Least of My Worries: Food Security, Diet Quality, and Antiretroviral Adherence among People Living with HIV

Charlotte Ann Noble

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Least of My Worries: Food Security, Diet Quality, and Antiretroviral Adherence
among People Living with HIV

by

Charlotte Ann Noble

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Anthropology
College of Arts and Sciences
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Keywords: Syndemics, HIV/AIDS, Food Insecurity, ART Adherence, Coping

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DEDICATION

I dedicate this dissertation to John, my husband of nearly thirty years. John, without your love, support, and patience—much of my adult life would have been impossible. I love you and, most importantly, like you a lot. If you sometimes look at me why I spend so much of it worrying about others, please know that I am just trying to use wisely this gift you have given me. Thank you for sticking with me. Thanks for picking up dinner. We still have seventy-two years left in our contract.

I also dedicate this dissertation to my two children. Caryn, you were the gift I was told never to expect, and I cherish you more than I can say. I am proud of the strong-willed women you have become. I hope that my finally leaping over this hurdle inspires you to keep being brave and maybe a bit stubborn, especially in fighting for what you believe in. Ryan, as I said recently, ‘we can’t return you, we’ve lost the receipt.’ Since you joined our family a decade ago, I have seen your struggles and understand the importance of a stable, loving home in helping someone have a strong foundation from which to learn and grow. I hope that my finishing this helps you consider leaping, even when you are afraid to fall.

Finally, I dedicate this dissertation to my father, Jose Luis Rodriguez. We lost you way too soon, and I miss you terribly. But Daddy, I finally became a doctor. Not the kind you thought I would be, but I did it. As the first in our family, I went all the way.
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TABLE OF CONTENTS

LIST OF TABLES......................................................................................................................... v

LIST OF FIGURES ......................................................................................................................... vi

ABSTRACT........................................................................................................................................ vii

CHAPTER 1: INTRODUCTION ........................................................................................................... 1
  Statement of the Problem.................................................................................................................. 2
  Study Objectives and Research Questions ..................................................................................... 7
  Overview of the Dissertation ......................................................................................................... 8
  Significance and Contributions ........................................................................................................ 10

CHAPTER 2: EMERGING SYNDEMIC IN SOUTHERN U.S.............................................................. 12
  Defining Syndemics ....................................................................................................................... 13
  Evolution of Syndemics, and Comparisons to Other Frameworks ............................................... 16
  Syndemics: Case Study, Strengths & Weaknesses ........................................................................ 20
    Case Study: The Substance Abuse, Violence and AIDS (SAVA) Syndemic ............................. 20
    Strengths and Weaknesses of the Syndemic Framework ............................................................. 23
  Why Syndemics? ............................................................................................................................ 25
  Emerging Syndemics in Southern US ............................................................................................. 26
    Food Security ............................................................................................................................... 28
    HIV/AIDS .................................................................................................................................. 28
    Florida and the ACA ..................................................................................................................... 29
    When Policy Renders Risk .......................................................................................................... 32
  A Way Forward................................................................................................................................. 33

CHAPTER 3: SYNDEMIC COMPONENTS .......................................................................................... 35
  Conceptual Model of Syndemic ....................................................................................................... 35
  Food Security ................................................................................................................................. 36
    Brief History of Food Security Research ...................................................................................... 36
    Definitions and Constructs .......................................................................................................... 38
      Food Insecurity, Malnutrition, and Hunger ................................................................................ 39
      Links to Depression ................................................................................................................... 40
    Measuring Food Security ............................................................................................................ 42
      Quantitative Assessment of Food Insecurity ............................................................................. 43
      Qualitative Assessment of Food Security and Food Insecurity ................................................ 44
      Measuring of Food Security in People Living with HIV/AIDS ............................................... 45
<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structural Barriers .....................................................................</td>
<td>48</td>
</tr>
<tr>
<td>Access ......................................................................................</td>
<td>48</td>
</tr>
<tr>
<td>Household Resources ....................................................................</td>
<td>49</td>
</tr>
<tr>
<td>Organizational ..........................................................................</td>
<td>49</td>
</tr>
<tr>
<td>HIV/AIDS and Food Insecurity ..................................................</td>
<td>50</td>
</tr>
<tr>
<td>Within Body Synergies ..................................................................</td>
<td>51</td>
</tr>
<tr>
<td>Impact on Overall Health .........................................................</td>
<td>52</td>
</tr>
<tr>
<td>Food Insecurity and the Risk of HIV Transmission ..........................</td>
<td>53</td>
</tr>
<tr>
<td>Coping .......................................................................................</td>
<td>55</td>
</tr>
<tr>
<td>Adherence .................................................................................</td>
<td>59</td>
</tr>
<tr>
<td>Antiretroviral Adherence: Definitions and Constructs ....................</td>
<td>60</td>
</tr>
<tr>
<td>Theoretical Approaches to Adherence .........................................</td>
<td>63</td>
</tr>
<tr>
<td>Barriers and Facilitators to ART Adherence ..................................</td>
<td>65</td>
</tr>
<tr>
<td>Food Security and ART Adherence ...............................................</td>
<td>67</td>
</tr>
<tr>
<td>Measurement of Adherence ..........................................................</td>
<td>70</td>
</tr>
<tr>
<td>Mental Health ............................................................................</td>
<td>72</td>
</tr>
<tr>
<td>Linking Mental Health, Food Security and HIV ................................</td>
<td>73</td>
</tr>
<tr>
<td>Summary .....................................................................................</td>
<td>75</td>
</tr>
</tbody>
</table>

CHAPTER 4: RESEARCH SETTING AND METHODS .................................... | 76   |
| Research Setting .......................................................................... | 76   |
| Overview of Research Activities ................................................ | 77   |
| Recruitment and Sample Size ...................................................... | 80   |
| Study Survey ............................................................................... | 81   |
| Food Insecurity and Diet Quality ............................................... | 82   |
| Adherence to ART ........................................................................... | 84   |
| Depression, Stress, and Anxiety .................................................. | 86   |
| Socio-Demographic Variables ....................................................... | 87   |
| Semi-Structured Interview .......................................................... | 87   |
| Data Analysis ............................................................................... | 88   |
| Ethical Considerations .................................................................. | 91   |

CHAPTER 5: FOOD SECURITY ............................................................. | 93   |
| Socio-Demographics ....................................................................... | 93   |
| Food Security ............................................................................... | 96   |
| Access to Food ............................................................................. | 103  |
| Experiences of Food Insecurity ................................................... | 106  |
| Diet Quality .................................................................................. | 107  |
| Healthy Eating Index ..................................................................... | 108  |
| Experiences of Low Diet Quality ................................................ | 110  |
| Coping with Food Insecurity ....................................................... | 111  |
| Summary ...................................................................................... | 114  |

CHAPTER 6: ANTIRETROVIAL ADHERENCE ...................................... | 115  |
| Socio-Demographics ....................................................................... | 115  |
CHAPTER 7: MENTAL HEALTH, ADHERENCE, AND FOOD SECURITY ...........................................140
Depression, Anxiety, and Stress .................................................................140
  Hopkins Symptoms Checklist .................................................................141
  Perceived Stress Scale ...............................................................................141
Mental Health and ART Adherence ..........................................................142
Mental Health and Food Security ...............................................................143
Linking Mental Health, ART Adherence, and Food Security ......................144
Emergent Theme: Unstable Housing ........................................................152
The Gray Place ............................................................................................162
Summary ......................................................................................................164

CHAPTER 8: DISCUSSION ..............................................................................166
Food Security-Related Findings .................................................................167
Mental Health-Related Findings .................................................................169
Syndemic Framework-Related Findings .....................................................171
Limitations of this Study ............................................................................175
Lessons Learned ........................................................................................176
Strengths of this Study ...............................................................................178
Recommendations ......................................................................................179
Dissemination Plan ....................................................................................182
Implications for Policy ...............................................................................183
Suggestions for Future Research ...............................................................186
Reflections ..................................................................................................187

REFERENCES ...............................................................................................192

APPENDICES ...............................................................................................225
Appendix A: Informed Consent ....................................................................226
Appendix B: 24-hour Dietary Recall Form ....................................................232
Appendix C: Survey ......................................................................................233
Appendix D: Semi-Structured Interview .......................................................239
Appendix E: Institutional Review Board Approval ........................................241
Appendix F: Quality Assurance/Quality Improvement Evaluation Findings ......251
Appendix G: Acceptance of Quality Assurance/Quality Improvement Evaluation ......255
LIST OF TABLES

Table 1: Research Questions, Measures, and Variables ..........................................................79
Table 2: Comparison between SRSI, SRSI Recode Values, and VAS Mean.........................86
Table 3: Characteristics of Study Population.................................................................94
Table 4: Affirmative Responses to HFSSM Questions (n=131)........................................96
Table 5: HFSSM Score by Demographic Variables .........................................................98
Table 6: Affirmative Responses to Other Food Access Questions (n=131)........................104
Table 7: Healthy Eating Index .........................................................................................109
Table 8: Characteristics of People Living with HIV and on ART in Tampa, FL .............116
Table 9: Food Security Status by Adherence, Participant Quotes ....................................131
Table 10: Healthy Eating Index by Adherence ..................................................................137
Table 11: Correlation Matrix, Key Variables ......................................................................145
Table 12: Logistic Regression, Predicting ART Adherence .............................................147
Table 13: Chi-Square, SNAP by Adherence .................................................................147
LIST OF FIGURES

Figure 1: Syndemic Model ................................................................................................................. 14
Figure 2: Epidemiological Triangle .................................................................................................... 14
Figure 3: Factors Associated with Non-Adherence ............................................................................. 62
Figure 4: Common Barriers to ART Adherence ................................................................................. 85
Figure 5: HFSSM Categories, Whole Sample ..................................................................................... 103
Figure 6: HFSSM Category by Adherence .......................................................................................... 129
Figure 7: HFSSM Categories by Adherence ....................................................................................... 129
Figure 8: HSCL-10 by Adherence ....................................................................................................... 142
Figure 9: PSS-10 by Adherence ......................................................................................................... 143
Figure 10: Mental Health Scales by Levels of Food Security ............................................................... 144
Figure 11: Coding Stripes for Overlapping Themes .......................................................................... 148
Figure 12: Check Box to Refuse Disclosure of Protected Health Information .................................... 257
ABSTRACT

More than forty years into the epidemic, HIV continues to impact the health and well-being of millions of people – nearly 37 million across the globe and in excess of 1 million in the U.S. – more than 44% of which live in the Southern United States. HIV continues to disproportionately affect marginalized populations, and vast amounts of money, time, and effort have been spent to understand how to slow the rate of new infections and improve health outcomes for People Living with HIV (PLWH). This study aims to understand the experience of living with and managing HIV while on an antiretroviral (ARV) regimen in the Southern United States. This dissertation presents data collected in surveys (n=131) and semi-structured interviews (n=45) to describe the lives of PLWA in the Tampa Bay, Florida region with regards to their food security, diet quality, mental health (stress, anxiety, and depression), antiretroviral treatment (ART), access to health care, and other characteristics, such as stable housing and experiences with forms of public support. Though the impetus for this study is grounded in an understanding of the synergistic relationship among food security, mental health, and adherence to ART, this study’s goals are to add the perspectives of PLWH to the syndemic literature. By exploring how these individuals and groups understand the relationship between syndemic factors, as well as other issues that emerge while discussing their attempts to manage HIV, my hope is that their words will provide programs and policies a better understanding of barriers and facilitators to ART adherence.
Participants in this study experienced varying levels of food security, but it is concerning that 19% experience low food security, and 35% very low food security. Regardless of food security scores or categories, overall the dietary quality of respondents is low and in need of improvement. Nearly three-quarters rely on SNAP to supplement their food purchases, though 60% reported that the amount they receive is not sufficient to meet their household needs.

Participants reported struggling with a number of issues beyond attempts to manage their HIV. Nearly half of the participants in this study struggle with mental distress in the form of depression and anxiety (HSCL-10; 46%) as well as high levels of perceived stress (PSS-10; 48%). Many of them report experiencing stress related to shifting forms of support, attempts to meet basic needs such as housing, food, utilities, and hygiene items, and the overall wear and tear on their mental health that these frequent and overlapping issues present. Rather than be able to report any one stressor that rises above the rest in importance, through the course of their narratives, we find myriad issues that require some form of coping – with some things within their control, but many others were not. Access to housing was a prominent theme throughout the interviews, as well as the ways that housing influenced their ability to adhere to ART, cook or store food, have a safe place to sleep, and avoid interactions with authorities.

In addition to housing difficulties, participants talked about a sense that they were not being seen or that they had fallen through the cracks – described as a ‘shadow place,’ the ‘gray place,’ ‘the place between’ or the place where one is invisible. They spoke about the struggle of navigating complex social safety net rules, including eligibility requirements and situations where gains in one form of support could mean loss in another. In this place, even maintaining the status quo – let alone getting ahead - is impossible and the system seems to be against you. In this place, food – and even HIV – is the least of their worries.
CHAPTER 1: INTRODUCTION

The goal of this study is to understand how people living with HIV experience and manage their HIV treatment in relation to other concerns such as food insecurity, diet quality, mental health (stress, anxiety, and depression), and other circumstances impacting their lives. Several extensive, clinical studies have examined food security and adherence to HIV regimens in large city centers such as Atlanta (Kalichman et al. 2010; Kalichman and Grebler 2010; Kalichman et al. 2014; Kalichman et al. 2011), San Francisco (Carrico et al. 2011; Palar et al. 2014; Weiser et al. 2009b; Weiser et al. 2013), and British Columbia (Weiser et al. 2011a). These studies have demonstrated high rates of food insecurity among those living with HIV (Wang et al. 2011; Wang et al. 2013; Weiser et al. 2009; Weiser et al. 2013). However, at the time this study was proposed, few U.S.-based studies had been published that examined the day-to-day experiences of those individuals attempting to manage these various conditions – what dealing with these multiple issues was like on a regular basis, how people tried to cope with them, and what happens when they fail.

People living with HIV who were on an antiretroviral treatment regimen, and who received services at an HIV service organization/day respite center, were recruited for this study. This population was chosen to capture details about the lives of those who epitomize many aspects of the HIV epidemic in the Southern United States. These populations include those who may be unstably housed, on multiple forms of public assistance, living in poverty but have access to medication and clinical case management, or even those living above the poverty level but who are still struggling. This mixed-methods study investigates the food security, mental
health, and adherence status of this group of individuals, as well as factors that affect these issues. Understanding the ways that people living with HIV experience and manage their HIV while experiencing numerous other challenges can help to inform actionable policies and effective support programs to improve their lives and the health of our communities.

**Statement of the Problem**

Globally, 36.9 million people are living with HIV, with 1.1 million people living with HIV in the United States (Centers for Disease Control and Prevention 2017b). The prevalence of HIV/AIDS is not randomly spread throughout the United States; rather, the disease is found in geographic clusters and is more prevalent in certain racial/ethnic groups. For example, HIV is clustered in large cities on the East and West coasts, but also in suburban and rural areas in the southern states (Centers for Disease Control and Prevention 2017a). States that the CDC designates as ‘the South’\(^1\) accounted for 50% of the estimated 37,600 new HIV infections in 2014, while only making up 38% of the U.S. population. Forty-four percent of all persons living with HIV in the U.S. live in ‘The South.’ Though the U.S. saw a 10% decrease in new infections between 2010 (41,900) and 2014 (37,600), an additional 39,782 people received an HIV diagnosis in 2016 (CDC 2017b), a 5% increase from 2014.

The impact of the HIV epidemic is not uniformly distributed. Racial and ethnic disparities persist in the United States, with African Americans/Blacks being hardest hit; they account for 43% of HIV diagnoses, represent 42% of those living with HIV, and their deaths account for 43% of all HIV deaths, though they only make up 12% of the U.S. population (Kaiser Family Foundation 2019a). In the South, Blacks made up 63% of new HIV infections.

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\(^1\) Alabama, Arkansas, Delaware, Washington, DC, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia.
and 58% of PLWH (Centers for Disease Control and Prevention (CDC) 2018). Of the ten states with the highest numbers of African Americans living with HIV, Florida, and New York are among the highest in the list (CDC 2018). The state of Florida ranks second in the nation in the number of new HIV diagnoses, and fifth in the prevalence of new HIV diagnoses per 100,000 (Kaiser Family Foundation 2019b). The racial/ethnic disparities in HIV mortality among African Americans – particularly women and the elderly – have only grown over time since the introduction of highly active antiretroviral therapy in 1996 (Levine et al. 2007).

Forty years into the HIV epidemic, antiretroviral treatment (ART) has changed the face of the disease. With ART, HIV can become a manageable, chronic condition—but who has access to treatment, and who achieves better health outcomes varies widely by social and economic conditions (Pellowski et al. 2013). In the U.S., roughly half of those aware of their HIV status receive medical care, and a quarter of those in care which should be on ART are not. Of those who are on ART only about 60-80% are sufficiently adherent to achieve viral suppression (Gardner et al. 2011).

In the U.S., ART is accessible to some extent with health insurance, though there have been reports of barriers in terms of insurance companies putting some drugs in high tiers and pricing them with very high co-pays (Andrews 2016). Without health insurance, PLWH may face waitlisting for underfunded government programs such as Ryan White (Reif et al. 2017; Reif et al. 2014). ART has the potential to lead to a longer, healthier life—for those with access, and those who can adhere to their regimens. Improvement in health outcomes achieved through antiretroviral treatment is threatened by unequal access to the Affordable Care Act (ACA); 43% of people living with HIV/AIDS (PLWHA) live in states where Medicaid was not expanded, and
many of them face a “coverage gap” access to treatment may be interrupted or non-existent (Cahill, Mayer, and Boswell 2015).

Links between poor HIV treatment outcomes and food insecurity (that is, being without reliable access to a sufficient quantity of affordable, nutritious food; Oxford 2019) has been established for some time in resource-poor settings, only relatively recently have researchers begun to explore food security in resource-rich settings (e.g., United States and Canada) to determine what role, if any, food insecurity plays in poor health outcomes. Despite clear differences in social, cultural, and economic contexts of HIV+ populations in resource-poor and resource-rich settings, several studies have shown alarmingly high levels of food insecurity—up to 91%— in vulnerable populations in “resource-rich” settings. Some examples include studies of individuals in a drug treatment program in British Columbia (Weiser et al. 2009), marginally housed and homeless individuals in San Francisco (Weiser et al. 2013), individuals recently released from prison (Wang et al. 2013) and veterans (Wang et al. 2011). These recent studies and others conducted in the United States and Canada demonstrate that food insecurity is associated with poor HIV/AIDS treatment outcomes such as lower CD-4 counts (Kalichman et al. 2010; James H. McMahon et al. 2011), higher HIV viral loads (Kalichman et al. 2010), greater acute care utilization (Weiser et al. 2013), higher HIV/AIDS-related morbidity and mortality (Weiser et al. 2009), and suboptimal antiretroviral treatment (ART) adherence (Kalichman et al. 2010; Kalichman and Grebler 2010).

These findings mirror what is known in resource-poor settings: that for these co-occurring epidemics (food insecurity and high rates of HIV infection), there is synergistic interaction in which one condition exacerbates the adverse health effects of the other (Young et al. 2013b). As Young and colleagues (2013) note in a review of the relationship between food
security and ART adherence, food insecurity has been shown to heighten vulnerability to HIV infection, exacerbate poor clinical outcomes (Weiser et al. 2007; Weiser et al. 2009) and has been associated with incomplete HIV RNA suppression (Weiser et al. 2009b; Wang et al. 2011). Food-related interventions (such as supplementation) have been shown to interrupt this relationship and improve clinical outcomes, as well as adherence to ART (Ivers et al. 2010; Bärnighausen et al. 2011).

One rationale for this study is that the research linking HIV treatment outcomes and food insecurity have, to date, utilized a narrow conceptualization of “food insecurity,” which is a “complex, multidimensional phenomenon which varies through a continuum of successive stages as the condition becomes more severe” (Bickel 2000:2). As the body of knowledge surrounding the food insecurity - HIV/AIDS treatment outcome syndemic in resource-rich settings grows, one common issue in these studies is that food security is analyzed as a dichotomous variable. In these studies that examine the syndemic, individuals and households are typically categorized as either food secure or not, often with the use of a single screening question. Current research linking food insecurity and poor treatment outcomes (such as suboptimal adherence) have yet to consider levels and domains of food insecurity, or the experience of stress and enacting coping strategies to determine how they influence those outcomes.

Also, even though food security instruments typically capture the access domain of food security, little is known about the potential influence of diet quality (as a potential mediator) between food insecurity and ART adherence. Until we better understand how food insecurity affects these outcomes, we cannot determine how to address these issues among HIV+ populations in the US, who are already typically impoverished, marginalized, and suffering from other health disparities (Pellowski et al. 2013; Singer 1994). Finally, depression and anxiety have
also been linked with both food insecurity (Weaver and Hadley 2009) and poorer adherence to ART (Mugavero et al. 2006), so it will be important to measure and understand the relationships between these issues common among people living with HIV (Bing et al. 2001; Salters et al. 2017).

It is also important to note that though syndemics were proposed some 20 years ago (Singer 1996), the past several years have seen increased attention on the topic as well as methods of analysis. A syndemic is when two or more epidemics synergistically interact, contributing to an excess burden of disease (Singer and Clair 2003). While conducting data collection for this dissertation, Tsai and Venkataraman (2016) published an important contribution to the literature on previous quantitative analyses of syndemics, arguing that these studies had used faulty logic in utilizing an additive score as a method of empirically establishing the existence of syndemics. Tsai and Burns (2015) conducted a systematic review of empirical tests of syndemics and found that of the 40 studies testing the existing of syndemics, 78% used a sum score method. The sum score method means researchers assigned a point for each potential syndemic component (such as drug use, food insecurity, or depression), added up these points, and assessed the relationship between this score and their outcome variable. In another article, Tsai (2018) points out that using an additive score does not establish the disease interaction required of a syndemic, the definition of which argues for a synergy between the components, not a mere additive effect.

During the data analysis phase of this dissertation, Tsai (2018) published again, suggesting four approaches for advancing syndemics literature, highlighting that these approaches should be complementary and used in tandem “to minimize their limitations and reinforce their strengths” (Tsai 2018: 120). These approaches included: 1) extending beyond the
individual as a unit of analysis (as many previous studies rely on individual-level data), and 2) using methods such as SEM and path analysis to map the timing of health risks. In addition, he proposes 3) creating models of potential syndemics using agent-based simulations, which forces researchers to make assumptions explicit and allow theory testing as well as testing the impact of proposed interventions. Lastly, he recommends 4) utilizing rich data from anthropological fieldwork (ethnography, interviews, and mixed methods) to understand better the “unique insights into under-researched political, economic, and cultural mechanisms that influence disease clustering and amplify disease burden” (Tsai 2018:121).

As a result of the analytical decisions made before these publications, this dissertation does not aim to test the existence of a syndemic. Instead, given relationships established in the literature, my goals were as follows: 1) to describe the components that make up the potential adherence syndemic (research question 1), determine the relationship between the components (research questions 2 and 3) and more importantly, describe the ways that individuals experience these conditions (separately and together) in their daily lives (research question 4), as well as how they try to cope with them - regardless if the coping strategy is successful or not (research question 5).

**Study Objectives and Research Questions**

This study aims to examine the experiences of people in terms of their food insecurity, diet quality, adherence to antiretroviral therapy (ART), and mental health. The first phase of the study consisted of a survey instrument including a food security survey (USDA Household Food Security Scale Module), scales to measure perceived stress (Cohen’s Perceived Stress Scale-10), depression and anxiety (Hopkins Symptoms Checklist-10), as well as interview questions about
coping strategies PLWH might use to address their situation. The survey also included a 24-hour dietary recall (to assess diet quality), measures of ART adherence (Visual Analog Scale, Self-Rating Scale Item), socio-demographic variables, and questions about other potential covariates such as common ART adherence barriers. The second phase consisted of qualitative interviews to elicit narratives on the topics of food security, mental health, and ART adherence to explore how participants experience and cope with these issues.

**Phase 1 Questions:**

1. What is the food security level and diet quality of participating clients enrolled in a special services program?
2. What is the relationship among ART adherence, food security status, and dietary quality?
3. What is the relationship among anxiety and depression, food security status, and ART adherence?

**Phase 2 Questions:**

4. How does the lived experience of food insecurity and diet quality vary by adherence to ART?
5. What coping strategies are utilized by participants to ameliorate issues related to food insecurity and diet quality?

**Overview of the Dissertation**

In Chapter Two, I discuss the history of syndemic theory and compare it with other theoretical frameworks. The strengths and weaknesses are examined using case studies, and a
rationale is provided for using syndemic theory in this dissertation. I conclude with a discussion about the emerging HIV syndemic here in the southern U.S.

Chapter Three introduces the conceptual model of the syndemic as well as reviews literature related to each syndemic component: food insecurity, diet quality, adherence, and mental health. This chapter provides background on the understanding, assessment, and analysis of each of these components.

Chapter Four provides an introduction to the research setting and a review of the research methods for this dissertation. This chapter provides an overview of the mixed methods data collection and analysis activities, recruitment, and overall sample size for the two different phases, as well as ethical concerns related to this work.

Chapter Five is the first of three results chapters. It presents the findings for research questions 1 and 5 – description of food insecurity, dietary quality, as well as coping strategies used by participants to ameliorate these issues. As noted in the significance and contributions section, this chapter will go beyond single question measures of food security and will including measures of diet quality, methods of food acquisition, and food safety and storage.

Chapter Six is the second results chapter and presents research findings related to ART adherence (research questions 2 and 4). This chapter will describe the HIV status of participants, including demographic data, years living with HIV and on ART, and common barriers to ART adherence. Data are also presented on the relationship between ART adherence and food insecurity, including qualitative data on the variation between the food security experiences of those who were adherent versus those with suboptimal adherence to their ART regimen.

Chapter Seven presents the findings from research question 3. This chapter starts with an overview of the mental health-related findings of this dissertation then delves into the
relationship among food security, mental health, and ART adherence, using quantitative and qualitative data. Additionally, themes that emerged during the surveys and interviews, including disability, unstable housing, and the ‘gray place’—a sense that one is invisible or has fallen through the cracks—are discussed.

Chapter Eight presents an overview of the main research findings and offers recommendations and policy implications of these findings. Following established policies in other areas of the U.S., I provide suggestions on ways to improve the types of supports available to people living with HIV and ART. I also review the limitations and strengths of this study and suggestions for future research.

Significance and Contributions

While relatively recent studies have linked food insecurity with several HIV/AIDS treatment outcomes, these studies have done so using one to two questions about whether the participant experiences food insecurity. However, food security—as defined above—is difficult to capture with a single indicator. Food security is a complex, multidimensional phenomenon that varies through a continuum of experiences, from food security to food insecurity. The measurement of food security requires questions that are capable of capturing the increasing severity of the experience (Frongillo 1999; Wolfe and Frongillo 2001), including diet quality, food safety, and social acceptability so that we can better understand the links between food insecurity and adherence. These tools and questions exist, but there are few published studies examining the link between food insecurity and HIV treatment outcomes that use these more nuanced questions. Thus, this study contributes to the literature by providing richer information through the use of the full food security survey as well as qualitative interviews to describe the
experiences of food security, diet quality, mental health concerns, and medication adherence for people living with HIV in Florida.

In addition, research questions 4 and 5 anticipated Tsai’s call for anthropological data to inform the syndemics literature, such as Mendenhall’s (2012) ethnographic work, which has given voice to the experiences of Mexican immigrant women experiencing the VIDDA (Violence, Immigration, Depression, Diabetes, Abuse) syndemic. An additional contribution of this study is that we can understand the relationship between food security, mental health, and adherence through the words of people living with HIV and managing an ART regimen in the Tampa Bay area. Their stories about juggling competing decisions and supports related to their health offer insights into the complexities of managing HIV in the Southern U.S.
CHAPTER 2: EMERGING SYNDEMIC IN SOUTHERN U.S.

In this chapter, I will introduce various definitions of Syndemic theory (or Syndemics) and situate it within the development of the framework within the broader anthropological literature. Then, using case studies from the literature (one in-depth, and several other brief examples), I will outline how Syndemics helped to organize thoughts about those case studies, and discuss the strengths and weaknesses of using this framework in examining those issues. Finally, I summarize information on the burgeoning syndemic in the Southern U.S., focusing on Florida in particular, in terms of food insecurity, health disparities, and health care access. This section will include a discussion of the Affordable Care Act, including ways that syndemics can contribute to understanding the impact of the ACA as well as inform health policy.

The links between food insecurity and HIV are myriad, and a syndemic lens has been applied along most of the “lifespan” of HIV. Given the complex, bidirectional relationship between food insecurity and through entire lifecourse of HIV/AIDS—from the risk of exposure to HIV through the possibility of early death from AIDS—it is appropriate to utilize syndemic theory to frame this study to highlight how the biological, geographic, and social determinants of the disease interact and exacerbate poor health. Mendenhall (2012) notes that several conditions are implied in syndemics theory: 1) two or more issues cluster within a specific population; 2) contextual and social factors (such as poverty, depression, or lack of access to health care) promote the clustering of these issues; and 3) this clustering creates the potential for adverse interactions that increase the disease burden (Mendenhall 2012).
Defining Syndemics

Syndemics theory (combining the words “synergy” and “epidemics”) was proposed by Merrill Singer to describe the “mutual exacerbation of concurrent epidemics”—that is, syndemics are comprised of multiple concurrent epidemics. A syndemic is when two or more epidemics synergistically interact, contributing to an excess burden of disease (Singer and Clair 2003; see Figure 1, pg. 14). Syndemic theory argues that adverse health conditions of marginalized populations as systemically connected, and that their co-occurrence adds to that population’s vulnerability to other adverse outcomes. Another definition emphasizes that while disease interactions occur at the biological level, they develop and are sustained in a group because of social conditions or harmful social connections (Starks et al. 2014). Romero-Daza et al. elucidate the definition further, stating that conditions “exacerbate one another biologically by activating symptoms, accelerating detriments of disease and/or increasing contagious” (Romero-Daza et al. 2012:235). Syndemics were first conceptualized during the late 1990s of mutually reinforcing health and social issues among vulnerable populations in Hartford, CT (Singer 1996; Singer and Romero-Daza 1999). This seminal research demonstrated the ways that substance abuse, violence, and HIV/AIDS were mutually reinforcing and exacerbated by the social conditions in which the urban poor lived (Singer and Romero-Daza 1999).

Syndemic theory is an extension of social epidemiology, which builds on classic epidemiological theory, recognizing a tripartite interaction between host, agent, and environment (Figure 2). Social epidemiology adds an examination of the distribution of those health outcomes and their social determinants (Poundstone, Strathdee, and Celentano 2004; Singer 2009). The syndemics lens contributes to the idea that multiple agents, environments, hosts (or characteristics of these factors) synergistically interact, further escalating deleterious health.
Pulling out parts of the definition, there are some issues to explore further: 1) what type of issues can make up a syndemic (agents); 2) how can we characterize connections between issues, or what is meant by synergism?; 3) how do we characterize a host (or population)?; 4) what do we mean by environment?

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First, in terms of ‘agents,' syndemics can involve a myriad of issues. These can be infectious or non-communicable diseases, acute or chronic disease, behavioral or social conditions, malnutrition, to name a few. We are not limited to biological agents, viruses, and so forth. Syndemics can involve substance abuse, drug use, high-risk sexual behavior, diabetes, cardiovascular disease, even exposure to violence. We must be able to describe the connection or pathway between the two issues through which poorer outcomes emerge, of which there are three types of syndemic interactions (Baer, Singer, and Susser 2013):

1. **micro-level:** the pathways and mechanisms between two or more comorbidities
2. **meso-level:** cultural beliefs and practices that shape behaviors with effective enhancing or diminishing disease interaction for disease course (this is the level of human experience, and where coping and social support occurs)
3. **macro-level:** socio-ecological determinants of disease spread and clustering

At the micro-level, diseases may interact through changes within the body caused by one disease that predispose their vulnerability to another (like damage from smoking promotes influenza). A syndemic might involve enhancing the virulence of another disease (such as the relationship between herpes simplex virus and HIV). It can also assist in the physical transmission of the disease (such as the relationship between other STIs and HIV) or the simultaneous transmission of two diseases via a single act (such as HIV and Hepatitis B or C). Central to syndemic theory is the idea that there needs to be a pathway, though not necessarily a biological one—the pathway alone is not enough. Regarding the substance abuse, violence, abuse (SAVA) syndemic, Singer (1996) points out that there are potential biochemical links between violence and drug use but that these alone are not enough to explain the issue. There may be meso-level factors (like coping) that serve to enhance or diminish the interactions. Therefore, we need to critically examine interactions at all levels, including the underlying
conditions that allow such interactions to occur (Romero-Daza et al. 2012). These are important distinctions, as they help us to avoid a biomedical or reductionist view of syndemic interactions.

In an early definition utilized by the Syndemic Prevention Network at the CDC, it was added to that, “syndemics occur when health-related problems cluster by person, place, or time” (Centers for Disease Control and Prevention (CDC) 2005b). This clustering dimension of the macro-level is of particular importance because it may mean a concentration of an issue or disease in a specific population (such as Latinos, or those who engage in intravenous drug use (IDU)), people in a particular type of social condition (such as the urban poor), or people within a bounded space (those exposed to the Gulf Oil Spill or Hurricane Katrina victims). Environmental factors may include exposure to toxic substances, or access to grocery stores, public transportation, or healthcare. Syndemics is an ideal framework for examining the complex social factors related to ART adherence. Syndemics asserts that two or more epidemics that occur within contexts that promote the clustering of health issues (like poverty or social inequality) are mutually reinforcing and lead to an increased disease burden (Singer et al. 2011).

Evolution of Syndemics, and Comparisons to Other Frameworks

Syndemics has in its lineage not only epidemiological and social epidemiological strains, but also emerges from biocultural anthropology and critical medical anthropology. Biocultural anthropology, briefly, is an approach that aims to situate human biology within the environment, employing a political-economic focus that emphasizes the impact of an unequal distribution of resources on health, as well as examining related responses or adaptations to those conditions (Leatherman, Goodman, and Thomas 1993; Leatherman and Goodman 1997; Goodman and Leatherman 1998; Leatherman and Goodman 2011). Critical medical anthropology (CMA) also
highlights linkages between groups, behaviors, or health outcomes to broader political and economic forces, and to the “arrangement of social relationships they help produce and reproduce over time” (Singer et al. 2011:160; Singer 1995). An important feature of CMA is that, at its core, it is critical and political, openly engaged in questioning knowledge production and activism (if needed) to change “culturally inappropriate, oppressive, and exploitive patterns in the health arena and beyond” (Singer 1990:81). Though there were heated exchanges in various journals between these schools of thought, Singer points out that the goal of CMA was not to deny the importance of a biocultural approach. Instead, it was to “to emphasize the relevance of culture to issues of power, control, and resistance associated with health, illness, and healing, and to rethink nature itself in light of historic anthropogenic (intended and unintended) restructurings of the environment” (Singer et al. 2011:160). The merging of these approaches yielded critical biocultural anthropology, lending valuable perspectives from each; syndemics is a type of critical biocultural approach that recognizes interactions between diseases or conditions.

Considering the definitions of syndemics again, and how they align with critical biocultural anthropology, an important distinction that Singer makes is that syndemics are not just the issues themselves, but the reasons or forces behind the clustering, as well as the resulting outcomes (Singer and Clair 2003). In line with the goals of CMA, syndemics also acknowledges “the fundamental importance of class, racial, and sexual inequity in determining the distribution of health, disease, living and working conditions, and health care” (Singer 1995:81)—which is somewhat difficult, since one variable that Singer says is typically missing from analyses of health conditions in the United States is social class (Singer 1994). Social forces are embedded in bodies—but only certain bodies are rendered vulnerable.
An important concept in critical medical anthropology is that of structural violence. The term is first thought to have been used by Johan Galtung (1969) to describe as a form of violence that corresponds to the systematic ways that a given social structure or social institution kills people slowly by preventing them from meeting their basic needs. Unlike interpersonal/child/intimate partner violence discussed elsewhere in this paper, structural violence is not limited to physical violence (though it can be); it may take other forms, such as exclusion. In fact, it is argued that even the absence of action (when that action is possible or necessary to alleviate suffering or death) can also be considered a form of violence (Galtung 1969). Paul Farmer (2004) has more recently defined structural violence as “violence exerted systematically” and indicates, “the concept of structural violence is intended to inform the study of the social machinery of oppression” (Farmer 2004:307). This violence manifests itself in any number of ways; food insecurity, malnutrition, a high prevalence of infectious disease, lack of employment opportunities or access to health care, and “shapes the choices and limits the ability of men and women to act” (Carroll 2013:42)—limits, but does eliminate agency.

A critical biocultural perspective is one that merges biocultural anthropology and critical medical anthropology. Biocultural anthropology is an integrated approach (drawing from biological and cultural anthropology) that, employing a political-economic focus, sought to situate human biology within the environment, emphasize the impact of an unequal distribution of resources on health, and examine related responses or adaptations to those conditions (Leatherman, Goodman, and Thomas 1993; Leatherman and Goodman 1997; Goodman and Leatherman 1998; Leatherman and Goodman 2011). Critical medical anthropology (CMA) also highlights linkages among groups, behaviors, or health outcomes to broader political and economic forces, and to the “arrangement of social relationships they help produce and
reproduce over time” (Singer et al. 2011:160; Singer 1995). Such an approach is inherently
critical, political, and openly engaged activism and questioning knowledge production. The
merging of these two approaches yields a “critical biocultural anthropological” framework that
borrows important perspectives from each, and syndemics is a type of critical biocultural
approach that recognizes interactions between diseases or conditions. Though my proposed study
explicitly calls for the use of the syndemic framework, it should be recognized that syndemics
are a form of critical biocultural anthropology—a form that explicitly calls out and characterizes
the relationship between diseases or health conditions, and the social conditions in which they
are developed or sustained.

Here, it might be important to discuss what syndemics is not. Syndemics can be
contrasted with typical Western biomedical approaches that tend to isolate diseases in terms of
their etiologies, disease course, treatment—and policies tend to follow that type of linearity
(Singer 2009). This is despite the fact that most medical practitioners, as well as anthropologists,
can agree that in the real world, diseases do not exist in a vacuum (unless one considers the gold
standard of research, randomized control trials, when one can attempt to control for covariates
rather than investigate disease under messy, real-world conditions). Co-morbid conditions are
recognized by public health and western biomedicine, but as syndemic definitions clearly state,
the co-occurrence of diseases or conditions is not enough; there must be an interaction that
makes one or more of the conditions worse. In addition, diseases can co-exist (be co-morbid) and
be counter-syndemic, providing protective benefits (Baer, Singer, and Susser 2013). For
example, in a prospective study that examined the effects of measles and HIV co-infection, the
findings suggested that early in the course of measles, HIV replication is suppressed for a time
(Moss et al. 2002). One potential mechanism that they identified is that, due to changes in
lymphocyte count during measles infection, there is the potential for fewer CD4+ cells available for HIV replication.

**Syndemics: Case Study, Strengths & Weaknesses**

The syndemics framework has been applied to several health issues to better understand the co-occurrence of diseases or conditions within particular social contexts. The framework was first applied to attempt to understand the Substance Abuse, Violence, and AIDS (SAVA) syndemic (Singer 2013). In this section, I offer an in-depth case study of the Substance Abuse, Violence, and AIDS (SAVA) syndemic, then discuss the contributions of other syndemics-framed research to understanding the strengths and weaknesses of the framework.

*Case Study: The Substance Abuse, Violence and AIDS (SAVA) Syndemic*

The Substance Abuse, Violence, and AIDS (SAVA) Syndemic was conceptualized by Singer in the late 1990s and was drawn from mixed methods research conducted by the Hispanic Health Council in the Puerto Rican community of Hartford, CT (Singer 1996). The SAVA Syndemic — substance abuse, violence, and HIV/AIDS — is a broad anthropological term used to describe these mutually reinforcing health and social issues among vulnerable populations -- initially, the urban poor in the United States. In a seminal study, Singer and Romero-Daza (1999) provide evidence of these mutually reinforcing issues, where drugs may lead to loss of employment, social support, housing, or access to care (including drug treatment). This isolation can lead to a need to engage in sex work, exposes vulnerable individuals to STIs (including HIV/AIDS), and may also expose them to violence, depression, and anxiety, further encouraging the use of drugs to cope (Romero-Daza et al. 2012). Since identifying this particular syndemic,
research on the SAVA syndemic has been extended to include men who have sex with men (MSM) (Stall et al. 2003; Stall, Friedman, and Catania 2008), and forms of violence goes beyond gang and intimate partner violence to include child abuse (Kalichman et al. 2002). Meyer et al. (2011) also argue that research should be extended to include rural populations.

When “AIDS and the Health Crisis of the U.S. Urban Poor: The Perspective of Critical Medical Anthropology” was written (1994), Singer already worked in Hartford for ten years, and the conditions that he identified were playing out around him. In that article, Singer identified a number of issues experienced by the U.S. urban poor, such as high rates of chronic and acute health issues (diabetes, hypertension, cirrhosis, cardiovascular disease, tuberculosis, human immunodeficiency disease, and sexually-transmitted diseases), as well as social issues like poverty, socially devalued ethnicity, substance abuse, hunger and malnutrition (Singer 1994). This broad-reaching article reviewed the research and statistics highlighting the deleterious environments in which the urban poor live out their lives. From this “in the trenches” point of view, Singer and researchers at the Hispanic Health Council were able to identify that gang violence, substance abuse, and AIDS were not parallel epidemics, but instead mutually reinforcing issues taking a devastating toll on the lives of the urban poor.

When discussing the myriad of issues in this syndemic, it can be hard to know where to jump in. Starting with any one issue offers the possibility that readers, especially those new to the topic, might assume that particular issue has primacy—that it is the issue that starts the cycle. It is like a chicken-and-egg question—which came first? However, not only do some issues occur throughout an individual’s lifespan (childhood abuse and a higher risk of abusive relationships as an adult), but some are argued to persist across generations, such as poverty (Wagmiller and Adelman 2009), alcoholism, and abuse (Sheridan 1995). Without certain
methodological tools (such as longitudinal studies and associated statistical analyses), it would be difficult to assign causality; and prospective studies examining intergenerational alcoholism and abuse would be highly unethical.

As already noted, the most important and distinguishing characteristic of syndemics is that each component not only co-exist but that they interact synergistically to create even worse health outcomes. In most cases, the individual components of syndemics work cyclically, continually making matters worse. Considering the interactions studied early in the SAVA syndemic, Romero-Daza and colleagues (1998) found that women who have witnessed violence, either as adults or children, are at increased risk of engaging in alcohol or drug abuse, which in turn increases the possibility of engaging in high-risk sexual behaviors or engaging in transactional sex (Romero-Daza and Himmelgreen 1998). Singer (1996) noted that the relationship between substance abuse and violence varied, depending on the mode and type of substance involved. Some substances are linked to aggression and violence through pharmacological or biochemical pathways, though it’s important to note that these are not the only ways that drugs beget violence. People living with HIV (PLWH) may experience violence as a result of fear or stigma, particularly MSM or transgender individuals. Drug use may be linked to violence because of the need to acquire resources to obtain drugs, or drugs may be used as self-medication to dull the impacts (physical, psychological, emotional) of various forms of violence.

Studies have also examined SAVA’s influence on mental health (Kalichman et al. 2002; Gonzalez-Guarda 2013). Other researchers have studied the association between SAVA and HIV-associated risk-taking behaviors (Collins et al. 2005), disclosure of HIV status (Gielen et al. 2000), health care utilization including antiretroviral adherence (Meade et al. 2009), and HIV
health-related outcomes such as viral suppression (Messer et al. 2014). In terms of mental health, Illangasekare and colleagues (2013) found that even when controlling for socio-demographics, social support, and alcohol abuse, HIV+ women who reported IPV and hard drug use in the last 30 days were nearly seven times more likely to experience depressive symptoms than women who experienced none of those issues. In a study of sexual risk behaviors of young MSM (YMSM), Mustanski and colleagues (2007) measured six psychosocial health issues (regular binge drinking, street drug use, regular marijuana use, psychological distress, intimate partner violence, and sexual assault) and found that there was an additive effect. Higher numbers of reported psychosocial health issues were associated with the increased odds of engaging in high-risk sexual health behaviors or being HIV+. Finally, in a review of research on the SAVA syndemic, the authors note that there is a growing body of literature that demonstrates a bidirectional link between HIV status and violence in a context of substance abuse (Meyer, Springer, and Altice 2011:997) and that in some cases, IPV does not occur until HIV+ status is disclosed (Gielen et al. 2000).

**Strengths and Weaknesses of the Syndemic Framework**

As demonstrated by the SAVA case study, one strength of syndemics is that it allows the U.S. AIDS epidemic to be examined within a broader framework, to help “demystify the rapid spread of the disease in marginalized populations” (Singer 1994:937). Indeed, by examining the broader social, economic, and political conditions which foster the presence of these issues, it becomes possible to “de-racialize” (Reitmanova and Gustafson 2011; Baer, Singer, and Susser 2013)—that is, uncouple race/ethnicity from consideration as etiological or risk factors. Instead, we can focus on the social conditions that produce inequities, particularly when the same noxious conditions lead to similar health outcomes in different populations.
Syndemic theory calls for the simultaneous consideration of proximal and distal causes of disease or ill health, the mechanisms and directionality of interaction, patterns of vulnerability, and the consequences of synergies that affect the health of populations (Talman, Bolton, and Walson 2013). In a study of the HIV/AIDS pandemic in southern Africa, Talman and colleagues (2013) hypothesized a syndemic between environmental degradation and HIV/AIDS, in which land degradation could lead to decreased food security, increased vulnerability, behavior changes to cope which may expose individuals to HIV. If infected, HIV-related illness could reduce the ability to support themselves and their families, leading to an increased reliance on wild foods and natural resources, which can lead to land degradation. This cycle is further exacerbated by climate change, which, through land degradation, can also make households more vulnerable.

Another example of holistically viewing health issues is a recent examination of HIV/AIDS in Saskatchewan. Cessna (2014) identifies co-infection (simultaneous infectious diseases like HIV and TB, or HIV and hepatitis C), injection drug use, poverty, and other social determinants of health (such as gender and ethnicity) as contributing to the HIV epidemic in the area. As she points out, when researchers examine diseases from a biomedical perspective, the drivers are often reduced to biochemical or physiological problems; however, use of the syndemic framework allows you to reject such a narrow conceptualizing of disease and instead requires that you examine the issues more holistically (Cessna 2014).

The use of a syndemic lens can be a strength and weakness, and the goals of the research questions are key to maximizing the utility of syndemics. While an emphasis on qualitative methods can help you understand the context in which individuals and communities are at risk for poor health and how they cope, you might lack the explanatory power that large, primarily quantitative studies, can offer in providing the “proof” many organizations require to support or
fund an intervention. There is a push to include mathematical modeling as a tool to lend support for the existence and quantification of syndemics (the cluster of issues) and syndemic interaction (the relationship between the interactions). Herring and Sattenspiel (2007) have modeled the 1918 Influenza epidemic, Starks et al. (2014) applied modeling to examine syndemic factors associated with HIV risk for gay and bisexual men, and Abu-Raddad, Patnaik, and Kublin (2006) examined the impact of HIV and malaria on one another. Modeling syndemics offers the ability not only to understand micro- and macro-level interactions that have already occurred; it also offers the potential to predict future syndemics (Singer 2009). But modeling a syndemic can mean the voices of those affected are lost, or that the agency that they exert to push back against those forces may be overlooked.

Why Syndemics?

This type of research can be challenging, particularly for researchers without significant funding or other resources. Studies that can adequately capture the complexities of syndemic interactions without removing or over-simplifying the human elements at the meso-level require mixed methods—large studies for the statistical power to model, and ethnographically rich studies to understand how diseases or health issues are experienced and managed on a day-to-day basis over time. In a study of social distress, depression, and diabetes, Mendenhall (2012) revealed that she assumed diabetes would be the number one stressor in her participants lives; but when she analyzed the narrative themes she found that they placed a much lower priority on their diabetes than she did despite the fact that 90% of her study participants had poorly controlled diabetes (HbA1C ≥ 6.5). Ethnographic insights often provide “light-bulb” moments
(Madden 2010), offering links to issues you may not have considered, or countering assumptions derived from literature reviews.

Studies of syndemics that cannot examine all aspects of the problem are best served (as in all research) by identifying specifically what issues, pathways, or interactions they will examine to contribute to the body of literature. Some lines of inquiry suggested by Singer and Clair (2003) include examining conditions likely to give rise to syndemics, mechanisms (univariate, bidirectional, dialectic) for how disease occurs, and research on how issues emerge and function to reduce health-related consequences. There is research needed on how to address social inequities more effectively, including the possibility of developing screening tools that identify the co-occurrence of known syndemic social conditions for targeting treatment or support (Gonzalez-Guarda 2013). As the use of the syndemics perspective becomes more interdisciplinary, biomedical boundaries between chronic and acute diseases are breaking down (R. Barrett 2010) offering new series of change new alliances among interest groups new funding policies and new levels of achievement in protecting the public’s health (Centers for Disease Control and Prevention (CDC) 2005a).

**Emerging Syndemics in Southern US**

The southern U.S. has emerged as an epicenter of HIV. In 2014, 40% of new cases of HIV emerged from a nine-state region referred to as ‘The Deep South,’ including Alabama, Florida, Georgia, Louisiana, Mississippi, North and South Carolina, Tennessee, and Texas – though they only make up 28% of the U.S. population (Reif et al. 2016). States in the ‘Deep South’ are not only disproportionately affected by HIV; other health disparities are prevalent, including overall poorer health indicators, such as higher rates of obesity, cancer, infant
mortality, overall mortality (Department of Health & Human Services 2015), as well as higher poverty, unemployment, and lower rates of health care access (Reif et al. 2017), factors that influence not only the risk of HIV infection but also the day-to-day experiences of living with HIV. Though the CDC has reported expanding and strengthening its support for HIV prevention in the South (Centers for Disease Control and Prevention 2016), there are still lower rates of funding per PLWH in the southern U.S. as compared with the country as a whole (Reif et al. 2014; Institute of Medicine 2004).

Syndemics theory highlights the synergistic, multiplicative relationship between conditions, as well as their relationship with social conditions (Weaver and Mendenhall 2014). Research has shown that the determinants of the HIV pandemic are rooted in poverty and inequality, creating local situations of risk (Farmer 2001; Pellowski et al. 2013; Loevinsohn and Gillespie 2003; Farmer 2003, 2006). In these contexts, AIDS emerges as an opportunistic disease--one of compromise health and social conditions--a disease of poverty (Singer 1994; Farmer 1996, 2001). Pellowski et al. (2013:198) observed that the transmission of HIV “is a biological event that is entirely dependent on social context and behavioral practices” and hinges upon four factors: biological factors, individual behaviors, local factors, and social conditions. Given the health disparities attested to by the patterns HIV/AIDS prevalence (Pellowski et al. 2013), food insecurity (Mabli et al. 2010), and access to health care (Kates 2012; Kates and Garfield 2014; Kates et al. 2014), many individuals in Florida (HIV+ or not) are being exposed to “local situations of risk”. It will be essential to understand more about how households experience and manage these multiple issues. Below, I briefly summarize the literature on food security and HIV, then will review policies related to the Affordable Care Act (ACA) and the
impact of state-level decisions on the health of Floridians. I will close with what a syndemic
framework can contribute to this analysis.

Food Security

In 2018, 11.1% of U.S. households experienced food insecurity at some point during the
year (Coleman-Jensen et al. 2019), a figure that was down from 11.8% in 2017. There were
twelve states with food insecurity rates higher than the national average (a statistically significant
difference). Many of them were in the South; though Florida was not one of these states, it has
had rates higher than the national average in the past. Using Feeding America’s “Map the Meal
Gap” feature, we can see that throughout the state of Florida, there were 2,806,770 food
insecure people in 2017. In Hillsborough County in the same year, 13.3% of households were
food insecure, representing 179,280 people. Rates across Florida vary from 9.5% in Miami-Dade
County (255,680 people) to 22.2% in Gadsden and Madison Counties (10,260 and 4,110 people,
respectively). These data poignantly demonstrate the variability of a local risk of food insecurity.

HIV/AIDS

Globally, 36.9 million people are living with HIV, with 1.1 million people living with
HIV in the United States (WHO 2014). The prevalence of HIV/AIDS is not randomly spread
throughout the United States; the disease is found in geographic clusters and is more prevalent in
certain ethnicities. For example, HIV was clustered in urban centers on the coasts but is now
more prominent in the southern states. In 20, the South (which differs from the “Deep South”;
AL, AR, DE, DC, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV) accounted for

44% of people living with an HIV diagnosis though these states only account for 37% of the US Population (Centers for Disease Control and Prevention 2016).

According to the July 2014 monthly surveillance data from the Florida Department of Health (up to 6/30/2014), Hillsborough County ranks 4th in new HIV infections, with 229 cases (behind Miami-Dade, Broward, and Orange County), and up 27% from this same period last year (FLDOH 2014). For the number of presumed living HIV/AIDS cases, Hillsborough County ranks 5th with 6,543 cases (behind Miami-Dade, Broward, Orange, Palm Beach County). In the U.S., African Americans comprise roughly 13% of the US population but represent nearly 50% HIV cases (CDC 2012). In Hillsborough County, individuals that self-report “Black” race/ethnicity comprise 48% of HIV/AIDS cases, though they represent 16.6% of the population in Hillsborough County4. Although 78.1% of people in FL self-report as “White,” they represent 29% of cases; Hispanics make up 23.6% of the state’s population but account for 21% of HIV/AIDS cases (FLDOH 2014).

Florida and the ACA

The Affordable Care Act (ACA), signed into law in 2010, was initiated to help millions of Americans gain access to health insurance coverage. Through Medicaid expansion, the creation of health insurance exchanges, and the provision of subsidies, the ACA sought to expand health insurance coverage, with the intent of making it more affordable (http://www.hhs.gov/healthcare/). Tax credits are available for those households earning between 100% to 400% of the Federal Poverty Level (FPL) and subsidies for those earning 100% to 250% of the FPL. The Federal Poverty Level is $11,490 for individuals and $19,530 for a family

4 https://statisticalatlas.com/county/Florida/Hillsborough-County/Race-and-Ethnicity
of 3. Medicaid expansion involves a lowering of the required income level to 138% of the Federal Poverty Level (FPL) and removes categorical requirements such as being a child, a parent with a dependent child, a pregnant woman, or an individual with disabilities. The Affordable Care Act emphasizes preventative services, with certain services offered at no cost, including routine HIV screening.

As a result of the Supreme Court ruling in 2012 (National Federation of Independent Business v. Sebelius), Medicaid expansion was made optional. To date, 25 states are not planning to expand (Kates et al. 2014). Having insurance is important to the continuity of care and the receipt of antiretroviral therapy (ART) (Snider et al. 2014; Kates and Garfield 2014; Kates et al. 2014). Thus, states’ decisions to expand Medicaid (or not) serve to create geographic pools of risk in places where risks are already higher. Even for those without HIV, the state decisions not to expand Medicaid create situations of risk. The low income childless receive Medicaid benefits in 9 states (22% of individuals are exempted from categorical requirements), less than the coverage currently provided by Medicaid in 16 states (30% receive some benefits), and 26 states provide no coverage to the low-income childless (48%).

It has been noted that the ACA is one of the most important pieces of legislation for those living with or those at risk for HIV/AIDS (Centers for Disease Control and Prevention 2019a). People living with HIV/AIDS are expected to benefit from the ACA primarily through three key provisions: 1) the elimination of pre-existing conditions as a reason to deny insurance; 2) the ban on premium rate setting based on health status; 3) and the end of annual and lifetime caps on insurance benefits. An estimated 35-45% of people diagnosed with HIV already have AIDS by the time they are tested, which speaks to delays in testing potentially related to insurance status and overall access to healthcare (Pellowski et al. 2013). Thus, the reduction of barriers to
treatment afforded by the ACA is an important part of obtaining UN 90-90-90 targets (Adamson, Lipira, and Katz 2019).

Alarmingly, 43% of PLWHA in the United States reside in non-expansion states (Kates et al. 2014). In 2014, there were over 20,000 uninsured PLWH who would be eligible to access coverage from the Health Insurance Marketplaces if their states expanded Medicaid; Florida and Texas alone accounted for half of those individuals (KFF 2014; Kates et al. 2014). Even without Medicaid expansion, Medicaid is the largest payer of HIV care in the United States, covering 41% of the non-elderly population with HIV (Kates et al. 2014). As the analyses noted, there is a catch-22 in that low-income individuals cannot qualify for Medicaid until they are sick, disabled, and likely not until they are diagnosed with AIDS — even though the early treatment could stave off disability, the progression of HIV to AIDS, and could prevent HIV transmission. In a review of two data sets (one of surveillance data, another containing estimates of prevalence), researchers have determined that of the estimated 1.1 million individuals infected with HIV, there are 700,000 not currently in care; about 200,000 individuals would be newly eligible for free or subsidized care if all states expanded Medicaid (Kates et al. 2014; Snider et al. 2014). Those residing in states that are not expanding (the 43% mentioned above) fall into a “coverage gap” — not eligible for Medicaid (either because of income or category requirements) but too poor to qualify for subsidies. Most likely, these individuals will be covered by the Ryan White program. However, this coverage gap reveals that the ACA will not necessarily mean that the Ryan White program can be eliminated, particularly when one considers other services that the program offers.

The Ryan White program, created in 1990, is a critical safety net for HIV+ individuals with limited or no health insurance coverage. Ryan White offers “wrap around” services,
including counseling and testing, outreach, premium, and cost-sharing assistance, medical and nonmedical case management, treatment adherence services, transportation, and referral services. In 2009, approximately 40,000 of all people living with HIV who are currently in care received medical services, medications, and other services through the Ryan White program (Kates 2012). It is important to note that those accessing Ryan White services are not just of the uninsured—31% of program recipients have some type of insurance—and the program does cover gaps in an individual’s existing coverage. These statistics, coupled with the fact that several states will not be expanding Medicaid coverage, highlight the fact that this “payer of last resort” cannot readily be eliminated if we will continue to provide care for people with HIV.

When Policy Renders Risk

Nichter (2003:13) observes that vulnerability speaks more to the experience of weakness, fear, or worry about being susceptible to illness or misfortune, whereas risk tends to refer to probability or the chance that an event or exposure will occur. Policies can render risk or make individuals feel vulnerable when they exacerbate existing differences in access (Derose, Escarce, and Lurie 2007).

Such is the case with health policy in South Africa. Several researchers (Jones 2011, 2014; Kagee et al. 2011; Leclerc-Madlala 2006; Macgregor 2006) have examined the impact of disability grant policies in South Africa, where individuals who have CD4+ counts under a certain level are eligible to receive cash subsidies. These subsidies have been shown to operate as disincentives to antiretroviral adherence, because individuals are faced with decisions about whether to take their medications daily and potentially lose the funds as their health improves -
or not to take (or intermittently take) their medications, so they can stay below required CD4+ levels and thus retain their grants.

Similarly, Brouwer (2014) argues that while the ACA will likely result in increased access to healthcare - particularly as a result of expanding Medicaid because Medicaid is an income-based benefit. However, women may experience increased instability as they find themselves “churning” between the health insurance exchange and Medicaid benefits. Thus, it will be important to talk with participants to understand their experiences with a regular source of health care, whether or not they are experiencing this instability, and how it may be impacting their health.

A Way Forward

Adopting a syndemic framework seems prudent when we consider the number of health crises merging in Florida (and many other southern states). A syndemic perspective offers a different perspective to biomedical models that target discrete issues. Models that focus on single diseases or health concerns often fail to recognize the real-life complexity of how diseases and social conditions interact and get ‘under the skin.’ Academics and practitioners are progressively calling for the application of syndemics in health-related research and practice (Romero-Daza et al. 2012), especially as practitioners attempt to manage individuals with multiple coexisting diseases (Singer, Bulled, and Ostrach 2012).

Syndemic theory offers an approach for reconfiguring how a number of fields conceptualize “disease” and “disease interaction” – offering the potential to forge alliances among other interest groups, tap into existing (and potentially generate new) funding policies, and offer a way forward to realize holistic promotion of the public’s health (CDC 2005a). As the
theory continues to be developed, and new methods are tested, there is the potential for developing a body of evidence about syndemic interactions as well as for “piloting integrated interventions that address the phenomena as intertwined and for identifying best practices for scaling up” (Talman, Bolton, and Walson 2013:253).
CHAPTER 3: SYNDEMIC COMPONENTS

Chapter Three introduces the conceptual model of the syndemic as well as reviews literature related to each syndemic component: food insecurity, adherence, and mental health. This chapter provides background on the understanding, assessment, and analysis of each of these components.

Conceptual Model of Syndemic

In Weiser et al. (2011b), the authors propose a conceptual framework for understanding the synergistic and bidirectional relationship between food insecurity and HIV through three pathways: nutritional, mental health, and behavioral. The nutritional pathway is characterized by deficiencies in intake (macro- and micronutrients), interactions between food and ART, and other nutrition-related conditions such as obesity and lipodystrophy. The mental health pathway considers issues such as anxiety, depression, and substance use. The behavioral pathway highlights actions such as not adhering to ART, missing clinic visits, and other interruptions to treatment. Food security status affects and is affected by items listed under each of these pathways. In addition, items in the pathways can impact each other (such as the impact of mental health on behaviors). The three pathways lead to the potential for poorer outcomes such as lower levels of viral suppression and CD4 count, which in turn can lead to increased HIV morbidity and mortality. The syndemic components from this study draw from this conceptual framework and are each described more in-depth below.
Food Security

Brief History of Food Security Research

Concerns about food security have a long history. Well over sixty years ago, the Universal Declaration of Human Rights (UN 1948) highlighted the right to food as a basic human right. Subsequent crises and famines, such as the world food crisis in the early seventies, the African famine in the mid-eighties, and the food-fuel price crisis in late 2000s served to revive interests in food security (Maxwell and Smith 1992). Intellectual concerns, such as the effects of structural adjustment and the emergence of entitlement theory, also contributed to this revival (Maxwell and Smith 1992). The next several decades resulted in the dissemination of a number of food security definitions by the Food and Agriculture Organization of the United Nations and the World Bank, not to mention the myriad circulated in white and gray literature.

In the early 1990s, Maxwell and Smith (1992) systematically documented over 200 definitions for food security. Over time, the concept has continued to evolve, and Devereux and Maxwell (2001) observed that the concept of food security showed three paradigm shifts. The first definition of food security in 1974 focused on food availability and food price stability issues (United Nations 1975). The first paradigm shift moved away from examining global and national food levels to focus on the household and individual level because though a nation might contain sufficient food stores to provide enough calories for their population, you could not assume all households or individuals had access. Amartya Sen’s entitlement approach (Sen 1983) was pivotal to the examination of access as a key component of food security (Himmelgreen and Romero-Daza 2010; Coates et al. 2006). As a result, the FAO revised the definition of food security to incorporate the accessibility of available food for vulnerable groups.
through a consideration of both the supply and demand sides of the food security equation (Food and Agriculture Organization (FAO) of the United Nations 1983).

The next shift moved from a food-first focus toward a livelihood perspective, where it was recognized that “food is only one important basic need among several, and adequate food consumption may be sacrificed for other important needs” (Frankenberger, Drinkwater, and Maxwell 2000). The final paradigm shift has been from the use of objective indicators to subjective perception, which also includes issues associated with food quality and safety (Devereux and Maxwell 2001; Maxwell 1996). Other definitions continued to hone the concept, adding in linkages to healthy life (World Bank 1986), nutrition, food safety, preferences, and stability over time (Food and Agriculture Organization (FAO) of the United Nations 1996), with further refinement of the access dimension to include “physical, social and economic access” to food (Panagariya 2002), and cultural acceptability of food.

In 1990, the US Congress mandated that the federal government pass the National Nutrition Monitoring and Related Research Act of 1990 (Public Law 101-445 - Oct. 22, 1990), which required nutrition monitoring and “related research as those activities necessary to provide timely information about the contributions of food and nutrient consumption and nutritional status to the health of the United States population” (Moshfegh 1994). This law initiated the process of developing food security measures for the United States, ultimately resulting in the inclusion of the U.S. Household Food Security Survey Module (HFSSM) being administered as part of the US Census in 1995 (Cook et al. 2013). In the early 90s, Radimer and colleagues began their work at Cornell, to develop an indicator of hunger so its prevalence could be determined (Coates 2013; Himmelgreen and Romero-Daza 2010). The HFSSM includes elements of the Radimer/Cornell Scale (Leroy et al. 2015). In the next section, I will focus on the
development of definitions and constructs that contribute to the measurement of food security in the United States.

**Definitions and Constructs**

One definition of food security is “access by all people at all times to enough food for an active, healthy life” (Nord et al. 2010:2). Food insecurity, then, “exists whenever the availability of nutritionally adequate and safe foods or the ability to acquire acceptable food in socially acceptable ways is limited or uncertain” (Anderson 1990:1560). Current definitions of food security tend to encompass three generally accepted “pillars” or dimensions: Availability, Accessibility, and Utilization. These dimensions of food security are hierarchical, in that availability is a necessary but not sufficient condition to ensure access, while accessibility, in turn, is a necessary but not sufficient condition for effective utilization (C. B. Barrett 2010; Webb et al. 2006). Availability means that sufficient quantities of food are consistently available. Without availability, there cannot be access to food; access means having sufficient resources to obtain appropriate foods for a nutritious diet. However, having access to food does not guarantee utilization, defined as the proper biological use of food, and can be affected by health status/illness management, food preparation, food safety, and sanitation (WHO, n.d.). A fourth dimension, Stability, highlights the temporality inherent in achieving food security, as all three pillars must be in place for food security to exist (Vink 2012). Of all the pillars, utilization and stability are the least studied aspects of food security (Hadley and Crooks 2012).

In defining food insecurity, there are four key elements that seem to be consistent cross-culturally: 1) worry or uncertainty about food resources; 2) lack of access to food resources of adequate quality; 3) lack of access to food resources in adequate quantities; or 4) acquisition of
food through socially unacceptable means (Coates et al. 2006). Food insecurity is a complex, multidimensional phenomenon that varies through a “continuum of successive stages as the condition becomes more severe” (Bickel 2000:2). As individuals and households lack regular availability of and access to food, mental health issues such as worry and anxiety can arise, regardless of whether or not sufficient intake is maintained (Hadley and Wutich 2009; Weaver and Hadley 2009).

**Food Insecurity, Malnutrition, and Hunger.** Food security is an important but insufficient condition for adequate nutrition (Gillespie and Mason 1991), though food insecurity does not necessarily mean individuals or households are facing malnutrition and hunger. As already reviewed, there are many definitions of food security. Malnutrition refers to undernutrition and overnutrition, as well as obesity and micronutrient deficiencies, while an often-used definition of hunger is the physical discomfort caused by a lack of food (C. B. Barrett 2010). Hunger in the United States is largely hidden, without the typical outward signs one might view in the developing world (Carlson, Andrews, and Bickel 1999); though recognition of the hunger-obesity paradox (Dinour, Bergen, and Yeh 2007; Dietz 1995)—which highlights overconsumption of certain macronutrients but limited intake of micronutrients—may be one manifestation.

Hunger has become a hotly contested concept (Himmelgreen and Romero-Daza 2010) as a result of a relatively recent change in terminology used to describe the food security situation in the United States. When Nord argued that “hunger” is “not a scientifically accurate term (Williamson 2006)”, and the USDA replaced the term “hunger” with “very low food security” (Nord et al. 2010), it caused a fervor in the press and popular media (Allen 2007). As
Himmelgreen and Romero-Daza argue (2010), while there may be legitimate technical concerns about the use of the concept (especially in terms of measurement), the elimination of the term has the potential to gloss over the increasingly difficult food security situations U.S. households face. As the USDA applied significant time and resources to the conceptualization of food security and appropriate measures, it has been argued that there needs to be an effort to reconceptualize hunger. This reconceptualization needs to take into account a number of facets—associated health configurations (nutritional deficiencies, weight loss and growth stunting), suffering (physiological pain and emotional stress), economic impacts (loss of productivity) and behavior (ways of coping) so that the issue can be better understood, assessed, and addressed (Himmelgreen and Romero-Daza 2010:108).

**Links to Depression.** Food insecurity has been described as a form of economic hardship which acts as a chronic stressor (Ross and Hill 2013). In a review of research on poor mental health (including anxiety and depression) and food insecurity, Weaver and Hadley (2009) point out that research in developing countries by both anthropologists and epidemiologists has suggested a strong association between food insecurity and common mental health disorders, though directionality is still uncertain and may be bidirectional. An analysis of data from the population surveys from the US and Canada found that food insecurity was highly correlated to both chronic physical and mental health conditions, though the direction of this relationship is not known (Tarasuk et al. 2013). In that study, the authors found that adults who had been diagnosed with a mood or anxiety disorder were nearly twice as likely to be food insecure compared with adults who had not, even after controlling for other sociodemographic factors (Tarasuk et al. 2013). Similarly, Martin et al. (2016) found that self-reported mental illness (such
as depression, mania, and bipolar, anxiety, or panic disorders) were more prevalent in food insecure households.

Diet quality has also been found to be linked to mental health. An analysis of data from the Canadian Community Health Survey found that poor-quality diets (measured using the Healthy Eating Index) were more likely among those who reported poorer mental health than those who reported having good mental health (Davidson et al. 2017). Interestingly, in a study of adults in Flint, MI, food insecurity was found to be associated with an increased in the likelihood (3.2 times) of poor mental health, though access to fruits and vegetables did moderate this relationship (Bergmans et al. 2019). The review by Weaver and Hadley (2009) also identified research suggesting a biological link between micronutrient deficiencies (such as vitamins B\textsubscript{1}, B\textsubscript{6}, B\textsubscript{12}, E, and folic acid--alone or in combination with B vitamins) and depression, suggesting that it is not merely the mental concerns about food security that may lead to poorer mental health.

It is estimated that as many as 50% of PLWH may experience depression (Vogenthaler et al. 2010) which is a concern because depression is associated with a decreased likelihood of using ART based on a meta-analysis of nine studies with a pooled sample size of 7,375 (Tao et al. 2018). In a study of stress and poverty as predictors of poor antiretroviral adherence, individuals with poor adherence reported more symptoms of depression and higher levels of internalized stigma (Kalichman and Grebler 2010). Individuals experiencing depression and PTSD were found to be less likely to adhere to antiretroviral treatment (Sledjeski, Delahanty, and Bogart 2005). The degree of social support an individual has can act as an effect modifier between food insecurity and depression (Tsai et al. 2012), which has potential applications for various interventions. However, it should be noted that depression has been linked to decreased
immune function, which in turn leads to faster progression to later stages of HIV disease (Cruess et al. 2003). Thus, though successfully treating depression can lead to improved immune function (Cruess et al. 2003; Irwin and Miller 2007), and successfully addressing micronutrient deficiencies could help reduce depression, it is important to recognize that not all depression can be solved with micronutrient or dietary supplementation. (Kaplan et al. 2007).

Measuring Food Security

Though food security has been studied and the definition refined for decades, it continues to pose methodological challenges (Webb et al. 2006). Measurement innovations can be viewed as having occurred in waves that tend to align closely with the three pillars of food security. First-generation food security indicators considered aggregate food availability from a supply lens, while second-generation indicators emphasized individual- and household-level access to food (demand) (Barrett 2002). Second generation food security indicators, such as income or consumption, were considered inadequate because they were indirect and costly to obtain (Barrett 2002; Coates et al. 2006). Third generation indicators, now in their second decade, represent a movement towards objective measures of food insecurity to understand the “actual experience of becoming hungry” (Webb et al. 2006:1406S). Critiques of the current measures of U.S. household food security exists; Barrett (2010:826) points out that each “measure captures and neglects different phenomena intrinsic to the concept of Food Security, thereby subtly influencing prioritization of food security interventions” Thus, how we define and how we measure these phenomena have implications for recognition of the issues and formulating responses.
Quantitative Assessment of Food Insecurity. In the early 90s and beginning with the work of Radimer and colleagues at Cornell, researchers answered the call from the President’s Task Force Report on Food Assistance (1984) to develop an indicator of hunger so its prevalence could be determined (Coates 2013; Himmelgreen and Romero-Daza 2010). Through qualitative research, a food security survey was developed; and in 1995, the first Food Security Supplement (FSS) was used in the Current Population Supplement (CPS) to assess the prevalence of food insecurity and hunger in the United States. Since then, like the definition of food security, the measure has been continually refined and has been adapted for use in other countries. The current measure, the U.S. Household Food Security Survey Module (US HFSSM), is an 18-item validated survey that asks participants to report their subjective experiences with four domains of food insecurity (anxiety, perceptions of reduced quality or quantity of food, reduced adult food intake, and reduced intake for children).

The measurement of food security requires these multiple indicator questions that are capable of capturing the increasing severity of the food insecurity experience (Frongillo 1999; Wolfe and Frongillo 2001). The different levels of food security are significant when analyzing health outcomes. In a review of 41,515 child and caregiver dyads, the authors found 61.8% were food secure, 14.9% were marginally food secure, and 23.3% were food insecure (Cook et al. 2013). Moderate food insecurity was associated with poor health outcomes, though the relationship was not as strong as with low or very low food insecurity. These findings suggest that food insecurity may act in a dose-response type manner. Their analysis showed that marginal food security households were more like food insecure households than food secure households, and its differences from those two types merit it not being collapsed with either category (Cook et al. 2013).
Only by measuring the full range of experiences can we better understand the links between food insecurity and adherence. The HFSSM has ten questions if the household contains only adults, and an additional eight if the household includes children. The 10 or 18 question version of the HFSSM has higher specificity than the six-question version of the tool, which lowers participant burden but may underestimate severe child or adult food insecurity (Bickel 2000; Tayie 2008). However, even utilizing the full USDA core module to assess food security (rather than a screening question or two) does not entirely capture the experience of food security. Bickel (2000) notes that other elements such as food safety, the nutritional quality of diets, and "social acceptability" of food sources--including some coping behaviors, are not measured by the food security scale. Nord (2010) notes that the questions in the core module do not specifically address whether the household’s food intake was sufficient for active, healthy lives—an important aspect not only in the definition of food security but also in the lives of HIV+ individuals who are receiving ART.

**Qualitative Assessment of Food Security and Food Insecurity.** One example from the literature is a study that sought to understand how food insecurity interferes with ART regimens. Using a semi-structured interview guide with open-ended questions, participants were asked about their overall food situation, experience with hunger, and strategies they used to feed themselves and their families. Participants were also asked about general barriers to ART adherence and if food acted as a barrier to adherence. If food acted as a barrier to adherence, how did it affected their ability to adhere to their regimen? If participants had not initiated ART, they were asked what barriers, if any, including food, they had experienced (Weiser et al. 2010). In an assessment of experiences and perceptions of food insecurity in Oregon, the authors identified
several subthemes that participants said explained why they were facing food insecurity, including illness and injury, un- or underemployment, family changes (divorce, birth of a child) and having other bills to pay (De Marco, Thorburn, and Kue 2009). Another consideration identified by the literature that can be explored qualitatively is the reason for missed meals (Weiser et al. 2010). While a quantitative survey of food insecurity clearly outlines that respondents should indicate “yes” if they missed a meal or reduced the amount of food that they consumed due to a lack of resources. A qualitative exploration of food security can identify other reasons for reduced intake, such as decreased appetite, or diet monotony (Noble 2010).

**Measuring of Food Security in People Living with HIV/AIDS.** Recently published articles have made recommendations on considerations and measures for the assessment of food insecurity among people living with HIV. In addition to the concepts of availability, access, utilization and stability, three other components of food security—food sufficiency, dietary quality, and food safety—may be useful for understanding the food security needs to PLWHA (Anema et al. 2013). Given these considerations, these authors (Anema et al. 2013; Fielden et al. 2013) recommend the use of an abbreviated food security measure (to assess food sufficiency and reduce respondent burden) and a measure of diet quality. Though food safety is a concern for PLWHA, there is not yet a standardized, validated measure, though one is in development. It should be recognized that certain measures that are more extensively used internationally than in the United States, and so the choice of measures should fall in line with what has been validated in those settings (Fielden et al. 2013).

Over and above the measurement of food insecurity, it may be important to consider the use of measures that capture dietary quantity and quality, particularly given the relationship
between malnutrition and HIV. Another key concern when working with PLWHA is the recognition that HIV and food insecurity work synergistically; some measures of food security may be capturing the impact of HIV on the body. Because HIV effects metabolism, any assessment should consider the increased nutritional needs of PLWHA (Fielden et al. 2013).

Studies from early in the HIV epidemic up to the present have demonstrated that PLWH have macro- and micronutrient needs that are greater than the population in general. Resting energy expenditure (REE) is the amount of calories used by your body to perform basic functions like circulation, respiration, and maintaining body temperature (Melchior et al. 1991). According to a report from the World Health Organization, the REE needs of PLWH increases when HIV infection is left untreated (WHO 2003). Asymptomatic adults can experience as much as a 10% increase in calories needed, and adults who are symptomatic might see as much as a 20-30% increase. Children experiencing weight loss are the most affected, with an increase of 50–100% increase in calories needed just to perform basic functions. Similarly, Mittelsteadt and colleagues (2013) also found that resting energy expenditure (REE) is higher in HIV-infected women who have never taken ART. However, they also found that even after ART were introduced, and regardless of whether the women achieved viral suppression, REE was still found to be higher, suggesting that the increase is due to HIV infection, not ART.

In addition to higher caloric needs irrespective of ART or viral suppression status, several studies early in the HIV epidemic found micronutrient intakes under the recommended daily allowance (RDA) among various groups of HIV-infected adults in the U.S. (Tang et al. 1993; Luder et al. 1995; Woods et al. 2002). In a review of the relationship between nutritional status and HIV infection, de Pee and Semba (2010) note that while these types of micronutrient deficient are not limited to PLWH in the U.S., there is some evidence that suggests that even
attaining suggested levels of micronutrient RDA may not be sufficient. Even for individuals who report adequate micronutrient intakes (higher than the RDA), evidence of low levels of circulating micronutrients have been found among PLWH (Baum et al. 1992). These deficiencies are important because several have been linked to poor HIV-related health outcomes, such as increased shedding of HIV in the genitals, increased transmission from mother-to-child, faster disease progression, and increased mortality (de Pee and Semba 2010).

The use of dietary diversity measures or food frequency questionnaires can provide information about normal dietary intake, but may mask seasonal or atypical patterns of consumption due to periodic changes in household resources, such as job loss, or seasonal increases in utilities cost (Bansah, Holben, and Basta 2013; Nord and Kantor 2006). Laboratory-based measures of diet quality (macro- and micro-nutrients) may be useful, but also should take into consideration changing nutrient needs (Anema et al. 2013). Anthropometric measures, such as BMI, may not useful because of the potential for confounding with the metabolic changes, wasting, or even obesity in PLWHA (Fielden et al. 2013). Given the reduced respondent burden (no diaries, weighing, or certain levels of literacy needed), 24-hour dietary recalls, especially using the USDA multi-pass method, are a popular method for capturing information about food consumption.

Data from food frequency questionnaires or dietary recalls can be used to create a summary of diet quality by transforming that data into a Healthy Eating Index (HEI). The HEI, first proposed in the mid-90s and developed by the USDA, is a measure of diet quality that assesses conformity to federal dietary guidance (Guenther et al. 2013; Kennedy et al. 1995). The motivation for the creation of the index was driven by recognition that concerns about the American diet centered fewer nutritional deficiencies, and instead, a way was needed to assess
imbalances or even excess (Kennedy et al. 1995). The index contains 12 components such as total fruit, whole fruit, total vegetables, dark-green vegetables/orange vegetables/legumes, total grains, whole grains, milk, meats, beans, oils, SFA, sodium, and discretionary calories from solid fats, added sugar, and alcoholic beverages. Scores from the HEI range from 0-100, with higher scores indicating healthier diet quality.

*Structural Barriers*

Though there are many frameworks available that organize the determinants of malnutrition, one that I find useful is the World Food Program’s Food and Nutrition Security Conceptual Model, which utilizes multiple levels (individual, household, community, and so forth) as a means to frame the determinants of malnutrition. Individual-level determinants (nutritional status and health) will be discussed in an upcoming section. In this section, I will review the determinants of food insecurity related to access, household resources, and the surrounding environment.

**Access.** Some research makes distinctions between individual-level and household-level access to food. This distinction is typically made to highlight that not all individuals within a household can be assumed to have equal access to all resources. Individual-level access is linked to household resources but could also be associated with the geographic location or the availability of transportation. A lack of the geographic availability of “high-quality, healthy, affordable food necessary to live a healthy life” (Lehmann et al. 2014:274) can act as a barrier to food insecurity. In addition, communities with high numbers of convenience stores and fast-food restaurants, and lacking supermarkets or places to acquire high quality, healthy, affordable food
are said to be ‘underserved by supermarkets,’ experiencing a ‘grocery gap,’ and have been referred to as ‘food deserts’ (Lehmann et al. 2014).

**Household Resources.** Income is a key determinant of food security, but many other factors also matter (Nord 2014). Poverty is associated with many factors (such as homelessness, substance abuse, depression, and food insecurity), which in turn contribute both to HIV infection and ART adherence (Willig and Overton 2014). In states that experience seasonally varied utilities-associated costs (like cooling in Florida, or heating in Maine), Nord and Kantor (2006) found that households with incomes below the poverty line were significantly more vulnerable to very low food security (VLFS) during the summer months (similar to the “heat or eat” phenomena observed by Bhattacharya and colleagues (2003)). It is difficult to tease out differences between poverty and food insecurity, especially since the measure is built on the idea that households do not have access to a sufficient quantity and quality of food due to a lack of resources; therefore, any study that examines food insecurity using the USFSSM should also control for income (Nord 2014).

**Organizational.** Spool and colleagues describe the issues facing their food insecure clients, observing that food assistance programs are not geared towards addressing the increased nutritional needs of people living with HIV/AIDS (Spool, Torino, and Gay Men's Health Crisis 2008). They also highlight the issues of access in low-income areas: few outlets offer fresh, whole foods or markets that do tend to be prohibitively expensive, making it difficult for people living with HIV/AIDS to obtain the types of foods they need through food stamps and other
supplemental subsidies. Further, for those that obtain the majority of their foods from charities and food distributions, their access to food is limited by the constraints on the organization.

HIV/AIDS and Food Insecurity

The vicious cycle between malnutrition and HIV has been widely documented in the literature (Colecraft 2008; Pribram 2010; Panagides et al. 2007; Anabwani and Navario 2005; Semba and Tang 1999; Gillespie and Kadiyala 2005; Ivers et al. 2009). Malnutrition leads to immune impairment, worsens the effects of HIV, and contributes to a more rapid progression of the disease; thus, malnutrition both contributes to and is a result of HIV disease progression (Lisam and Lisam 2009). Infectious diseases often decrease appetite and, in turn, food consumption, even while demands of the immune system increase macro- and micronutrient need, and diarrhea and vomiting while ill can exacerbate nutrient loss (Lanata and Black 2001). In addition, malnutrition affects the severity of infections, leading to increased morbidity and mortality (Food and Agriculture Organization of the United Nations 2004; Rice et al. 2000; Piwoz and Preble 2000; Brabin and Coulter 2003; Black, Morris, and Bryce 2003; Muller and Krawinkel 2005; Himmelgreen et al. 2009). These issues are important biological considerations when examining food security in the context of HIV.

Food insecurity continues to be an issue in the United States, with health consequences including malnutrition (both over- and under-nutrition). Worldwide, food and nutrition insecurity has been linked to the transmission of HIV and poor disease outcomes (Fields-Gardner and Fergusson 2004). Food insecurity can be linked to malnutrition, which compromises the immune system through biological pathways, paving the way for increased susceptibility to HIV/AIDS. The impact on the immune system contributes to a more rapid progression of the disease; thus,
malnutrition both contributes to and is a result of HIV disease progression (Lisam and Lisam 2009). In this section, I will outline the within-body synergies of the relationship between HIV and food security. Included in this section will be issues of food insecurities linked to faster disease progression, impairment, and facilitation of HIV transmission.

Within Body Synergies

In the late 1960s, the World Health Organization led the way in acknowledging a synergistic relationship between malnutrition and infection, and public health has long supported the importance of adequate nutrition for protection from disease. In describing the linkage between food insecurity and health outcomes, one international food researcher described nutrition as the “pivotal interface” (Gillespie 2006:11), due to the relationship between nutritional status, immune function, and disease risk. Malnutrition weakens the immune system, increasing the risk of ill-health, which in turn can aggravate malnutrition. It is a vicious cycle (Scrimshaw, Taylor, and Gordon 1968; Tomkins and Watson 1989). Infections are thus longer lasting and more severe in someone who is malnourished. They may also be more frequent.

Research has borne out this relationship, in which diseases such as tuberculosis, HIV/AIDS, and malaria all adversely affect nutritional status (Scrimshaw and SanGiovanni 1997). In turn, susceptibility to any disease depends on the strength of the immune system. Both undernutrition and micronutrient deficiency, even in the absence of readily observable symptoms, weaken every component of the immune system (Murray and Lopez 1997; Stillwaggon 2006).

If within-body synergies are not enough, infectious diseases often decrease appetite, which frequently leads to reduced food consumption (even while demands of the immune system
increase macro- and micronutrient need). While food intake decreases, diarrhea, and vomiting while ill can also exacerbate nutrient loss (Lanata and Black 2001). As Singer (2011) notes, malnutrition and HIV/AIDS are the two most common causes of acquired immune dysfunction, and when these two conditions are concurrent, “their effect on the immune system is synergistic” and severe (Anabwani and Navario 2005:98). These issues are important biological considerations when examining food security in the context of HIV.

**Impact on Overall Health**

Malnutrition both contributes to and is a result of HIV disease progression. Malnutrition affects the severity of infections, leading to a greater likelihood of illness and death from disease, (Black, Morris, and Bryce 2003; Brabin and Coulter 2003; De Onis et al. 1993; Murray and Lopez 1997; Rice et al. 2000; Food and Agriculture Organization (FAO) of the United Nations 2004; Himmelgreen and Romero-Daza 2008). For example, once someone is infected with HIV, inadequate nutrition – perhaps related to malabsorption, lesions in the mouth, diarrhea, or changes in metabolism (Kotler 1989) can hasten the progression towards active AIDS disease (typically defined as having a CD4+ count of <200 cells/mm$^3$) and death (Duggal, Chugh, and Duggal 2012; Guenter et al. 1993).

Food insecurity itself (not malnutrition) has been associated with higher HIV viral loads (Kalichman et al. 2010) and higher HIV/AIDS-related morbidity and mortality (Weiser et al. 2009). Anema and colleagues (2014) examined the relationship between a qualitative measure of self-reported hunger and plasma HIV RNA suppression and found that self-reported hunger is associated with lower odds of plasma HIV RNA suppression (OR = .59).
Infectious disease also impairs the health status of individuals by affecting their ability to produce an adequate and appropriate diet for themselves and their families (Himmelgreen et al. 2009; de Waal and Whiteside 2003). It accomplishes this by weakening bodies and decreasing their ability to work to their full physical or even mental or cognitive potential (Gillespie and Kadiyala 2005). HIV infection is also associated with an increased risk of various chronic diseases. People living with HIV have 1½ - 2 times higher risk of dying from acute myocardial infarction, experience an increased risk for progressive atherosclerosis, and higher diabetes risk (Willig and Overton 2014). In a study of HIV infected marginally housed or homeless individuals in San Francisco, food insecurity was associated with greater acute care utilization and experienced increased odds for hospitalizations and emergency room visits, even after adjusting for various sociodemographic and clinical variables (Weiser et al. 2013).

Food Insecurity and the Risk of HIV Transmission

Studies of HIV/AIDS have demonstrated that micronutrient deficiencies (either pre- or post-HIV infection) are important factors in the transmission and progression of HIV (Friis, Gomo, and Michaelsen 2001). Along a biological pathway, this risk increased due to the synergistic relations already discussed in detail above. However, other pathways for this risk include gender inequality and social vulnerability (Romero-Daza and Himmelgreen 1998; Sellen and Hadley 2011). Due to varying degrees of gender inequality in developing and developed world settings, often food insecurity is associated with the need to engage in high-risk behaviors (such as transactional or “survival” sex) to provide for themselves or their families. Romero-Daza (1998) describes the experience of women in Lesotho who engage in serial monogamous relations with men outside of their primary relationships as a means to gain access to resources.
The exchange of money is not necessarily implied in “transactional” sex—partners may bring food, provide a place to stay, or other resources.

Farmer (2006), in his book, “AIDS and Accusation: Haiti and the Geography of Blame,” tells the story of Annette Jean, a story of a life and death at the nexus of any number of social vulnerabilities. As part of the water refugees of Do Kay, as a child, she was exposed to cyclical hunger during the dry season, which brought with it her father’s anger. As conditions at home grew worse, she ran away to Port-au-Prince and took the only job she could—as a maid. Her work was hard, and she received little compensation, and eventually lost her job when her employer did. As she cast around looking for other work, trying to find a place to live—she entered her first sexual relationship at the age of 15 with a man working at the airport. When her partner fell ill and died, Anita Jean also fell ill. Her health declined, and though she made her way back home and still tried to work, eventually, she succumbed to AIDS.

Anita Jean’s story poignantly highlights the perils of gender and social inequality of the risk of contracting HIV. As women lack access to economic resources, they have to rely on men for things they need (Bryceson and Fonseca 2006). Exposure to violence within their relationship can put women as risk, as they try to decide if they should stay in a bad situation or leave, risking food insecurity (Miller et al. 2011). These situations likely increase mental health issues such as depression, which may, in turn, affect their ability to acquire food.

Considering the number of vulnerabilities that these women face, it would be easy to assume that poor health outcomes are inevitable. However, it is important to recognize that, sometimes—despite even the hardest circumstances—some people can experience these types of vulnerabilities and use various resources at their disposal to mitigate harm.
Coping

Coping is defined as “efforts to prevent or diminish threat, harm, and loss from a given event or to reduce the distress associated with those experiences” (Carver 2014). Lazarus and Folkman (1984) were the first to parse out different kinds of coping by differentiating between direct and indirect coping efforts. They noted that “problem-focused” or “active coping” is directed at the stressor itself, made up of efforts to “remove or to evade it or to somehow diminish its impact if it cannot be evaded” (Carver 2014:17). Coping efforts can also seek to diminish the suffering that is triggered by stressful events, which is called “emotion-focused coping.” Behaviors themselves do not often lend themselves to easy categorization; however, one has to understand the intention behind a particular behavior. Carver (2014) provides an example of this for the behavior or seeking support from others. Whether or not seeking support is a problem-focused or emotion-focused coping strategy depends on whether or not the person is seeking reassurance or some sort of instrumental (or tangible) support such as transportation or money.

Stressful events are an inevitable part of life and contribute (often negatively) to the human condition. It is argued that while stressful events are unavoidable, it is coping that makes the “biggest difference in adaptation outcomes” (Lazarus and Folkman 1984:6). Thus, it is not necessarily the exposure itself, but how people respond to the exposures and, indeed, how the adaptations they make can constrain future options.

Households faced with food insecurity adopt coping strategies that can be divided into food-based and non-food-based responses (Ruel et al. 2010). Some of these can be categorized as “active,” and often the responses occur along a “progressive series of events” (Connell et al. 2001:1) that are typically ordered depending on the severity of the food insecurity situation that
the household faces (Maxwell 1996; Connell et al. 2001). Responses to food insecurity will also depend on what strategies are available to household members and other resources at their disposal. Measures such as the Coping Strategies Index have been widely used in settings outside the United States (Maxwell, Caldwell, and Langworthy 2008; Maxwell et al. 1999; Maxwell et al. 2003); though some of the questions may be difficult to apply in many areas of the United States. For example, in urban settings, coping strategies like consuming seed stock held for next season, or hunting wild game or foods might seem incongruous. Still, whether in settings here in the U.S. or abroad, when households face similar food-related challenges, there are some overarching patterns in how those households will respond (Fitchen 1988).

Typical when households are facing food security issues, they begin with food-based responses. They first alter the quality of foods they eat, switching to cheaper, lower quality but energy-dense food such as staples (Drewnowski and Specter 2004; Ruel et al. 2010; Carlson, Andrews, and Bickel 1999; Brinkman et al. 2010). This quality-reduction strategy typically means cutting foods such as meat, eggs, dairy, fruits, and vegetables as they are frequently the most expensive (Ruel et al. 2010). Overall, the diet may become less diverse; cutting these foods and substituting for highly processed foods (“junk foods”) can lead to micronutrient deficiencies that impact overall health and is particularly problematic for women of reproductive age and infants and young children who have higher nutritional needs. In the US, strategies related to changing food quality can also include shopping at bargain stores and using coupons (De Marco, Thorburn, and Kue 2009).

If the situation does not improve, then households tend to change the quantity of the food that is consumed—they may purchase less food, skip meals, or otherwise reduce intake. A study by Mammen and colleagues (2009) reported that methods for reducing consumption included
taking up dieting narratives, using tobacco, alcohol, or drugs to curb feelings of hunger.

Strategies used to reduce consumption are not necessarily undertaken by all members of the household. Some may engage in a form of “triage” to decide which household member(s) will reduce intake (Mammen, Bauer, and Richards 2009). Mothers reportedly eat less preferred foods or even skip meals to buffer children and adult males (Carney 2010).

Households may then enact non-food-based strategies, such as drawing on social relationships or community resources such as local or church food banks to obtain access to food (Costello 2007; Chan et al. 2008; De Marco and Thorburn 2009; De Marco, Thorburn, and Kue 2009). Examples of relying on social relationships could include sending children to eat elsewhere or borrowing food. One mother noted that while she could rely on family in times of need, sometimes the necessary reciprocation could cause her to run out of food (Stevens 2009).

Household might then resort to reallocation of other resources; that is, households might purchase food on credit, or encourage household members not currently employed to enter the workplace; however, it was noted that with the recent food, fuel, and financial crisis, formal employment opportunities might be scarce and this may not be a viable coping strategy (Ruel et al. 2010). Money meant for other purposes such as health care, transportation, or education may be diverted to pay for food. Personal belongings may be sold (Tarasuk 2001), people may walk instead of drive (Carney 2010; Chan et al. 2008), and in some cases, people may write bad checks or juggle the payment of bills (Mammen, Bauer, and Richards 2009). Finally, households may choose to access formal government agencies to increase access to foods.

Though there is overall agreement about the most frequently used coping strategies, some variation does exist. It has been argued that the order in which strategies are used can vary depending on a number of factors, including personal, household, or even state-level
characteristics (Mammen, Bauer, and Richards 2009). Thus, it will be important to understand differences that may exist in how LFS and VLFS households cope with food insecurity because food insecurity may act in a dose-response manner. In a review of studies addressing marginal food security (Cook et al. 2013), the authors found that while ‘marginally food secure’ households were more like food insecure households (though usually merged into the food secure category), these households were different enough to stay a separate category. The authors make this recommendation due to the relationships they found between the marginal category and various adverse child/caregiver health outcomes (Cook et al. 2013). Interestingly, Coleman and Jensen (2013) found that low-income households eligible to receive aid (but did not) were less likely to be food insecure than those that did receive various forms of government assistance, suggesting that some low-income households are able to meet their food needs through other forms of assistance or coping.

That being said, Kahn and colleagues (1964) point out that the concept of coping needs to be comprised of coping behaviors themselves, not just the success of those actions. They argue that studying the behaviors that fail (and their consequences) provides the best insight into the costs or ramifications of those strategies (Kahn et al. 1964:385). Strategies themselves cannot be viewed as inherently better than others. Instead, the coping effort can only be determined as positive or negative in relation to its success at mitigating the issue or helping to manage it, as well as consideration of the long-term effects of any given strategy. Strategies that alleviate present events but ultimately constrain future abilities to respond to other crises are not typically viewed as beneficial. For example, a household may decide to sell assets, such as a car, to pay rent or past due utility bills, especially if there is a threat of eviction or power being turned off. However, selling the car might mean difficulties down the road, such as a lack of transportation
to the clinic or grocery store, leaving household members at the mercy of public transportation systems. Delays in bus routes could make them late for appointments. Traveling by bus could limit the amount of groceries they can buy at once, or require them to buy at smaller, potentially more expensive neighborhood stores, adding further stress on the household.

What should be clear from this review of coping strategies is that structural vulnerabilities such as poverty and food insecurity are not automatically embedded under the skin. Though these ‘determinants’ of health have the potential to produce poorer health outcomes, those outcomes are not inevitable. That is because people can respond to exposures or experiences using various coping strategies in their attempts to ameliorate the effects of those events. Recognition of the ways that people push back against potentially harmful forces is important for understanding that individuals, families, and communities as more than merely passive receptors of the vagaries of social inequality. They seek out forms of assistance, they work to make do, and they try out lots of strategies to address challenges that they experience.

Adherence

It is estimated that about 375,000 individuals are currently on antiretroviral treatment (ART) (WHO 2014). Antiretroviral therapy (ART) adherence is critical not only for the suppression of HIV viral replication and avoiding viral resistance, but also to slow the destruction of CD4 cells, promote immune reconstitution, and slow disease progression overall (Weiser et al. 2010; Young et al. 2013b; Weiser et al. 2014; Kalichman et al. 2011). Antiretrovirals have brought longer and healthier lives to thousands of people with AIDS (Palella et al. 1998), and it is estimated that 3 million years of life have been saved in the US alone (Walensky et al. 2006).
Adherence to ART is critical not only for the suppression of HIV viral replication and avoiding viral resistance, but also to slow the destruction of CD4 cells, promote immune reconstitution, and slow disease progression overall (Weiser et al. 2014; Weiser et al. 2010; Young et al. 2013b; Kalichman et al. 2011). Further, when viral loads drop to undetectable levels (<40 copies/ml), the risk of transmitting HIV to others is lower, though not eliminated (Wilson et al. 2008).

Despite the recognized benefits of ART, 20-45% of current ART users do not achieve adherence due to various reasons related to nutritional, social, and economic conditions (Hardon et al. 2007; Musumari et al. 2014; Kalichman et al. 2011; Kalichman et al. 2010). Near-perfect adherence is required to achieve positive health impacts and to avoid drug resistance, illness, and death; yet, the levels of adherence achieved in clinical trials are rarely ever achieved in real life (Simoni et al. 2008). In general, rates of medication adherence are higher in acute versus chronic conditions. Adherence rates are highest in cancer patients (~80%), followed by cardiovascular disease, infectious disease, and diabetes (~75%), psychiatric disease and depression (~60%), and COPD and asthma (~55%) (van Dulmen et al. 2007). Also, adherence tends to drop dramatically over time. Outcomes of poor adherence include enhanced viral replication, treatment failure, and the emergence of drug-resistant strains (Chesney et al. 2000).

**Antiretroviral Adherence: Definitions and Constructs**

Adherence to ART can be defined as taking a certain percentage of required medications, typically 90-95%, though some treatment regimens require “only” 85% adherence (Parienti et al.
2008) to achieve viral suppression. To be described as adherent, one must take the prescribed doses at the right time(s) and in specified ways, such as with or without food.

Adherence to medical treatment has long been recognized as an issue, and studies of the problem began as early as the 1940s (DiMatteo 2004). In the nearly 40 years since Sackett and Haynes (Sackett and Haynes 1976; Haynes, Taylor, and Sackett 1979) first developed the most cited definition of adherence: “The extent to which a person’s behavior [in terms of taking medication, following a diet, modifying habits, or attending clinics] coincides with medical or health advice,” research on patient adherence has continued to flourish (Bosworth, Oddone, and Weinberger 2006:3).

Adherence has been alternatively referred to as compliance, concordance, therapeutic alliance, cooperation, mutuality (Bosworth, Oddone, and Weinberger 2006). While these terms are sometimes used interchangeably, in the early 1990s, there was some discussion as to the difference between these terms. While “compliance” often implies obedience, the willingness to follow instruction, and more passive action, “adherence” implies the freedom to choose or undertake a behavior, to plan, to have input, and indeed collaborate in the process of self-care (Brawley and Culos-Reed 2000). Frequently, the word that is chosen to illustrate patient action has implications for the theory that is applied to behavior change.

Adherence was first conceived of as a very individual behavior, emphasizing personal responsibility (Mendelsohn et al. 2014; Fisher et al. 2006), but has shifted to consider social conditions or the interplay of factors (micro-, meso-, and macro-) that may be influencing the individual (Mendelsohn et al. 2014). In the past decades of examining adherence, the focus of research has moved from patient behavior to provider behavior; in line with these shifts, studies

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5 Not all ART require food to be consumed with medication.
have shifted what is considered appropriate measures—such as moving from biomarkers to clinic ratings and treatment satisfaction (Brawley and Culos-Reed 2000). As can be expected, behavior models to guide research have aligned with the shift, examining the factors that facilitate adherence.

Most definitions of adherence contained three elements: the patient’s self-care responsibilities, their role in treatment, and their collaboration with providers (Bosworth, Oddone, and Weinberger 2006). When Haynes et al. (2008:2) defined adherence as “the extent to which patients follow the instructions they are given for prescribed treatments” they also highlighted that adherence should be a *process measure*; that is, it should be considered a means to an end—improved outcomes—not an end in itself (Haynes et al. 2008). In addition, adherence should be viewed as a spectrum of activities from taking less medication, not following dietary advice, the occasional missed dose, to full disengagement with care. Reasons for non-adherence will likely vary depending on where in the adherence spectrum the individual is.

Factors associated with non-adherence can be parsed into several categories: 1) patient variables, 2) treatment regimen, 3) disease characteristics, 4) patient-provider relationship, and 5) clinical setting (Simoni et al. 2009; Ickovics and Meisler 1997). From Simoni (2008:192):

- **Patient variables** consist of socio-demographics and psychosocial factors such as substance abuse, psychological distress, social support, self/body-image and self-efficacy
- **Treatment regimen** includes the complexity of the regimen and associated treatment configurations (diet, length of course of treatment, how treatment is administered)
- **Disease characteristics** include severity of the disease, impact on immune function, and presence of opportunistic infections or other complications (which may increase adherence)
- **Patient-provider relationship** includes belief about the knowledge, abilities and competence of the provider and how much time and perceived genuine interest they demonstrate
- **Clinical setting** includes consistent access to treatment, other supports (like transportation and child care), and overall positive clinic characteristics like friendliness, convenience, and satisfaction with the site

*Figure 3: Factors Associated with Non-Adherence*
Additional research has expanded the domains associated with adherence to include environmental factors such as weather (O’Shea, Taylor, and Paratz 2007), social support (Ware et al. 2009), being marginally housed or homeless (Weiser et al. 2009b), and experiencing food insecurity (Singer, Weiser, and McCoy 2015; Weiser et al. 2011a). While it is often recognized that a number of factors influence adherence, research tends to focus on patient-related factors rather than issues related to providers or the health system (Bosworth, Oddone, and Weinberger 2006).

**Theoretical Approaches to Adherence**

In a study discussing the importance of theory in the design of interventions (Munro et al. 2007), the authors note that there are six main theoretical perspectives related to adherence—five identified by Leventhal and Cameron (1987) which include 1) biomedical; 2) behavioral; 3) communication; 4) cognitive; and 5) self-regulatory, and a more recent 6) “stage” perspective. (Munro et al. 2007). The biomedical perspective tends to view participants as passive recipients of a doctor’s instructions, and so, typical solutions tend to be mechanical—such as technical innovations and monitoring. The other perspectives tap into various theories of behavior change, such as the Health Belief Model, Theory of Reasoned Action, Theory of Planned Behavior, Transtheoretical Model, and Social Cognitive Theory/Self-Efficacy approaches. The central assumption of these theories is that people are capable of planning, making rational decisions, and are goal-oriented, self-regulating, willing to learn as they go, and adjust to changing circumstances (Brawley and Culos-Reed 2000:158S). A key criticism of the use of these theories is that they do not adequately address the structural issues that are potentially influencing
adherence. Despite the use of these theories, Haynes et al. (2008:7) “lament the limited theoretical underpinnings and lack of consistent features of most adherence interventions.”

In 2000, Brawley and Culos-Reed (2000) held that there was not a clear endorsement for any one theory of adherence; just a few years later, van Dulman (2007) agreed, indicating that the slow progress in adherence research was due to the lack of theory’s ability to predict and explain non-adherence adequately. While theoretical models have advantages for the study of adherence, Brawley and Culos-Reed (2000) noted that the models being considered at that time still could not account for large amounts of explained variance, drawing on other research from Baranowski et al. (1997) who observed that current theories do not completely predict behavior or behavior change, though it was clear that interventions did have modest effects.

In spite of advances in adherence research, medication nonadherence rates have remained relatively constant over the last several decades (van Dulmen et al. 2007; Burke, Dunbar-Jacob, and Hill 1997). In an extensive, stringent review of unconfounded clinical trials examining medication adherence in a number of conditions (Haynes et al. 2005), it was determined that a mere 45% actually improved medication adherence, and only 33% resulted in better health outcomes. Effective interventions were complex, labor-intensive, and even the most effective did not lead to large improvements in adherence or treatment outcomes. This review was updated in 2008; the authors remarked that of the additional 21 studies that examined both adherence and treatment outcomes, only 23% showed improvements in both (Haynes et al. 2008). Adherence interventions use considerable resources such as staffing and funding, and can have adverse effects such as a loss of privacy (Sabaté 2003); given these risks, the use of evidence-based, effective adherence interventions should be part of ethical practices, whether as research or practice.
Barriers and Facilitators to ART Adherence

Despite the recognized benefits of ART, 20-45% of current ART users do not achieve adherence due to various reasons related to nutritional, social, and economic conditions (Hardon et al. 2007; Kalichman et al. 2011; Kalichman et al. 2010). For example, transportation to clinics and pharmacies has been shown to be a significant barrier to adherence (Hardon et al. 2007). Food insecurity was associated with transportation issues for PLWHA (Kalichman et al. 2010), and distance to a city center (where various resources are located) interacted with food insecurity and predicted poor ART adherence Kalichman et al. (2011), highlighting the interactive effects of nutritional, social and economic issues. Social and health-related stressors such as disclosing HIV status to friends, family, or partners, experiencing discrimination, changes in health status, or treatment were all also found to be related to poor ART adherence (Kalichman and Grebler 2010).

Patient-related barriers to adherence include the complexity of the regimen, emotional distress, illness costs to the household, stigma, health beliefs and poverty, limited knowledge of the disease, difficulty remembering pills, intentional nonadherence due to adverse drug reactions or other reasons (de Pee et al. 2014a). Other barriers to antiretroviral adherence are the relative absence of symptoms until later stages of active AIDS disease, the prospect of indefinite treatment, questions of treatment efficacy, and the frequency of adverse side effects (Simoni et al. 2008:192). The one time a monthly pharmacy refill, intended to help monitor adherence, actually appeared to make adherence more difficult through the additional transportation costs needed (Hardon et al. 2007). One author argues that poverty itself is often mistakenly assumed to be a barrier, though it is likely that poverty is associated with conditions that are the real barriers (Mills et al. 2006).
While adherence is often viewed as a product of information, motivation, behaviors, and skill (characteristics within the individual), this focus on individual action de-emphasizes the social context within which HIV-positive individuals must make decisions. Research that focuses solely on patient-related barriers to adherence potentially overlook adherence facilitators that social support can provide. Social support has been defined as “aid and assistance exchanged through social relationships and interpersonal transactions (Coreil 2009:114). Social support can take several forms: 1) Emotional support (expressions of empathy, love, trust and caring), 2) Instrumental (tangible aid and service), 3) Informational (advice, suggestions, and information) and 4) Appraisal (information that is useful for self-evaluation)—and these forms of support (their presence or absence) can have positive or negative influences (Coreil 2009). For example, interventions utilizing home-based help (CHW, DOT, support partners) are emerging as important facilitators of treatment adherence (Ware et al. 2009). Treatment adherence is nearly twice as high in cohesive families (Bosworth, Oddone, and Weinberger 2006).

Ware (2009) argues that social capital, defined as resources accruing from a network of relationships that help individuals to solve problems and get done, add significantly to the study of adherence and may offer explanations for behaviors. Even in difficult situations, patients can overcome economic struggles, reshuffling resources, or tapping into social capital to prioritize adherence (Ware et al. 2009). Use of these strategies (begging, borrowing, or relying on others) creates a debt, though; these “adherence partners” expect adherence in return, and “patients adhere to promote goodwill on the part of their helpers ensuring that help will be available when future needs arise” (Ware et al. 2009:e1000011). Adherence to medication can lead to better health outcomes, which can result in individuals requiring less help; thus, people might often feel
pressure to adhere to medication to ease the burden on their caregivers (Ware et al. 2009). Thus adherence becomes an interpersonal act, one heavy with social connections.

**Food Security and ART Adherence**

While the recognition of links between poor HIV/AIDS treatment outcomes and food insecurity has been established for some time in resource-poor settings, only relatively recently have researchers begun to explore food security in resource-rich settings (such as the United States and Canada) to determine what role, if any, food insecurity plays in poor health outcomes in PLWHA. Despite clear differences in social, cultural, and economic contexts of HIV+ populations in resource-poor and resource-rich settings, studies of various HIV-positive subpopulations such as individuals in a drug treatment program in British Columbia (Weiser et al. 2009a), marginally-housed and homeless individuals in San Francisco (Weiser et al. 2013), individuals recently release from prison (Wang et al. 2013) and veterans (Wang et al. 2011) have all shown alarmingly high levels of food insecurity—up to 91%— in these vulnerable populations in “resource-rich” settings. These recent studies and others conducted in the United States and Canada have demonstrated that food insecurity is associated with poor HIV/AIDS treatment outcomes such as lower CD-4 counts (Kalichman et al. 2010; James H McMahon et al. 2011), higher HIV viral loads (Kalichman et al. 2010), greater acute care utilization (Weiser et al. 2013), higher HIV/AIDS-related morbidity and mortality (Weiser et al. 2009a), and suboptimal antiretroviral treatment (ART) adherence (Kalichman et al. 2010).

These findings mirror what is known in resource-poor settings: that for these concurrent epidemics (food insecurity and HIV), there is synergistic biological and social interaction in which one condition exacerbates the negative health effects of the other (Young et al. 2013a). As
Young and colleagues (2013a) note in a recent review of the relationship between food security and adherence, food insecurity has been shown to heighten vulnerability to HIV infection and exacerbates poor clinical outcomes (Weiser et al. 2007; Weiser et al. 2009a), has been associated with incomplete HIV RNA suppression (Weiser et al. 2009b; Wang et al. 2011), and food-related interventions (such as supplementation) can interrupt this relationship and have been shown to improve clinical outcomes, including adherence to ART (Ivers et al. 2010; Bärnighausen et al. 2011; de Pee et al. 2014b).

In a study that examined the effect of poverty markers as predictors of non-adherence, Kalichman and Grebler (2010) correctly hypothesized that food insecurity would predict poor adherence outcomes over and above any other stressor. The study found that poorer adherence was significantly related to every indicator of food insufficiency, including having to choose between food and medicine, running out of food, cutting back on meals, and going hungry. Multivariate analyses revealed that food insufficiency predicted non-adherence above depression, HIV-related stigma, substance abuse, and other HIV-related social stressors (Kalichman and Grebler 2010). Musumari (2014), in a quantitative study of food security and antiretroviral adherence in Africa, found that nearly 60% of their sample were food insecure and that food insecure households were twice as likely to be non-adherent. Other studies have found similar links between food insecurity and suboptimal adherence (Franke et al. 2011; S. D. Weiser et al. 2014; Young et al. 2013a), which in turn predicts drug resistance (Parienti et al. 2008), disease progression and death (Bangsberg et al. 2001; Hogg 2002).

In a qualitative study examining food insecurity as a barrier to sustained antiretroviral therapy adherence in Uganda, Weiser et al. (2010) identified five mechanisms through which food insecurity undermined ART adherence and affected decisions about ART initiation. These
five themes offer opportunities to explore the biocultural nature of non-adherence in Africa and may inform our understanding of adherence among food insecure individuals in the U.S.

The first theme Weiser’s team identified was that ART often increased appetite, and food scarcities exacerbated the resulting hunger. While there is a biological mechanism potentially behind the increased hunger, it is, in fact, scarcities that are the underlying issue. Another theme identified as a barrier was the potential side effects of ART, which were reported to be much worse in the absence of food. A third theme was that people avoided starting ART because they believed they needed a balanced nutritious diet or the treatment would not work but knew they could not afford it. Here in the United States, as food insecurity rates climb and public assistance funding is reduced, those who are food insecure find themselves at risk of non-adherence not simply because of a physiological synergy, but rather, social conditions.

The last two themes had to do with competing demands between the cost of obtaining food and the cost of medical treatment and competing demands of work and taking medications. As my review of the emerging syndemic in Florida identifies, given state-level decisions not to expand Medicaid, individuals in Florida may find themselves facing greater instability in accessing health care. Like in Uganda, individuals may find themselves juggling between paying for transportation to clinic visits, deciding between food or drugs, completely defaulting from treatment, or giving up food and wages to get medications.

As these studies reveal, the relationship between food insecurity and ART adherence is characterized by relationships that “exacerbate one another biologically by activating symptoms, accelerating detriments of disease and/or increasing contagious” (Romero-Daza et al. 2012:235) and that deleterious social conditions exacerbate these issues.
Measurement of Adherence

The measurement of ART adherence is a continually evolving area of research. To rigorously evaluate adherence interventions, it is important to accurately capture the phenomenon, which offers a number of measurement challenges (Berg and Arnsten 2006). How medication adherence is conceptualized varies widely across studies, and as a result, there are a number of adherence measures, often categorized as direct (pharmacy refills, pill count, electronic monitoring via medicine caps), indirect (provider assessment, self-report) measures, or physiological (viral loads or blood drug levels), each offering important information for understanding adherence. The definition of adherence used by a study and the measures it employs should be well-linked. For example, if using a definition that defines adherence as taking the prescribed doses at the right time(s) and in specified ways, such as with or without food—then a measure capturing those dimensions is most appropriate.

Adherence to antiretroviral treatment is often defined as taking a certain percentage of required medications, again - typically 90-95%. This percentage can be derived from direct (pill counts) or indirect (self-report) measures. Though a threshold of greater than 95% is commonly used and believed to be necessary for maximum viral suppression (Haas et al. 2016; Kim et al. 2018; Bisson et al. 2008), some studies only consider 100% adherence as acceptable to be conservative (Wise and Operario 2008). Studies utilize other minimum thresholds; for example, one study observed that some treatment regimens require “only” 85% adherence (Parienti et al. 2008) to achieve viral suppression. Another more recent study found that ART regimens require a range of adherence levels to be effective at reducing viral loads (70 to 90%), depending on the type of drugs or drug combinations that are administered (Nachega, Mills, and Schechter 2010). Parenti and colleagues (2008) note that all missed doses are not comparable; unboosted protease
inhibitors (PI) require higher levels and near-perfect adherence, while nonnucleoside reverse transcriptase inhibitors (NNRTI) and ritonavir-boosted protease inhibitors can achieve reliable virologic suppression at more moderate levels of adherence for most individuals.

Direct measures of adherence seemingly offer an objective assessment of medication adherence. Unannounced or announced pill counts, comparing anticipated versus actual pharmacy refills, or even MEMS (which records the number of times the pill bottle is opened) seem to offer a more valid measure of adherence. However, MEMS (considered a gold standard) has some issues, including improper use due to “pocket dosing” or “curiosity opening” that can lead to over- or under-estimates of adherence (Berg and Arnsten 2006; Bova et al. 2005; Wendel et al. 2001; Haberer et al. 2010).

Indirect assessments of adherence have included qualitative and quantitative measures, with survey instruments of varying lengths. Recent studies on adherence scales have worked to reduce respondent burden, particularly in clinical settings, and research has shown that self-reported adherence scales of even just a single question are valid when compared to more objective measures of adherence such as pill counts and pharmacy records. Self-report is the easiest and most often used and does correlate with viral and clinical outcomes (Reda and Biadgilign 2012; Liu et al. 2001; Nieuwkerk and Oort 2005). Self-report measures of adherence (such as the VAS and SRSI) have correlated well with viral load and clinical outcomes (Amico et al. 2006; Feldman et al. 2013; Liu et al. 2001; Nieuwkerk and Oort 2005). For example, the Visual Analog Scale (VAS; Amico et al. 2006) consists of a single item and asks respondents to estimate their adherence over the last 3-4 week period by marking an “X” on a line with anchors at 10% intervals between 0%-100%. Another measure of adherence, the Self-Rating Scale Item
(SRSI), is a single item like the VAS but used 6 Likert responses (very poor to excellent) to rate adherence.

Another consideration in the measurement of adherence is that achieving a certain percentage of adherence or lower number of missed doses is not a positive health outcome in its own right (though research has strongly linked adherence to treatment outcomes). As Sabatè (2003) notes, adherence is a *process measure*; that is, it should be considered a means to an end—improved outcomes—not an end in itself. Where possible, studies—especially research on adherence interventions—should include outcome measures so that the efficacy of the intervention can be determined. Physiological measures may also be used to assess adherence (or triangulate with other measures) as a means to establish validity (Williams et al. 2013); however, it should be noted that some (such as blood drug levels) may be affected by absorption, metabolism, and excretion (Bosworth, Oddone, and Weinberger 2006). Some other issues related to these adherence measures are that they are expensive, invasive, and only approximate recent adherence (Berg and Arnsten 2006). Physiological measures, such as CD4+ count and viral load, can also be used as outcome measures, and their relationship to adherence measures (such as pill counts or self-report) can be assessed.

**Mental Health**

The Hopkins Symptom Checklist (HSCL) is a widely used assessment of psychological distress of varying lengths (5-90 items) that has been adapted and validated in a number of languages and settings (Bech et al. 2014; Derogatis et al. 1974; Derogatis and Melisaratos 1983). One version - the HSCL-10 (though not a diagnostic tool) does allow for the measurement of symptoms of anxiety and depression using items such as feeling fearful, troubles with sleeping,
feelings of worthlessness, and so forth. Recent studies have found that symptoms align with
clinical assessments of anxiety and depression and thus allow for quick screening of the issues
(Sweetland, Belkin, and Verdeli 2014; Lundin, Hallgren, and Forsell 2015) as well as use in
comparing the psychological distress of one group versus another.

The Perceived Stress Scale (Cohen, Kamarck, and Mermelstein 1983; Cohen 1988) is a
widely used assessment of stress that was “designed to tap how unpredictable, uncontrollable,
and overloading respondents find their lives” (Cohen and Janicki-Deverts 2012:1323). Higher
scores on the PSS assessment (which assesses perceived stress) has been shown to be associated
with a range of biomarkers and health conditions. For example, the PSS was found to be
correlated with higher levels of cortisol - a primary stress hormone (Pruessner, Hellhammer, and
Kirschbaum 1999) and lower levels of immune antibodies (Burns et al. 2002). Further, higher
levels of perceived stressed (measured by the PSS) have been found to be associated with
autoimmune diseases (Heijnen and Kavelaars 2005) including HIV (Cole and Kemeny 2001;
Pereira 2005); higher levels of perceived stress have been linked to slower wound healing in
healthy adult males (Ebrecht et al. 2004) and is linked to susceptibility to the common cold
(Cohen, Tyrrell, and Smith 1993).

**Linking Mental Health, Food Security and HIV**

It is estimated that 20-30% of PLWHA receiving care or treatment in the US have
symptoms of major depression (Bing et al. 2001; Orlando et al. 2002). Studies have linked
mental illnesses (such as depression and anxiety) to poor HIV outcomes, including faster disease
progression and higher mortality (Rabkin 2008; Carrico et al. 2011; Cook et al. 2004; Palar et al.
2014). Mental health indicators are associated with sub-optimal levels of ART adherence
A prospective study of PLWHA from five southern states (AL, GA, LA, NC, SC) found that depression and anxiety were linked with poorer adherence to ART (Mugavero et al. 2006). As Gonzalez and colleagues (2011) point out in their review and meta-analysis, though a large number of studies have examined the relationship between depression and non-adherence, none of the studies examined how depression is related to non-adherence, leaving an important gap in our knowledge of this issue.

In addition, studies of individuals without HIV and of PLWHA have highlighted links between food insecurity and poor mental health outcomes, which appears to be a bi-directional relationship (Weaver and Hadley 2009). One study by Kalichman and colleagues (2014) of PLWHA in Atlanta showed that food insecure participants reported greater levels of depression, stress, and emotional distress, and were more likely to have been treated for depression. In a longitudinal study of PLWHA from the Research on Access to Care in the Homeless cohort in San Francisco, Palar and colleagues (2014) found that more than half of participants were food insecure, and one-third had symptoms of depression. Further, severe food insecurity at a previous data collection point was associated with increased depressive symptom severity during the subsequent period (Palar et al. 2014).

Given the associations between measures of mental health, food security, and HIV (including ART adherence), it was important to measure and understand the relationships between these myriad issues. Qualitative and quantitative research can contribute not only to a better understanding of how depression, food security, and adherence are related but also how they might be ameliorated.
Summary

This chapter provided background information on the various syndemic components that were of interest in this study, as well as their relationships with each other as laid out in the literature. As highlighted in the conceptual model from Weiser et al. 2011b, the relationships between the variables of interest are complex and mutually-reinforcing, and the synergistic relationships between them result in a number of poorer health outcomes related to food security, nutrition, mental health, adherence – and these outcomes are exacerbated in vulnerable populations. The information in this review was used to inform the study design and will be used to interpret the findings in this study.
CHAPTER 4: RESEARCH SETTING AND METHODS

Chapter Four provides an introduction to the research setting and a review of the research methods for this dissertation. This chapter provides an overview of the mixed methods data collection and analysis activities, recruitment, and overall sample size for the two different phases, as well as ethical concerns related to this work. This study used mixed methods - surveys, 24-hour dietary recalls, and semi-structured interviews - to better understand the relationship between food security, mental health, and ART adherence within the context of the emerging HIV syndemic in Florida. Further, I aimed to understand how people living with HIV experience and cope with these various issues on a day-to-day basis. While the methodologies used in this study are not novel, they serve to expand upon existing syndemic literature with the addition of qualitative data to explore the lived experiences of the synergistic relationship between HIV and food insecurity attested to in the literature.

Research Setting

This study was conducted at Francis House in Tampa, Florida. Francis House is an HIV service organization that provides a number of services, including case management, linkage to housing assistance, daily support groups, breakfast, and hot lunches, food banks, mental health, and substance abuse counseling, and HIV/AIDS educational services. At the time of data collection (2014-2015), the organization provided about 320 clients per year with supportive
services, with roughly 20-50 individuals on-site daily to access those services. In addition, there was an overall case management client base of roughly 3000 individuals.

**Overview of Research Activities**

Data collection proceeded in two phases. The quantitative survey (n=131) was administered first, which informed decisions about who to approach for the second interview phase. The survey instrument consisted of five sections: 1) a 24-hour Dietary Recall, the USDA Core Food Security Module (18 questions), and additional questions related to accessing food; 2) demographic information; 3) access to health care; 4) mental health measures including the Hopkins Symptoms Checklist (HSCL-10) and Perceived Stress Scale (PSS-10), and 5) adherence to ART measures including the Visual Analog Scale (VAS), Self-Rating Scale Item (SRSI), and an unannounced pill count. The dietary data from the 24-hour recall was converted into the Healthy Eating Index; this data yields information about macro- and micronutrient intake as well as an index of diet quality (see Table 1 for a summary of the methods and variables for each research question). During the informed consent process (the form can be found in Appendix A), participants were asked if they wanted to be contacted for phase two of the study, and contact information was collected for those responding in the affirmative.

During the quantitative phase of the study, I had assistance from an additional study (and committee) member, Lauri Y. Wright, Ph.D., RDN, LD/N, as well as from a student who had worked with me on another project, Amber Windsor-Hardy. Ms. Windsor-Hardy, an undergraduate public health student, had served as a data collector for a federally funded randomized control trial examining a teen pregnancy prevention program. Dr. Wright, as a registered dietitian, was well-versed in the methods for administering a 24-hour dietary recall.
She and Ms. Windsor-Hardy participated in a 2-hour training on May 8, 2014, to review the survey instrument and instructions for the 24-hour dietary recall. In addition, because Ms. Windsor-Hardy was newly trained in the methods for the dietary recall, she also accompanied me (only after permission from participants) on four surveys early in the process to ensure she felt comfortable with the procedures. She and I also debriefed after each day of surveys to review the forms and any questions. Ms. Windsor-Hardy completed 16 of 131 surveys, and Dr. Wright completed eight. A third person (a graduate student of Dr. Wright’s) and a registered dietician also attended the training on May 8 but was never able to complete a survey due to scheduling issues. All parties – Dr. Wright, Ms. Windsor-Hardy, Dr. Palak Gupta, and myself – were added to the USF IRB.

The qualitative phase of the study included a semi-structured interview that explored themes of food security, adherence to antiretroviral therapy (ART), health care access, and general mental health to examine how people talk about and understand these experiences including how they cope with them. Based on the average of the two adherence measures, survey participants were sorted into categories of adherent (≥95%) and non-adherent (<95%) and approached to participate in an interview. No participants declined to participate in the interview though several (n=7) could not be reached at the numbers provided.

Eligibility criteria included being 18 years of age or older and being on ART (demonstrated by providing a photo ID and a prescription bottle for anti-retroviral medications that matched the name on the photo identification) and receiving services at Francis House. Participants who were pregnant, receiving ART for hepatitis C, cognitively impaired, or non-English speaking were not eligible to participate.
Table 1: Research Questions, Measures, and Variables

<table>
<thead>
<tr>
<th>#</th>
<th>Question</th>
<th>Methods</th>
<th>Variables</th>
</tr>
</thead>
</table>
| 1  | What is the food security level and diet quality of participating clients enrolled in a special services program? | USDA Household Food Security Scale Module (HFSSM) 24-hour dietary recall | • Food Security Scale (O, I)  
• Occurrence of Food Security Events (D)  
• Frequency of Food Security Events (C)  
• Healthy Eating Index (O) |
| 2  | What is the relationship between ART adherence and measures of food security and dietary quality? | Visual Analog Scale (VAS) (score 0-100)  
Self-Rating Scale Item (SRSI) | • Level of Medication Adherence (O)  
• Self-reported Adherence Score (O) |
| 3  | What is the relationship between anxiety and depression, food security, and ART adherence? | Hopkins Symptoms Checklist 10 Perceived Stress Scale | • Depression and Anxiety Score (O)  
• Perceived Stress Score (O) |
| 4  | How does the experience of food (in)security, including dietary quality, vary by adherence to ART? | Semi-structured Interview Instrument | • Text at the sentence level  
• Interview Themes |
| 5  | What strategies are utilized by participants to ameliorate issues related to food security and diet quality? | Semi-structured Interview Instrument | • Text at the sentence level  
• Interview Themes |

Variable Levels: D-Dichotomous, I-Interval, O-Ordinal/Categorical, C-Continuous

This study employed the use of mixed methods, in that it incorporated quantitative and qualitative measures of food insecurity, antiretroviral adherence, mental health, and coping. Agencies such as the National Institutes of Health have long recognized the value of using qualitative methods to better understand the social and cultural dimensions of health (National Institutes of Health 2001); examining adherence to antiretroviral therapy using qualitative methods is consistent with these recommendations (Sankar et al. 2006). My primary consideration, given my review of the literature, was an ethnographic exploration of factors
associated with the potential syndemic conditions. I wanted to understand more about how food insecurity might influence adherence to antiretroviral therapies within the emerging syndemic in Florida. It is informative to understand any instances where individuals who are struggling with multiple issues still manage to remain adherent to their regimen. Understanding more about how food insecure individuals might still be adherent to their medications can provide potential recommendations for policies or additional research.

Thus, the specific type of mixed methods design employed in this dissertation is the explanatory sequential model. This study design calls for the quantitative data collection and analysis phase to precede the qualitative data collection and analysis phase, with parallel variables being collected both qualitatively and quantitatively. Because the goal is to understand the similarities and differences in the daily lives of those who are able to achieve adherence as compared to those with suboptimal adherence, the results of the quantitative analysis of adherence will be used to select participants for the second phase of the study. In addition, interviews will be used to tease out more in-depth information about coping strategies data collected during the first phase of the study, as well as the success or failure of such strategies.

**Recruitment and Sample Size**

Participants were recruited through staff, flyers, and word of mouth at the HIV service organization, Francis House. Based on sample calculations using G*Power 3.1 (Faul et al. 2009), I surveyed 131 individuals to detect a moderate effect size (.5) using an independent t-test. For qualitative data collection, guidance from Creswell (1998) recommends 20 to 30 interviews, and Bernard (2000) notes that studies in ethnoscience are often based on samples between 30 and 50 interviews. An important goal when determining sample size in qualitative data collection is the
achievement of ‘saturation’, or the “point in coding when you find that no new codes occur in the data” (Urquhart 2013:194) or when you have increased frequencies of the same codes, but no new codes arise (Given 2016). While Guest (2006) says that saturation can occur in as few as 12 interviews, my goal was to interview at least 20 individuals each from two categories: optimal and suboptimal adherence, to understand how the variety of experiences related to food insecurity and other factors that might differ depending on adherence to ART. Based on field notes about the recruitment process, it seemed that individuals with optimal adherence were easier to reach than those with suboptimal adherence. Those with suboptimal adherence either required several phone calls to schedule an appointment, had to reschedule appointments (mainly, due to no-shows), and in some cases were unreachable by phone when it seemed that phone service had been turned off.

Participants received a $25 gift card as compensation for the survey portion of the research, which took approximately 45 minutes to complete (range: 24 minutes to 2 hours, 34 minutes). Individuals who participated in the interview, which averaged 55 minutes (range: 32 minutes to 3 hours, 15 minutes), received an additional $25 gift card.

Study Survey

The first phase of this study utilized an in-person, pencil and paper survey that was facilitated and completed by study staff. The survey began with questions around food security and food access, then demographic information, and access to health care. The next section covered self-reported mental health measures and access to health care. The last section of the survey covered the topic of ART adherence. In the sections below, I outline the survey section and any specifics for administering that section.
Food insecurity and diet quality

To assess food security and diet quality, the survey began with a 24-hour dietary recall (Appendix B). This in-person dietary recall was conducted using a five-step multiple-pass method (Moshfegh et al. 1999) and aided by several plastic food models (Nasco; Fort Atkinson, WI) to help participants estimate portion sizes. This food recall method starts with generating an uninterrupted, quick list of foods and beverages consumed the day before, starting with the last thing it was they ate or drank before going to bed, then moving back in time through typical meals (dinner, lunch, breakfast) and any foods or beverages consumed outside of mealtimes. This quick list is followed by prompts to recall any potential forgotten foods such as condiments, fats, snacks, and so forth, an extensive list which can be found on the survey form for reference. Participants are then asked to identify the time, meal, or occasion at which these items were consumed, such as a snack before bed, lunch, foods eaten while out running errands. These questions can sometimes stimulate memories of other meals or foods eaten. Next, participants are asked to provide details about each item listed, including descriptions of portion sizes (aided by the use of food models), cooking methods (if applicable), and if foods/beverages were finished. The last step includes a final review of items to ensure nothing was forgotten, and all details were captured. During the proposal phase, the use of a validated, online Automated Multi-Pass Method (AMPM) for participants to complete either on- or off-site, before or after the survey was considered. The National Cancer Institute (NCI) hosts a web portal for the Automated Self-Administered 24-hour (ASA24®) Dietary Assessment Tool (NCI 2019), which facilitates self-administered 24-hour recalls that are automatically coded. However, technology constraints on-site at Francis House and the potential for literacy issues influenced the decision.
to move forward with the paper-and-pencil version of the recall. The conversion of dietary data in the Healthy Eating Index (HEI) will be discussed in the data analysis section.

After completing the recall, participants were led through the rest of the survey (Appendix C), including the full 18-question USDA Household Food Security Survey Module (HFSSM) to measure household food security status. Higher scores indicate an increase in events associated with food insecurity, and the resulting score can be analyzed as a continuous measure or used to classify participants into one of four categories. For the adult version of the scale (HFSSM-10), the categories are based on raw scores as follows: High Food Security (0), Marginal Food Security (1-2), Low Food Security (3-5), and Very Low Food Security (6-10). Both the continuous measure and the food security categories were used in the analysis.

Participants were also asked additional questions from the Current Population Survey Food Security Supplement Questionnaire (CPS-FSS) to elicit further information about participant’s ability to access food (USDA 2019; Wunderlich and Norwood 2006). These questions included participation in food programs such as Women, Infant, and Children (WIC) program\(^6\) and SNAP, locations of food expenditures, minimum spending needed to have enough food, and if participants ever ran short of food in the last 30 days and had to try to make their food or money stretch. In addition to these questions from the CPS-FSS, they were also asked about the number of meals eaten, including those eaten at Francis House.

\(^6\) The Women, Infant and Children (WIC) Program provides several benefits, but the main benefit of interest for this dissertation in relationship to assessing an individual’s access to food would be the funds provided for supplementary nutrition for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women.
Adherence to ART

This study used two single self-report indicators of antiretroviral adherence, the Visual Analog Scale (VAS; Amico et al. 2006) and the Self-Rating Scale Item (SRSI; Feldman et al. (2013), to assess adherence and assign participants into categories of adherent and suboptimal adherence (less than 95%). During the administration of the survey, upon reaching the last page, which focused on adherence, we took a moment to explain the upcoming section, using recommendations by Williams and colleagues (2013). Best practices that the authors proposed that were used in this study include: 1) limiting praise for reports of high adherence, 2) conveying that a wide range of adherence experiences is valuable to the research, 3) avoiding the use of additional questions/increased burden for non-adherence, 4) being cautious about the use of negative terms in evaluating adherence, and 5) offering a permission statement (which was used in its entirety - see Appendix C, page 237):

“Taking pills is difficult for a lot of people. It is not uncommon for people to miss doses from time to time. These items/questions ask you about doses you took and doses you missed. Please try to remember as best you can what actually happened and not what you intended to have happen or what you think that other people want you to report. By answering these questions accurately, you are making a big contribution to this research.” (Williams et al. 2013:288)

The Visual Analog Scale asks respondents to estimate their adherence over the previous three to four-week period by marking an “X” on a line\textsuperscript{7} with anchors at 10\% intervals between

\textsuperscript{7} The line for the VAS is typically 10 centimeters long, and a ruler can be used to measure where the mark lies between the 1 centimeter marks to approximate the adherence percentage.
0% and 100%. Similarly, the Self-Rating Scale Item (SRSI) uses Likert scale responses (very poor to excellent) to rate adherence. These ordinal-level measures were chosen because they have performed well when compared to objective adherence measures such as pill counts and pharmacy records, as well as when analyzed against clinical outcomes such as CD-4 and viral load (Feldman et al. 2013; Amico et al. 2006; Finitsis et al. 2016). I also included a five-item index (yes/no responses) from Kalichman and colleagues (2010) to assess common barriers to ART adherence, such as side effects or costs of medicine and transportation issues.

A single measure of self-reported adherence was created by recoding the responses in the SRSI into values of 99%, 95%, 90%, 70%, 60%, and 20% respectively for the categories of excellent to very poor, based on an analysis from Feldman et al. (2013). Once the SRSI Likert response was transformed into a percentage, the transformed SRSI value was averaged with the adherence value reported using the VAS to obtain a single adherence. This single measure was created to address some disagreement between responses to the VAS and SRSI. For example, a respondent marked their SRSI as ‘excellent’ but reported their adherence on the VAS as 50%. This recoding aligned somewhat with reported means within each of the six categories (Table 2), observed in the Feldman et al. 2013 analysis, though responses in this study trended lower, with SRSI means aligning better with the category one rank lower. For example, the VAS mean (95.95%) for those reporting “6 – Excellent” in this study aligned better with proposed values for

- I sometimes run out of my medications before I can get a refill.
- I experience side effects from my antiretroviral medications.
- I cannot afford the cost of medications.
- I was not able to get where I needed to go because I did not have transportation.
- I could not get to a clinic or doctor because I did not have transportation.

Figure 4: Common Barriers to ART Adherence
“5 – Very Good”. Similarly, the VAS mean (90.73%) for those reporting “5 – Excellent” aligned better with the suggested recode value for “4 – Good”. This pattern is observed throughout the responses.

<table>
<thead>
<tr>
<th>SRSI Category</th>
<th>Proposed Recode Value</th>
<th>Actual VAS Mean</th>
<th>Final Recode Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 – Excellent</td>
<td>99%</td>
<td>95.95%</td>
<td>95%</td>
</tr>
<tr>
<td>5 – Very Good</td>
<td>95%</td>
<td>90.73%</td>
<td>90%</td>
</tr>
<tr>
<td>4 – Good</td>
<td>90%</td>
<td>74.06%</td>
<td>70%</td>
</tr>
<tr>
<td>3 – Fair</td>
<td>70%</td>
<td>57.92%</td>
<td>60%</td>
</tr>
<tr>
<td>2 – Poor</td>
<td>60%</td>
<td>25.00%</td>
<td>20%</td>
</tr>
<tr>
<td>1 – Very Poor</td>
<td>20%</td>
<td>0.00%</td>
<td>0%</td>
</tr>
</tbody>
</table>

After determining the adherence category based on the analysis of survey data, individuals were approached for participation in the second phase of the study, which involved discussing participant experiences with food insecurity, including dietary quality.

*Depression, Stress, and Anxiety*

To assess the mental health of participants, this study used established and validated measures of psychosocial stress (Perceived Stress Scale or PSS) and general depression and anxiety (Hopkins Symptom Checklist or HSCL) to better understand the impact of coping with multiple health conditions. The Perceived Stress Scale (PSS) was developed by Cohen in the early 1980s (Cohen 1988; Cohen, Kamarck, and Mermelstein 1983) and has been used to measure stress in people with HIV (Thompson, Nanni, and Levine 1996) and the relationship between perceived stress, coping, and social support (Koopman et al. 2000). The 10-item version of the PSS has responses that range from never to very often, with possible scores from 0-4. To
calculate the PSS-10 score, four positively phrased items must be reversed, then sum all ten items for a possible score range of 0-40. For the PSS, the higher the score, the higher the reported level of perceived stress; a score greater than 20 is considered ‘high stress’ (Kizhakkeveettil et al. 2017; Willert et al. 2009; George and Joseph 2018).

Though there are several versions of the Hopkins Symptom Checklist, the 10-item version (HSCL-10) focuses on assessing symptoms of depression and anxiety and has been shown to be a reliable measure of those issues (Syed et al. 2008). This instrument consists of 10 items that are scored on a 4-point Likert scale, with responses that range from ‘not at all’ to ‘extremely’ to questions about whether or not, in the last week, respondents have felt suddenly scared for no reason, feeling tense or keyed up, feeling blue, and so forth. To calculate the HSCL-10 score, the responses are summed then divided by the number of items (10) for a possible score range of 1-4. Like the PSS, the higher the score, the higher the reported level of depression and anxiety. There is also an established cut-off for dichotomizing the variable; scores > 1.85 indicate mental distress (Søgaard et al. 2003; Strand et al. 2003).

**Socio-Demographic Variables**

Socio-demographic variables collected in the survey included gender, age, race/ethnicity, level of education, work/school status, household income, household composition, and access to stable housing.

**Semi-Structured Interview**

Individuals from Phase 1, divided into categories of adherence/suboptimal adherence, were recruited to participate in face-to-face, semi-structured interviews to explore the day to day
experiences of food insecurity, health and health care access, depression stress and anxiety, and related coping strategies (see the interview guide, Appendix D). Questions were framed using a distancing device, in that they were not initially posed to ask about the respondent directly. Instead, the questions began with the idea that some people face certain issues such as food insecurity and follow up by asking if the respondents are familiar with those issues. If so, do they know people who face such issues. Another follow-up question asks if they would say that they face those issues. Prompts were used to ask participants to talk about these experiences so that participants can lead the discussion about themes they find most salient about that particular issue. The interview also includes questions about potential issues related to ART adherence. These include experiences with the treatment itself, side effects, food-related issues for taking medicines such as skipping meals or difficulty meeting food prescriptions/recommendations), as well as any factors that may make taking ART easier or more difficult, allowing respondents to discuss themes of their choosing. Again, the questions were framed using a distancing device, to minimize potential stigma and allow participants to talk about how “others” might feel in these situations without necessarily endorsing certain potentially “undesirable” behaviors themselves. Finally, following qualitative examples of questions proposed by DeRoche and Lahman (2008) I asked questions about general mental health to explore the sources of anxiety, probing for topics of interest (food security, adherence) if they are not mentioned.

**Data Analysis**

Descriptive statistics were obtained for important variables measuring various domains, including food security, diet quality, depression/anxiety, and perceptions of ART adherence. Microsoft Excel and the statistical software SPSS 25.0 (IBM Corp 2017) were used to analyze
quantitative data. Group differences between optimal and suboptimal adherence were examined using t-tests, chi-square tests, and Mann Whitney U tests. Correlations and logistic regressions were conducted to examine relationships between food security, diet quality, and ART adherence. Prior to conducting the regression analysis, correlational analyses were carried out to examine the relationship between the following variables: HFSSM-10 (Food Security), HEI Total (Diet Quality), HSCL-10 (Depression-Anxiety), PSS-10 (Perceived Stress), Unstable Housing, Disability, and SNAP. To predict adherence to ART, I entered only the variables that were statistically significant from the correlation analysis into the model using a forward stepwise method.

When analyzing the HFSSM, it was important to conduct some analyses that retained all categories of food security levels rather than collapse them. This is because a review of the literature indicated that though the high food security category is often collapsed with the moderate food security category (which is the least severe food insecurity category) research has been shown that moderate food security is associated with poor health outcomes in a way that approximates a dose-response relationship (Cook et al. 2013). That is, moderate food security is related to poorer health outcomes—though not as strongly associated with low or very low food security.

The 24-hour dietary recall provides information about macro- and micronutrients consumed, and the resulting data can be used to create an index of diet quality called the Healthy Eating Index, or HEI. The HEI, developed by the USDA, assesses conformity to federal dietary guidance (Guenther et al. 2013; Kennedy et al. 1995). The index contains 12 components such as total fruit, whole fruit, total vegetables, dark-green vegetables/orange vegetables/legumes, total grains, whole grains, milk, meats, beans, oils, SFA, sodium, and discretionary calories from solid
fats, added sugar, and alcoholic beverages. Possible scores range from 0-100, with higher scores indicating “healthier diet” – that is, one that conforms to federal dietary guidance.

As previously mentioned, dietary data were collected using an in-person multiple-pass method; the online automated method was not used due to concerns about the participant's ability to access and use the online portal. That being said, the ASA24 portal still allows for the easiest method of converting data from a 24-hour recall into 126 different fields of dietary data, including calories, proteins, fats, individual micronutrients, cholesterol, and so forth. Because of this, I created a study in the ASA24 portal, uploaded survey IDs, and obtained unique login and password information. I logged into the participant side of the portal for each individual recall and entered the dietary data using information collected on the paper and pencil form. Once data entry was complete, I logged into the research side of the portal and downloaded the detailed nutritional data files.

The multiple nutrition files obtained for each individual were then converted into the HEI-2010 component scores and total score, using SAS code provided by the NCI. Though there was an updated version of the HEI (HEI-2015) available at the time of dietary data entry, I was required to use the HEI-2010 because the NCI had yet to release SAS code for the HEI-2015. Dietary data from the ASA-24 portal was transformed into twelve food categories that comprise the HEI: total fruit, whole fruit, total vegetables, greens and beans, whole grains, dairy, total protein foods, seafood and plant proteins, fatty acids, refined grains, sodium, and empty calories (Guenther et al. 2013). For the first nine categories, higher scores are awarded for consuming more of those items; the remaining three items are recommended in moderation, so higher scores are awarded for consuming amounts under set thresholds.
With participants’ consent, text-based data from individual interviews were transcribed and entered into MAXQDA 2018 qualitative data analysis software (VERBI Software 2017), which allows for text to be searched, coded, and organized into themes. In addition, quantitative results were entered into MAXQDA 2018 as document variables, to allow for parsing interview themes by key variables of interest, including food security scores and categories, diet quality, mental health measures, sociodemographic data and so forth. The research questions guided the creation of several a priori codes, particular those around domains of food security, food acquisition and diet, adherence, and other topics of interest in the research questions. As the interviews were being analyzed, more codes were inductively added; coding memos and analytic notes were also developed (Russell 2002; Saldaña 2016). Once the codebook had been finalized, all interview texts were reviewed again to ensure all items had been captured.

Ethical Considerations

This study was conducted according to ethical guidelines set by the American Anthropological Association (1998; 2012) as well as the federal policy for the protection of human subjects (Department of Health and Human Services (DHHS) 2016). This project was subject to IRB approval and oversight by the University of South Florida (IRB# Pro00020738; see Appendix E for initial and continuing reviews). Informed consent was sought from all participants who were, at minimum, over the age of 18. The names of participants were collected for the purposes of recording informed consent and receipt of compensation for participating in research, and contact information was collected from participants in case follow up is required. Any identifying or contact information was kept separate from interview and survey data, and a key was created (under a separate file) that linked a numeric ID and participant names and
contact information. The confidentiality of participants in this study is protected by using a numeric code in place of their names in all notes, records, and audio recordings. These items are stored on password-protected computers, in locked cabinets in a locked office, or in otherwise secured conditions. The participants were offered compensation to participate in each stage of the research: the quantitative survey assessing food security, diet quality, adherence, and the qualitative semi-structured interview.

In August of 2016, this study was randomly selected for a routine Quality Assurance/Quality Improvement (QA/QI) Evaluation from a list of USF IRB approved studies. The process review involved a review of this study’s regulatory files and informed consent (IC) documentation, then a quick wrap-up meeting with one study team member (Noble) to discuss initial findings from the visit. Though there were issues found with incomplete dates, with the researcher completing the printed names of participants, and errors in dating IC forms (see Appendix F for report findings), all issues were deemed minor and we were advised to add descriptions of them and corrective action plans to the minor deviations log for the study. The review of the study was successfully completed on February 16, 2017 (see Appendix G).

Individuals who had become visibly upset during the informed consent process (n=2) or qualitative interview (n=1) were asked if they wanted to stop the survey or interview, with no penalty for doing so. None of the participants chose to stop the survey or interview. I describe these three events, and how they were resolved in Appendix H. In all three events, participants were referred to mental health services available from Francis House.
CHAPTER 5: FOOD SECURITY

Chapter Five presents the findings for research questions 1 and 5. This chapter will begin by describing the study sample, then describe the food security and dietary quality status of all study participants, using quantitative and qualitative data. I will also provide an overview of themes related to food-related challenges, as well as the coping strategies used by participants to ameliorate these issues.

Research Questions:

1. What is the food security level and diet quality of participating clients enrolled in a special services program?

5. What coping strategies are utilized by participants to ameliorate issues related to food insecurity and diet quality?

Socio-Demographics

As noted in the methods chapter, 131 individuals were recruited from Francis House to participate in this study. Because of the nature of the services that Francis House provides in addition to clinical case management (food pantry, hot and cold breakfasts, hot lunches), we can expect that many of the individuals who are on-site on a regular basis may be in need of these services; thus, their socioeconomic status may be skewed towards lower incomes and other associated measures. These data are summarized in Table 3.
Table 3: Characteristics of Study Population

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total (N=131)</th>
<th>Range (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean</td>
<td>48.91</td>
<td>22-80 (9.72)</td>
</tr>
<tr>
<td>Years on ART, mean</td>
<td>12.94</td>
<td>0.5-32 (8.20)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>50.4%</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>48.9%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0.8%</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>64.9%</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>21.4%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>9.2%</td>
<td></td>
</tr>
<tr>
<td>American Indian</td>
<td>0.8%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3.8%</td>
<td></td>
</tr>
<tr>
<td>Years of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>31.3%</td>
<td></td>
</tr>
<tr>
<td>High School Graduate, GED</td>
<td>31.3%</td>
<td></td>
</tr>
<tr>
<td>Some College (1-3 years)</td>
<td>28.2%</td>
<td></td>
</tr>
<tr>
<td>College (4+ years)</td>
<td>8.4%</td>
<td></td>
</tr>
<tr>
<td>Work Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>61%</td>
<td></td>
</tr>
<tr>
<td>Unemployed, Not Student</td>
<td>21.4%</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>5.3%</td>
<td></td>
</tr>
<tr>
<td>Employed Part-Time</td>
<td>3.8%</td>
<td></td>
</tr>
<tr>
<td>Employed Full-Time</td>
<td>3.1%</td>
<td></td>
</tr>
<tr>
<td>Self-Employed</td>
<td>2.3%</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>2.3%</td>
<td></td>
</tr>
<tr>
<td>Stable Housing</td>
<td>67.2%</td>
<td></td>
</tr>
<tr>
<td>Monthly Income, mean</td>
<td>$786</td>
<td>$0-3,333 (SD 543)</td>
</tr>
</tbody>
</table>

The gender of those individuals who participated in this study was roughly the same for males and females, with 0.8% opting not to answer this question. The average age of participants was 49 years, with more than half of the sample being aged 44-55 years of age. Participants predominantly identified as Black/African American. Roughly a third of the study population
each reported receiving less than a high school education (31%), completing high school or GED (31%), or attending some college (28%), while 8% attended college for four or more years. About one-third of study participants describe themselves as lacking access to stable housing; that is, residing in a hotel, boarding house, group home, being homeless or having no fixed address.

The average monthly income of study participants was $786, with 50% of participants having a monthly income between $680 and $976. The most frequently given number for monthly income was $733 (21%); this number was frequently cited as the amount that an individual would receive while ‘on disability,’ which some participants identified as “SSD” (Social Security Disability; n=3), or “SSI” (Supplemental Security Income; n=5), though most simply referred to it as disability. More than half of the sample (61%) reported their work status as ‘on disability,’ with an average household income of $921/month. Those who reported working full- or part-time made an average of $919 per month; part-time averaged $776 per month, and full-time $1,300 per month. Those who reported being undergraduate or graduate students had an average monthly income of $333, while those who were neither employed nor a student (but not retired) averaged $295 per month. Lastly, those who indicated that they were retired averaged a monthly income of $1,161. Regardless of work status, 47% report that their income does not cover basic living expenses. The average household size was 1.8 people, ranging from one to ten individuals within the household who were related to the participant or not (SD 1.45), with the majority of households having 1-2 individuals.
Food Security

As part of the quantitative survey, all participants responded to a series of ten questions that assessed their food security status over the last 12 months. The additional eight questions in the full HFSSM scale apply only to households with children. Table 4 reports one summary of the results of the HSFFM survey, which is the percentage of households who responded ‘yes’ that the food security event occurred at least sometimes (if not often) in the last year. Questions 5 and 9 were eliminated from this table of affirmative responses, as those questions ask participants to report how frequently the previous item had occurred. For example, question five asks: “If yes to the previous question, how often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?”

<table>
<thead>
<tr>
<th>HFSSM Questions</th>
<th>% Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>We worried whether our food would run out before we got money to buy more.</td>
<td>58.78%</td>
</tr>
<tr>
<td>The food that we bought just didn’t last, and we didn’t have money to get more.</td>
<td>51.15%</td>
</tr>
<tr>
<td>We couldn’t afford to eat balanced meals.</td>
<td>51.91%</td>
</tr>
<tr>
<td>Did you or other adults in the household ever cut the size of your meals or skip meals because there wasn’t enough money for food?</td>
<td>47.33%</td>
</tr>
<tr>
<td>Did you ever eat less than you felt you should because there wasn’t enough money for food?</td>
<td>45.80%</td>
</tr>
<tr>
<td>Were you ever hungry, but didn’t eat, because there wasn’t enough money for food?</td>
<td>32.06%</td>
</tr>
<tr>
<td>Did you lose weight because there wasn’t enough money for food?</td>
<td>28.24%</td>
</tr>
<tr>
<td>Did you or other adults in your household ever not eat for a whole day because there wasn’t enough money for food?</td>
<td>22.90%</td>
</tr>
</tbody>
</table>
As expected from research on the development of the HFSSM, the observed responses reflect the idea that these food security events increase in severity, ideally seeing lower affirmative responses for later questions. Nearly 60% of participants report being worried that food would run out before they had money to get more over the last year, and almost 23% of individuals reported that they, or someone in their house – at some point in the last year – did not eat for a whole day because there was no money for food.

All individuals answered the first 10 questions in the HFSSM scale, which yields a food security score of 0-10 for all adults in the households reported on by the study population. As the score increases, the food security situation is worse. The mean of this continuous (ordinal) score is reported in Table 5 by demographics variables, to see where food security status may differ by these characteristics. None of the differences below were found to be statistically significant.

Though not statistically significant, food security status does vary by gender, with females report slightly higher levels of food security (3.72) than males in the study (4.09). Participants who self-identified as White or Hispanic had very similar HFSSM means (4.79 and 4.75 respectively) though those who identified as Black reported higher food security scores (3.78). Food security status also varied by education, with those having completed some college reporting higher levels of food insecurity (5.32) than any other educational status. Those with less than a high school education reported the highest food security status (3.15).

In terms of work status, students (6.00), those employed part-time (5.80), and those who were unemployed (5.32) reported the highest levels of food insecurity. Those who indicated that they did not have access to stable housing reported higher levels of food insecurity (4.55 compared to 3.69 for those with stable housing), though again, none of these differences were statistically significant.
Table 5: HFSSM Score by Demographic Variables

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total (N=131)</th>
<th>HFSSM Score (Mean)</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>50.4%</td>
<td>4.09</td>
<td>3.54</td>
</tr>
<tr>
<td>Female</td>
<td>48.9%</td>
<td>3.72</td>
<td>3.74</td>
</tr>
<tr>
<td>Other</td>
<td>0.8%</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>64.9%</td>
<td>3.78</td>
<td>3.56</td>
</tr>
<tr>
<td>White</td>
<td>21.4%</td>
<td>4.79</td>
<td>3.93</td>
</tr>
<tr>
<td>Hispanic</td>
<td>9.2%</td>
<td>4.75</td>
<td>3.44</td>
</tr>
<tr>
<td>American Indian</td>
<td>0.8%</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>3.8%</td>
<td>1.33</td>
<td>2.04</td>
</tr>
<tr>
<td>Years of Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>31.3%</td>
<td>3.15</td>
<td>3.32</td>
</tr>
<tr>
<td>High School Graduate, GED</td>
<td>31.3%</td>
<td>3.63</td>
<td>3.84</td>
</tr>
<tr>
<td>Some College (1-3 years)</td>
<td>28.2%</td>
<td>5.32</td>
<td>3.49</td>
</tr>
<tr>
<td>College (4+ years)</td>
<td>8.4%</td>
<td>3.55</td>
<td>3.75</td>
</tr>
<tr>
<td>Work Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>61%</td>
<td>3.58</td>
<td>3.64</td>
</tr>
<tr>
<td>Unemployed, Not Student</td>
<td>21.4%</td>
<td>5.32</td>
<td>3.74</td>
</tr>
<tr>
<td>Retired</td>
<td>5.3%</td>
<td>2.14</td>
<td>2.73</td>
</tr>
<tr>
<td>Employed Part-Time</td>
<td>3.8%</td>
<td>5.80</td>
<td>3.36</td>
</tr>
<tr>
<td>Employed Full-Time</td>
<td>3.1%</td>
<td>3.50</td>
<td>3.51</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>2.3%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Student</td>
<td>2.3%</td>
<td>6.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Stable Housing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>67.2%</td>
<td>3.69</td>
<td>3.61</td>
</tr>
<tr>
<td>No</td>
<td>32.8%</td>
<td>4.55</td>
<td>3.66</td>
</tr>
</tbody>
</table>

In the study sample, only 10 participants (7.7%) reported having at least one child in the house. The mean HFSSM score for households with children was 7.5/18 (Range 0-16; SD 5.70), which would be categorized as ‘low food security.’ Sixty percent of households with children scored between 8 and 16 (out of 18 total points possible), placing them in the ‘very low food
security’ category. Households without children had an average HFSSM score of 3.80/10 (Range 0-10; SD 3.59), which would also place them in the ‘low food security’ category as a whole.

Of the forty-five interviews conducted for this study, three of them were with women whose households had children. In all three cases, the women were living alone with their children, regardless of the stability of their housing status. In all three interviews, these mothers identified ways that their food security status (HFSSM scores ranging from 6-9) affected both themselves and their children, including trying to meet children’s food preferences, ensuring they have enough, and the mother triaging her children’s food needs above her own.

I can control my own food here, as long as I can put it in my basket in the fridge or can keep it in my room. I do things like buy that almond milk that’s in the small cartons? Those are good on the shelf, then when you open it, you can put it in the fridge. But the kids, they don’t like some of the things they cook here, so sometimes I gotta keep stuff in our room for them. Stuff you can microwave or toast. Stuff they might want to eat.

-Interview #33

Shopping for food is always a trick. Me, my go-to protein is eggs...and chicken. Chicken wings – they used to be so cheap! Now after that shortage – salmonella or something? – now they’re $4 a pound. But I get what I can, and my son is like, chicken again? I’m tired of chicken, he says. Look, you gotta be appreciative, okay? It’ll be hard for me if they cut them (food stamps) back. But I do try to get little things for them – for after school, you know? But I count them out – no seriously! Thirty things of this, thirty things of that. Hide stuff at the back of the tall cabinet. So, we can space it out. When I get coupons, I can get
them some good stuff. Every once in a while, a $5 pizza. They’re like, mommy – you want some pizza? Naw baby, it’s okay. I need to lose some weight anyway.

- Interview #7

Respondent: I got three kids, but as they get older, they get hungrier.

Interviewer: What does that look like?

Respondent: Bigger portions, and then they want seconds. I get the meat plan for $90, and I try to make it last for the month, but it only lasts like two weeks. I try to spend only half, and I don’t eat. I get something at Francis House. So, I spend half, save half for the second half of the month. Once you get in that store, all my kids want something there, put their stuff, they want their own, they don’t want it, sometimes they don’t want to eat what I made.

Interviewer: What kinds of things are they asking for?

Respondent: [laughs] Lunchables, Cheese-Its…Lunchables, and cheese sticks and pudding and fruit cocktail, applesauce. They like to heat things up themselves so you can…so I provide it for them, but sometimes it just pulls so much more dollars, you know? It just does.

- Interview #39

Interviewer: Okay. Often times people will say, when they don’t have enough food, they have to change the way they shop; like maybe they shop in different places, or they buy different foods. Do you think that's something that you've had to do?
Respondent: Yeah.

Interviewer: What changes do you think you’ve made?

Respondent: I go and tried to do the list, and I tried to get what we need. Sometimes, I try to double up on what we need like if we had mayonnaise or soap, I like to put one in the cabinet so that one stays until that runs out. So, we buy two mayonnaises and hot sauce, my kids love hot sauce, so I have to buy like three bottles of that. It goes pretty much on the little doodads, the money goes on stuff you’re not eating, it’s stuff you’re eating with - like sauces, might have brought those pickles.

Interviewer: Do you have any tips or tricks for getting your family through those last two weeks like, how do you manage to get through those last two weeks?

Respondent: Sometimes, we don’t eat.

Interviewer: Sometimes, you don’t eat.

Respondent: I’ll buy a lot of lunch meat - I buy a lot of those baloney, turkey, cheese and I buy a lot of that, so if I’m not cooking, they eat that. And they do get tired of that, but you know that’s how it is. It’s food.

Interviewer: So, in those last two weeks, the kids might be eating sandwiches?

Respondent: Sandwiches.

Interviewer: And you said earlier, you will skip a meal.

Respondent: I’ll skip a meal. I’ll cook it, and I’ll still skip it.

Interviewer: To make sure that there’s leftovers for the next day?

Respondent: For them.
**Interviewer:**  Okay. What do you think…do you think your kids know that? Why you're skipping meals?

**Respondent:**  No, they don't. They're not aware of that. They just know that sometimes, I don't wanna eat.

**Interviewer:**  They don't know why.

**Respondent:**  No, they don't know why.

- Interview #39

Though total HFSSM scores differ for households with adults only versus those with children, both household types can be assigned a food security category based on how they responded to the scale questions. Figure 5 summarizes the distribution of food security levels for the study population. Though nearly a third of the sample can be categorized as having high food security, this means that the remaining 70% experience at least some level of food insecurity. This would include experiences such as worry about having enough food or money for food, eating less or different kinds of food than you want or feel that you need, skipping meals, and even potentially not eating for a full day.
Access to Food

As part of the survey, participants were asked additional questions about their access to food, including the use of WIC and SNAP, where they have shopped for food in the past week, whether they feel they have sufficient resources to meet their food needs, and how often they eat meals, including meals eaten at Francis House. Table 6 shows that very few of the participants were receiving WIC benefits (3.05%), but as previously mentioned, only ten households reported having children. However, a large majority (72%) used SNAP in the last 30 days. Even with this high participation in SNAP, 60% of participants still reported that in the last 30 days, they had run short of money and had to try to make their money or food stretch. Participants were asked whether they felt that they needed to spend more to meet their family’s food needs, or could they spend less; those who responded ‘yes’ further indicated that they would need an average of $50 more per week to meet their household’s needs.
Table 6: Affirmative Responses to Other Food Access Questions (n=131)

<table>
<thead>
<tr>
<th>Other Food Access Questions</th>
<th>% Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last 30 days, did you or any member of your household receive benefits from the WIC program—that is, the Women, Infant, and Children program?</td>
<td>3.05%</td>
</tr>
<tr>
<td>In the last 30 days, did you or any member of your household receive benefits from the SNAP program—that is, the Supplemental Nutrition Assistant Program, formerly known as the food stamp program?</td>
<td>71.76%</td>
</tr>
<tr>
<td>In the last 30 days, did you ever run short of money and try to make your food or your food money go further?</td>
<td>60.31%</td>
</tr>
</tbody>
</table>

Among the interviews conducted for the study, 82% (n=37) had reported receiving SNAP at the time of their survey. However, during the interviews, 7% (n=3) reported interviews that they had acquired SNAP since we last spoke, another 7% (n=3) had experienced reductions in the amount they received, and 4% (n=2) lost SNAP altogether. Due to the sequential study design, the average gap between the initial survey and interview dates was 98 days (Range 10-175 days; SD 53.35).

When asked about where they have shopped for food in the last week, 65% indicated that they had shopped in a supermarket, and 48% had shopped in another type of food store, such as a meat market, produce stand, bakery, or warehouse club. Similarly, about 44% had shopped for food in a restaurant, fast food place, cafeteria, or vending machine, while 15% reported buying food from other places, such as dollar stores, a roadside hot food stand, or a hospital.
Participants frequently reported a sort of hierarchy in terms of the stores that were accessible to them, as well as comment on the desirability of such stores. Overwhelmingly, Publix was viewed as not affordable, even with their buy one, get one free deals. Walmart is frequently compared with Publix as a more affordable option, but one that may be harder to get to. This hierarchy continues through stores like Winn-Dixie (which merits shoppers points to apply to discounts for gas), Save-A-Lot and Aldi (less selection but cheaper) and dollar stores.

- Now we do a Publix near me, but Publix can be high for certain products. (Int #8)
- I usually prefer Wal-Mart, but Publix do have BOGO. But you gotta work with what they have on the week (Int #11)
- So, I was like, "No, Publix is too high. They try to tell me where the Publix is, but that's too high. Even if you do the coupons and the buy one and get one, it's still too high. I was like, "Wal-Mart's more better than Publix but in a different way?" (Int #5)
- Publix good too, but ooh! It's too expensive. (Int #10)

A key strategy that participants reported using as well as recommending to others was purchasing a meat plan at a local market instead of buying at a large supermarket or retail store. One-third of interview participants (n=15) mentioned purchasing a set-priced selection of meats from about $32 to $120 dollars, consisting of items such as ground beef or cube steaks, chicken wings or leg quarters, turkey legs, oxtails, Uncle John’s sausages, pork steaks, with the intention of trying to make the meat plan last for the full month. The variety and prices of plans available can be wide; one flyer that a participant passed along to me listed 13 different options, but plans were numbered as high as ‘Plan #26.’ Certain plans also provided ‘free’ items, such as free canned goods, gallon-sized juice, or extra meats for the more expensive plans.
Experiences of Food Insecurity

Themes that emerged as people spoke about their experiences with food insecurity align closely with what has previously been reported in the literature. Respondents who reported changes in their SNAP also talked about the impact this change had on their intake, from reductions in quality and number of meals to increases in access to food if they obtained food stamps.

"Because I don’t eat three meals a day. I don’t, and I’m supposed too. Why? Because I don’t have the food. They just cut my food stamps down to $67. I’d like to know how they want me to live on $67 worth of food stamps."

- Interview #24

"I was getting $194 in food stamps - that means that I was eating lovely. Now I don’t know how I’m going to do for December. I wanted it-- I’m not going to be reduced to eating cat food. It needs to be a set price for everything. If you are going to give $194, give $194."

- Interview #17

"Yeah, because they were $98, and then it went down to $96. Now they're going down to $81. And I don’t know why. There's no change in my rent, my nothing. Nothing has changed, and I don’t understand why they went down on me. Every time, I gotta get used to eating just a little less."

- Interview #16
Well, like I told you before, I was struggling because I was on the streets and trying to get and make ends meet and go to soup kitchens and make it to one place to another. But everything has changed a little bit now because my food stamps were approved. I am staying on somebody’s couch, and he’s letting me cook and prepare my meals, and it becomes a lot easier that I can hold stuff, you know, without it going bad. You know, I got a refrigerator, there’s food and a stove to cook it in. Making up food for the day and some for later like lunch or the next day and that’s been working out better I mean, it’s less stressful and all that. Not having to worry about where my next meal is coming from or what you’re going to have whether you like it or not.

-Interview #11

I just got food stamps, and while I didn’t get the whole amount that I thought I would, I did get something. I can actually shop for food.

- Interview #7

While this section focuses primarily on the experience of food insecurity and how households access food, as is already apparent from some of these quotes, the impact of food insecurity has broader implications for food safety, as well as mental health. These themes will be explored in later sections.

**Diet Quality**

As indicated in the methods section, as part of the survey, participants were guided through a 24-hour dietary recall to assess the diet quality of the group as a whole, as well as
subgroups of interest. The primary variables of interest for this dissertation were the overall intake (calories) as well as the Healthy Eating Index, which provides a 0-100 score for how closely participants adhere to dietary recommendations from the Dietary Guidelines for Americans. This section will also provide narratives about the experiences of diet quality derived from participant interviews.

*Healthy Eating Index*

The results of the transformation of dietary data into the Healthy Eating Index (HEI) are summarized in Table 7. In this table, we can see that as a whole, participants consumed roughly 2000 calories a day, with high variation in consumption – from no intake the previous day for one participant, to over 4,000 calories for another. About 50% of participants consumed between 1200 and 2700 calories, bearing in mind that the caloric needs of individuals in this group will vary by their body size, metabolism, disease state, and other factors.

The average HEI for the group is 41.02, which is lower than the national average for Americans (59)\(^8\). Scores equal to or under 50 are characterized as having ‘poor’ diet quality, while those with scores between 51 and 80 would be characterized as ‘needing improvement.’\(^9\) Again we see a wide variation in the total HEI score, with the range for the 25-75% quartiles being from about 32-49 – still indicative of diets in need of improvement.

A closer examination of the individual components can provide additional information about dietary components that contribute to these scores. For example, this group of participants seems to be consuming adequate total protein based on the scores for HEI 7, Total Protein. The lowest mean component scores include seafood or plant proteins (HEI 8; mean 1.29 out of 5),


green vegetables and beans (HEI 2; mean 1.32 out of 10), whole grains (HEI 5; mean 1.37 out of 10), as well as whole fruit (HEI 4; mean 1.49 out of 5), and total fruit (HEI 3; mean 1.50 out of 5). If we look at the median for these five items, three of them (greens and beans, whole fruit, whole grain) have zero as the measure of central tendency, with the other two (total fruit, and seafood/plant protein) having a median only slightly over zero. Also notable are the scores on the last three components, sodium (HEI 10), refined grains (HEI 11), and empty calories (HEI 12). For these, low scores for these items that should be eaten in moderation mean that as a group, participants exceeded the recommendations for these measures of diet quality.

Table 7: Healthy Eating Index

<table>
<thead>
<tr>
<th>Dietary Components</th>
<th>MAX Score</th>
<th>Mean</th>
<th>Median</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
<th>25-75% quartile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Calories</td>
<td>n/a</td>
<td>2013.02</td>
<td>1891.8</td>
<td>985.5</td>
<td>0</td>
<td>4437</td>
<td>1266.41-2670.87</td>
</tr>
<tr>
<td>HEI Total Score</td>
<td>100</td>
<td>41.02</td>
<td>39.71</td>
<td>14.16</td>
<td>0</td>
<td>80.85</td>
<td>31.98-48.92</td>
</tr>
<tr>
<td>HEI 1 Total Veg</td>
<td>5</td>
<td>2.67</td>
<td>2.68</td>
<td>1.69</td>
<td>0</td>
<td>5</td>
<td>1.32-4.24</td>
</tr>
<tr>
<td>HEI 2 Greens, Beans</td>
<td>5</td>
<td>1.32</td>
<td>0.00</td>
<td>2.09</td>
<td>0</td>
<td>5</td>
<td>0.00-3.09</td>
</tr>
<tr>
<td>HEI 3 Total Fruit</td>
<td>5</td>
<td>1.50</td>
<td>0.39</td>
<td>1.86</td>
<td>0</td>
<td>5</td>
<td>0.00-3.02</td>
</tr>
<tr>
<td>HEI 4 Whole Fruit</td>
<td>5</td>
<td>1.49</td>
<td>0.00</td>
<td>2.09</td>
<td>0</td>
<td>5</td>
<td>0.00-3.90</td>
</tr>
<tr>
<td>HEI 5 Whole Grain</td>
<td>10</td>
<td>1.37</td>
<td>0.00</td>
<td>2.57</td>
<td>0</td>
<td>10</td>
<td>0.00-1.69</td>
</tr>
<tr>
<td>HEI 6 Total Dairy</td>
<td>10</td>
<td>2.84</td>
<td>2.06</td>
<td>2.94</td>
<td>0</td>
<td>10</td>
<td>0.20-1.69</td>
</tr>
<tr>
<td>HEI 7 Total Protein</td>
<td>5</td>
<td>4.46</td>
<td>5.00</td>
<td>1.30</td>
<td>0</td>
<td>5</td>
<td>4.93-5.00</td>
</tr>
<tr>
<td>HEI 8 Seafood, Plant Protein</td>
<td>5</td>
<td>1.29</td>
<td>0.03</td>
<td>1.99</td>
<td>0</td>
<td>5</td>
<td>0.00-2.30</td>
</tr>
<tr>
<td>HEI 9 Fatty Acids</td>
<td>10</td>
<td>5.01</td>
<td>4.98</td>
<td>3.55</td>
<td>0</td>
<td>10</td>
<td>2.09-8.55</td>
</tr>
<tr>
<td>HEI 10 Sodium</td>
<td>10</td>
<td>3.11</td>
<td>1.70</td>
<td>3.42</td>
<td>0</td>
<td>10</td>
<td>0.00-5.72</td>
</tr>
<tr>
<td>HEI 11 Refined Grain</td>
<td>10</td>
<td>5.52</td>
<td>6.26</td>
<td>3.97</td>
<td>0</td>
<td>10</td>
<td>1.24-9.94</td>
</tr>
<tr>
<td>HEI 12 Empty Cals</td>
<td>20</td>
<td>10.42</td>
<td>10.46</td>
<td>5.88</td>
<td>0</td>
<td>20</td>
<td>5.84-14.78</td>
</tr>
</tbody>
</table>

109


Experiences of Low Diet Quality

In previous quotes about food security and experiences with SNAP, participants have identified concerns about reductions in diet quality, such as fears that they will be reduced to eating cat food or needing to switch to sandwiches in the second half of the month. But participants also have concerns about other aspects of diet quality, including their access to healthier foods, fruits and vegetables, and processed foods. These quotes also demonstrate that participants are aware of the potential health outcomes related to their diets and highlight their struggles with making ‘the right choices.’

Sometimes I don't eat as much vegetables like I should. But I try. Might have to get canned something. Fresh – huh. And meats. I love meats, but you know. Meat's kind of expensive right now.

- Interview #10

Interviewer: The way your food situation is, do you feel like it affects your health?

Respondent: Yeah, yeah, that’s a given, it does affect my health.

Interviewer: How does it affect your health?

Respondent: Okay, they said alright when you are living with this situation (HIV), it is just like fruits, vegetables, that’s why people have high blood pressure, cholesterols, and that’s ‘cause they are not getting the stuff that they really need. Not just for me, what I’m saying what I mean for anybody. If you are poor in America, you are fucked. Simple as everything. Thank God for a couple of years, I had high cholesterol or like high blood pressure, and you know, that and this? They coexist.

- Interview #45
It is, it's hard. Having all that food is, it's hard. You notice all the healthy foods cost more. I'm expected to lose weight, and it's just, to me, that's crazy. Make it easier for me, yea? Okay? That's the struggle with the healthy food part. Even if you want to make the right choices, it's so hard to.

- Interview #7

We need healthier food banks. And give me a box of Tagalongs since they're from - sure, so I'm going to gain 40-50 pounds. And I'm going to be like, [sighs] because it doesn't give you energy. It gives you an instant burst, and then you crash. That's not cool. Vegetables, fresh fruit, fresh leafy greens, lettuce, tomatoes, onions, bell peppers, carrots, things that people can eat, just hand it to them. Rinse it off into the water, they eat it. I would like to see this pantry get a cooler. So, our people could donate ham steaks, the flat ones that are these thick. And their round. That's true meals. Or two sandwiches, a ham salad, and you're good. I don't think they could handle it.

- Interview #24

**Coping with Food Insecurity**

As previously indicated, the HFSSM is written around increasingly severe food security events, beginning with worry about having enough food through statements that describe common food-security related coping strategies, such as reductions in food quality and quantity. In addition, some of the participants’ experiences reviewed in the previous section also highlight coping strategies such as reducing quality or diversity of their diet, eating or buying less, and triage among household members – with mothers typically sacrificing their own intake for
children in the household. In other quotes, participants discuss their reliance on others such as family members; one participant has a brother who obtains and prepares food for him, while another asks her sister if she can help out with food when she can. As that same quote demonstrates, people need to be careful with these requests to lean on others; in that particular case, she recognizes that her sister is trying to feed four children of her own and so she can only do so much.

This issue seems of less concern when relying on others in the sense of various charities and food distribution options. Participants often rely on more than one location/organization for obtaining food donations; in some cases, respondents have a routine to visit different places on certain days of the week or month. In a few cases – because of the strain that people are under in trying to obtain enough food – we can see frustration and anger that organizations are not doing more. During interviews, nearly a third (31%) mentioned without prompting that one potential source of supplementary food – the Francis House food pantry - was frequently empty and had been for some time.

Reliance on these coping strategies results in varying levels of success. There were participants who reported worry about having enough food but had time and access to transportation, which allowed them to utilize resources in the community to the degree that a small minority (three individuals) reported having enough of a surplus at home that they could share with others. There were a few individuals who even used the words ‘hoarding’ to describe the surplus of food in the home. During a survey, one participant revealed that due to having spent some time on the street and struggling with having enough food, they now had a room in their house where they hoarded canned goods and other non-perishable foods that they could collect from various food distributions. These foods, the participant said, provide insurance
against future scarcity. Their current situation was not a stable one; they still struggled with covering their rent, paying for utilities and other bills, having enough cash to purchase fresh foods such as meats and milk. But collecting the available non-perishables and ‘lining the walls’ of a hallway with these goods provided a sense of security that they would always have something to eat.

Despite several participants listing the numerous places that they could obtain food on multiple days of the week, other participants described the barriers to utilizing these resources. Five participants noted that while they had heard about food distributions, it was difficult to travel to locations without their own transportation, and even if they used public transportation – they would have to carry a box of food on the bus. These same barriers were highlighted when discussing shopping at cheaper large retail stores like Wal-Mart. One participant even remarked that he had seen people walk down to the park and use wagons, put food in baskets on bikes, or even travel in wheelchairs, balancing food boxes on their knees. This example was used to illustrate that some people are willing to do what they need to in order to get food; anyone who was not willing to do these things was ‘lazy.’

*There’s too much being handed out on any corner in this neighborhood. If you’re hungry in this town, that’s your own fault. Well, they know about these things. They know. They are just lazy. They don’t wanna get up, that’s what I think.*

- Interview #31
Summary

Participants in this study face varying levels of food security, with the largest groups being represented at both ends of the spectrum – 30% experiencing high food security, and 35% very low food security. Regardless of food security scores or categories, overall, the dietary quality of respondents is low and in need of improvement, characterized by low consumption levels of key healthy foods and higher levels of consumption for empty calories, sodium, and refined grains. Nearly three-quarters rely on SNAP to supplement their food purchases, though 60% reported that the amount they receive is not sufficient to meet their household needs.

Further, 11% of the interview group reported a reduction or loss in SNAP supports between the time of their survey and their interview, as well as the experience of precarity that accompanies such changes. However, another 7% gained access to SNAP between the two time points; those respondents indicated an increase in their ability to purchase and consume foods as a result of that change. Many participants exhibit attempts to manage food security difficulties through strategies well attested to in the literature, reducing the quality and quantity of foods consumed, triaging food consumption to buffer children, relying on others such as family or charitable organizations, or reallocating resources. These coping strategies are not unique to PLWH; as we will see in subsequent chapters, they simply add another layer of complexity to their lived experiences with HIV.
Chapter 6 presents the research findings related to ART adherence (research questions 2 and 4). This chapter first describes the characteristics of the sample based on their assignment to adherence categories, then reviews the HIV status of study participants, including years receiving ART, and common barriers to ART adherence. Then, using correlations and mixed methods displays of quantitative and qualitative data, this chapter will describe the relationship between ART adherence and food security.

Research Questions:

2. What is the relationship among ART adherence, food security status, and dietary quality?

4. How does the lived experience of food insecurity and diet quality vary by adherence to ART?

Socio-Demographics

I start by presenting the socio-demographic information for this study sample, but this time parsed by the adherence status calculated from the two self-report items, the VAS and SRSI. Table 8 shows that there are no statistically significant differences between the socio-demographic variables for these two groups. However, there is a trend with more than a 13% difference between the housing status of the two groups.
<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total (N=131)</th>
<th>Adherent (N=71)</th>
<th>Non-Adherent (N=60)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>48.91 (9.72)</td>
<td>48.90 (9.70)</td>
<td>48.92 (9.82)</td>
<td>.993</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td>.332</td>
</tr>
<tr>
<td>Male</td>
<td>50.4%</td>
<td>47.89%</td>
<td>53.33%</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>48.9%</td>
<td>52.11%</td>
<td>45.00%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0.8%</td>
<td>-</td>
<td>1.67%</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity</td>
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<td></td>
<td></td>
<td>.888</td>
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<tr>
<td>Black</td>
<td>64.9%</td>
<td>60.56%</td>
<td>70.00%</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>21.4%</td>
<td>22.54%</td>
<td>20.00%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>9.2%</td>
<td>11.27%</td>
<td>6.67%</td>
<td></td>
</tr>
<tr>
<td>American Indian</td>
<td>0.8%</td>
<td>1.4%</td>
<td>0.00%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3.8%</td>
<td>4.23%</td>
<td>3.33%</td>
<td></td>
</tr>
<tr>
<td>Years of Education</td>
<td></td>
<td></td>
<td></td>
<td>.543</td>
</tr>
<tr>
<td>Less than High School</td>
<td>31.3%</td>
<td>35.21%</td>
<td>26.67%</td>
<td></td>
</tr>
<tr>
<td>High School Graduate, GED</td>
<td>31.3%</td>
<td>32.39%</td>
<td>30.00%</td>
<td></td>
</tr>
<tr>
<td>Some College (1-3 years)</td>
<td>28.2%</td>
<td>23.94%</td>
<td>33.33%</td>
<td></td>
</tr>
<tr>
<td>College (4+ years)</td>
<td>8.4%</td>
<td>5.63%</td>
<td>10.00%</td>
<td></td>
</tr>
<tr>
<td>Work Status</td>
<td></td>
<td></td>
<td></td>
<td>.399</td>
</tr>
<tr>
<td>Disabled</td>
<td>61%</td>
<td>69.01%</td>
<td>50.00%</td>
<td></td>
</tr>
<tr>
<td>Unemployed, Not Student</td>
<td>21.4%</td>
<td>14.08%</td>
<td>31.67%</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>5.3%</td>
<td>7.04%</td>
<td>3.33%</td>
<td></td>
</tr>
<tr>
<td>Employed Part Time</td>
<td>3.8%</td>
<td>2.82%</td>
<td>5.00%</td>
<td></td>
</tr>
<tr>
<td>Employed Full Time</td>
<td>3.1%</td>
<td>1.41%</td>
<td>5.00%</td>
<td></td>
</tr>
<tr>
<td>Self-Employed</td>
<td>2.3%</td>
<td>4.23%</td>
<td>0.00%</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>2.3%</td>
<td>1.41%</td>
<td>3.33%</td>
<td></td>
</tr>
<tr>
<td>Years on ART, mean (SD)</td>
<td>12.94 (8.20)</td>
<td>13.00 (8.46)</td>
<td>12.87 (7.95)</td>
<td>.926</td>
</tr>
<tr>
<td>Stable Housing</td>
<td>67.2%</td>
<td>73.24%</td>
<td>60.00%</td>
<td>.140</td>
</tr>
</tbody>
</table>

**Adherence to ART**

This study used two single self-report indicators of antiretroviral adherence, the Visual Analog Scale (VAS) and the Self-Rating Scale Item (SRSI). Participants were also asked to
respond to questions about their access to care, both in the form of survey items as well as interview questions to assess their experiences with care. The findings from these items are summarized below.

**Adherence by Self-Rating Scale Item**

Participants were asked to report a self-assessment of the ability to take all of their HIV medications as prescribed over the previous four weeks. Possible responses to this question fell along a Likert scale from very poor (1) to excellent (6). Again, it should be noted that participants were first offered a ‘permission’ statement, indicating that it is understood that taking medications is difficult for a lot of people, but that by answering accurately they would be making a big contribution to better understanding people's experiences with taking antiretroviral medications.

For the full study sample, the mean SRSI score was 5 (very good; Range 1-6, SD=1.23). Nearly half (47.3%) reported ‘excellent’ adherence, with 26% reporting ‘very good,’ 12.2% ‘good,’ 9.2% ‘fair,’ 4.6% ‘poor,’ and 0.8% indicated ‘very poor.’ Based on the average of the two self-report items described in Chapter 4, those assigned to the optimal adherence group had an average SRSI score of 5.67 (Range 1-6; SD 1.31) while those assigned to the suboptimal group had an average of 4.20 (Range 4-6, SD 0.58).

**Adherence by Visual Analog Scale**

Additionally, participants were asked to self-assess their ‘best guess’ of how much of their current antiretroviral medications they had taken in the last 30 days. Using a ten-centimeter long visual scale (Visual Analog Scale; VAS), with markings at 10% increments from 0% to
100%, participants were asked to mark an ‘X’ on the scale with their response. Percentages were assessed using a ruler with markings to the millimeter, to capture percentages to the whole number.

For the full study sample, the mean reported percentage of medicine taken using the VAS was 84.08% (Range 0-100, SD=25.92). More than half (53%) reported an adherence rate of 95% or more, with responses in the 25-75 percentile being between 80 and 100%. Responses were more heavily concentrated on the higher end of the scale, with only just under 14% reporting VAS values 50% or under. Those assigned to the optimal adherence group had an average VAS score of 5.67 (Range 95-100; SD 1.52), while those assigned to the suboptimal group had an average of 4.20 (Range 0-90, SD 29.40).

*Combined Adherence Score*

As noted in Chapter 4, after transforming the SRSI score, the two self-report adherence measures were averaged to obtain a combined adherence score that was used to assign interview participants to optimal and suboptimal adherence status, as well as to parse the survey data for comparisons against other variables of interest. This combined score had a mean of 87.95 (Range 10-99.5, SD=18.18), similar to the VAS mean of 84.08. Again, similar to the VAS, the range of scores between the 25 -75 percentile was 85% -99.5%. Using the 95% cut off, 54% (n=71) and 46% (n=60) were assigned to optimal and suboptimal adherence, respectively.

*Years on ART*

Participants exhibited a wide range of experiences with their ART regimens. Though the mean length of time on ART was 13 years, the length of time taking HIV medications ranged
from six months to 32 years. There were participants who spoke about living through the early years of the HIV epidemic; one participant described being tested, handed a pink slip of paper and told to go to the health department, then learning he had HIV and lost his job within a few days. A small number of participants shared experiences with taking or knowing friends who took AZT, an early HIV medication that one participant said, ‘scared him.’ Individuals who had been living with HIV for close to thirty or more years reported having gone through a number of different regimens over the years; as many as 15 pills at one time, though their regimens now were typically from one to three pills.

Access to Health Care

The survey section on access to health care included questions about overall health, regular sources of care including how that care is paid for, and if the participant has someone that they think of as a personal doctor or health care provider. In terms of overall health, the most frequently reported answer was ‘good’ (3) from a Likert scare of responses from poor (1) to excellent (5). Nearly a fifth (18%) reported being in excellent health, followed by 21% very good, 32% good, 23% fair, and 5% poor.

Participants were asked to report regular sources of care. If there were more than one source, they were asked to choose the one they used most often. More than one-third (34.4%) reported receiving care from the health department, followed by a clinic at a hospital (26.7%), private doctor (23.7%), community health center (9.2%), emergency room (3.8%), and VA or nowhere (0.8% each). The most frequent source of health coverage came from Medicaid (27.5%), Ryan White (19.1%), Medicaid and Ryan White (18.3%), Medicaid and Medicare (12.2%), Medicaid, Medicare, and Ryan White (8.4%), Medicare (8%) with smaller percentages
for other sources such as employers, a spouses’ employer, and Tri-Care (veterans administration). A large majority of respondents (88.5%) indicated that they had someone that they thought of as a personal doctor or healthcare provider.

As part of the semi-structured interview, participants were asked about their regular sources of care, if anything had changed recently, and if they felt like they were getting the care that they needed. Several key themes emerged from the discussion about their access to health care. First, with one-third of participants receiving care at the health department (HD), there were a few participants (n=3) that mentioned privacy concerns about getting HIV care in this type of setting. A few more (n=5) highlighted the difficulty of getting to the HD to pick up their HIV medications, though one person said, picking up there was something they preferred to do. Several participants (n=6) spoke highly of certain practitioners there, while a few others (n=3) indicated that they had left the HD and moved to other sources of care because they felt like the treatment that they were receiving at the HD was rushed.

Yes. It’s been over, I think, a year now. When I first got it, I was at the health department, and I just think they weren’t giving me enough care there. To be honest with you, it's the exact same thing at the health department as Tampa Care. Only difference is, you spend at least 45 minutes to an hour with Tampa Care, which you do about 30 minutes over at the health department. [The Clinician] is a lot more thorough, and I think she cares a lot about her patients - because she asks me personal questions that they didn't ask me down there [HD]. She made me feel a lot more comfortable talking with her. That means a lot when you find somebody that you're comfortable with, and you can share. I mean, I would never say nothing to [another clinician] about my diarrhea because I didn't-- It
just made me feel uncomfortable. [They] just didn’t – [they] wasn't appealing to talk to,
more or less. Not saying she was an ugly person, just her approach wasn't right for me.
We were just weren't clicking. It wasn’t what I needed.

- Interview #44

There were a small number of respondents (n=2) who reported that they had some
difficulties figuring out changes in ways that their health care was covered, including payment of
coopays for services, what is covered, and receiving bills at a much later date for services that
they thought were covered. Another confusing issue that was raised by several participants (n=7)
was the question about who to go to depending on what was ailing them. For example, nearly
half of interview participants (n=19) discussed competing health issues, such as high blood
pressure, diabetes, gynecological concerns, seizures, GERD, migraines, heart conditions, cancer,
and even injuries or general aches and pains. So, while a large majority (88.5%) reported having
a regular source of care, several indicated that they were not sure who (if anyone) would take
care of things that were not HIV-related. In the first narrative below, this participant notes that as
their coverage changed, they feel that they have lost access to care for anything that is not HIV-
related, and they have concerns about going to just any place that is not familiar with their
medical history.

I'm kind of irritated about that right now because I have ADAP. So, Tampa Care, they
take really good care of me, but I was on--before it happened, before I lost my job. I was
still able to be on Obama care, then there was a program that paid my monthly –
whatever. Meds. Now that my income has even dropped lower, I fell out of that window
and it's all or nothing. When I do get sick or something does happen and it's not HIV related or anything, then I am in trouble.

That makes me...that bothers me because I'm not old, but I'm not young anymore. You know. Right now, I am having some pain in my tooth, this sensitivity, not just pain, pain. You know like that aching, annoying pain and I don't know if it's just the cold air because I have not eaten something hot or cold and normally it's time to get it checked out. Same thing with my eyes and stuff. It's just they don't give me referrals to go, then I have to go to who they want me to go to. With your eyes and your teeth, the things that we treasure. If you get in a comfortable zone of a doctor you trust, you want to go to them. But they might think nothing is wrong if you go to a stranger. They might come up with something totally different, or they might be correct, but you're still well. How can I resolve it? When I go to someone new, I'm scared.

- Interview 34

In a related discussion, the following participant noted how important it was for them that their HIV care provider was the first person that they saw before they moved away from a specialist and went to their primary. For him, the primary doctor does not have the expertise to understand that what he is feeling is related or not related to his HIV – the primary is just ‘guessing.’ So, this participant (and two others) preferred that their infectious disease care provider was their first source of care, and could refer them out for anything else they could not or did not provide – even if the participant said that they knew the HD preferred that they went to a primary doctor first.
**Interviewer:** Okay. So, related to that, what about health care? Do you have a regular source of medical care?

**Respondent:** My only source is the health department.

**Interviewer:** Health department? Okay.

**Respondent:** Yeah. All the time, when I go to the health department for an issue, then they make me go to my primary.

**Interviewer:** Okay.

**Respondent:** Because I think my primary is not about my disease, okay? They’re just a doctor. So, if I'm going in with an ailment that I think may or may not be related to my disease and you tell me this and that, you're guessing. I can do that. You know what, I don't want you saying a might be or could be...when I can go to my infections doctor and tell him how I feel. And he says, "Well, maybe it's different." Or it might be different for me. So, I can't do that. So, the only time I really go to the primary is when my infection doc sends me to my primary. So, they like they shoot me insulin once a year, you know. That's the only time I go. My primary, I promise I don't wanna ask for him or make an appointment once a year because I won't go to them for nothing. Now that's I stand right there from my infections doctor.

**Interviewer:** So, what happens when you have those things you mentioned, like colds or mysterious aches and pains? Do you go...

**Respondent:** Yeah, exactly. I go see the infectious disease doctor first, and then it's not related to HIV...then I go see that other doctor. That's what I do.

- Interview #41
Facilitators and Barriers to ART Adherence

Participants were also asked on the survey to report their experiences with common barriers to adherence, drawn from a five-item index (with yes/no responses) used by Kalichman and colleagues (2010). Somewhat surprisingly, 58.0% endorsed the item “I cannot afford the cost of medications. When conducting the survey, I entered the response they indicated but then asked them a follow-up question not on the survey because of my concern that they lacked access to the medications. Participants frequently responded that if they had to pay for these medications themselves, there is no way they could afford them – but that they did indeed have access to the medications. Though I did not keep a count, easily more than twenty respondents used a similar phrase to describe this issue: “These meds are like $3,000 a month. Who could afford that?” The $3,000 figure was a consistent one in response to my follow-up questions, and it did make me wonder if there was someone (like a pharmacist or someone certifying their benefits) disseminating this information to participants.

In terms of the other common barriers, nearly half (48.1%) reported general transportation issues, and 35.8% reported not being able to get to a clinic or doctor due to transportation issues. Nearly half of participants (42.7%) reported experiencing side effects from ART, and 19.1% reported running out of medications before they could get a refill.

In a related issue – while one-fifth of participants reported running out of medication, there were quite a few individuals who mentioned in passing during their surveys that they had a surplus of medication. This was not data that were collected systematically, but reasons for the surplus (besides not taking medications as they should) included issues such as the pharmacy bringing medicines a few days earlier each month to ensure they never ran out or filling more than a month at a time (such as for someone receiving care from the VA). Participants remarked
that because pharmacies made so much money from providing their medications, that they might be motivated to provide participants with ‘extras.’ These extras were not simply more medication than they needed, but also could take the form of gifts such as free toiletries and household goods if they switched to a certain pharmacy, or a $25 gift card if they referred a friend to the pharmacy. While one participant reported using this to help stretch her food budget, another indicated that they did not want to let others know they had HIV, so they did not feel comfortable with this practice.

While the survey captured common barriers to ART adherence, participants were also asked to describe what makes taking their medicines easy, or what makes it hard? The themes that emerged from these questions were not surprising and again are attested to in the literature. What made taking ART easier included things like reminders, going down to a one-pill regimen, having little to no side effects, or it being a habit – especially for those on regimens for several years or those indicating that they had other lifelong health conditions that required a regular pill regimen. However, two participants had other specific recommendations for what would make taking their medications easier – housing and food assistance.

“There were two big things that changed my ability to take my meds: going down to just one pill a day and getting my food stamps. Before, it would be so easy to miss that second pill, and if I didn’t eat or if I didn’t eat enough, I’d get sick. I do so much better now.”

- Interview #34

**Interviewer:** Is there anything that makes taking your medicines easy? That would help you with taking them.

**Respondent:** Food and Housing.
Interviewer:  Food and Housing would make that so much easier?

Respondent:  Yes, that’s a given. Food and housing. Yea.

In terms of what makes taking medications hard, participants reported such issues as difficulties swallowing large pills, the taste of the pill, or having multi-pill regimens (or having to take a lot of other pills in general, so ART simply add another layer). Other familiar barriers include side effects, forgetting (usually linked to having a busy schedule), which was often reported along with taking the pill but late, from a few to as many as 12 hours late. After side effects (n=25), the most frequently mentioned difficulty with taking ART was medication-related fears (n=9). Participants report concerns about the toxicity of the medications – regardless of single or multi-pill regimens, but particularly when taking them over time. They also reported concerns about interactions between their ART and any other medication they might be taking for other health conditions.

I don’t know which way I’m going or coming. Eating is not on my top priority for real. Taking pills aren’t either. Coz taking pills when you stressed out make you want to kill your damn self. They (medications) killed my aunty, who just had her daughter. She took too many pills. They gave her Methadone, Xanax, Oxycontin, and there’s one more pill in her. She accidentally overdosed. You know? Now I don’t trust the HIV doctor I got since I been down there, he done changed my medicine twice, and I'm like that's bullshit. We need to look at these numbers and do something. He said I need to be taking three pills. Then I went back to him this time, and he said you was supposed to be taking four pills. I
say, well you told me not to take that fourth pill that it didn’t go with all that other stuff I was taking. Oh no, I didn’t, he said. I’m like, bullshit. My mom heard you, and my husband heard you. And I know that I hadn’t been taking Emtriva. I’ve been throwing that shit in the garbage for the last year. And my numbers have been okay without the Emtriva. He is going to say my number is like 900 something, and he said I had like 230 copies of viral load – well that’s because I’ve been skipping around them pills, and I’m like well if my numbers are that low, seems like I don’t need it. I shouldn’t have to take it. Well I feel like you should take it, he said. How you gonna tell me what I got to do? It’s my body you want those four pills to go into, but I gotta deal with them damn side effects. If without the fourth pill, it’s working, why do I need to add the fourth pill? See what I mean? It sounded all wrong. These people, their doctors are crazy, they have their own fucking herbs in their offices. It’s crazy.

- Interview #6

**Respondent:** I don’t like medications. I just don’t. I was taking, you know, Truvada, Prezista, Norvir, Gaviscon, vitamins, calcium pills, diarrhea pills. I was taking seven pills a day. I didn’t -- it made me sick. I can imagine you have 1800 milligrams in your belly a day. I’m not really distressed in the food, pay a little more than that. I feel a lot better than what I did last month, mentally-wise.

**Interviewer:** Are you saying you feel better from taking your medicine or from not taking it?

**Respondent:** I feel better now because I’m decreasing it.

**Interviewer:** Okay.
**Respondent:** Mentally, it plays the part. Believe it or not, your mind's a tricky thing. I think mentally, my subconscious is saying, "Man, it's too much. It's going to make you sick". Now I'm getting down to two a day. I feel good about it. I don't have a problem with taking it. That's just what I think. I think we're overloaded with the pills. That's just me. I still am taking 8-9 a day, 4-5 a day. I think the pill they got-- you take one, it's got full medication, with the steroid in it. I think it would be an excellent pill for everybody to take because the liver, it eats your liver up, I think.

- Interview #44

**Relationship between Food Security and ART Adherence**

While the previous section presented the information about the adherence status and experiences of this study’s participant, in this next section, I will review the questions that are central to this chapter - the relationship between food security and ART adherence. This section will review comparisons related to the household food security survey (HFSSM), dietary quality (HEI), and the experiences with both food security and diet quality by adherence status.

When comparing the distribution of food security categories across adherence (Figure 6), we can see that there appear to be large differences between the groups. Just over 48% of the sub-optimal adherence group experienced very low food security, while only 23.9% of the optimal group had this same level of food security. On the other side of the spectrum, 38% of the optimal adherence group was categorized as having high food security, while only 20% of the sub-optimal group were placed in this category. The adherence group had a mean HFSSM category of 3 (low food security), while the suboptimal adherence group had a mean of 2
(marginal food security). The distributions in the two groups differed significantly (Mann–Whitney U = 1523.5, n1 = 60, n2 = 71, P = 0.003 two-tailed; see Figure 7).

During the interview, participants were first asked if they knew of anyone who struggled to have enough to feed themselves or their families, then they were asked if they experienced...
these issues themselves. Regardless of their response, they were asked to describe their current food situation. Using quantitative findings from the survey, in Table 9, respondents have been organized by adherence status and then food security category, to facilitate comparisons between their experiences. This table also reports the number and percentage of interview participants’ food security categories (n=45) by adherence, with 25 participants being categorized as adherent and 20 participants assigned to the non-adherent group.

In these quotes, some interesting patterns emerge. In both adherence groups, participants in the high food security category seem to report a lack of knowledge of people struggling with their food situations and do not endorse dealing with these issues themselves. Some reported having support from families or charitable organizations. Participants in both adherence groups who experience marginal food security also seem to report similar experiences; neither adherence group endorsed struggling with food security issues themselves, though all reported relying on distributions of hot food or food boxes from various organizations. Participants in the adherent group who experience low food security either described limiting quantities of food – in most cases, eating just once a day, while the small group of individuals in the non-adherent group described struggling with issues such as school or work schedules contributing to their concerns about their food consumption. In the exemplar quote, one participant highlighted that the food they acquire through food distributions is not easily portable for their busy schedule, meaning that she has food at home, but that does not stop her from being hungry during the day or spending limited funds on foods from vending machines – foods that do little to satisfy her hunger while draining her wallet.
## Table 9: Food Security Status by Adherence, Participant Quotes

<table>
<thead>
<tr>
<th>HFSSM category</th>
<th>N (%)</th>
<th>Adh</th>
<th>Participant Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5 (11%)</td>
<td>Y</td>
<td>No, I’m not having any trouble with food at all. My brother does all the cooking for me. He makes sure I eat. He brings home like stuff to cook or bringing stuff home from the school, and I eat like I got breakfast stuff. I ate early this morning, try not to be a pig too much. But I get enough nutrition, and he makes sure of that. He makes very sure of that. (Do you know anyone who struggles to feed their family?) Mmmm…[long pause] Really at this moment all the people I know they, you know, they have…they doing good for their families and stuff. (Would you say that’s something you struggle with) No, ma’am.</td>
</tr>
<tr>
<td>2</td>
<td>4 (9%)</td>
<td>Y</td>
<td>No, I’m not struggling. Only people I know that really struggle are the homeless people. (how do you usually get the food that you need?) I go to pantries – like, 3-4 places. That last one’s a church. (how often do you visit those places?) Every week. Every week. I have neighbors that struggle. They from Africa; they like refugees or something. Since I been collecting food at Francis House, at the park, I just know me and [partner] won’t eat that much. So, I take them a little something. No, I don’t worry like that. I have more food in my house than this place (Francis House) does. But I’m like a hunter. If they’re giving out food somewhere, I am first in line. Maybe fifth – I’m not young anymore [laughs] I get there like 6:30 am for a 9:00 am – and I’m not first, but I’m close. I know I’ll get something.</td>
</tr>
<tr>
<td>3</td>
<td>6 (13%)</td>
<td>Y</td>
<td>I mean, I just eat one meal a day. I don’t have nowhere else I can eat really, so if I am not eating here at [group home] or at Francis House, I don’t eat. So, I basically eat once a day. That’s something I struggle with every day. It’s like – I might get some substance, but it just fills a void. And they haven’t been giving out stuff here [at Francis House] lately. It’s been empty. Around the holidays, it’s like everyone’s food pantry hits a shortage.</td>
</tr>
<tr>
<td>4</td>
<td>10 (22%)</td>
<td>Y</td>
<td>Yea, I’m struggling, that’s me. I was on food stamps, but it’s all up and down then they lost my application. I was like, wow. It’s really hard because even if you go to different churches and pantries, you have to look at, they’re trying to help a lot of people, they cannot give you a whole bunch of items. Maybe just enough for a day or two, if that. So, yea, I was on pantries. I was asking my sister – she’s got like 4 kids, so she’s like, I can’t give you a lot. But she do what she can, and I do the pantries. It’s a lot of work. I get $183 a month in food stamps. (Would you say that’s enough for you?) No, for a month? When the price of food has gone up? You’re paying anywhere from a dollar fifty to two dollars for one bell pepper. I mean, this is outrageous. I have grown in my backyard until somebody destroyed my garden. I had seven rows of vegetables. Somebody just – trashed it. They didn’t take it – they smashed it up. I was doing okay buying meat then getting my vegetables here, but now there’s just not enough. They reduced [my food stamps] down to $81, from $96. It’s kind of when you want to try to eat, buy some healthy things if you can’t buy all healthy things, so I’m just gonna do my best until I go to this place where Food America-- Feed America. I go to them twice a month now. They do it twice a month. I go there and--this month I got five meals. And vegetables--you get vegetables. You get--they have rice, but they have snacks too. They put it in your box. You get bread. You know. And it helps. It helps a lot. Everybody gets a box. Might be lined up around the block, but everybody gets a box.</td>
</tr>
</tbody>
</table>
Table 9: (Continued)

<table>
<thead>
<tr>
<th>HFSSM category</th>
<th>N (%)</th>
<th>Adh</th>
<th>Participant Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7 (16%)</td>
<td>N</td>
<td>No, I don’t know no one like that. I live with my parents. I got to move out soon – they got this oldy old man living in their house, and they buy all the groceries. If I want something special, I’ll buy it but …I don’t get food stamps. I used to get $10, but they finally wrote me a letter and said they was canceling that. I’ll probably get them back when I move out. I eat well. I have a place to eat every night. In the park they have churches that come out and bring you food, and they bring you bags of sandwiches, or they bring you-- and you go over, they’ll fix plates, yellow rice, beans, chicken and it'll all be hot food. They give you vegetables if you like salad, an apple or an orange and they also give you something to drink. You have food -- I go down to Trinity on the weekends. Trinity cafe and they have-- they serve breakfast - they have big breakfast. Yes, they give you French toast, eggs, yellow grits, and they give you a very nice-- they serve you like a five-star restaurant. I love Trinity. Everything’s good. I buy my own food now. Cook my own food. Eat when and what I want. It’s good now.</td>
</tr>
<tr>
<td>2</td>
<td>1 (2%)</td>
<td>N</td>
<td>I wouldn’t say I have a problem, no. I always have breakfast here (FH) on Tuesday and Friday mornings. Lunches are here. On Tuesday nights, I will be out at the church called Bethel Church. On Wednesdays I’ll go... I found place behind the Family Dollar, a little church behind there on Wednesday nights. Thursday nights tonight - I go down...well, I have two options - to either eat at the Well or to go further south, which I like, is to go to the Presbyterian Church in Hyde Park. And then on Fridays, umm... There is somewhere. Saturdays I start, I have breakfast and lunch options...dinner – I go to the Salvation Army now. Just on Saturday nights for dinner. On Sunday mornings... Oh I love that...there’s a Methodist which is my church now; they feed the homeless in the morning at 7:30. Breakfast for 200 people.</td>
</tr>
<tr>
<td>3</td>
<td>2 (4%)</td>
<td>N</td>
<td>My trouble is them vending machines. Since I started school, I don’t have time to eat, and them machines don’t carry anything healthy. And I don’t have a lot of cash, but I gotta put something on my stomach. Sometimes those candies and bars just make me hungrier, but who has time to cook? I gotta learn to buy me some fruit and take it with me. Them churches in the park will give you like packets of ham, packs of hot dogs, but I can’t carry that stuff to school.</td>
</tr>
<tr>
<td>4</td>
<td>10 (22%)</td>
<td>N</td>
<td>My food situation? Shit. It’s hard. This place is so hard. There needs to be changes made the top down to the bottom. And as much money Publix get, and Wally World, they need to be donating 24/7 - I seen a food truck out there that says, “Feeding America,” I said bullshit. No you not. Why is the pantry empty over there? It’s not right. One month, we absolutely had no money. No [bus] pass, not $100 in the bank. And I came up here, and I said, you know what I said? “Andrea, help!” and she went to the food pantry and grabbed me everything she could. [laughs] Dealing with what you’re dealing with, not getting into the basics of that. Sometimes you just don’t have the time to make the proper nutritious food that you need. Got to have the starch, got to have the bread, got to have the meat, all like that, be cooked at the same time. You just have time to cook one thing. It’s like that sometimes. As long as it’s something something, but it’s not enough. It is just annoying, and it's very trying because it causes weight issues. I'm a snacker, because I'm alone. Where I normally come get a handful of grapes or a piece of fruit, something like that, nutritious. I don’t have it. I can’t afford that. So I go to the Girl Scout cookies that I get for free here. Shouldn't have it. [wry laughter] I’m gaining weight. As far as meals, I eat less at any given time, simply to make it stretch further.</td>
</tr>
</tbody>
</table>
For those experiencing very low food security, the predominant theme among those who were adherent was the role that food stamps play; participants talked about how changes in the amount made things difficult, or simply the amount in general, was insufficient to meet their household’s needs. In the non-adherent group, they spoke about food pantries – either not providing sufficient quantity or quality of foods to meet their needs, or in relying on food pantries as an emergency safety net with all other options fail. For the four participants these exemplar quotes were drawn from, one received $10 in food stamps (which the participant wryly noted could only buy him ‘a coke’), had lost food stamps, or did not qualify to receive them. For those participants that received food stamps, there was uncertainty and the feeling of not enough; for those who lacked those supports, their food situations appeared to be even more precarious.

Experiences with Food Security, Diet Quality, and ART adherence

While the mixed-methods matrix in Table 9 focuses primarily on the experience of food security but is parsed by food security categories, in the quotes below, I wanted to highlight the experiences that participants relayed about how food security, diet quality, and ART adherence are related in their daily lives. I have included some brief quotes from participants who indicated that food does not affect their ability to take their medications. The participants were adherent.

- **Respondent**: *I have no side effects from my medication, and mine's not taken with food.*
  *It's taken without food, so, no issues.* (Int #30)

- **Interviewer**: *Some people say that having enough food affects whether or not they can take their medicine as they should. Do you think that's an issue for you?*

- **Respondent**: *Um-um (no). Not at all.* (Int #32)
• **Interviewer:** Some people have said that not having enough food affects whether or not people take their medication ...

**Respondent:** Nope. That’s not me. (Int # 35)

Participants were first asked what makes taking medications easier or harder, then – if they did not mention food specifically, they were asked a follow-up question about whether or not food influenced their ability to adhere to their ART. Eleven participants indicated that food played some role in their ability to take their medication, though their responses (even within the same participant) were mixed between saying that food made it easier, or food made it harder.

In terms of a lack of food, participants said some pills were better on an empty stomach, while others felt you needed something in your stomach – even a glass of milk, a piece of bread – to ‘coat’ your stomach before taking your pills. Others noted that taking the pills made you hungry, so taking them on an empty stomach (either because that’s how they were directed, or due to a lack of food) made the experience of taking medications more difficult.

*Make sure you’re not on an empty stomach, but if you eat something like a piece of bread or tuna whatever you give medication, something to eat on instead of the lining of your stomach. Because it's toxic for one thing because that’s this is what it is. You know what I'm saying? And then some food you can take, some you take for without food. It’s according to the medication you’re taking. A lot of the time, I get out of bed, get some coffee, take my meds, and I'm cool. And it still has a great effect.*

- Interview # 13, non-adherent
Yes. That is hard. Trouble is, I know I need to take it, and I know what it does to my appetite, and the more hungry I am, the less food there is in the house. Every once in a while, I am afraid of opening up the refrigerator door, and not finding anything except for condiments. Saying, "Oh, boy. I've got relish and ketchup. Let's see, am I going to make a sandwich today? Nope." But that's where we are right now.

- Interview #37, non-adherent

I don't have to eat food with it, but I like to have something on my stomach because I've been dealing with what I'm dealing with for 23 years. Sometimes I get nauseous, sometimes the medication, so I have to have a little something to eat with it.

- Interview #10, non-adherent

**Interviewer:** Now this--your food situation, you've talked about that the pressure affects your body, affects your mind affects your stress level. Do you think it affects your ability to take your HIV medicines?

**Respondent:** Yeah, it does.

**Interviewer:** How does it that affect that?

**Respondent:** Because if you're hungry – they tell me to take it with no food. But if you take your meds, you get hungry. More hungry. And you look in the fridge, and the only thing you have is water. So, yes.

**Interviewer:** So, when you know there's no food, do you take your medicines?

**Respondent:** Pretty much, no.

**Interviewer:** And because your food situation is – You said you could not be eating for
days at a time. Does that mean that there could be days at a time when you don’t take your HIV medications?

Respondent: Yeah.

Interviewer: Is that a hard decision for you to make? Does it worry you to make that decision?

Respondent: Yeah, because I know if I don’t take my medications, then I’m going to die. And if I don’t eat my food I’m going to die. Pretty much, it’s a hard decision.

Interviewer: And you have to make that decision pretty often, you said.

Respondent: Yeah, why not?

- Interview #45, non-adherent

Both through survey and interview data, we see some evidence that food security is related to participants’ ability to take their medication, though this is not consistently the case. However, several participants do struggle a great deal with remaining adherent to medication when food is lacking, so this is an important consideration when trying to end the HIV epidemic.

As part of the comparisons between the adherence groups and their food security status, I also examined the differences in diet quality by assessing the distribution of calories, total HEI score, and HEI components between groups. The results of this comparison are found in Table 10. Only two of the items were found to be statistically significant between groups; the HEI 2 (greens and beans) and HEI 10 (sodium), though both groups demonstrated a need for improvement in these dietary components. This may reflect the idea that regardless of adherence
Table 10: Healthy Eating Index by Adherence

<table>
<thead>
<tr>
<th>Dietary Components</th>
<th>Suboptimal Adherence (n=60)</th>
<th>Optimal Adherence (n=71)</th>
<th>( p )-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MAX Score</td>
<td>mean</td>
<td>median</td>
</tr>
<tr>
<td>Total Calories</td>
<td>n/a</td>
<td>1966.04</td>
<td>1988.56</td>
</tr>
<tr>
<td>HEI Total Score</td>
<td>100</td>
<td>40.06</td>
<td>37.18</td>
</tr>
<tr>
<td>HEI 1 Total Veg</td>
<td>5</td>
<td>2.47</td>
<td>2.25</td>
</tr>
<tr>
<td>HEI 2 Greens</td>
<td>5</td>
<td>0.78</td>
<td>0.00</td>
</tr>
<tr>
<td>HEI 3 Total Fruit</td>
<td>5</td>
<td>1.51</td>
<td>0.42</td>
</tr>
<tr>
<td>HEI 4 Whole Fruit</td>
<td>5</td>
<td>1.43</td>
<td>0.00</td>
</tr>
<tr>
<td>HEI 5 Whole Grain</td>
<td>10</td>
<td>0.99</td>
<td>0.00</td>
</tr>
<tr>
<td>HEI 6 Total Dairy</td>
<td>10</td>
<td>2.91</td>
<td>2.00</td>
</tr>
<tr>
<td>HEI 7 Total Protein</td>
<td>5</td>
<td>4.24</td>
<td>5.00</td>
</tr>
<tr>
<td>HEI 8 Seafood,</td>
<td>5</td>
<td>1.33</td>
<td>0.10</td>
</tr>
<tr>
<td>Plant Protein</td>
<td>10</td>
<td>4.90</td>
<td>4.89</td>
</tr>
<tr>
<td>HEI 9 Fatty Acids</td>
<td>10</td>
<td>4.12</td>
<td>3.73</td>
</tr>
<tr>
<td>HEI 10 Sodium</td>
<td>10</td>
<td>5.99</td>
<td>6.82</td>
</tr>
<tr>
<td>HEI 11 Refined</td>
<td>20</td>
<td>9.40</td>
<td>9.58</td>
</tr>
<tr>
<td>Grain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HEI 12 Empty Cals</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Mann-Whitney U
status, participants in this study overall experience relatively low diet quality, with improvement needed to meet dietary recommendations. However, one participant did offer a poignant picture of how he experiences the intersection of these issues of food security, diet quality, and ART adherence.

“It happens every month. That last week or ten days, I’m scraping together whatever I can find. Sometimes, it’s ketchup and white rice. Sometimes, I’m standing at Taco Bell with a dollar trying to figure out what will give me enough calories to take my meds.”

- Interview #37

Summary

The participants in this study are roughly divided in half in terms of their ability to be adherent to their ART regimens, with 54% determined to be adherent (optimal adherence, ≥95%) and 46% being non-adherent (<95%) based on self-report measures. These numbers do not reflect what statistics at the federal level indicate; however, there are some important considerations when evaluating these findings. Because the participants in this study are drawn from an HIV service organization that offers additional supportive services such as a food pantry and hot meals, the population that this study is drawn from might be skewed towards those needing additional supports. In contrast, again, this study draws from participants at an HIV service organization. To get there and avail themselves of these services, participants may have to travel some distance by foot, public transportation, or car; thus, this study might not capture those who might be considered truly lost to care, because they are not coming into Francis House
at all. Therefore, it is important to understand that the analysis and narratives here reflect a particular subset of PLWH.

That being said, there are some important findings. While the study population is accessing special services in addition to case management from Francis House, we observe that nearly 50% of the study participants are not currently adherent to their ART regimen. Participants identify several barriers to adherence, including transportation, side effects, running out of medication, medication fears, and the role that food plays in influencing their ability to take their ART as prescribed. With regard to food, we see statistically significant differences between the ways that food security is distributed between optimal and suboptimal adherence. In the adherent group, 38% are experiencing high food security, while 28% are facing very low food security. In contrast, the non-adherent group has 20% that are categorized as having high food security, while 38% of this group are facing very low food security. A pattern emerged through the analysis of the qualitative data, with adherent participants indicating that food did not really affect their adherence at all, while those who were not adherent seemed to struggle with various side effects. We can see in some of the narratives above that there are mental health impacts for these interacting issues, which I will explore in the next chapter.
CHAPTER 7: MENTAL HEALTH, ADHERENCE, AND FOOD SECURITY

Chapter Seven is the last results chapter, which presents the findings from research question 3. It will first provide an overview of the mental health-related findings, then, using correlations and qualitative data, delves into the relationship among food security, mental health, and ART adherence. I will also attempt to predict adherence to ART using logistic regression in order to understand what variables increase the odds of optimal or suboptimal adherence. Finally, themes that emerged during the surveys and interviews are examined, such as disability, unstable housing, and the ‘gray space/the space between.’

Research Question:

3. What is the relationship among anxiety and depression, food security status, and ART adherence?

Depression, Anxiety, and Stress

This study used two validated scales, the Hopkins Symptoms Checklist (HSCL-10) and the Perceived Stress Scale (PSS-10), to assess depression, anxiety, and stress. The HSCL-10 assesses depression and anxiety, while the PSS-10 assesses perceived stress. First is a summary of the survey for the whole study sample. This is followed by comparisons of the mental health findings to other study variables of interest.
**Hopkins Symptoms Checklist**

Participants were asked to respond to ten questions related to symptoms of depression and anxiety, with Likert-scale responses that ranged from not at all (1) to extremely (4). Items in the scale include questions about whether participants have felt suddenly scared for no reason, felt fearful, tense or keyed up, felt worthless, or hopeless about the future in the last week (See Appendix D for the survey). The ten-items were averaged in order to compute the HSCL-10 score. For the full study sample, the mean HSCL-10 score was 1.93 (‘a little bit’; Range 1-4, SD=.72), with responses in the 25-75% percentile being between 1.4 and 1.7. Nearly half of participants (46%) reported a mean HSCL-10 score over the cut-off of >1.85, which indicates mental distress.

**Perceived Stress Scale**

In addition, participants were asked to report levels of stress using the PSS-10, which also had Likert-scale responses from never (0) to very often (4). Items for the PSS-10 include: being upset because of something that happened unexpectedly, having felt like they were unable to control important things in their lives, having felt nervous or stressed, and so forth in the last month. To calculate the PSS, responses are summed; scores over 20 are considered to be indicative of high stress levels. For the full study sample, the mean reported PSS 19.28 (Range 0-38, SD=7.80). Again, nearly half (48%) reported a PSS score of >20, with responses in the 25-75% percentile being between 14 and 25.
Mental Health and ART Adherence

When examining the mean depression and anxiety scores (HSCL-10) by adherence status, we find that 33% of those who were adherent to ART are under the 1.85 cut-off for high levels of mental distress. On the opposite side of the spectrum, 24% of those who are over the mental distress cut-off are non-adherent. However, the differences in the two group means are relatively small (2.04 for non-adherent compared to 1.83 for adherent) and the distributions for the HSCL-10 between the two adherence groups did not differ significantly (Mann–Whitney U = 1796.5, n1 = 60, n2 = 71, P = 0.123 two-tailed; see Figure 8).

![Figure 8: HSCL-10 by Adherence](image)

Similarly, when looking at the differences between the adherence groups for the PSS, we find that 29% of those with scores above the 20 point cut off for high levels of stress are not adherent, while 34% of those who are adherent are below the stress level cut off. The difference in the group means here are slightly larger than for the HSCL, with non-adherent participants having a PSS score of 20.83 and adherent participants having a score of 17.94. Unlike the
HSCL-10, the distributions in the PSS scores for two groups by adherence status did differ significantly (Mann–Whitney $U = 1628.5$, $n_1 = 60$, $n_2 = 71$, $P = 0.028$ two-tailed; see Figure 9).

Figure 9: PSS-10 by Adherence

Mental Health and Food Security

To understand the relationship between food security and the mental health measures, I first calculated and then graphed the means of the two mental health measures against the food security categories. When examining the means of the mental health measures, it was apparent that there was an upward trend as the food security category became more severe, which is in line with the assertion that food insecurity might act in a dose-response manner on other health outcomes. Figure 10 displays the mean HSCL-10 and PSS-10 by levels of food security. Because the HSCL-10 is a mean of the ten items, its axis values (1-4) are displayed on the left side of the figure. The axis values for the PSS-10 sum score (0-40) are shown on the right. The figure shows the means of the HSCL-10 increasing from 1.7 for individuals with high food security, up to 2.2 for those experiencing very low food security. Similarly, the figure depicts the sum score of the
PSS-10 increasing from 15.5 for individuals with high food security, up to 22.8 for those experiencing very low food security.

**Figure 10: Mental Health Scales by Levels of Food Security**

**Linking Mental Health, ART Adherence, and Food Security**

The primary question of concern for this chapter is to understand the relationship among mental health (stress, anxiety, and depression), food security status, and ART adherence. Though this dissertation does not aim to demonstrate evidence of a syndemic through the use of statistics, there are some ways to examine these relationships (such as correlations and logistic regression) before delving into the day to day experiences of the study participants. Correlations are used simply to identify bivariate relationships, while logistic regression is used to determine which key variables of interest in this study could best predict ART adherence. Again, these analyses will not be able to detect if there is a synergy between the variables that contribute to poorer
adherence, but they can be used to describe the relationships – for which interview data can then provide more in-depth explanation.

Prior to conducting the regression analysis, correlational analyses were carried out to examine the relationship between the following variables: HFSSM-10 (Food Security), HEI Total (Dietary Quality), HSCL-10 (Depression-Anxiety), PSS-10 (Perceived Stress), Unstable Housing, Disability, and SNAP. A strong correlation, r(129) = .748, p<0.01, was observed between the HSCL-10 and PSS-10, which is not surprising given that they are both mental health measures. Because of the strong relationship between these items, one had to be removed from the final regression model. Given that the HSCL-10 had missing data (n=1) while the PSS-10 did not, the decision was made to remove the HSCL-10 from the possible model. Surprisingly, there was not a statistically significant relationship between the food security measure (HFSSM-10) and the dietary quality measure (HEI). In addition to the relationship between HSCL-10 and PSS-10, there were six other relationships – four weak (r = .1 - .3) and two moderate (r = .3-.5), but none of these were strong enough to require removing them from the regression analysis.

### Table 11: Correlation Matrix, Key Variables

<table>
<thead>
<tr>
<th></th>
<th>HFSSM-10</th>
<th>HEI Total</th>
<th>HSCL-10</th>
<th>PSS-10</th>
<th>Unstable Housing</th>
<th>Disability</th>
<th>SNAP</th>
</tr>
</thead>
<tbody>
<tr>
<td>HFSSM-10</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HEI Total</td>
<td>-.076</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HSCL-10</td>
<td>.331**</td>
<td>.047</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSS-10</td>
<td>.398**</td>
<td>.006</td>
<td>.748**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unstable Housing</td>
<td>.110</td>
<td>-.030</td>
<td>.259**</td>
<td>.179*</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td>-.130</td>
<td>.029</td>
<td>-.052</td>
<td>-.004</td>
<td>-.018</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>SNAP</td>
<td>-.067</td>
<td>-.185*</td>
<td>-.060</td>
<td>-.100</td>
<td>-.184*</td>
<td>-.014</td>
<td>1</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

145
Table 11 shows that there are positive, moderate, but statistically significant ($p<0.01$) relationships between the HFSSM and both mental health measures – that is, as the mental health measures increase (worsen) food insecurity increases. However, there was not a statistically significant relationship between the food security measure (HFSSM) and HEI, an indicator of diet quality. We also see positive, weak, but statistically significant relationships between housing status and both mental health measures, the HSCL-10 ($p<0.01$), and the PSS-10 ($p<0.05$), with unstable housing is related to higher (worse) mental health scores. Further, SNAP has two negative but weak yet statistically significant relationships ($p<0.05$) with HEI (diet quality) and stable housing. This means that SNAP is negatively associated with diet quality (HEI), so we see lower diet quality (HEI) with those receiving SNAP. For SNAP’s relationship with housing, though – those with SNAP are less likely to be unstably housed.

Logistic regression was then used to predict adherence to ART, using variables collected from the survey. All items that were statistically significant from the correlation analysis were entered into the model. However, only food security (HFSSM) and SNAP were significant, so the model was re-run with only those variables. In the final model, food security (HFSSM) and SNAP were significant predictors of adherence ($\chi^2=13.197$, df=2, $p=.001$), and this model correctly predicted 66.4% of the cases. The odds ratio (OR) for HFSSM is 1.150 (95% CI: 1.039 – 1.272) and for SNAP is 2.483 (95% CI 1.109-5.561). This means that study participants who did not receive SNAP were 2.483 times more likely to be non-adherent to ART than SNAP recipients – or put another way – people who received SNAP were 2.483 times more likely to be adherent. Further, for each unit of increase in the HFSSM (higher scores meaning worse food security), participants were 1.15 times more likely to be non-adherent. See Table 12 for the results of the logistic regression. Table 13 shows the distribution of SNAP (yes/no) by adherence.
(yes/no) using a two-sided Pearson Chi-Square. Just over sixty percent of those on SNAP were found to be adherent to ART, while nearly the same amount (62.2%) who were not one SNAP were non-adherent to ART. These differences were statically significant ($\chi^2=5.560$, df=1, $p=.021$).

Table 12: Logistic Regression, Predicting ART Adherence

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\beta$</th>
<th>Odds Ratio</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>HFSSM</td>
<td>.139</td>
<td>1.150</td>
<td>.007</td>
</tr>
<tr>
<td>Received SNAP</td>
<td>.909</td>
<td>2.483</td>
<td>.027</td>
</tr>
</tbody>
</table>

N = 131
Non-Adherence = 1, Adherence = 0
Hosmer and Lemeshow Test (p=0.484)
Model Chi Square=13.197, df=2, $p=.001$
Nagelkerke Pseudo R Square=0.128

Table 13: Chi-Square, SNAP by Adherence

<table>
<thead>
<tr>
<th></th>
<th>Non-Adherent</th>
<th>Adherent</th>
</tr>
</thead>
<tbody>
<tr>
<td>SNAP-NO</td>
<td>62.2% (n=23)</td>
<td>37.8% (n=14)</td>
</tr>
<tr>
<td>SNAP-YES</td>
<td>39.4% (n=37)</td>
<td>60.6% (n=57)</td>
</tr>
</tbody>
</table>

$\chi^2=5.560$, df=1, $p=.021$

What do these analyses mean in light of the day-to-day experiences of PLWH? From here, it becomes harder to parse out quotes that only link mental health to food security or mental health to adherence; as people tell their stories, the relationships appear more complex than the
statistical methods in this dissertation can convey. For now, I leave more sophisticated analyses for completion outside of this dissertation.

While coding the interviews for this study, one of the challenges was understanding how to best capture the relationships between the various domains, or strands. I decided to color-code each of the major domains of the study (food security, HIV status, adherence, and so forth), then apply multiple codes to sections of text where domains overlapped. As I coded interviews, I could see sections of text emerge with rainbows of codes on the left margin in the document browser in MAXQDA. In searching for the narratives for the last part of this last results chapters, I went in search of these more densely coded sections of text.

![Figure 11: Coding Stripes for Overlapping Themes](image)

Though this first quote was part of the discussion above about the experience of accessing adequate food, I wanted to include the next couple of sentences from this same exchange to highlight the complexity that some of the participants in this study are attempting to navigate. For this individual, she recognized that other Francis House clients had seen reductions in their food stamps due to changes in other circumstances; for example, if your rent was reduced and you had the potential for additional cash flow, your food stamps might be cut. In this exemplar quote, the participant is trying to understand why she sees a reduction in one area when
there have been no changes in another. This sense of entanglement was a common theme among participants. Where respondents sometimes differed was in their response (in that moment) to how they would handle those concerns. While one participant indicated that she would not ‘waste her time’ or fight the reduction, other participants reported pursuing every form of assistance, no matter how small.

Yeah, because they [food stamps] were $98, and then it went down to $96. Now they're going down to $81. And I don’t know why. There's no change in my rent, my nothing. Nothing has changed, and I don’t understand why they went down on me. Every time, I gotta get used to eating just a little less. But I'm not going to waste my time going down there trying to figure out why because it don't make sense. They just give you the runaround. I don't like wasting my time like that. I gotta make do.

-Interview #16

Well, I'm going to go with the flow, I'm not going to give up, I'm not going to give in. I have been so low with this food stamp thing that they have cut me down to $10. I've been adapting to $10. I didn't proceed to not use it when they want to re-certify me for them $10, I recertify for them $10. I know most people would have looked at it and like "ohh ahhh" and it’s a hassle, but no, I'm not going to get out of that system, I'm not going to get out of your system. I'm going to deal with your system any time you write my name in for anything whatever it’s for, say food stamps this that, that, you're not going to never have me say nothing, no, no. I'm going to stay, I'm going to be a fighter hopefully a survivor, but no, I'm not going to get weary about the trip I'm making. But it gets
frustrating, it gets very frustrating, especially you are unable to find different outlets of support. - Interview #17

For this next participant, merely asking about their food situation elicited this response that highlighted issues related to food security, adherence, medication side effects, access to a place to stay, and mental health. This participant had been recently released from a short stint in jail and spent about an hour and a half talking about the differences between being incarcerated and living on the streets, as he had done before he was jailed and now after his release.

Right now, just for right now, I’m facing that (food insecurity), yes. It's been ongoing because I don’t have a place to stay. Other than that, I get food assistance through the food stamps. The Francis House provides food for me...though sometimes, something's not available. Lunch is hot here. I can eat two meals a day. I get enough. When I have a medication change though - last week because I wasn't getting the food in the morning-time sometimes, because the new pills I think, it made me nauseous too bad. I went last week to Tampa Care and got it switched to two pills a day, and other than that, everything's okay. But my viral load is 316. I mean my T-cell’s 316. My viral load like 26, maybe. It fluctuates so much, I believe, because of the environment I’m in and the stress I’ve got on me. When I was incarcerated for them 120 days, it was a relief because I had a place to stay, the environment was feasible for me. I was getting food. I know I couldn't do much, so stress wasn't that factor, that bad. You know, I think part of me wanted to get arrested, tried to get arrested? Because inside, I had less to worry about. - Interview #44
While I was startled to hear someone say that they might have pursued incarceration in order to reduce stress, it was not the last time that this thought was endorsed by participants. Two other male respondents indicated either that they had done this or had been thinking about doing this, just to reduce the strain.

Another theme that arose when examining sections of interviews with multiple coded items was the tension between needs and available resources. One participant spoke about needs that they had beyond housing and food, such as personal and other hygiene items that put a strain on their budget – something that came up in several other interviews. During one survey, a participant noted that the reason they had a hard time affording food was that the limited resources they had to purchase food were being reduced so that she could purchase cleaning items. She did not have access to stable housing and was staying with friends. However, because these friends knew that she had HIV, she was required to bleach the bathroom ‘from top to bottom’ every time she used it, and she was going through about eight bottles of bleach a month.

A friend of mine gets $800 in VA benefits. You know how much food stamps she gets? $44 a month. And she pays $350 in rent. I'm on a housing voucher too. But had I still had a phone, cable, Internet, electricity, household needs, bleach, a new mop, a new broom, paper towels, toilet paper, and then you needed the toiletries. I bathe daily. Have at least one. And you know, so there's body wash, and you got to have detergent to wash the clothes that you just taken off. And then you have to pay for the washer and dryer, even if you just rent it, that still costs money. It doesn't go far, and it does not go far. And would you think people like us living with HIV, they would consider our voice. We need more food to eat healthily, and they are not giving it to us. You are telling us, "Okay, here is
$67, survive a month out of it." If I didn't have friends, family, and neighbors. I couldn't make it.

- Interview #24

As these exemplar quotes demonstrate, the individuals in this study are attempting to cope with myriad conditions and situations that demand complex solutions but are working with such limited resources that – as one participant noted – they are simply “robbing Peter to pay Paul.” More often than not, their coping strategies are not enough, leading to a seemingly endless cycle of trials and failures.

Emergent Theme: Unstable Housing

Though I asked a single question about access to stable housing as part of the quantitative survey, perhaps due to my own biases or interests, I hypothesized that food security would be a more pressing issue for participants. Given that I had my own experiences with the housing market in the Tampa Bay area, I should not have been so surprised at the proportion of study participants who indicated that they were not stably housed (33%). But even among those that were housed, myriad issues were raised about their living conditions, the safety of the neighborhoods where they could find ‘affordable’ housing, and the struggles they experienced trying to pay rents that took up a large proportion of their income – most frequently, disability income of about $733 per month.

One participant who invited me to her home to conduct the interview warned me to make sure I used the bathroom before I came (and don’t drink a lot of water, she laughed), then proceeded to give me a tour of her rental home. She worried because sewage was backing up into
her tub and she had to keep bleaching it before using it, and the fumes were irritating her throat. She expressed concern for her pet that she had to expose them to that environment, but she had had a hard time finding such a large place for only $500 (which left $100 for electric, and $33 for food each month) that she was not sure she could leave. She had asked the landlord repeatedly to come to repair the bathroom, but he kept putting her off. “This can’t be good for my immune system’, she said, but there was not much more she could so at this time but keep the door closed and keep cleaning as she could.

Two participants indicated that they had moved to the Tampa area for different reasons, but now they were ‘stuck’ due to their incomes and their housing situations, which made leaving difficult. In both cases, they indicated that supports were better where they came from – from HIV-related assistance, housing, and food supports.

*A big source of stress is housing. We moved to FL 2 years ago and were really surprised by how high the cost of housing was. Now, we’re just kind of stuck, though. Because we live so paycheck to paycheck, there’s no way to save up enough to move to another place in FL, let alone move back home. The sense that we’re trapped, that it’s never going to get any better, is just too much.*

- Interview #12

The second participant shared their story about the past two years that they had been in Tampa Bay. Since moving here to help a sick relative (who promptly kicked them out, then died), they mentioned having lived in five different places, including being homeless for three weeks. From a rental home to a motel to a shelter, then homeless, and now again in a rental home that she was at risk of losing due to getting behind on her utilities – they had never spent more
than a few months in one place. She indicated that her housing situation was stressful, but that she had many other sources of stress – too many to keep track of.

*Your income levels influence housing opportunities, even for Section 8 or the Housing Authority in Tampa. And the waiting list (for housing) is so damn long that you couldn't done died three or four times while you're still waiting for your name to get on the list to get help. It's... it's not right. I mean, it's like the state of Florida don't give a damn about people if they don't have any money. It seems like it's geared around tourism. And between the tourism and gambling, they got a whole bunch of things going on that makes plenty of money, including the driver's license that's overcharged and they don't give anything back to people that don't...to people that are without, including kids. And that's kind of sad that this place has that much money and they won’t or don't help people.*

- Interview #6

Several individuals transitioned from homeless to housed, even if only temporarily, between the time of their survey and follow-up interview. Overwhelmingly, these participants reported a significant reduction in their stress levels related to several different areas of their lives – personal safety, a safe place to store medicines, and a place to cook and store food, among others.

*Interviewer:  So how is it getting used to that? You said at the start that's been a stress relief for you because of finally getting HOPWA.*
Respondent:  It’s great, it’s really great. I mean, I go shopping. I do get food stamps. I go shop, go back home and cook what I want to, eat what I want to. I got everything there, you know - picking plates and spoons, and looking great - and don’t have to worry about others acting crazy.

Interviewer:  Acting crazy?

Respondent:  Maybe just staying with somebody wasn’t it, that's all. People are so funny when you stay with them. I was riding crazy. I was using again for a little bit, and the next thing - I seem frustrated because people always rob, frustrated because I couldn't find an apartment. And meanwhile, there people using. I'm like shit. I'm like what's going then. But you know I was like No. I got to get out. I could have been homeless, I put myself in that situation. I'm like you know what, God is good - like there it is, there’s HOPWA. I don’t like staying with people. It’s hard when all of your goals are different.

- Interview #13

Interviewer:  So, we didn’t record your survey, but I wanted to ask - it sounds like you’re happier now?

Respondent:  Yeah. Man, let's make it much happier, of course, healthier and caught up in pounds, stronger, you know. I did this job this last week, and if I weren’t been eating right and rest then I wouldn’t have made it through a week. So...

Interviewer:  But while you are on the street...?

Respondent:  Yeah. I couldn’t, I couldn’t endure a day’s work. But that’s all I have. You know? Really, I stand going to the spasms and stuff you know and buy a lot of iced tea
and drinks and sodas and things like that. Water, so it’s very much different now than being on the streets - that made a big deal. It’s pretty scary to think about it, but when people are out there on the street with AIDS, HIV and they don’t know what to do. If this helps more power to them, you know.

- Interview #11

While the majority of respondents who transition from homeless to housed reported mainly positive changes, one participant described the complexities of managing multiple concerns now that she was housed – including accessing food, paying utilities, and maintaining her housing support.

**Respondent:** I live on Section 8, that and what my son can help me with. I found somebody that would give me like at least 75% of the food stamps, and that's my lights.

**Interviewer:** Okay.

**Respondent:** I'm going to pay my water now.

**Interviewer:** Hmm.

**Respondent:** And I solely eat pantry food.

**Interviewer:** Okay.

**Respondent:** If I were to open my cabinets now, everything in there is pantry food.

**Interviewer:** Hmm.

**Respondent:** Everything in there is pantry food.

**Interviewer:** Wow. Okay.

**Respondent:** And I can show you.
Interviewer:  *Section 8 - What does that cover for you? Does it cover everything or?*

Respondent:  *Yes, it does.*

Interviewer:  *Okay.*

Respondent:  *Since I have zero income, they charge me no rent. They took... like they pay the full rent. When my child is returned to me, they have income and then that means I have income, so then they gonna charge me [rent]. But then I get Medicaid again and I think the food stamp is more or less stay the same. Not sure. They also give me an allowance of $36 dollars towards the light.*

Interviewer:  *Thirty-six dollars? Just to be sure I heard right - Thirty-six dollars?*

Respondent:  *Yea, it just went up this year because it was $27. But even though it’s a little bit, it’s a lot. You know that $36 dollars go straight into the [electric company] account and gets credited, and every little bit counts. But the thing is, you gotta stay up on it. If they cut your lights, you’ll lose Section 8. Then you gotta start all over again.*

Interviewer:  *Okay.*

Respondent:  *You know what I’m saying? They pay all my rent. They didn’t throw me out, so that counts for a lot. This is the first time I’ve ever used Section 8 or food stamps. You know that because of my homelessness, I have to pay everything. Wow! I mean, I’m eating all pantry food. I’m surviving, I mean. You know, you can’t stay still. You can’t lay back, or you can’t make it.*

Though participants experienced mixed reactions (though overwhelmingly positive) to transitioning from homeless to housed, a frequent theme among those who were unstably or
perhaps under-housed\textsuperscript{10} was that housing assistance was nearly impossible to attain. Eight interview participants commented on long wait times for housing assistance, with many more survey participants echoing the idea that gaining access to housing support was a years-long process. One participant who transitioned from homeless to housed had been on one list for five years. As noted in a previous quote, a few participants (n=3) wondered aloud if they would die on the streets before gaining access to housing.

**Interviewer:** How do you take care of your rent right now? Is that something that you pay out of your disability for?

**Respondent:** Out of my disability.

**Interviewer:** Do you have access to any assistance, like through Section 8 or anything like that?

**Respondent:** No, ma’am. I think she (caseworker) looked online, and it was something like seven thousand. Down the line, so you know.

**Interviewer:** $7,000? Like income level?

**Respondent:** No, we’re like number 7,000 on the list. The list is so long.

**Interviewer:** 7,000. Have you talked to (caseworker) about that?

**Respondent:** Not yet. We got an appointment to see her, I think, on December the 11th. I don’t know from there.

**Interviewer:** How did you get on the housing list? Did you do that through here, or did you do that somewhere else?

\textsuperscript{10} housing that does not meet your needs or strains your budget.
Respondent:  
*I don't know how she did it. She got me on it. I think we went through that, what they call it, right down the street here? Okay, let me see.*

Interviewer:  
*It's not Metro, is it?*

Respondent:  
*Metro. We kind of went through them. They put us on there.*

Interviewer:  
*Okay and you’ll also talk to (caseworker)?*

Respondent:  
*I think so. But I was already on the list anyway.*

Interviewer:  
*(Caseworker) put you on the list after you put yourself on the list?*

Respondent:  
*Because it’s so many. It’s so many people doing worse than I am.*

Right now, I have a roof over my head and lights and food in my refrigerator, even if it’s a struggle. I'm doing pretty good compared to most people I do see. That's like today. It was a guy; he was at the bus stop. I only had two dollars, I gave him one and I kept one for myself. He was grateful.

- Interview #26

A couple of years ago – after collecting the data for this dissertation but before writing up, I attended a local HIV symposium where I presented a poster with some preliminary findings. During a work session at the symposium, I found myself seated next to someone from the City of Tampa’s Housing Authority office. I took the opportunity to introduce myself and describe my dissertation research. My fieldnotes on the encounter are supplied below.

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Noble:  
*“The participants in my study have shared with me that they are really struggling to access housing here in Tampa. They’ve said that the housing list is*
thousands of people long and that the wait time is something like 5 years.” I did not have the chance to form my question because she broke in.

City of Tampa employee (CTE): “That’s because they ask for the wrong thing.”

Noble: “I’m sorry?”

CTE: “They don’t know how to ask. They come in asking for HOPWA (Housing Opportunities for People Living with HIV), and if they do that, I can only put them on one list.”


CTE: “If they just came in and said, ‘I need housing assistance,’ I could put them on five lists. But if they say “HOPWA,” I can only put them on HOPWA.

Noble: “Hmm, that’s interesting. Who teaches them how to ask the right way?”

CTE: “What?”

Noble: “Does anyone teach them how to ask the right way? Do caseworkers know how to ask the right way? I am just trying to understand.”

CTE: “What do you mean?”

Noble: “Do they know there’s a right way to ask? Could you tell them the right way while they are in your office?”

CTE: “No, that’s not possible.”

The working session started, and she’s talking to the fellow on her right. CTE pulled out her phone, grabbed bag, walked over to drink table, grabbed water and exited into the hall. I’d looked for her later and found her at a table towards the back (I was seated up front). Card in notebook for reference.
Qs

- Are these really the rules?
- I know FH does lunch and learns. Can we do something there?
- Do FH caseworkers know this?
- Potential issue – housing waitlist is 5 years long. What if they knew the ‘right’ way?

Is this an issue of funding? Bureaucracy? An implementation issue?
Miscommunication? Cruelty?

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This conversation seems to be indicative of the kinds of barriers and stumbling blocks that participants encounter when attempting to obtain forms of social support to meet their needs. The tone of the exchange with the CTE was short, matter of fact, and perhaps tinged with annoyance. It seemed apparent that, at least in this one employee’s view, there were rules in place that forbade her from offering other forms of assistance, regardless of whether the person seeking that assistance was eligible or not. In addition, questions about who knew these rules and if they could be shared with caseworkers or potential applicants were met with seeming confusion. When the employee abruptly left the table at the start of the session and moved to the back of the large room, I began to wonder if her behaviors were a form of gatekeeping or if there were, in fact, rules in place that disallowed offering other services. What would be the goal of having such a rule in place? As mentioned in my field notes – the HOPWA waiting list is reportedly so long that it takes roughly five years to be approved for supportive housing. This leads to unanswered questions about how long would the housing list be if people learned to ask the right way.
The Gray Place

While some means of coping with these various issues are within their control, most participants find that the ones they need most are not. Resources like SNAP, HIV medication support, disability, and housing all require regular recertification, have complex rules and processes, and failure to meet requirements threatens to topple an already delicate balance. This constant struggle seems to contribute to a sense of hopelessness because they feel like they have fallen through the cracks. Some participants described this as a ‘shadow place,’ the ‘gray place,’ ‘the place between,’ or a place where one is invisible.

I can't change my situation. Acceptance. I turn God...give it up to God. [pause] And I cry. I never cried like this before. I was waiting six months to a year to find a place to live, then maybe I cry once a year and can't breathe in all this. I can't eat. No one cares if they see me at the doctor's or not. It's like I've disappeared. But now I know how to calm myself down. I know how to let my emotions go. I know how to let you know how I feel. I never knew life was like this, so like the weight of the world. I want to hide and run to an island in woods. That's it and to learn how to eat trees, but you can do it and stay alive. So, I've been asking people and stuff like that and people who live in the woods, and that's how they choose to live. It can't be harder than all this.

- Interview #23

Respondent: All I know is this. I gotta get some money. I gotta eat. I got to be able to get a place to stay, I need transportation, so if I am constantly going from this place to that place. I got to be able to have a time to get employment, to not be in this situation. It’s a daily situation in this, and it’s not good – this gray place - it’s not good though,
seriously. And if you do get employment then say your prayers, you’re a guy, or you’re a woman, and you get your day to day job, let’s say you gotta work from 9-5. And you got HIV. You will never ever get the help that you need in state of Florida because everybody shuts off at 4:00 pm pretty much. Not even 5:00pm. 4:00pm. There’s no walking in, no nothing. And for the people who have HIV, and they’re functioning – Guess what. They are gonna have a primary doctor, they do this right here, they don’t associate, and they can’t associate because, after 4:00, there is no place open – name a place in the whole state of Florida that’s open for HIV after – let’s say pretty much after 4:00.

**Interviewer:** So, are you saying that, if you have a job, even a job that could fix these other areas of their lives? That it would be a barrier to your health?

**Respondent:** No, it wouldn’t be a barrier to my health. It’s just – when can I get my meds? Can we get a 5:00 – 9:00 pm program or whatever it can be? For those who have HIV who actually do function? That would help. But not in this state. We don’t exist.

- Interview #45

It’s like we’re in this shadow place. The system here is set up so that people fail. No one person could possibly fight them to get the housing they need, help to get enough food, help with your medicines. All my problems have a pill – if I took them all, I would die. If I took all my medicines, I’d never get out of bed. Who’s gonna take care of my husband, who is on oxygen? Who’s gonna take care of the house? The bills? My food and my medicine are the last things on my mind. Half the time, I gotta leave it.

- Interview #41
I keep telling the doctors, "I'm not the statistic, I'm an individual human, and I want to be treated like that, and if you can’t treat me like that, I don’t want to see you. I deserve to be seen.

- Interview #9

Girl, this place is set up for failure. Anywhere you look at it. I don't know if I'm just blaming, but all I can say is that I've had problems from the judicial system to the food places to the HIV places. Stuck in this place in between. It’s just - I feel like a horror story.

- Interview #6

Tampa is one of the hardest places to live. THE hardest. If you’re disabled, it’s extra hard. Add in being HIV+ on top of that? It’s triple hard. The cost of living here, the cost of housing...the bureaucracy? I’m struggling, but food is the least of my worries.

- Interview #26

Summary

In this chapter, the mental health findings are summarized from the quantitative part of the study. Participant narratives about the experience of managing various issues related to their everyday lives are presented. Nearly half of the participants in this study report struggling with mental distress in the form of depression and anxiety (HSCL-10; 46%) as well as high levels of perceived stress (PSS-10; 48%) – and there is a statistically significant difference in PSS when comparing the different adherent groups. Correlation analysis indicates that there are significant relationships between mental health and food security, as well as between mental health and
stable housing. Further, SNAP is linked with lower levels of diet quality, though people with SNAP are more likely to be stably housed. People who do not receive SNAP are 2.483 times more likely to be non-adherent, and for each unit of increase in the HFSSM (food security scale; higher scores mean worse food security), the individuals in this study are 1.115 times more likely to be non-adherent.

Participants in this study frequently struggle with issues beyond any attempt to manage their HIV. They report experiencing stress related to shifting forms of support, attempts to meet basic needs such as housing, food, utilities, and hygiene items, and the overall wear and tear on their mental health that these frequent and overlapping issues present. Housing offers opportunities to improve the situation for participants in this study – and indeed, it has already helped a small number, but housing alone is not a panacea and brings with it another set of circumstances that must be managed. Additional barriers to housing include potential implementation or funding issues that are outside the scope of this dissertation but may offer opportunities for future research.
CHAPTER 8: DISCUSSION

The men and women in this study live with HIV while experiencing a myriad of other challenges that threaten their ability to adhere to an ART regimen. Many face concurrent health issues - each with their own symptoms, pill schedules, doctors’ appointments, and impacts. They experience these issues in the context of poverty, unstable housing, food insecurity, poor diet quality. While struggling to survive, they frequently experience frustration when they make gains in one area only to lose ground in another – such as gaining access to housing supports but then having their food stamps reduced or canceled. The burden of dealing with these issues concurrently and repeatedly is overwhelming, and their feelings of anger, shame, and exasperation are palpable. As they discussed the ways they have tried to cope with these various issues, it is not hard to understand why more than half experience high rates of emotional distress.

Through the lens of critical medical anthropology, their collective experiences illustrate the grueling impact of the structural violence of poverty and their “common forms of lived oppression” (Singer and Erickson 2011:1) while living with HIV. The distress they feel as a result of trying – and often failing – to meet their needs, let alone manage HIV, is a form of social suffering – or the problems that result from “what political, economic, and institutional power does to people” (Kleinman, Das, and Lock 1997:ix). It is not only the synergistic relationships at a biological level between food insecurity, diet quality, HIV, and mental health that affect people living with HIV. For people living with HIV who also experience poverty, it is
also the stress of interactions between various forms of social support that constrain their ability merely to get by.

In this chapter, the main findings are summarized as they relate to food security, adherence to ART, and mental health, using the syndemics framework. The study results are then examined in relation to the research questions and in the context of the literature. Recommendations and implications for policy are offered for consideration. The chapter concludes with a discussion of the study limitations, lessons learned, and suggestions for future research.

**Food Security-Related Findings**

Looking broadly at the experiences of food insecurity, in Chapter 5, it is clear that there was some variation, with 30% experiencing high food security, and 35% experiencing very low food security. However, seven out of ten participants reported at least some degree of food insecurity, and just under 60% worried about whether they would run out of food before they could get more. These concerns often led to significant efforts to ameliorate food insecurity. Many attended group sessions at Francis House or signed up to do tasks around the site to earn Francis House ‘dollars’ which could be spent in the on-site food pantry. Others shared strategies such as attempting to coupon, purchasing set ‘meat plans’ from local markets, selecting grocery stores based on perceived value for the dollar, or visiting other food distribution sites in the area. These strategies align with those found in other research on food insecurity (Anater et al. 2011; De Marco, Thorburn, and Kue 2009; Jacknowitz et al. 2019). Challenges in utilizing these strategies included lack of transportation or time to travel to the cheapest grocery stores or wait at food distribution sites.
Regardless of food security scores or categories, overall, the dietary quality of respondents is low and in need of improvement. As demonstrated by the findings from the 24-hour dietary recall that was converted into the Healthy Eating Index, diets are characterized by low consumption levels of key healthy foods such as whole grains, whole fruits, and whole vegetables. In addition, there was a higher consumption of empty calories, sodium, and refined grains such as sodas, juices, and snacks like chips and cookies. In many cases, foods for the household were obtained through SNAP or food pantries. Though three-quarters of participants rely on SNAP to supplement their food purchases, roughly 60% reported that the amount they receive is not sufficient to meet their household needs. Participants frequently reported consuming foods they did not necessarily want to eat, particularly later in the month before the next cycle of benefits was released. Diets became less varied, and people had to work with fewer and fewer items left in the cabinet – rice, beans, condiments such as the individual who considered eating a ketchup and relish sandwich. Again, these finds align with what is seen in the literature in terms of cyclical nature of food access throughout the month related to SNAP (Whiteman et al. 2018) as well as low diet quality for those on SNAP (Whiteman et al. 2018; Robaina et al. 2013).

Participants reported experiencing gains and losses in terms of access to and amount of SNAP. Many participants exhibit attempts to manage food insecurity difficulties through familiar strategies: reducing the quality and quantity of foods consumed, triaging food consumption to buffer children, relying on others such as family or charitable organizations, or reallocating resources. For example, cheaper cuts of meat or generics might be purchased to stretch the food budget. Mothers eat less or decline to eat at all, telling their children that they are not hungry. People seek out food donations from churches and community organizations to
supplement their pantry. Individuals might sell items, or put off paying a bill, in order to afford putting food on the table. Though these coping strategies are not unique to PLWH, they do contribute to the daily struggle of managing their HIV while also attempting to cope with other issues.

Participants remarked that food distributions did not always provide the healthiest food options. One participant discussed wanting more fresh fruit since she liked to snack in the evening but instead had to reach for the cookies that she received in a pantry box. Other participants remarked on the minimal amount or lack of fresh fruits and vegetables and explicitly linked the lack of these healthy options to high rates of obesity and heart disease. Often, food boxes were laden with day-old baked goods, processed meats, and canned vegetables; thus, it is not surprising that dietary consumption patterns mirror this.

Another strategy used to ameliorate food insecurity is survival or transactional sex, where food, money, or other resources might be exchanged (Bryceson and Fonseca 2006; Romero-Daza 1998). Some participants reported engaging in these strategies now or in the past. For example, a woman might stay with a partner they do not love in order to gain or maintain access to food and housing. Another reported engaging in sexual acts as a child to earn money to help their family purchase food and other items. These early strategies were linked to later bouts of depression and sexual risk-taking, and highlight the synergies between food insecurity, mental health, and HIV.

**Mental Health-Related Findings**

In Chapter 6, it was noted that nearly half of the participants in this study struggle with mental distress in the form of depression and anxiety (HSCL-10; 46%). This finding aligns with a Cochrane review of the prevalence of depression among PLWH, which had an average range
of 40-42% (Nanni et al. 2015). Participants reported numerous issues that affected their mental health, including worries over having enough food, having enough money to pay bills, having concurrent illnesses to manage, and struggling to make ends meet. But they also described other issues such as interpersonal interactions among other Francis House clients, family members, loved ones, school, and crime. These were things like might cause them to have ‘a bad day,’ but they were frequently described as short-lived concerns.

Mendenhall (2012) noted that going into her dissertation that she thought that diabetes would be the number one stressor that her participants faced. Instead, her participant’s narratives identified ten forms of social stress. These included various forms of abuse (interpersonal, physical, sexual), financial, work, or immigration stress, neighborhood violence, family stress, loss of a family member, and health stress - and diabetes was only part of this theme (Mendenhall 2012). Health stress was the fourth most prevalent stressor. These findings arose despite the finding that 90% of her participants had poorly controlled diabetes.

Similarly, I thought that the participants in this study would report that food insecurity was their number one stressor. Instead, I found that while they had difficulties with having enough food, that food was the ‘least of their worries.’ Food insecurity seemed to be the most modifiable need, the one they might have the most control over. Their options to address food insecurity ranged from altering the quality of their foods, reducing the quantity, obtaining food from churches or other organizations, or reallocating resources, and so forth. Less flexible were responsibilities such as utilities, rent or house payments, or other bills. Often outside of their control were issues like unstable housing, unreliable transportation, difficulties getting to and from appointments, aggravations dealing with the staff at state, county, and city offices where they sought assistance. While some aspects of managing their HIV were under their control,
many participants were preoccupied with dealing with a myriad of other, more immediate stressors.

**Syndemic Framework-Related Findings**

As noted in the previous chapter, participants frequently struggle with issues beyond any attempt to manage their HIV. They report experiencing stress related to shifting forms of support, attempts to meet basic needs such as housing, food, utilities, and hygiene items, and the overall wear and tear on their mental health that these frequent and overlapping issues present. Rather than be able to report any one stressor that rises above the rest in importance, through the course of their narratives, we find myriad issues that require some form of coping – with some things within their control, but many others were not.

Housing was a prominent, emerging theme, and many participants spoke about challenges as well as opportunities. While more than 30% of participants reported having unstable housing, there were a few individuals who transitioned from homeless to housed between survey administration and the interview. Most of the attending changes were positive, such as having a safe place sleep as well as store food and medicine. Access to affordable, stable housing has the potential to improve the situation for many PLWH, but it was discovered that housing alone is not a panacea. One participant reported having to sell their food stamps to obtain enough cash to pay a utility bill, which could not be late or turned off, or they would lose access to their housing support. This finding is similar to a recent exploratory study of previously homeless adults found that even when provided with permanent supportive housing, participants still struggled to cover other expenses such as bills or food (Bowen et al. 2019). Further, in a large multi-site prospective study, Giordano and colleagues (2018) found that providing
participants required more than housing and HIV treatment to improve quality of life. The participants still had unmet needs in areas such as mental health, food insecurity, and unemployment (Giordano et al. 2018). Housing is important, but only meets some of the needs of people living with HIV.

This study found that participants who have SNAP are 2.5 times more likely to be adherent. Though this would make SNAP appear to be protective for ART adherence, there are some factors to consider. Having SNAP might mean that someone meets the income requirements and needs financial support to acquire food. But not having SNAP does not mean that someone does not need that support. People might not have SNAP because they are not aware of the resource, or they cannot figure out how to apply. Someone might not have SNAP because they cannot produce the documentation to prove their eligibility. In addition, participants in this study sometimes reported receiving low funds from SNAP (such as $10 per month); it would be difficult to argue that SNAP in such a low amount could significantly impact food security. Thus, more research would be needed to better understand the relationship between SNAP and adherence. Similar to the impetus for exploring food security categories rather than a simple binary yes/no food security status that motivated this study, future research should consider exploring the complexities of SNAP status and its relationship to ART adherence.

Further, as previously noted – interactions with various social service agencies were a source of stress and anxiety for participants. Resources like SNAP, HIV medication support, disability, and housing that require regular recertification have complex rules and processes. Participants reported losing SNAP due to a missed recertification appointment, reductions in SNAP amounts, housing vouchers approved after a five-year wait, and disability finally awarded. Even when outcomes were positive, there still seemed to be concerns that the balance could be
upset. One participant was trying to figure out how to pay back social security benefits that had been overpaid to him. “All I did was cash the check they sent me,” he remarked, but he was told there was no point in fighting the government. “Go to the judge and throw yourself on the mercy of the court,” was the advice that someone else had given him. He owed thousands and would need to pay it off a little at a time.

This constant struggle seemed to contribute to a sense of hopelessness for some because they felt like they have fallen through the cracks. These participants who really struggled with maintaining social supports described this as a place where one is invisible, or a ‘shadow place,’ the ‘gray place,’ ‘the place between.’ One participant noted that they had swallowed their pride and asked for help – thinking that overcoming the stigma of requesting government assistance would be the hardest part of the process. Instead, the participant has made more than six attempts to register themselves online for housing support or has called to request a call back to apply for housing support. After six months, she still did not see her name on the list and had never gotten a call back. She has lived in motels, a shelter, and on the street but has received no response to her requests. Her frustration spills over when she relays this story each of the times I see her. She says she knows that they will think she is the ‘typical angry black woman,’ but she cannot help it. She is angry. She feels like the system here has set her up to fail, that it is corrupt and that she is invisible to those in positions of power.

This frustration is apparent in other interactions. One participant screamed abuse at me because I had taken another individual into the interview room when he had been 45 minutes late. I had been told that he had called and canceled, so I moved up the later appointment. He arrived and banged on the door, demanding to be seen right away. Since the interview room was off the main entrance, I guided him outside so we could talk quietly away from everyone else.
He yelled that he did not cancel and had taken two buses to get there. He complained that he was always being treated like shit. At one point, he turned and raised his fist – in frustration or to strike - I was not sure at the time. I said that I could see him after I finished with the person that I was with, and we were close to finishing. I appreciated his going through all of those efforts to get there. I could still see him that day if he could wait a few minutes. He cursed at me and walked away, saying he had other things to do. I gave him the benefit of the doubt and tried to contact him again for an interview, but he never responded.

I confess that in my initial assessments of this interaction, I focused on the perceived risk to my safety. I debated whether it had been wise to have this discussion outside. I was concerned that his flash of anger was not something he could contain. He was seething.

On reflection, I wonder how much of his reaction is related to the gray space, or the sense that one has fallen through the cracks, is invisible, or their needs are not being met. The participant had undertaken a considerable effort to get there for his appointment. Participation in the study would net him a $25 gift card. He had made an appointment, and though he had been late, this had been out of his control. One of the buses he planned to take had never come, and he had to wait for the next. If he had called me, there is a chance that I would not have heard it after I took the next appointment. He had had to bring a photo ID and medication bottle; he could not find the ID, but at his request, his caseworker provided me with a photocopy of an ID that he had provided to them so that he could prove who he was and participate. After all of that effort, he arrived to find that someone else had taken ‘his’ appointment. And then, the woman doing the interview tells him, if you sit and wait, I will get to you soon. I do not know if it matters how politely I tried to let him know that I could still take him. Did this encounter remind him of another time when someone had failed him? Did his comment that ‘everyone treats him like shit’
reflect a history of challenging encounters with caseworkers, social support staff, and so forth? I do not know for sure because he walked away angrily and never came back.

The data in this study demonstrate the difficulties of remaining adherent to antiretroviral treatment for people living with HIV in the southern United States, who are also struggling with issues such as food insecurity, poorer mental health, and economic scarcity. Each of these is a challenge they regularly face, with some waxing and waning through the time of the month, though the seasons, or through periods of eligibility and paperwork. The participants in this study attest to the burden of dealing with one or more of these issues and how they influence one another, as well as to how the mental wear and tear of precarity can bring a sense of hopelessness, a sense that they are not seen as human. Given the synergistic relationships between these myriad hardships – in positive and negative ways – it is difficult to make policy recommendations that call for anything less than comprehensive, wraparound support. Overlooking the intricate relationships between their struggles invites adding an additional burden to an already vulnerable population.

**Limitations of this Study**

This study has several limitations. First, studies that retrospectively examine food security, including dietary intake methods, are subject to participant recall (Gibson 2005; Willett 2013). Participants asked to self-report levels of adherence may be subject to social desirability and response bias (King and Bruner 2000) in that participants might wish to report behavior they believe others will view positively and are less likely to report behaviors that may be viewed negatively. As a cross-sectional study, and one that focuses on a particular population in Tampa Florida, the findings from this study are not generalizable, though the findings from this study
reflect those found in other published research that examines food security and ART adherence here in the United States. For the qualitative phase of the study, participants were asked to discuss their experiences with food insecurity, adherence to ART, and experiences accessing health care. Discussions about these topics may again be subject to social desirability and recall bias; however, the way that individuals experience and talk about their subjective reality—whether or not it conveys an ‘objective’ truth or series of facts, still serves to provide participant viewpoints about the relationship between their health issues.

**Lessons Learned**

One key challenge encountered early on was the attempt to perform an unannounced pill count as an ‘objective’ measure of ART adherence. Through a misunderstanding this researcher had at the start of the study, I instructed participants to bring ‘a bottle’ of their HIV medications as well as a picture ID, as a way to demonstrate their eligibility for the study. For the first 25 or so surveys, nothing seemed amiss. However, I started to notice that some participants brought unopened bottles of medication, with dates that would seem to indicate that they were prescribed 2-3 weeks or more prior to the survey yet. At first, I thought this was indicative of poor adherence; I continued to capture the information from the bottles (with permission from participants) and used the data to calculate adherence based on pills expected, pills present, and the refill date.

Around interview 35, a participant brought in three brand new, unopened bottles with the same refill date, one week prior to the survey appointment. Upon questioning this interesting circumstance, the participant let me know that based on their health care coverage, they received three months of medication at one time. Subsequently, other participants indicated that they had
‘extra’ medication at home. This could be due to changing regimens (but some wanted to use up the old medication so it did not go to waste) or because pharmacies were said to bring prescriptions ‘early’ to avoid lapses in medication, resulting in a surplus.

Because of the obvious implications for the quality of this data, I continued to use the process as a method of confirming eligibility but decided that I would have to use only the self-reported measures of adherence. It should go without saying, but one recommendation from this experience is to be certain that you are completely comfortable with any methods proposed in your dissertation and potentially perform a pilot test to ensure that they work as intended.

A second lesson learned would be to audio record (with permission, of course) any encounter with study participants. During the course of the survey, the majority of participants seemed to feel compelled to qualify the answers they provided for the paper and pencil survey that I completed with them, face to face. I typically sat nearly knee to knee with participants, the paper survey attached to a clipboard that sat on my lap as I asked them questions. Though most questions only required the selection of a multiple-choice response, participants often elaborated on their responses and made linkages on the fly to other topics of interest in this study (usually one or two pages back in the survey). In many cases, I was able to quickly jot down field notes after the survey to capture the encounter, but occasionally these narratives extended beyond the typical hour that had been set for surveys that – once, I did 4 surveys back to back without a chance to immediately capture notes. A recording of those sessions would have allowed for better recall as well as capturing verbatim some of the connections that respondents were making as we spoke.
**Strengths of this Study**

At the time that this study was proposed in 2014, to my knowledge, there had been no qualitative research that examined the relationship between experiences of food security and ART adherence in the United States. In the gap between proposal and dissertation completion, I found two studies that qualitatively explore issues related to the conceptual framework that Weiser, Young et al. 2011b were published by members of the study team at the University of California, San Francisco (Whittle et al. 2017; Whittle et al. 2016). One strength of this study is that it contributes a more in-depth examination of the relationship between food security and ART adherence, including the presentation of mixed methods displayed to better understand the relationship between ART adherence and the different categories of food security.

Whittle and colleagues also qualitatively investigated the impacts of food insecurity on ART and found that key mechanisms for these impacts included, 1) worsened ART side effects when participants lacked food, 2) physical sensations of being hungry and tired, as well as experiencing HIV-related stigma at food distribution sites (Whittle et al. 2016). In this study, participants also noted the influence that food had on ART side effects, but also highlighted the sense that not only did a lack of food worsen the experience of taking ART – ART worsened the experience of having enough food. Similar to findings from my thesis research in Lesotho, where participants referred to ART as “a parasite that consumed everything she put into her mouth, leaving nothing for her” (Noble 2010:85), participants characterized ART as “hungry” or “thirsty” and needing something to satisfy it.

For their second article, Whittle and colleagues investigated the ways that people living with HIV or diabetes experience the system of disability benefits (Whittle et al. 2017). Participants in that study identified experiences with “excessive, obstructive, and penalizing
bureaucracy from social institutions” (Whittle et al. 2017:181). Participants in this dissertation also highlighted the difficulties they had with navigating the process of recertification, managing multiple forms of social supports, and the push and pull that arose when something in the process failed. These narratives, as well as the encounter I had with a City of Tampa Housing Authority employee, raise questions about the ‘user experience’ of applying and recertifying for various forms of social supports (Hebert 2012) and whether or not these processes add further barriers to ART adherence by ‘rationing through inconvenience’ (Kingfisher 1998; Susser 2012).

Related to this sense of exclusion, this dissertation also contributes to social science theory by exploring the lived experience of the structural violence of poverty and the ways that policy renders risk. In truth, the daily challenges and grueling impact of their collective experiences have much in common with other anthropological and sociological studies of urban poverty in the US, such as Kathryn Edin’s work on single welfare mothers (1997), families in the US living on less than $2.00 a day (Edin and Shaefer 2015), as well as Matthew Desmond’s (2016) work on families facing eviction. Substitute any other health condition or chronic disease for HIV or move this study to another urban city and the experiences would not change much. The findings in this study demonstrate that the need to juggle various forms of social support in order to make ends meet extends well beyond the realm of health.

**Recommendations**

This study’s findings compel me to make several recommendations for on-the-ground interventions aiming to improve the health and well-being of PLWH.

- **One recommendation would be for HIV service organizations to seek out reliable funding for purchasing food and other items as well as covering staff time (or hiring**
part-time staff) to manage a food pantry. The organization that served as the site of this study (Francis House) offers several supports to address food insecurity among the clients – from hot breakfasts or pastries and coffee in the morning, and hot lunches offered Monday through Friday, as well as an on-site food pantry. However, the food pantry was frequently empty during the year that I spent actively going to Francis House. This was attributed to both funding issues as well as lack of staff dedicated to retrieving, stocking, then distributing food, as caseworkers and staff had other responsibilities. Participants highlighted how helpful this pantry was when it was filled, as this resource often helped them fill gaps that SNAP and other food distributions left in their own pantries. In addition, their food pantry was set up in a way that clients could earn dollars for attending group sessions and doing tasks around the building, such as cleaning up after lunch. This purchasing mechanism allows participants the agency to choose which foods or other goods they would purchase with their efforts.

- **A second recommendation would be for HIV service organizations to consider initiating a food or meal delivery program for their most food insecure clients.** Many participants reported that part of the reason they went to groups at Francis House was to earn a free monthly bus pass, which enabled them to attend health-related and other appointments, continue to travel to Francis House, or shop. However, making a big shopping trip at a cheaper store, or traveling to a food distribution point, is difficult to do when the bus is your one source of transportation. Based on findings that even formerly homeless but currently housed individuals still struggle with other costs such as bills and food (Bowen et al. 2019, HIV service organizations might consider delivering boxes from their food pantries or hot meal programs to clients lacking transportation. These types of
services were seen as desirable to potential clients in a study of Latina women living with HIV in New York City (Chase 2011). Services like these were also seen as instrumental in demonstrating that the organizations cared about the clients as whole human beings, rather than simply numbers that caseworkers could bill for seeing (Chase 2011). In addition, these deliveries could reduce food insecurity rates among clients, reduce anxiety around having enough food, and potentially open up resources to apply to other needs.

- **A third recommendation would be for HIV service organizations to consider delivering workshops or lunch and learns on the topics of obtaining and maintaining social supports such as SNAP, disability, Medicaid/Medicare, and housing.** Participants often indicated confusion, difficulties, and frustration around the requirements of various forms of social support. For example, some PLWH are eligible to apply for both Social Security Disability (SSD) and Supplemental Security Income (SSI), though, as Chase (2011) points out, most individuals have a hard enough time applying for one form of support, let alone two. While no workshop could cover all of the intricacies of an individual application, broad knowledge about eligibility requirements, typical processes for application and recertification, and potential implications for accessing more than one form of social support might serve to reduce anxiety around these processes.

- **A fourth recommendation would be for HIV service organizations to consider support groups focused on the challenges and experiences of obtaining and maintaining social supports such as SNAP, disability, Medicaid/Medicare, and housing.** As previously noted, participants often indicated confusion, difficulties, and frustration around the requirements of various forms of social support. This frustration
often resulted in long conversations about not only the struggle of the process of obtaining access to supports, but also themes of not being seen, not being viewed as fully human, or of falling through the cracks. Some participants expressed relief at simply being about to talk about these challenges with someone willing to listen. Support groups could give the opportunity for clients to hear and learn from the experiences of others, as well as offer a venue to tell their stories.

**Dissemination Plan**

The findings from this dissertation will be disseminated in a number of venues. The most immediate formats will include a comprehensive report, executive summary, and one-page data sheets provided to the HIV service organization, Francis House. The executive director has indicated interest in reviewing these findings for use in program improvement as well as to support grant applications for funding comprehensive supports such as food and housing. In addition, the findings will be presented during a ‘lunch and learn’ with the clients of Francis House, to obtain their comments and suggestions about the results and recommendations of this study. Further, a presentation is planned within the month to the board of directors at EPIC (the parent organization of Francis House) to inform multi-county HIV efforts.

In addition to these efforts, a webinar will be crafted and proposed to entities such as the Southeast AETC (AIDS Education and Training Centers). The SE AETC conducts ‘Webinar Wednesdays’ on various HIV-related topics, which would allow these findings to be disseminated to healthcare and program delivery professionals. Findings will also be disseminated through peer reviewed articles in professional journals.
Implications for Policy

In early 2019, CDC reported that progress in HIV prevention has stalled in the U.S. (Centers for Disease Control and Prevention 2019b), primarily due to gaps in effective prevention and treatment reaching vulnerable populations including racial and ethnic groups disproportionately affected by HIV, as well as in rural areas and the South. This stall is particularly concerning given that Florida, one of the top ten states for new HIV infections and the only one to experience an increase from 2010-2017, returned $54 million in unspent grant funds from HRSA that could have been used to combat HIV (Ryan 2019). Efforts in cities such as New York and Washington D.C. have demonstrated that comprehensive HIV services focused on controlling local epidemics can result in substantial strides towards ‘bending the curve.’ New York realized a 23% decrease in new HIV infections between 2010 and 2016, while D.C. saw an astonishing 40% decrease in the same time period (Centers for Disease Control and Prevention 2019c).

Washington D.C. has begun to address their local HIV epidemic by implementing extensive reforms and partnerships to target not only points in the HIV treatment cascade but with a particular focus on broad supports for vulnerable groups with increased risk of infection or falling out of care (DC Appleseed Center for Law and Justice 2018). New York has also implemented an integrated HIV care program, of which one piece is to ensure that PLWH remain in care (Shubert and Harrington 2015). In both D.C. and New York, part of those efforts to help the most vulnerable PLWH persist in treatment and achieve viral suppression includes housing support (DC Appleseed Center for Law and Justice 2018; Shubert and Harrington 2015). These efforts, though requiring financial investments, not only contribute to ending the epidemic –
which beneficial to individuals and communities - but also result in significant cost savings (DC Appleseed Center for Law and Justice 2018; Shubert and Harrington 2015).

When disease and social interactions operate synergistically, there are opportunities for interventions to do the same. Though federal policies such as SNAP may not be able to be specifically tailored for people living with HIV (PLWH), there are other potential sources for other programs that can improve their lives. PLWH have increased nutritional needs because HIV affect their metabolism (Fielden et al. 2013) and SNAP does not take this increased need into consideration. However, the Ryan White Care program has provided food and nutrition supports to PLWH in the forms of home-delivered meals, pantry or grocery bag programs, congregate meal sites, and vouchers (Aidala et al. 2015). These types of supports have the potential to extend beyond the positive impacts on the nutritional status of PLWH, including improvements in mental health and ART adherence.

In addition, Dr. Robert Redfield, director of the Centers for Disease Control and Prevention, highlighted the existence of small, localized ‘hotspots’ in the HIV epidemic in the U.S., with more than half of HIV infections occurring in only roughly 50 areas out of 3,000 – including 48 counties, D.C. and San Juan, Puerto Rico (Johnson 2019). Seven of those counties - including Hillsborough County - are in Florida. This realization helped to bring about renewed efforts to tackle the HIV epidemic in the U.S., including the “Ending the HIV Epidemic: A Plan for America” – which proposes to target these hardest-hit areas with additional resources to assist with four goals: 1) early diagnosis of all individuals with HIV, 2) rapid and effective treatment to achieve viral suppression – including increased investment in the Ryan White Care program 3) use of interventions like PrEP and syringe services as part of efforts to prevent new HIV
transmissions, and 4) ensure that communities have the tools and knowledge needed to quickly investigate and respond to potential HIV outbreaks (HIV.gov 2019).

Given that 61.3% of HIV transmissions in 2009 could be attributed to PLWH who know they are infected but are not retained in care (Skarbinski et al. 2015), increasing investments in ensuring PLWH have the supports they need to manage this HIV is paramount. Whether using models from D.C., New York, or the new federal plan to tackle HIV – ideally, this focus on local epidemics, with calls for increased investment of attention and resources for the most vulnerable populations and places – can serve to address the myriad barriers that stand in the way of ending the HIV epidemic.

This is where applied anthropology, critical medical anthropology, and syndemics can contribute most to ending the HIV epidemic. While epidemiology has helped to identify HIV hotspots in the U.S., applied anthropology and the lens of critical medical anthropology is needed to map out the particular sets of syndemic factors contributing to poorer outcomes in that location. This understanding must draw on both a biological understanding of the synergistic relationships involved, but also the social and economic conditions within which the syndemic thrives.

In seeking this understanding, the use of mixed methods is vital. Quantitative data are needed to assess and quantify the synergistic relationships driving poor health outcomes. To better understand how populations experience and cope with food insecurity and other challenges, we need rich, qualitative data. Integration of both allow for triangulation and the contextualization of findings, and rigorous testing of syndemic interactions could increase the precision and predictive power of syndemic theory.
Suggestions for Future Research

This study’s findings offer insights into the relationship between food security, diet quality, mental health, and ART adherence. I offer some suggestions for future research based on findings from this study as well as unanswered questions.

It would be interesting to explore narratives about the process of applying and recertifying for various forms of social supports. While conducting these interviews, I did not believe my task was to assess whether or not the barriers that participants reported were ‘true’; I wanted to understand how they experienced these multiple issues. But after relaying the conversation that I had had with the City of Tampa employee (CTE) about housing eligibility discussed in the housing emergent theme section, I was assured by someone with expertise in this area that such a rule did not exist. I began to wonder if there were any more misconceptions on the parts of participants, caseworkers, and employees that worked in organizations offering these social supports. From these questions I draw two strands of potential future work: 1) to assess the accuracy of the knowledge that the participant/client has about the barriers they face (is this something we can address with behavioral change?) and 2) expand the inquiry to include multiple stakeholders to get a better understanding of systems-level factors that may be influencing user experiences of these barriers.

Finally, as Singer (1994; 1996) has noted, HIV is not a standard set of issues. It is more useful to imagine it as a series of ‘micro-epidemics’ among different populations and influenced by its own set of syndemic factors influencing behaviors and outcomes (Chase 2011; Goosby 2007). Because of the unique set of circumstances in each social setting, it would be useful to see this type of work conducted in additional geographic locations and communities, particularly those hardest hit by the HIV epidemic in the Southern US. Tampa Bay is one of the least
affordable cities in the U.S.; in other areas of the south, we might find that the relationship between syndemic factors of interest is slightly different depending on the conditions that shape local situations of risk. Understanding these site-specific factors may provide a key to ending the HIV epidemic.

Reflections

“My dissertation broke me.”

When I first said those words aloud a year ago in the summer of 2018, and as I write these words now, some three and a half years after I completed my last interview – I do not mean them lightly. There’s some trepidation in writing and acknowledging these things publicly – what sort of an anthropologist admits that their fieldwork evoked such mental distress that they could not function? If the field is where we earn our stripes, then to admit our weakness and failure is to say that we could not handle the work. I worried about potential career-influencing circumstances for acknowledging the trauma that the researcher experiences, let alone the shame that surrounds such admissions (Beckett 2019). I held close the idea that the very admission of such emotional impacts rendered me incapable of objective analysis, and in fact, betrayed my participants. How could I flounder in the expectation that I would convey these stories entrusted to me? How dare I compare what I feel now with the experiences the participants in this dissertation bear?

I want to emphasize that in no way do I blame anyone who shared their stories with me. As someone who carries past traumas, I know the guilt and shame that comes from trusting someone with your story, only to later regret that trust. I can pinpoint exact moments of fracture, though, in truth, it was a gradual wearing down that I did not pay attention to. On reflection, I
can see it now in my ethnographic notes. I see now that there was an event, a break, and a gradual descent into becoming too frozen and fearful of moving forward. While I had a protocol for addressing any participant’s distress, which emerged during the surveys and interviews, I did not anticipate nor have a plan for managing my own feelings.

There were two interviews in particular that led to the break. The first was when a participant revealed a time in her life where she no longer cared about herself enough to care about who she became sexually involved with. She recalled this past behavior with nonchalance. This narrative so closely described a time in my own life that I was startled and instantly became filled with shame. I was in the middle of an interview, and the memories of my adolescent ‘acting out’ in response to earlier trauma filled my head.

The rush in my head as she told her story was nearly overwhelming. But just as quickly, I slammed down a protective wall. NO. There is no place for that here, I said to myself. I was immediately back in the moment and listening, asking questions. I was successful in completing the interview without any overly emotional displays. However, this incident added to my general sense of anxiety and dread, as well as reintroducing an enormous sense of shame.

A mere two weeks after this incident, I interviewed the participant who described their history of childhood sexual abuse. Again, these experiences so closely aligned with some of my own – things I had not thought of in decades, that my ears began to roar. And again, I slammed down the barriers in my mind between remembering those things and what I was currently trying to do. I was again successful at being in the moment to hear their story. But I sat in my car afterward, trembling. I think I disassociated for a few minutes. I closed my eyes and parts of myself. I could not go there. I would not go there.
There were a few other incidents that made my dissertation difficult. There was a sexual harassment incident with one participant, whose verbal comments made me nervous but also, anxious to not offend him. We were in a closed room, and while I could shout if I truly feared for my safety, I knew the outer area was often loud, and the doors are thick. It might take a lot to be heard. Play nice, fend him off gently, finish the interview.

In addition, I had experienced food insecurity myself as a child, and when I moved out on my own at 17 years of age. Upon hearing the stories of how participants struggled with obtaining enough food for themselves and their families, I found myself adopting their coping strategies into my daily life to deal with the anxiety that I had started to feel. Ramen once again became a staple food for me, despite the fact that my income was sufficient to meet my food needs and preferences. I once again purchased cheaper quality meats, canned vegetables, shopped in dollar stores for food, even though my food budget did not require such strategies. I found myself skipping meals when I ate dinner with the family – if the roast I had cooked seemed a little on the small size to me, rather than add another side (and take more food from the cupboard), I told my family I wasn’t hungry. Or I would say that my stomach would not tolerate such a meal – I would just make a sandwich or toast. I was re-enacting events from my younger years and reliving their food-related distress. I frequently became anxious even without experiencing an inadequate food situation. My physical and mental health began to suffer.

After completing interviews in early February of 2016, I vacillated between numbness and panic. The panic frequently emerged as events of my past tried to tumble out. The things I learned during interviews snagged on memories of events in my own past. To clarify, I knew I had experienced trauma as a child – this was not a case of ‘discovering’ past abuse. I had experienced flashbacks and understood the nature of my trauma. But up until that time, I had (for
the most part) managed to suppress nearly a decade of abuse and had been able to carry on with my life.

The next two years after data collection were a blur. I took on the anxiety that my participants felt, and these struggles became tiny cracks in my armor. The memories of my own trauma became chinks in that armor, and then gaping holes. I could barely control the flood of memories, and at times I thought I could not continue on – not just with my dissertation, but at all. I had never processed the experiences of my childhood, and during this time it flooded back with a vengeance. I was frightened of everything. I found days and weeks of peace by mercilessly clamping down my emotions. I could feel… or not feel. Those seemed to be my only choices. And increasingly, I chose not feeling. I self-sabotaged diet and exercise and withdrew from relationships in all but the most superficial ways. I did my best to mimic normal but frequently failed. I broke promises, didn’t call people back, was unable to meet expectations. Every failure was another block in my ability to move on - further evidence I was unworthy. Every time I tried to approach my dissertation, to try to move things forward, I was unsuccessful. As a dear friend and mentor pointed out recently, I was ‘dead in the water.’

Individual cognitive behavioral therapy over the last year has helped me to begin to understand better what happened and, perhaps, more importantly, learn how to respond to emotional flashbacks and dissociation related to my own trauma. I also learned about vicarious trauma, or the reactions to trauma reported to you by others (Baird and Kracen 2006), such as participants and clients. This year brought me a diagnosis, a safe place to process trauma, and understand its impacts on my life now. But it also brought me a safe distance from which to approach my dissertation again.
I am grateful for the resources to seek professional help. But I also lament how ill-prepared I was to face the possibility of vicarious trauma while researching potentially sensitive topics. Though my research focused on food security, housing, and ART adherence, the literature is laden with research that links past traumas such as interpersonal violence, sexual assault, and childhood sexual abuse to high rates of HIV infection and poor health outcomes (Simoni and Ng 2000). I should have considered that hearing about past sexual trauma was a possibility, but I had such blinders due to my own experiences that it did not occur to me to prepare myself.

I share this reflection both as an explanation for the time it took to complete my dissertation but also to make others aware of the potential hazards of fieldwork. I wish these topics had come up in a graduate-level seminar. I wish a mentor would have broached the topic of the potential emotion ramifications of fieldwork, or sexual or physical harassment in the field with me. I am starting to see these stories now, but I did not know what I did not know when I started this work. There is emerging attention being paid to the mental health of graduate students, which is gratifying to see. As we move forward, I would like to encourage faculty mentors to talk with your students about these topics in classes, in reviewing proposals, and before they head into the field. An article I read recently spoke of an exercise that a graduate student had to complete before entering the field – to write a worst-case scenario and how they would cope with it, as well as a creating a mental health safety plan (Pollard 2009). I would recommend these practices. We also need to shed light on these issues, create workshops or activities to help think through possible events and responses, remove the stigma for feeling traumatized by fieldwork experiences and create or link students to institutional supports to recover from any encounters. These actions may help to alleviate the mental health impacts of the dissertation process as well as improve dissertation timelines and completion rates.
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APPENDICES
Appendix A: Informed Consent

Informed Consent Document, Page 1

Study ID: Pro00020738 Date Approved: 4/27/2015 Expiration Date: 4/27/2016

Informed Consent to Participate in Research Involving Minimal Risk
Information to Consider Before Taking Part in this Research Study

IRB Study # Pro00020738

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called: Food and Nutrition Security among People Living with HIV/AIDS.

The person who is in charge of this research study is Dr. Lauri Wright. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge.

The research will be conducted at Francis House, or may be conducted in a place where you feel safe.

Purpose of the study
The purpose of the study is to learn more about the experiences of food security among people living with HIV. “Food security” means having safe and regular access to affordable food, and enough food that you can remain healthy and active. We also want to learn more about your experiences with anti-retroviral medications. Part of this research study is being conducted for a dissertation.

Why are you being asked to take part?
We are asking you to take part in this study because you are a person living with HIV who is currently taking anti-retroviral (ARV) medications, and you are receiving services at the HIV care organization, Francis House. We want to find out how people taking ARVs understand and manage their ability to regularly get and consume enough food for healthy lives. To verify eligibility for the study, we ask that you bring photo identification and at least one of your anti-retroviral medication bottles with you to your first study appointment.

Study Procedures: What will happen during this study?
If you take part in this study, you will be asked to talk with the PI or research assistant, who will ask you questions about your access to food, your diet, and your adherence to anti-retroviral treatment. The first part of the study consists of a survey which will take about 1-1.5 hours. People who participate in this survey will be eligible to participate in part 2 of the study.
At a later time, we will ask people with different adherence rates to participate in the second part of the study (a one-on-one interview which will take an additional 1-1.5 hours. With your permission, we will audio-tape the interview. We will ask you more in-depth questions about your experiences with accessing food and taking anti-retroviral treatment. Both the survey and interview (if applicable) will be conducted in a private area. We will also request your most recent viral load test results from Francis House case managers, to help us to understand your HIV-related health. To do this, we will provide a list of study participant names and unique identifying numbers to the case managers, who will return a separate form with viral load information but without any names.

Any information that could potentially identify you will be removed from the surveys, forms, and interviews (including audio files). However, we will retain your contact information in a separate file, in a secured file on a password protected computer so that we can contact you to ask if you would like to participate in the interview. Surveys, audio files, and transcripts will be entered into a computer file. The original surveys, forms, and the computer file will be securely stored for at least 5 years. All information will be destroyed when it is no longer useful. The original surveys and transcripts will be shredded and the computer file will be deleted.

Total Number of Participants
About 130 individuals will take part in this study at USF.

Alternatives / Voluntary Participation / Withdrawal
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. 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. Your decision to participate or not to participate will not affect your ability to receive care at Francis House.

Benefits
The potential benefits for participating in this research may include: Feeling good that you are contributing to research about food insecurity in people living with HIV/AIDS.

Risks or Discomfort
Taking part in the activities of this study is considered to be minimal risk. That means that the risks related to your participation are about the same as what you face every day. There are no known additional risks to those who take part in this study. You might get annoyed, uncomfortable, or even embarrassed by some of the questions, because they will ask you about personal things. If you get a question that makes you feel uncomfortable, you should know that you don’t have to answer it. If you feel like the questions are very uncomfortable, you can decide to stop answering them altogether. You are free to stop taking part in the study at any time.

We will work hard to protect the information you share with us and to keep it private. But sometimes private information is accidentally shared with people who are not members of the study staff. This is a risk of taking part in the study that you should be aware of. You should consider this risk when making your decision whether or not to take part in this study.
**Compensation**

We will pay you for the time you volunteer while being in this study. All payments will be made with Wal-Mart gift cards. People asked to participate in both parts of the study can receive up to $50 in gift cards.

1. Baseline Survey 1-1.5 hours $25 for completion
2. One-on-one Interview 1-1.5 hours $25 for completion

**Privacy and Confidentiality**

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, study coordinator, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study. Staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

**You can get the answers to your questions, concerns, or complaints**

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Dr. Laur Wright at 813-974-8261.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

**HIPAA: Authorization to Use and Disclose Protected Health Information**

Who will see your health information?

In this research study, we use and share your health information to the extent authorized (permitted) by you. We know that this information is private. The federal privacy regulations of the Health Insurance Portability & Accountability Act (HIPAA) protect your identifiable health information. If you authorize us to use your information we will protect it as required by the law.

Research at Francis House is conducted jointly with the University of South Florida. By signing this form, you are permitting Francis House and the University of South Florida to use personal health information collected about you for research purposes. You are also allowing Francis House to share
your personal health information with individuals or organizations other than USF and Francis House who are also involved in the research and listed below.

Who will disclose (share), receive, and/or use your information?
To conduct this research, USF and the people and organizations may use or share your information. They may only use and share your information:

- With the people and organizations on this list;
- With you or your personal representative; and
- As allowed by law.

In addition to the people and organizations listed in the Privacy and Confidentiality section of this document, the following groups of people may also be able to see information about you and may use the information to conduct the research:

- Each research site for this study. This includes the research and staff at each site and USF;

Who else can use and share this information?
Anyone listed above may use consultants in this research and for the purpose of this study, may share your information with them. If you have questions about who they are, you should ask the study team.

Individuals who receive your health information for this research study may not be required by the HIPAA Privacy Rule to protect it and may share your information with others without your permission. They can only do so if permitted by the laws governing them. For example, the study sponsor may share your information with others. If the sponsor or others share your information, your information may no longer be protected under the HIPAA Privacy Rule.

How will my information be used?
By signing this form, you are giving your permission to use and/or share your health information as described in this document for any and all study/research related purposes. Your authorization to use your health information will not expire unless you revoke it in writing.

As part of this research, USF may collect, use, and share the following information:

- Your whole research record, including survey, interview, and viral load data.

You can list any particular information that you do not want us to use or share in the space below. If you list nothing here, we can use and share all of the information listed above for this research but for nothing else.

For the Research Participant (you) to complete:

☐ I am asking USF and the researchers not to include, use, or share the following health information in this research (if blank, then no information will be excluded):

Your Rights:
You can refuse to sign this form. If you do not sign this form you will not be able to take part in this research study and therefore not be able to receive the research related interventions. However, your health care outside of this study and benefits will not change.
How Do I Withdraw Permission to Use My Information?
You can revoke this form at any time by sending a letter clearly stating that you wish to withdraw your authorization to use of your health information in the research. If you revoke your permission:

- You will no longer be a participant in this research study;
- We will stop collecting new information about you;
- We will use the information collected prior to the revocation of your authorization. This information may already have been used or shared with others, or we may need it to complete and protect the validity of the research; and
- Staff may need to follow-up with you if there is a medical reason to do so.

To revoke this form, please write to:

Principal Investigator: Food and Nutrition Security in People Living with HIV/AIDS Study
For IRB Study # Pro00020738
13201 Bruce B. Downs Blvd. MDC 56
Tampa, Florida 33612-3805

While we are conducting the research study, we cannot let you see or copy the research information we have about you. After the research is completed, you have a right to see the information about you, as allowed by USF policies.

Consent to Take Part in this Research Study and Authorization for the Collection, Use and Disclosure of Health Information

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true:

I freely give my consent to take part in this study and authorize that my health information be collected/disclosed in this study as agreed above. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

__________________________
Signature of Person Taking Part in Study

__________________________
Date

__________________________
Printed Name of Person Taking Part in Study

__________________________
Date

Statement of Person Obtaining Informed Consent and Research Authorization
I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:

- What the study is about;
- What procedures will be used;
- What the potential benefits might be; and
- What the known risks might be.

Version #1

Date: 4/1/2015
Study ID: ProS0020738 Date Approved: 4/27/2015 Expiration Date: 4/27/2016

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore make it hard to understand what is being explained and can, therefore, give legally effective informed consent.

Signature of Person obtaining Informed Consent/Research Authorization

Date

Printed Name of Person Obtaining Informed Consent/Research Authorization

Version #1

Date: 4/1/2015

Page 6 of 6
Appendix B: 24-hour Dietary Recall Form

24-Hour Diet Recall

Participant ID: __________________

I am going to ask you to tell me everything you ate and drank during the last 24 hours. I will ask questions to get the most accurate food intake possible. Please be sure you tell me everything you ate or drank, even small things like butter, salad dressings, cream, candies, water, coffee, tea, and any vitamins or mineral supplements taken.

Would you say that yesterday was a typical day in terms of food consumption? [ ] Y [ ] N

Let’s start by making a quick list of things you ate yesterday, then I will ask questions to get more details.

<table>
<thead>
<tr>
<th>Last thing ate before bed</th>
<th>Dinner</th>
<th>Anything between dinner &amp; evening snack?</th>
<th>Lunch</th>
<th>Anything between lunch &amp; dinner?</th>
<th>Breakfast</th>
<th>Anything between breakfast &amp; lunch?</th>
<th>First thing you ate?</th>
</tr>
</thead>
</table>

**Recall Method:**
- Quick List – Item per line
- Forgotten Foods
- Line by Line – Food Prep & Portion Size
- Review

**Forgotten Foods:** Easy to forget foods like butter, half & half, mayonnaise, salad dressings, fats used in cooking and snacks may contain many calories and few nutrients. Check to see that all beverages are recorded, including sodas, coffee, teas, juices and any type of water-based beverage.

<table>
<thead>
<tr>
<th>TIME/Meal Category</th>
<th>FOOD ITEM</th>
<th>HOW FOOD IS PREPARED</th>
<th>AMOUNT EATEN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Table continues on the back of the form

Version #1, 4/15/2005
Appendix C: Survey

Survey Instrument, Page 1

<table>
<thead>
<tr>
<th>Food Security Core Module</th>
<th>Participant ID: ____________</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCR1: Which of these statements best describes the food eaten in your household?</td>
<td>1: Yes 2: No 3: Sometimes 4: Never True</td>
</tr>
<tr>
<td>SCR2: People do different things when they are running out of money for food in order to make their food or their food money go further. In the last 12 months, did you ever run short of money and try to make your food or your food money go further?</td>
<td>1: Yes 2: No 3: Sometimes 4: Never True</td>
</tr>
</tbody>
</table>

| FS1: "We worried whether our food would run out before we got money to buy more." | often | sometimes | never true |
| FS2: "The food that we bought just didn't last and we didn't have money to get more." | often | sometimes | never true |
| FS3: "We couldn't afford to eat balanced meals." | often | sometimes | never true |
| FS4: "In the last 12 months, did you or other adults in the household ever cut the size of your meals or skip meals because there wasn't enough money for food?" | 1. Yes 2. No 3. Sometimes 4. Never True |
| FS5: (If yes to FS4): How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months? | 1. almost every 2. some months 3. only 1-2 months |
| FS6: In the last 12 months, did you ever eat less than you felt you should because there wasn't enough money for food? | Yes | No |
| FS7: In the last 12 months, were you ever hungry, but didn't eat, because there wasn't enough money for food? | Yes | No |
| FS8: In the last 12 months, did you lose weight because there wasn't enough money for food? | Yes | No |
| FS9: In the last 12 months did you or other adults in your household ever not eat for a whole day because there wasn't enough money for food? | Yes | No |
| FS10: (If yes to question FS9) How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months? | 1. almost every 2. some months 3. only 1-2 months |
| Are there children in your household under 17 years of age? [ ] Yes (proceed) [ ] No (gotos back of page) | 1. Yes 2. No |
| (Questions 11-18 were asked only if the household included children age 0-17) | 1. Yes 2. No |
| FS11: "We relied on only a few kinds of low-cost food to feed our children because we were running out of money to buy food." Was that often, sometimes, or never true for you in the last 12 months? | often | sometimes | never true |
| FS12: "We couldn't feed our children a balanced meal, because we couldn't afford that." Was that often, sometimes, or never true for you in the last 12 months? | often | sometimes | never true |
| FS13: "The children were not eating enough because we just couldn't afford enough food." Was that often, sometimes, or never true for you in the last 12 months? | often | sometimes | never true |
| FS14: In the last 12 months, did you ever cut the size of any of the children's meals because there wasn't enough money for food? | Yes | No |
| FS15: In the last 12 months, were the children ever hungry but you just couldn't afford more food? | Yes | No |
| FS16: In the last 12 months, did any of the children ever skip a meal because there wasn't enough money for food? | Yes (gotos FS17) No (skips FS16) |
| FS17: (If yes to question FS16) How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months? | almost every 2. some months 3. only 1-2 months |
| FS18: In the last 12 months did any of the children ever not eat for a whole day because there wasn't enough money for food? | Yes | No |
### Other Food Access Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>1: Yes</th>
<th>0: No</th>
<th>3: Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>FA1. In the last 30 days, did you or any member of your household receive benefits from the WIC program—that is, the Women, Infant and Children program?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>FA2. In the last 30 days, did you or any member of your household receive benefits from the SNAP program—that is, the Supplemental Nutrition Assistance Program, formerly known as the food stamp program?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FA3. Did (you/anyone in your household) shop for food at a supermarket or grocery store LAST WEEK?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FA4. Think about other places where people buy food, such as meat markets, produce stands, bakeries, warehouse clubs, and convenience stores. Did (you/anyone in your household) buy food from any stores such as those LAST WEEK?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FA5. LAST WEEK, did (you/anyone in your household) buy food at a restaurant, fast food place, cafeteria, or vending machine? (Include any children who may have bought food at the school cafeteria).</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>FA6. Did (you/anyone in your household) buy food from any other kind of place LAST WEEK?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>FA7. From what other places did you buy food?</td>
<td></td>
<td></td>
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<tr>
<td>FA8. In order to buy just enough food to meet (your needs/the needs of your household), would you need to spend more than you do now, or could you spend less?</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>FA9. About how much MORE would you need to spend each week to buy just enough food to meet the needs of your household?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FA10. About how much LESS could you spend each week and still buy enough food to meet the needs of your household?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FA11. In the last 30 days, did you ever run short of money and try to make your food or your food money go further?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>FA12. In the last 30 days, on average, how many meals would you say you consumed in a day?</td>
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<tr>
<td>FA13. In the last 30 days, how many times have you come to Francis House for breakfast?</td>
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<tr>
<td>FA14. In the last 30 days, about how many times have you come to Francis House for lunch?</td>
<td></td>
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</tr>
</tbody>
</table>

### Nutritional Health Assessment

“These next 10 questions will help us to better understand your overall nutritional health.”

<table>
<thead>
<tr>
<th>Nutritional Health Question</th>
<th>YES</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>NH1. I have an illness or condition that made me change the kind and/or amount of food I eat.</td>
<td></td>
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<tr>
<td>NH2. I eat fewer than two meals a day.</td>
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<tr>
<td>NH3. I eat few fruits or vegetables, or milk products.</td>
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<tr>
<td>NH4. I have three or more drinks of beer, liquor or wine almost every day.</td>
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<tr>
<td>NH5. I have tooth or mouth problems that make it hard for me to eat.</td>
<td></td>
<td></td>
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<tr>
<td>NH6. I don’t always have enough money to buy the food I need.</td>
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</tr>
<tr>
<td>NH7. I eat alone most of the time.</td>
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<tr>
<td>NH8. I take three or more different prescribed or over-the-counter drugs a day.</td>
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<tr>
<td>NH9. Without wanting to, I have lost or gained ten pounds in the last six months.</td>
<td></td>
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</tr>
<tr>
<td>NH10. I am not always physically able to shop, cook and/or feed myself.</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Nutritional Health Score**

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2</td>
<td>Good</td>
</tr>
<tr>
<td>3-5</td>
<td>Moderate Nutritional Risk</td>
</tr>
<tr>
<td>6+</td>
<td>High Nutritional Risk</td>
</tr>
</tbody>
</table>

Interviewers: Read the statements below. If yes, circle the number in the yes column for that question.
Demographics & Access to Health Care

Demographics

<table>
<thead>
<tr>
<th>D1: To what gender do you most closely identify?</th>
<th>1: Female</th>
<th>2: Male</th>
<th>3: Other (Please Specify)</th>
<th>D2: What was your age at your most recent birthday?</th>
<th>age in years</th>
</tr>
</thead>
</table>

| D3: To what race/ethnicity do you most closely identify? | 1: Arab or Arab American | 2: American Indian | 3: Asian, Asian American | 4: Black, African American | 5: Hispanic, Latino/a | 6: White or Caucasian | 7: Other racial/ethnic identity not listed | 8: Prefer not to answer |

| D4: Of the following choices, what is the highest grade or year of school you completed? | 1: Less than High school | 2: HS graduate or GED | 3: Some college (1-3 yrs) or tech school | 4: College 4 years or more (graduate) | 5: Don't Know / Not Sure | 6: Prefer not to answer |

| D5: What is your work and/or school status? (choose all that apply) | 1: I am: neither employed nor a student | 2: Retired | 3: ... employed full time (35+ hrs/week) | 4: ... employed part time (<35 hours) | 5: ... self-employed | 6: ... an undergraduate student | 7: ... a graduate student | 8: Other (explain) |

D6: The next question is about your combined household income. By household income we mean the combined income from everyone living in the household including even roommates or those on disability income. Could you please tell me your estimated combined household income?

$ [ ]

| D7: Which of these statements do you think best describes your household income? | 1: My income does not cover my basic living expenses | 2: My income covers my basic living expenses | 3: My income covers more than my basic living expenses |

| D8: How many people (related to you or not) lived in your place of residence in the last 30 days? | D9: How many of these people were adults between the ages of 18 and 65? | D10: How many were older than 65 years of age? | D11: How many were under the age of 18? |

| D12: Unstable housing would be defined as living in a hotel, boarding house, group home, jail in the street, or having no fixed address. Can you tell me if you have access to stable housing—that is, a place to live besides those I just listed? | 1: Yes | 0: No |

Access to Health Care

| HC1: On a scale of 1-5 with 5 being Excellent, how would you rate your overall health right now? | [ ] 5: Excellent | [ ] 4: Very Good | [ ] 3: Good | [ ] 2: Fair | [ ] 1: Poor |

| HC2: If you need health care, where do you usually go to get it? (If you go to more than one of these, please choose the one you go to most often.) | 1: Private doctor | 2: Community Health Center | 3: Emergency room | 4: Health department clinic | 5: Clinic at a hospital | 6: Alternative medicine provider (chiropractor, acupuncturist) | 7: Workplace | 8: Nowhere | 9: Some other place (please specify) |

| HC3: Of the following choices, what type of health care insurance do you use? (If you do not have insurance, enter "No insurance") | 1: Your employer | 2: Someone else's employer | 3: A plan that you or someone else buys on your own | 4: Medicare | 5: Family Health Plus or Medicaid | 6: The military, CHAMPUS, TriCare, or the VA | 7: Ryan White funding | 8: Some other source | 9: None (no health insurance) | 10: Don't Know / Not Sure | 11: Refused |

| HC4: Do you have someone you think of as your personal doctor or health care provider? | 1: Yes | 2: No | 3: Don't know, not sure | 4: Refused |
Stress, Anxiety and Depression

This next section of the survey asks about your stress and anxiety levels. In both, you have a range of responses you can use to describe how you are feeling.

**Perceived Stress Scale:** The questions in this scale ask you about your feelings and thoughts during the last month. You can answer “Never, almost never, sometimes, fairly often, or very often.”

*Interviewer: Please circle the response given.*

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Fairly Often</th>
<th>Very Often</th>
<th>Refuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSS1: How often have you been upset because of something that happened unexpectedly?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS2: How often have you felt that you were unable to control the important things in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS3: How often have you felt nervous and “stressed”?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS4: How often have you felt confident about your ability to handle your personal problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS5: How often have you felt that things were going your way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS6: How often have you found that you could not cope with all the things that you had to do?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS7: How often have you been able to control irritations in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS8: How often have you felt that you were on top of things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS9: How often have you been angered because of things that were outside of your control?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>PSS10: How often have you felt difficulties were piling up so high that you could not overcome them?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
</tbody>
</table>

**Hopkins Symptoms Checklist:** Listed below are some symptoms or problems that people sometimes have. Please listen to each one carefully and decide how much the symptoms bothered or distressed you during the last week, including today. You can respond Not at all, a little, quite a bit, and extremely. *Interviewer: Circle the response given.*

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>Extremely</th>
<th>Refuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSC1: Suddenly scared for no reason</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC2: Feeling fearful</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC3: Faintness, dizziness, or weakness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC4: Feeling tense or keyed up</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC5: Blaming yourself for things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC6: Difficulty in falling asleep or staying asleep</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC7: Feeling blue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC8: Feeling of worthlessness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC9: Feeling everything is an effort</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
<tr>
<td>HSC10: Feeling hopeless about future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>88</td>
</tr>
</tbody>
</table>
Adherence & Unannounced Pill Count

Participant ID: ____________

Taking pills is difficult for a lot of people. It is not uncommon to miss doses from time to time. The following questions ask about doses you’ve missed in the last 30 days. Please try to remember what actually happened, not what you think other people want you to say. By answering accurately, you are making a big contribution to better understanding of how people experience taking antiretroviral medications.

AD1: How many years have you been on an anti-retroviral regimen?

AD2: [Show Participant the VAS index on the back of this page]: This image is a visual assessment of your adherence to anti-retroviral medication over the past month.

Please place an “X” on the line below showing your best guess about how much of your current antiretroviral medication you have taken in the past 30 days. 0% means you have taken none of your current ARV medication, 50% means you have taken half of your current ARV medication, and 100% means you have taken every single dose of your current ARV medication in the past 30 days.

AD3: Rate your ability to take all your medications as prescribed during the last 4 weeks

1: very poor 3: fair 5: very good
2: poor 4: good

AD4: We asked you to bring a bottle of antiretroviral medications with you today. With your permission, I’d like to get some of the information from the label and then count the number of pills inside. This will provide another measure of ARV adherence. I will put on gloves and use a clean plate to carefully count while you watch. Do you have your permission to do this? [ ] Yes [ ] No (Interviewer: Examine bottle for the following information)

PC1: Name of medication:
PC2: Quantity provided (Dispensed):

PC3: # of Days for provided:
PC4: # Pills / Day:
PC5: Date of Refill:

Interviewer: Confirm that information above makes sense (if 90 are dispensed, and pills are 3x day, there should be 30 days of medication provided). Then, put on a pair of gloves and using a clean plate, count the pills in the bottle. Be very careful not to drop any pills. When complete, carefully return medications to the bottle.

PC6: # of pills in bottle (Count):

Next, I want to ask about some common barriers to ARV adherence. Please tell me if the following are True or False.

CB1: I sometimes run out of my medications before I can get a refill.

[ ] True [ ] False

CB2: I experience side effects from my anti-retroviral medications.

[ ] True [ ] False

CB3: I cannot afford the cost of medications.

[ ] True [ ] False

CB4: I was not able to get where I needed to go because I did not have transportation.

[ ] True [ ] False

CB5: I could not get to a clinic or doctor because I did not have transportation.

[ ] True [ ] False

CB6: Total True Responses

This last question asks about the use of substances that are illegal, or legal but not used as prescribed. I am only asking this question because sometimes adherence to ARVs, food security, diet, or even general mental health can be affected by this type of substance use. Your response will not affect your eligibility in the study, nor will it affect your access to services at Francis House. In fact, Francis House can provide you access to additional services should you want help.

“How many times in the past year have you used an illegal drug or used a prescription medication for nonmedical reasons?”

[ ] Never [ ] # times

Thank you so much for your participation!
This image is a visual assessment of your adherence to antiretroviral medication over the past month.

Please place an “X” on the line below showing your best guess about how much of your current antiretroviral medication you have taken in the past 30 days.

- 0% means you have taken none of your current ARV medication
- 50% means you have taken about half of your current ARV medication
- 100% means you have taken every single dose of your current ARV medication in the past 30 days.

[Visual Analog Scale]

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Appendix D: Semi-Structured Interview

My name is ___________ and I am a graduate student at the University of South Florida. I am interviewing people to better understand the day-to-day experiences of people living with HIV. The interview will cover questions in 4 main areas: Food security, adherence to ART, Access to Health Care, and Stress and Anxiety. We’ve already gone over the informed consent; do you have any questions for me before we start?

Food Security

- Some people struggle with having enough food to feed themselves or their families. Do you know people who struggle like that?
  - Would you say this is something that you experience? Can you tell me more about that?

- Some people say that when there’s not enough food, sometimes you have to change the way you do things just to make sure you can eat. That could be shopping in places you would rather not shop, or getting and eating foods you would rather not eat. Do you know anything about these types of experiences?
  - Would you say this is something that you experience? Can you tell me more about that? [Probe for shopping locations.]

- What are some of the hardships you face when trying to feed yourself or your family?

- Do you have any difficulties storing or cooking food that make feeding your family difficult?

- What are some tips or tricks you use for getting yourself or your family through lean times? Are there things you do, or people or organizations that help you during those times?

Antiretroviral Adherence

- Some people struggle with taking their anti-retroviral medications. Sometimes people experience things like side effects, or find the pill schedule is too complicated, or they have to take their medicines with food and that’s difficult for them. Are you familiar with these types of issues?

- Would you say that you have things that come up that make it hard to take your medications?
  - (Prompts to elicit additional responses—are there any other issues that make taking your medications difficult?)

- Is there anything that makes taking your medications easier?
• What would you say is the most difficult thing about taking your medications?

If food insecurity arises are part of the above discussion (not related to taking medicine with food), pursue that topic. However, if not mentioned as part of the discussion above, I will ask:

• Some people have said that not having enough food affects whether or not people take their medicine as they should. Have you heard about this issue?

• Would you say that you experience this? Can you tell me more about this?

Access to Health Care

• What is your regular source of medical care? Do you have a personal doctor who regularly provides care?

• Has your personal doctor or regular source of care changed in the last few months? Can you tell me more about this?

• During the past year, have you had any trouble getting the medical care that you thought you needed? Have you had any trouble getting any medication you were prescribed? Or, did you not get any medication you were prescribed? Did you have any trouble getting your ART?

Stress and Anxiety: Mental Health

• We’re almost finished, so I’d like to just talk in general about your daily life. Can you tell me: What does a good day look like for you?

• What does a bad day look like for you?

• [If not mentioned, probe]: Do issues related to having enough food contribute to your bad days?

• What about the task of taking your medications, or other health related issues?

• How do you cope with your bad days? What could help make your bad days better?
Appendix E: Institutional Review Board Approval

2015 Expedited Approval for Initial Review, Page 1

April 27, 2015

Lauri Wright, PhD
Community and Family Health
1201 Bruce B. Downs Blvd. MDC 56
Tampa, FL 33612

RE: Expedited Approval for Initial Review
IRB#: Pro00020738
Title: Food and Nutrition Security among People Living with HIV/AIDS


Dear Dr. Wright:

On 4/27/2015, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents outlined below.

Approved Item(s):
Protocol Document(s):
Wright, Noble Proposal

Consent/Assent Document(s)*:
SB Adult Minimal Risk with HIPAA_CN.docx.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:
(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

John Schinka, Ph.D., Chairperson
USF Institutional Review Board
4/11/2016

Lauri Wright, PhD
USF Community and Family Health
13201 Bruce B. Downs Blvd. MDC 36
Tampa, FL 33612

RE: Expedited Approval for Continuing Review
IRB#: CR1_Pro00020738
Title: Food and Nutrition Security among People Living with HIV/AIDS.

Study Approval Period: 4/27/2016 to 4/27/2017

Dear Dr. Wright:

On 4/9/2016, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within including those outlined below.

Approved Item(s):
Protocol Document(s):
Wright, Noble Proposal

Consent/Assent Document(s)*:
SRAdultMinimalRiskwithHIPAA_CN.docx pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab on the main study's workspace. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s) and replace the previously approved versions.

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

(3) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).
(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

John Schinka, Ph.D., Chairperson
USF Institutional Review Board
5/19/2017

Lauri Wright, PhD
USF Community and Family Health
13201 Bruce B. Downs Blvd MDC-36
Tampa, FL 33612

RE: Expedited Approval for Continuing Review
IRB#: CR2_Pro00020738
Title: Food and Nutrition Security among People Living with HIV/AIDS.

Study Approval Period: 5/18/2017 to 5/18/2018

Dear Dr. Wright:

On 5/18/2017, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within including those outlined below.

Approved Item(s):
Protocol Document(s):
Wright, Noble Proposal

Following Chair Review: Deviation log has been reviewed, Non-compliance was not serious and non-continuing. There was no increased risk to participants and no further action is required.

"As a reminder, please submit a personnel change request to remove Palak Gupta from the study team.

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.
(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

John Schinka, Ph.D., Chairperson
USF Institutional Review Board
5/8/2018

Lauri Wright, PhD
Community and Family Health
13201 Bruce B. Downs Blvd. MDC 56
Tampa, FL 33612

RE: Expedited Approval for Continuing Review
IRB#: CR3_Pro00020738
Title: Food and Nutrition Security among People Living with HIV/AIDS.

Study Approval Period: 5/18/2018 to 5/18/2019

Dear Dr. Wright:

On 5/5/2018, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within including those outlined below.

Approved Item(s):
Protocol Document(s):
Wright, Noble Proposal

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

Mark Ruiz, PhD, Vice Chairperson
USF Institutional Review Board
5/6/2019

Lauri Wright, PhD
Community and Family Health
13201 Bruce B. Downs Blvd. MDC 55
Tampa, FL 33612

RE: Expedited Approval for Continuing Review
IRB#: CRd_Pro000020738
Title: Food and Nutrition Security among People Living with HIV/AIDS.

Study Approval Period: 5/18/2019

Dear Dr. Wright:

On 5/3/2019, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within including those outlined below. Please note this study is approved under the 2018 version of 45 CFR 46 and you will be asked to confirm ongoing research annually in place of a full Continuing Review. Amendments and Reportable Events must still be submitted per USF HRPP policy.

Approved Item(s):
Protocol Document(s):
Wright_NobleProposal

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

(3) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB via an Amendment for review and approval. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) business days.

We appreciate your dedication to the ethical conduct of human subjects research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

Melissa Sloan, PhD, Vice Chairperson
USF Institutional Review Board
Appendix F: Quality Assurance/Quality Improvement Evaluation Findings

Quality Assurance/Quality Improvement (QA/QI) Program
Research Integrity & Compliance

October 27, 2016

IRB Number: Pro00020738
Study Title: Food and Nutrition Security among People Living with HIV/AIDS

Current Principal Investigator: Lauri Wright
Current Coordinators: Charlotte Noble
Previous PI: NA
Previous Coordinators: NA

This Report summarizes the findings of the investigator’s research records and related USF IRB records reviewed by the Quality Assurance/Quality Improvement Program. The purpose of this report is to 1) assist the investigator in meeting regulatory and institutional standards governing the protection of human participants in research as outlined in USF Human Research Protection Program (HRPP) policy, and 2) bring to the attention of the IRB any instances of noncompliance which may impact participant safety or welfare for subsequent review and determination.

The primary objective of this evaluation is to review the informed consent process and signed consent documents for this study. During the QA/QI Evaluation, 131 subject consent documents were reviewed.

Number of subjects enrolled: 131
Number of records reviewed: 131 consents
Date of Pre-Evaluation Meeting: 10/27/16
Attendees: Charlotte Noble, Wendy Duncan RN BSN, Jessica Delargy, CRA-QA
Date(s) of on-site review: 10/27/16
Evaluation completed by: Wendy Duncan RN BSN, Jessica Delargy, CRA-QA
Date of Wrap-Up Meeting: 10/27/16
Attendees: Charlotte Noble, Wendy Duncan RN BSN, Jessica Delargy, CRA-QA and Lauri Wright by phone on 12/7/2016.

I. Study Selection Criteria

The Research Integrity and Compliance (RIC) Quality Assurance/Quality Improvement Program randomly selected the above identified study for a QA/QI Informed Consent Process Evaluation.

II. Study Summary

A. Study Objective:
O1) Determine food security, nutritional status, and diet quality of PWA enrolled in a special services program with an HIV care organization.

O2) Determine relationship between ART adherence and measures of food security, nutritional status, dietary quality, and anxiety and depression.

O3) Using structural equation modeling (SEM), use a path analysis to model the relationship between these factors.

O4) Interview participants about the lived experience of food (in)security (including nutritional status and dietary quality) to determine how these experiences are related to adherence to ART, and determine what strategies are utilized by participants to ameliorate issues related to food security and diet quality, including use of the hot meal program and food pantry.

B. Sponsor: Non-sponsored (no funding)

C. Current Study Status: This study is currently approved and is now open to enrolling subjects but they have completed their enrollment. They were approved for 132 and a total of 131 subjects have signed the informed consent.
### III. Summary of Findings:

<table>
<thead>
<tr>
<th>HRPP Standards</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IRB Approval for the Study:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IRB approval for the study was continuous</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjects were enrolled on the study during IRB-approved study periods.</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of subjects enrolled in the study was confined to the number approved by the IRB</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Informed Consent Documentation:</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Informed consent process completed before study interventions (research) began.</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All ICDs were accurately completed and without strike-throughs or modifications.</td>
<td>X(0)</td>
<td></td>
<td></td>
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<tr>
<td>All ICDs were the correct USF IRB-approved version</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>All ICDs were signed and dated by the participant or the participant’s legally authorized representative (e.g. proxy, health care surrogate).</td>
<td>X(0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All ICDs were signed and dated by the person obtaining informed consent/research authorization who was authorized by the IRB to obtain informed consent.</td>
<td>X(0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All subjects were re-consented with new versions of ICDs as specified by sponsors, the IRB, or for updated risk information.</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>All ICDs used to document the informed consent process were stamped, watermarked, and approved by the USF IRB.</td>
<td>X</td>
<td></td>
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<tr>
<td>All ICDs had a valid phone number for reporting unanticipated problems, adverse events, or requesting study information.</td>
<td>X</td>
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<tr>
<td>All ICDs were complete; that is, all pages were present.</td>
<td>X</td>
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<tr>
<td>All ICDs had the correct phone number for the USF IRB.</td>
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<tr>
<td>All subjects were provided with a copy of the ICD.</td>
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<tr>
<td>Assent documents were appropriately signed, dated, and completed by each enrolled child over the age of 12.</td>
<td>X</td>
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<tr>
<td>The assent process was performed as approved by the IRB and verbal assent documented in the research records for each enrolled child between 7 and 11 years of age (elementary school aged children).</td>
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<tr>
<td>The assent process was performed and documented in accordance with the IRB-approved verbal script for each enrolled child under the age of 7 years.</td>
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<td>X</td>
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<tr>
<td>Parental Permission documents were appropriately signed, dated and completed for each child enrolled in the study.</td>
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<td>X</td>
<td></td>
</tr>
</tbody>
</table>

**Informed Consent Documentation**

1. Some consent forms had areas lined through which apparently was done by the study staff to assure the participant the viral load would not be obtained per their request. For the future, they confirmed they will amend any areas of the consent document signed by the participant. Per the study team, they will add these to their minor deviation log.

2. Some subjects did not print and/or date their own signature. This was done by the study staff for the participant. The study team provided the following CAPA plan:

   "In future, study staff will ensure that ICF trainings include these various rules to ensure the ICF process is conducted correctly and completely. Study staff will also be sure to check ICFs for completeness, changes, etc. and ensure any deviations are logged and follow up is provided to study staff."

IRB #Pro00020738

CONFIDENTIAL
Please add this to your deviation log to be uploaded into eIRB at your next continuing review.

3. Staff inadvertently missed signing and/or dating several consents and another member of the team printed the consenter's name and date of the consenting process.
   The study team provided the following CAPA plan:
   The deviation log entry notes that in the future, should staff inadvertently not complete the signature, they should do so at the earliest opportunity, noting the date that the signature (not the survey) occurred, and an entry should be made in the deviation log that the ICF was not signed when it was executed.
   Please add this to your deviation log to be uploaded into eIRB at your next continuing review.

Additional Comments
During the interview, it was apparent that great effort was used to protect the participants' privacy, rights and wishes. The participant and regulatory records on file were well organized. The staff appear interested in high quality research and should be commended for their contribution.

    Thank you to the study team for your assistance and cooperation during the QA/QI evaluation of this trial.
Appendix G: Acceptance of Quality Assurance/Quality Improvement Evaluation

February 16, 2017
Lauri Wright, PhD
Community and Family Health
12201 Bruce B. Downs Blvd. MDC 56
Tampa, FL 33612

RE: Acceptance of QA/QI Evaluation
IRB #: Pro00020738
Study Title: Food and Nutrition Security among People Living with HIV/AIDS.

Dear Dr. Lauri Wright:

On February 9, 2017, as the Associate Director of Regulatory Affairs overseeing the Quality Assurance/Quality Improvement (QA/QI) Program, I reviewed and accepted the QA Report of the above-referenced study dated October 27, 2016 and your responses to the findings.

Add deviations to your minor deviation log to be submitted at your next continuing review or study closure. No further action is required unless directed by the IRB.

We appreciate your dedication to the ethical conduct of human subjects research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

Julie Moore, J.D., M.S., PA, CIP
Associate Director of Regulatory Affairs
Research Integrity & Compliance
Appendix H: Ethical Considerations - Events

Event #1: Viral Load Extraction

The first participant who seemingly became upset during the informed consent process for administering a survey and dietary recall. The participant’s behaviors seemed to indicate that they were startled at the request for permission to extract protected health information, using a chart extraction form to obtain viral load results and examination date. Upon reaching that section of the informed consent (IC; pages 228-229, Appendix A), the participant looked up at me (Noble) with wide eyes, seemingly startled, and asked who would see that information. I proceeded to detail the information in the IC (Who will see your health information?, Who will disclose (share), receive, and/or use your information?) and explained that the participant’s caseworker would extract the viral load results and text date information only from their case management file, and – using a numeric code in place of their name – would submit that information to me for entry into the secured database. The participant glanced around the interview room, seeming to be nervous. I stopped reading the consent form and gave them a moment.

I then asked the participant in what I perceived to be a neutral tone: “By signing this form, you would be giving your permission to use and/or share your health information as described in this document for any and all study/research-related purposes. Do you consent to this – that is, give your permission to do this, or would you prefer that we not have that information?” This added script is not in the informed consent, but given their demeanor, I wanted to make sure they understood their options. They haltingly (and I perceived, hesitantly) said, “Well, I guess that’s okay. It’s fine. I will sign it.” I said, “Now, let’s wait a moment. As it says here at the bottom of page 4, you have the right not to sign this form. You also have the
right to refuse to allow us to access this protected health information. Please look here,” I said, indicating the checkbox near the bottom of page 4 of the IC (seen in Figure 12).

![For the Research Participant (you) to complete:](image)

### Figure 12: Check Box to Refuse Disclosure of Protected Health Information

I continued, “If we check this box here, this means that we will not obtain your viral load information. Should we check this box? It’s completely fine.” The participant shook their head, eyes starting to fill with tears, and said, “No, it’s fine.” I replied, “I am not sure I feel comfortable leaving this unchecked. You seem upset or worried. You should absolutely be comfortable with this decision. This survey, and especially this part of the survey, is voluntary. If you aren’t comfortable, it’s completely fine. We can check this box to exclude it. We can stop. We could do this another day. No problem at all. You let me know. Shall we take a minute?”

The participant sighed audibly and said, “No, it’s fine. Let’s go on.” I responded that I still didn’t feel comfortable. “Your eyes are seeming to tell me something different than your mouth is saying. I think we should check this box. Really, it’s okay. Or again, we can stop. I don’t want to upset you.” I waited, giving them time to consider. Again, a loud sigh, but then a smile. “Yes, please, let’s check the box. I’m undetectable and have been for some time, but the idea that my information would just be out there – I just don’t feel safe about that.” I assured her that it was perfectly fine. I asked her to check the box indicating that she was asking us (USF researchers) not to include, use, or share the following health information, then wrote the words “viral load information” on the line below. The participant dabbed at their eyes and smiled again.
I asked if they wanted to take a moment, reschedule, or proceed. They indicated that they were ready to proceed with the survey, and the survey was completed without further issues.

*Event #2: Legal versus Preferred Name*

The second event where a participant was visibly upset was again during the informed consent process for a survey and dietary recall. The informed consent procedure includes verifying eligibility (inclusion and exclusion criteria) and completing a cover sheet where the participant contact information was recorded, including whether or not we had their permission to contact them for the second (interview) phase of the study. When scheduling the survey appointment and orally confirming eligibility over the phone, I was provided with a generally assumed-to-be female name. As outlined in the study procedures, I requested that the potential participant bring a photo ID and their HIV medication bottle (that matches the ID) in with them for the appointment, to confirm eligibility.

At the time of the appointment, the participant was dressed in a skirt and tank top. She presented a state ID with a male name that matched the medication bottle. The participant clearly appeared to me to be the same person, though presenting differently through dress and appearance. I made no comment, smiled, and handed back the items. I began to fill out the cover sheet, telling her that I was writing down her name and asking if she could provide one form of contact information (as indicated on the form). She said, “You have to use my legal name on that form, don’t you?” No, I said. You’ve told me your name, that’s what I have written down. Her eyes started to well with tears. I asked if she was okay, and did she still want to proceed? She said yes but also indicated that it would be wise for me also to record her legal name, as that would be the name on her case management paperwork. “They always make me use that name,”
she said, voice shaking. “Who does?” I asked. “Most of them,” she responded. She shook her head, and I asked again if she was okay. Do you still want to continue? We don’t have to, I said. She smiled and said, “No, I’m fine. (Female name) it is, then”. I nodded and said, thanks, (female name) affirming my intent to use her female name. At the signature page for the informed consent, she signed her name, and in quotation marks also signed her legal name. The survey proceeded without further incident. Following her example, I later filled in both names on the ‘printed name’ line, as I had not ensured that this was filled out entirely before we proceeded.

During an IRB Informed Consent audit conducted in 2016 (after data collection was completed; see Appendix F and G), a team of USF Quality Assurance/Quality Improvement (QA/QI) Research Compliance Administrators assessed the informed consent procedures and documentation of this study and highlighted this IC document as an incident that needed to be added to a protocol deviations log. Their handwritten notes and subsequent verbal debrief on October 27, 2016, indicated that the “legal name only (of the participant) is best.” I explained the interaction, but the QA/QI staff affirmed that it would be best if the legal name were the only name on the signature line. I said I did what I felt was in the best interest of my participant. In the deviations log that needed to be submitted by January 6, 2017, under the deviation description I wrote that “Noble had allowed a participant to sign the IC form with both their preferred name and legal name out of respect for their trans identity.” Under corrective actions, I did not specify a corrective action unlike I had done with other items; I only mentioned that the “IRB has indicated that the legal name only is preferred.” Until a better solution can be found, I would conduct myself in the same way.
Event #3: Past Trauma

The third event where a participant seemed to become visibly upset happened during the course of an interview. Though we started the interview using the semi-structured guide, with the participant describing their current circumstances of dealing with unstable housing and food insecurity - they quickly linked their ‘downslide’ to a recent stint of incarceration, where they subsequently lost access to various forms of financial and housing supports. This led to an hour-long conversation about the sexual violence they experienced in prison as well as their experiences with childhood sexual abuse and food insecurity. The participant seemed calm while speaking, though I noticed that they gripped their hands repeatedly, and at times would not meet my eyes. They spent some time providing their justification for their “choices” as they called them, and memories still seemed to hurt them deeply, and the shame almost palpable. Through my body language and facial expressions, I tried to assure them that they were safe, that they could share only what they needed or wanted to share. They asked that we stop the interview at the hour mark so that they could get their hot lunch for the day, and I honored that request. I asked them if they felt alright heading out to the lunch area, and if they wanted to speak to the mental health counselor about what they had shared – now or in the near future. They assured me that they spoke with her all the time, even about this and that they were fine. We set an appointment to complete the interview, and the participant left the interview room with a smile, hugging me.
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