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#### SELF-CARE PRACTICES OF POPULATIONS AT RISK FOR HIV

by

#### NASIM MAHBOUBI FLUKER

Under the Direction of Dawn Michelle Baunach, PhD

## **ABSTRACT**

Studies have shown that health outcomes are disproportionately worse for homeless individuals as compared with individuals with stable housing (Brickner, Scanlan, and Conanan 1986); however, the unique coping mechanisms that they employ to protect their health have been largely understudied. Better understanding of attitudes and behaviors that individuals adopt to maintain their health, collectively termed "self-care" is imperative to the design and implementation of effective public health interventions for this population. The purpose of this thesis is to better understand both the barriers and coping strategies of transient populations. The two research questions guiding this thesis are: What barriers to health do transient residents in high-risk neighborhoods experience, and how do they mitigate the perceived or existing barriers? Findings from this analysis indicate that the most salient barriers for transient populations are

lack of transportation, lack of health insurance, beliefs about health, and mental illness. The agency exercised by participants to improve their own health outcomes has important implications for the efficacy of health promotion campaigns and health policy aimed at high-risk populations.

INDEX WORDS: Public Health, Qualitative Research, Homelessness, Poverty, Health Outcomes, Barriers to Health

## SELF-CARE PRACTICES OF POPULATIONS AT RISK FOR HIV

by

## NASIM MAHBOUBI FLUKER

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Masters of Arts

in the College of Arts and Sciences

Georgia State University

2015

## SELF-CARE PRACTICES OF POPULATIONS AT RISK FOR HIV

by

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## TABLE OF CONTENTS

A	CKN	OWLEDGEMENTS	İV
I	IST (	OF TABLES	ix
1	IN'	TRODUCTION	1
2	Lit	erature review	2
	2.1	Social Determinants of Health	2
	2.2	Defining Self-Care	3
	2.3	Self-Care and Culture	6
	2.4	Stigma and Health Status	8
	2.5	Homelessness and Health Status	9
3	Th	eoretical frameworks 1	.1
	3.1	The Social Ecological ApproachError! Bookmark not define	d.
	3.2	The Sojourner Syndrome and Resiliency 1	.1
4	Me	thods 1	.3
	4.1	Respondents and Data	.3
	4.2	Sample Selection	4
	4.3	Data Collection	4
	4.4	Data Analysis 1	.5
	4.5	Credibility and Trustworthiness	.7
	4.:	5.1 Positionality 1	9

5	Int	trod	uction to participants	20
	5.1	Int	roduction to Participants	. 21
	5.	1.1	Mark	21
	5.	1.2	Sam	21
	5.	1.3	Lucy	22
	5.	1.4	Bernard	23
	5.	1.5	Roland	24
	5.	1.6	Michelle	24
	5.	1.7	Veronica	25
6	FI	NDI	NGS	. 26
	6.1	Fir	nancial Resources	. 26
	6.2	Ac	cessing Healthcare	. 29
	6.2	2.1	Self-Medicating and Addiction	31
	6.2	2.2	Disease Management	32
	6.3	Ac	cessing Food and Other Social Services	. 34
	6.4	Be	liefs as a Self-Care Strategy	. 38
	6.5	Ho	ousing	. 39
	6.6	Sex	kual Strategies	. 42
7	Co	nclu	sion	. 42
	7.1	Pol	licy Implications	47

REFERENCES	48
APPENDICES	55
Appendix A: Complete Interview Guide	55
Appendix B: Coding Scheme	58

## LIST OF TABLES

Table 1: Coding Themes	17
Table 2: Key Respondents' Demographics	20

#### 1 INTRODUCTION

Homeless African Americans experience higher rates of hypertension, respiratory illness, tuberculosis, and HIV/AIDS compared with their housed counterparts (Brickner, Scanlan, and Conanan 1986). In addition to the negative impacts that homelessness itself has on overall health outcomes, transient African Americans experience a convergence of social statuses that place them at higher risk for negative health outcomes. Being African American, earning no to little income, and being a member of stigmatized social groups are all statuses that adversely impact health outcomes (Berkman and Kawachi 2000; Link and Phelan 1995). My specific research questions are:

1) What barriers to health do transient residents in high-risk neighborhoods for HIV and drug use experience? 2) How do they mitigate the perceived or existing barriers?

While significant research has been done on the health outcomes of transient residents in underserved urban neighborhoods, little research has been done to examine the coping strategies, protective measures, and self-care strategies they employ to attempt to mitigate negative health outcomes. Both poverty and homelessness are key determinants in the utilization of self-care strategies and access to preventative healthcare; this thesis seeks to highlight the strategic behaviors and attitudes that the extremely poor and non-traditionally housed use to protect their physical and mental health. Examining the self-care practices in transient African American populations is imperative in designing effective intervention strategies. Through better understanding of how this group conceptualizes its own health and healing strategies, public health and medical practitioners can incorporate such attitudes and behaviors into more culturally competent, and ultimately more effective, models of care.

#### 2 LITERATURE REVIEW

### 2.1 Social Determinants of Health

Literature on the social determinants of health provides useful perspectives to understand the social construction of health. Scholars have identified social determinants of health, such as stress, stigma, socio-economic status, racism, discrimination, and segregation, as key variables that correlate with health outcomes (Hatzenbuehler, Phelan, and Link 2013). Despite the more recent focus on social determinants of health in mainstream public health research, evidence of correlations of health disparities and social class has long been accepted in sociology. Engels (1887) referenced a report on the sanitary conditions of the working class that indicated they had a shorter lifespan than the higher class by 15 years (Smith, Davey, and Brunner 1997). He found that the working class received their wages and went to the market on Saturday evenings, hours after the upper classes had picked over the freshest produce. Engels recalls the explanation of a worker strike given by factory owners, noting their naiveté. "In fact, it was their high wages which enabled them to maintain a stipendiary committee in affluence, and to pamper themselves into nervous ailments, by a diet too rich and exciting for their indoor employments" (Engels 1887: 168). Engels' findings transformed the apparent individual-level behavior into a socially constructed health outcome, imposed upon the poor by the wealthy class in the form of limited access to healthy food. Contemporary health disparities researchers experience a similar tension between individual behaviors and structural barriers to health.

Although researchers have long identified differences in health outcomes along social lines, the causes for these differences are not so easily agreed upon. For example, in the 1830's and 1840's, the debate about the poor health outcomes of African Americans centered on whether or not they were intrinsically inferior to White Americans. It was not until two African American

physicians, Dr. James McCune Smith and Dr. James S. Rock (Kreiger 2001), reframed the question by asking whether blacks experienced poor health outcomes because they were enslaved. The introduction of historical and social context into the realm of health studies is an important contribution of social scientists, which was a departure from the tradition of individual-level analysis in the biomedical arena. Continuing in this tradition, Nancy Kreiger brings attention to this historic debate between structure and individual agency in what she terms "blame-the-victim" ideology (DeJong 1980; Herek, Capitanio, and Widaman 2003; Puhl and Heuer 2010). "Blaming the victim" ideology is not unique to health disparities literature, but in this context the ideology places all responsibility on the individual for their health and highlights lifestyle behaviors as the primary causes for health outcomes, deflecting attention from structural barriers such as geographic and financial access to healthy food, healthcare, and even restrictive government policies.

## 2.2 Defining Self-Care

The concept of self-care, as it will be used in this thesis, relates to the theory framed by Dorothea Orem (1971). Orem coined the term in 1971 to discuss patient behaviors specific to the nursing field, but self-care has since been used broadly, with specific definitions varying by discipline and scholar. Orem identifies ten basic factors that influence the ability to practice self-care and the ways self-care is practiced: age, gender, developmental state, health state, sociocultural orientation, health care system, family system, patterns of learning, environmental factors, and resource availability and adequacy (Morales-Mann and Jiang 1993; Orem, Taylor, and Renpenning 2001).

Orem described self-care as the action systems that individuals perform in conformity with healthcare requirements (Orem, Taylor, and Renpenning 2001). Self-care has also been described as the attitudes and activities individuals adopt to maintain wellness (Barrosso 1995; Dean 1989a;

Dean 1989b; Denyes, Orem, and Bekel 2001). While Orem provides a technical definition that is most applicable to the theories and practices of nursing, the World Health Organization provides a broadened definition that will be used for the purposes of this thesis. It defines self-care as "the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health" (World Health Organization 1983: 2). Self-care behaviors are crucial to health disparities research because they have been linked to improved health status, increased quality of life, and decreased medical costs (Plach, Stevens, and Keigher 2005). Therefore, the working definition for self-care that will be used in this thesis is: the behaviors that individuals undertake to protect and enhance their health.

The self-care model is often associated with harm reduction principles. An example of this application follows. In their study of nine HIV-positive women, Plach and colleagues (2005) found that women engaged in health promoting behaviors on a spectrum. One woman who smoked cigarettes attempted to cut down the number of cigarettes she smoked in a day and tried to keep windows open while she smoked to attempt to decrease the negative effects. Another woman tried to eat large meals despite her reduced appetite and insomnia due to the side effects of her medication as a way to stay nourished but also as a sleep aid. These examples of self-care practices, while seemingly simple and isolated acts, are indicative of the types of changes individuals make to improve their health. Self-care behaviors also shed light on the way individuals understand their health status. A more nuanced exploration of such practices can lead to more effective health interventions, treatment plans, and health promotion campaigns.

Self-care is broadly defined as the attitudes and activities individuals adopt to maintain wellness (Barrosso 1995; Dean 1989a; Dean 1989b; Denyes, Orem, and Bekel 2001). Scholars of public health and health practitioners began to examine the influences of self-care on overall health

outcomes as early as the 1980's (Becker, Gates, and Newsom 2004). Self-care has been generally accepted as a key factor in preventative health and treatment strategies (Allison 2007; Denyes, Orem, and Bekel 2001; Orem, Taylor, and Renpenning 2001). The ways that individuals develop and employ self-care practices differ, however, based on a number of factors.

Limited financial resources and homelessness contribute to poor health and present barriers to self-care strategies (Zlotnick, Zerger, and Wolfe 2013). Understanding the mechanisms of self-care practices has become the subject of increased empirical study because as the cost of healthcare rises, individual behavior modification can reduce the costs associated with treatment of preventable diseases (Dean 1989; Orem 1995; Plach, Stevens, and Keigher 2005; Riegel, Carlson, and Glaser 2000; Thorne, Paterson, and Russell 2003). Additionally, as the prevalence of diseases that can be linked to health behaviors increase (e.g. hypertension and heart disease), so too does public speculation around treatment, prevention strategies, and healthcare options.

Transient populations experience barriers to healthcare when medical advice assumes the availability of financial resources and stable housing. These assumptions can make implementation of healthy behaviors challenging. For example, advice to change a transient person's diet may prove challenging if individuals are reliant on food pantries or outreach services to receive food. While the individual may be able to exercise some agency with regard to the types of food they eat, they may not have regular access to specific items or access to refrigeration. In that light, medical advice that would necessitate complete dietary overhaul would prove nearly impossible. Similarly, sleeping in crowded shelters or exposure to the elements outside severely limits the possibility for recovery from routine illnesses. The inability to properly store medications or to take the medicines according to prescribed instructions makes homeless individuals less likely to comply with medical advice. Women who do not have stable housing or are routine drug users face more obstacles to

negotiating safer sexual interactions, which put them at risk for sexually transmitted infections, and physical and emotional abuse from men who provide shelter, drugs, or other resources. Self-care practices are seemingly individual-level behaviors and attitudes that impact health; however, they need to be contextualized in light of the particular social milieu of the individual and the communities in which they live.

### 2.3 Self-Care and Culture

African American self-care practices can be interpreted as a site of resistance to the medicalization and control of black bodies. In a study conducted in a mid-low income black community with individuals living with one or more chronic illnesses, Becker, Gates, and Newsom (2004) attempted to understand the cultural underpinnings of self-care beliefs and processes that guided practices. Through a series of qualitative interviews, the researchers found recurrent themes of spirituality, mutual aid, social support and advice, and non-biomedical treatments in self-care approaches. This thesis tests whether these themes are also indicators of self-care strategies in transient populations who are significantly less economically stable than Becker and colleagues' sample.

Current discourse around self-care acknowledges the role culture plays in how individuals manage and protect against disease (Becker, Gates, and Newsom 2004; Morales-Mann and Jiang 1993; Thompson and Hirschman 1995). Self-care was imperative to the survival of the African American community under the oppressive structures of slavery, Jim Crow, and arguably racist policies and institutions that continue to touch the lives of so many (Becker et al. 2004). These treatments can involve specific types of food, teas, or salves, but also rely on social support and spirituality. These findings are relevant to understanding social cohesion in some black contexts more fully because the authors found linkages between the well-being of the individual, the health

of the larger community, and the community to its spiritual life, illustrating a collective narrative around self-reliance and individual behavior. Understanding the cultural narratives and meanings surrounding health can lend perspective into intervention strategies (Becker et al. 2004).

Self-care practices that involve elements of non-biomedical or herbal treatments are common in African American communities (Becker et al. 2004). For example, participants in Airhihenbuwa and colleagues' (1996) study spoke repeatedly about the curative properties of pot-liquor, the cooking liquid remaining after cooking greens. In rural settings, the liquid was used as food for infants, similar to formula, when mothers were unable to lactate. While these treatments may be effective or ineffective, it is incumbent upon doctors and researchers alike to be familiar with the health beliefs of the communities they study.

Many African Americans experience a "legacy of mistrust" (Gamble 1993) of the medical industry, which has generally been accepted to be a result of many instances of coercion into medical trials, such as the Tuskegee Syphilis experiments (Corbie-Smith et al. 1999; Crawley 2001; Dovidio 2008; Gamble 1993; Gamble 1997). Dovidio and colleagues conducted a study in 2008 that found physician's racism had routinely influenced diagnoses and perception of minority patients. Perhaps not surprising, then, are corresponding findings that African Americans have less trust in the health care system and in their health care providers that are not the same race than white Americans have (Dovidio et al. 2008). Racism as a form of stigma coupled with the stigma of being homeless, impoverished, and socially deviant will likely further decrease the level of trust, necessitating the need to understand health care that takes outside of the traditional biomedical industry.

Zlonick and Zerger (2009) and Osbourne (2002) found that homeless people, often in the greatest need for help from institutions such as hospitals or government assistance, are often the

most mistrustful of such established institutions. Individuals who identify highly with the homeless identity are less likely to utilize outreach services but had higher self-esteem scores (Osbourne 2002). This inverse relationship between homeless identity recognition and outreach service usage (Christian, Clapham and Abrams 2011) further indicates the need to understand whether health outreach provision can be changed to better preserve the self-esteem of homeless people while still treating their health needs.

## 2.4 Stigma and Health Status

Goffman (1963) describes three types of stigma. The first is the stigma related to the body, which is experienced by people with physical deformities or abnormalities. Tribal stigma stems from the person's race, nationality, or religion, and the third type of stigma involves the person's character being reduced in value. He states that 'normals' or those without the particular stigma in question treat stigmatized individuals as though they are unhuman and in need of benevolent social action (Goffman 1963: 5). Goffman (1963) goes on to describe that the behaviors of stigmatized people, which may indeed be their defensive response to their stigma or defect, as a justification for stigmatizing them in the first place. Of course, examples of this type of justification are common for drug users, sex workers, and poor people more generally. What may be perceived self-care strategies, such as prostitution as a means of income or temporary shelter, is often seen as a reason for social exclusion and judgment by 'normals.'

Zlotnick and Zerger (2009) draw from Goffman (1963) to explain the way that stigma works to affect health outcomes in homeless individuals. They found that homeless people experience one or more types of stigma (Zlotnick and Zerger 2009). In the case of the sample analyzed in this thesis, participants are African American, often disabled or addicted to substances, and reduced in

social and financial value because they have no physical home. In this way, they experience all three types of stigma.

Hatzenbuehler, Phelan, and Link (2013) identify stigma as a fundamental cause for health inequalities. Together with the stress induced by stigmatized social identities and the social disadvantages it provides for stigmatized peoples, stigma operates to limit health resources, social relationships, and coping strategies. Link and Phelan (2006) discuss stigma as generated by five integrated components: people identify and label human difference; process of stereotyping in which the labeled person is linked to undesirable characteristics; group doing the labeling separates "them"—the stigmatized group—from "us;" stigmatized people experience discrimination and loss of status; and the exercise of power.

#### 2.5 Homelessness and Health Status

Snow and Anderson's (1978) monumental article on the social construction of homeless identities provides a useful lens for research that highlights the experiences of transient populations. In their ethnographic study, they find that as a response to the stigmatized identity of being homeless, individuals without shelter construct identities through speech in order to maintain their self-worth. They were interested in the ways the homeless "generate personal identities that yield a measure of self-respect and dignity" (Snow and Anderson 1978: 1339) in response to the stigma symbols they experienced in their social world.

Snow and Anderson (1978) also found that homeless individuals used social psychological strategies to develop and maintain their self-concept and self-esteem in the face of intense stigmatization from the larger society. Within their social groups, they used storytelling and language to create identities. While Snow and Anderson's research focused on maintaining self-concept, which is considered a protective factor against negative health outcomes, additional

research on other protective behavior is needed (Bandura 2004; Rosenstock et al. 1994; Strecher et al. 1986). In some ways, this thesis builds upon the findings of Snow and Anderson in looking for the mechanisms that homeless individuals employ to protect their health – be it mental, physical, and at times both. I extend the scope of coping mechanisms used by homeless individuals for the maintenance of both their physical and mental health. In this thesis, I seek to understand the health behaviors that homeless people employ that may too be distinct from housed people, but normalized on the streets.

#### 3 THEORETICAL FRAMEWORKS

This research is situated in the Sojourner Syndrome framework. The following section explains how it was employed.

## 3.1 The Sojourner Syndrome and Resiliency

A focus on self-care practices is seemingly an attempt to focus on individual-level behaviors and has the potential to fall into blame-the-victim rhetoric. The goal of this work is to highlight the strategies that individuals employ to exert agency over the overt structural barriers to living healthy lives. The tension between individual and structural level explanations is acknowledged and challenged throughout the data analysis in an attempt to continuously check for bias on the part of the researcher. The role of resilience is explored through the data analysis as a mechanism to identify structural barriers while acknowledging any protective behaviors or attitudes that mitigate poor health.

In order to better address the seemingly paradoxical inclination to study individual-level behaviors through a lens that accounts for structural barriers, I employ the Sojourner Syndrome framework. Named for Sojourner Truth, the Sojourner Syndrome offers scholars an intersectional lens through which to understand how race, gender, and class operate in the lives of African American women to produce health effects (Mullings 2005). Lekan (2009) describes the Sojourner Syndrome as a mechanism that explains the spirit of resilience and persistence that has led to the protection and survival of African Americans despite the legacy of dehumanization and health-degrading experiences they, as a group, have experienced.

Mullings (2005) uses the Sojourner Syndrome as an intersectional framework to reframe scholarship to account for power dynamics. She suggests that by looking at racism and not race, gender subordination instead of gender, and resource distribution as factors that influence how

apparently "voluntary" individual-level lifestyle choices are constrained and enabled. The Sojourner Syndrome lens offers an alternative approach to contextualizing health disparities by focusing researchers' attention on not only how the victims of oppression behave, but also on how unequal societal structures and policies influence behaviors. I extend the utility of the framework to incorporate, to the extent possible, the lives of African American men in the sample who also inhabit stigmatized identities such as non-traditional housing status, severe poverty, and drug use. I also use the framework to actively locate and contextualize adaptive behaviors and strategies in the narratives, which I consider sites of resistance.

Below is an example of using the Sojourner Syndrome as a way of framing a health narrative. A female crack user describes the way she sells her body for shelter during the winter months: a researcher using the Sojourner Syndrome as a framing mechanism may cite prostitution not only as a risky health behavior but also as a protective strategy, employed during the harshest weather months. Layered on top of her individual-level behavior would be laws that penalize sex work, which put her at risk for incarceration or exposure to harsh weather, if she cannot find other means of income to secure shelter. When viewed through a historical lens, this woman's lived experience is congruent with the experiences of her black ancestors, who were forced by circumstance to use their bodies as a commodity (Collins 2000). This brief example shows a way that self-care can be at once understood and complicated by considering the historic role of oppression of black women, the objectification of their bodies, and their resourcefulness in the face of limited options.

While there is no variation of race in my sample, there is variation in housing status, gender, age, and neighborhood. Sojourner Syndrome will be used as an intersectional approach to look at the interplay of the aforementioned variables that impact self-care strategies.

#### 4 METHODS

## 4.1 Respondents and Data

Analysis of secondary data collected under the direction of co-principal investigators, Dr. Richard Rothenberg and Mary Anne Adams, was used for this project. The individuals in the sample were selected because they live in non-traditional housing arrangements, engage in risky sexual behavior, or were active drug users. The Principal Investigator, Dr. Richard Rothenberg, identified risky behavior as: residency in one of the five Atlanta zip codes, substance use and/or abuse, or involvement in sex work. The participants were selected for part of a larger project conducted in the Community Research Center in the School of Public Health at Georgia State University. The original street ethnography team was composed of two staff members and six graduate students to examine community members' perceptions about their neighbors and the utility of community and faith-based outreach services. The original study recruited individuals from zip codes at high risk for HIV transmission. Those zip codes were: 30310 (Pittsburgh); 30312 (Boulevard); 30314 (Vine City); 30315 (Lakewood), and 30318 (the Bluff). These zip codes also house census tracks identified as having both low-access to fresh foods (food deserts) and low-levels of household income (USDA 2014).

Forty-one respondents residing in five zip codes in metropolitan Atlanta participated in one-one interviews. The interview guide is provided in Appendix I. A majority of the respondents lived in the zip code 30314 (26.8%), followed by 30312 (22%), 30315 (19.5%), 30310 (17.1%), and 30318 (14.6%). Almost all respondents identified as African American, except one who identified as Black/Cuban. The sample was predominantly male (58.5% male), followed by female (39%), with one transgender respondent. Respondents ranged from age 33 to 63 with an average age of 50.

## **4.2 Sample Selection**

A team of graduate students and staff of the Community Engagement Core in the Center of Excellence for Health Disparities Research at Georgia State University screened participants for both participation in risky behavior and zip code of residence prior to conducting interviews. Key informants and gatekeepers who have collaborated with the School of Public Health on previous projects and with whom rapport has been built over the years recruited the participants. During this time participants were recruited using snowball sampling to participate in the individual interview phase of this study.

In order to discuss the findings and allow for the reader to gain an in-depth perspective into the lives of the respondents, seven interviews were randomly selected for in depth discussion in the findings section. Excel was used to randomly select cases that proportionately represented the gender breakdown in the sample. Two female respondents, four male respondents, and one transwoman respondent make up the smaller sample that will be discussed in the following section, representing the larger sample's gender breakdown (58.5% male, 39% female, and 2% transgender). While these seven cases will be discussed in depth, the findings and conclusions will also point to findings for the full range of cases.

#### 4.3 Data Collection

The original research team located in the Community Research Center (CRC) within the School of Public Health at Georgia State University was composed of a project director, data manager, field supervisor, one research interviewer, three community services specialists, six graduate research assistants, and two community members. The participants in the study were selected by the two most senior staff, with over 21 years of combined public health field

experience, who screened and recruited individuals who were deemed 'high risk' for HIV and/or sexually transmitted infections and who lived in one of the five zip codes represented in the study.

This study utilized a qualitative design, and data were collected from June to August 2012. The ethnography team mapped out street communities of interest within the five-targeted zip codes. The ethnography team identified a set of street "allies" or gatekeepers to these local communities in each zip code. During this time, participants were recruited via street outreach using snowball sampling for the individual interview phase of this study. Of those recruited, 41 participants were interviewed for approximately one hour. These face-to-face interviews took place in private offices on the campus of Georgia State University. Each participant received a copy of his or her signed informed consent form and \$25 at the conclusion of the interview. All of the interviews were tape recorded and transcribed by a graduate research assistant. I use these transcribed interviews for my analysis.

## **4.4 Data Analysis**

While *pure* grounded theory would not outline existing theoretical frameworks or hypotheses, for the purposes of this thesis, the author narrowed the scope of the analysis. Drawing from existing theory and the research questions, four main themes were selected to code the interviews: Social Networks, Housing Status, Self-Care Strategies, and Health Status. Building upon the findings in a similar study on the self-care strategies of injection and chronic drug users (Drumm et al. 2005), the following are possible self-care domains that may emerge as a theme called "self-care strategies:" nutritional, physical, substance use, medical, and sexual. Respondents were not asked specifically about self-care practices, but the interview guide was focused around the themes of personal biography, outreach service utilization, and general perceptions of health risks within communities.

Dedoose web-based software was used to securely store and code the data. This software assisted in coding and in visualizing emerging themes. In the initial coding phase, key phrases and words were highlighted to develop a code list, looking specifically for indicators of living situation, health attitudes, health behaviors, and protective strategies. While this larger project does not have a specific hypothesis, the author looked for indicators of respondents' living situations and self-care behaviors. Living situation will encompass concepts such as type of dwelling, neighborhood characteristics, and perceived stability of living situation. The author performed all coding, which is a limitation in terms of the credibility of the data analysis. Although the scope of this thesis does not provide for a second coder to test for inter-rater reliability, the single coder provides strength in overall consistency in the coding process.

The following diagram shows the four themes that guided my initial coding phase: Living Situation, Health, Self-Care Strategies, and Social Network. This framework provided the guidelines for my coding process. The findings section of the thesis illuminates any relationships between the four themes.

In the initial coding phase, the author simply highlighted key phrases and words, then the preliminary code list was developed (Appendix II).

Table 1: Coding Themes



## 4.5 Credibility and Trustworthiness

The purpose of qualitative research is to seek a broader understanding of social phenomenon using inductive reasoning, which departs from the focus of quantitative research to provide and test hypotheses, uncover causal relationships, and predict outcomes (Golafshani 2003, Hoepfl 1997).

Golafshani (2003) describes reliability as whether the result of a study is replicable and validity as

whether the means of measurement accurately measures what is intended. Some qualitative researchers reject the use the terms "reliability and validity" to evaluate qualitative research and suggest that their use is most appropriate for use through a more positivist, quantitative lens. For the purposes of this research, which is qualitative in nature, "trustworthiness" and "credibility" will be used instead to address issues of validity and reliability (Golafshani 2003).

Measures were put in place in the initial sample selection to increase the trustworthiness of the study. Trustworthiness is a concept referring to the quality of the research performed. Similar to validity in quantitative research, trustworthiness addresses concerns that the research measures the intended variables. In the case of qualitative research, trustworthiness refers to the rigor with which research is conducted. In this study design, key informants were identified to train staff on cultural competency in doing community-based research. These informants also participated in focus groups to ensure language and terminology used in the interview guides were appropriate for the intended audience. Frequent debriefing sessions were also conducted to ensure proper interviewing methods were maintained throughout the data collection phase.

There are several limitations to this research in addition to social desirability bias, which was discussed above. Graduate research assistants, staff, and community liaisons conducted the interviews at Georgia State. This mix of interviewers provided for a range in the quality of interviews. On the one hand, some of the graduate students tried to conduct their interviews as objectively as possible, refraining from prompting the respondent in certain ways and refraining from value statements. On the other hand, some of the community liaisons shared similar histories with respondents, were more familiar with the neighborhoods the respondents were coming from, and shared more cultural context. There were benefits and limitations to each dynamic. It was clear that some interviewers did not have enough rapport with respondents to facilitate a rich

discussion. Such instances could be seen in one-word responses, the interviewer speaking too much, or the interviewer asking blatantly leading questions. Another limitation to this research is the fact that the author was not present for the interviews, which means that certain nonverbal cues could not be included in the analysis.

## 4.5.1 Positionality

It is appropriate to incorporate a discussion about the positionality of the researcher to address issues of credibility. LaRossa (2005) describes the researchers as a second-order storyteller. He describes the role "The second-order stories that researchers impart are also about their lives— and ultimately about their 'selves.'" (LaRossa 2005, p. 851) As a storyteller, the researcher must weave together a coherent story through the analysis of data. By disclosing social location, the researcher enhances the reader's understanding by providing the context for the overarching story.

In addition, an attempt to disclose information about the researcher is a way of examining the credibility of the analysis (Thompson 1992). Feminist standpoint theory asserts that researchers cannot separate themselves from their lived experiences, which will, despite attempts to maintain objectivity, influence the way they analyze data. In the following section, the author provides information about her own social location in order to paint a fuller picture of herself as a researcher and identify factors that may color her analysis.

I identify as a straight woman of color who is from Atlanta. I grew up in an Atlanta suburb and attended both public and private schools in the city of Atlanta from elementary through high school. Because of my family ties in Atlanta, I was familiar with the neighborhoods that participants referred to in their interviews. A key component of subject recruitment for this study was street-based ethnography. Members of the team scouted locations, spoke with stakeholders, and were granted access to meet potential respondents. While I acknowledge that my phenotype

allowed me a certain level of access to the predominantly African American communities we sampled in, I also must acknowledge that the difference in socio-economic position between the respondents and me could also have influenced responses in public interactions and interviews.

The stories presented below highlight the impact that precarious housing situations and food insecurity can have on existing health conditions and some of the particular concerns for transient populations and healthcare. By delving deeper into the lived experiences of the respondents, the overarching aim of this project is to depict the stories of individuals that exercise agency over their lives and not simply groupings of statistical cases.

### 5 INTRODUCTION TO PARTICIPANTS

Pseudonym	Zip Code	Gender	Age
Mark	30314	Male	58
Lucy	30310	Trans-	49
		Woman	
Sam	30315	Male	53
Bernard	30310	Male	50
Roland	30312	Male	61
Michelle	30314	Female	36
Veronica	30315	Female	50

Table 2: Key Respondents' Demographics

The table above shows the demographic information about the seven key subjects whose stories will be examined in-depth in the findings section. As discussed above, the gender distribution aligns with the overall sample distribution. The following section will provide brief introductions to the key subjects, give background about their situations and contextualize the

quotes used to discuss findings. Other respondents' commentary will also be discussed in the findings section, but in an attempt to provide more information about the context of the participants' lives, the next section will paint a fuller picture of the day-to-day lives of the sample population.

## **5.1 Introduction to Participants**

#### 5.1.1 Mark

Mark<sup>1</sup> is a 58-year-old male. He has spent the majority of his life living in a ten-mile radius in Atlanta, mostly in Summer Hill (the area surrounding the Turner Field) and the Bluff (near the Georgia Dome), where he currently resides. He describes his childhood neighborhood of Summer Hill "just as rough as it is now." He noted that at that time, it was "alcohol-infested" as opposed to now, when it is "drug-infested." His siblings all live near him, and while at one point he was living with his sister, he felt like the rent he paid went to support her alcohol addiction, so he moved out. Now he lives with his nephew, a few blocks away. He openly discussed the normalcy of violence in his neighborhood.

#### 5.1.2 Sam

Sam is a 53-year-old man who was also raised in Atlanta. Born in the Grady Homes public housing complex, Sam has stayed in the metropolitan area his whole life. He currently squats in "catholes" (abandoned or vacant houses) around Cleveland Avenue, south of the city. Sam is an active drug user who works as a runner, exchanging money and drugs with customers on behalf of dealers. He supplements his income by robbing and selling goods, mostly stealing merchandise from grocery stores like Kroger or Piggly Wiggly for resale on the streets. He tries to steal items

<sup>&</sup>lt;sup>1</sup> All names that are used throughout the paper are pseudonyms. I did not have access to any of the respondents' names. The only identification for interviewees was an ID number.

like beef steaks and other "high-ticket" items from grocery stores that have a high resale value on the street. He explains his business model in the following excerpt.

You try to get the highest priced shit in there that you can get. Most of the steaks around \$14 or \$15. Shit, you steal three, four packs of that and hey...that get me in for the day cause I take it to the dope man and let him see the price...steak \$15...steak right here \$32.

Sam describes his hierarchy of needs as 1) finding food, 2) bathing and shaving, 3) a place to stay, and 4) a place to get money to get around. He discusses his planning process to go about each day and how he maps out his movement so that he can accomplish his goals. Because he uses most of his earnings to buy drugs, he finds food for his own consumption in dumpsters. He laughs when he says that some people in the neighborhood call him "Dumpster King."

Sam's daughter died a few years ago from HIV complications. He is haunted by the experience of watching her die in part because of her resistance to comply with medical advice. He attributes his depression after her death to the catalyst for his drug and alcohol abuse. He also talked about his risky sexual behaviors including multiple sex partners and refusal to use condoms. While he was incarcerated, Sam found out that he, too, was HIV positive. He refers to the diagnosis as having "the package" or the "full package." He explains the way he tries to stay healthy in the following terms. "I haven't been taking care of myself but I still look at it as like...long as I eat, walk, drink water, and sleep kinda properly, I'm not too bad off." This statement illustrates his attempt to maintain a relatively healthy routine as best he can in light of his addiction and precarious housing situation.

### 5.1.3 Lucy

Lucy is a transwoman who is 49 years old. She lives in a transitional home in the West End, where she is the primary caregiver for the other boarders, the cook, and the house manager. She began living there when she became homeless, and when she did get back on her feet, she did not

want to leave the community she had become a part of by living in the boarding house. The organization that operates the house allowed her stay as a full-time employee. It is unclear whether she receives a salary for her work or if her services are bartered in exchange for living rent and expense-free. She enjoys her position as house manager. Lucy grew up in Columbus, Georgia, but when many members of her family died of cancer, she moved to Atlanta in search of job opportunities and a new start. Unlike the other six respondents and the majority of the larger sample, she expressed high satisfaction for her neighborhood and feels very secure in her living situation. She supplements her SSI income by collecting cans and selling them to scrap metal buyers. She suffers from post-traumatic stress disorder since being gang-raped, paranoid schizophrenia, high blood pressure, and HIV. She is compliant with her medications and treatments. She likes to participate in survey research because they pay in gift cards to different food vendors like McDonalds, Kroger, or Subway. Lucy says that "...food always get a person or people to stuff. Like when yall giving out lunch or something like that or yall feeding them brunch or whether it's just some fruits or something like that. That'll get people there."

#### 5.1.4 Bernard

Bernard is a 50-year-old man. He grew up in Herndon Homes, a housing project located near the Atlanta University Center. Currently, he does not have his own housing. Sometimes he stays with his sister, but most of the time he stays with friends downtown. He describes the neighborhood where his sister lives as a neighborhood where "working people live." From his description, it appears that he does not feel as comfortable in her neighborhood as he does downtown. Bernard has been clean for about 14-15 years, ever since he went through a drug rehabilitation program at Jefferson Place, a transitional housing location for men dealing with substance abuse.

Bernard says that he decided to move downtown when he "really needed some help." He found it easier to get to Grady Hospital, and he was closer to public transportation. He mentioned that if he lived downtown and did not have money for bus fare, he could still walk to get where he needed to go. A few months ago, Bernard filed for disability. He is still waiting to hear the results of his claim.

#### **5.1.5** Roland

Roland is from Boston, Massachusetts. He is 61. He moved to Atlanta with his mother and a sister about 10 years ago. He has eight sisters in total and two daughters. He does temporary work installing satellites for hotels and buildings. Sometimes he will work as many as three months on a job, but he waits indefinitely until he is called back for the next project. He alludes to having struggled with drug abuse, but during his interview, when he did discuss drug use, he mostly reprimanded his neighbors who use drugs.

Roland considers himself borderline homeless, because he is currently staying with an old man who he helped apply to get into a high-rise downtown. Roland stays with him from time to time when he does not have anywhere else to go. He says that his daughters check on him daily, and one sister calls once a week to make sure he is okay.

#### 5.1.6 Michelle

Michelle is from Atlanta. She grew up in Perry Homes, a public housing community, and she reflects that in her neighborhood, there have always been "crazy things going on," alluding to violence, drug use, and crime. She says that she has had drug users and sellers on both her mother and father's sides of her family. Most of the time she lives with her fiancé, his friend and his fiancé. Sometimes Michelle stays with a girlfriend. Her fiancé's place does not have water, a stove, or a refrigerator.

Michelle has eight children and is pregnant. She is worried about having a risky pregnancy because she is 36. She has Medicaid because she is pregnant, so she can go to almost any doctor she wants to visit. Her children live with their fathers because she is struggling with cocaine addiction and does not have a stable living situation. While she knows that her children are better off living with their fathers, the depression she experiences as a result drives her to use drugs. She is trying to stay clean because she is pregnant.

When Michelle was younger, she was convicted of felony charges for forgery. She forged checks to be able to afford housing and food for her children. Because of her criminal record, she is not qualified for any subsidized housing and finding work is near impossible. She works at a nightclub on Saturday nights, but her hours have been cut back significantly. She also sells drugs sometimes and does hair. Michelle is becoming a certified organic chef through a program at her church, Berean Seventh Day Adventist.

## 5.1.7 Veronica

Veronica is 50 years old and lives in south Atlanta around Cleveland Avenue. When she isn't sleeping in the street, she stays with a friend who she takes care of in return for a room. Before she hurt her leg, she drove trucks. One of her biggest challenges is the lack of transportation and access to social services in South Atlanta. If she gets sick, she has to travel two hours to get to Grady.

Because she heard about women getting raped around where she lives, she travels with others whenever she goes anywhere. She has a group of five people who she refers to as her "little family." They share resources, panhandle together, and look out for each other when they sleep under highway bridges. She used to have an aunt that she would stay with in Decatur, but since her aunt has moved to an assisted living home, she has nowhere to go.

When Veronica gets sick, she prefers to go to Mercy Care, where they give 60-90 days-worth of blood pressure and pain pills - unlike Grady or other clinics who give you a few pills and a prescription to get filled. She gets most of her food on the weekends, which is when most churches and missionary groups distribute food. While she appreciates the sack lunches, she looks forward to hot lunches and fish fries. When the churches do not feed, she and her friends go from restaurant to restaurant along Cleveland Avenue asking for a plate. She says that after a while, someone will usually give them something. Veronica hopes to find a job driving vans or smaller trucks, because she still has her license. She wants to get her life back on track.

#### 6 FINDINGS

The purpose of this research was to examine more closely the barriers to health care that transient populations perceive and experience and the mitigating strategies they use to improve their health outcomes. Findings from this analysis indicate that the most salient barriers for transient populations were lack of financial resources, lack of health insurance, beliefs about health, addiction, and mental illness. These barriers were mitigated through one or more self-care behaviors exhibited by the participants. For this research, I defined any mitigating strategy that the participant conducted with the intention of improving their overall health, both physical and mental, as a self-care strategy. The following sections will explore both the barriers and mitigating self-care strategies discussed by participants.

### **6.1 Financial Resources**

Participants most frequently named the lack of economic resources as a barrier to accessing healthcare or practicing healthy behaviors. As expected, lack of financial resources was also a root cause of related barriers such as unstable housing, food insecurity, and lack of transportation. While

participants did not talk about their economic status, they did allude to it by discussing self-care strategies to mitigate their lack of financial resources. In the case of this analysis, it was their discussion of the strategies to cope with poverty that I use as evidence of its permeation throughout their lifestyles.

Bartering was a common strategy used by respondents to access resources. While bartering was mentioned by some participants as a way to trade goods such as food or Marta cards, bartering was most discussed as it related to shelter. Participants would receive shelter and food in exchange for caring for an older landlord. That landlord may receive housing assistance or live in a senior housing facility but may be unable to afford in-home care. Respondents who were in these types of reciprocal relationships with friends, family members, or acquaintances did not report to be homeless, although, in essence, they oftentimes did not live in stable situations. This informal eldercare system is an example of self-care strategies for the caregiver and the care-receiver that may not be able to afford traditional in-home services or the costs associated with assisted living facilities.

Black market sales were commonly discussed in the sample such as vending stolen goods for cash or reselling donated food. Since jobs are limited in the communities, black market sales are a viable way to make quick cash. One participant, Bernard, discussed how he used to work as a day laborer, but has found it more and more difficult to find work. He is frustrated because he sees how much cash is being exchanged between drug dealers and users in his neighborhood, and he does not know where they get it. He assumes it is through prostitution or stealing in return for drugs. He is resentful that he struggles to find cash to get his basic needs met while drug addicts find money to support their habits.

Most participants are heavily reliant on social service providers in the neighborhood, the majority of which are churches and mission-based charities. Sam gets his food through either dumpster diving, stealing, donations from churches, or from women who want to sleep with him. He mentioned one "fat woman" who he cons out of food because he knows she wants to sleep with him, so he asks her to feed him, then leaves. When he receives food from churches, especially the Seventh Day Adventist church that gives away groceries and not prepared foods, he can only eat the food that does not require cooking, as he does not have a working stove in the abandoned homes where he lives. He sells the dry food and vegetables in order to supplement his income.

Sam, another respondent, no longer qualifies for food stamps because he lied about his criminal record in order to qualify for them in the first place. He cannot receive SSI or disability for HIV because his T-cell count is too high to qualify. As an ex-convict, it is difficult for him to find work. In contrast to Mark, who believes that if he works hard enough seeking out help to get back on his feet, he will be able to have a stable life, Sam explains his situation in the following passage.

And then when I do commit these crimes and they ask me why...I had no choice. It's like kill or be killed. I knocked on the door and asked for help, and they wouldn't let me in. I knocked again and I said please let me in, I'm hungry. Give us something to eat. They wouldn't let me in. So guess what? I came back next time with a gun and my knife and I kicked the door in. I said gotdammit, this is it. I'll take it. And they said "whoa!" It's too late now. Boom, boom, boom! Ok? They turned me into what I am. And that's how I wound up right now with a very serious...criminal history.

In this passage, the reader can clearly understand the dilemma in which Sam finds himself. He is unable to work and unable to qualify for the social services he needs to feed himself. He also alludes to the fact that it was this despair that led him to commit crimes. While there is no way of knowing the actual sequence of events that led to Sam's incarceration, the fact that he is now in a system that is almost impossible to navigate his way out of is undeniable.

## **6.2** Accessing Healthcare

Accessing traditional health care facilities and resources is not a linear path for most of the respondents. Preventative healthcare was not discussed in the sample, unless it was related to disease management such as for mentally ill respondents or respondents who were managing their HIV. Grady was by far the most accessed healthcare facility, despite the handful of neighborhood clinics. Respondents were most comfortable with Grady and accessing emergency care.

Roland goes to Grady when he gets sick. He says that he has to pay and that it is expensive for him. He said that once, he was prescribed medication and was given a few sample pills, but he did not have enough money to go to a pharmacy to actually fill the entire prescription. Instead, he broke the sample pills in half and took them for as long as they lasted. He supposes, "his body just healed itself." He brushed off the incident saying that he is skeptical of hospitals and pills anyway and prefers natural remedies. In this explanation Roland exhibits his willingness to access healthcare services, but he also illuminates a clear gap in service provision. By creating an additional step between doctor and medicine, Roland, and many like him, lose the ability to fully access healthcare. Roland also describes a belief he has about health in the passage. He believes that, despite the fact that he went to the doctor and took medicine, his body healed itself. This belief may be a barrier to Roland accessing healthcare in the future. It may also comfort him since he may not be able to fully access it anyway due to financial restraints.

In the next exchanges, two respondents discuss the way they access healthcare. The first respondent does not formally engage with the healthcare system, despite the fact that his sister is a nurse. He prefers to get his medical advice from a trusted family member.

I don't get sick. I ain't been sick. (inaudible) the only time I get sick but basically, I been in good health. Besides a little back trouble. But it goes away...I ain't' been to a checkup in years. My sister been working at Grady 30 years but like I say, I (inaudible). Yeah she been there 30 years. She a LPN. I just call her sometimes and she tells me what to take.

Another participant describes his healthcare specialist in the following passage.

My grandboo [grandmother]. Mama, I'm hurt. I'm on my way. "Baby what's wrong?" I'll tell you when I get there. I was sick...January and February. Real bad cold. I had my snowsuit...I got on my blue jeans, pullover hoody, a snowsuit, and a faded jacket, and I was still cold. I called my grandboo. She said, "boy come on down here." That's my healthcare specialist. I got down there, she ran me some hot water, went downstairs, fixed me some chicken broth, I did that, and I started feeling a little better. She said "I tell you what I'mma do...I'mma fix you one of those old remedies, those tonics." The next morning, I was feeling maybe...40% better. And when I got back to my maximum self, she was like "you feeling better?" I was like "yeah", but I gotta go. She said "no you don't. Boy you still got a fever." Mama, stop. (laughs) But that's my healthcare specialist.

This participant relies on his grandmother's home remedies when he gets sick. While he lives on the street and in abandoned houses, he does have a place to recharge and escape the harsh weather. Maintaining relationships with family members that are caregivers is a self-care strategy that both participants practice. In the later passage, it is evident that the grandmother utilizes homeremedies either as opposed to or in addition to pharmaceuticals.

The same participant goes on to describe how others in his neighborhood access healthcare. "If it's really something wrong with you, you best believe it's somebody in that neck of the woods that was going through the same thing and they got some medication that's gone help you out." In this passage, we learn that medication is shared and distributed within social networks. While only one person may go access a traditional healthcare facility or pharmacy, the impact of that visit may benefit a number of people. This is a key finding that supports programs that attempt to change health behaviors by focusing on community-wide or family-wide interventions, as opposed to programs that focus only on impacting individual's health choices. Information and resource sharing is a prominent characteristic of the residents in the communities in this sample, even when respondents claimed not to have strong social ties with neighbors. He goes on to explain his last visit to a doctor.

I ain't been to the hospital in so long. Every time I break my knuckle hitting them young guys in the mouth...I know the last time I went to the hospital was actually '84 or '85...that was the first time I broke my knuckle. And I notice how they snapped it out...pulled it and put it back in place and put a splint on it. So now every time I hit a person in the mouth and I feel it pop, I get me a stick, put it in my mouth, then snatch it and put a brace on it and I'm good. I go in the store and get me some Aleve or Ibuprofen or some PM pills and go swallow half and go to sleep.

This participant, aware that he would not be changing his risky behavior of fighting and subsequently injuring himself, decided to learn how to heal himself after altercations. Rather than rely on the healthcare industry, he relies on his own method, as he cannot or will not access medical care. He self-medicates with pain pills, which represents another recurrent self-care strategy seen throughout the sample.

Few participants discussed preemptive healthcare. Generally, they seemed to wait until their conditions were severe to seek medical attention due to the difficulty in getting to the facility, the amount of time needed to see a doctor, and cost of medication. Even when participants were able to see a doctor free of charge, often they were required to fill their own prescription, which proved challenging to some. One strategy that emerged was the rationing of the sample pills given during the doctor's visit for as long as possible when a respondent was unable to pay for a full prescription.

# 6.2.1 Self-Medicating and Addiction

The original sample selection screened specifically for individuals actively engaging in risky behaviors, so issues of addiction were recurrent throughout the majority of the sample, with approximately 86% of participants indicating they were actively using drugs or alcohol. In this light, findings from this analysis cannot be generalized to encompass all residents in the target zip codes, nor all transient populations. This sample has a disproportionate number of drug users.

Almost all participants reported using either drugs and/or alcohol. The most commonly used drug was crack. Some participants had moved to the specific neighborhoods because of the ease of

access to drugs. Those looking for recovery acknowledged that they would need to move out of the Bluff, specifically, if they wanted to get clean. When discussing his recovery, Bernard admitted that it could be difficult for him to live in a place where so many drug dealers are always trying to sell him drugs. Disease Management

Many participants noted symptoms of depression and anxiety as well as official diagnoses.

Many attributed their drug use to feeling of helplessness and depression and saw it as a coping strategy. Several respondents expressed that their lack of family ties as a catalyst for their drug use – be it the loss of contact with children, deaths of loved ones, and feelings of guilt surrounding family issues.

Sam is HIV positive and also reports self-diagnosed depression. It is unclear from the data whether he has been formally diagnosed with depression, but for the purposes of this analysis, we will consider Sam's self-reported mood disorder as a mental illness. Lucy suffers from post-traumatic stress disorder after being gang-raped and is a paranoid schizophrenic. She is also HIV positive.

Mark suffers from uncontrolled diabetes, for which he has been prescribed insulin to be taken twice a day. He also has a heart condition. In total, he takes five pills a day for his various health conditions. Given their compromised immune systems and chronic illnesses, regular access to food and medication is critical for the health of these individuals. Despite their illnesses and limited resources, they frequent approximately six different facilities to get meals, medication, clothing, and other essential resources. Their stories shed light on the agency and resourcefulness needed to live with chronic disease while being resource-poor.

Complicating Mark's food procurement strategies are his health conditions. Mark suffers from diabetes for which he has been prescribed insulin. He also takes medications for a heart condition.

Even though these are diet-related illnesses, Mark is unable to make many choices about the food he consumes due to is reliance on donated food and a limited amount of food stamps. From his description of foods he normally eats at home, the reader can see that he ingests a large sodium and saturated fat content. The reasons for these decisions are varied, but we note a correlation between food insecurity and negative health outcomes.

Michelle is pregnant and struggling with addiction to cocaine and marijuana. She is in an abusive relationship with her unborn child's father. She does not have a stable housing situation, which undoubtedly impacts her pregnancy, which is already risky due to her age. She is worried because her fiancé has what appears to be genital herpes. She got tested, and came back negative, but she is afraid of what else he may be exposing her to. She tries not to speak about her health concerns because she does not want to "claim them" and speak them into existence.

Beliefs and perceptions about both health and illness guided behaviors of respondents. These beliefs ranged anywhere from belief in natural remedies to the belief that speaking about illness in specific ways could cause one to embody it. Beliefs and perceptions about doctors and healthcare specifically can be linked to behaviors.

Veronica struggles with high blood pressure and pain. She may have other health issues undisclosed during the interview. In order to go to Grady, where she received the majority of her healthcare, she has to take MARTA, which can take her upward of two hours from where she lives. She is dependent on handouts for food and does not have a secure way of keeping food, because she lives on the street. The majority of her day is spent panhandling and trying to get food from fast food restaurants. She is disabled and unable to work because of a leg injury.

While Sam does have a doctor and receives medication at the IDP clinic, he has not been in a while. When he is using drugs, he does not take his HIV medication because the interaction is

unpleasant. He also feels he cannot take the medication because he does not eat enough. He says he needs heavier food like "rice, greens, and macaroni" to take with the pills, otherwise he has terrible cramps.

Sam receives services from a church group who delivers food in a van. He does not know the name of the organization, but he is uplifted by the sermons they give and said he will be returning regularly to get food and feel good. He does admit that if he is high on crack, he does not go near the church groups because of the paranoia that is induced by the drug.

These participants used food as symbols for stability. Mark cited a longing at times for a "downhome meal," but because he did not have control over his living quarters, he was unable to prepare the food he desired. Lucy loves to cook. She took pride in providing meals for the other tenants in the transient house where she lives. As a transwoman, cooking and caregiving may be acts that are more socially acceptable for her to perform as a woman than as a man in that community.

## **6.3** Accessing Food and Other Social Services

Michelle is very resourceful. She is actively trying to seek social services for herself and her fiancé, who suffers from epilepsy. She has been talking with lawyers about getting him a personal injury settlement and is aware of several programs that can assist her. She is vocal about her challenges but tries not to let them get her down.

Michelle feels like the only way she will get any help is if she advocates for herself and tells people what she needs. In this passage, she explains how hard it is for people with felony convictions to get services.

So that's why a lot of us homeless, a lot of us out doing drugs, that's why a lot of us out doing unnecessary shit that we not supposed to be doing because when we try then they turn they back on us. Constantly. Not one time, not two times. Everybody turn they back on us. So we going back to our old phase, which is not good. It's not good. And it's making us seek

out for these different helps that we asked for in a legal way that we do not qualify for because of our addiction, past...it's just hard, it's really hard. And me, I've always been a outspoken person, so a lot of folks look at me like "she telling all her business!" but that's the only way I'ma get some help. When I got out of prison in 2010, I did a testimony inside my church. I had to tell my business in front of the whole church in order for somebody to help me.

This passage illustrates the hoops Michelle has to jump through and the humiliation of discussing their problems in public in order to receive services. It also shows the reader that for underserved populations, accessing medical resources and social services can be extremely time consuming, so much so that in order to work through the system. The sentiment of despair and hopelessness with both trying to work within the system and outside of it ran through the interviews. Michelle has gleaned from her experience trying to get healthcare and social services, that the louder you are, the more chances you will have to get resources.

The majority of the participants' time was consumed with locating food and other services. Food stuck out as a key area of interest because of the multiple strategies employed to procure it. I chose to look for indicators of symbolic meaning of food and impact of food insecurity on health status. Although a causal relationship could not be established between food insecurity and access and health status, the state of being food insecure did impact the severity of diet-related illnesses.

Mark receives food stamps, and he supplements his allotment with seeking donated food from churches in his neighborhood. When asked to discuss some of the types of services he receives from churches, Mark began to list about six different churches or organizations that he regularly attends to get either clothing, food, health care, or administrative assistance. When Mark described his experiences with the churches, he constantly praised the work they were doing in the community. He was generally pleased with their presence, especially the presence of street ministries. One church, Forway, makes a point to set up their food distribution service at an

abandoned church that is known in the community as a heroin dealing location. He credits the church for slowing down the drug dealing activity, if only for the Saturday mornings when they distribute food. Mark also visits Antioch Baptist Church to receive food on Fridays. He explains,

We go up there in the back. On Fridays they come in at the back and line up. Everybody, men and women, line up. And you have to be there before 8 o'clock in the morning. And we go up there and line up. The doors open up about 8 or 8:30 or quarter to 9. And the guy up there, he always let the women in first, which I can respect... Then when we go in, they give you a number and a piece of paper to sign. So they monitor so you don't come up there twice. So you don't come up there the next day. So they get that and write that down and you sit in there. And they kinda do a little church song. They sit down, preacher come in there, and it's just like we sitting in church. You get a word for a good 30 minutes. Then after that, they'll start passing out grocery or whatever they go to give.

In Mark's discussion of the process to receive food at this church, the reader can learn about the sense of monitoring that goes into his experience. While he makes a point to express his gratitude for the services, it is noteworthy that the individuals receiving food have to go to the "back of the church," and they are "monitored." Themes of monitoring and policing the behavior of this underserved population are recurrent throughout the interviews. In addition, the participants expect to "get a word" in order to receive food or groceries, demonstrating the power held by the church goers to control the circumstances under which they distribute food. In this case, the church uses its power to give food to proselytize. By requiring participants to listen to a sermon before being served, the church demonstrates its power. Because of the mere order of service delivery, food can be seen as a symbol for a reward or incentive to sit through the service or a communion or blessing as associated with church tradition of purification.

While Mark conveys his appreciation for the church's services throughout his interview, he contrasts his opinions with the actions of other community members who take the services for granted.

Churches are helping a lot of people that really need help. You got people out there need help and you also got a lot of people out there that take advantage of it, such as: they get

things from these churches they really don't need. Because the reason I said that is when they take something from some churches, they'll turn around and go out and try to sell it. Therefore, they don't need it.

For Mark, donated food should only be consumed not sold for cash. This opinion is mirrored in the church's attempts to curb the sale of food items by monitoring the number of times individuals can receive food and limiting the types of food they distribute. It assumes that the individuals who take donated food only need food to survive and not cash to pay for other goods or services. While Mark believes that those who sell the food are often buying drugs, alcohol, or sex with the money, it can be seen as a survival strategy.

Mark lives with his nephew, and in addition to the meals he procures from various agencies, he eats with his family at home. Because he is not the principle food purchaser or preparer, he has to eat what the family prepares. He complains that he tires of the fast food, hamburgers, and hotdogs that they eat. He relies on ramen noodles because they are cost efficient, one pack of which can last him one week. Mark prides himself on his ability to budget his money, especially with food.

I do know how to survive on food. I know how to go to the store. I just can't get what I really want. I want some collard greens, oxtails and stuff like that but I can't. Gas ain't on. It ain't nothing but electric. So I can't cook that kinda meal like I want to. So I have to get what I can.

Here we see that Mark does not have access to a stove, so even though he may have the means to access more nutrient-rich food, he does not have the facilities to cook. One way that he does get "downhome meals" is by buying groceries for others to cook and asking for a plate of food in return. Even though he would not be able to have all of the food he bought, the cost is worth having the type of food he wants.

## **6.4Beliefs as a Self-Care Strategy**

Respondents in this study were screened at churches that provided social services. Because of the original scope of this project, respondents were asked specifically about church attendance and attitudes about religion. While the focus of this analysis is not to dig deep into the implications of spirituality on health, it will discuss, in broad strokes, the direct comments participants made about religion and their particular belief systems that informed their self-care strategies.

Roland is religious but does not attend church much. The big churches used to send vans to pick him up, but he stopped going when he started to feel like he was on display with the other homeless people they would bring. Now when he does go to church, he attends one that primary serves "disadvantaged people" like him. He feels respected there.

He says that he prayed to God to get him out of his situation about four-five years ago, but says that when he forgot about God, he ended up right back where he started on drugs and in the streets. Through this passage, we learn that Roland believes that both his successes and failures are directly correlated to his belief and reliance on God. He also prefers to worship among individuals who are in a similar socio-economic status.

Positive self-talk also emerged as self-care strategies. At one point Michelle states "It's just that I have a strong mind. And I have God walking within me." At another, "Because it's not like I'm a dummy. I'm a very smart young lady, it's just that it's hard because I'm a convicted felon." At another, she becomes exacerbated and explains:

I've been crying out ever since February. And I'm still homeless. I'm still on the streets. I'm still living here and there. And I'm still using these drugs here and there. So...I feel if I didn't have the strong mind that I have, yes I might be one of those bums sleeping under the bridge, somewhere laid down with a paper bag. It's just me. I don't tell my business to everybody. They think cause they still smile in my face that I'm ok. No I'm not. I'm hurt on the inside. I really am.

In this excerpt, the reader can clearly see that although she puts on a strong outer shield, Michelle is in pain. Her commentary can be a vivid description of the Sojourner Syndrome discussed in earlier sections. The juxtaposition of her humiliation and vulnerability with her strength illustrates the paradox of the Syndrome. Michelle feels like she needs to embody strength as a way to deal with the difficulty of her situation. She feels that if she shows weakness, then she will become prey to others and may not be able to control her drug addiction.

Another participant describes his personal hierarchy of needs in the following passage.

I tell myself each and every day that as long as I watch myself, there's a standard I have to live off of where I...number one, I gotta eat. Number two, I have to bathe and shave. Number three, I gotta have a place to stay. Number four, I gotta have some kinda place to get money from point A to point B.

This hierarchy was not articulated by any other respondents; however, it gives the reader an idea of the priorities in the lives of individuals living in transient housing, who are very low income, and who rely on social services to survive. While each day, the individual may find himself or herself trying to achieve one or all of these goals, healthcare is not high on the list unless it prevents them from one of the more urgent objectives. It is only until physical health presents itself as a barrier to achieving the daily necessities of life that it needs to be dealt with. Until that point, individuals in this survey take care of themselves as best as they can to move through the sequence of priorities.

## 6.5 Housing

For respondents who did not rent or own their own space, four types of housing were most common: shelters, rooming houses, the streets, or temporary housing with friends, family, or associates that was typically bartered for through services such as care-giving, cooking, or cleaning. Rooming houses were generally used by participants as temporary solutions when they were transitioning off of drugs, recently released from incarceration, or attempting to get off of the street.

Additionally, specialized rooming houses for individuals with HIV and developmental disabilities were also seen in this sample.

Participants who lived on the streets instead in shelters or rooming houses typically did so because they did not like the way they were treated in shelters, did not feel safe in shelters, or preferred the freedom of movement that being on the streets allowed them. Many respondents complained because of the strict policies of the shelters. Veronica complained that she had been staying in a shelter downtown on a mat on the floor, which was policy for overflow clients. She was offered a room with a friend for one night, and when she returned to the shelter the next day, she learned that was not allowed back because she had not stayed consecutive nights. Rather than deal with the regulations, she prefers to sleep on the street than on the floor on a mat. Other respondents cited violence, theft, and a general feeling of insecurity in the shelters as reasons for refusing to stay in them. This is a way that Veronica, and others, exercise agency in their situations despite limited options. One participant explains their housing situation in the following passage:

Yeah. Well you can say I'm homeless cause I ain't got no light and gas cause it's one big cat hole but it's my house. A family house, right. But I almost consider myself homeless. [I don't have] Light and gas and water. I'm employed and barely working and they say if it wasn't for the house being paid for, I would have lost the house. And I still gotta pay the property tax this year.

This passage is informative because it describes the overlooked plight of many residents in blighted and underserved communities. Even though this respondent owns the house he lives in, he is unable to afford the necessary utilities and taxes to maintain home ownership.

David, another participant, describes the way he chooses to manage his meager resources by staying in an abandoned house rather than pay for a hotel room by the night. David is a 'booster'. He takes orders from people in his community, then shoplifts the requested items for a fee. During the time of this interview, he lived on Cleveland Avenue.

I found an abandoned house, and on the side of the house, the bushes go up so high that if you don't pay attention, you can't see. It's a garage right there. And I happened to be coming through there going to a friend's of mine house. I just happened to look in and see the garage. So I stopped, looked in...the house is abandoned, no one lives here...so I'm like, I don't have to go here. I can keep my money in my pocket. Get me a broom and get me some carpet...put it down...that's what I did. But by me being there, there are no windows. No window panes. But the window frames is there. If I don't keep me a can of mosquito spray around they will (inaudible). I have to buy me the Deep Woods Off. Buy me a can every three days. Because it's just that rough.

David is willing to endure the elements in the abandoned house, rather than pay for more traditional housing option for someone with little income such as an extended stay hotel or rooming house. Because David's income is sporadic, he sees the abandoned house with no cost associated with it as a stable type of housing, because he will not have to move in and out depending on his income. It is also off of the grid, so it is unlikely that he will get kicked out.

Participants were less likely to identify themselves as homeless if they were living with friends or family, although those arrangements were often just as unpredictable and unstable as living in shelters. Those who lived in individual apartments, rooming houses, and in abandoned houses were the most satisfied with their living arrangements because they felt the most freedom to come and go as they pleased without the interference of others. Those that lived with romantic partners were either at the giving or receiving end of the financial support of the other. There was little explicit discussion about the sharing of resources, but rather that one was living with the other who either had an apartment or a regular monthly income (usually from SSI). The following quote illustrates this type of relationship.

It's just me and my lady friend, she wanna move in with me. She on that dope and I really don't want her to move in with me. I don't let that stuff in my heart. I don't mind a little liquor and a cigarette. She says she going to rehab to try to get off but when you on that dope, anybody can talk...It's a friend but as time goes on, it's my girlfriend now. I still call her my lady friend cause I ain't officially confirmed that she my girlfriend. I just call her my lady friend. I use words like that.

This participant distances himself from his partner, by making sure to mention that she is not his girlfriend, but instead, she is his lady friend, which is presumably less committal. He distances himself from her both through his language and physically by limiting their physical proximity. He also discusses the way he negotiates the impact of his girlfriend's drug use by not allowing her to move in with him. He is unique to the sample; in which many cohabitating couples are either both using or one supports the drug-using partner. Throughout the sample, interpersonal relationships were discussed in relationship to securing caregiving, housing and other resources.

### 6.6 Sexual Strategies

The self-care strategies related to sexual health were few as compared to the other categories. Male participants discussed their personal condom use most often and female participants discussed abstinence as their main form of sexual self-care. Additionally, both women and men discussed trying to pick sexual partners based on how healthy they seemed as a way to guard against STI's. Sex and romantic relationships were also discussed as ways of securing resources. There were instances of both men and women who lived with older or ailing partners. In exchange for housing, the respondents provided caregiving services. It was not clear from any interviews whether sex was also a component of the negotiations.

### 7 CONCLUSION

Overall, respondents in this study discuss the barriers they experience to traditional healthcare in terms of their lack of financial resources. Through my analysis, however, financial resources are only one barrier to healthcare, and they were not the primary barrier for all participants. Lack of transportation and lack of trust in institutionalized social services were also a factor that contributed to the underutilization of healthcare access. Respondents in this study exhibited a range of self-care

behaviors that they viewed as both preventative and reactionary healthcare strategies. My findings in this analysis supported the findings of Drumm et. al. (2005) in their analysis of self-care strategies among active drug users. They found that key strategies could be categorized into nutritional, physical, substance use, medical, and sexual strategies.

Perceived barriers to healthcare were primarily discussed in terms of lack of time to get to the doctors and to wait to be seen. It is also noted that while the Emergency Room visits were known to be free for low-income respondents, participants in this survey did not discuss the availability or use of preventative care options. Perhaps if they were more aware of the services available for them and at what cost, they would be more likely to use them. Respondents did not find a need to access healthcare unless there was something wrong. Unless they had a pre-diagnosed illness that required follow up, they were not likely to seek medical services. Respondents were most likely to attend check-ups if they were associated with getting or maintaining resources such as a disability check or housing.

Individuals who were chronically transient were less likely to engage with social service providers and were often the most in need of supportive services. This finding supports the findings of Snow and Anderson (1978) in their study of homeless men. In the case of the population I studied, this resistance to engage with the social service providers was directly correlated with the resources they could access such as temporary housing, health clinics, and government assistance. Those who were willing to engage with service providers, such as Michelle, found that they could access resources if they just fought through the red tape long enough. Michelle described the humiliation she felt when begging for services. Her willingness to be vulnerable to the donors was the price to pay for resources; however, many respondents were not willing to negotiate their sense of independence and pride.

Social service institutions and programs emerged as key "touchpoints" for participants, locations where they interfaced with the world outside of their individual social networks and transient community. These organizations played a larger role than expected because they dispersed information, resources, and were sites where power was negotiated. Respondents who needed fewer services or chose not to access services from them were more self-sufficient and less likely to discuss feelings of worthiness, merit, or even to exhibit low self-esteem. In essence, those who did not engage social services had less contact with the "outside world" and required less approval from institutions such as churches, hospitals, or social workers.

Organizations looking to administer studies, like universities or healthcare providers, often "paid" participants in gift cards for food. Whether provided as payment or an incentive, food is symbolically used to reinforce power dynamics between the underserved and the donors or researchers. While payment in the form of food would be considered unthinkable in higher social classes, it is accepted as commonplace for the underserved. I argue that payment in the form of food is a form of social control, attempting to control the purchasing behavior of resource-poor individuals. When individuals who may need other items besides food sell their gift cards or food items for cash, institutions change their food distribution policies to limit the ability to resell items. It would be unheard of for employers to dictate how their employees spent their paychecks; however, the same freedoms do not apply to individuals who receive food aid.

Socio-ecological perspectives were used to understand the reciprocal relationship between access to food through various strategies that the respondents employed and the structural and institutional barriers they face. While flaws in the food stamp and disability benefits programs were two of the named culprits for lack of access to food, it seemed that stable housing was a key reason that the participants were unable to eat. Lucy, the only participant with stable housing, seemed to be

the most content with her food supply, even though she supplemented her food stamps by going to local churches. Three of the other respondents were unable to take full advantage of the food being offered at churches because they could not cook in their homes without gas connections.

The seven cases presented in depth in this thesis, as well as the additional 34 interviews, which were coded and analyzed, provide valuable insights into the structural barriers and coping strategies of transient residents in Atlanta. Most respondents chose to distance themselves from their immediate social network, choosing often to call them associates or acquaintances rather than friends. These insights also support findings from previous research done by Snow and Anderson (1978), Zlotnick, Zerger, and Wolfe (2013), and Clapham and Abrams (2011) indicating the role distancing from other homeless counterparts as a practice of self-esteem maintenance through role distancing. This disassociation continued when discussing their individual risk for illness, especially sexually transmitted infections and HIV. While a large percentage of respondents personally knew someone who had died from AIDS and said that their associates and communities were at high risk for infection, when discussing their personal risk, most respondents believed that they had low risk despite varying degrees of risky sexual behavior.

Drumm et. al. (2005), and Zlotnick, Zerger, and Wolfe (2013) found that homeless individuals engaged in self-care behaviors of some type whether or not they were active drug users. Findings in this sample support a similar conclusion. While the self-care strategy may or may not have been effective, individuals were able to identify ways in which they tried to mitigate negative health impacts of their lifestyles. For example, Veronica does not travel alone when she walks to ward off potential sexual and physical violence. Many women in the sample discussed similar self-protecting strategies ranging from getting high with people they knew and felt safe around to only buying drugs from a trusted dealer. One respondent noted that she only dealt with one, female, dealer for

her drugs because she knew that when she was pregnant, that dealer would not sell her drugs and essentially protect her from herself and her addiction. Particularly in the female respondents, there was a desire to protect or shelter their children from their lifestyles, which led to their children living apart from them either purposefully or a result of legal ordinances.

While none of the interview questions specifically addressed self-care as it related to mental and physical health, several trends emerged from the responses. The strategic use of service providers was notable across all ages and housing situations. Participants had preferred providers for their healthcare. Some participants figured out how to receive free healthcare at Grady through their sliding scale programs. Almost all of the participants had some medical issue that they had been treated for in the past three months. Participants with veteran's benefits, Medicaid, and a personal doctor at the Ryan White HIV/AIDS clinic had the most positive responses about their experiences with healthcare providers. Those unwilling or unable to access healthcare services at hospitals and doctor's offices had trusted family members or relations that they had designated their healthcare specialists. These individuals relied heavily on their social networks to support them when they were sick, which supports similar research findings by Zlotnick, Zerger, and Wolfe (2013).

In additional to tangible resources and strategies, belief system and religiosity emerged as self-care strategies. While few respondents went to church regularly, many discussed their reliance on god during times of great turmoil and stress. Some attributed their good fortune or lack thereof on their level of connectedness to god. Whether or not there is truth in their sentiments is irrelevant for this research. The rationalization of their situation represents a self-care strategy that they have control over. Instead of viewing their situation as a result of fate or luck only, those that did identify reliance on god as a strategy felt that they could influence their situation. Few felt supported in a

religious community, so in this population, the individual relationship with spirituality or religion was more prevalent as a self-care strategy than on a supportive faith community.

# 7.1 Policy Implications

In 2015, Mayor Kasim Reed formed a commission on homelessness to address issues that impact the homeless population in the city (City of Atlanta, 2015). This milestone indicates the urgent policy implications of populations that experience any level of insecure housing. Housing is one of the key factors for consideration for a holistic approach to community and economic development. Housing directly impacts physical and mental health, employability, and education outcomes. Interaction with housing services is also a touchpoint where policy makers and social service providers can interface with the range of needs that the transient population faces. While the focus of this research looked specifically at housing and health, relationships arose between health and employment and between housing and crime. As the City of Atlanta and the corporate community continue to allocate funding to the Westside neighborhoods, all of which were part of this geographic sample, it is recommended that policy makers consider the role housing plays in holistic interventions that address the interrelated barriers that individuals face to accessing healthcare. Additionally, I recommend that emphasis also be placed on supporting and encouraging the types of self-care strategies that individuals are already exhibiting. By emphasizing both the barriers to health and the existing coping strategies, more effective interventions can be crafted that reach people who are at all levels on the spectrum of self-care and preventative health care utilization.

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### **APPENDICES**

# **Appendix A: Complete Interview Guide**

zip code.

Thank you for agreeing to participate in these in-depth interviews looking at the role religion plays in reducing drug abuse and helping to prevent STDs, HIV/AIDS transmission and Blood Borne infections. Again, we want to remind you that your participation in this interview is completely voluntary. You can refuse to answer any questions or stop the interview at any time. Also, please know that your responses to the interview questions will be kept confidential and your name will never be reported with any of your answers. Throughout our discussion, I'll ask you to speak generally rather than specifically. In other words, please refrain from referring to specific people by name, so that we don't inadvertently violate the confidentiality of those who aren't present. We are audio taping this interview so that we can accurately record your answers to open-ended questions. Once the audiotape is transcribed, it will be destroyed and any identifying information about you will be removed from the transcript. This interview should last about an hour. Do you have any questions before we get started?

During this interview, we would like to understand more about your neighborhood, religious organizations, attitudes toward STDs, HIV and AIDS in your community, and access to health care.

	General Background Information:
	Where did you grow up?
	How long you have lived in [specify place name]?
	If you moved here within the last year or two, what brought you here?
can (	Do you have a stable place to live? By 'stable,' we mean a place you feel secure, where you come and go at will, and where you are not in danger of being made to leave yesno
	If you do not have a stable place to live, do you consider yourself homeless at this time? _yesno
pers	Who do you live with and what is your relationship to them? [Define relationship to each on in the household as relative, friend, or sexual partner]
	What is it like to live in your neighborhood?
	Tell me about any violence you have heard about or witnessed in your home/ neighborhood/

T zip cod	Tell me about any drug use you have heard about or witnessed in your home/ neighborhood/ le.
D	Oo you have a job?yesno
Is	s this a part-time or full-time job?part-timefull-time
Н	Iow long have you had this job?# months
D	Oo you attend church?yesno
Н	Now often do you attend church?# weekly# monthly #yearly
D	Oo you belong to a church or religious group?yesno
Н	Iow long have you belonged to this church or religious group?#months
D	Oo you receive any services from the church?yesno
V	Vhat services do you receive?
	Please describe your social support network: Who do you hang out with?
Н	Health Care Access:
V	What things in your community help your health?
V	When you are sick, where do you go for health care?
Is	s this service free? If not, how much does it usually cost?
A	are there free clinics or low-cost health care providers in your community?
D	Oo you or anyone in your family have health insurance?
V	Where do people in the neighborhood go for health care?
A	are there things in your community that hurt your health?
T	Think about the last time you were sick and went to the doctor:
D	Did you have to take any medicine to get better?
F	For how long were you told to take the medicine?

Did you take all the medicine you were supposed to?

STDs, HIV Knowledge, Risk Perceptions and Stigma:

In these next questions, we want to find out how STDs, HIV and AIDS have affected you and your neighborhood.

Are STDs or HIV an issue of concern for you or for people living in your neighborhood?

What do you know about the way that STDs and HIV is passed from one person to another?

Do you feel that you are at risk for contracting an STD or HIV?

Do you feel that friends or family living in the neighborhood are at risk for STD or HIV/AIDS?

What do you or people in the neighborhood do to reduce their chances of getting STDs HIV/AIDS?

If you, your friends or family living in the neighborhood were given a chance to be tested free in the neighborhood for STDs or HIV, would you do it? Would they do it? Why or why not?

What would be your/ their questions and concerns about being tested for STDs or HIV?

What would be your concerns about someone coming to your home to test you?

What would your concerns be about being tested in a mobile van?

How far would you be willing to go for a one time STD or HIV testing?

How far would you be willing to go for regular HIV testing?

How often would you be willing to go for regular HIV testing?

Would the cost of regular transportation be a concern to you?

What locations would be most convenient and comfortable for you?

Please discuss the advantages or disadvantages of some of the following potential locations:

Local community organization [insert names]

Local pharmacies [insert names]

Local health clinic [name]

Local church or religious organizations [insert names]

County Department of Health

Ponce Clinic

**Grady Hospital** 

#### Conclusion:

What other questions should we be asking in order to understand how you or your community might respond if asked to participate in a community-wide STD or HIV testing program or to receive services from a church or religious organization?

Do you have any final questions or comments?

[Thank you/incentive distribution / goodbye, etc...]

# **Appendix B: Coding Scheme**

Word Cloud produced by Dedoose Software, based on codes allocated to excerpts

