

DISSERTATION

BARRIERS TO NUTRITION MANAGEMENT AMONG PEOPLE LIVING
WITH HIV ON ANTIRETROVIRAL THERAPY

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In partial fulfillment of the requirements

For the Degree of Doctor of Philosophy

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Summer 2011

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ABSTRACT

BARRIERS TO NUTRITION MANAGEMENT AMONG PEOPLE LIVING WITH HIV ON ANTIRETROVIRAL THERAPY

Human Immunodeficiency Virus (HIV) is a virus that attacks and impairs the body's natural defense system against disease and infection, in part through depletion of individual nutrients that are also implicated in malnutrition and potential weight loss. Many nutritional problems among people living with HIV can be managed via nutrition counseling, which is often lacking or inconsistent in primary healthcare. No wide scale evaluation of HIV patient access or adherence to comprehensive nutrition intervention exists; however, there are potential barriers among patients to following nutrition advice from healthcare providers even when delivered.

An online questionnaire among healthcare providers, along with focus groups and semi-structured interviews among patients living with HIV at three healthcare settings in Colorado were utilized in the current study in an effort to identify the barriers to nutrition management among people living with HIV. In accordance with an Interpretative Phenomenological Analysis approach, four stages of data analysis were undertaken to analyze the text for patterns, trends, and themes that emerged and developed from the participants' responses. The analysis used questionnaire data and personal, in-depth detail derived from individual and focus group interviews to describe patients' and healthcare providers' experiences of barriers to HIV-related nutrition management.

Healthcare providers who answered the questionnaire thought that nutrition education was important in the management of HIV, and attempted to give well-rounded and consistent advice to patients. They were, however, limited in the amount of education they could provide based on a lack of time and in-house referral services, and the co-occurrence of multiple illnesses among patients that demanded time and energy during appointments. HIV-positive patients who were interviewed individually or via focus groups reported that they felt their primary healthcare providers generally gave fair dietary advice, and said they tried to manage diet as best they could by monitoring the safety of their food and maintaining a balanced diet low in fat, salt, and processed sugars. Patients were limited in their ability to optimally manage their diet based on finances and transportation available for acquiring food, side effects associated with ARV (antiretroviral) medications, and their own cooking and meal planning skills. All patients said they would participate in the opportunity to learn more specific nutrition management techniques (e.g., cooking, shopping, balancing food with illness) if education were available and accessible. The nature of the barriers identified in the current study suggested a systems approach to optimizing nutrition management may be an appropriate future direction of action.

TABLE OF CONTENTS

| | |
|--|------|
| ABSTRACT | ii |
| LIST OF TABLES | viii |
| CHAPTER 1: INTRODUCTION | |
| Background of the Problem | 1 |
| Purpose of the Study | 4 |
| Research Questions | 6 |
| Theoretical Lens | 7 |
| Organization of the Paper | 8 |
| CHAPTER 2: REVIEW OF THE LITERATURE | |
| Clinical Factors, Nutrition, and HIV | 9 |
| Nutrition and Immunity | 9 |
| Nutrition and Weight Loss | 10 |
| ARV-Related Issues | 11 |
| Food-Related Side Effects | 12 |
| Metabolic Effects | 12 |
| Social Factors, Nutrition, and HIV | 13 |
| Food Insecurity | 13 |
| Dietary and Lifestyle Recommendations for People Living with HIV ... | 14 |
| Standard Nutrition Therapy Protocols for Clinicians | 17 |

| | |
|---|----|
| Potential Barriers to Receiving and Adhering to Recommendations | 18 |
| Summary..... | 21 |
| CHAPTER 3: THEORETICAL FRAMEWORK | |
| Relevant Models of Health Behavior Change | 22 |
| The Information, Motivation, Behavioral Skills (IMB) Model | 24 |
| Summary..... | 26 |
| CHAPTER 4: METHODOLOGY | |
| Research Design..... | 27 |
| Phenomenology..... | 27 |
| Interpretative Phenomenology | 27 |
| Study Overview | 29 |
| Ethical Considerations | 29 |
| Data Collection | 31 |
| Sampling | 31 |
| Participants..... | 33 |
| Procedure | 33 |
| Interview Strategy | 34 |
| Instrumentation | 36 |
| Data Analysis..... | 37 |
| Trustworthiness..... | 40 |
| Consistency | 40 |
| Truth Value | 43 |
| Neutrality | 45 |

| | |
|--|----|
| Summary | 46 |
| CHAPTER 5: RESULTS | |
| Review of the Study Purpose | 48 |
| Healthcare Provider Demographic Summary | 49 |
| Healthcare Provider Themes | 49 |
| Nutrition Education Perceptions | 49 |
| Nutrition Education Practices | 51 |
| Influences on Nutrition Education | 53 |
| Patient Demographic Summary | 55 |
| Patient Themes | 56 |
| Perceptions about Nutrition and HIV | 56 |
| HIV-Related Eating Habits | 59 |
| Influences on Nutrition Management | 63 |
| Learning Opportunities | 67 |
| Summary | 69 |
| CHAPTER 6: DISCUSSION | |
| Review of Results | 71 |
| Barriers to HIV-Related Nutrition Management | 75 |
| Theoretical Elements | 81 |
| Limitations and Delimitations | 83 |
| Future Directions | 86 |
| Summary | 89 |
| REFERENCES | 92 |

| | |
|---|-----|
| APPENDIX A: Notice of IRB Approval | 124 |
| APPENDIX B: Recruitment Brochure | 126 |
| APPENDIX C: Informed Consent Form | 127 |
| APPENDIX D: Confidentiality Agreement..... | 130 |
| APPENDIX E: Demographics Questionnaire | 131 |
| APPENDIX F: Interview/Focus Group Protocol..... | 133 |
| APPENDIX G: Healthcare Provider Survey | 135 |
| APPENDIX H: Codes, Themes and Sub-themes: Providers | 136 |
| APPENDIX I: Codes, Themes and Sub-themes: Patients | 138 |

LIST OF TABLES

| | |
|--|----|
| Table 1. Patient and Provider Demographic Summary | 47 |
| Table 2. Patient Antiretroviral Medication Prescriptions | 90 |
| Table 3. Summary of Themes | 91 |

Chapter 1: Introduction

Background of the Problem

The latest available epidemiologic data indicate that the number of people living with Human Immunodeficiency Virus (HIV) in the United States has continued to rise over the past two decades to a current 1.1 million, and that the incidence, or number of new infections has remained fairly steady since the early 1990s (56,000 per year; Moore, 2011; UNAIDS, 2009). Furthermore, AIDS-related deaths have decreased dramatically, dropping from around 50,000 per year in the mid-1990s to an estimated 18,000 per year currently (Centers for Disease Control; CDC, 2009). Increased longevity for an increasing number of people living with HIV is certainly an important local and global health priority. However, prolonging life can present challenges to disease management due to a number of clinical and social issues associated with HIV. If such trends continue it will become increasingly important to identify ways to refine and maintain long-term management of HIV for an ever-multiplying number of individuals.

The advent of antiretroviral medications (ARV) have been cited as the most dramatic development in the management of HIV, and are largely responsible for declines in AIDS-related deaths despite increases in new diagnoses (U.S. Department of Health & Human Services, 2002). ARVs support sustained cessation of HIV replication (i.e., therapy stops the virus from making copies of itself), often resulting in undetectable levels of plasma viral load which in turn is associated with reduced rates of hospitalization, opportunistic infections, progression to AIDS, and death (Lima et al., 2009; Pradier et al., 2001; Roca, Gomez, & Arnedo, 2000). However, side effects such as

nausea and vomiting, as well as metabolic complications involving unbalanced glucose and lipid metabolism, have been associated with the use of certain ARV drugs and can lead to compromised nutritional status (Shevitz & Knox, 2001).

ARV-related nutritional consequences can coalesce with the inherent aggravation between infection and malnutrition to complicate nutritional management of HIV, bringing dietary issues to the forefront of HIV management concerns (Fields-Gardner & Campa, 2010). Malnutrition and HIV have similar effects on the immune system, including reduced CD4 and CD8 T-lymphocyte numbers and general bactericidal properties (i.e., a reduced ability of the body's immune system to identify and kill infectious agents; Chandra, 1999; Suttajit, 2007). When people infected with HIV fail to meet their nutritional needs, decreased immunity associated with both the virus itself and malnutrition leads to increased susceptibility to opportunistic infections, which in turn can lead to more malnutrition. As such, both malnutrition and lowered immunity are important predictors of poor health and possible progression of HIV to AIDS (Semba & Tang, 1999).

In addition to the clinical issues described above, there are social issues that affect the ability to acquire the kind of food needed to maintain optimal health among people living with HIV. Food insecure HIV-positive individuals do not have both physical and economic access at all times to sufficient food to meet their dietary needs for a productive and healthy life. Achieving a food-secure state is contingent on food being available, accessible, and utilized by the body (Bonnard, 2002). People with HIV often identify their highest priority need as food (FANTA, 2007). Being infected with HIV can limit productivity, leading, in turn, to loss of income while health care costs continue to

increase (Boudreau & Holleman, 2002). Research indicates that food insecurity is more likely to occur in racial and ethnic minorities, low-income families, and households with children (Nord, Andrews, & Carlson, 2006). The current demography of HIV infection thus intensifies food insecurity; the poor, minority racial/ethnic groups, and women account for a greater proportion of infections than ever before (Moore, 2011). Moreover, lower income can affect food choices and the ability to follow dietary recommendations (Franco et al., 2009; Mello et al., 2010). Low or decreased income is also related to individual or family location of residence, which may impact food accessibility. Food insecurity is a significant problem for people living with HIV in the United States (Weiser, Bangsberg et al., 2009) and can result in outcomes that are especially problematic for this population (Campa et al., 2005; Parker, Widome, Nettleton, & Pereira, 2010; Weiser, Fernandes et al. 2009, Weiser et al., 2008).

As reviewed above, food-related clinical and social factors clearly contribute to substandard health problems such as immunologic complications and greater risk for disease (Faintuch, Soeters, and Osmo, 2006; Seligman, Laraia, & Kushel, 2010). Such problems are an important cause of morbidity and a compromised quality of life in individuals infected with HIV (Malvy, Thie´baut, Marimoutou, & Dabis, 2001; Seumo-Fosso et al., 2005). In recognition of such documented nutrition-related health risks, the American Dietetic Association (ADA) has long advocated nutrition education to HIV-positive patients during primary care visits (ADA, 1998). However, discussion of nutrition and other prevention issues relevant to people living with HIV has been demonstrated to be inconsistent in primary healthcare (Drainoni, Dekker, Lee-Hood, Boehmer, & Relf, 2009; Morin et al., 2004; Pereyra, Metsch, & Gooden, 2009). Even

when nutrition education is present during primary care visits there are multiple reasons why patients with various illnesses may not follow their healthcare providers' recommendations (Agondi, Gallani, Rodrigues, & Cornelio, 2011; Correia, Pinhao, Poinhos, de Oliveira, & Galvao-Teles, 2009; Heo, Lennie, Moser, & Okoli, 2009; Whitfield-Brown, Hamer, Ellahi, Burden, & Durrington, 2009). Extensive research has been conducted among HIV-positive patients to explore reasons why they may not adhere to ARV medication regimens (For reviews, see Geocze, Mucci, de Marco, Nogueira-Martins, & de Albuquerque Citero, 2010; Lovejoy & Suhr, 2009; Malta, Magnanini, Strathdee, & Bastos, 2010). There is relatively little exploration, however, of whether they either receive or adhere to nutritional recommendations from primary healthcare providers.

Purpose of the Study

As people with HIV live longer and new cases of infection continue to be added each year, the prevalence of HIV in the United States will continue to escalate. Nutritional intervention is critical because of a unique combination of health consequences related to long-term ARV medication use, the vicious cycle of malnutrition and immunity, and to the threat of food insecurity among HIV-infected individuals. Although endorsed by the ADA, the frequency and content of nutrition education and counseling in HIV primary care is unclear. Even if provided, little is known about patient adherence to healthcare provider advice about the dietary behavior necessary for optimal management of HIV. Thus, the purpose of this interpretative phenomenological study was to describe the barriers to HIV-related nutrition management among patients and healthcare providers at three different healthcare settings in Colorado. The specific goal

for the current research was to explore patients' and healthcare providers' perceptions, experiences and interpretations of nutrition as it relates to HIV. For the purpose of the current research, adoption and integration of dietary and lifestyle recommendations related to nutritional management was referred to as 'adherence'.

A qualitative interpretive phenomenological analysis (IPA) approach was appropriate to the current study. IPA is about exploring people's everyday experiences of reality, in great detail, in order to gain an understanding of the phenomenon in question (McLeod, 2001). In a typical IPA study, the researcher identifies a phenomenon of interest, collects data from individuals who have experienced the phenomenon, and develops a composite description of the essence of the experience for all of the participants (Willig, 2001). In addition to describing the phenomenon itself, another primary characteristic common among qualitative methods is the emphasis on process; the ways in which features of a specific situation or setting influence the phenomenon being explored and how outcomes are achieved. Because qualitative research focuses on the study of process, it doesn't have the ability to provide evidence about cause and effect or outcomes in the traditional sense. However, from a clinical perspective it can produce insight into why particular interventions and attempts at implementation are successful or not (Barbour, 2000). According to Harding & Gantley, 'qualitative research can offer an understanding both of social processes and how they may be modified in the pursuit of desired ends' (Harding & Gantley, 1998, p. 79).

Most clinical professions are currently under pressure to utilize a more 'evidence-based' agenda. Despite this push to base clinical methods on quantitative results, those involved in direct practice often rely heavily on evidence from qualitative sources in their

daily work (Flemming, Adamson, & Atkin, 2008; Hopper, Morris, & Tickle, 2011; Murdach, 2010; Neumann et al., 2009). Qualitative IPA is thus an apt methodology for the exploration of perceptions, experiences and interpretations of nutrition among healthcare providers and HIV-positive patients. Such an approach can describe the phenomenon of nutrition management, along with the difficulties and barriers encountered by patients and providers in an effort to inform future clinical methods of nutrition intervention.

Research Questions

To meet the specific goals of the current study delineated above, the following research questions were addressed:

1. What are healthcare providers' perceptions about nutrition as it relates to HIV?
2. What do healthcare providers advise HIV-positive patients to do with regards to nutrition?
3. What makes it either easy or difficult for healthcare providers to deliver nutritional recommendations to patients with HIV?
4. What are HIV patients' perceptions about nutrition as it relates to HIV?
5. What dietary practices do HIV patients engage in, relative to being infected with HIV?
6. What makes it either easy or difficult for patients with HIV to manage nutrition as it relates to HIV?
7. What kinds of information about nutrition would HIV patients find useful to help manage their diet?

Theoretical Lens

Management of HIV is optimized through positive health behaviors that include nutritional maintenance and adherence to ARV medications. The information-motivation-behavioral skills model of health behavior change is based on integration of theory in social and health psychology (IMB; J. D. Fisher & Fisher, 1992a, 2000, 2002; W. A. Fisher & Fisher, 1993), and has been used to understand adherence to ARV regimens as well as a number of other health promotion behaviors relevant to HIV (Amico, Toro-Alfonso, & Fisher, 2005; Fisher, Fisher, Amico, & Harman, 2006; Fisher, Fisher, & Harman, 2003; Osborn, Amico, Fisher, Egede, & Fisher, 2010; Starace, Massa, Amico, & Fisher, 2006). Within the model, information, motivation, and behavioral skills are fundamental determinants of behavior change; if individuals are well-informed about what they should be doing to maximize health, are motivated to do so, and possess the necessary skills they are more likely to engage in prescribed health behaviors over time.

From both an individual and public health perspective, it is helpful to explore HIV-positive patients' experiences and interpretations of nutrition management within the framework of the IMB model. Although many qualitative studies describe the phenomena under study without orientation to social science theory, doing so can often derive arguments which are theoretically generalizable and thereby provided added value (Barbour, 2000). To this end, framing the understanding of how patients perceive nutrition as it relates to HIV within the context of informational, motivational, and behavioral skill factors that may be necessary for changing dietary behaviors facilitates its application to constructing, implementing, and evaluating nutrition management interventions (Fisher & Fisher, 1992b).

Organization of the Paper

This dissertation is divided into six chapters. Chapter One includes a background of the research problem, the purpose of the study research questions, and offers a theoretical lens through which to frame the exploration and results. Chapter Two presents a review of the literature. Chapter Three describes the theoretical framework more in depth and compares the proposed model to other pertinent models of health behavior change. Chapter Four explains the research methodology used in the current qualitative study, including data collection methods, the analysis process, and steps taken to ensure trustworthiness. Chapter Five presents the findings. Chapter Six provides a review of results, how they map on to theoretical elements described in Chapter Three, limitations of the findings, and potentials for future research.

Chapter 2: Review of the Literature

Clinical Factors, Nutrition, and HIV

Nutrition and Immunity. It is the position of the ADA that in addition to ARV routines, optimization of nutritional status is a vital component of health care available to those living with HIV/AIDS (Fields-Gardner & Campa, 2010). At the outset, HIV is a virus that attacks and impairs the body's natural defense system against disease and infection. An HIV-infected person's defense system thus becomes vulnerable over time to other viruses that further weaken the body and cause symptoms and illnesses like diarrhea, fever, vomiting, thrush, or anemia (Seumo-Fosso et al., 2005). These kinds of ailments give rise to depletion of individual nutrients that are implicated in malnutrition, including vitamins A, E, C, B₆ and B₁₂, as well as zinc (Zn), Selenium (Se) and iron (Fe) (Chandra, 1999; de Pee & Semba, 2010). By and large, the synergistic relationship between HIV and malnutrition results in a deleterious cycle for the immune system. Nutrient depletion leading to generalized malnutrition causes widespread atrophy of lymphoid tissues, the greatest of which is in the T-lymphocyte areas. Such atrophy results in immunosuppressive effects including a decrease in the number and function of T-helper (CD4) cells, an inverted T-helper/T-suppressor (CD4:CD8) ratio, and loss of the ability of killer lymphocytes to recognize and destroy foreign tissues (Beisel, 1996; Chandra, 1999; Jain & Chandra, 1984). In other words, the bodies of those with malnutrition have fewer and less active T-lymphocytes that are needed to enhance the immune response to infection. Malnutrition is also associated with the presence of many

of other types of lymphocytes (T-suppressor cells) that normally suppress the immune system to keep it in balance. Decreased immunity may lead to increased susceptibility to infections, which lead to increased nutrient requirements. If such requirements are not sufficiently met, the result is even more malnutrition, and increased potential for secondary infections by opportunistic agents (Jain & Chandra, 1984; Seumo-Fosso et al., 2005).

Nutrition and Weight Loss. Clearly, the interaction between HIV and malnutrition threatens the immune system. Another way the two interact to produce health risk is through significant weight loss or wasting (weight loss \geq 10% of body weight). Wasting has been shown to be a significant predictor of HIV progression to AIDS (Malvy et al., 2001). Increases in resting energy expenditure (REE), reductions in food intake, and nutrient malabsorption and loss culminate in weight loss and wasting common in AIDS. REE is the amount of calories needed by the body during a non-active 24-hour period, and is believed to be increased in HIV due to immune system changes that lead to increased protein metabolism (Colecraft, 2008). In non-HIV related cases of malnutrition, the body responds with a compensatory drop in REE to preserve its lean mass (Batterham, 2005). Attempts have been made to understand if REE is chronically elevated in malnourished people living with HIV, or whether nutrient malabsorption or the decreased energy intake inherent to HIV are more important contributors to significant weight loss (Batterham, 2005; Jiménez-Expósito et al., 1998; Macallen, 1999a; Salas-Salvadó & Garcia-Lorda, 2001). A meta-analysis of such studies indicates that REE is significantly higher in HIV-positive patients than in non-infected controls. However, some suggest that weight loss is driven by a decrease intake due to poor

appetite, or lack of desire to eat due to gastrointestinal complications or dental problems (Salas-Salvadó & Garcia-Lorda, 2001).

Still others have shown that HIV patients' difficulties absorbing nutrients from food are associated with weight loss beyond what can be accounted for by REE (Jiménez-Expósito et al., 1998). Several micronutrient deficits are recognized to occur with HIV infection due to malabsorption, especially vitamins A, E, C, B₆ and B₁₂, selenium, zinc, and iron (Drain, Kupka, Mugusi, & Fawzi, 2007; Fawzi, Msamanga, Spiegelman, & Hunter, 2005; Jones et al., 2006; Salomon, De Truchis, & Melchior, 2002; Suttajit, 2007). There is evidence that weight and other clinical outcomes (i.e., viral load and CD4 counts) are substandard in individuals with compromised levels of these nutrients (Faintuch et al., 2006; Macallan, 1999b; McDermid & Prentice, 2006; Webb & Villamor, 2007). Although some studies suggest that micronutrient levels are less likely to be low among HIV-positive patients already taking ARVs (Jones et al., 2006), micronutrient maintenance has proven to be beneficial in maintaining weight and delaying HIV progression (Fawzi, Msamanga, Spiegelman, & Hunter, 2005). It is likely that interactions between REE, food intake, and micronutrient levels in addition to other potential confounders (i.e., additional opportunistic infections) contribute to the problem of weight loss among those with HIV.

ARV-Related Issues. Since the advent of ARV medications, the outlook for survival rate among HIV-positive patients in developed countries has jumped from approximately 10 years to about 40 years post-diagnosis (Cooper, 2008). HIV uses three viral enzymes for its replication: reverse transcriptase, protease, and integrase. ARV drugs work by targeting viruses at key stages and suppressing their replication (Ghosh,

Ghosh, & Chawla, 2011). Currently available ARVs target the reverse transcriptase and protease enzymes. They are divided into six classes: nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, protease inhibitors, fusion inhibitors, entry inhibitors, and integrase inhibitors (Fields-Gardner & Campa, 2010). Dual-class fixed-dose combination drugs also exist that allow for fewer pills or once daily doses (Ghosh et al., 2011). Beneficial as they are, antiretroviral (ARV) drugs pose challenges to nutrition and metabolic processes.

Food-Related Side Effects. ARV drugs may interact with food (FANTA, 2004), with other ARVs, or with drugs used to treat opportunistic infections (Anabwani, & Nazario, 2005) in ways that impact the nutritional and metabolic status of people living with HIV. One kind of non-nucleoside reverse transcriptase inhibitor is associated with central nervous system changes and side effects that can affect food intake (LAHIVC, 2002). Protease inhibitors often cause nausea and diarrhea, and nucleoside reverse transcriptase inhibitors are associated with nausea, anemia, and fatigue (Anabwani & Nazario, 2005). In addition to impacting adherence to ARVs, such side effects also influence people's desire to eat, or to only be inclined to eat certain foods (Johnson, Dilworth, Taylor, & Neilands, 2011; Mohammadpour, Yekta, & Nasrabadi, 2010). Extended bouts of vomiting and diarrhea in immunocompromised patients are a major challenge for the treatment and prevention of wasting due to resulting malabsorption of nutrients (Drain et al., 2007).

Metabolic Effects. The clustering of risk factors for cardiovascular disease and diabetes comprises metabolic syndrome. Risks of long-term use of ARV medications include these same metabolic problems due to lipodystrophy, which is associated with all

classes of ARVs (Chen, Misra, & Garg, 2002). Lipodystrophy is characterized by redistribution of body fat from the face and extremities to the midsection and upper back (McDermott et al., 2001), and is implicated in the development of insulin resistance and related metabolic complications such as impaired glucose tolerance and dyslipidemia (Chen et al., 2002; Farley et al., 2005; Gelato, 2003; March et al., 2010; San Francisco AIDS Foundation, 2006; Shikuma et al., 2007; Wanke, Gerrior, Hendricks, McNamara, & Schaefer, 2005). Over the long term, impaired glucose tolerance can be a precursor to pre-or Type 2 diabetes. Dyslipidemia involves elevation of plasma cholesterol (LDL) and triglycerides and a low high density lipoprotein (HDL) level, all of which contribute to the development of hypertension and related cardiovascular disease (Chen et al., 2002; Manfredi & Calza, 2009; Neumann, Lulsdorf, Krings, Reinsch, & Erbel, 2011).

Social Factors, Nutrition, and HIV

Food Insecurity. Food insecurity occurs when there is uncertainty about future food availability and access, insufficiency in the amount and kind of food required for a healthy lifestyle, or the need to use socially unacceptable ways to acquire food because of resource or physical constraint (National Research Council, 2006). The prevalence of food insecurity among people living with HIV has been found to be substantially higher than that of both the general population, and other populations including the homeless and individuals with very low income levels (Anema et al., 2011; Weiser et al., 2009). Individuals with HIV may be at an increased risk for food insecurity when a limited ability to work leads to income and health insurance loss while health care costs continue to increase (Boudreau & Holleman, 2002; Weiser et al., 2009). People with lower incomes are less likely to be able to either afford or access nutritionally appropriate foods

(Franco et al., 2009). In a recent study, predominantly black and lower-income neighborhoods had a lower availability of healthy foods than white and higher-income neighborhoods due to the differential placement of types of stores as well as differential offerings of healthy foods within similar stores (Franco, Diez-Roux, Glass, Caballero, & Brancati, 2008; Hendrickson, Smith, & Eikenberry, 2006).

The impact of food insecurity for the general population includes both poor nutritional status and obesity (Parker, Widome, Nettleton, & Pereira, 2010). Among people living with HIV it has the additional consequences of reduced body mass, lower CD4 cell counts and odds of virologic suppression, and higher risk of metabolic syndrome and mortality (Campa et al., 2005; Parker et al., 2010; Weiser, Fernandes et al. 2009, Weiser et al., 2008). Such problems can be caused by food choices and food-preparation methods, including low fruit and vegetable consumption and a lack of fat-lowering behaviors (Dammann & Smith, 2010; Mello et al., 2010). Foods that are inexpensive and easily accessible tend to be energy dense and have low nutritional value. Although such foods allow people to avoid hunger and maintain caloric requirements, they may also be high in refined grains and added sugars which contribute to hyperglycemia, hypertension, and dyslipidemia (Parker et al., 2010). Moreover, food insecurity may compromise ARV treatment efficacy and is associated with lower levels of ARV adherence (Weiser et al., 2008).

Dietary and Lifestyle Recommendations for People Living with HIV

Many clinical nutritional and metabolic problems can be managed via nutrition intervention. Because the biggest nutritional concerns for those with HIV are immunologic threat and weight loss, nutrition recommendations focus on maintaining

basic nutrition, minimizing the consequences of gastrointestinal disorders and other side effects, managing metabolic problems, and reducing the incidence of opportunistic infections. Maintaining adequate nutritional status means consuming a variety and adequate quantity of foods to meet energy, protein, and micronutrients needs. People living with HIV are encouraged to eat a balanced and diverse diet (i.e., starchy staples, cooked legumes, nuts and nut butters, animal foods, fat and oil, fruits, and vegetables), as this will ensure that the individual consumes sufficient nutrients to meet energy requirements, normalize weight, and ensure the body's proper functioning (FANTA, 2004; Polo et al., 2007). The use of micronutrient supplements among individuals on ARVs has been met with mixed success, and there is not sufficient data to yet state that micronutrient augmentation is beneficial for such individuals (Drain et al., 2007; Fawzi et al., 2005; Jones et al., 2006)

The gastrointestinal side effects of ARVs (i.e., nausea, vomiting, or diarrhea) can have a significant effect on dietary intake among HIV-positive individuals (for a review, see Fields-Gardner et al., 2004; Fields-Gardner & Campa, 2010), and providing specific strategies to support patients through these challenges is an important part of nutrition therapy. The primary recommendations for symptom management are to drink plenty of fluids, eat small, frequent meals, to avoid lying down after eating, to maintain regular exercise, and to eat softer foods if pain or chewing is an issue (FANTA, 2004).

The prevailing recommendations for metabolic complications have been to monitor anthropometric measurements and to follow the guidelines established for lipid disorders, diabetes, and hypertension (Blanco et al., 2010; LAHIVC, 2002). To counteract dyslipidemia and insulin resistance, dietary fat restriction and increased

physical activity, particularly aerobic exercise, are encouraged (Blanco et al., 2010). The lowering of serum triglycerides is managed by recommending resistance exercise (Chen et al., 2002). Increased doses of ω -3 polyunsaturated fatty acids from concentrated fish oil may also effectively lower plasma triglyceride concentrations and do not thus far appear to have a negative effect on ARVs in clinical trials (Chen et al., 2002; McComsey, 2006). Newer antiretroviral regimens using metabolic-friendly agents are also a possibility for some patients, as long as suppression of viral replication is not compromised (Blanco et al., 2010).

In addition to nutritional and metabolic concerns, immunocompromised people have an increased risk of contracting foodborne illness and should take specific precautions with regard to food (ODPHP, 2009). Food and waterborne illnesses can cause diarrhea, nausea, and vomiting that can lead to weight loss and thus contribute to the morbidity and mortality of people living with HIV (Hayes, Elliot, Krales, & Downer, 2003). Such illnesses can be the source of secondary infections by either supporting growth of some pathogens, or simply by serving as a means of transmission. Either way, people with HIV are more susceptible to such illness because of their weakened immune system (Hayes et al., 2003).

Recommendations for increasing food safety to avoid foodborne illnesses in the general population emphasize thorough cooking of meat and seafood to safe temperatures ($\sim 170^{\circ}\text{F}$), keeping raw and cooked foods separate, washing hands, surfaces, and utensils used for foods with hot soapy water, and refrigerating perishable foods or leftovers promptly (ODPHP, 2009). A panel of food safety experts also identified behaviors of special importance in reducing the risk of foodborne illness for immune-compromised

people (Kendall, Medeiros, Hillers, Chen, & DiMascola, 2003). Specifically, this population should eat hot dogs and lunchmeats that have been reheated to steaming, and should avoid raw seafood or sprouts, stay away from soft cheeses, smoked fish and deli salads, and avoid anything containing raw eggs. People living with HIV should also drink only pasteurized milk and fruit juices, and eat only cheese and yogurt made from pasteurized milk (Kendall et al., 2003).

Food interaction and food timing guidelines are also typically provided during nutrition counseling. Several supplements, such as garlic, grapefruit, or St. John's Wort, should not be used while taking ARV drugs. Furthermore, specific recommendations exist for timing food and medications; some ARVs should be taken with a meal and others are best taken on an empty stomach (FANTA, 2004). Antiretroviral studies have revealed that if nelfinavir, a protease inhibitor, is taken with food versus an empty stomach, drug levels in the blood as much as double; this effect has been demonstrated to increase the number of individuals with undetectable viral loads from 58.8 to 80.5% after one year (Clay, 2003).

Standard Nutrition Therapy Protocols for Clinicians

The Bureau of Primary Health Care recognize nutritional requirements and challenges among those living longer with HIV, and the Standards of Care Committee of the Los Angeles County Commission on HIV advises specific medical nutrition assessment and education for patients with HIV as a part of their total health care program (ADA, 1998; BPHC, 1997). Such clinical practice guidelines are beneficial for both patient and clinicians. They have the potential to improve patient outcomes and improve the consistency of care, as well as to offer explicit recommendations for

clinicians who are uncertain about how to proceed (Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). The primary goals of nutrition therapy are to optimize nutrition status and overall well-being, to prevent specific nutrient deficiencies and weight loss, to maximize the effectiveness of ARV medications, and to minimize health care costs (LAHIVC, 2002). The recommended therapy (ADA, 1998) consists of six components. *Screening* identifies individuals in need of medical nutrition therapy based upon specific criteria, including but not limited to weight status, food intake, symptomatology (i.e., diarrhea, nausea, vomiting), blood lipids, and financial ability to meet nutritional needs. Depending on state requirements, healthcare providers may provide *referral* to a registered dietitian with a prescription that includes the diagnosis and outcome desired. Nutrition *assessment* guides the development of an individualized plan based on information derived from the original screening, and other potential physical or psychosocial factors such as exercise/activity levels or alcohol/drug use patterns. Based upon assessment, nutrition *intervention* provides self-management training and appropriate referrals to other medical professionals or community resources. Dietitians should maintain *communication* with the referring primary healthcare provider regarding assessment and intervention strategies, and subsequent patient progress should be measured in order to *evaluate* treatment success (ADA, 1998).

Potential Barriers to Receiving and Adhering to Recommendations

With recommended nutrition assessment and education guidelines in mind, healthcare providers have reason to offer dietary and lifestyle recommendations to their HIV-positive patients. Providing the prescribed nutritional protocol is critical for management of the progression of HIV, but some suggest that nutrition and other

prevention counseling may be lacking or inconsistent in primary care (Harting, Rutten, Rutten, & Kremers, 2009; Kates, Sorian, Crowley, & Summers, 2002; Morin et al., 2004; Pollak et al., 2008). At the outset clinical nutrition practice guidelines appear to offer a useful venue for translating evidence into practice. The impact of guidelines on nutrition practice in has however been modest, with physicians spending less time than recommended on nutritional counseling (M. K. Jain et al., 2006; Pollak et al., 2008). Some reasons such guidelines may not be effective are a limited organizational budget, lack of access to specialist services, poor patient prognosis or other priorities of care (Cahill, Suurdt, Ouellette-Kuntz, & Heyland, 2010; Kolasa & Rickett; 2010). Healthcare providers also tend to feel that they have inadequate training in nutrition, and most don't use nutrition-related resources to supplement their knowledge (Wynn, Trudeau, Taunton, Gowns, & Scott, 2010).

Similarly, clinical guidelines for incorporating HIV prevention into routine medical care have been developed (CDC, 2003). A lack of time, training, providers' understanding of their roles, and patient challenges such as mental illness, poverty and illiteracy influence whether prevention counseling is provided (Drainoni et al., 2009; Morin et al., 2004). Provider fatalism in particular (the belief that behavior change among HIV-positive patients is unlikely regardless of prevention counseling) is associated with less prevention counseling at all types of medical care visits (Grodensky et al., 2007; Myers et al., 2007; Steward, Koester, Myers, & Morin, 2006) Comparable barriers may apply to the provision of nutrition education to HIV patients.

Even when provided, people generally have low compliance to recommendations that require changes to lifestyle routines. After counseling or intervention many

individuals eventually fail to completely embrace new habits and revert to old behavior (Aldana et al., 2005; Keogh, Luscombe-Marsh, Noakes, Noakes, Wittert, & Clifton, 2007). Despite multiple studies demonstrating the relationship between the success of drug protocols and adherence to them in the management of HIV infection and other diseases (CDC, 2009), inadequate patient adherence continues to be one of the most frequent reasons for poor treatment outcomes and lack of sustained treatment benefits (Conway, 2007). A multitude of factors are known to influence patient adherence to ARVs and other medication regimens. Barriers to adherence to ARV drugs typically include pill burden, dosing complexity, and side effects (Altice & Friedland, 1998; Altice, Mostashari, & Friedland, 2001; Andrews & Friedland, 2000; Conway, 2007). However, there is comparatively little research exploring factors pertinent to nutritional adherence among HIV-positive patients.

No wide scale evaluation of HIV patient adherence to comprehensive nutrition intervention exists; however, there are potential barriers to following nutrition advice from healthcare providers in general (Klein et al., 1997; Fields-Garner et al., 2004). Potential obstacles include knowledge and understanding of basic nutrition concepts or medication-nutrition interactions (Athearn et al., 2004; Hoffman et al., 2005), dietary cultural behaviors and ethnic beliefs (Abdale & Kraak, 1995; Torres, Zive, Scolari, Olshefsky, & Zuniga, 2008), and food-preparation skills (Caraher, 1999; Caraher, Dixon, & Lang, 1999). Research in nutrition further suggests that motivational factors such as a lack of interest in cooking (Hartman, McCarthy, Park, Schuster, & Kushi, 1994), attitudes toward and perceived benefits of food recommendations (Athearn et al., 2004; Hoffman

et al., 2005) and family support or expectations (Albarran, Ballesteros, Morales, & Ortega, 2006; Auld et al., 2002) are possible barriers to adherence.

Summary

HIV is a virus that attacks and impairs the body's natural defense system against disease and infection through depletion of individual nutrients that are implicated in malnutrition and potential weight loss. ARV medicines have increased the survival rate among HIV-positive patients in developed countries, but it can interact with food and other drugs in ways that impact the people's nutritional and metabolic status. Side effects and metabolic syndrome can negatively impact quality of life. Individuals with HIV may also be at an increased risk for food insecurity which is related to poor nutritional status, reduced body mass, lessened virologic suppression, and higher risk of metabolic syndrome and mortality. Many nutritional problems can be managed via nutrition counseling, which is often lacking or inconsistent in primary care. No wide scale evaluation of HIV patient adherence to comprehensive nutrition intervention exists; however, there are potential barriers to following nutrition advice from healthcare providers in general. The unique combination of clinical and social factors that impact nutrition management among people living with HIV may interact to produce barriers specific to this population.

Chapter 3: Theoretical Framework

Relevant Models of Health Behavior Change

As reviewed in Chapter 2, research studies have identified potential barriers to behavior change in areas relevant to the changes necessary for nutrition management among people living with HIV. Many theories have been applied to the study of health behavior change (i.e., The Health Belief Model; Rosenstock, Stretcher, & Becker, 1988; The AIDS Risk Reduction Model; Catania, Kegeles, & Coates, 1990; the Theory of Reasoned Action; Fishbein & Ajzen, 1975; The Theory of Planned Behavior; Ajzen, 1985). The Health Belief Model (HBM; Rosenstock, Stretcher, & Becker, 1988) is a model of conscious decision making wherein health behavior is determined by personal beliefs about a disease and the strategies available to decrease its occurrence. The model asserts that if people feel susceptible to a health condition, believe the condition has negative outcomes, and feel the benefits of prevention outweigh the costs, they will then engage in preventive behavior. In terms of its use for HIV-related behavior change, relationships between most HBM constructs and HIV preventative behaviors have been inconsistent; also, even when related the percentage of variance accounted for is generally low (Fisher & Fisher, 2000). More broadly, beliefs have inconsistently been demonstrated to be related to behaviors, and have been shown to actually promote behavior change even more rarely (Rosenstock, 1990).

The AIDS Risk Reduction Model (ARRM; Catania et al., 1990) is a stage model of behavior change. The fundamental assumption of the model is that one must label his

or her actions as risky, make a commitment to changing risky behavior, and seek and enact strategies to attain risk behavior change. The ARRM was developed specifically in context of HIV prevention and does provide insight into HIV-related behavior change. One of the model's strengths is that it takes into consideration that factors which don't directly impact behavior may have implications at different stages of the behavior change process. However, it does not directly specify the proposed relationship between different constructs, making it difficult to test as an integrated model (Fisher & Fisher, 2000). It also contains factors that affect more than one stage of change making it less parsimonious than other models.

The Theory of Planned Behavior (TPB; Ajzen, 1985) is an extension of the Theory of Reasoned Action (TRA; Fishbein & Ajzen, 1975). The TRA specified that an individual's behavior is a function of his or her intention to perform a given act. In turn, such intentions are proposed to be a function of a person's attitude toward performance as well as their perceived norm or social support for performance. The TPB was later developed to address the possibility that the TRA may not apply to change in behaviors that are not entirely under an individual's volitional control. It added the construct of perceived behavioral control to the TRA's original assertions concerning intentions, attitudes and norms as determinants of behavior. The TPB has been applied widely and its assumptions have been confirmed across a number of studies of HIV preventive behavior (Albarracin, Johnson, Fishbein, & Muellerleile, 2001). However, it is possible to critique the TPB (as well as the TRA) as a primarily motivational model that doesn't strongly consider informational and behavioral skill sets necessary for HIV-related health behaviors (Fisher & Fisher, 2000).

The Information, Motivation, Behavioral Skills (IMB) Model

The IMB model of adherence focuses comprehensively on the information, motivation, and behavioral skills factors that are conceptually and empirically linked HIV-related health behaviors. The model has been used extensively to understand and predict adherence to ARV medication regimens (For reviews, see Geocze et al., 2010; Lovejoy & Suhr, 2009; Malta et al., 2010). Such research is central to the current study because ARV medication adherence may be related to people's tendency to adhere to other behaviors necessary for HIV management, including nutrition management. Within the model, information is thought to be a prerequisite for correct and consistent use of ARVs; this construct includes not only regimen specifics, drug interactions, and side effects, but also adherence-related heuristics that permit automatic decision making (e.g., "I'm feeling OK; I must be taking enough medication"; Fisher et al., 2006). Motivation is determined by an individual's attitudes toward adhering to his or her regimen and is based on his or her beliefs about the outcomes of ARV adherence and evaluations of these outcomes. Motivation to adhere also depends on the individual's perceptions of social support from significant others or peers for adhering to the protocol (Fisher et al., 2006). Finally, the behavioral skills component of the IMB model of adherence includes objective abilities as well as perceived self-efficacy in performing the complex sequence of behaviors that are involved in adhering to ARV medicine (Fisher et al., 2006). These may include self-dosing, competently coping with side effects, and obtaining needed social support. The model further specifies that information and motivation are independent constructs, and both work primarily through behavioral skills to influence HIV health-related behavior.

At its most basic level, the IMB model purports that information, motivation, and behavioral skills are fundamental determinants of behavior change among HIV-infected individuals. In other words, to the extent that HIV-positive individuals are well-informed, motivated to act, and have the behavioral skills required to act effectively, they will be more likely to engage in both proactive and preventative behaviors that will delay the progression of HIV to AIDS. To the extent that HIV-positive individuals are poorly informed, unmotivated to act, and lack the behavioral skills required to act effectively, they will be unlikely to engage in such behaviors and thus experience their health benefits. Given previous research in nutrition education and counseling, it is feasible that the IMB components of information (food-related knowledge and beliefs, being aware of food and water safety), motivation (attitudes toward recommendations, interest in cooking or food preparation, expectations or preferences of family members), and behavioral skills (meal timing, food-preparation, managing side effects, and feeling able to obtain food) may be lacking among people living with HIV and thus result in barriers to behaving effectively in managing HIV via nutritional adherence.

The IMB model is parsimonious compared to some other models of health behavior change, has been comprehensively tested as an integrated model, and has been shown to explain considerable variance in HIV health-related behaviors across at-risk populations (Amico et al., 2005; Bryan, Fisher, Fisher, & Murray, 2000; Fisher, Fisher, Williams, & Malloy, 1994; Fisher, Fisher, Misovich, & Kimble, 1996). Additionally, it specifies that elicitation research procedures similar to those employed in the current study can be applied toward translation of the model into behavior change interventions. The way this can be done is by applying the IMB model to constructing, implementing,

and evaluating HIV/AIDS behavior change interventions (Fisher & Fisher, 1992b). This approach specifies three steps in the change process; elicitation, intervention, and evaluation. The first step involves elicitation research, which in the case of nutritional adherence involves assessment of a group's pre-intervention information about adherent behavior, their motivation to practice adherent behavior, and their behavioral skills for the practice of key adherent behaviors. Elicitation refers to the use of techniques in which people provide information to researchers in a context in which no correct answers or alternatives are provided. The second step involves the design of population-specific interventions, based on elicitation research findings that address deficits of information, motivation, behavioral skills and behavior. The third step employs evaluation research to determine whether a health behavior change intervention has had significant and sustained effects (Fisher, Cornman, Norton, & Fisher, 2006).

Summary

Many theories have been applied to the study of health behavior change. The Health Belief Model, the AIDS Risk Reduction Model, and the Theory of Planned Behavior provide insight into HIV-related behavior change. However, the Information-Motivation-Behavioral skills model is parsimonious, has been comprehensively tested as an integrated model, and has been shown to explain considerable variance in HIV health-related behaviors across at-risk populations. It is helpful to explore participants' experiences and interpretations of nutrition management within this framework such that doing so facilitates its application to constructing, implementing, and evaluating nutrition management interventions.

Chapter 4: Methodology

Research Design

Phenomenology. Phenomenology is a qualitative method of research that emerged at the end of the 19th century as a way to answer in-depth questions posed by the human sciences that could not be adequately answered by a positivist approach (Sadala & Adorno, 2002). As part of a philosophical movement initiated by Husserl (1859-1938), phenomenology views individuals as whole beings, complete with past experiences, attitudes, beliefs and values who live in a world with both cultural and social influences (van Manen, 1997; Willis, 2001). The phenomenological method seeks to understand the core of a phenomenon by describing an experience in a person's daily life. The methodology allows unexpected meanings to emerge, thus creating a link between a phenomenon and the participant (Giorgi, 1997). As researchers, phenomenologists collect data from people who have all experienced the same phenomenon of interest, and develop a composite description of the essence of the experience for all individuals (Creswell, 2007).

Interpretative Phenomenology. Interpretative phenomenology follows Husserl's lead in the pursuit of describing the meaning for individuals of their lived experiences of a phenomenon. However, as a methodology interpretative phenomenology goes beyond just describing a phenomenon. It accepts the impossibility of gaining direct access to participants' life worlds, and recognizes that exploration of people's experiences must include the researcher's own view of the world as well as the nature of the interaction

between researcher and participant (Willig, 2001). Interpretative phenomenologists thus impose their own insights and theoretical concepts onto participants' descriptions in order to give a textual interpretation of the phenomenon of interest (Kleiman, 2004). IPA studies are conducted on relatively small sample sizes, and immediate claims are 'bounded by the group studied but an extension can be considered through theoretical generalizability, where the reader is able to assess the evidence in relation to their existing professional and experiential knowledge' (Smith, Flowers, & Larkin, 2009, p. 4).

IPA primarily works with transcripts of semi-structured interviews, which are analyzed case by case and converted into a narrative account where the researcher's analytic interpretation is presented in detail and supported with verbatim extracts from participants (Smith et al., 2009). Interpretative phenomenology was an appropriate method for the current study because it attempted to use personal, in-depth detail derived from individual interviews among patients, and open-ended questionnaires among healthcare providers to describe their experiences of barriers to HIV-related nutrition management, and examine how this phenomenon worked within the framework of the IMB model.

Other methods were considered for the current research. A grounded theory approach is similar to IPA in that it focuses on the description of an experience for a number of individuals who have all experienced the same process. However, grounded theory moves beyond description to generate or discover a theory (Creswell, 2007; Strauss & Corbin, 1998). Since many workable models of HIV-related health behaviors already exist, it was not necessary to develop a new theory of adherence to nutrition management. Ethnography focuses on an entire cultural group who is located in the same

place and/or interacts on such a frequent basis that they develop shared patterns of behavior, beliefs, and language (Creswell, 2007). Although participants in the current study did share the location where they receive their primary health care or case management, most did not spend much time there, or interact with each other regularly (or at all) such that they formed or shared a distinct culture. Furthermore, ethnographers generally spend an extensive amount of time immersed in the day-to-day lives of people where they both observe and interview participants (Creswell, 2007). Such an approach and duration was not feasible for the scope of the current research.

Study Overview. The ADA endorses the importance of nutritional intervention among HIV-infected individuals in primary care. Despite such endorsements, discussion of nutrition and other prevention issues relevant to people living with HIV is historically inconsistent in primary care. As such, little is currently known about whether and what nutrition services healthcare providers deliver to their HIV-positive clients who are taking ARVs. Extensive research has identified reasons why HIV-positive patients may not adhere to ARV medication regimens. There is a paucity of exploration, however, into whether HIV patients adhere to nutritional recommendations from primary healthcare providers. The current study thus used online questionnaires among healthcare providers, along with focus groups and semi-structured interviews among patients living with HIV at three healthcare settings in Colorado to explore their perceptions, experiences and interpretations of nutrition as it relates to HIV.

Ethical Considerations. An ethics review of the current study was approved by the Institutional Review Board for Human Subject Research at Colorado State University (See Appendix A).

Informed consent was obtained from all participants. Prior to signing the consent form, participants were asked to read an approved consent form that described the purpose of the study (see Appendix C). They were encouraged to seek clarification and ask questions regarding the study or the research process before signing the consent form. The researcher also signed the consent form as a witness. A copy of this signed consent form was given to each participant. Where interviews were conducted by phone, the researcher described the purpose of the study and issues of confidentiality and compensation. Participants were similarly encouraged to seek clarification, and were asked for verbal consent that was recorded as part of the interview transcript.

Participants in the focus groups were also asked to sign a confidentiality agreement (see Appendix D). The agreement indicated the possibility that participants may know other people in the groups, and were told not to disclose any information they didn't feel comfortable having identified with them. The document indicated that researchers cannot guarantee the material disclosed will not be repeated by other members of the group.

In this study, there was no participant who was personally known to the researcher or the Faculty Supervisor of the project. To ensure the confidentiality of participants, their names and other identifying information were only available to the research team. No personal or other identifying information appeared in participants' files or in databases. Transcripts, recorded interviews, surveys and consent forms were kept in a locked filing cabinet to which only the researcher had access, and they will be destroyed three years after completion of the research project. To protect participants' identities, pseudonyms were assigned to them. The data gathered in these group sessions

were collected specifically for the purposes of the current research, and the tapes were only heard by the transcriptionist, and by the primary researcher.

The interviewer/focus group facilitator (Julie Maertens) was trained to review confidentiality and anonymity, maintain rigor regarding the research protocol, encourage disclosure without duress, and encourage participation among all focus group members. The facilitator made it clear, during the actual group and interview sessions, that participants did not have to reveal any personal information if they were not comfortable doing so. During the focus groups and interviews, only first names were used so that individuals were not identifiable from the tapes or transcriptions or even fully identifiable in person unless another group participant knew the individual from a previous encounter.

Data Collection

Sampling. A primary objective of qualitative research is to obtain information by engaging individuals who are involved or affected by the issue under study (Morse, 2001). From this perspective the appropriate participants should have knowledge and experience of the topic being studied, the ability to critically examine and articulate their experiences, and a willingness to share their thoughts (Morse, 1991). Selection of participants for the current study was thus carried out by purposeful sampling. Purposeful sampling is a method wherein the researcher selects individuals for study because they can inform an understanding of the research problem and central phenomenon in the study (Creswell, 2007). Selection criteria for healthcare providers were that respondents worked at the selected healthcare sites, delivered routine direct primary care to patients infected with HIV, and were willing to participate. The selection criteria for patients were

that they were HIV-positive, willing to participate, currently taking ARV medication, and that they receive their routine primary care or case management services at the selected healthcare sites.

A recruitment brochure for patients was created in both English and Spanish and supplied to all settings (see Appendix B). The brochure described the study interests, where and with whom the study would take place, and provided the primary researcher's contact information including an email address and local phone numbers. The original study plan was to conduct focus groups that people signed up for ahead of time such that some control over the homogeneity of the groups was provided. However, pre-scheduling at some sites was not feasible due to patient transportation issues, and various other patient characteristics. Thus, the primary researcher visited the healthcare sites for blocks of five to six hours, thus 'catching' patients who had time for and were interested in being interviewed. Patients were recruited from clinic and pharmacy waiting areas with the help of site staff throughout the day. Healthcare providers were recruited for the study through the site directors, who sent initial and reminder emails to potential clinicians based on the selection criteria described above. The emails contained a link to an online survey (see Appendix G) that healthcare providers could anonymously complete.

Case managers at some sites also worked with the primary researcher to organize and recruit for focus group meetings using the selection criteria described above. The primary researcher arranged three group meeting times with client services directors, and case managers then recruited interested clients to sign up and attend. One phone interview was also arranged with patients who lived an hour outside of town but still wanted to participate. In all cases, steps were taken to address concerns (respect of

participants, minimal intrusiveness, trusting relationships) related to collecting data as an outsider in the community of interest (Marshall, 2006). The primary researcher engaged in multiple meetings with all healthcare setting directors to describe and discuss the study purpose, procedures, and ethical concerns. The primary researcher also delivered a presentation about the study background, rationale, and procedures to healthcare providers prior to site entry and data collection.

Participants. Based on the sampling method and selection criteria described above, participants were 44 HIV-positive patients currently taking ARV medications, and 9 healthcare providers (see Table 1). In collecting and interpreting interview data about a particular category, over time a point of diminishing returns (saturation) is reached (Krueger & Casey, 2000). At the conclusion of three focus group meetings and 18 individual interviews with patients, participant responses added nothing to what was already known about a particular category, its properties, and its relationship to the core issues of barriers to nutrition management. There are approximately 6,000 people of different ethnicities in the state of Colorado living with HIV (Colorado ethnic representation: 47.8% White, 18.4% African American/Black, 30.2% Hispanic, 3.5% Asian, Native Hawaiian, American Indian, or other). It should be noted that percentages of different participant ethnicities in the current study (Table 1) were not completely representative of either the Colorado or U.S. population (U.S. ethnic representation: 33% White, 48% African American/Black, 17% Hispanic, 3% Asian, Native Hawaiian, American Indian, or other).

Procedure. Healthcare providers were recruited for the study as described above. Potential respondents received an email link to an online survey that they could fill out

anonymously. The survey contained 12 questions and took an average of 16 minutes to complete.

Focus groups and interviews were conducted in private conference rooms; all sessions were audiotaped and transcribed. At the beginning of the interview or group session, participants completed a demographics questionnaire (Appendix E), informed consent form, and confidentiality agreement where necessary. A protocol and script to were used to introduce the study and the focus group/interview questions (Appendix F). The average length of the groups was 58 minutes, and the average length of interviews was 24 minutes. Healthy snacks were provided at all sessions, and participants received \$25 along with a brochure for food safety and dietary tips (http://www.fsis.usda.gov/PDF/Food_Safety_for_People_with_HIV.pdf) at the completion of the focus group or interview.

Interview Strategy. Qualitative research uses interviews to discover meaning structures that participants use to organize their experiences and make sense of their world. These structures are often hidden from direct observation and taken for granted by participants, and qualitative interview techniques can bring such meanings to the surface (Hatch, 2002). Kvale defines the qualitative research interview as ‘an interview, whose purpose is to gather descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described phenomena’ (Kvale, 1983; p. 174). The goal of any qualitative research interview is therefore to see the research topic from the perspective of the interviewee, and to understand how and why they have come to this particular perspective (King, 2004).

There are several types of qualitative interviews researchers may use to meet different objectives. Semi-structured, or in-depth, interviews can generally be adapted for use within any of the qualitative paradigms. They are semi-structured because, although researchers come to the interview with guiding questions, they are open to following the leads of participants and probing into areas that arise during interview interactions (Hatch, 2002). They are in-depth in that they are designed to go deeply into the understandings of participants, thus making them appropriate for a phenomenological approach (King, 2004). Semi-structured interviews can be time-consuming for both researchers and participants, and have the potential to result in a large volume of data to sort through. However, they are an extremely flexible way to collect qualitative data and are a method generally accepted readily by participants (King, 2004).

Because they meet the goals and carry the advantages described above, focus groups and individual interviews using a semi-structured approach were used as elicitation research among patients with HIV in the current study. Focus groups are frequently used to help understand health-related behaviors and have been advised as one way to advance health education strategies (Basch, 1987). The viability of using this technique with HIV-positive patients in a medical setting to identify barriers to HIV prevention has been demonstrated (McCaffrey, Pugh, & O'Conner, 2007; Monge-Rojas, Garita, Sánchez, & Muñoz, 2005; Razani et al., 2007; Williams et al., 1992). Semi-structured interviews have been used effectively to determine the diagnosis decision-making process among clinicians, and also to explore available services and patient-provider dynamics regarding antiretroviral adherence (Fehringer et al., 2006; Harman, Amico, & Johnson, 2005; Rousseau, McColl, Newton, Grimshaw, & Eccles, 2003).

Similar to Fisher & Fisher (1992a; 1993) and Fisher et al. (1996), ‘elicitation’ in the context of the current study referred to the use of techniques in which people provided information wherein no correct answers or options were supplied to them. Participants described the perceptions, experiences, and interpretations that were spontaneously accessible to them in an open-ended, relatively prompt-free context. As opposed to using a quantitative survey or individual interviews with closed-ended questions, this strategy provided the benefit of rich contextualized detail (challenges, barriers, successes, etc.) of each participant. In addition, the focus group settings carried benefits for participants in that a group structure allowed them to listen to and interact with others regarding challenges and practices related to medication, diet, and other HIV-management issues.

Instrumentation. The primary data for this study were collected through face-to-face, semi-structured interviews and focus groups with people living with HIV who were taking ARV medications. Data were also collected via an online questionnaire among healthcare providers serving HIV-positive patients. The interview/focus group guide and questionnaire both contained open-ended questions designed to solicit information about providers’ and patients’ nutritional perceptions, experiences, and interpretations. The ways words are used in questions can impact the kinds of answers participants will give. Thus, recommendations provided by Hatch (2002) were followed to generate effective questions. Recommendations include writing questions that are open-ended, clear, neutral, and that use language that is familiar to participants, that respect participants and presume they have valuable knowledge, and that engender answers related to the objectives of the research (Hatch, 2002).

On the basis of potential barriers to nutrition education availability and effectiveness (reviewed previously), participants were asked to reflect upon personal experiences that may influence whether they deliver or adhere to nutrition education and recommendations. Questions were about basic nutrition concepts and habits, readiness to make dietary changes, perceived importance for changing dietary routine, access to food, and food-preparation and handling skills. An expert in nutrition as well as focus group and interviewing methods at Colorado State University provided consultation on the development and structure of the focus group/interview guide.

Data Analysis

All interviews and focus group sessions were transcribed by Duncan Business Services, Inc. in Loveland, Colorado and returned electronically to the primary researcher for analysis. Transcription included a word-for-word account of participant-facilitator exchanges, as well as critical pauses, overlaps, or emotional responses. *Atlas.ti* (version 6.2) was used in the current study in order to structure the data generated by interviews, focus groups, and questionnaires in a meaningful and systematic way, to code that data with thematic key words, and retrieve the data in ways that allowed the research team to evaluate patterns in the data.

The use of qualitative data analysis (QDA) software such as *Atlas.ti* allow researchers to deal with large amounts of all different kinds of qualitative information (e.g., text, audio, video), and saves vast amounts of clerical time by allowing organization, along with quick coding and retrieval of data (St. John & Johnson, 2000). The point of using such software is not to turn participant accounts into quantifiable data that can be the subject of statistical analysis, but rather to reference quotations or

occurrences of concepts in a way that makes the analysis more systematic and less anecdotal. Similarly, QDA does not ‘do the thinking’ in terms of extracting the meaning of participant experiences and perceptions, but instead assists in systematizing data by helping researchers see the larger picture. QDA programs can facilitate this by helping users avoid producing an analysis that is skewed toward recent or memorable accounts (Dohan & Sánchez-Jankowski, 1998).

IPA methods were used to analyze the data (Smith et al., 2009; Willig, 2001). The first step of an IPA analysis involves immersing oneself in the original data by reading and re-reading the participant responses, and producing notes reflecting initial thoughts of the researcher in response to the text. Step two requires reduction of the volume of detail in the data by identifying and labeling themes that characterize each section of the text. Theme titles at this stage are ‘conceptual, and should capture something about the essential quality of what is represented by the text’ (Willig, 2001, p. 55). Step three involves searching for connections across identified themes, and clustering them into structured themes that make sense in relation to the original data. This step can be accomplished in a number of ways by looking for patterns between themes based on abstraction (assigning super-ordinate themes), polarization (assigning themes based on oppositional relationships), contextualization (e.g., assigning temporal or cultural themes), or numeration (assigning themes based on frequency; Smith et al., 2009). During the last step, the researcher looks for patterns across cases in order to integrate themes into an inclusive, master list with which to summarize an understanding of the phenomenon of interest (Smith et al., 2009; Willig, 2001). In accordance with this

approach, four stages of data analysis were undertaken to analyze the text for patterns, trends, and themes that emerged and developed from the participants' responses.

A research team consisting of the primary researcher and two research assistants took part in analyzing the data. Both research assistants were female undergraduate students attending Colorado State University majoring in psychology. Before analysis began, research assistants read journal articles assigned by the primary researcher pertaining to the phenomenological research perspective and interpretative phenomenological data analysis, and were briefed on the purpose, background and rationale of the study, and completed practice theme-development exercises. They were subsequently trained by the primary researcher how to use *Atlas.ti*.

The research team engaged in a step-by-step process to analyze the data. First, the primary researcher read the answers and transcripts separately, made notes about points of interest, and established a list of descriptive key words and concepts that emerged thematically from the notes. Transcripts were divided into sets which were assigned to each member of the research team, and re-read to substantiate the original list and add additional concepts. In order to organize the data, the research team used the original concept list to conduct index coding on a small set of transcripts by using *Atlas.ti* to apply the developed codes to relevant participant quotations. Next, coded quotations were examined to identify and further organize similar idea clusters within the text. From these clusters, the team began to develop interpretative, structured themes that made sense in relation to the original data. Finally, the team used the interpretative list of themes to code subsequent transcripts, adding, subtracting, or elaborating themes in the process. As

a result of this procedure a list of overarching themes and several subthemes were generated that captured the essence of nutrition management among participants.

Trustworthiness

Trustworthiness provides an evaluation of the extent to which the findings of a study are deemed to accurately reconstruct and represent the multiple realities conveyed by participants. It attempts to answer the question of how a researcher can ‘persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of’ (Lincoln & Guba, 1985, p. 290). The evaluative criteria used to establish reliability and validity in quantitative research are not particularly relevant for evaluating the trustworthiness of qualitative research. Instead, alternative evaluative phraseology such as ‘consistency’, ‘truth value’, and ‘neutrality’ are advocated (Lincoln & Guba, 1985). Viewing verification as a process occurring throughout data collection, analysis, and report writing of a study (Creswell, 2007), the primary researcher engaged in a number of processes to deal with potential threats to the trustworthiness of the current study.

Consistency. According to Silverman (2005), reliability in qualitative studies can be enhanced when interviews are audiotaped and then transcribed such that pauses, overlaps, and side comments as well as emotion are indicated. Reliability can also be bolstered by the use of qualitative computer programs to organize the data and by attending to coder agreement (Miles & Huberman, 1994; Silverman, 2005). Since audiotaping, transcription, and computer-assisted analysis have been discussed elsewhere, the following discussion of consistency will focus on team member coding agreement. A theoretical resolution has not been reached regarding the place of the

traditional concept of reliability within qualitative methodology. On the one hand are those researchers who believe the demonstration of consistency through calculated inter-rater reliability should be a benchmark for judging qualitative research (Mays & Pope, 1995). A contrary position is taken by those who argue that expecting two or more researchers to have the same insights from a limited qualitative data base is unrealistic (Morse, 1994). In the process of coding loosely structured data similar to that yielded by the current study, it may be unreasonable to expect multiple coders to have high rates of coding agreement because not all team members likely have the same theoretical background, familiarity with the literature, or intimate knowledge of the interviews as has the primary investigator (Meadows & Morse, 2001). The method used for the current research thus reflects an approach midway between two extreme concepts of consistency. A numerical value of inter-rater reliability was not calculated to demonstrate the degree of consistency between team members; however, the steps taken to reach coding and theme development agreement among three research team members were made transparent, as follows.

Although the same procedure was followed for both patient and healthcare provider data, the next part of the discussion focuses on the process for analyzing the patient interview transcripts. The purpose of the first stage of analysis was to develop a list of key words and concepts that could be used as a stable preliminary method of identifying relevant transcript quotations among three independent research team members. To achieve this goal, the primary researcher read the transcripts thoroughly, made notes about key ideas that emerged from the data, and developed an initial list of indexing codes. Transcripts were subsequently divided into sets and distributed among all

members of the research team, and re-read to further develop the initial list. After this second reading, the team met and examined the codes and their names, and discussed ideas for additional codes and clarified any questions or concerns about existing codes.

During the next stage of analysis, the primary researcher chose one transcript to be coded independently by each member of the team using the index codes. This process consisted of organizing the interview transcript into text segments by assigning the index codes to selected participant quotations (e.g., Food behavior – cooking). The team then met to compare code assignment. During this meeting, disagreements about the way quotations were index coded were discussed until resolved, and revisions were made resulting in a final list. Two additional transcripts were chosen to be coded independently using the new list.

After coding the two additional transcripts, the team met again to compare coded quotations and resolve any differences in codes assigned to text. At this point, the team began the process of sorting codes into similar idea clusters within the text. The formation of such clusters in IPA requires the researcher to examine the index-coded quotations and think about how they relate to each other. Code clusters should be given names that capture their essence in relation to the original data (Willig, 2001). Based on these requirements the team arranged emerging concepts into clusters and made decisions about how they should be labeled. The primary researcher read through the transcripts again to ensure the concepts and labels represented the participants' quotations, and then assigned two additional transcripts to be coded independently by the team using the revised code clusters.

Once organizational coding has been achieved, the data need to be further examined for patterns, regularities, and conceptual coherence in order to generate thematic meaning (Coffey & Atkinson, 1996). The team thus met once again to compare coded quotations using the new list, to discuss and resolve differences, and to develop a list of interpretative themes and definitions that made sense in relation to the original data. Team members used the list of resulting thematic codes to analyze the remainder of the transcripts. The team continued to meet weekly until all transcripts were coded and themes were expanded, minimized, or rearranged as necessary. To minimize gradual changes in team members' interpretations of themes, one additional transcript per week was coded by everyone and compared among coders at each meeting. Any disagreements were discussed by comparing the text passages with definitions of the various themes until consensus was reached. As a result of this procedure a list of three overarching themes and eight subthemes captured the essence of nutrition management among healthcare providers (Appendix H). Similarly, four overarching themes and eleven subthemes were extracted from the patient data (Appendix I).

Truth Value. Member checking provides a means of assessing trustworthiness by ensuring that participants' experiences have been accurately represented (Lincoln & Guba, 1985; Miles & Huberman, 1994). This approach involves taking data and interpretations back to the participants so that they can judge the accuracy of the account. A thorough enactment of this process would involve getting feedback on a summary of the written results of the study after analyses were complete; this degree of member checking was not encompassed by the scope of the current study. However, the primary researcher did engage in a lesser degree of member checking by summarizing the

interaction between the participant and researcher at the end of each interview, and asking if the summary sounded like an accurate account of what transpired or if anything should be added. Based on participants' responses, clarifications were made and information was appended where necessary.

Triangulation is a strategy wherein researchers make use of multiple sources to provide corroborating evidence (e.g., methods of data collection, more than one investigator, or multiple theories or perspectives; Denzin, 2010; Lincoln & Guba, 1985; Miles & Huberman, 1994). From this perspective, the validity of a piece of evidence can be assessed by comparing it with other kinds of evidence on the same point. The data for this study were collected from the perspectives of both HIV healthcare providers and HIV-positive patients, which were used comparatively and complementarily during the process of data interpretation. Using evidence from different sources was instrumental in shedding light on theme-development and interpretation of results.

Peer review is another strategy that adds truth value to a given study (Lincoln & Guba, 1985). A peer reviewer is someone who asks questions about the methods, meanings, and interpretations within the study and provides an objective opinion and suggestions. The primary researcher met with an expert in qualitative research at Colorado State University at critical junctures during the study tenure in an effort to ensure appropriate and reasonable data analysis and interpretation. As described previously, an expert in nutrition and focus group and interviewing methods at Colorado State University provided consultation on the development and structure of the focus group/interview guide. The study's research plan was also presented at selected healthcare settings and was discussed at length with case managers and healthcare

providers, which afforded multiple expert perspectives about the objectivity and ethical soundness of the research protocol for the population of interest.

Neutrality. One aspect of qualitative research paradigms that make them different from many quantitative designs is that the researcher is an integral part of the data collection process. In addition, researcher interests, opinions, and beliefs about the topic of study can result in researcher bias (Hutchinson & Skodal-Wilson, 2001).

Two steps were taken to manage researcher bias in the current study. First, very open-ended questions and follow up questions were constructed for the interview protocol such that participants were able to answer and elaborate based on their own perceptions and experiences. Although open-ended questions are useful in reducing researcher bias, the risk of asking leading questions after hearing some responses repeated by participants over time remained. Because qualitative methods require researcher-immersion in the environment being studied, self-awareness of one's mindset, values, beliefs, and preconceptions are important so these biases will not interfere with the data collection and interview process (Hutchinson & Skodal-Wilson, 2001).

The second step taken to manage researcher bias was thus for the primary researcher to listen to recorded interviews and keep brief notes about participant-researcher interactions, and also to summarize personal reactions to conversations with patients throughout the data collection period. During the listening and notation process, attention was given to specific interactive nuances including whether participants were given enough time to fully answer questions, whether the primary researcher was flexible in using the interview script, whether follow up questions were used in response to participant answers, and whether the follow up questions were open or leading. These

experiences served as regular reminders for the primary researcher to remain flexible and objective during each interview, and to allow each individual participant or group member to answer questions without undue influence.

Summary

Online questionnaires among healthcare providers, and focus groups and semi-structured interviews among patients living with HIV at three healthcare settings in Colorado were utilized in the current study. An ethics review of the research was approved by the Institutional Review Board for Human Subject Research at Colorado State University. Selection of participants was carried out by purposeful sampling. Focus groups and interviews were conducted in private conference rooms and all sessions were audiotaped and transcribed.

The primary researcher engaged in a number of processes to deal with potential threats to the trustworthiness during the study. In accordance with an IPA approach, four stages of data analysis were undertaken to analyze the text for patterns, trends, and themes that emerged and developed from the participants' responses. The analysis used personal, in-depth detail derived from individual and focus group interviews to describe patients' and healthcare providers' experiences of barriers to HIV-related nutrition management, and examine how this phenomenon operated within the framework of the IMB model.

Table 1.

Patient and Provider Demographic Summary.

| | <i>M</i> | <i>SD</i> | Range |
|------------------------|----------|-----------|---------|
| Healthcare Providers | | | |
| Age | 47.8 | 7.2 | 41-54 |
| Gender | | | |
| Male (frequency) | 4 | | |
| Ethnicity | | | |
| White (%) | 100 | | |
| HIV-Positive Patients | | | |
| Age | 47.9 | 10.3 | 18-69 |
| Gender | | | |
| Male (frequency) | 34 | | |
| Female (frequency) | 10 | | |
| Ethnicity | | | |
| White (%) | 55.8 | | |
| Black (%) | 11.6 | | |
| Hispanic (%) | 23.3 | | |
| Native American (%) | 2.3 | | |
| More than 1 race (%) | 4.7 | | |
| Other race (%) | 2.3 | | |
| Years with HIV | 15.2 | 8.3 | 2-31 |
| Weight (M) | 156.2 | 24.6 | 110-210 |
| Weight (F) | 177.7 | 42.6 | 111-238 |
| Income | | | |
| Under \$10,000 (%) | 41.9 | | |
| \$10,000 – 19,999(%) | 32.6 | | |
| \$20,000 – 29,999 (%) | 14.0 | | |
| \$30,000 – 39,999 (%) | 7.0 | | |
| \$75,000 – 99,999(%) | 2.3 | | |
| I would rather not say | 2.3 | | |

Chapter 5: Results

Review of the Study Purpose

The main objective of this interpretative phenomenological study was to describe the barriers to HIV-related nutrition management among patients and healthcare providers at three different healthcare settings in Colorado. The specific goal for the current research was to explore patients' and healthcare providers' perceptions, experiences and interpretations of nutrition as they relate to HIV. To accomplish the objective, interview questions were developed for patients and healthcare providers and administered via either semi-structured interviews or focus group meetings (among patients), or via online questionnaire (among providers). Four main themes were identified from the interviews and focus groups, and three main themes were extracted from the questionnaires. Each theme is described below and presented individually along with its sub-themes. Sub-themes were representative of topics discussed during data collection, and substantiated by direct quotations from participants.

Participants were asked to reflect upon personal perceptions and experiences that may have influenced whether they prescribed or adhered to nutrition education and recommendations. The themes presented here were developed by first organizing, and then examining the data for patterns, regularities, and conceptual coherence that served to generate thematic meaning.

Healthcare Provider Demographic Summary

A total of 9 healthcare providers participated in the current study. Only 4 participants completed the questionnaire's demographic questions. It is possible that participants wished for their answers to remain completely confidential; because only 15 providers were invited to complete the questionnaire, providing demographic details would potentially make participants identifiable and thus allow their answers to be linked to them. The 4 participants who responded were all white males, and had an average age of 47.8 (SD = 7.2; Range 41-54 years). One participant described his job position as the Interim Director, one identified himself as a registered nurse, and two reported that they were physicians.

Healthcare Provider Themes

Theme 1: Nutrition Education Perceptions

Healthcare providers were asked to discuss their perceptions regarding providing nutrition education to HIV-positive patients. Discussion focused on what participants knew about the accepted practice for nutrition education at their healthcare setting, and whether they thought this education was important in the scheme of other kinds HIV counseling or education with patients. These perceptions were organized into two sub-themes: Lack of formal procedures and nutrition importance over time.

Lack of formal procedures. Participants discussed their understanding of their healthcare setting's expectations for providing nutrition education to HIV-positive patients. Most healthcare providers said there were few or no formal procedures in place.

[There are] no specific recommendations for HIV+ patients.

When patients are either under or overweight, discussions of their diets should ensue.

There are no accepted standards [for nutrition education].

[The protocol is] basic at best, and [includes] the usual USDA, Heart Association, and Diabetes Association [recommendations].

Nutrition importance over time. Healthcare providers talked about whether they thought nutrition was an important factor in the management of HIV, and also discussed their beliefs about what components of nutrition and diet were significant for patients. About half of participants said they thought nutrition was very important in managing HIV, and about half said they felt nutrition was moderately important. Providers said that although nutrition management was consequential for patients, its primary value lay in attenuating HIV-related health problems that would also be applicable to the general population. Participants also articulated that their priority was to address acute issues associated with HIV, and that nutrition became a more important factor over the long-term.

Obviously diet is an important part of addressing specific issues such as glucose intolerance, hyperlipidemia and hypertension, but the advice isn't really different whether HIV is present or not. In the HAART era, under nutrition (wasting) has become very rare, but would need to be addressed specifically if present.

I think nutrition has relatively little to do with the success of antiretroviral therapy. Current regimens are not dependent on timing in relation to meals or specific foods. However, in patients with well-controlled HIV infection, nutrition has a substantial effect on long-term outcomes, as is true for the general population.

I place nutrition somewhat middle on the list of what's important for a patient with HIV. More important in the immediate sense are that a patient is plugged into HIV care with providers who understand the HIV/AIDS issues, that the patient is on an appropriate medications. Once a patient is stable and emergent issues are stable, then nutrition may be next on the agenda. Patients today, 2011 may expect to live a respectable length of life - therefore as the patient population ages, all the normal ailments for aging adults come into play, and here nutrition becomes more and more important.

Nutrition and dietary habits are important for individuals with HIV. They tend to gain importance over time. By that I mean that up front newly diagnosed and/or individuals newly entering care have many medical, psychological, and social issues. These areas tend to take precedence. In the current treatment era, individuals can live long productive lives. Over time at least four factors contribute to an increasing need for nutritional diligence 1) aging, 2) HIV infection, 3) HIV medicines, and 4) weight gain which is typical during successful HIV treatment.

Dietary education takes a back seat until HIV infection is under control.

Theme 2: Nutrition Education Practices

Healthcare providers were asked about their approach to nutrition education among HIV-positive patients. Participants brought up several topics in relation to their own personal approach, which led to the identification of three sub-themes: Concern about over- or underweight, giving well-rounded advice, and messaging.

Concern about over- or underweight. Many participants talked about their patients' weight and how it influenced their approach to nutrition education. Because health risks for people with HIV can be exacerbated by being either over- or underweight, most healthcare providers said they discussed weight with patients at routine primary visits.

Obesity counseling is the most common form of dietary education in this setting, followed by support for gaining weight in undernourished patients.

I evaluate the patient's weight. If they are overweight, we review ways to cut calories such as getting rid of soda. I talk to my underweight patients about ways to increase their calories.

If a patient is losing weight unexpectedly, is gaining undesired weight or is overweight, I ask about what they eat, when they eat and why they eat.

Giving well-rounded advice. Healthcare providers talked about food or supplement recommendations they discussed with patients during routine care visits. Most participants said they tended to provide the same well-rounded advice about what

foods to eat or avoid that they would discuss with the average patient who was not infected with HIV. A few said they gave recommendations for diet that were related to other medical conditions patients had, which may or may not be related to HIV or ARVs.

I talk to everyone about it in one form or another. I am always advising a decrease in animal product in one's diet.

I discuss diet and nutrition as I do with the general population - the advisability of decreased calories, decreased fats, decreased meat, increased fruits and vegetables. I couple this with a discussion of exercise.

[I] encourage moderation and balance. In general I discourage herbal or alternative supplements as potential interactions with ARVs are largely unknown.

I particularly focus on dietary education for individuals with other medical conditions such as HTN (hypertension), hypercholesterolemia (high cholesterol), cardiovascular disease, etc.

I like written material to give the patients. There a lots of good informational fliers and booklets directed towards specific illnesses.

Messaging. Several participants talked about the importance of the type of messages used when counseling patients about nutrition practices. Because behavior change is generally difficult for people, many healthcare providers said they advocated being consistent, acting as a coach, and/or using simple messaging among their patients.

Advice alone is almost always useless but if you can provide support in the form of teaching and coaching it seems a bit more effective.

I believe that the more credible people from whom a person gets a message, the better and more effective. I believe that any major life change takes lots and lots of input, and being one more person delivering the correct message is still effective even if I don't see an immediate change.

I think consistent and simple messaging about big picture nutritional concepts are likely the most effective for the most people. However, as with other behaviors, I suspect the long-term effectiveness of education and counseling for behavior change regarding diet is minimal to moderate at best. For a significant subpopulation (maybe 25% of the clinic), however, their knowledge of nutrition and self-care is very high. For these individuals more detailed information is necessary and is probably pretty effective.

Theme 3: Influences on Nutrition Education

Healthcare providers were asked about influential factors that determined the level of nutrition education provided during primary care appointments. Participants talked about a number of patient and clinic dynamics that made it either easier or more difficult to provide nutrition education on a regular basis. These dynamics were organized into three sub-themes: Patient willingness to change, presence of comorbidities, and lack of time and services.

Patient willingness to change. Healthcare providers discussed patient attitudes toward receiving and adhering to nutritional advice delivered at primary care visits. The majority of participants said that the depth and kind of information they would provide was largely influenced by patients' interest and motivation related to the topic.

Behavior change is hard for all of us, so few will change unless they are seeking the advice.

A patient's motivation to learn is important, but also their basic intellect and ability to incorporate information into their lives. I can't always tell accurately who can take the bait and run with it.

Some degree of fatalism in some patients [influences what advice I deliver]. It is difficult to change a behavior as basic as diet, so we are dependent on attitudes of the society at large. We need more peer-based interventions, it seems to me.

For [some patients], chaotic life with drug use, nonadherence [to medications], and medical instability make it very difficult to ever address nutritional concerns.

A patient's non-acceptance of either the problem or advice [influences how much education I will provide].

Some patients lack discernment around what they can expect nutrition to do for them, so we want to be sensitive about re-aligning their ideas with reality.

Presence of comorbidities. Participants talked about the degree to which the presence of one or more diseases in addition to HIV influenced discussions of nutrition

during routine care appointments. All providers mentioned this issue at some point, and said that the kind of nutrition education they provided was impacted by whether patients presented with health conditions that required dietary intervention.

A large number of patients have common nutritional problems [that require nutrition education – obesity, hyperlipidemia, etc.

[My advice depends on] whether a condition is present that diet clearly might have an impact on.

Patient inquiry, underweight/overweight patients, medications or conditions requiring dietary discretion (Warfarin, hypokalemia, hypophosphatemia, liver disease, diabetes, renal disease, hyperlipidemia) [all influence the nutrition education I provide].

[The first things I consider are] weight, lipid status, presence of diabetes, hypertension, vascular disease, tobacco use.

[My provision of education is] usually triggered by other medical conditions; obesity, and/or too much weight gain on therapy.

Lack of time and services. Participants discussed whether they had the resources needed to deliver adequate education and advice. In general, healthcare providers reported that nutrition services were not currently available for referral within their healthcare setting. One participant mentioned referral to Project Angel Heart, a service that provides meals to low-income, HIV-positive individuals (Project Angel Heart delivers meals to people with life-threatening illnesses, free of charge, and specifically prepared to meet the nutritional needs of each individual client). Six out of nine providers also mentioned being hindered by time constraints during primary appointments, such that the available time was necessarily spent addressing more immediate issues.

We do not commonly refer for nutrition services, particularly because for the last 2 or 3 years we have not had in-clinic services.

I'm not aware of any [nutrition services].

[I refer eligible patients to] Project Angel Heart to provide meals. [There is]

no nutritionist available.

[It] would be great to also have nutritionist who could spend more time discussing diet.

We don't have a dietitian, so our options are limited.

Time restriction on appointments is a major limiter. Also, the lack of professionals and/or services to make referrals to is a problem.

The time allotted and the amount of other pressing issues going on at the visit [determine whether I provide nutrition education]. If there are a lot of other things to address, lack time is a major influence.

Patient Demographic Summary

A total of 44 HIV-positive patients participated in the current study.

Twenty patients were interviewed individually, and 24 patients participated in three focus group sessions. Thirty-four of the participants were male, and 10 were female.

Participants had an average age of 47.9 ($SD = 10.3$; Range = 18-69 years). Percentages of different participant ethnicities were not completely representative of people in Colorado living with HIV (current sample: 55.8% white, 11.6% African American/black, 23.3% Hispanic, 2.3% Native American, 4.7% more than one race, and 2.3% other race). In the current sample, whites were generally overrepresented, while African Americans and Hispanics were generally underrepresented. Most participants (88.5%) reported having an income of under \$30,000/year, and a large proportion (41.9%) reported income under \$10,000/year. Participants had been HIV-positive for an average of 15.2 years ($SD = 8.3$; Range = 2-31 years). Average weight among males was 156.2 pounds ($SD = 24.6$; Range = 110-210), and the average among females was 177.7 pounds ($SD = 42.6$; Range = 111-238).

Patient Themes

Theme 1: Perceptions about Nutrition and HIV

Patients were asked to discuss their perceptions about food and nutrition relative to being infected with HIV. Discussion focused on what participants knew about what was best for them in terms of food, supplements, or food safety. Patients also talked about what kinds of nutrition counseling or education they receive at primary health care visits. These perceptions were organized into two sub-themes: Receiving appropriate general advice, and staying safe and balanced.

Receiving appropriate general advice. Participants discussed advice or education they had received from healthcare providers about nutrition as it related to HIV. Patients' reflections indicated that nutrition education provided at primary care visits was appropriate for their needs. They received weight and dietary advice that was relevant to general health, to medications they were taking, and to food safety concerns. Patients at one setting said that they did not get referred to an in-house nutritionist; however, patients at two other healthcare sites said that they do get referred to nutritionists for nutrition education as part of their client services.

I don't know if I was picking up bacteria from the meat, but the doctor told me that he wanted me to start cooking the meat and make sure the blood was out of it and since then I've done pretty good (Male, Focus group participant).

When I was young I used to like everything raw. And now I've learned that raw food is not good, especially for somebody like me (Male, clinic patient).

I've been told to stay away from grapefruits because of a problem with the pills (Male, Focus group participant).

I used to take like all these vitamins and calcium, magnesium, and zinc and all that. But my doctor told me that she said like just any old generic One-a-Day vitamin is just as good (Male, Focus group participant).

Well they tell me just pretty much stay away especially from drugs and drinking and just eat right, drink right, just be healthy. I mean pretty normal stuff, you know. Pretty common sense stuff, what we should be doing anyway but. But they never steer me wrong. Just always, they always steer me in the right direction in other words (Male, clinic patient).

And when I talked to my doctor about it, you know I find [I should] eat a balanced diet and don't overdo anything (Male, Focus group participant).

It's very important. That's why I'm trying to stick with things, number one that aren't loaded in sugar, what else did they say ... but try and be nutritious and I forget what else. I know there's a lot that's good for you, like peanut butter (Male, clinic patient).

It's just all general stuff here. And that's what's so good about here. I mean these people here, they care. They care about you and they want to make sure you take care of yourself. And if they see, like if you're overweight and you need to lose weight ... come on, now ... let's put you on a diet. So it's good. It's pretty good (Male, clinic patient).

My nurse practitioner seems to think that I should lose some weight. So [I'm] kind of like, okay ... He talks about how it's not good for men my age to be that big in the mid-section. Which I think it has something to do with being HIV positive because I have read that when you're on meds long enough, your fat starts getting redistributed differently (Male, clinic patient).

Yes, I've been told that my medications are increasing my triglyceride levels. I have to be careful of what I eat which is really tough because I've got a sweet tooth and also I work in a bakery at Target. Yeah, so I'm supposed to stay away from baked sweets. Also I'm supposed to eat lots of things that contain fish oil so I have a lot of tuna, fish sticks ... I don't eat so much of the trout and salmon that they keep telling me about, but I guess not many people are going to be able to afford that (Male, clinic patient).

Honestly? Here? No [I do not see a nutritionist]. But when I went to the UCLA, the care clinic down there, my doctor was, she was telling me I needed to change the way I eat and she wanted me to have a nutritionist and everything so I had one of those in California (Female, clinic patient).

They always refer you to the nutritionist you know. My blood pressure was really high so she was trying to tell me not to eat salt. So I already knew that, but the [blood pressure medication] I take brings my blood pressure down into a reality. 114/68, so that's a perfect blood pressure. Because mine was high for a long time (Male, clinic patient).

Staying safe and balanced. Most patients said they thought taking care of one's nutrition was very important for managing HIV. They discussed what they believed to be key dietary factors for staying healthy and they emphasized maintaining a balanced diet, staying away from unsafe foods, eating less fat, processed food and sugar, and including more fruits and vegetables. Several patients mentioned the importance of 'listening to the body' for cues about eating what one needs.

I always cook at home. I don't go out to eat. Eating out scares me. I've just seen too many people and ... you know my sister, her and her husband they love to eat out and at least twice a week she gets sick. And I keep telling her it's because she eats out. I don't care what restaurant you're going to, there's so many people that touch that food before you get it, you have no idea what you're eating (Male, Focus group participant).

I hate things that are dead and processed because I feel like that brings no life into your body and that means no sunlight, no energy of any kind. Take a tomato for instance. It has to be grown at a local farmer or a big farmer, it's getting sunlight, it has to grow. Vitamins from the earth come up, you know. That's what I want in my body because obviously something made that tomato grow. So ... I look for things that naturally grow and that is the only thing I eat. The only thing I eat (Male, clinic patient).

I go to Whole Foods for fish. They have the best fish; they don't put a whole bunch of chemicals on it (Male, Focus group participant).

[So much food is] full of grease and sugar. I think fresh is so helpful for your immune system so I like to try to think of things that are alive or fresh. It's good whether it's meat or vegetable, but fresh (Male, Focus group participant).

I just try to think of what makes me excited about foods, not like to go home and there's some food there. It's more like, what turns me on you know like, I feel like having some ... whatever. I like that. I think that [it's best] if you listen to your inner, your higher power (Male, Focus group participant).

... and but I still listen to what my body tells me I need. But because I'm eating at a regular time it's like, I really feel like I need some meat protein, or you know I really feel like I need some green vegetables. So that determines what I'm going to eat for that next meal (Male, Focus group participant).

I do think that [I] need to also eat better than junk! I mean you have to have your A's, your B's, and your C's ... oranges, fruits and vegetables. You

have to. I think a person would get sick if all they did was just junked out and they were compromised. I do believe it's related. Eat good. Stay healthy. Feel better (Female, clinic patient).

It's very important. Nutrition is ... you eating the right foods to keep you going so I mean you want to keep living so you should eat nutritiously. That's very important (Male, clinic patient).

I think [nutrition is important] for my health because I mean my health ... I don't want to get any more sick than I am so But I think it's important, very important for me for my health (Female, clinic patient).

A couple of years ago I watched a thing on Discovery where more and more freshwater fish are actually picking up parasites so you want to make sure your fish is really cooked well because some of those parasites are really deadly (Male, Focus group participant).

And the end result, you know. Eat right, you're going to get far. Eat wrong, I'm sure you're going to be dead (Male, clinic patient).

Theme 2: HIV-Related Eating Habits

Patients were asked about their basic dietary practices and what kinds of changes they had made over time based on being diagnosed with HIV. Participants talked about what they do about food safety concerns, and what kinds of things they tried to include or avoid in their daily diet. Patients also discussed strategies for coordinating food intake with ARV medications. These behaviors were organized into three sub-themes: Staying safe, staying balanced, and working with ARVs.

Staying safe. Participants discussed HIV-related eating habits they had developed since being diagnosed that pertained to food safety. They said the main things they tried to do entailed keeping their kitchen areas and the food itself clean, cooking meats thoroughly, and staying away from spoiled foods.

What I do now, what I didn't used to think about is when I'd go to buy milk and make sure it [isn't] expired. I drank some spoiled milk that made me sick because I poured some cold milk in the coffee and it curdled up, looked like cottage cheese. That's when you know it's spoiled. And also I'd be concerned about wiping the cans off the top of whatever I drink, get the dust

off of that, no stains, no tidbits But things I didn't used to be concerned about (Male, clinic patient).

Oh yeah, I wash all meats. I wash all my vegetables. Everything gets washed before I cook it. And that's just to get the excess malarkey off of it because there's a lot of ... people handle that meat. And I do temp all my foods because I like my red meat medium rare. So you have to temp it and know where it's at if it's well, medium well, or just well done or whatever (Male, clinic patient).

Just make sure like when I cook chicken that I don't turn a piece of chicken over with a fork and then go over and stir the peas with it. I make sure every utensil is cleaned, that kind of stuff. But as far as types of foods or anything, no. But just in terms of food safety, making sure they've been washed and cleaned (Male, clinic patient).

At my age I've lived long enough and have made enough mistakes not to do anything stupid like defrost something and then refreeze it and then think it's gonna be good. I don't do that. I also seal everything because I don't want to attract insects or mice in my foods (Male, clinic patient).

[Make sure my] meat temperature is always above 165 [degrees] no matter what. I don't know where that meat came from and what they did to it. Regardless of if they say organic on it. There's only so much you can believe on that too. You know? I will always have it cooked to temp meat-wise. Vegetables, always rinse them off. I mean, who knows what truck they came in on. Who knows what pesticides are on them, you know. Do you really want things in your body that kill bugs? (Male, clinic patient).

Staying balanced. Patients talked about foods or strategies they incorporated into their daily diets as efforts to maximize nutrition as it was important to being HIV-positive. Most participants had taken a varied approach to balancing nutrition, which included eating more vegetables and fruits, cutting down on processed foods, utilizing healthier cooking methods, and incorporating more holistic elements such as green tea.

I bought a wok, I think a wok is really important; a big thing you can cook in and it's easy to cook a bunch of vegetables, just stir them up for a little bit with a little bit of shrimp or meat or just go veggie (Male, Focus group participant).

You know I make a lot of vegetable salads and different ways and you'll be amazed in how many different ways you can make a salad. You know. Salads are made to be made different ways. You can put just about anything that's nutritious in a salad. You know what I mean. So it's wonderful. I just practice

and I spend most of my time in the kitchen and it's like, why are you in the kitchen? Get out and go do something! You know, I'm busy. Leave me alone. I'm creating (Male, clinic patient).

... maybe well my one cup of tea a day which will be ... I don't care what brand it is. Tea is tea. It's good no matter how cheap or expensive it is. It still has antioxidants, it still has the caffeine to keep me at a good, high energy level at times, and it's got the beautifulness of sunlight drying the tea leaves (Male, clinic patient).

Well. I do the tea thing, lots of green tea because I've noticed when I drink it I do feel different and so I know it's good for you. I mean a couple glasses of tea. And I do a multi-vitamin, multi-mineral regimen thing. I've always done that (Female, clinic patient).

Over the last few years I eat a lot less meat than I used to. More vegetables. I eat sweet potatoes instead of white potatoes, but I like them better anyway (Male, clinic patient).

[I eat] more fruits and vegetables, and less sweets. I am a sugar fanatic, so instead of sugar I use Splenda. I've changed that. I grew up on Kool-Aid. I've always loved Kool-Aid but instead of the sugar now I'll do Crystal Light to try to change that (Male, clinic patient).

I eat no fast foods. No fast foods at all. That fast food is very addictive. It's just like a cigarette. It's just very addictive (Male, clinic patient).

I always eat really big salads during the day, like at lunchtime, like I call it my salad trough. Pretty much every vegetable in there ... sometimes I'll throw protein in with it, too, but I feel like I tend to feel better even though I eat this huge salad, it's still pretty light with very light dressing with it and I feel better not eating a lot of heavy food in the middle of my day. I just feel better that way (Female, Focus group participant).

Well I use a lot of herbs in my cooking where you get a lot of vitamins. And I'm always willing to experiment with new herbs too see how they taste and see what benefits they might make me feel better or more energetic (Male, Focus group participant).

I kind of gave up on that white sugar. And I get sugar in the raw now for my coffee and it seems to digest better. I'm not ... I mean I was eating like white sugar I could feel it in my organs were hurting. But then when I switched to that unprocessed sugar it's better. I don't know what it is (Male, Focus group participant).

Working with ARVs. Participants discussed how their food and nutrition routine had changed since being diagnosed with HIV and beginning ARV therapy. Conversation focused on the burden of coordinating food intake with medications. Patients also emphasized that some foods had to be eliminated from their diet due to interactions with medications they were taking. For some people, finding foods they could tolerate took priority over trying to eat foods with appropriate nutrition.

There are some meds that I take that I'm supposed to take with food, some that I'm supposed to take within a half hour of eating, and if I stuck to the schedules that are involved in all the pills that I take, I would be literally taking pills all day long. So I just take the handful of pills and wait about a half hour and have breakfast, you know, and then I'll take my evening pills within a half hour of when I finish eating dinner (Male, Focus group participant).

It's just being able to work out a schedule of this one has to be taken with food, that one has to be taken on an empty stomach ... and still through it all get all the vitamins and four food groups and everything else that I need. So it's trying (Female, Focus group participant).

Well, all the 3 that I take, you're supposed to eat it with, not on an empty stomach. So I take them at night around 5 or 6 when I have dinner. So that was something different. I had to time that all together. Or whenever I ate my last meal I take my meds before I go to sleep. I [took them without eating] one day and I just got kind of real nauseous. I said, now I know not to do that anymore (Male, clinic patient).

Certain things I like, like grapefruit I tend to have a problem with even though I love it. It's just the mess it makes and the seeds in it. So I stay away from that. Plus some of the meds I take used to say don't take it if eating grapefruit (Male, clinic patient).

I set my pills to where I would take them, you know because my eating habits always changed. So I would set my alarm clock for 9:30, I would make sure I'd eaten something by 9:30 and then I would take my pills. And then that changed. So I started waiting until like 12. Right now, like I say, everything's been messing around with my stomach (Male, Focus group participant).

I think that pineapple's really good for my constitution it has a lot of enzymes and natural fruits and roughage and ... it keeps me feeling really good with my meds. I've found that it's kept me from being as nauseous. . . like nausea

will wake me up so I've got to go down and eat something. I found it by accident (Male, Focus group participant).

Really. Because if I skip a meal before I take my medicines I get really sick all day. And I found Cheerios work really good because they're really bland in milk (Male, Focus group participant).

One thing that I learned and this just sort of relates is if you have a lot of problems with nausea with your meds, if you eat corn. When I first started on meds I would just heat up a little bowl of frozen corn before taking my meds and I don't know what is in the corn but it really helps, gets rid of the nausea (Female, Focus group participant).

My husband eats a lot of plain toast and stuff like that when he feels like eating food. The bread absorbs the meds I guess (Female, Focus group participant).

Cookies and Cream chocolate bars [help me with the side effects] ... really. Honestly. When I was diagnosed and I was in the hospital, they kept bringing me hospital food and my body was still getting used to the drug load, nothing looked good. I mean take this tray away from me, it's making me ill just having it in the room. A friend of mine brought me a bunch of Hershey's cookies and cream bars (Male, Focus group participant).

Theme 3: Influences on Nutrition Management

Patients were asked about influential factors that determined how they were able to manage their nutrition and diet in a way that was appropriate for being HIV-positive. Participants talked about a number of factors that made it either easier or more difficult to manage their nutritional intake on a daily basis. These factors were organized into four sub-themes: Presence of ARV side effects, providing or receiving support, acquiring the right food, and family and personal preferences.

Presence of ARV side effects. Participants discussed medication-related side effects as a significant contributor to how diet and nutrition were managed. Many patients said that they often did not feel like eating at all, and that it could be a struggle to find nutritionally appropriate foods that attenuated side effects.

Sometimes when you take those strong meds you don't feel like ... when you first get them you don't feel like eating it just makes you nauseous and diarrhea for weeks and months, sometimes longer right? You don't feel like it (Female, Focus group participant).

So during the day I'd probably eat only 1 meal a day and usually about 6 o'clock at night which usually during the day, you know I'd get up in the morning and I know I should have something for breakfast, I know I should eat something, but I ... there's just nothing that I really want. So that's why I've been trying to do the protein shakes so that way I can see if I can at least get something in there (Male, Focus group participant).

Yeah, you just kind of have to check out different things. Sometimes bland cereal would help or bananas seemed to help me a lot. They calmed my stomach. Other fruits and vegetables, like grapefruits or anything that had a lot of acidity in it would cause it to be worse (Male, Focus group participant).

I have really, really bad gas, so I take my HIV meds at night so that seems to better during the day. So I stay away from dairy because of the HIV. But I notice that when I cut down on my dairy I cut down on the gas thing and the stuff, but that's what makes me gassy is the medicine. I wasn't a gassy person before that (Female, clinic patient).

When I got out of the hospital I wasn't eating at all. You know I would go 2, 3, 4, 5 days without eating. A meal would be half a bowl of cereal on Monday and maybe eat the other half on Wednesday and go 'til Friday or Saturday without eating. Just drinking water too, I still have to make meds, but then I'd ... you know my stomach was all messed up because ... it gives you the runs (Male, Focus group participant).

Providing or receiving support. Patients discussed social support as an influential factor in their daily dietary practices. Many participants said that they had people in their lives that provided support, both for accessing food and for eating the right foods. Some people also mentioned that providing support to others actually helped them to better manage their own nutritional needs.

You know I've noticed, too, that helping other people really helps me forget my problems like I've got HIV and all that. And let go of that worry because like my [two friends] from next door ... they don't eat right and so I usually make everybody dinner and that way I can cook for 3; you know make something worth fixing like tacos or you know put a chicken in the oven with some vegetables. And just by helping them it helps me eat a lot better. I

do, I get my 3 meals in a day, I'll get up and have my Cheerios and then you know about 2 or 3 I'll eat some lunch, and dinner with the guys (Male, Focus group participant).

I'm renting a room from a friend and she actually says you need to eat. I've made you salad and here, you're eating. Because otherwise I won't eat ... I don't get hungry after I cook (Male, Focus group participant).

See my caregiver does that, too. He'll hook me up if I'm really flat on my back. And then as soon as I call him up he'd come down and bring me some you know, and he wouldn't charge me or anything. Bring me ice cream, you know (Male, Focus group participant).

And then my neighbors are incredible. He says, I got a new microwave at the pawn shop, I can't get it to work, can you come and look? I go over there and checked every knob, every dial, I said, sorry Lawrence, I can't get it to work. He says I'm going to have to take it back. I said okay, he says, hey, do you want some food? He says, I got these ribs and he says I don't want them. I said, okay, I'll take them. He says, I got these steaks, do you want them? I said, okay, I'll take them. And then he says, what else do you want? Opens his cupboard. So my neighbor's very generous (Male, clinic patient).

But as far as eating I mean, there's always one of my 6 siblings always making sure I have something to eat 24 hours a day. I ... usually if I don't have food they'll bring me food. Even if I don't want food, they'll get upset. You have to, you must, you will ... I don't care. They pretty much on me about that (Male, clinic patient).

Well, Kasey tries to make me eat a salad all the time. Vegetables, he's good about that. So he makes sure that comes into the diet. You know, being a chef, he makes all kinds of different stuff for us so our diet's pretty varied (Male, clinic patient).

Acquiring the right food. Participants discussed whether they had the resources needed to acquire the kinds of food needed to adequately manage their diet. In general, people reported that it was difficult to afford the best nutritional options. The high price of fresher, healthier foods versus less healthy, processed foods played a major role in patients' ability to manage their own nutrition the way they wanted to. Patients also talked about being limited in possibilities based on the necessity of purchasing food with food stamps, and based on limited transportation.

I think it could be just the price ...if it's easier to prepare then why prepare food? Price alters whatever kind of menu you try to set up (Male, Focus group participant).

I cook for a family of children and it's sort of discouraging that it's more economical to eat food that is not so good for you than it is to always eat healthy ... especially when you have to cook for kids and you'd like to have more fresh fruits and vegetables and things like that. But when the money is tight, you have to stretch it. It's really a shame, you can get more bang for your buck by a lot of processed food, a lot of food that's not that great for you (Female, Focus group participant).

[What I eat] really is not to do with the AIDS, it's to do with the amount of money I make (Male, clinic patient).

And [there are a lot of places that] don't take food stamps. That's a big downfall. That's a *big* downfall (Male, Focus group participant).

But when you go buy a bag of oranges and it's almost \$7, you know, or I was lucky I found a bag for \$4.99 the other day. And apples, I mean, I can't afford it, they're just so much more expensive. And I'm supposed to be eating all these good foods for your body, well, duh? You know, you can't! (Female, Focus group participant).

Another thing that, personally, I rolled my truck in October so I've been without wheels and so it's, I'm at the mercy of friends or relatives to get me to the store a lot of the time (Male, Focus group participant).

It should be cheaper to eat well and to eat the right kinds of stuff. Not more expensive. And it seems like it's just ... the obesity problem in America, that's a real problem and it's just so much processed, on-the-go foods, but it's cheaper (Male, clinic patient).

Well usually what I do, because I only get food stamps and ... they don't last long so I have to go buy the whole thing and just put in my freezer. When I go grocery shopping it takes me about 2-3 hours to get all the groceries because I'm like, I check everything out, price and everything, because the way some of the food is, you know, the meats and that, they're expensive and it takes me longer (Female, clinic patient).

So I think Rosa (name changed), I was interpreting for Rosa what your question was and I guess for her, I think she struggles in trying to balance keeping you know healthy, trying to be able to cook healthy in her home. She says she's learned quite a bit, but she continues to struggle in terms of probably getting to the places that she would like to go for shopping. Even though like I think Sunflower Market takes food stamps, but she struggles with transportation so she can only go to the nearest place and get what she needs there. And a

little bit at a time. So that's what kind of hinders her. A lot of times she may just grab what she can or needs at the time and go with that (Female, Focus group participant).

Family and personal preferences. Patients talked about their own and significant others' attitudes toward changing their diet as necessitated by being HIV-positive. Many participants said that their preferences for less healthy foods, along with their families' needs and preferences, made managing nutrition more challenging on a daily basis.

And it's *daily*, it's just a fight every single day because I want everything that I see to eat. And I'm one of those out of sight out of mind [people], which drives my boyfriend nuts because he's young and he loves all this stuff. His mother's a great cook, and she's a Latino and there's this culture of just feeding everybody constantly so he brings stuff home and when I go over to their place and I really don't want it but I see it and I'll eat it and that's my problem (Male, clinic patient).

It's hard because I'm, I love fried foods and I have to get away from that. And it's kind of hard, there's certain stuff it's just good fried, like chicken wings. You know they're good baked, and catfish, you know ... it's good baked, but fried catfish just sounds good by itself though. Yeah. The hardest thing is to try to shy away from fried foods a lot and you know. Being ethnic, African Americans we grew up on fried chicken and fried foods (Male, clinic patient).

I don't want to deprive my kids ... kids like snacks and things like that and they're really active. I can pass by cookies, I like them, but Doritos, Sun Chips, that kind of thing I can't pass up ... so I try to watch the fat and be mindful of it. Otherwise I think if you cut things out completely you just want it more (Female, Focus group participant).

Rosa thinks, she's telling me that in terms of her stuff and because she's female and she's getting older, her provider advises and encourages her to start taking up more on dairy products 2%, 1%, low-fat type of stuff, cheeses, and milk and stuff like that and certainly the vegetables and fruits. But she says it doesn't really make it easy sometimes for her because having her own traditional and culture type of way of preparing foods (Female, Focus group participant).

Theme 4: Learning Opportunities

HIV-positive patients were asked what kinds of education would be most useful in helping them manage their diet and nutrition on a daily basis. Participants brought up

several topics they felt they would like to learn more about. Patient suggestions led to the identification of two sub-themes: Help with meal planning and cooking and strategizing to manage HIV.

Help with meal planning and cooking. Participants said there were specific things they would like to learn about that could help them with nutrition management. All patients indicated that nutrition education would be of interest to them, and specifically emphasized a desire to learn more about how to cook, recipes that would be nutritious and economical, and where best to shop for affordable food.

[It would be helpful] if they actually show you, like brought in samples of ways to cook, of the best things to cook. [Then] I could go, oh, that was a better choice than my chips. And I'd go and get some oranges or whatever (Female, clinic patient).

What would I like to know more ... I would like to know how to cook. I don't know how to cook very well. There are certain things that I know how to cook real well and I tend to stick to what I know how to do (Male, clinic patient).

It's interesting that you asked that. CAP (the Colorado AIDS Project) used to have a nutritional cooking class, something like that. And I always wanted to go to that, but CAP was like so far from where I live. But how to prepare the meals. Like a class like that, I think that would be kind of interesting to do (Male, clinic patient).

Hmmm I don't know, maybe making meals, other stuff like with recipes for like salads and stuff like that, other stuff you know that would help, you know (Female, clinic patient).

You know what would be helpful, is if a list could be compiled. I've never heard of Save-a-Lot [before today]. And I want to check them out. I think a class that would also include, where are good places to shop to get the foods we should be eating (Male, Focus group participant).

I think I'd like to know easier, like little ideas on what to cook for dinner. I get so stuck in my old recipes and the things I'm used to fixing, I wish I knew a few little more tricks, you know (Male, Focus group participant).

Strategizing to manage HIV. Patients talked about educational information they would like to acquire regarding specific things they could do to manage HIV-related indications. Topics that were mentioned most often included foods that would be beneficial for the immune system, that could help assuage specific symptoms and side effects, and that would help counteract ARV-induced health problems.

So if they could have maybe suggestions on what foods help fight fatigue, you know, or this certain food that can do certain things that help you. It'd be nice to know other things like is sea salt better than regular salt? What type of artificial sweetener is better? I would like to know those things. Because you know like I said on a certain kind of budget you can only afford so much, but yet you want to eat better and do better for your body (Female, Focus group participant).

I think there's a lot of information out there that certain foods help your immune system and things like that. Is that really valid? Do they really benefit you? I mean I think every doctor has a different opinion too. And like if I knew that there was really documented information that certain foods really worked well with the medicines you are on, and did really, truly help your immune system ... not just, you know someone's opinion (Female, Focus group participant).

Sort of like a HIV food chart or a symptoms food chart. Like my thing, like my cramps on my legs, you know ... if you're feeling weak and lazy, you know, when do I need sugar? Because I really don't know, and I don't like to just do pills. If I'm going to eat something, I'd like to put something in that's doing my body good at this point you know (Male, clinic patient).

I think knowing little things about how it helps somebody's stomach, like learning about the Cheerios, or learning about something else that can help calm your stomach or relax you or something, I want to say almost like holistic in a sense would be helpful (Male, Focus group participant).

[I'd like to find out] more about triglycerides. I just ... what I find on the internet is very confusing to me, it seems to be contradictory a lot of the time. I've spoken to a nutritionist here before and she was kind of vague as to exactly what I could do to lower my triglycerides through diet except that she kept saying... you know trout and salmon. It's like, well I can't afford that (Male, clinic patient).

Summary

The current study was designed to explore patients' and healthcare providers' perceptions, experiences and interpretations of nutrition as it relates to HIV. Providing

nutrition education and adhering to recommended practices depends on a myriad of varied factors. Healthcare providers who answered questionnaires thought that nutrition education was important in the management of HIV, and attempted to give well-rounded and consistent advice to patients. The frequency and depth of education, however, was influenced by patient attitudes, accompanying illnesses, and availability of time and referral services. HIV-positive patients who were interviewed individually or via focus groups reported that they felt their primary healthcare providers gave appropriate general dietary advice, and said they tried to manage diet as best they could by monitoring the safety of their food and maintaining a balanced diet. Their ability to do so was influenced by the intensity of ARV-related side effects, level of available social support, financial and physical access to food, and food preferences. All patients said they would benefit from learning more specific nutrition management techniques (e.g., cooking, shopping, balancing food with illness) if education were available.

Chapter 6: Discussion

Review of Results

The current study focused on describing the barriers to HIV-related nutrition management among patients and healthcare providers at three different settings. Interview and questionnaire data were collected from 9 healthcare providers and 44 HIV-positive patients in Colorado. Analysis of healthcare provider data led to the identification of 3 main themes, while the patient data yielded 4 main themes (Table 3). The themes that emerged were related to each of the current study's research questions, and also informed the identification and description of barriers to nutrition management.

The first healthcare provider theme, 'Nutrition education perceptions', addressed the research question of healthcare providers' perceptions about nutrition as it related to HIV. Providers' discussion around their perceptions regarding delivering advice to HIV-positive patients focused on a lack of formal procedures at their site for providing such education, and also on whether such education was important. Although participants reported that nutrition recommendations they delivered weren't driven by specific clinical practice guidelines, they did agree they felt nutrition was important in the management of HIV. That said, providers also emphasized that their primary agenda was to make sure patients' acute health issues were under control and that they were taking appropriate medications. Once this was accomplished, then nutrition was next on the agenda as a long-term health concern.

The second healthcare provider theme, 'Nutrition education practices', answered the research question of what healthcare providers advised HIV-positive patients to do with regards to nutrition. Participants tended to provide the same kinds of recommendations that they would give to the average patient. Nutrition education they delivered that was more specific to HIV-positive patients was related to co-occurring illnesses influenced by ARV medications such as glucose intolerance, hypertension, and high cholesterol. Due to the fact that health risks for people living with HIV can be exacerbated by being either over- or underweight, providers said that a patient's weight is evaluated at every appointment and counseling provided where necessary. Participants also talked about the importance of consistent, concise, and simple messaging to discuss nutrition with patients.

The question of what made education delivery easy or difficult was answered within the theme of 'Influences on nutrition education'. Healthcare providers said that though they do provide dietary advice to everyone, the level of interest and motivation among patients determines the depth of education delivered. Factors that made education more difficult were the lack of time during appointments, lack of available referral services available to bolster brief recommendations provided in routine care, and the presence of multiple illnesses among patients. The need to address numerous health issues during each appointment further limited (or eliminated) the time providers could spend on nutrition-related topics.

The first patient theme, 'Perceptions about nutrition and HIV', addressed the research question of patients' perceptions about nutrition as it related to HIV. Patients' discussion around their perceptions regarding nutrition management focused on the

advice they received from healthcare providers and what they believed was best for their health. Participants heard from their providers that they needed to be careful about maintaining a healthy weight, that they should avoid certain foods and supplements (e.g., grapefruit, St. John's Wort) while taking ARV medications, that they should eat more produce and less meat product, and that they should make sure foods were washed and cooked thoroughly. Participants' descriptions of their perceptions also included their perceived importance of diet to their overall health. They thought nutrition was very important to disease management and believed they needed to be careful about the safety of foods, and about maintaining a balanced diet that was limited in fat, salt, sugar, and starch.

The research question about which dietary practices patients engage in relative to being infected with HIV was addressed by the theme of 'HIV-related eating habits'. Patients conveyed that they emphasized food safety in their diet. This included taking precautions with regard to cleanliness of foods and surfaces, cross-contamination of meats and other foods, and refrigeration and thorough cooking of foods. They also emphasized that as much as possible, they tried to avoid processed foods, consume more fruits and vegetables, eat less meat and especially fried foods, and incorporate natural foods and supplements. Participants also spoke about diet in relation to their prescribed ARV medications. Many talked about coordinating meals with the times they needed to take their pills. They also discussed which kinds of foods helped them facilitate their medication routine; not all foods and dietary behaviors used for this purpose were nutritionally beneficial.

The third patient theme, 'Influences on nutrition management' addressed the research question of what makes HIV-related nutrition management easy or difficult. Many patients talked about how the presence of social support, or providing social support to others, made nutrition management easier. A fair number of participants had friends, neighbors, or family they could rely on to help them acquire food or that encouraged them to eat healthier foods. Factors that made management more difficult were the ability to acquire the best foods on a regular basis, family or personal preferences, and the presence of ARV side effects. Many people were very limited on where and how they could shop for food based on transportation and finances. Some patients said they had to go shopping frequently due to the inability to carry much home when walking or on the bus. Using food stamps was a constraint because of which stores would accept food stamps, and also because of the extra time it took to find enough of the right-priced items that would meet dietary needs and still fit within the budget. Family and personal preferences made it more challenging to adhere to diets that were most appropriate for HIV-management, but most participants said this was not a major inhibitor. Side effects were a fairly significant problem to eating the best foods for a number of people, but not everyone. Details about side effects are discussed below.

Finally, the theme of 'Learning opportunities' lent information about what patients would find useful to help manage their diet. All participants said they would like to learn more about meal planning and cooking. They were particularly interested in recipes that incorporated appropriate foods, cooking skills, and information about which stores and resources were best to find healthy and economical choices. Patients also wanted to learn more about which kinds of foods could help them manage HIV-related

issues. This included things like fighting fatigue and stress, eating for certain symptoms like nausea or cramps, and finding foods to help manage ARV-related issues like elevated triglycerides or blood pressure.

Barriers to HIV-Related Nutrition Management

The themes that emerged within the current study helped identify several barriers to the delivery of nutrition education encountered by healthcare providers. Although participants talked about multiple factors that influenced nutritional management of HIV, not all factors were considered barriers based on the valence and frequency of related statements. For instance, providers indicated that patient attitudes influenced the depth and extent of advice they offered. Patient willingness to change did not, however, stop providers from delivering general nutritional recommendations. Similarly, patients reported that family and personal preferences made managing nutrition more challenging but did not preclude them from continuing to make efforts toward dietary management. In general, providers were limited by the lack of in-house nutrition services available to them for patient referral, the restricted amount of time they had to spend with each patient, and the existence of more acute health issues among patients that demanded precedence over nutritional factors during primary care appointments. There are no current studies that specifically examine the tendency of healthcare providers to deliver nutrition education to HIV-positive patients. However, related research examines barriers to providing sexual risk prevention counseling to patients at risk of, or infected with HIV. There has also been exploration into whether and why general practitioners customarily provide nutrition counseling to patients with diet-related issues.

Providers in the current study emphasized the lack of nutrition services available at their site for patient referral as a barrier to delivering adequate nutrition care. Cahill and colleagues (2010) examined why the impact of nutrition-related clinical practice guidelines such as those set forth by the ADA (1998) has been modest despite a rigorous development and active dissemination process. Similar to providers in the current study, key informants in intensive care units who were asked about their perceptions and attitudes toward such guidelines identified the lack of available referral resources as a primary barrier. A large sample of family practice physicians in Canada had mildly positive attitudes toward the potential effects of nutrition counseling on patient behavior. However, there was no associated increase in the frequency of dietitian referrals (Wynn et al., 2010). Previous studies have identified inaccessibility of services as a key factor in why physicians may underuse dietitians (Nicholas, Roberts, & Pond, 2003).

Almost every healthcare provider in the current study identified limited appointment time as a major obstacle to delivering nutrition education. Lack of time among primary care physicians is one of the most strongly identified barriers to providing any kind of preventive care to patients during appointments (Drainoni et al., 2009; Kolasa & Rickett, 2010; Pollak et al., 2008; Wynn et al., 2010). It has been estimated that if physicians were to provide all services recommended by preventive service guidelines, it would require over seven working hours per day (Yarnall, Pollak, Østbye, Krause, & Michener, 2003). Because physicians clearly cannot spend this amount of time on prevention, they may have to forego some services either by omitting them completely or addressing them only briefly. Pollak and coworkers (2008) calculated the amount of time spent per preventive service during the average primary care appointment, and discovered

that that the time spent on nutrition counseling services did not meet the recommendations for adequate delivery. Similar to practices described by healthcare providers in the current study, time constraints may cause clinicians to rely on their personal intuition or bias, chronic illness triggers or patients' requests to determine the time they will spend on preventive services during each visit. Moreover, the low level of education of some patients demands more time to explain prevention effectively (Drainoni et al., 2009).

The third barrier to delivering nutrition education that was acknowledged by providers in the current research was the impact of competing patient health demands. This obstacle exists in tandem with the barrier of time constraints; the more comorbidities a patient has and the less time there is during an appointment, the lower the likelihood that providers will discuss nutrition requirements. Similarly, when asked about adherence to nutrition guidelines clinicians have reported that it is more difficult in patients with a poor prognosis or for whom there are more urgent priorities of care (Cahill et al., 2010). In a fairly recent qualitative study (Grodensky et al., 2008), many providers said the priority for their HIV-positive patients during appointments was to manage their viral loads and prevent further morbidity and mortality. Furthermore, participants felt it was difficult to justify a large degree of prevention-related counseling during appointments when patients have been waiting a long time for appointments, and have specific needs that need to be met (Grodensky et al., 2008).

Provider fatalism was briefly mentioned by two providers in the current study, but did not emerge as a strong barrier to presenting nutrition education to patients. Provider fatalism, or the belief that behavior change among patients is unlikely regardless of

prevention counseling, has been reported to be a common obstacle to providing prevention education to patients in other studies. Grodensky and colleagues (2008) found that providers were particularly concerned that their prevention counseling would be ineffective in changing their HIV-positive patients' risky sexual behaviors. In other research, a higher degree of fatalism predicted less prevention counseling in all types of medical care visits (Myers et al., 2007). Likewise, over 50% of family practice physicians reported that they only 'somewhat agreed' that nutrition counseling was effective at changing patients' behavior (Wynn et al, 2010). Results from other studies are consistent with this perceived modest effectiveness of nutrition counseling, especially when compared with other preventive interventions such as smoking cessation counseling and cervical and prostate cancer screening (Cornuz, Ghali, DiCarlantonio, Pecoud, & Paccaud, 2000; Litaker, Flocke, Frolkis, & Stange, 2005).

Themes that emerged from interviews with HIV-positive patients helped define three major barriers to the adherence of nutrition education provided by healthcare providers. By and large, patients were limited by financial and physical access to the foods they needed to adequately maintain recommended nutritional status. Lack of nutrition adherence was also precipitated by the presence of physical side effects that affected food choices and the desire to eat, and by inadequate cooking and meal planning skills.

Patients in the current study emphasized their limited financial and physical access to food as a barrier to following nutrition recommendations received from healthcare providers. The inability to afford nutritionally adequate and safe foods is fairly common among people living with HIV, and is a barrier that has become recognized as

an important cause of worse health outcomes among HIV-positive individuals (Gillespie & Kadiyala, 2005). In two studies conducted among low income HIV-positive individuals in San Francisco, over half reported being unable to routinely afford or access nutritionally adequate and safe foods (Weiser et al., 2008; Weiser et al., 2009).

The association between limited food access and clinical evidence of diet-sensitive chronic disease has also been examined (Seligman et al., 2010). Among nonelderly adults with low household incomes, the inability to afford adequate food was associated with clinical evidence of hypertension and diabetes. It has been demonstrated in similar studies that less access to food is most common among individuals with the worst health profiles, combined with a lack of health insurance (Weiser et al., 2009).

There are several mechanisms whereby chronic disease may intensify barriers to acquiring healthy food. First, individuals with more advanced disease and poor functional health status may be less able to spend much time or energy shopping for food. Second, individuals without health insurance may have to spend some of their limited resources on health care costs rather than procuring food.

Many patients in the current study also identified the existence of gastrointestinal side effects as a barrier to managing nutrition as they felt they would like. Among HIV-positive individuals, life-long pharmacotherapy with combinations of medications may be required for continuous disease management and presents challenges to nutritional status maintenance by introducing potential interactions with food, body metabolism, and side effects (Fields-Gardner & Campa, 2010). As such, HIV-infected patients often name adverse effects as the number one barrier to disease management (Jain, Clark, Diaz-Linares, & Grim, 2006).

HIV drug side effects can include flu-like symptoms that make it difficult to eat or desire food such as fever, nausea, vomiting, fatigue, and headache. In addition, diarrhea is a significant and common concern among HIV-infected patients that often impairs quality of life and results in non-optimal dietary changes made in an effort to remedy the problem (Siddiqui et al., 2007; Siegel, Schrimshaw, Brown-Bradley, & Lekas, 2010). It is possible that different combinations of drugs result in different side effects and cause different problems (R. Jain et al., 2006). Within the current study, 16 significant statements related to gastrointestinal side effects were extracted from the patient transcripts. Of those, most (10) came from participants interviewed at Site 3. As depicted in Table 2, participants from this site reported taking prescribed ARV medications that varied greatly from medications taken by patients from Sites 1 or 2. The resulting reports of side effects among these patients could be a function of regional variation, stage of disease, or individual differences in response to ARVs. Many of the prescriptions reportedly taken by patients at Site 1 are ‘first-line’ therapies, meaning that they are recommended for the initial treatment of a disease on the basis of empirical evidence for their efficacy. Some of the medications in the other locations are used in ‘salvage’ therapy after multiple prior failures with other drugs. It could be that many participants from Site 3 had a low tolerance in general for ARV drugs and had thus been switched to various alternative therapies by their primary healthcare provider.

The third barrier to adhering to nutrition education recommendations that was acknowledged by patients in the current research was the lack of adequate cooking and meal planning skills. Although patients acknowledged receiving adequate general advice from healthcare providers about balanced diet, increasing fruit and vegetable intake,

decreasing fats and meat products, being mindful of food safety, and other advice specific to HIV-related illnesses they did not appear to have adequate skills to consistently translate knowledge into practice.

Research in barriers to dietary management among diabetic patients supports this finding. In general, the overall demands of diabetes management can influence individuals' perceived or actual ability to adequately manage their diet. One study that sought to examine the barriers to adherence to dietary advice in first-degree relatives of patients with type 2 diabetes found that similar to patients in the current study, participants were in favor of advice aimed at improving general diet. However, lack of meal planning skills and ideas for cooking to meet healthcare provider recommendations were barriers to adherence (Brekke, Sunesson, Axelsen, & Lenner, 2004). In a similar study, parents of diabetic children discussed skills they had to work on acquiring in order to adhere to dietary prescriptions. These included shopping to ensure availability of the foods needed to prepare meals, planning, cooking meals in advance, and using simplified cooking methods (Rovner et al., 2010).

Theoretical Elements

Although it is not feasible to claim statistical generalizability of the current findings based on the small sample size and limited geographic location of participants, it is possible to consider their analytic generalizability. In analytic generalization, a previously developed theory may be used as a template against which to compare the empirical results of a given study (Yin, 2003). In turn, the original theory may have much wider applicability than the particular sample studied. Examining perceptions of the current study's HIV-positive patients through the lens of the IMB model (discussed in

Chapter 3) may thus provide information about understanding and changing the dietary behaviors of a larger population of patients.

According to the IMB model of health behavior change, to the extent that HIV-positive individuals are well-informed, motivated to act, and have the behavioral skills required to act effectively, they will be more likely to engage in both proactive and preventative behaviors that will delay the progression of HIV to AIDS (J. D. Fisher & Fisher, 1992a, 2000, 2002; W. A. Fisher & Fisher, 1993). To the extent that HIV-positive individuals are poorly informed, unmotivated to act, and lack the behavioral skills required to act effectively, they will be unlikely to engage in such behaviors and thus experience their health benefits. Consistent with research conducted to understand patients' adherence to ARV medication regimens and also to self-care recommendations among diabetic patients (Amico et al., 2005; Osborn et al., 2010), HIV-positive patients in the current study talked about factors that reflected information, motivation, and behavioral skills important to nutrition management.

One theme was similar to the information component of the model. Patients perceived that they received appropriate general advice from their healthcare providers, and had a good working knowledge of the kinds of foods they should eat or stay away from, and how to keep foods safe. Two themes were comparable to the motivation component of the model. Patients conveyed that they perceived managing their nutrition to be very important to their health, and that social support and family preferences influenced their dietary behaviors. The skills component of the model was represented by three themes. Patients conveyed that food safety and working with ARV medications were skills used in everyday eating habits, and that managing side effects and acquiring

food were influential in managing nutrition. They also indicated that cooking and meal planning were skills they lacked and would like to learn more about.

The understanding of how patients perceive nutrition as it relates to HIV within the context of informational, motivational, and behavioral skill factors that may be necessary for changing dietary behaviors facilitates its application to constructing, implementing, and evaluating nutrition management interventions (Fisher & Fisher, 1992b). The first step of this process has been achieved in the current research. Elicitation research assessed a small group's pre-intervention information about adherent behavior, their motivation to practice adherent behavior, and their behavioral skills for the practice of key adherent behaviors. This assessment revealed that the primary barriers to nutrition management among patients were related to the skills element of the IMB model. The second step may involve the implementation of population-specific interventions that address the identified deficits in behavioral skills. This step is discussed below in 'Future Directions'. Subsequently, the third step should employ evaluation research to determine whether such interventions have had significant and sustained effects (Fisher et al., 2006).

Limitations and Delimitations

Delimitations of a study define the boundaries of the research, and are determined by exclusionary and inclusionary decisions made throughout the study development. The scope of the current study was limited to the perceptions and experiences of nutrition management among a relatively small group of healthcare providers and HIV-positive patients at three healthcare settings in Colorado who volunteered to participate. Given the small sample size and limited geographical location, the findings may not be statistically

generalizable. To date, there is a paucity of HIV-related research available to support the results, and readers should determine the appropriateness of the study findings for their given circumstances. The primary objective of the current research was to describe the barriers to HIV-related nutrition management among patients and healthcare providers. The study's research questions, questionnaires, and interview protocol were driven in part by potential economical and sociocultural barriers suggested by related literature and the selected theoretical perspective. Although questions were open-ended and participants were given the opportunity to discuss whatever salient perceptions and experiences that came to mind, including interview and/or demographic questions that were more specific to physical factors such as additional illnesses people were experiencing or other medications participants were taking may have yielded slightly different or additional results.

Limitations of a study refer to methodological decisions that set parameters on the generalizability and utility of research findings. One limitation of the current study was that the primary researcher was not fluent in Spanish, and thus was not able to interview Spanish-only speaking patients. Recruitment materials, as well as informed consent forms and confidentiality agreements were translated and available in Spanish. A Spanish-speaker with extensive qualitative research experience was also available to facilitate focus groups and interviews. However, due to the aforementioned patient recruitment challenges (discussed in Chapter 4) it was not feasible to arrange meetings at some locations in advance in order for this facilitator to be present. As a percentage of potential participants only spoke Spanish, HIV-positive patients with valuable perspectives and information related to nutrition management at these sites may have been excluded from

the study, rendering it impractical to capture and interpret their experiences. Two Spanish-only speaking patients from other sites were able to participate in the focus group settings, and a translator at those sites was available during the group meetings.

A second set of limitations within the current study were produced by the data collection methods. First, the integrity of data collected from both healthcare providers and HIV-positive patients relied on the accuracy of participant self-reports. Conclusions drawn from results obtained via self-report were limited to the honesty of the participants, and to their ability to recall detailed information and describe adequately their experiences as they related to nutrition management. Second, the integrity of data collected from patients relied in part on the interviewing skill and objectivity of the interviewer. Although the primary researcher was trained in focus group facilitation and took measures to decrease researcher bias during data collection (discussed in Chapter 4), there was still the potential for various forms of subtle persuasion that are sometimes unconsciously embedded in an interview format. There is a natural power dynamic that exists within the researcher-participant relationship (Kvale, 2006), and it is almost always possible for interviewer questions or probes (asking for further explanation of an answer) to include unintentional ‘hints’ about adequate answers or to be interpreted by interviewees as an activity that challenges their original answer or reasoning (Suoninen & Jokinen, 2005). It is thus conceivable that the route of questioning led some participants to say they thought nutrition was very important to their health, or otherwise describe their dietary habits based on what they believed the primary researcher wanted to hear.

A third limitation relates to the primary researcher’s ‘monopoly of interpretation’ common to qualitative social science research (Kvale, 2006). This refers to the exclusive

privilege of the researcher (or research team) to interpret and report what interviewees really meant, or to frame what a participant said within his or her own theoretical schemes. The use of IPA as a method of analysis for the current study provides room for the notion that the report of people's experiences integrates the researcher's own views along with the nature of the interaction between researcher and participant. IPA also requires the researcher to constantly compare developing themes back to the actual data from which they were derived. Although steps were taken throughout the study to bolster the trustworthiness of the findings, it is possible that some of the current research team's perceptions of participants' experiences were biased.

Future Directions

Many of the barriers to nutrition management identified by both healthcare providers and patients in the current study (lack of physical and financial access to food, multiple long-term health conditions, lack of cooking and meal planning skills) were associated with issues of food insecurity. This is not surprising, given that over 40% of patients interviewed reported yearly incomes below the current national poverty threshold (Table 1; USDHHS, 2011). Household income is the most frequently identified factor associated with food insecurity, but the relationship between income and food insecurity is not straightforward (Gorton, Bullen, & Mhurchu, 2010). United States surveys have shown that up to half of the people who are food insecure have income levels above the poverty line (Rose, 1999). This suggests that even though a strong association between income and food insecurity exists, income alone is not fully explanatory.

Physical and sociocultural factors including, but certainly not limited to multiple health problems, transportation, and food preparation skills are also linked to food

insecurity. Poor health or disability has been associated with difficulty accessing food stores (Nolan, Williams, Rikard-Bell, & Mohsin, 2006). As reviewed previously, people with a greater number of long-term health conditions have a greater probability of experiencing food insecurity (Seligman et al., 2010; Temple, 2006; Weiser et al., 2008; Weiser et al., 2009). Transportation is often needed to shop for food because of the distance between the home and food stores and the quantity of items that need to be carried, and a lack of transport for food shopping has been linked with food insecurity (Nolan et al., 2006). In order to acquire and prepare healthy food on a budget, some level of knowledge and skills are required. The odds of being food insecure have been found to be lower in those with higher levels of food preparation and financial skills compared to those with a low skill level (Olson, Anderson, Kiss, Lawrence, & Seiling, 2004).

Given the nature of the barriers identified in the current study, the most advantageous future efforts will focus on a systems approach to addressing food insecurity. At the healthcare provider level, screening, dissemination of handouts or toolkits, and development of innovative programs that provide nutrition education and build skills may be useful. Although healthcare providers indicate that they have inadequate time during appointments as it is, research suggests that interventions do not need to be time-intensive for physicians. Some physicians have used strategies such as using brief interventions during teachable moments, and leveraging this with referral to other resources both within the practice and the community as a way to quickly and effectively deliver education (Flocke, Crabtree, & Stange, 2007). Furthermore, such strategies have been demonstrated to be effective when used in conjunction with simple tools and practices such as dietary questionnaires and educational handouts, flagging high

risk patients, and scheduling “well-care” visits (Delichatsios, Hunt, Lobb, Emmons, & Gillman, 2001; Eaton, Goodwin, & Stange, 2002; Ockene et al., 1999). Resources for providing nutrition counseling to patients are widely available, and many are inexpensive or free and easily accessible through the internet (Kolasa & Rikett, 2010).

At the patient level, interventions that teach people the necessary skills to make better use of their food resources are needed. The efficacy of several preexisting programs has been demonstrated. The Basic Shelf Experience program is a 6-week intervention designed to help low income individuals utilize limited food resources more effectively through planning and preparing meals and discussing food-related issues. Results from a focus group study among participants of this program suggest that such programs can help people living on limited incomes to decrease food insecurity (DeWolfe & Greaves, 2003). Studies investigating similar programs, such as Community Kitchens, suggest that such efforts enable the development of food knowledge and cooking skills, as well as social skills and support networks among participants and facilitators (Engler-Stringer & Berenbaum, 2006; Lee, McCartan, Palermo, & Bryce, 2010).

Clinics that serve HIV-positive patients may also build stronger networks with organizations and programs addressing food insecurity in the local community in order to provide a list of resources for eligible individuals. Local resources may include food and nutrition assistance programs, emergency food and meal programs, meal delivery programs, community gardens, or food cooperatives. These and similar ‘bottom-up’ tactics work together to meet the needs of both provider and patient; implementation of a systems approach is likely to make a substantial difference for people living with HIV

who are food insecure and thus encounter barriers to managing their own nutritional status.

Summary

Healthcare providers who participated in the current study felt that nutrition education was important to the health of their HIV-positive patients. They made an effort to provide recommendations to patients using appropriate messaging styles on a consistent basis. Providers were, however, limited in the amount of education they could provide based on a lack of time and in-house referral services, and the co-occurrence of multiple illnesses among patients that demanded time and energy during appointments. HIV-positive patients perceived diet and nutrition to be very important to disease management. They felt general nutrition recommendations from their primary healthcare providers were appropriate, and made an effort to incorporate dietary and food safety advice into their daily routine. Patients were limited in their ability to optimally manage their diet based on finances and transportation available for acquiring food, side effects associated with ARV medications, and their own cooking and meal planning skills. The nature of the barriers identified in the current study made a systems approach to addressing food insecurity the most appropriate future direction of action. There were several important limitations to the current study, including a relatively small sample in a limited geographic area, the lack of ethnic diversity of the participants, the reliance on self-reports, and possible researcher bias.

Table 2.

Patient Antiretroviral Medication Prescriptions.

| Drug Name | Type* | Patient Prescriptions by Location | | |
|------------|----------------------------|-----------------------------------|--------|--------|
| | | Site 1 | Site 2 | Site 3 |
| Atripla | Combination NRTI and NNRTI | X | X | |
| Sustiva | NNRTI | X | X | |
| Epzicom | NRTI | X | X | |
| Kaletra | PI | X | X | |
| Trizivir | NRTI | X | | |
| Norvir | PI | X | X | X |
| Truvada | NRTI | X | X | X |
| Isentress | HIVISTI | | X | |
| Epivir | NRTI | | X | X |
| Viread | NRTI | | X | X |
| Combivir | NRTI | | X | |
| Tipranavir | PI | | X | |
| Ziagen | NRTI | | | X |
| Reyataz | PI | X | | X |
| Lexiva | PI | | | X |
| Prezista | PI | | | X |
| Zerit | NRTI | | | X |
| Viracept | PI | | | X |

*NNRTI: Non-Nucleoside Reverse Transcriptase Inhibitor; NRTI: Nucleoside Reverse Transcriptase Inhibitor; PI: Protease Inhibitor; HIVISTI: HIV Integrase Strand Transfer Inhibitors

Table 3.

Summary of Themes.

| Main Themes | Sub-themes |
|-------------------------------------|---|
| Healthcare Providers | |
| Nutrition education perceptions | <ul style="list-style-type: none"> • Lack of formal procedures • Nutrition importance over time |
| Nutrition education practices | <ul style="list-style-type: none"> • Concern about over- or underweight • Giving well-rounded advice • Messaging |
| Influences on nutrition education | <ul style="list-style-type: none"> • Patient willingness to change • Presence of comorbidities • Lack of time and services |
| HIV-Positive Patients | |
| Perceptions about nutrition and HIV | <ul style="list-style-type: none"> • Receiving appropriate general advice • Staying safe and balanced |
| HIV-related eating habits | <ul style="list-style-type: none"> • Staying safe • Staying balanced • Working with ARVs |
| Influences on nutrition management | <ul style="list-style-type: none"> • Presence of ARV side effects • Providing or receiving support • Acquiring the right food • Family and personal preferences |
| Learning opportunities | <ul style="list-style-type: none"> • Help with meal planning and cooking • Strategizing to manage HIV |

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APPENDIX A

Notice of IRB Approval



NOTICE OF APPROVAL FOR HUMAN RESEARCH

DATE: September 29, 2010
TO: Harman, Jennifer, 1876 Psychology
Chavez, Ernest, 1876 Psychology, Maertens, Julie,
Psychology
FROM: Barker, Janell, CSU IRB 1
PROTOCOL TITLE: Barriers to Nutrition Management among People Living
with HIV
FUNDING SOURCE: NONE
PROTOCOL NUMBER: 10-1677H
APPROVAL PERIOD: Approval Date: September 29, 2010 Expiration Date:
March 10, 2011

The CSU Institutional Review Board (IRB) for the protection of human subjects has reviewed the protocol entitled: Barriers to Nutrition Management among People Living with HIV. The project has been approved for the procedures and subjects described in the protocol. This protocol must be reviewed for renewal on a yearly basis for as long as the research remains active. Should the protocol not be renewed before expiration, all activities must cease until the protocol has been re-reviewed.

If approval did not accompany a proposal when it was submitted to a sponsor, it is the PI's responsibility to provide the sponsor with the approval notice.

This approval is issued under Colorado State University's Federal Wide Assurance 00000647 with the Office for Human Research Protections (OHRP). If you have any

questions regarding your obligations under CSU's Assurance, please do not hesitate to contact us.

Please direct any questions about the IRB's actions on this project to:

Janell Barker, Senior IRB Coordinator - (970) xxx-xxxx Janell.Barker@xxxx.edu

Evelyn Swiss, IRB Coordinator - (970) xxx-xxxx Evelyn.Swiss@xxxx.edu

Includes: Approval is for a maximum of 80 participants living with HIV. The approved consent form must be used to obtain consent.

Approval Period: September 29, 2010 through March 10, 2011

Review Type: FULLBOARD

IRB Number: 00000202

Research Integrity & Compliance Review Office

Office of the Vice President for Research

321 General Services Building - Campus Delivery 2011

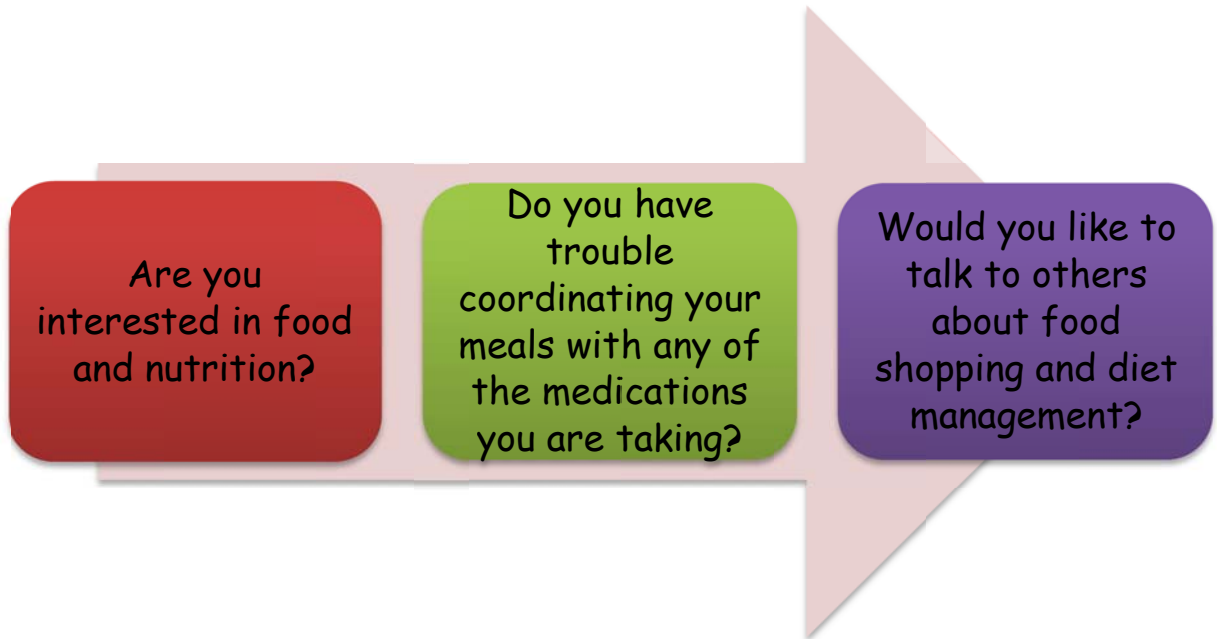
Fort Collins, CO

TEL: (970) xxx-xxxx

FAX: (970) xxx-xxxx

APPENDIX B

Recruitment Brochure



If you answered "YES" to these questions, you're invited to join a research study!

- This activity will be
- ✓ A group discussion
 - ✓ With others living with HIV

If interested please call/email:
Julie Maertens
at Colorado State University

(303)XXX-XXXX
Or
maertens@xxxx.edu

APPENDIX C

Informed Consent Form

TITLE OF STUDY: Barriers to Nutrition Management among People Living with HIV.

PRINCIPAL INVESTIGATOR: Jennifer J. Harman, Department of Psychology,
(970)xxx-xxxx, Jennifer.Harman@xxxx.EDU.

CO-PRINCIPAL INVESTIGATOR: Julie A. Maertens, Department of Psychology,
(970)xxx-xxxx, maertens@xxxx.edu.

WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?

You have been asked to take part in this research study because you are currently living with HIV, and we want to find out more about how your diet or eating has changed since receiving this diagnosis.

WHO IS DOING THE STUDY?

The individuals who are in charge of this research study are Dr. Jennifer Harman and Julie Maertens. These people are the Primary Investigators.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to find out if people living with HIV need to make a lot of changes to their diet, eating patterns, or nutritional intake, and to learn about any problems or issues they face when they do this.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST? The research will be done at xxx and will take about 90 minutes.

WHAT WILL I BE ASKED TO DO?

You will be asked to spend about 60 minutes participating in a focus group discussion. The group will meet only once and will consist of other volunteers and two “facilitators” (people who will lead the group discussion). During the group discussion, you will be asked a series of questions about a variety of topics, including problems you have faced in managing food or diet since being diagnosed with HIV. Discussion topics may include knowledge and education about diet change, the importance of food or food problems in your life right now, and skills related to preparing food or managing diet and nutrition. The focus group discussion will be recorded on audiotape so that the research staff may review everyone’s comments after the session is over. These tapes will not identify people in the group except for their first names. The tapes will be reviewed only by qualified research staff.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

As a participant in the focus group you are considered to be a low risk. There is the possibility that you could become uncomfortable as a result of talking about any challenges inherent to managing your HIV status. Because other people are also participating in the focus group, there is the possible risk that the information you provide may be revealed outside the group. You do not need to talk about anything that makes you uncomfortable. To address this, all participants are asked to sign a statement indicating that he or she will keep the information shared during the group confidential. The researchers cannot guarantee, however, that the group members will keep your information private. It is not possible to identify all potential risks in research procedures, but the researchers have taken reasonable safeguards to minimize any known and potential, but unknown, risks.

ARE THERE ANY BENEFITS FROM TAKING PART IN THIS STUDY?

Benefits to you from participating in this study include the opportunity to learn and get support from other people who have been experiencing challenges related to food and diet. The group will also discuss ways that others have handled or coped with such issues. Your participation will also help in the development of a workshop for clinic staff that will give information to them about what kinds of things to discuss with patients about food, as well as food challenges that patients might encounter and how to deal with them.

DO I HAVE TO TAKE PART IN THE STUDY?

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study, to please the investigator or the research staff. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

WHO WILL SEE THE INFORMATION THAT I GIVE?

We will keep private all research records that identify you, to the extent allowed by law. During your participation in the focus groups, you will only be identified by the name you select to use during the group (first name, or a false name). All information gathered during your participation will be used for research purposes only, and will only be seen by members of the research staff. The Colorado State University Institutional Review Board (IRB) and the Office of Research Compliance (ORC) may inspect study records. The IRB and ORC are groups that monitor research to make sure that they are safe for participants. Therefore, your responses will remain secure and anonymous.

We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be identified in these written materials.

APPENDIX D

Confidentiality Agreement

TITLE OF STUDY: Barriers to Nutrition Management among People Living with HIV.

PRINCIPAL INVESTIGATOR: Jennifer J. Harman, Department of Psychology,
(970)xxx-xxxx, Jennifer.Harman@xxxx.edu.

CO-PRINCIPAL INVESTIGATOR: Julie A. Maertens, Department of Psychology,
(970)xxx-xxxx, maertens@xxxx.edu.

As a participant in this research I understand that I may hear and exchange confidential information with other participants. I understand that I may know other people in the group, and that although all group members will sign this agreement the researchers cannot guarantee that information will not be divulged. I will not disclose anything I do not want identified with me. By signing this statement, I am indicating my understanding of my responsibilities to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about other participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to anyone outside the discussion group any information obtained in the course of this research project that could identify the people who participated in the study.
- I understand that all information about other participants heard by me is confidential. I agree not to divulge or otherwise make known to anyone outside the discussion group any of this information.
- I agree to notify clinic staff or the local principal investigator immediately should I become aware of an actual breach of confidentiality or a situation which could potentially result in a breach, whether this be on my part or on the part of another person.

| | | |
|---------------------------------|---------------|-----------------------|
| _____ Participant | _____ Date | _____ Printed name |
| _____ Principal Investigator | _____ Date | _____ Printed name |

APPENDIX E

Demographic Questionnaire

Thank you for coming today. We are interested in finding out what people know or have been advised to do about food, nutrition, and general dietary practices, and also what kinds of practices work or don't work since being diagnosed with HIV and beginning antiretroviral therapy. We are also collecting information about shopping patterns and about why people shop the way they do. We ultimately want to understand what kind of information or help you could best use to manage your own diet, and also whether food resources available to you need to be improved.

We have a few background questions before we start with the focus group. Please answer the following questions about yourself:

1. What is your age? _____
2. Gender M _____ F _____
3. Ethnicity Black/African American _____ American Indian/Native American _____
Asian _____ White _____ Hispanic/Latino _____
Native Hawaiian/Pacific Islander _____ More than one race _____
Other _____ I would rather not say _____
4. When were you diagnosed with HIV? _____ (MM/YYYY)
5. When did you begin antiretroviral (ARV) therapy? _____ (MM/YYYY)
6. What ARV medications are you currently taking?

7. What is your weight in pounds? _____
8. What is your home address zip code? _____

9. What is your current household income in U.S. dollars?

- Under \$10,000
- \$10,000 – \$19,999
- \$20,000 – \$29,999
- \$30,000 – \$39,999
- \$40,000 – \$49,999
- \$50,000 – \$74,999
- \$75,000 – \$99,999
- \$100,000 – \$150,000
- Over \$150,000
- I would rather not say

APPENDIX F

Interview and Focus Group Script

Interviewer/Moderator: Julie A. Maertens

General Introduction: Thank you for agreeing to participate in this discussion group. For those of you who have never done this before, I just want to tell you that it is a research technique commonly used in social science research to gather data from informed sources. Your answers to our questions will not be considered ‘right’ or ‘wrong’. They are merely information that you will supply based on your experiences, observations, or feelings.

Focus Group Introduction: As mentioned before, we are interested in finding out what people know or have been advised to do about food, nutrition, and general dietary practices, and also what kinds of practices work or don’t work since being diagnosed with HIV and beginning antiretroviral therapy. We are also collecting information about shopping patterns – the stores you use and why – and about why people shop the way they do. We ultimately want to understand what kind of information or help you could best use to manage your own nutrition and dietary practices, and also whether food resources available to you need to be improved.

Introduction of participants: Before we begin, let’s go around the room and introduce ourselves. Instead of just telling us just your name, why don’t you also tell us how long you have lived in this area, and what your 2 most favorite foods are?

Open-Ended Questions. 40 minutes

1. There are many different types of stores you can shop at for food – what type of store do you use to buy most of your household groceries?
2. What characteristics of stores attract you to them?
3. What problems do you have getting to the store? Getting home?
4. What would help you have an easier time getting the types of foods you want or need?
5. What are some of the main things you know about food and nutrition relative to HIV?
6. What kind of counseling/guidance have you received about what and when you should eat, or how to handle food?
7. How important do you think diet is in your life right now?
8. What changes to your dietary practices have you made recently?
9. What kinds of things have lead you to make changes?

10. What kinds of things have kept you from making changes?
11. Are there things that have made it easier to follow the recommendations/make changes?
12. What about things that have made it particularly hard?
13. What kinds of things would help you follow the advice you have gotten, or make the changes you would like to make?
14. If informational materials or classes were offered here at the clinic, what kinds of things do you think would be the most helpful and useful?

Wrap-up. 20 minutes. Here's a summary of the main things we talked about today (moderator will give a summary of key points).

15. Does that sound like everything we discussed? Is there anything else you would like to add?

APPENDIX G

Healthcare Provider Survey

Thanks very much for being willing to answer these few survey questions about nutrition education provided to HIV+ patients at your clinic!

I'm interested in finding out what patients with HIV know or have been advised to do about food, nutrition, and general dietary practices.

I hope you'll have time to elaborate as much as possible when answering the next few questions; it shouldn't take more than about 15 minutes.

Thanks again!

1. Age _____
2. Gender _____
3. Ethnicity _____
4. Job Title _____
5. How important do you think a patient's nutrition and dietary habits are for the management of HIV?
6. What is the general understanding at your clinic about what nutrition/dietary education is appropriate for HIV+ patients?
7. How would you describe your approach to nutrition/dietary education?
8. What kinds of factors determine whether you provide a patient with nutrition/dietary advice?
9. Do you ever refer patients to nutrition intervention services? Which ones?
10. What kinds of issues make it easy or difficult to provide nutrition/dietary education to your patients?
11. What are your thoughts about whether providing nutrition/dietary advice is effective for your HIV+ patients?
12. Is there anything else you'd like to add about this topic?

APPENDIX H

Codes, Themes and Sub-themes: Providers

Index Code List

1. Nutrition Knowledge
2. Nutrition Beliefs
3. Advice Provided
4. Easy Advice
5. Difficult Advice

List of Clustered Codes

1. Perceptions
 - 1.1. Knowledge
 - 1.2. Beliefs
2. Advice
 - 2.1. Dietary
 - 2.2. Referral
3. Easy Advice
 - 3.1. Patient factors
 - 3.2. Clinic factors
4. Difficult Advice
 - 4.1. Patient factors
 - 4.2. Clinic factors

Initial List of Themes and Sub-themes

1. Provider Perceptions
 - 1.1. Clinic protocol
 - 1.2. Personal convictions
2. Nutrition Education Practices
 - 2.1. Patient weight concerns
 - 2.2. General dietary recommendations
 - 2.3. Service referral
3. Influences on Nutrition Education
 - 3.1. Patient-related issues
 - 3.2. Clinic-related constraints

Final List of Themes and Sub-themes

1. Nutrition Education Perceptions
 - 1.1. Lack of formal procedures
 - 1.2. Nutrition importance over time
2. Nutrition Education Practices
 - 2.1. Concern about over- or underweight
 - 2.2. Giving well-rounded advice
 - 2.3. Messaging
3. Influences on Nutrition Education
 - 3.1. Patient willingness to change
 - 3.2. Presence of comorbidities
 - 3.3. Lack of time and services

APPENDIX I

Codes, Themes and Sub-themes: Patients

Index Code List

1. Food Knowledge
 - 1.1. What to eat
 - 1.2. Food safety
 - 1.3. Side effects
 - 1.4. Drug interactions
2. Food Beliefs
 - 2.1. What to eat
 - 2.2. Food safety
 - 2.3. Side effects
 - 2.4. Drug interactions
3. Easy Management
 - 3.1. Acquisition
 - 3.2. Support
 - 3.3. Benefits
 - 3.4. Costs
 - 3.5. Importance
 - 3.6. Desire to eat/importance of food
4. Difficult Management
 - 4.1. Acquisition
 - 4.2. Support
 - 4.3. Benefits
 - 4.4. Costs
 - 4.5. Importance
 - 4.6. Desire to eat/importance of food
5. Food Behavior
 - 5.1. Diet
 - 5.2. Cooking
 - 5.3. Meal planning
 - 5.4. Coordinating food with medications
 - 5.5. Other health issues
 - 5.6. Minimizing side effects
6. Helpful
 - 6.1. Recipes
 - 6.2. Side effects help
 - 6.3. Medicine interactions

- 6.4. Food for HIV issues
- 6.5. Supplements
- 6.6. Cooking skills
- 6.7. Shopping list/affordable

List of Clustered Codes

- 1. Perceptions about food and HIV
 - 1.1. Knowledge
 - 1.1.1. What to eat
 - 1.1.2. Food safety
 - 1.1.3. Side effects
 - 1.1.4. Drug interactions
 - 1.2. Beliefs
 - 1.2.1. What to eat
 - 1.2.2. Food safety
 - 1.2.3. Side effects
 - 1.2.4. Drug interactions
- 2. HIV Food Management
 - 2.1. Things that make it difficult
 - 2.1.1. Acquisition
 - 2.1.2. Support
 - 2.1.3. Benefits
 - 2.1.4. Costs
 - 2.1.5. Importance
 - 2.1.6. Desire to eat/importance of food
 - 2.2. Things that help
 - 2.2.1. Acquisition
 - 2.2.2. Support
 - 2.2.3. Benefits
 - 2.2.4. Costs
 - 2.2.5. Importance
 - 2.2.6. Desire to eat/importance of food
- 3. Eating Habits
 - 3.1. Diet
 - 3.2. Food preparation
 - 3.2.1. Meal planning
 - 3.2.2. Cooking
 - 3.2.3. Food safety
 - 3.3. Working with Illness

- 3.3.1. Food and medicine
- 3.3.2. Food and other disease
- 3.3.3. Food and side effects
- 4. Learning Opportunities
 - 4.1. Food Preparation
 - 4.1.1. Recipes
 - 4.1.2. Cooking
 - 4.1.3. Shopping alternatives
 - 4.2. Working with Illness
 - 4.2.1. Food and medicine
 - 4.2.2. Food and HIV
 - 4.2.3. Food and side effects

Initial List of Themes and Sub-themes

- 1. Perceptions About Nutrition and HIV
 - 1.1. Doctor's advice
 - 1.2. Personal beliefs
 - 1.3. Other Sources
- 2. Eating Habits
 - 2.1. Food preparation
 - 2.2. Working with Illness
- 3. Influences on Nutrition Management
 - 3.1. Things that make it difficult
 - 3.2. Things that help
- 4. Learning Opportunities
 - 4.1. Food Preparation
 - 4.2. Working with Illness

Final List of Themes and Sub-themes

- 1. Perceptions about Nutrition and HIV
 - 1.1. Receiving appropriate general advice
 - 1.2. Staying safe and balanced
- 2. HIV-Related Eating Habits
 - 2.1. Staying safe
 - 2.2. Staying balanced
 - 2.3. Working with ARVs
- 3. Influences on Nutrition Management
 - 3.1. Presence of ARV side effects

- 3.2. Providing or receiving support
- 3.3. Acquiring the right food
- 3.4. Family and personal preferences
- 4. Learning Opportunities
 - 4.1. Help with meal planning and cooking
 - 4.2. Strategizing to manage HIV