now being infected are not being met.

The documents could have been improved for low-income women living with HIV. Because of their low educational level, the language in the documents for persons living with HIV and women living with HIV needs to be simplified. Suggestions of what to do would probably be beneficial because the women had little time to sort through information. Suggestions for low-cost foods that are available at food charities as well as a list of food charity organizations with their hours of operation would be useful. Quick and easy foods that do not require refrigeration or cooking should be recommended. Because fresh fruits and vegetables were commonly mentioned as foods that the participants could not afford, suggestions of alternates such as canned or frozen items should be recommended.
Chapter 6: Discussion

Recommendations of foods should also take into account their weight for easy transport. Recommendations of soft foods would be beneficial for those persons who are experiencing dental problems. Because concerns about weight and body shape changes were the second major food and nutrition concern of the participants, weight concerns that are germane to women must be included in these documents. Complementary therapies that are free and available within the community should also be noted so that members of this population may access them. Recommendations of foods that are convenient and information on food charity availability would be constructive for substance users.

6.6 Study Limitations

Because participants were primarily recruited through an HIV clinic, the data would be transferable to other similar populations of women living with HIV with similar characteristics who received treatment through HIV clinics in large metropolitan Canadian cities. Although the number of participants included in a qualitative study is ideally sufficient to saturate the themes that derive from analysis (Patton, 1990, p.185-186), for this study 13 women were interviewed based on the expectations of a Masters degree and my time and resources. The number of women that were included in the study was sufficient to elucidate the major themes of the effects of poverty, substance use, and dominant weight norms and HIV concerns on food and nutrition concerns, however, the inclusion of more participants would have allowed more clarification of minor themes such as the effect of children on food and nutrition concerns.

The study was limited in the manner that the participants were recruited. I relied on the interpretation of the inclusion/exclusion criteria by the HIV clinic dietitian (DP) for recruiting the participants. Although I had discussed the criteria with her, potential
candidates were also chosen on the basis of their concerns (wide-ranging in order to compare and contrast concerns) and their perceived ability to share information. Therefore women who had similar concerns and may have perceived to be less articulate may not have been invited to participate.

Interested participants contacted the investigators by phone, therefore, prospective participants who had no phone may have been excluded. Because of the selectivity of the advertising for the study, women who did not attend the clinic or who did not frequent the support organization for women living with HIV would also not have been aware of the study and would have been excluded. Also, I had difficulties in arranging a second interview with some of the participants because they had moved or were using drugs at that point. In that circumstance, another candidate was chosen who was similar in characteristics to the participant who was lost to the study process.

Interviewing this population was particularly difficult because many of the women were not especially forthcoming or articulate in their responses. Because my background was in such contrast with that of my participants, the interviewing process was made especially difficult. I attempted to close the gap between myself and my participants by dressing appropriately, using simple language, and being accepting of their background of substance use. However, I am not sure how successful I was in making the participants comfortable in speaking with me. As a result, some of the participants may have not discussed in full all their food and nutrition concerns. I was also fairly inexperienced in conducting qualitative interviews although I had taken a preparatory course in “basic interviewing skills”. Compounded with my relative inexperience, I had experience as a dietitian in collecting nutritional information. However, the approach of a dietitian in a
nutrition counselling session was different than that as a qualitative researcher in this study. For example, the question, “what do you eat in the course of a day” might be asked as a dietitian and also in a qualitative interview but the probes resulting from that original question might be different. A dietitian might be more interested in the exact amounts of food consumed whereas a qualitative researcher might be satisfied to know what foods were eaten. I sometimes reverted to questions that were more suitable to a dietetic interview instead of collecting more relevant information. My interest in weight and dieting issues also affected the information I obtained from my participants. Because I strongly believed that I would find that the participants would be affected by the normative weight concerns and HIV fears in their perceptions of weight changes, I did not fully explore with the participants the factors that would allow weight concerns to offset HIV concerns or vice versa.

As previously mentioned, not all the data collected from one of the participants was used in the analysis. About 5% of the data was excluded because it was deemed to be unbelievable, however, these excluded data did not change the overall results.

6.7 Implications for Future Research

Different weight discourses may predominate within different contexts. Although the participants in this study were affected by the dominant weight discourse for women, HIV concerns, and poverty, it is not clear what contexts fostered the dominance of predominant weight concerns over HIV concerns. Further study to determine what factors assist in giving one discourse precedence over another would be useful. Give the dramatic effects of substance use on weight, it would be interesting to explore the possibility of substance use as an intentional weight loss method. One study has suggested that cocaine

190
use has been used as a dieting method (Cochrane, Malcolm, & Brewerton, 1998).

6.8 Conclusions

- Poverty had the most profound influence on the food and nutrition concerns of the participants. Income assistance needs to be increased to meet the special needs of persons living with HIV. Dietitians need to determine what resources are available to these clients to make nutritional advice relevant.

- Weight and body shape changes were the second most predominant food and nutrition concern for the participants. Perceptions of weight and body shape changes which are influenced by dominant weight norms need to be addressed and taken into consideration so that weight goals may be negotiated.

- Low-income women living with HIV may be following different eating patterns, some of which may be inappropriate for the participant's needs. Dietitians need to assess the circumstances of each client individually so that inappropriate eating patterns may be identified and corrected.

- Although the participants were using complementary therapies, there was a lack of interest in them. Health care providers need to assess the interest in these therapies and support their clients' decision to take them while ensuring that the therapies are not harmful.

- Documents that are available for persons living with HIV need to be tailored to the growing number of low-income persons, women, and substance users who are affected by HIV. Concerns about poverty, women's special needs, and substance use need to be addressed in food- and nutrition-related documents.

- Substance use was pervasive among the participants. Given its refractory nature, health
Care professionals need to monitor each client in order to provide appropriate advice. More drug rehabilitation programs would be of use to this population because of the relationship between cessation of drug use and weight gain.
7. References


attitudes and practices of individuals who are infected with human immunodeficiency virus and who live in south Florida. *Journal of the American Dietetic Association*. 93(1), 70-72.


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208


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Appendices

8.1 Appendix A: Recruitment Letters

Recruitment: Individual Interviews with Mary Pilipenko

The Food and Nutrition Concerns of Low-Income Women Living with Human Immunodeficiency Virus/ Acquired Immunodeficiency syndrome (HIV/AIDS)

I am a Graduate student at the University of British Columbia and am doing a study about the food and nutrition concerns of low-income women living with HIV/AIDS. I am doing the study because I want to identify what food-related problems you have experienced.

By talking to you and other HIV+ women, I hope to find suggestions on ways to deal with these problems. I am also interested in the following three areas:
a) how you feel about unintentional weight loss associated with HIV/AIDS,
b) how living on a reduced income and living with HIV/AIDS has affected your life, and
c) how you view complementary therapies.

As part of the study, I will be holding in-depth interviews and participating in community kitchen sessions at the Positive Women’s Network. To participate in the study you must:
1) have been diagnosed with HIV at least 3 months ago,
2) have lived in Canada for at least 4 years, if immigrating from outside of North America,
3) be receiving income assistance under BC Benefits, and
4) have involuntarily lost 5 or more lbs. of your normal body weight.

Volunteering for the study will involve participating in at least on interview (about one hour) with Mary Pilipenko which will be audio-taped. Interviews will be conducted at a location that is mutually agreeable. Following the interview, you will be asked to fill out a brief questionnaire. For your participation, you will be given $25.00 after each interview.

If you are interested in participating in the study, you must give permission to have your name and phone number (if available) released to me (Mary Pilipenko). I will call you and arrange an interview at your convenience. If you do not have a phone, Diana Peabody will arrange the interview time and location with you and will let me know when to meet with you.

Before the interview begins, you must give written permission to be a part of the study. You may refuse to participate or withdraw from the study at any time without
Recruitment: Individual Interviews with Mary Pilipenko and Diana Peabody

The Food and Nutrition Concerns of Low-Income Women Living with Human Immunodeficiency Virus/ Acquired Immunodeficiency syndrome (HIV/AIDS)

I am a Graduate student at the University of British Columbia and am doing a study about the food and nutrition concerns of low-income women living with HIV/AIDS. I am doing the study because I want to identify what food-related problems you have experienced.

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3) be receiving income assistance under BC Benefits, and
4) have involuntarily lost 5 or more lbs. of your normal body weight.

Volunteering for the study will involve participating in at least one interview (about one hour) with myself (Mary Pilipenko) and Diana Peabody which will be audio-taped. Diana will be present, with your permission, so that you will feel more comfortable during the interview. Interviews will be conducted at a location that is mutually agreeable. Following the interview, you will be asked to fill out a brief questionnaire. For your participation, you will be given $25.00 after each interview.

If you are interested in participating in the study, you must give permission to have your name and phone number (if available) released to me (Mary Pilipenko). I will call you and arrange an interview at your convenience. If you do not have a phone, Diana Peabody will arrange the interview time and location with you and will let me know when to meet with you.

Before the interview begins, you must give written permission to be a part of the study. You may refuse to participate or withdraw from the study at any time without affecting your access to community services and ongoing medical care. With your permission, I will find out what current medications you are taking through the BC Drug Treatment Registry. You may refuse to answer any question in the questionnaire. You may refuse to have Diana Peabody present during the interview. All information will be kept confidential.
Appendix B: Informed Consent

b) any unintended weight loss you have experienced,
c) changes you have made in your food choices with regard to income and HIV/AIDS, and
d) your beliefs and feelings surrounding complementary therapies.

The interviews will be audio-taped. At the end of the session, you will be asked to fill out a brief questionnaire so that I will be able to describe the characteristics of the participants. The questionnaire should take about 10 minutes to fill out. I will ask you if you want to have more than one interview to tell "your story".

Confidentiality:
Any information will be kept strictly confidential. Your real name will be coded and you will not be identified by name in any reports of the completed study. All documents will be kept in a locked filing cabinet. Data records will be kept on computer hard drive (accessed by password) and/or on floppy disk (stored in a locked filing cabinet).

Remuneration/Compensation:
For your participation, you will be given $25.00 after the interview.

Contact:
If you have any questions, you may contact Dr. Gwen Chapman at 822-6874. If you have questions about your treatment or rights as a research subject, you can call Dr. Richard Spratley (Director of Research Services, University of British Columbia) at 822-8598.

Consent:
You understand that your participation in this study is entirely voluntary and that you may refuse to participate or withdraw from the study at any time without affecting your access to community services and ongoing medical care. With your permission, information about your current medications will be obtained from the BC Drug Treatment Registry. You may refuse to answer any question in the questionnaire.

You have received a copy of this consent form for your own records. You consent to participate in this study.

Subject Signature Date

Signature of a Witness Date

224
Appendix B: Informed Consent

Study Procedures:
If you agree to participate, I will interview you for about one hour at a mutually-agreeable location. In order to increase your comfort level during the interview and with your permission, Diana Peabody will be present. I will ask questions about:

a) food-related problems you identify,
b) any unintended weight loss you have experienced,
c) changes you have made in your food choices with regard to income and HIV/AIDS, and
d) your beliefs and feelings surrounding complementary therapies.

The interviews will be audio-taped. At the end of the session, you will be asked to fill out a brief questionnaire so that I will be able to describe the characteristics of the participants. The questionnaire should take about 10 minutes to fill out. I will ask you if you want to have more than one interview to tell "your story".

Confidentiality:
Any information will be kept strictly confidential. Your real name will be coded and you will not be identified by name in any reports of the completed study. All documents will be kept in a locked filing cabinet. Data records will be kept on computer hard drive (accessed by password) and/or on floppy disk (stored in a locked filing cabinet).

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You have received a copy of this consent form for your own records. You consent to participate in this study.

Subject Signature Date

Signature of a Witness Date
Appendix C: Semi-Structured Interview Guide

8.3 Appendix C: Semi-Structured Interview Guide

Interview Objectives:
• to describe what food and nutrition concerns and solutions women living with HIV/AIDS perceive,
• to learn how the combined issues of poverty and HIV/AIDS impact on the women's experience of food-related issues,
• to explore the meaning of weight loss associated with HIV/AIDS, and
• to examine the meaning of complementary therapies which are food- and/or nutrition-based.

Thesis Introduction:
I am a Graduate student working on my masters’ degree in Human Nutrition at UBC and I am interested in learning more about the food and nutrition concerns of women living with HIV/AIDS. The information you give me will be useful to other HIV-positive women, support agencies, dietitians and other health care providers in helping you and other women living with HIV/AIDS with food and nutrition concerns. All information will be kept confidential.

Preamble:
Where were you born? How long have you lived in Canada?
Can you tell me about your current living situation?
  Can you describe where you live?
  Do you live with anyone? How long have you lived with them?
  Can you describe what facilities you have for cooking and storing food?
  Do you have any problems with mice, cockroaches, etc.?

Talking about food:
• Could you tell me about any food or nutrition concerns you have?

• Tell me about what you put into your mouth and swallow over the course of a day.
  Drinks?
  Meds?
  Complementary Therapies? (#?, reasons for use?, efficacy?, vs. before dx?, budgeting?, CHF?)
  How do you decide what you will eat?
  How do the people you live with (parents, partners, children) affect how and what you eat?
  How much control do you have over what YOU eat, if living with others?
  What are some of the things that you do just for yourself? To pamper yourself?
  How many people do you cook for?
  How does your eating change when you’re alone vs. eating with someone?
Appendix C: Semi-Structured Interview Guide

Where do you normally eat? (how do you budget eating out?)
What do you consider to be a “proper meal”?
How much of the food that you eat is food that you enjoy?

• Can you describe any food cravings you get?
  How do you satisfy these cravings?

• How healthy is your current diet?
  What does healthy eating mean to you?
  How does this compare to the diet you had before being diagnosed?
  Where do you get information about healthy eating?

• How do you make sure your food is safe to eat?

• What strategies do you use the help you to eat well?
• What would help you eat better?
• What barriers exist for you in terms of eating well?

• What are the recommendations for eating for HIV?
  What barriers prevent you from following them?
• How has being HIV+ changed your body’s food needs?
  How has HIV affected what you eat?
  How has HIV affected how you get your food?
  How do you “keep the shit together”? Explore.

Food and Substance Abuse:

• How has using drugs/alcohol affected your eating?
  Where do you get your food when you’re using?
• How has rehab affected your eating?
  Explore issues of forced eating?
  What happens to your food when your using on and off?

Food and Reduced Income:

• Have you always lived on welfare?
  What factors contributed to your reduced income?
  What level of benefits are you on now?

• Let’s pretend it’s cheque day. You have nothing in the house to eat or drink. How do you get food on that day? What about on the day before cheque day?
  How has being on welfare affected the way you eat?
  How do you budget your money?
  How has living on welfare changed how you see a proper meal?
  How often do you try new foods?
  How do your eating habits change in the beginning vs. the middle vs. the end of the
Appendix C: Semi-Structured Interview Guide

- Where do you get your food? (# times at grocery store?)
  How do you get your food?
  What do you eat when you're short of money?
  How does this differ from how you normally eat?
  When do you waste food?
  Can you describe any time that you've ever shared food or money for food?

- What is your experience in using the food bank? (# of food banks used?) Food lines for free meals?
  How do you feel about using these services?
  How do you decide to use these services?
  Do you feel that these services are of benefit to you besides getting food?
  Which foods do you actually eat? Why?

- Children: How does living on a reduced income and having children affected how you eat?
  Are the children in daycare? School lunch program?
  How do you ensure that your children have enough to eat?

- What is your experience of using BC Transit to get food?

Weight Changes and Body Image:

Start off with a line diagram:
- time of dx
- welfare start
- highest weight, reasons, FEELINGS
- lowest weight, reasons, FEELINGS
- time of SA? (when taken and how taken?)

- What is current weight goal?
- What recommendations have been made to you about your weight?
  Explore discrepancies.
- What do you feel is your best weight? Why?
  If you are not at that weight, how do you feel about not being at that weight?
  How do you feel about your present weight? (Attractiveness?)
  How would you feel if you lost 10 lbs. without trying? (Benefits/disadvantages?)
  How would you feel if you gained 10 lbs. without trying? (Benefits/disadvantages?)
  How do you feel about your attractiveness at your current weight?
  Explore reasons why currently gaining or losing weight and how far they would tolerate that change?
• How do you know if you need to diet?
  What strategies do you use to lose weight? Gain weight?
  Can you describe any reasons you have for wanting to be thin?

• SA: How has using drugs and/or alcohol affected your weight?
  What drugs were/are you using?
  How did you perceive that you looked when you were using?

• What do you discuss when you meet with the dietitian at the Oak Tree Clinic?
  What was their best weight for you?

• How has HIV affected your weight? weight regain???
• How have the HIV meds affected your weight?
• How has your body shape changed since your diagnosis?

Complementary Therapies:

• Can you tell me about your experience of the “Complementary Health Fund”?
  How did you find out about the “Complementary Health Fund”?
  What reasons do you have for not using it? For stopping it?

• What complementary therapies do you use that you eat or swallow? Special diets?
  Before diagnosis?
  How many therapies do you currently use?
  What reasons do you have for not using complementary therapies? For stopping them?
  How much money do you spend on them each month?
  How do you budget for this money?
  How many months a year do you spend money for these therapies?
  How do you feel about buying therapies that you may not use?

• What reasons do you have for using them? (distinguish physical vs. psychological)
  How do you know which complementary therapies to try?
  How has using complementary therapies affected your health?
  Explore if level of perceived sickness affects use of therapies?

• What harm, if any, do you see in using complementary therapies?
  What bad reactions, if any, have you had?
  Which therapies would you avoid? Why?

• How has being HIV+ affected your use of complementary therapies?

Closure:
How did you find the interview? Were there any surprises for you in my questions?
8.4 Appendix D: Food and Nutrition Documents


Appendix D: Food and Nutrition Documents


41. Collection of recipes photocopied from:


   Oddy, R. (1994). Instant chef 2: Simple meals for small budgets (pp. 6-7, 12-17, 21, 30-33, 36-37, 42-45, 71). Edmonton, AL: Grant MacEwan Community College.
8.5 Appendix E: Demographic Questionnaire

Questionnaire for Demographic Information:
This information will help the researchers understand how your characteristics and life's circumstances affect what food and nutrition concerns you have. You may refuse to answer any question in this questionnaire. This questionnaire should take about 10 minutes to complete.

1) When were you born? _______ year _______ month _______ day

2) What was the highest level of education you have completed?

3) What ethnic group or family background do you identify with?
   - Caucasian/White
   - Chinese
   - South-Asian (e.g. Indian, Pakistani)
   - Other Asian (e.g. Vietnamese, Japanese)
   - Latin American
   - Middle Eastern
   - Black-African
   - Black-Caribbean
   - First Nations
   - Other

4) How tall are you? _______ feet _______ inches

5) How much do you weigh? _______ lbs.

6) How long have you been receiving income assistance under BC Benefits?

7) What are the first three digits of your postal code?

8) Are you taking any medications for HIV/AIDS?
   - no
   - yes (If yes, please list them)

9) When were you diagnosed with HIV? _______ year _______ month
Appendix E: Demographic Questionnaire

10) Do you know your last CD4 count?
   □ No
   □ Yes (If yes, please indicate the approximate range:
       □ 0-50
       □ 51-200
       □ 201-500
       □ 501-999
       □ >1000)

Thank you for your participation.