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The Effect of Familial Support, Socioeconomic Status and Stigma on Adherence to Antiretroviral Therapy Among Women in Hartford CT: A Qualitative Approach

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**The Effect of Familial Support, Socioeconomic Status and Stigma on
Adherence to Antiretroviral Therapy Among Women in Hartford CT:
A Qualitative Approach**

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**Submitted in Partial Fulfillment of the requirements for the degree of Bachelor of
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Introduction

Despite the fact that researchers have spent decades attempting to study why people continue to struggle with reaching the required levels of adherence to ART, a concrete set of factors has not yet emerged. Just like any other social phenomenon, medication-taking behavior is influenced by a wide variety of potential causes and my study seeks to contribute to the growing body of knowledge about adherence to ART. To accomplish this I have selected familial support as my main topic of investigation and will study how it affects ART adherence among women. To further explore the topic of familial support, however, I will also analyze it in the context of two other social factors, which have been found to impact adherence: socioeconomic status and stigma. By incorporating these topics I will be able to study the potential interdependent relationship that exists between socioeconomic status and familial support as well as stigma and familial support. Ultimately my desire is to explore how various aspects of the social-cultural world can work to influence one another in order to shape the unique experiences that women have while attempting to adhere to ART.

To accomplish my objective I conducted ten semi-structured interviews at Connections, an outreach organization that helps prevent and treat HIV in Connecticut. I subsequently transcribed all ten interviews and then selected five interviews to include in my discussion. The other five were excluded because three lacked sufficient detail and two were with transgendered women. I ultimately decided that the experience of the transgender women would be potentially too different for me to account for given my sample size. Despite the small sample size, however, there are interesting similarities as

well as differences in the data which allowed for reasonable, generalizable conclusions to be made.

Chapter 1 is an introduction to the various sources of familial support that women mentioned most frequently: children and grandchildren, mothers, and extended family. The women I spoke with consistently reported that the children and grandchildren they did not live with as well as their mothers were sources of positive, emotional support, which most women claimed help them to take their medication. Conversely, when participants were living with their grown children and grandchildren, they depicted those relationships as negative and did not consider them to be supportive. Aside from a few notable exceptions, most women reported that they were largely alienated from extended family members (including siblings), which resulted in no significant perceptions of their support as being positive or negative. Despite some groups being positive forms of support, I conclude that due to the ages of the participants I interviewed (40-60), their family support structure was not extensive and they lacked regular, supportive contact with members of their family. Most women reported feelings of loneliness and isolation and many expressed a need to find something to occupy their mind during the day because there were not many people around. I argue that this contributed to their desire to seek alternative forms of support such as Connections, which has been able to supplement the support they would have otherwise received from family members. This conclusion suggests that rather than a woman needing a specific source of support, the presence of *any* kind of social support is what is necessary to help them adhere to their medication regimen.

Chapter 2 addresses the relationship between familial support, socioeconomic status and medication adherence. There appeared to be two ways that the women I interviewed, all of whom live at or below the federal poverty line, expressed the effect that their relative wealth had on their ability to adhere to ART and their perceptions of familial support. The first part of my analysis is based on the idea that there is a direct relationship between wealth and access to family members as a means of reaffirming support. From the data I conclude that not having enough money can prevent women from having access to adequate transportation, time or spare cash that are all necessary, in one situation or another, for women to maintain close contact with their families. For women, one of the effects of not being able to afford to maintain relationships that provide social support could be an onset of feelings of isolation and alienation, which are addressed in Chapter 1. The second effect that socioeconomic status appeared to have on familial support and medication adherence is a lack of financial support among women and their family members. I determined this was because both the women and their families are in similar financial situations, where resources are scarce. I argue that this obligatory financial independence could affect medication adherence if women find themselves struggling financially. Food scarcity and other markers of poverty have been linked to decreased adherence to ART; without the “wealth cushion” of financial support it is possible that women who start struggling even more significantly could start failing to take their medication properly.

Chapter 3 analyzes the connection between stigma, familial support and medication adherence. This chapter contains the most varied results with participants reporting a wide range of experiences involving family and stigma. These included participants who

said that they had no trouble telling their family that they were HIV positive as well as participants who had decided to avoid telling certain family members for a variety of reasons which appear to be in part due to perceptions of stigma. I associate the lack of continuity in my findings from this section to two factors: my small sample size, which is not sufficient enough to account for the variable nature of stigma, and the fact that I had not originally planned to study stigma. This meant that I had to use questions I had already asked instead of questions specifically designed to study stigma and familial support. However, the data does allow for some interesting observations to be made about the relationship between stigma and support, which should be explored further in future research.

Ultimately, the nature of my study allowed me to explore some of the sources of family support that women experience, the positive or negative nature of that support and how it was affected by socioeconomic status and perceptions of stigma. My data allows me to conclude that age, relative wealth and stigma are all important factors that should be accounted for when studying social support as a concept which may help or hurt ART adherence among women.

Literature Review

HIV and Antiretroviral Therapy Background:

Human Immunodeficiency Virus (HIV) invades the t-cells or CD4 cells of the human body in order to reproduce. These cells are necessary to fight off infection, which means that the immune system of someone who is infected with HIV will eventually start to deteriorate. When HIV progresses into AIDS a person affected by the illness is unable to fight off even minor infections like the flu, which can eventually cause their death (AIDS.gov). HIV was first diagnosed in the United States in 1981 and spread rapidly, infecting nearly 50,000 people by 1987, just six years after it arrived (Curran 1988). According to the Centers for Disease Control (CDC) more than 1.2 million Americans are living with HIV as of 2011 (CDC, *HIV/AIDS Basic Statistics*). Within this group of 1.2 million people, men who have sex with men (MSM) and African Americans are both disproportionately represented, which indicates that there are gaps in equity of prevention and care that need to be addressed (CDC, *HIV/AIDS Basic Statistics*, 2011).

Antiretroviral (ARV) medication – a treatment for HIV – was first introduced to the US in the mid-1990's. Although this medication did not offer a cure it was expected to yield great results for patients suffering from HIV. When properly taken, antiretroviral therapy (ART) decreases patients' viral load, preventing their disease from progressing to AIDS and allowing them to live significantly longer, relatively normal lives (Amico 2013, Nakagawa 2012). However, in order for ART to provide these potential benefits, the patient must adhere to their medication regimen at rates that range between 90-95%, as defined by the ratio of prescribed pills to pills taken (Ortego 2011). Initially problems with ART adherence were associated with regimen complexity and significant side

effects like excessive weight gain and gastrointestinal irritation. Advances in medicine have allowed researchers to develop ARV medication that can be taken as infrequently as once a day and has fewer serious side effects; however patients are still struggling to reach necessary levels of adherence (Amico 2013). As of 2009, when 1.15 million people had HIV in the US, the CDC estimated that only 33% of those people had access to ART and of that 33% only 25% reached adherence rates that would allow them to achieve appropriate viral load suppression to extend life and prevent transmission (Charania 2013). These statistics indicate that simplifying the medication regimen and decreasing the number of side effects is not alone sufficient to increase levels of adherence. Rather, it can reasonably be concluded that other factors, such as social ones, play a significant role in dictating how those living with HIV adhere to ART.

HIV models other chronic conditions like heart disease and diabetes because there is no known cure and therefore it can only be managed if patients adequately adhere to their medication regimen (George 2009). Therefore the consequences of high levels of poor adherence to ART can be understood, at least in part, much like other chronic conditions. It has been well documented in the compliance literature that patients with chronic conditions tend to struggle with effective adherence to medication regimens (Chesney 2000). Specifically, there are two distinct consequences that arise when a significant number of people struggle to adhere to their medication regimens. The first effect is that high levels of poor adherence result in increased morbidity and mortality, which, in the case of HIV, means that hundreds of thousands of people are suffering, becoming sicker and could eventually die from a disease that has been manageable with medication since the 1990's. The second reason is that poor adherence to medication

regimens for chronic conditions has been found to place a significant financial burden on the healthcare system and ultimately have a negative impact on the economy (Johnson 2006, Scheurer 2012). Since levels of adequate adherence to ART are so low, this translates into an entire population of people that will be forced to use expensive hospital and emergency care services while their immune systems deteriorate and they begin to die of their disease. Meanwhile they are unable to work or contribute to the economy because they are so sick. These reasons make the study of how to improve low adherence rates to ART one that is motivated by both economic and moral concerns regarding its negative effect on society.

Medication-Taking Behavior: Adherence vs. Compliance:

Medication taking behavior was initially discussed in terms of “compliance”, which was meant to connote the level to which a patient’s behavior aligned with what the health care provider had prescribed (Sackett 1976). Since the 1970’s when this term was introduced researchers have begun to recognize the fact that it places the patient in a subservient position to the doctor, essentially eliminating a patient’s right to exercise agency over health decisions regarding their own body (Drotar 2000, Vrijens 2012). Since then, “adherence” has replaced compliance as the appropriate term for talking about medication taking behavior. The term adherence requires that the patient must first agree to the treatment plan, after which their participation in that treatment plan is measured (Balkrishnan 2005).

This study will seek to understand medication-taking behavior in terms of adherence by incorporating questions meant to address how participants feel about their regimens (Appendix A). These questions will allow me to assess whether or not each

woman is a willing participant in her treatment thereby minimizing the possibility that I will evaluate a participant's poor medication-taking behavior in terms of compliance rather than adherence.

Attempting to measure adherence is a difficult problem with no easy solution. One potential method for determining levels of adherence involves measuring the number of pills a patient takes and comparing that to the number of pills prescribed (Jerant 2008). This is a technical method for quantifying adherence and, if executed properly, would yield relatively accurate results which could then be compared to the adherence rate of 90-95% necessary to achieve viral load suppression. Pill counting allows the researcher to empirically judge levels of adherence, however it requires a significant investment of time on the part of the researcher and results could still be impacted if a participant simply disposed of the pills they either forgot or did not want to take. Additional, similarly empirical methods, include measuring refill rates for prescriptions and electronic monitoring systems that record when and how frequently pill bottles are opened. These methods however, like pill counting, are expensive, require a burdensome time commitment and are not completely accurate (Osterberg 2005). A less empirical method is to select a set of time frames, for example 2 weeks, 1 month and 6 months, and then ask the participant how many times they've missed doses within each of those time ranges. This method would appear to be less precise than the previous method because the participant could either over or under estimate the number of times they missed doses. Some research, however, has found that patient reports of pills taken versus prescribed over a three to four day period are nearly as accurate as pill counting and can be correctly extrapolated to estimate adherence over longer periods of time (Jerant 2008). One final

example of a method for measuring adherence is to simply ask the participant how often they think they miss doses and how they feel as though they are able to adhere to their regimen. Unique to this method is that it yields largely qualitative data that is entirely based on the participant's evaluation of their medication taking behavior. This type of self-reporting would likely yield the most subjective results, where participants could intentionally or unintentionally over or under-report their adherence levels. Research on medication adherence for chronic conditions has sought to better understand what motivates patients to self-report higher or lower levels of adherence. Explanations for this occurrence include a variety of reasons from perceiving that the interviewer would be critical of them if they admitted to forgetting frequently to memory bias (Stone 1999). Despite these drawbacks one of the benefits is that it seeks to understand a *patient's* perception of their medicine taking behavior. This approach coincides nicely with the definition of adherence, previously discussed, because it returns agency to the participant thereby allowing them to decide what is too much and what is not enough medication.

Factors that Impact Adherence – Social Support:

The factors believed to have a negative effect on adherence to ART can be loosely categorized into the following groups: demographics (age, gender, race), psychosocial comorbidities (drug use, depression), regimen characteristics and patient beliefs (self-efficacy) (Beer 2014). Initial investigations into ART adherence focused on “cognitive processes,” namely individual and mental barriers to medication adherence like forgetfulness. This research focus logically coincides with the biomedical model that is pervasive in American medicine culture. Recently, however, researchers have begun to

investigate social causes for poor adherence like socioeconomic status, stigma and perceived levels of social support (Katz 2013).

Social support is an interesting topic to focus on because the literature is contradictory: studies conclude that social support has a range of effects on adherence. Some studies have found that social support can be linked to improved adherence to medication regimens and decreased risk that an individual's disease will progress into AIDS (Johnson 2009, Enriquez 2004, Katz 2013, Sandelowski 2009, Gardenier 2010). One study investigated individuals who had failed at least twice to adequately adhere to ART and found that participants frequently cited "finding the right support system" as a reason why they were finally able to adhere to their drug regimen (Enriquez 2004). Contradicting these studies is a body of research, which asserts that – compared to other factors like drug abuse, pill burden and adverse side effects – social support is *not* a significant factor in predicting patient adherence (Chesney 2000,).

To better comprehend why the literature on social support is relatively contentious, it is important to understand the complex nature of social support in adherence research. A variety of models are used to conceptualize social support; a diverse range of people can provide social support and social support can take a variety of forms. All of these factors must be accounted for when designing a study on social support. This extensive range of variables means that studies, particularly quantitative studies, where the methodology for collecting data on social support may not account for its variability, could end up making generalizations about the significance of the impact of social support on adherence to ART. For example, one such study assessed three groups that could potentially provide social support: significant others, family and

friends. The researchers found that only perceived partner support but not support from friends or family was connected with increased levels of adherence to ART (Power 2003). However, other studies, which investigated one specific group, like women, found that having a significant other actually hinders a woman's ability to appropriately take their medication (Rice 2013, Latkin 1999). The first study accounted for three socio-demographic groups: employment status, Latino and sexuality but made no distinction between men and women. It is possible that by not accounting for the fact that women would experience social support differently than men, the researchers ended up over-generalizing the importance of partner support for women attempting to adhere to ART. The difficulty in accounting for and measuring the various forms that social support can take appears to be a significant reason why there is little consensus among researchers about the impact social support has on medication taking behavior.

Differences in Methods for Defining and Conceptualizing Social Support:

Often confused with social networks, social support has a different connotation. The principle difference is that "social support studies assess the quality or quantity of a person's social ties" while "social network studies treat the ties themselves as objects of study potentially relevant to outcomes of interest, and thus draw them explicitly" (Smith 2008). While this definition does not completely coincide with how I plan to treat social support, it does contain relevant elements. Studies that seek to analyze social networks often map the social ties of a specific person or a community and then attempt to understand various behaviors through those ties. However, I will approach my question in reverse. I will first identify the behavior – how well a patient adheres to their medication regimen – and then I will endeavor to understand how the quality or quantity of a

participant's social ties affect that behavior.

Across the literature social support has been conceptualized with a variety of different models. Three of the most significant and informative models are formal versus informal (Rice 2013, George 2009, Waddell 2006), direct versus general (Lehavot 2011) and emotional, instrumental and informational (Rice 2013, George 2009). The first model identifies who a patient receives support from by placing people who could provide support into two categories. The first, formal support, includes the professional health sector, which could entail advice about how to manage their medication regimen or how to cope with potential side effects. The second category, informal support, refers to a patient's family, friends and community and may include anything from having a person to confide in to someone reminding the patient to take their medication (Rice 2013, George 2009). When studying social support with a formal versus informal model, studies have found that informal support is more common among low-income people living with HIV or AIDS (PLWA/A) and that encouragement from this sector is essential for improved access to formal treatment (Waddell 2006). This result demonstrates the type of information that can be obtained via the formal versus informal model – namely who is seeking out one type of support over another. Depending on the study this information could then be used to identify why a specific group of people tends to seek out formal versus informal support and how that preference could be utilized to improve levels of adherence.

One of the limitations of the formal versus informal model, however, is that it does not attempt to identify the type of support a person receives, and therefore there is a significant amount of crossover between the two identified sectors where both groups

could both be employed to serve the same purpose. For example, if a patient is struggling to remember to take their medication at night and is seeking assistance to solve this problem they could ask their health care provider, someone from their informal network or both. This example illustrates one of the limitations of this model because it can only identify, with certainty, who a person is receiving support from and does not reveal anything about the type of support received.

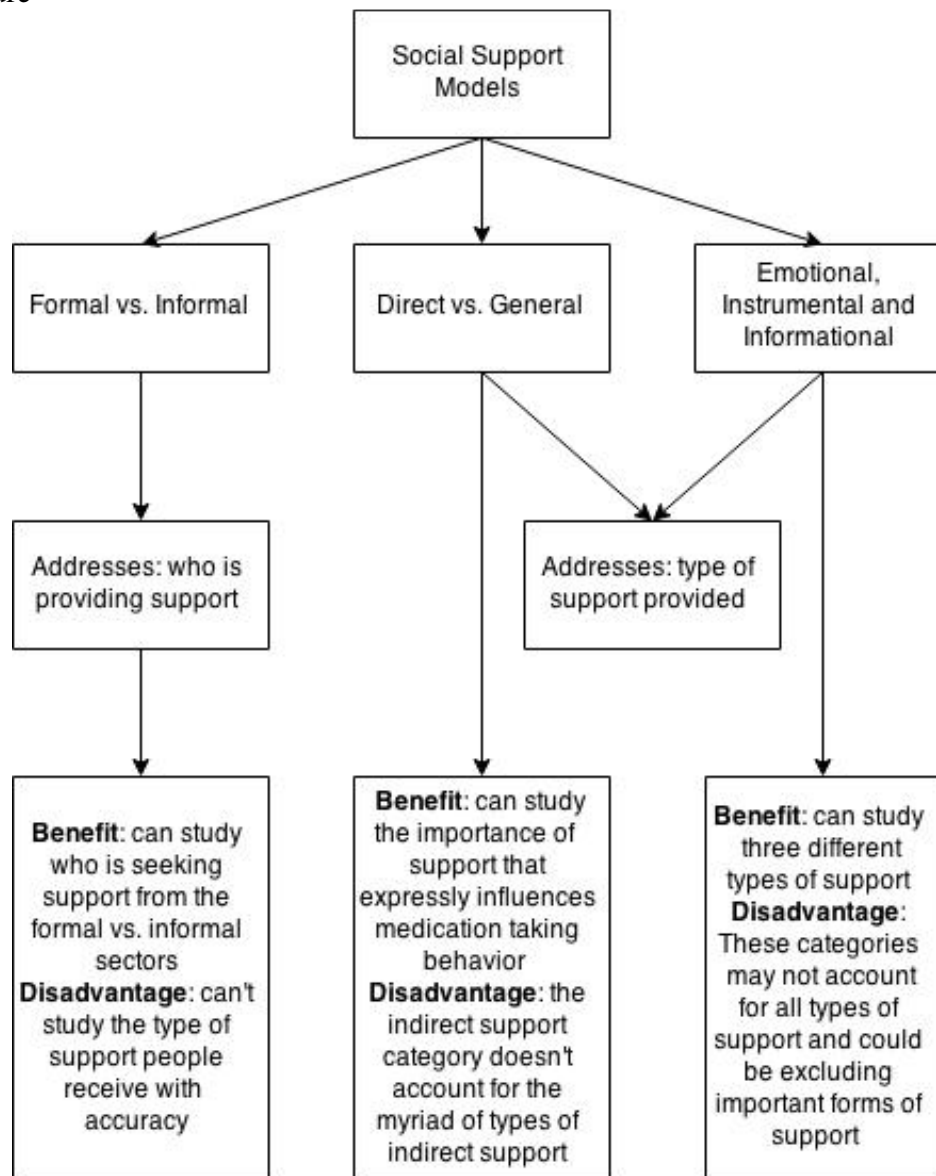
The second model for evaluating social support is direct versus general. This model seeks to understand how involved a member of a patient's social network is in their medication-taking behavior. A member of a patient's social network who provides direct support might remind the patient that they should take their medication or even help to pay for it. Conversely indirect support involves all other forms of support not specifically related to the patient's medication-taking behavior, which could include anything from lending the patient money to giving them advice if they are having a bad day (Lehavot 2011). The direct versus indirect model is useful when attempting to understand the effect that social support, of varying levels of connection with a patient's medication regimen, has on their ability to adhere to that regimen. However, as was the case with the previous model, the direct versus indirect model is limited by its inability to understand varying degrees of social support with a great deal of specificity. While direct support is clearly outlined as explicit participation in the process by which a patient takes their medication, the category of indirect support is more ambiguous and could connote anything from financial to emotional support. This ambiguity could skew results if one type of social support within the indirect category has a significant impact on medication-taking behavior but all other forms of indirect support show the opposite effect or no

effect at all on adherence levels. For example, having someone to lend her money may have a significant, positive effect on a patient's medication behavior but this result could be obscured in the data if other forms of indirect support have no effect, thereby leading the researcher to conclude that all forms of indirect support have no net effect on adherence.

The final model for understanding social support, which reoccurs throughout the literature, breaks down the type of support a person might receive into three categories: emotional, instrumental and informational. Emotional support refers to all support that a person may receive which is "non-tangible" thereby causing the person to feel cared for, included or valued (George 2009, Rice 2013). If a participant is receiving emotional support this could include anything from being able to confide in another person to receiving words of reassurance. The second type of social support outlined by this model is instrumental. "Tangible" help is characteristic of instrumental support where a person would receive money or a ride to their appointment from a member of their social network (George 2009, Rice 2013). The final form of social support, informational, refers to any advice that someone might provide. Examples of this type of support could include information on managing the patient's medication regimen or guidance regarding how to apply for benefits. This model for studying social support allows the researcher to study types of social support with a model that, unlike the formal versus informal and the direct versus indirect models, does not operate on a binary principal, instead it classifies the type of support a patient may receive into three categories. Theoretically this would allow for more flexibility in the type of research questions that could be answered because this model could investigate a variety of types of social support. One of the downfalls of this

model, however, is that by having three categories, the type of social support that a participant reports no longer falls into one category or the other. Rather there may be a type of social support that does not fit in the three categories this model uses. This could lead researchers to fail to recognize an important form of support. The three models for studying social support, outlined above, are summarized in **Figure 1**.

Figure 1: Summary of the three social support models most frequently addressed in the literature



Women, ART and Social Support:

HIV researchers primarily focus on men who have sex with men (MSM) and injection drug users (IDU). The likely motivation behind this trend is that people who fall into these categories are perceived as being at a higher risk for contracting HIV than the rest of the population. As a result women are underrepresented in adherence literature despite the fact that women have been found to have worse adherence rates to ART than men (Knowlton 2011, Ortego 2011, Puskas 2011). Much like any other demographic, women exhibit unique medication-taking behavior for a similarly unique set of reasons (Tapp 2011, Puskas 2011). This makes it critical to contribute to the academic knowledge surrounding medication-taking behavior which is unique to women, so that effective interventions can be implemented that improve levels of adherence within this demographic.

One of the factors that differentiates women from men, in terms of adherence, is social support, which has been found to have a significant impact on adherence levels among women, but not men (Puskas 2011). Women tend to identify two groups, which provide them with social support that affects their medication taking behavior – their family and their partner. In terms of a woman's partner, the literature is relatively divided with a significant number of studies debating whether a woman's partner has a positive or negative impact on adherence. Some studies concluded that women who felt they did not have the support of their partner were less likely to adhere to their medication regimen as oppose to women whose partner was also HIV positive and on a HAART regimen, in which case those women had significantly higher adherence rates to their medication regimens (Knowlton 2011). However, the results of other studies contradict these findings (Rice 2013, Latkin 1999). These concluded that having a partner, particularly

one that is also HIV positive, causes worse adherence among women because women tend to fill the role of caregiver with their partner. Assuming those responsibilities results in women who focus on the needs of their partner and end up neglecting their own health needs in the process. One study found that both of the outcomes outlined above could be true, depending on the participant and their partner. HIV positive women who are in a relationship with someone else (particularly a man) who also has HIV, often neglect their health so they can serve as a primary care giver although there were exceptions where some women found their HIV positive spouses to be a source of support (Edwards 2012). Ultimately the literature appears divided with some researchers concluding that partner support helps women take their medication, some saying that it hurts and some saying both results can be true depending on the situation.

The second form of social support that has been found to have a significant impact on medication taking behavior is familial support. Across numerous studies, positive familial support in particular has been associated with higher levels of adherence to ART among women (Sandelowski 2009, Rice 2013, Katz 2013, Elder 2009). Family members were found to be the primary source of informational support for women who are attempting to manage their disease. Participants' supportive family networks ultimately encouraged them to seek out more formalized medical care (Wohl 2010). Furthermore women report family as a significant source of social support at higher rates than other demographic groups like MSM (Wohl 2010). One possible explanation for this is that MSM must deal with the stigmatizing nature of how they acquired HIV, whereas women don't face similar levels of critique. This allows women to seek out support from their families while MSM end up turning to various subcultures which can potentially

provide them with the support they need (Power 2003). Perceived social support from friends and family has also been identified as an important factor for medication adherence. For African American women in particular, children and grandchildren were found to be a good source of social support (Rice 2013). Several other studies confirm a positive correlation between the social support that arises from motherhood and increased levels of adherence to ART. Researchers found that children tend to dominate women's inner circles and thereby serve as a significant source of familial support for their mothers (Grant 2013). Some studies contradict these findings, as was the case with the literature on partner support and medication adherence, with data that suggests that women who take on the role of caregiver in their family dynamic tend to have decreased levels of adherence to ART. This phenomenon happens because women tend to be more concerned with their duties as a mother, sister, daughter, etc. to monitor their health properly (Simoni 2012). Again there is disagreement in the literature regarding the effect that support has on adherence among women, in this case the effect of familial support.

Interdependencies: Familial Social Support, Socioeconomic Status and Stigma:

The idea of interdependencies is based in systems theory, which is a framework for understanding and researching ideas as concepts that are related to one another (Carrington 2005). Systems theory would posit that familial support should be understood within a set of social factors that might affect how it is expressed and interpreted. To begin my research on familial support within this framework I attempted to evaluate the literature that researched the effect that low socioeconomic status and stigma have on familial support and medication adherence. I was unable to find much research that incorporated all of these topics in an attempt to understand their causal relationship, but

by breaking down each set of three factors into composite groups it could be possible to begin to create an image of the impact they may have on one another.

Studies have found that “adverse social conditions associated with poverty” (Kalichman 2014) negatively impact a patient’s ability to adhere to their medication regimen, the most significant condition being food insecurity (Singer 2014, Young 2013). Food insecurity is unique in that it is a good indicator of other consequences of poverty like poor access to education or an unstable housing situation, however it has been found to have the most profound effect on non-adherence (Kalichman 2014). Furthermore, the social context associated with poverty has a more profound, negative effect on adherence for women as compared to men (Riley 2007). While there is not an extensive body of literature that draws a connection between medication adherence, familial support, and socioeconomic status, it is reasonable to postulate that, in an environment where resources are scarce, the stress of living below the federal poverty line could strain familial relationships which could then affect medication taking behavior. Furthermore, people who are economically disadvantaged have reported that social support for health related problems often comes from their friends or family members rather than from health care professionals (Cook-Craig 2012). These results indicate that familial relationships provide direct support for people who are of a low socioeconomic status at higher rates than their wealthier counterparts. This is logical because the informal sector of support is free despite having a host of social implications inherent to the exchange (Stack 1975). The gap that I perceive in the literature is that, despite the existence of research that makes claims about the frequency to which familial support is relied upon

by people of a low socioeconomic status, there is not a lot of information about the quality of those relationships as a variable which has been influenced by poverty.

Stigma has consistently been found to negatively impact ART adherence and access to care among both men and women with HIV (Katz 2013, Sayles 2009). In terms of stigma and social support, a direct relationship has been found between being able to safely reveal one's HIV positive status to family and friends and improved treatment options and access to care (Waddell 2006), however the stigmatizing nature of HIV does stand as a barrier to this. If an individual feels stigmatized or uncomfortable revealing their HIV positive status to members of their family this could impact their perceptions of the quality of familial support they receive, which could in turn affect their medication-taking behavior. This topic is particularly important given the demographic I chose to focus on, women, because researchers have found that they experience higher levels of perceived stigma than men, which has been associated with poorer adherence. Hopefully, by studying these social factors as a product of a system of interdependencies, this method will allow me to explore how those social variables relate with and affect one another.

Methods Draft:

How this project began:

I began this project with an interest in the social determinants of health particularly as they related to diseases that disproportionately affect people of low socioeconomic status. I was introduced to social disparities in the distribution and burden of HIV while taking a couple of different Medical Anthropology courses and because the topic interested me I realized that I wanted to try to do some investigating of my own. I thought it would be interesting to formulate a thesis question that looked at the intersection of social determinants of health and adherence. Adherence is another important concept in Medical Anthropology, which has experienced a significant degree of modification over the past couple of decades as academics have begun to realize the importance of the patient in the healing process. Ultimately I decided to focus my project on how adherence is affected by three reoccurring factors that the literature indicates influence medication-taking behavior: social support, socioeconomic status and perceptions of stigma.

While conducting my literature review I noticed that many studies dealt with either one determinant of adherence or analyzed the effect of a broad range of potential factors to determine which had the most significant impact on medication taking behavior. Instead of following these two models for studying patient compliance, I choose to evaluate the role interdependency itself plays in determining adherence. Interdependency refers to how variables affect and influence one another to determine an outcome. I concluded that the best method for analyzing this kind of data was through qualitative, semi-structured interviews. One of the problems that often obscures the effect of interdependencies in research is when variables are operationalized for quantitative

research without accounting for the effect that those variables may have on one another. By collecting qualitative data, connections can potentially be observed in participant responses about how various determinants of medication taking behavior, such as gender or familial support, influence one another. These connections would otherwise be lost because not enough information exists on the interdependency of factors that affect adherence to design a quantitative study that could appropriately study them.

This justification for the method I selected to address my research question is supported by other research on medication adherence. One study found that there is a lack of qualitative studies on women in general despite the fact that qualitative research is necessary in order to better ‘understand the subtleties of men and women’s experience with ART adherence’ (Puskas 2011). Furthermore qualitative methodology “allows [for] the inclusion of culturally specific influences on this combined experience” (Sacajiu 2009). Those “culturally specific influences” are the object of my study as I attempt to contribute to the existing knowledge about the unique perspective that women with HIV have on what affects their ability to adhere to ART.

Setting:

To begin the research process I reached out to contacts of mine at the Institute for Community Research (ICR). ICR is an organization that does public health research in the Hartford area – studying everything from the prevalence of HIV to drug use among Asian American teens. I had completed an internship at ICR and the staff there was willing to put me in contact with an HIV outreach programs in Hartford. The first program that I was introduced to was AIDS Connecticut, which oversees numerous satellite organizations that provide a range of services across Connecticut in order to

prevent and treat HIV. Since I was looking to conduct my research in the Hartford area I was then put in contact with Ms. Jones, one of the local coordinators for Connections Wellness Center – another outreach program, which is part of AIDS Connecticut.

Connections is located in one of Hartford's poorer neighborhoods. It provides a range of services to sufferers of HIV and AIDS, which are mediated by case managers. Connections primarily serves African and Latino clientele and the majority of members live below the federal poverty line, have had minimal education and are older than 40. Each client is assigned to a case manager who is then tasked with helping the client find access to affordable housing, funds to pay for medication, and any other support that the patient might need in order to adhere to her medication regimen. Also employed by Connections is a Medication Adherence Nurse whose is responsible for helping clients manage their disease and a Nutritionist who assists members with specific dietary needs or with maintaining a proper diet on a limited income.

One significant service provided by Connections is a place to interact with other HIV positive people. A wall divides the physical space of Connections. On one side are the case managers' offices and on the other side is a moderately sized room with a number of tables where the clients can socialize. Connections is open Monday through Friday 8am to 1pm. At 8:30am breakfast is provided by the organization and members are allowed to come and hang out until after lunch (also provided) has concluded at 1pm. This structure means that clients do not have to have a meeting with their case manager on a given day in order to go to Connections and hang out with friends. In fact a significant portion of members will stop in just for a chat or to grab some food.

Some of the benefits of this environment for the purpose of my study were that participants were in a relaxed setting where most felt quite comfortable and open to sharing their experiences. However the demographics of Connections does present some limitations to my ability to generalize broadly. The sample was biased towards older women since people above forty years old comprise a large part of the clientele at Connections. This is apparent in my study as I did not interview anyone who was younger than forty years old and the age range of the sample as a whole was approximately 40 to 60 years old. While this was an unexpected product of the setting where I chose to conduct my research, a benefit of interviewing at Connections was that I was able to focus my sample on women of low socioeconomic status. Since the literature indicated this was an important factor I was able to design my sample from that assumption and attempt to explore some of the reasons low socioeconomic status might negatively affect adherence or other influencing factors like stigma and familial support.

IRB approval:

Before I could begin interviewing I had to first obtain approval from the Institutional Review Board (IRB) at Trinity College. In order to do this I created sample interview questions (Appendix A). I wanted to employ a semi-structured interview process so that I could ensure that the components I was studying – adherence, socioeconomic status, stigma and familial support – were all addressed during the interview but that still allowed the participant enough space to explore the topic as it was relevant to them.

A significant portion of my IRB application was the consent form (Appendix B) I produced. I was going to be interviewing a marginalized population about having a

stigmatizing disease, which meant that maintaining confidentiality and ensuring that the study would not be exploitive were both significant hurdles that I needed to address in my application. To deal with these problems I generated a consent form that was clearly explained to participants before each interview. The consent form gave me permission to use a recording device during the interview at the participant's discretion and informed the participants of the objective of the study and that they were able to refuse to answer any questions they were not comfortable with. Confidentiality was maintained by deleting all recordings after they had been transferred to a folder on Trinity's secure server. Names of participants were never included in any interview transcripts and all consent forms were kept in a locked filing cabinet at Connections. To compensate participants for their time, two 20-dollar gift cards to Stop and Shop were raffled off, following the traditional compensation mechanism used by researchers at Connections.

Despite the sensitive nature of the topic that I was investigating, the IRB committee only took a couple of days to review and approve my application. The next week I sat down with Ms. Jones, gave her my approval letter from the IRB committee and received an introduction to the activities at Connections.

Pretesting:

While Ms. Jones oversees Connections, my contact at this organization was Mr. Diaz who works as a case manager. Mr. Diaz oriented me to the space at Connections, he introduced me to the case managers and some of the clients and helped me organize when would be best to go to Connections to conduct my interviews. However, before I began scheduling any interviews I first mock interviewed two friends and a Trinity employee who has diabetes. When I felt as though I was comfortable with

my questions and had worked out some of the potential kinks I then conducted a mock interview with Mr. Diaz, who was able to give me responses that were more applicable to what I could potentially receive while interviewing women at Connections. The purpose of this practice was so that I could become more comfortable with questioning people about sensitive topics and so I could refine my research questions and presentation as an interviewer.

Interviewing at Connections:

I spent several hours each week hanging out in the reception room at Connections where I was able to interact with clients. My intention by hanging out at Connections was to make clients feel more comfortable with my presence. When women arrived at Connections I would introduce myself and tell them about my study. If women were interested in participating we would go to the designated conference room, which guaranteed some privacy.

I tried to begin with questions meant to make the participants feel more comfortable talking with me about difficult topics (See interview guide included as Appendix A). Then I segued into questions about when they were diagnosed, how long they had been taking their medication and how well they felt they adhered to their regimen. Then I moved on to questions meant to establish perceived levels of familial support and the effect participants felt that it had on their medication taking behavior. In order to understand a participant's socioeconomic status I questioned each woman about how they paid their bills, how they got around and if they lived with anyone. The motive behind this approach was that I was looking for general markers of socioeconomic status rather than exact numbers. I concluded my interview questions by proposing a series of

prompts meant to directly question participants about what may impact their ability to comply with their medication regimens. It was articulated in my IRB application that my interview questions were going to serve merely as the backbone for each interview and all participants were going to be given free range to deviate based on what they considered significant. This approach enhanced my research because I had not originally planned on investigating stigma as a variable. However, while re-listening to the interviews I noticed that almost every woman I spoke with addressed the topic of stigma in one way or another. Due to this discovery I chose to modify my research question.

I ended up interviewing ten women over the course of two months. Some trouble associated with acquiring interviews could be because I started interviewing during the holiday seasons. My interviewing was then interrupted by winter break. I returned a month later to complete the rest of my interviews however the lack of continuity could have caused clients to lose interest or forget about my study making it more difficult to recruit participants.

While I was interviewing at Connections I started to pick up on a couple of potential response effects, which could have affected the quality of the data that I was able to obtain. The first is perceptions of race and class difference. Most of the members at Connections are either Hispanic or African American and almost all live below the federal poverty line. Conversely I am white and when I introduced my study I identified myself as a student from Trinity College, which carries a host of implications about my class for people living in Hartford. The many differences in our socioeconomic backgrounds would have made the distinction between participant and researcher even more obvious with potential implications for how respondents chose to answer my

questions. Another response effect that I picked up on while I was completing my transcriptions is the effect that my method for expressing to participants that I was actively listening could have had on their answers. This is well summarized in a sample from my third interview below:

I: Good and do you ever miss doses?

P: Once a, once a week

I: Once a week you do?

P: I try to take it ever morning.

I: Okay and so you miss doses once a week?

P: Yeah about once a week, I try not to but I don't miss it. If I miss it I always go back and take it.

Throughout my interviews I attempted to convey to the women I interviewed that I was listening and interested in their answers, meanwhile trying to encourage them to elaborate on their responses. I did this by repeating what they had previously said, however, this may not have been the best method. In the case above, as I repeated her response in question format the participant began to modify her original answer about the number of times she misses doses. Eventually she ended up contradicting her first response and concluded that, as opposed to once a week, she never truly missed doses and instead went back and took a dose if she forgot to take it initially. One possible reason that she changed her answer was because, rather than taking my line of questioning as representative of my interest, she felt as though I was being critical of how often she missed doses. Therefore, to avoid this critique, she concluded her response by stating that she never truly missed a dose. Since I employed this tactic for interviewing throughout my data collection process it is possible that it caused similar anomalies in participant responses. These anomalies between the responses I received and reality would likely occur when providing answers that they thought I would be critical of. This

could include anything from how they take their medication to how close they are to their family.

Analysis:

After every interview I recorded, I immediately transferred the audio file to Trinity's secure server and deleted it from my recording device. When I had completed all ten interviews I began to transcribe the data. First I downloaded the VLC application to my computer, which I used to open the audio file. Then I downloaded *Express Scribe*, a transcription application, which allowed me to slow the audio down to a speed where I could comfortably type as it played.

Once all of my interviews had been transcribed I went about analyzing them for relevant information. I employed two models for understanding social support: direct vs. general; and emotional, instrumental and information. I felt that it was useful to analyze the data in terms of these two models because participants vocalized their perception of support using language that indicated that those were the models they were using to understand the support they were receiving. For example, when I asked women about support they received in general they frequently referred to emotional or financial support. However, when I asked women if they received support taking their medication they would frequently speak in terms of direct assistance – whether or not family members helped or reminded them to take their medication. I chose to include both methods for analyzing the data in order to ensure that my analysis reflected how the women I spoke with conceptualized familial support.

Ultimately I selected five interviews for inclusion in my discussion because those were the five that were most complete and contained the most relevant information. Two

of the interviews I decided to exclude were with transgendered women because I thought it would be too difficult to examine how their experience as transgendered women could be distinct from women who were not transgendered given my sample size. I excluded three other interviews from my analysis because they were either incomplete or because the participants did not provide detailed responses. One exception to this exclusion process appears in Chapter 3 where I include excerpts from my interview with Participant 6, Eve. She was initially part of the group of five women I had decided to exclude from my analysis, because she was not very responsive when I interviewed her. However, she provided a couple of answers that addressed the topic of stigma in ways that the five interviews I had decided to include did not, therefore it seemed important to include her in that chapter.

Participant Profiles

(Note: all participant names are pseudonyms)

Participant 1:

“Joanne” is 60 years old and a grandmother of five girls. She was diagnosed with HIV in 1986 but is unsure how she contracted the disease. Joanne met her first husband at 23, he was addicted to drugs when they met but she didn’t start using until she was 30. She has been taking ART for years on and off but for the last two years has been able to adhere to her medication with relative success. Joanne attributed her bouts of poor adherence to alcohol and drug abuse. Now she has a system where if she doesn’t take her medication in the morning because she is in a rush to get out the door she puts it into little medication baggies provided by programs like Connections and brings it with her. She affirmed the efficacy of her medication by comparing the period of healthiness she is currently experiencing with several times in her life when she was not taking her medication and got seriously ill. Joanne’s support system consists of her two daughters, her five granddaughters, her two cousins and a clinician whom she has been seeing for over twenty years. She describes this relationship as being incredibly strong as it outlasted both of her marriages. She also describes a relationship with her clinician, which is one of equanimity, where he takes her opinion on her own health into consideration. During our interview, Joanne acknowledged that her two cousins and at least one of her daughters are aware of her HIV positive status. This is the daughter she is currently living with while her daughter’s two children live with their father. Joanne’s other daughter lives in an adjacent town with her other three granddaughters. Through the years she has allowed several family members to live with her including her stepson and three granddaughters whom she raised for three years, however Joanne has spent much of

the last six to seven years living alone, since her second husband passed away. Joanne describes herself as financially independent and takes considerable pride in her thriftiness, which she expressed is an integral component of her ability to be self-sufficient despite feeling as though there is never enough money.

Participant 2:

“Rosa” was diagnosed with HIV in 1989. She believes that she contracted HIV from her sister in law but was told by her doctors that it was through sexual contact. Rosa did not start taking ART until 2 to 3 years ago and associates this delay in seeking care with extended drug use and the fact that her viral load never increased to dangerous levels. She characterizes her life as a cycle of relapse and recovery, during which she gave birth to twins, one of whom was HIV positive. While she was using Rosa was repeatedly arrested and eventually went to jail for three years. Rosa’s mother died while she was incarcerated and when she was released she successfully remained sober for seven years. During that time, Rosa was able to find housing, get social security and increased her involvement in programs at Connections. This ended after an incident where she and a staff member at Connections got into an argument. Rosa said that following that argument she returned to her addiction and sank into a depression. When I interviewed her, Rosa was attempting to put her life back together. She had begun to visit Connections regularly and was in the process of submitting an application for an internship position at Connections. Throughout her interview Rosa referenced her four children, one girl and three boys. Two of her sons were in jail and one was living in her home. The only other family member that she considered to be a significant part of her life was her sister. There was some ambiguity surrounding how well Rosa adhered to her

medication regimen, as detailed in the methods section. She began by stating that she misses doses once a week but amended that response by saying that if she misses a dose she always goes back and takes it, meaning that she never misses a dose. Some of the practices that Rosa thinks help her adhere to ART include being sober and the fact that she developed a routine in the morning of engaging in various types of cleaning exercises. Rosa believes that by sweeping or washing the dishes every morning she helps to maintain order in her life that did not exist while she was doing drugs. That order allows her to manage her medication.

Participant 3:

“Cheryl” is a middle-aged, African American woman who was born in Florida. She was diagnosed with HIV in 2008 and found Connections soon after. We talked about some of the side effects she was experiencing from her medication, most importantly excessive weight gain, which had caused her to fall into what she terms “a depressed state”. On the day I interviewed her, Cheryl had arrived at Connections to meet with her case manager and try to move into a group home because she was unhappy living alone. Prior to the regimen she is currently on, Cheryl spent a couple months after her diagnosis changing her regimen to find medication that did not have serious side effects. Unfortunately, due to her recent experience with weight gain it would appear as though her current regimen is no longer working for her. Cheryl reports that she has always taken her medication and there have never been periods of time since she was diagnosed where she was not taking her medication. Cheryl said one of the reasons that she has been so successful with her regimen is because she has a visiting nurse who makes sure she takes her medication every morning. Cheryl’s family support system is comprised of her

daughter, sister, mother and a friend that she considers to be family. While Cheryl's daughter lives close by, her mother and sister live in Florida. Cheryl pays her bills through disability but does not feel as though she has enough, particularly because of the cost of her apartment. Cheryl said one of the reasons she was unhappy was that she was unable to buy clothes after having gained weight, which has caused her to feel lonely and also contributed to her "depressed state". Recently she has been thinking about moving to Florida in order to be closer to her mother and sister.

Participant 4:

"Raquel" found out that she was HIV positive 24 years ago, following the birth of her first set of twins and has been taking ART medication since then. Her ART regimen consists of two pills which she alternates taking every night. Raquel says that she doesn't miss any doses and thinks that she takes her meds well, which she attributes to her visiting nurse. Raquel thinks she takes too much medication, only part of which can be attributed to her HIV. She also takes medication for her depression and anxiety. Despite being adherent now, Raquel has struggled to take her medication which she attributes to her addiction to drugs, an addiction that she manages by going to the methadone clinic every morning.

Raquel indicated her mother, husband and children as being sources of support for her. She has five children who live in Hartford and whom she speaks with on the phone frequently and sees twice a week. They all know that she is HIV positive because her son (who passed away at 24) from her first set of twins and her daughter from her second set of twins were born HIV positive. Raquel raised her children until they were 4-5 years old at which point that were put in foster care as she had start using drugs again. Despite this

they maintain a close relationship. Aside from her children she also frequently speaks with her mother who lives close by. Her mother had 15 children who are now spread out across the East Coast but she did not mention them as being a source of support. A final, important component of Raquel's support network is her husband whom she met in a program for sufferers of HIV. In our interview she said that they work together to remind one another to take their medication.

Participant 5:

“Carol” has been HIV positive for 14 years and her parents and uncle all died from HIV/AIDS. Despite being a relatively new member at Connections (she had joined just a month before we spoke), Carol quickly became invested in the program. She said that she was looking to help spread awareness about HIV through her affiliation with the program in order to prevent its transmission and help to decrease stigma in the community. Carol used to use drugs and considers Connections to be a place where she can go to keep herself from becoming bored and relapsing. At the time when I interviewed her Carol had been taking her medication for 5 months and said that she does not miss doses. Prior to that she admitted to periods of non-adherence, which she attributes to her drug use.

Carol is a mother of seven, a grandmother of seventeen and describes her family as being incredibly supportive. Currently she is living with her eldest daughter, her daughter's children and her grandmother. Carol described a contentious relationship with her daughter but noted that it was improving and that she talks with the rest of her children regularly over the phone. According to Carol, all of her children know that she has HIV and she talks about her relationship with her family as being incredibly open and

supportive about her status. Carol supports herself through disability benefits and by working part time. Despite living in her daughter's house she still pays for her own food and rent.

Participant 6:

Eve (name has been changed) was diagnosed with HIV in 2006 and has been taking medication since then. While she had only discovered Connections a couple of weeks before our interview she had already integrated attending the program into her daily schedule. One of the reasons Eve took to Connections quickly was because it gave her something to do instead of just going home after her part time job. Eve believes she adheres to her medication with success and her viral load is currently undetectable. Eve's support system is made up of her son, ex-boyfriend, cousin and two sisters. Her son and ex-boyfriend, who currently live with her, and her cousin, who lives in Texas, all know that she is HIV positive but her sisters do not. Eve talks to her sisters on the phone and makes weekly visits to their homes. To supplement her income from working part time Eve receives social security and disability, which combined leave her feeling as though she has enough.

Chapter 1 – Sources of Familial Support for Women: A Review

Throughout the five interviews that I have selected to analyze here, participants only referred regularly to emotional and instrumental support. Although informational support was occasionally mentioned, this was almost exclusively as it related to maintaining financial stability. An excerpt from my interview with Cheryl clearly articulates this situation:

I: So if you were struggling financially what would happen if say you went to your daughter and you talked to her about it?

P: Well basically when I get like that I call my mom and tell her what's going on and she kind of, she tells me what to do and everything...

Participants expressed that emotional support, both directly and indirectly related to medication taking behavior, was the primary type of familial support they received. This result was typically unprompted, with women being initially asked if there was anyone in their life who was supportive and then what kind of support that person gave. Participants consistently recounted examples of emotional support first and then, once asked if they could rely on that person for money or a place to live, they would subsequently speak about instrumental support.

The most frequently addressed sources of familial support were children and grandchildren. These two categories naturally coincide because they can both be associated with the type of “care-giving” role that the literature cited as playing a significant part in generating a woman’s familial support structure. There are a number of different factors which could have affected the support that participants received from their children, in this case age appears to have played a significant part. All five women from this sample had children who were grown; this meant that their relationship with their children usually fit into one of two categories. Either they were living separately,

where interactions occurred over the phone and during periodic visits, or the participants and their children were living together – usually because one party was not able to support themselves independently. An excerpt from my interview with Raquel articulates the former situation:

P: I talk to them on the phone, when they come and see me. They come and see me once a week or twice a week.

Raquel has five adult children who she keeps in contact with over the phone and when they visit throughout the course of a week. Joanne, Rosa and Cheryl appear to have similar relationships with some of their children, relationships that consist largely of phone conversations because their children are busy living their own lives. This type of mother/child relationship appears to generate emotional support, which involved the participant's children taking an active interest in most aspects of these women's lives. For example, Cheryl who is currently living on her own, said the following about her relationship with her daughter:

I: Would you say she's supportive in other ways, like helping you take your medication?
P...she be calling me like I was saying to check on me...you know how you doing, have you ate, have you took your meds and stuff like that. Trying to be supportive and now I try to be supportive with her too.

In this case, Cheryl characterizes her relationship with her daughter as one that is emotionally supportive, where her daughter expresses concern for all aspects of her welfare and in exchange she attempts to reciprocate that support. Acknowledging that her daughter demonstrates positive involvement in her life by asking these questions appears to contradict one of the pervasive themes in the literature surrounding familial support and ART adherence among women. The literature states that occupying the role of caregiver, like that which exists between a mother and her child, detracts from the ability

of the mother to adhere to ART because she is more invested in the welfare of her child. However, this result indicates that women can experience the benefits of support from their children. My interpretation of this result is that the day-to-day difficulties that come with raising a child, rather than the children themselves, are what detract from achieving acceptable adherence rates among women. This is a reasonable conclusion given my sample because of the relative age of participants and their children. This changes their family dynamic from one where the women have to cope with the strain of raising children to one where they can (but do not always) support one another.

While Cheryl talks explicitly with her daughter about the difficulties of her disease and medication regimen, Joanne frames the support she receives from her daughter as available despite the fact that they chose not to discuss her disease:

I: Do you talk about it with her (daughter)?

P: We don't talk about, not because its uncomfortable just because we don't talk about. But if I wanted...I don't hide no pills, I take my pills. She know I have a nurse coming in everyday...she knows, do we discuss it? No. Can I discuss it? Yes.

Cheryl and Joanne both refer to emotional support in these examples despite the fact that in Cheryl's case that support is expressly vocalized and in Joanne's it is implied. This type of support could have an impact on ART adherence and I will explore that potential relationship in the subsequent analysis.

In my interview with Raquel, she agreed with the statement that her children help her take her medication. When asked to speak about family members who may or may not influence her medication taking behavior she said the following about her children:

I: Do you think that they help you take your medication?

P: Yeah they help me take...they say: "Mami you took your medicine? Make sure you take your medicine on time." So I told them, yeah I already took it. They make sure, they look at the box...to make sure that I took it.

According to Raquel, her children provide support by confirming that she has taken her medication and making the effort to check her pillbox to ensure that she is telling the truth. This quote is interesting because her children do not appear to genuinely remind her to take her medication when she forgets rather they express concern that she is not taking her medication by asking her about it. This distinction is important to observe because of the way that Raquel interprets the support she receives from her children. It consists of a series of events where they ask her if she has taken her medication, she tells them that she has and they subsequently confirm that fact. Her perception of the support she receives from her children is not an example of direct support, where it influences her medication taking behavior, rather it appears as though she thinks fondly of the relationship she has with her children where they express concern that she is not adhering to her regimen. Perhaps it is the feeling of being cared for by her children that then positively affects her medication taking behavior. This interpretation seems to indicate that it is helpful when women, in general, have a relationship with their children where their children are concerned and invested in their wellbeing because it might provide them with the motivation they need to adhere to their medication.

Carol spoke of having similar experiences with her grandchildren. When asked if her family was supportive she replied:

P: Mhm. I talk to my whole family. We don't necessarily sit down and have an HIV conversation but when I get sick, they're concerned "did you take your meds?" you know, like grandkids "grandma, you take your meds today?" I've got enough med reminders in the house.

In this example, Carol characterizes the support she receives from her grandchild as being one of concern, which manifests as friendly reminders or inquires about medication taking behavior. Again this example does not take the shape of direct support, which

would entail a member of the participant's social network reminding them to take their medication when they've forgotten. Instead, in both cases participants expressed that they adhere to their medication regimens with relative success, which implies that the "med reminders" that Carol spoke of are a manifestation of her children and grandchildren's concern and interest in their mother/grandmother's health.

In my opinion the reminders which Raquel and Carol referred to above do not actually help them to take their medication when they forget. Rather, it is the knowledge that their child or grandchild cares enough to enquire that becomes the support they need to help them feel motivated to continue taking their medication. This result indicates that indirect, emotional support from children can serve a purpose in medication taking behavior among women because it provides women with a reason and therefore the desire to take their medication and stay healthy.

When asked if there was someone in their life who is supportive only one participant, Rosa, completely rejected the idea that her children or grandchildren help her with her medication:

I: Is there anyone in your life that you would say is supportive?

P: Myself, I depend, I rely on myself.

I found this response interesting because, despite most participants expressing that they did not need anyone's assistance to take their medication, only Rosa felt as though there was no one in her life who was supportive. This statement should be judged within the context of Rosa's family structure which includes four children, two of whom were in jail, one of whom is her daughter and the other her son who is living with her in her home. Given this knowledge, I followed up with questions meant to understand if this

claim was merely an oversight or a genuine evaluation of the people she considered to be a part of her life. I questioned:

I: Okay and can you depend on one of your children? Like if something were to go wrong financially...

P: Nah

I: No, do you look to them for emotional support? Talk about things and...

P: No

In this statement, Rosa specifically separates the idea of being in a good relationship with her daughter, which she says has been steadily improving, with the idea that this relationship provides her with support. She expresses the positive nature of her relationship with her daughter, specifically, in the following excerpt:

I: You have four kids? You said your daughter is in your life? How often do you talk to her? (her: mhh?) How often do you talk to her?

P: Maybe twice a week, twice a day. I try to call when I think about her – I love you [name]. You know that type of stuff. Something positive.

Rosa clearly views her relationship with her daughter as positive but does not associate that positive relationship with one that provides support. This is a distinction that all other participants did not make. It is possible that she separated these two ideas because I had told her my study was about how familial support affects adherence. She may have kept this connection in mind while I was asking her questions and responded based on whether or not their financial or emotional support helps her take her medication. However, there is no particular reason why her answer should not be taken as her genuine feelings about the support she receives from her daughter. This could indicate that feelings, which are associated with emotional support in the literature, could still play a role in medication taking behavior for women despite the fact that the individual does not attribute those interactions with their personal conception of social support.

In all of the responses that have been addressed in this section, it is the perception that their children or grandchildren care for their emotional and physical health, which participants identified as support. This general definition applies to how Rosa outlined her relationship with her daughter despite the fact that she did not label it as support. It is possible that the emotional support, which appears at face value to not be related to medication taking behavior, could actually be a motivating factor for women to adhere to ART. The responses analyzed above seem to indicate that women are driven or incentivized, on a certain level, to take medication regularly when know that they have family, in this case children or grandchildren, who are concerned about their wellbeing.

The positive support seen in the relationships that participants describe with their children or grandchildren, appears to be influenced by whether or not those family members are living with the participants. This connection can be best understood by evaluating the relationship that Rosa has with her daughter compared to her son. Her daughter lives in West Hartford with her father while her son is currently living in her home. The tenor of her responses about her daughter was optimistic while she referred to her son almost exclusively as a nuisance and occasionally a serious problem:

P: I have two...three boys – two are in jail and one is in my house and he's driving me nuts. I think I mentioned that to you the other day, I'm not sure. He's driving me nuts.
I: He's driving you nuts? (her: yeah) How long has he been living with you?
P: Too long like a couple months but its too long. Sometimes I go in my dining room, the carpet is all...its just like oh go already.

In this quote, her opinion of her son is drastically different from the way she described her relationship with her daughter. Any number of factors could affect why Rosa feels one way about her daughter and the exact opposite about her son, but one significant difference is the fact that her son lives in her home. It can be assumed that this

plays a role for two reasons. The first is that she explicitly brings up problems that she has with him which involve their living situation, like the fact that the carpet is dirty when she comes home because of him. The other reason is that both Joanne and Carol, who were the only other women living in the same home as their children or grandchildren, expressed similar dissatisfaction with the family members they were living with.

Carol is currently living in the same home as her daughter, grandchildren and grandmother. The way that she depicts her relationship with her grandmother differs significantly from the relationship she has with her daughter:

I: And what about with your grandmother, do you find her to be supportive?

P: She's very helpful. If it wasn't her spending so much time with us, I wouldn't be clean.

I: Why do you say that?

P: Because I was out there and my daughter would piss me off and I had no reason to be in my daughter's house. But my grandmother makes me want to stay there more to help her with the kids because I know she's 84 years old. She doesn't have the motivation and the motor skills that I have, you know?

In the situation that she describes, her proximity to her daughter is harming their relationship, which she believes drove her from her daughter's home towards her addiction. Conversely, her grandmother appears to serve as a counter weight to the negative relationship she had with her daughter. Her feelings of social obligation to take care of her grandmother by alleviating some of the burden of raising her daughter's children motivated Carol to remain in her daughter's home. During her interview, Carol admitted that part of the reason her relationship with her daughter is so contentious is because she believes her daughter holds onto feelings of resentment towards her. Carol thinks that these negative feelings arose because her biological father sexually abused her daughter over the course of several years. Carol sent her daughter to live with her

grandmother who then sent her to live with her father. The nature of these events certainly impacts the strength of perceived social support that Carol receives from her daughter. However, the trend of women who live in the same home as their children or grandchildren reporting that they experience both negative and nonexistence support from those groups cannot be ignored. It is possible that when women live with their grown children, the proximity to one another ignites feelings of anger or annoyance which may already exist, but which would not factor into perceptions of support without the friction of living in the same house.

Joanne offers a unique example of the effect that living in close proximity to children or grandchildren can have on perceptions of support because she is currently living with her daughter and, several years prior, she was raising three of her grandchildren. Joanne articulates her feelings about having her grown daughter living in her home in the following excerpt:

P: No I'm serious, I know what hell is and for her to be in my house right, hell! I hate it, she knows I hate it, I'm not happy...me and my daughter do not get along, she cussed me out, I mean its just...hell, its hell.

As with Rosa there is a clear theme of annoyance towards the presence of her daughter in her home. It is possible this is preventing her from acknowledging her daughter as a positive form of familial support. This differs significantly from the reason that the literature provides for familial support having a negative impact on adherence among women, namely because women sacrifice their own health in order to take care of their children. One explanation for this difference is the relative age of the women I interviewed as well as the age of their children. Since their children are grown there might be an expectation that both parties will be living on their own. When that is not the

reality, resentment could invade the mother-child relationship that in turn prevents women from seeing the children they are living with as positive forms of support. If this is the case that would imply that perceptions of family support are affected by the relative situation of women and their children or grandchildren. Rather than being entirely positive or entirely negative, sources of support should be evaluated within a specific contextual framework – depending on the question a researcher may want to answer – in order to eliminate or account for the effects of variables like whether or not women are living in the same home as their grown children.

This difference between the effect that raising children versus living with them after they are grown has on perceptions of familial support can be best observed by comparing the experience Joanne is currently having with her daughter and the experience she shared with me about taking care of her grandchildren:

P: ...If you're at peace and you're not being stressed...you can take your meds. But if you're all stressed...cause I was raising my grandchildren...and it was a lot to do. It seemed like it never ended.

I: And would you say that when you were raising them that you were taking care of them more than you were taking care of yourself.

P: I was taking care of them more than I was taking care of myself.

Joanne's response to the effect that having to raise her grandchildren had on her medication taking behavior coincides more closely with the conclusions about familial support and adherence among women from the literature. The obligation that Joanne felt to take care of her grandchildren resulted in her putting their needs first and her needs, including taking her medication, second. This situation does not appear to be a lack of support on the part of her grandchildren – which seems to characterize the relationship she has with her daughter – rather the desire to provide as much support for her grandchildren as possible, to the point where she was unable to take care of herself.

The other significant source of familial support that participants frequently acknowledged was their mother. Again, this type of support is affected by the age of the women, which meant that some participants' mothers (Joanne, Rosa and Carol) were deceased. The role that mothers play in the familial structure of participants, similar to that of their children, is emotional support that is accessed through phone conversations and occasional visits. Raquel's mother lives in a different town but she describes her relationship as one where they maintain consistent contact:

I... You mentioned your mom, how often do you talk to her?

P: I talk to her on the phone, most of the, all the time. Everyday, everyday I talk to her on the phone, say hi, see how she's doing. I go see her, spend time with her too.

Living separately, and in many cases quite far from their mothers, resulted in emotional support that is largely communicated over the telephone. Cheryl's mother lives in Florida and as with Raquel, they stayed in good contact:

I: Is there anybody else in your family that you say...

P: I call my mom and my sister she's calls me every day. They're in Florida...my sister she calls me every day you know when she get off work at night and I call my mom to see how she's doing and she doesn't call me so...but I call her but you know, she's getting of age...

In these cases both women have told their mothers that they have HIV and the support that characterizes their relationship is entirely positive. They both said that they could talk with their mothers about anything, including their disease, and that they viewed those conversations as being beneficial and supportive. It is possible that, as was the case with their children and grandchildren, having someone who is invested in their wellbeing provides them with the motivation to adhere to their medication.

Although Joanne's mother is deceased she can still recall the important role her mother played in her familial support system:

I: So are there any family members who aren't in your life or maybe that you don't get along with...

P: ...I just deal with my immediate family. I don't deal with my brothers, I don't deal with my sisters...well that only been over the last few years, my mother passed away like three years ago and we divided, I divided myself and they probably divided their selves. We don't see each other, we don't call each other we don't nothing.

In this excerpt Joanne's mother appears to have held their family together but in her absence that extended family support system dissolved.

The dissolution of relationships with sisters and brothers appeared as a consistent theme throughout most women's characterization of their extended familial support systems. Most participants were alienated from their extended family with few exceptions. For example, Rosa only mentioned one extended family member, her sister, but did not depict that relationship as positive:

I: Okay, are there any family members that haven't been supportive?

P: Mhh some yes and some no.

I: Who hasn't been?

P: My sister.

...

I: Can you tell me a story of when your sister wasn't very supportive?

P: My sister, uh...no when oh when she said she was going to bring me some food and she never did. You know so its just, its nothing, its just (indiscernible) that I don't care about. Its negative. So I have to...do me.

In this situation, Rosa stated that she could not rely on her sister because of past negative experiences where her sister failed to support her in ways that she considered necessary. This belief left Rosa feeling as though she did not have anyone in her extended family that was genuinely supportive and perhaps contributed to belief that she could only depend on herself.

Joanne and Raquel similarly made a conscious effort to express their estrangement from their siblings, however the estrangement that they described was more complete than was described by Rosa. While she still had contact with her sister both

Joanne and Raquel noted that they no longer spoke with their siblings. Joanne said the following about her relationship with her sisters and brothers:

I: Do you mind my asking, is there any particular reason? (about why she doesn't talk with her siblings)

P: I don't like em and they don't like me that's what I say...I don't like em, well for one thing, I'm not here to talk about it but they're on drugs so we don't have anything in common...

By connecting the two statements that Joanne made about her siblings – that they stopped being close after the death of their mother and that they no longer have anything in common – it is possible to deduce that these events led them to grow apart. Again there appears to be a link between the relative ages of the women I interviewed and how they depicted their family structure. One explanation for this is that as women age their relationships with extended family members start to weaken because they are building their own families and living their own lives. This could have contributed to Joanne's lack of feelings of connectedness with her siblings, which in turn would have affected her perception of the support they provide her.

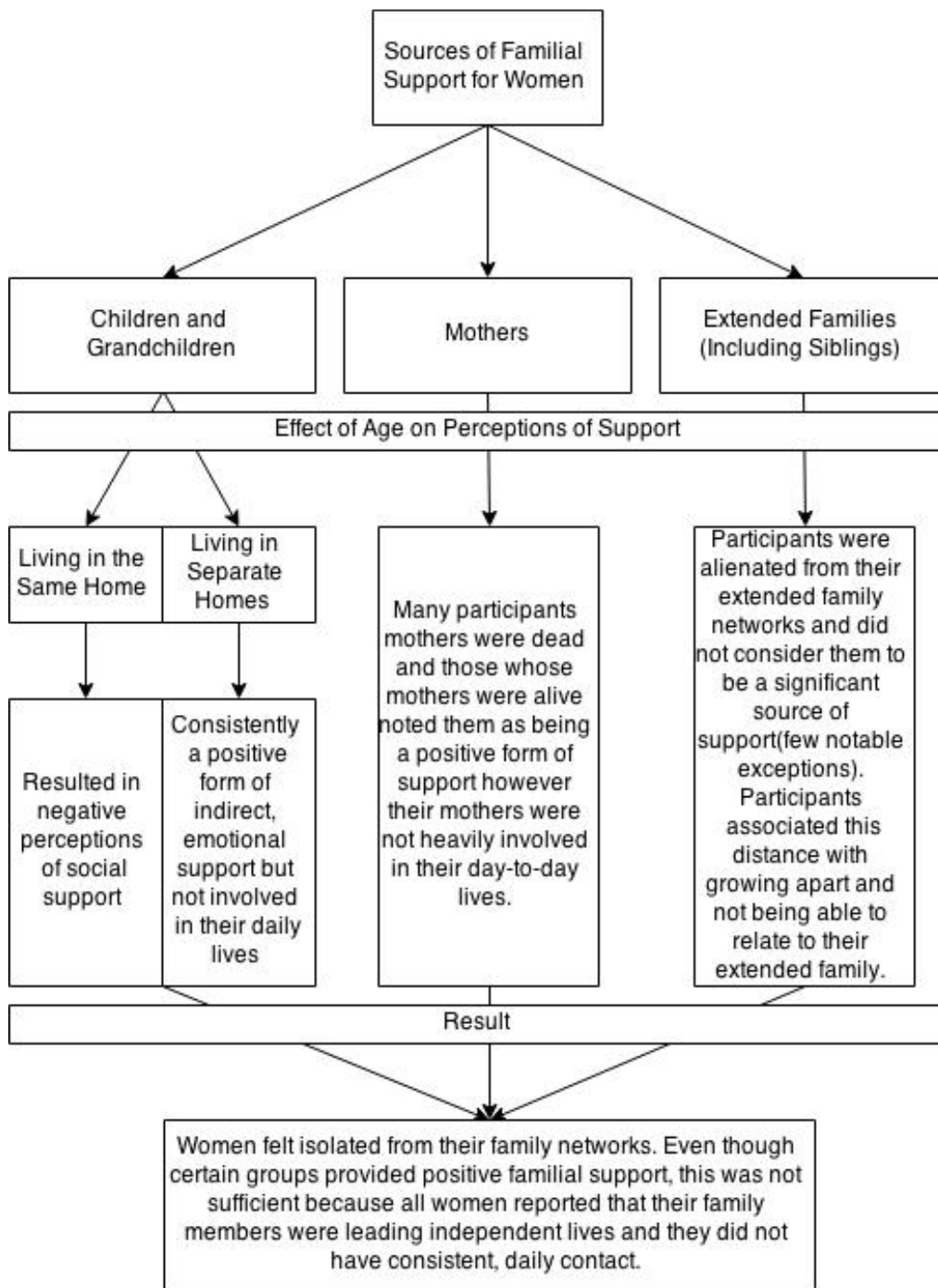
The theme that may connect the effect that these three groups of familial support (children or grandchildren, mothers and extended family) have on medication adherence is the idea of alienation from one's social network. The desire to avoid being alone was pervasive throughout every participant's response to questions about support. In my opinion this fear is a product of the age of the women I interviewed. Most of the participant's children or grandchildren were living independent lives that did not necessitate the involvement of the participants on a daily basis. The relationship appears to be positive but somehow incomplete:

I...do you go and see them or do you go to events that they have and things like that?

P: Well I spend time with them but they doing their own life... (Raquel)

Conversely participants who reported that they live with their children consistently stated that their relationship was negative and they did not believe that they were a source of support. Again this could be a product of age, where there is a certain expectation that both parties would be self-sufficient and independent. Participants who were able to have relationships with their mother's described them as positive but again incomplete. Distance and the fact that both parties were leading separate lives meant that their relationships typically entailed emotional support conveyed over the telephone. The extended family of participants appeared to be spread out and largely absent from each woman's life. One explanation for this is that as they aged participants grew apart from their siblings, which contributed to the dissolution of their relationships with their extended family. **Figure 2** summarizes these findings.

Figure 2: Summary of the types of social support participants reported, how they perceived that support and my interpretation of the effect that support has on their lives.



In my opinion, the evolution of participants' familial structure as a result of age contributed to repeated statements about being alone and not having anyone to rely on. These responses typically arose in relation to my questions about Connections. For

example when asked if there was anyone in her life who she considered to be supportive

Joanne stated:

P: Emotionally supportive? (I: yeah) probably coming here every day...if I didn't go every day I'd be sitting around, just what I said to you, I'm 60 years old, by that time you'd went through hell, couple of divorces, lost friendships, lost parents. It keeps you from sitting around thinking about all of that stuff...probably at this stage for me I've had enough bad stuff, I mean the good outweigh the bad but it just don't allow you to sit around and think about the fails...you have time on your hands to think negative.

In this excerpt Joanne expressed a desire to avoid being alone, something that could be a result of the evolving family structure previously mentioned which has left her without a significant number of close relatives who she feels can provide her with support. Cheryl echoed these sentiments first by expressing a desire to move to Florida in order to be closer to her sister and mother and then with the following response to my question about the three family members she referenced in her interview:

I: Do you think that they help you, or any of them help you take your medication?

P: Well right now I have this guy, he comes over and he keep me company and you know stuff. You know until I get tired and until I get ready to go to bed and stuff because I was saying I don't like to be by myself. I get depressed sometimes and when I'm alone I watch TV but when you watch TV so much you get tired of watching TV.

Again there appears to be an attempt on the part of the participant to fill the void left by the absence of strong familial ties with new relationships. This quote is particularly interesting because I asked her about family members who help her take her medication and she instead refers to a nurse who makes house calls, as if to imply that he performs the tasks that her family, in different circumstances, would otherwise do. It appears as though, in the absence of her daughter who is working and her mother and sister who are in Florida, Cheryl recasts the role they would play of keeping her company with another person. She depicts the assistance that this man gives with her adherence to ART as one of companionship. In doing so she confirms the importance of indirect, familial support

by stating that having someone to sit and talk with during the day helps her take her medication. Given the fact that I had asked her about her family, it seems reasonable to conclude that what contributes to the “depressed states” that hurt her ability to adhere to ART is due in part to loneliness and alienation from her social network, particularly her family. Cheryl’s situation confirms conclusions from the literature that stated that social support in general helps women adhere to their ART regimens, and that lacking social support – which could be conceptualized as isolation or alienation from one’s social network – does negatively impact how women take their medication.

In both of these cases it appears as though, in the absence of a strong, familial support structure, women seek out alternative outlets for acquiring support. This could be one explanation for why so many older people are clients at Connections. As the strength of their familial ties weaken over time, they seek out new communities or people that will allow them to feel supported. What this indicates is that social support plays a significant role in medication taking behavior but it is possible that the type of social support is not necessarily important. As relationships dissolve, new relationships can be made that fulfill the same purpose.

Chapter 2 – Familial Support, Socioeconomic Status and Adherence

The objectives of this chapter are to explore the interdependent relationship that potentially exists between familial support and socioeconomic status among women and to better understand its effect on adherence to ART. There were two distinct effects that low socioeconomic status had on how women discussed their perceptions of family support. The first was a direct connection between not having enough money and decreased access to sources of support. The second was a general perception that they were unable to rely on family members for financial assistance, which appeared to contribute to decreased perceptions of familial support in general, among the women I interviewed.

Only one participant stated that not having enough money directly affected the relationships that she shared with her family:

I: So how often do you see your daughter?

P: Basically since its cold when I can. Yeah cause during the summer time I visit more but when its cold...its hard to travel because it's slippery, its icy outside. I catch the bus, I don't drive so I catch the bus where I'm going and I don't want to fall and hurt myself.

The lack of personal transportation, which could in part be due to Cheryl's economic situation, resulted in her being forced to ride the bus. This meant that her journey to her daughter's house was considerably more difficult during the winter months when it was cold and icy. In this excerpt Cheryl indicates that not having a car or at least an easier means of moving around impacts the frequency of her visits with her daughter. While she never stated that being unable to see her daughter during the winter hurt their relationship or even how she adhered to her medication, the effect of loneliness, discussed in the previous chapter, does play a role in the significance of this admission.

Cheryl continued on in her interview to admit that because of this she felt the effects of isolation more acutely during the winter. As discussed in Chapter 1, when familial support was inadequate, participants attempted to supplement their social network with other sources of support. In this case, Cheryl's lack of ability to afford transportation, which would make it easier for her to move around, like a car, meant that she was isolated from not just her family but the rest of the people who made up her support system. When I met with Cheryl it was the middle of the winter and she admitted that it was the first time she had left her home in a while. She talked extensively about how the loneliness she felt when she was sitting at home was one of the factors that contributed to her being in "a depressed state". It appeared as though the nurse who she said visited her every day to help her take her medication and who tried to keep her company, was the only reason that she had not stopped taking her medication entirely.

In this chain of causal events there appears to be a connection between socioeconomic status, social support and Cheryl's desire to take her medication. The lack of a car and therefore access to her social network could have had disastrous consequences on her motivation to adhere to her medication regimen had there not been someone whose job it was to visit her every day. Given this apparent relationship, it seems likely that women of a low socioeconomic status could encounter a number of barriers that would affect their ability to connect with their family network and sources of support. In Cheryl's case it was having to ride the bus during the winter but other examples could include anything from having to work long hours at a minimum wage job to not being able to afford to participate in various social events. All of these situations would serve to separate women from people who provide them with support – familial or

otherwise – and could result in the feelings of isolation and lack of motivation to continue taking ART.

Rather than a lack of access to one's social network, the most frequently addressed effect that socioeconomic status had on familial support was the strength of those relationships. Consistently, and in many different ways, every woman I interviewed stated that there was no one they could depend on for financial assistance. Rosa expressed this rather succinctly:

I: Okay and can you depend on one of your children? Like if something were to go wrong financially...

P: Nah

Without hesitation she dismissed the possibility that she could seek out support from her family if her financial situation were to suddenly change for the worse.

When I questioned Joanne further about her thoughts on the financial support her family could provide her in hard times we shared the following conversation:

I: Is there somebody you could turn to maybe if things started to go...

P: No. If they started to what, go bad? You never know until you reach that point. My mother use to tell me, it won't be your friends that help you when you're in need. It will be a total stranger. She use to always say that.

I: Is that your experience?

P: It has been, through the years, yeah it has been. A total stranger that has...(me: helped you) yeah, not all the time but I have seen that come to pass in life.

When I began this project it seemed reasonable to assume that someone's strongest form of support, particularly financial support, would come from their family members because those relationships are often thought to imply a sense of mutual obligation that does not exist between friends and especially strangers. However, this is not the perspective that Joanne relayed. She makes a point to rearticulate a phrase her mother had spoken to her, which implies that support, and financial support in particular, would not

come from people who she was closest with but rather from someone whom she had never met. Carol echoed the sentiment that there was no one in her social network that she could rely on for financial support:

I: And, um, just a general question, how reliant on other people do you feel like you have to be? (P: huh?) How reliant on...

P: Oh not at all. I don't rely on nobody. They say you can't count on man but you can count on God. And that's a true statement.

When Carol provided this quote I was asking her specifically about being financially reliant on other people. Carol asserted that she only relied on herself for financial support, which appears to align with her belief that "you can't count on man but you can count on God". Given that Carol is living with her daughter and reported throughout her interview that she finds several family members to be supportive, it seems unreasonable to consider this statement as an indication that Carol is completely self-reliant. However, this does appear to coincide with the theme of isolation from one's social network, which was previously analyzed in terms of physical and emotional distance. In this context, Carol considered the idea of having to be reliant on other people for financial support and chose to separate herself from her social network by proclaiming that she only counts on herself and God.

To better understand the effect that low socioeconomic status has on the participants I interviewed and women in general, it seems important to first explore why they all asserted that there was next to no one they could rely on for financial support. Joanne began to help me understand why so many women may have rejected the idea of seeking financial support from their families:

I: What about family, could you turn to anybody in your family?

P: In my immediate family, brothers, sisters?

I: Or daughters or...

P: ...ah no. One has three children, basically single parent. The other one has...I mean if the push come to shove my son and law and her they would sacrifice because they know I would pay them back. But they're usually borrowing from me (laughter).

Joanne begins by explaining the financial situation of her daughters. Like Joanne they are struggling to make ends meet and given the fact that both her daughters are trying to raise children, Joanne seems hesitant to ask them for money. The lack of ability to rely on family members for financial support, specifically in the hypothetical scenarios I postulated, could explain why some women stated their financial situation in terms of obligatory self-reliance. Joanne addressed whether she thought she could receive financial assistance from the only other significant source of familial support that she had mentioned in our interview, her cousins:

I: What about your cousins, you mentioned your cousins.?

P: My cousin...she raising her grandchildren. You know, everybody's strapped, so I think that makes me say: "well I better do what the hell I'm suppose to be doing over here". You know how people, how money are and you know how your money is...

In this excerpt Joanne responded to my question about whether or not she could rely on a family member for financial support with an explanation that accounted for the financial situation of her cousin and members of her support system in general. The general message that her statement conveys is that everyone is "strapped". The pervasiveness and cyclical nature of poverty means that most of the women I spoke to, who themselves were struggling financially, almost exclusively mentioned people in their familial network who were in similar financial positions. With not nearly enough money to go around, this explains why most women felt as though they could not rely on their families for financial support.

With this explanation there appears to be a connection between familial support, socioeconomic status and medication adherence. Based on the women I spoke with,

living below the federal poverty line appears to be a good indication that a person's familial network is in a similar financial position. As a result, it is possible that women of low socioeconomic status are not able to rely on family members for financial support in ways that women of middle and upper class backgrounds might. This would indicate that socioeconomic status does influence the nature of familial support systems for women and it seems reasonable to conclude that by lacking a significant component of the instrumental category for defining social support that those relationships would suffer. As was noted in Chapter 1, weakened familial relationships are not necessarily indicators of poor adherence, rather those weakened relationships could contribute to the desire of women of low socioeconomic status to seek out other forms of social support. In the cases of Joanne and Carol this meant seeking support from strangers – case managers at Connections and God, respectively.

Scarcity of resources appeared to similarly impact familial relationships in reverse. For some women, feeling as though their resources are scarce translated into the opinion that they did not have enough to share with their family. This became most obvious when Rosa spoke about her son, who was living in her home at the time. I inquired about the support she was giving to members of her social network and she immediately characterized her feelings on the subject in terms of money:

I: Do you feel like maybe you help people out just a little bit too much?

P: Too much! Exactly, too much.

I: Can you give me an example?

P: Just giving people my money. Now they want it all the time. You know that type of shit. I don't got time for it. I gotta do me.

I: Is there maybe a story?

P: Nope just wanting my money all of the time. Its negative. Every time I'm high my son wants money or he wants money. They're always using me. Time to stop that and do what I was doing before, being responsible.

In this excerpt Rosa is clearly expressing her frustration that people in her social network, particularly her son, are attempting to use her for money. It is logical that just as the women I spoke with did not believe they could ask family members for financial assistance, they would similarly not approve of their family members doing the same to them. From this I can conclude that socioeconomic status does have an impact on perceptions of the financial support that women feel they can both give and receive. As noted above, lacking this component of support at a minimum makes familial support systems for women who are living near or below the federal poverty line different from those of women who are part of the middle or upper classes. However, it also seems reasonable to assert that this contributes to perceived holes in the familial support women receive which may encourage them to seek additional support from other sources.

Factors like socioeconomic status and age, as discussed in the previous chapter, work to construct an image of the familial networks of the women I interviewed, which appear to be somewhat limited in their ability to provide those women with sufficient support. The potential effect that age had on the familial support structures of participants seems to be consistent with that of the effect of low socioeconomic status. Both appear to have pushed women to seek relationships from people outside of their family, which again helps to explain why most of the people who are clients at Connections live below the federal poverty line. Besides the help they get with managing their medication, life and diets from the employees at Connections, it is also important to note that most of the women I interviewed remarked on the social opportunities it provides. The space at Connections where clients are allowed to gather, eat and socialize regardless of having an appointment or even being a member contributes to the idea that the people who frequent

Connections are also there for the community support that the environment is able to foster. In my opinion this support system helps to take the place of the familial support they have lost as a product of their age and the effects of poverty.

There is an additional component of the dynamic between familial support, socioeconomic status and medication adherence, which is worth noting. When asked to hypothesize whether or not a sudden change in their lifestyle, like losing their housing, benefits or job would impact their ability to adhere to their medication regimens, most women vehemently agreed it would have a negative effect:

I: So lets say in this situation, if things were maybe starting to go poorly, do you think that would affect your...how you take your meds? Cause you're obviously very good at it right now.

P: Yeah, that's because I'm in a comfortable situation, I'm not stressed out and worrying about where I'm gonna live, you know? Yeah it would affect me taking my dam meds because I'd be somewhere having a drink, you think solving the problems...

It is important to note that these questions were always theoretical as all the women I interviewed were not in what they considered terrible circumstances and while they were all certainly living below the federal poverty line most of the women's financial lives could be characterized with a certain degree of stability. In this example Joanne agreed that lacking the basic necessities of life like a home would negatively affect adherence. The effect of markers of poverty on medication adherence, like a lack of access to proper nutrition, has been well documented in the literature on ART. Similarly to the statement made by Joanne, it has been found to have a profound negative impact, however, the connection between poverty, familial support and medication adherence is not as well understood. One concept that could help to connect these factors is the idea that being of a low socioeconomic position seems to indicate that financial support from family members is not typically available. The lack of familial, financial

support could serve to compound effects of a sudden decline in a woman's financial situation. Without having members of their social network available to help them when they are in financial hardship, women could experience worse adherence over time as they struggle to correct their financial situation on their own.

The theory about "wealth cushion" appears to be analogous to this interpretation of the data. This theory states that there is a difference between income and wealth. Wealth is accrued over time and can help buffer a person's socioeconomic status during financial hardship. This theory has been used to explain financial inequality in the US as a racialized disparity, particularly during the recent recession where middle class African Americans were more frequently uprooted and forced back into the lower class because they had not accumulated wealth to rely on, unlike many white members of the middle class (Shapiro 2004). The ability to rely on family members for social support could be characterized in a similar way. While it does not matter nearly as much when the financial situation of women is relatively stable, were this to change it could have a negative impact on adherence. Poor women might have fewer, if any, family members they could rely on for the help they would need to quickly change their financial situation. This would in turn exacerbate the duration and effects of sudden impoverishment and lead to worse adherence over time.

A significant result, which arose by analyzing familial support and socioeconomic status, is that most of the people in participants' social networks were in similar financial situations. The fact that there is not enough money to go around appeared to negatively impact the perceived levels of familial support that participants reported. Most of the women I interviewed did not feel as though they could seek financial support from their

families and some expressed that they were not willing to act as a source of financial support as well. With no one to be there to provide financial support this left most women feeling as though they would be in a precarious position if they were to lose the income, assistance or benefits that were helping them scrape by. With no one to potentially help them out in that position most women postulated that this would negatively affect their adherence to their medication. Despite the limitations of my method in terms of the generalizability of my data, there are valuable implications for these conclusions.

Throughout my analysis there appears to be a central conclusion: the women I interviewed do not necessarily have strong familial support systems. However, because they are all relatively adherent and in light of their opinions on Connections, I have also concluded that Connections is one example of a program which can help to supplement familial support. This indicates that what impacts adherence is the presence of any social support rather than a specific type. In my opinion a similar model can be applied for understanding financial support and adherence. Rather than needing a family member to help them out of a bad financial situation in order to maintain adequate levels of adherence, it is possible that services provided by organizations like Connections or food pantries could serve the same purpose. Even just the knowledge that there are organizations that can step in where family members are unable could be both settling and encouraging to women attempting to adhere to ART. In place of financial support from family members, programs like these can provide support that helps to buffer the negative effects that financial hardship has on adherence.

Chapter 3 – Familial Support, Stigma and Adherence

The motivation behind including a section on how stigma might affect medication-taking behavior arose organically as a product of my conversations with the women I interviewed. I frequently heard responses to questions like who in their family knew they had HIV, what their reaction was and why they elected not to tell specific family members, which appeared to be related to participant's fear of or experience with stigma. As a result I thought it would be relevant to use the data I had already collected to explore whether or not the stigmatizing nature of HIV prevented women from sharing their diagnosis with family members and what their decision to share or not share might have had on their medication taking behavior.

Three participants, Rosa, Raquel and Carol, stated that they had shared their HIV positive status with all or most of their family:

I: Okay and uh do any of your children know that you are HIV positive?

P: Yeah they, everyone knows.

I: They all know. Okay and what was their reaction to finding out? (silence) Did anybody react with...negatively?

P: No

One interesting connection can be observed between two participants, Rosa and Raquel: both had given birth to at least one child who was HIV positive, both told their families about their HIV positive status and neither women stated that their children had reacted negatively or treated them negatively because of their disease. It is possible that having family members who are also HIV positive might make it easier for women to express that they have this disease and even help to reduce perceived levels of stigma between women and their families. Furthermore, with both Rosa and Raquel the family member who also had HIV was their child, whom they passed the disease along to during

pregnancy. Perhaps raising a child who is HIV positive removes the effects that stigma can have on familial relationships, at least in a woman's immediate family. This would suggest that to better understand the relationship between familial support and stigma it is important to study who women are sharing the experience of being HIV positive with.

Two other women, Joanne and Cheryl revealed that some members of their family were aware of their HIV positive status but the relationship between how and when family members were told, as well as what those family members' reactions were, is relevant to their experience with stigma.

Cheryl waited two years after her diagnosis to start sharing the information with her family. She noted that her daughter's reaction was particularly negative:

I: And what were their...Can we start with you daughter what was her reaction?

P: Well at the beginning it was hard, she wouldn't let me be around the kids and stuff. She wouldn't eat with me and she wouldn't let me share the same like, I guess food and stuff. Cause she was kind of nervous and I said its not contagious or nothing like that...

Cheryl goes on to say that eventually she was able to convince her daughter that there was no risk to either her or her grandchildren but the reaction she notes appears to be directly related to the stigmatizing nature of HIV. In this case Cheryl's daughter had misconceptions about how HIV is transmitted and appeared to treat Cheryl, at least for a period of time, as though she was contagious. This situation is just one example of a reaction that may keep women from being willing to disclose their HIV positive status to their family, and in the case of Cheryl this was part of the reason she waited two years to tell her daughter. However, she noted in her interview that she was glad she had told her family because eventually she was able to convince them that their fears about contracting HIV by being around her were misplaced and now she asserts that their relationship is stronger than when she was keeping her HIV positive status a secret:

I: Would you say its made the process easier or harder having them know?

P: I guess at first it was hard for me to tell them but now since I've told them, its out in the open and I don't have to be like...when I'm upset or depressed or anything and come out and just talk to them where before I couldn't and tell them why I was like that. It's kind of like easier for me to express to them what's going on.

In this particular example Cheryl was eventually honest with her family about having HIV, worked to overcome their misconceptions about the disease and finally reached a place where she found her family to be more supportive because she was able to be more open with them about what specifically was bothering her. However, it is important to keep in mind that this is an isolated incident and with no other participant experiences mirroring this one, it is impossible to say whether her decision is generalizable to women as the optimal choice. By that I mean Cheryl was open with her family despite fear of the stigmatizing effects her admission might have on their relationship. In the end she stated that it had a positive effect on her perceptions of the support they provide her. However, several factors could potentially interrupt the positive result that she experienced. For example, had she told her family and they had never come to the realization that she was not contagious and as a result not been a support system for her regarding her HIV or continued to treat her as if she could easily transmit the disease or even cut contact with her altogether. These scenarios either don't change, negatively impact or eliminate family support respectively. Further research would need to be done to better understand how women should handle the process of sharing their HIV positive status with family members when they anticipate that it might have a stigmatizing effect on their relationship.

A couple of participants expressed that some of their family members knew they were HIV positive but that they had not been the person to tell them. Joanne provided an example of this with regards to her cousins:

I: ...I was just wondering if there is anybody in your life who you find to be supportive?

P: Oh anybody that's supportive that I can talk freely about...well we never, I never talk about this disease but its too present in my life with just my two cousins.

I: Your two cousins?

P: One I got, somebody exposed me, the other one I wouldn't tell until forever and she was pissed because...I told her everything. I just told her I didn't want to talk about this disease, I didn't know how you would feel but here we are. We don't talk about it but I'm free to if I want to.

This example is an interesting situation where Joanne talks about being "exposed" to one cousin and having deliberately told the other. Joanne's perception of HIV related stigma could have played a role in how and when her cousins found out she was HIV positive.

While she never explicitly stated this, stigma does seem a reasonable component of Joanne's response when taken in context with the fact that she concludes her statement above by saying that she does not discuss her disease but "she's free to if she wants to".

This kind of acknowledgement without discussion is repeated in her relationship with her daughter:

I: Do either of them know or have you talked about it with them?

P: One knows.

I: Do you talk about it with her?

P: We don't talk about, not because its uncomfortable just because we don't talk about. But if I wanted...I don't hide no pills, I take my pills. She know I have a nurse coming in everyday...she knows, do we discuss it? No. Can I discuss it? Yes.

The fact that Joanne does not discuss aspects of her life related to her disease appears to negatively impact how open she is with the rest of her family. Throughout our interview Joanne stated that was able to share a large variety of her life with her family but this portion was off limits in day-to-day discussions even though she concedes that

she could talk about it if she wanted to. In my opinion this could be due to perceived levels of stigma. The semantics of her word choice where she talks about being “exposed” implies that there was something she felt she needed to hide. Furthermore she expresses that it took her “forever” to tell her other cousin, further confirming that she felt she the need to hide her status. While it appears as though this does not directly affect her medication taking behavior as she states that she does not hide pills or discontinue participating in a service that provides house calls in order to ensure that her daughter did not find out about her disease, it seems reasonable to conclude that by keeping this matter private the support she can receive from her family is somewhat limited. However, the importance of this finding in terms of generalizability is unclear. It is possible, as presented in Chapters 1 and 2, that when women feel uncomfortable sharing or discussing their disease with family members, they can supplement that loss of support by seeking support from other outlets.

The women I interviewed all appear to have some family members in their life who they have told about their HIV positive status, however, some women reported that they were not comfortable sharing this information with select family members:

I: Is there anyone that you would say, so you have your son, your cousin and your ex-boyfriend, is there anyone you would say isn't supportive?

P: Well, I haven't told my sisters cause they've got big mouths. They talk a lot.

Eve indicates that she has deliberately avoided telling her sisters about her HIV positive status for the last nine years since she was diagnosed. The reason she gives is that “they've got big mouths” which appears to imply that rather than fear of her sisters themselves stigmatizing her because of her disease, she is worried that if they know they will share the information with members of her community. This is an inversion of

causation compared to the rationales previously presented by participants, which serves to further illustrate the complexity of these variables. The idea that her family will share personal information to their community was not unique to Eve; other participants expressed similar concerns, which would indicate that fear of stigmatization by individuals outside of one's family, as a result of family members sharing sensitive information, influences whether or not women chose to share their diagnosis with family members. Joanne reinforced this statement when she spoke about her struggle over whether or not to become a member at Connections:

I: So how long have you been a member at Connections?

P: Here is this facility? Probably a year.

I: And what brought you here?

P: This one, well I actually started at another facility...and what brought me here is my case manager just kept suggesting that I come here, which I didn't wanna come because I just wasn't comfortable with coming in my own area.

There appears to be a relationship between fear of familial stigma and community stigma that may affect the relationship women have with their family support system. Fear that family members might disclose their HIV positive status could have similarly damaging effects on how women perceive familial support as the fear that their family members themselves would stigmatize them.

Cheryl's explanation for why she chose not to tell her family for an extended period of time helps answer why women might take a while to tell family members about their status:

I: And did you feel comfortable sharing with them?

P: It took me a while to tell them, it took like two years for me to tell them because I had to get you know, comfortable with it. God knows once I told them I had to explain it, explain it and like in details in what it was and what it do and like told them all the time I'm at risk when I don't take my meds.

In this passage Cheryl appears to have struggled with the decision to tell her family for quite a while and the reason that she gives is that she had to get comfortable with the idea. When taken in the context of how she expected her daughter to react it seems reasonable to believe that a component of becoming “comfortable” with her disease was taking the time to come to terms with her diagnosis and its implications before having to field what she thought was going to be a largely negative reaction from her family. It is possible to extend the analysis from Cheryl’s situation to women in general where the social implications of having HIV can be conceptualized as a factor that hinders whether or not women feel comfortable sharing their diagnosis and seeking familial support for their disease. Part of the process towards sharing then includes progressing towards a state of acceptance of their diagnosis. This could potentially coincide with ideas of internalized stigma, which women may have to grapple with first, before feeling they can share their status with family and begin to seek support.

As was stated in the above excerpt, Cheryl did eventually reveal to her family that she was HIV positive. In doing so she noted that their relationship grew stronger. She was pleased that she could finally share aspects of her life, like her depression, which, because it was related to her disease, she had previously kept quiet. When analyzed in the context of Chapter 1, for women, sharing their HIV positive status with their family is clearly an important step in order to receive the emotional support from their family that most women reported as being positive. Again, however, due to the inherent level of variability in Cheryl’s situation it is impossible to assume that all women should share their HIV positive status with family members, despite reservations, in the hope that their family will grow to be more supportive.

Given this speculation regarding the effect that sharing her status with her family had on Cheryl's perception of the support they provided her, it seems pertinent to analyze a situation where a woman specifically elected not to tell members of her family. Eve is the only clear example of this but her response seems to contradict what one would expect – that keeping her status a secret would weaken the perceived support that she receives from them:

I: Okay, what can you talk to them about?

P: I talk to them about everything else except my status

I: Is that hard?

P: (shakes head no)

I: No? Do you ever want to tell them? Do you ever wish that you could confide in them?

P: No, not really.

In this instance Eve does not find it hard to avoid talking about her status with them and she even says that she does not ever really want to tell them. She says that their not knowing doesn't directly effect her medication taking behavior or her management of her disease because they never go over her house, a location where they might see her pills. While skipping doses to avoid being "found out" is a consistent theme in the literature, this does not appear to play a significant role in how Eve is forced to navigate a relationship with sisters who do not know she is HIV positive.

An interesting part of Eve's statement is that she does not feel keeping her status a secret from her sisters hurts their relation, which was my hypothesis as I began to think about the relationship between family support, stigma and medication adherence. It is possible that the same theme relayed in the first two chapters is applicable here, which is that the specific type of support, familial or otherwise -- and in this case support from specific groups of people (her sisters) -- are not nearly as important as the support itself. In this case Eve has Connections, a clinician that she is close with, her son and her ex-

boyfriend all of whom are people or groups that are aware of her status and that provide her with support. It seems as though the support these people and organizations provide may help to alleviate Eve's need to confide in her sisters about her disease, because she has other forms of support that she can rely on.

The small size of this study makes it difficult to make any concrete assertions about the relationship between stigma, familial support and medication adherence. I only analyzed six interviews, which made it difficult to account for the variability that appears to be inherent to the relationship between familial support and stigma, particularly on an individual level. Furthermore, since I did not originally plan to investigate stigma, I did not plan any questions to ask while I was interviewing and instead had to base my analysis on the questions I had already asked such as whether or not participants had told members of their family if they were HIV positive. These limitations could explain why there is some variability in the data, which impacts my ability to make generalizations more broadly.

The examples that I was able to look at show stigma having a varying level of influence over family relations. In some cases it did not appear to inhibit how women perceived the support of their family, however, this did appear to be due in part to the fact that both women who reported this situation had given birth to and raised children that were HIV positive. Conversely some women reported that they struggled with the stigmatizing nature of their disease, which affected when they told family members that they were HIV positive and the treatment they received following their admission. Others did not address stigma specifically, instead alluded to it as a potential factor that influenced perceptions of support by using language like "exposed" or expressing fear

that family members would openly share their HIV positive status with their community. These situations are diverse and therefore require further study in order to appropriately investigate the variable nature of stigma and familial support. One study that would help to better understand these interdependencies could be about the effect that having HIV positive family members has on perceptions of stigma and support. Another important direction for research would be to better understand the effect that stigma has on family relationships when women are deciding whether or not to tell their family that they are HIV positive. An important component of this topic would be comparative research on the potential effects (both negative and positive) that sharing compared to withholding their HIV positive status would have on women's perceptions of familial support. This could help to answer the question, which is more advantageous when women are worried that their family will stigmatize them for their disease?

Conclusion

The idea of alienation is essential to my analysis of familial support and adherence to ART among the women I studied; a result which appeared to be largely contingent on the relative age of the participants. The physical separation that occurs as families mature appeared to result in most of the women I spoke with living, and in some cases desiring to live, lives that were separate from their children, grandchildren, mothers, brothers and sisters. Despite finding their children and grandchildren to generally be a positive form of emotional support, the women I spoke with expressed opposite sentiments when they were once again living in the same house as their children. This relationship appears to represent the situation that most of the elderly women I spoke to are attempting to navigate. They are at points in their lives where they are supposed to be on their own (or with their spouse), instead of living with members of their immediate and extended family. The friction that several women spoke of when they once again had to live with their children seems to indicate that it is not a desirable situation for experiencing positive, familial support. Conversely, however, women that were living alone or had lived alone described it as being profoundly isolating. By combining these components the relationship that these women have with their familial support system appears to be somewhat delicate – too much interaction could be detrimental, while too little has caused some women to feel depressed or “stuck in their head”.

A solution to this situation appears to be for women to seek out support from other areas. I refer to Connections frequently because that is the place I first met all of the participants I interviewed and therefore can vouch for the positive, social environment

that it fosters. However I also heard women talking about a range of services from home nursing, to visiting a food shelter and some even spoke of their job as being a way they avoided the isolating feeling that appears to be a result of the social position older women are placed in after they have raised their children. Based on the fact that the women I spoke with are all relatively adherent to ART, it seems reasonable to conclude that the topic of social support could be studied as a series of needs which must be met in order to improve adherence. This would replace the support method I chose to examine, which attempted to study the topic in terms of the *type* of support that an individual or group of individuals like a woman's family provide and the effect that type of support had on adherence.

The other significant result from this investigation deals with the relationship between socioeconomic status, social support and adherence. The studies that I found in the literature almost exclusively sought to understand the direct effects that poverty can have on adherence by identifying markers of poverty like food scarcity among individuals and operationalizing those variables to determine how participants who were food insecure, for example, adhered to ART. My study built on those findings by attempting to investigate how social factors like familial support impact and are impacted by low socioeconomic status. One interesting result was that all of the women I spoke to either hesitantly or directly stated that they would not be able to rely on their family members for financial assistance. This indicates that not only were the women I was interviewing at or below the federal poverty line; their families were as well. By expanding on this finding I was able to connect some of the negative effects poverty has been found to have on medication adherence with social support. In the absence of family

members who can be financially supportive, many women did admit they would be in a difficult position if things were to suddenly turn bad for them, such as losing their benefits or their housing. Most women agreed with the research and said that they would find it hard to keep taking their medication if they did not know where their next meal was coming from or if they did not have a roof over their heads. What makes the situation of the participants I interviewed different from the situation of, for example, a woman from a higher class background is that a middle or upper class woman might have family members who could help her get back on her feet. This would allow her to continue to adhere to ART without the burden of financial self-reliance that the participants I spoke with are forced to carry. In their case, adhering to ART would be much more difficult and they would likely have to endure a longer duration of financial distress and potentially poor adherence because there are few if any people in their familial networks who would be able to financially help them. However, I suggest that organizations like Connections, in addition to providing emotional support, have the resources to similarly provide women with instrumental support. Programs like these may help to fill the gaps in the support systems of poorer women with HIV, which their families are unable to fill.

Due to the exploratory nature of this research there is no one future research question or direction to continue with. Instead, given the results of my research I have chosen two future questions that I think would be valuable to continue studying. I would like to be able to conduct a project where I recruit women with similar demographics to the participants in my study but instead ensure that half of them do not attend an outreach or aid program. Much of my analysis is based on the idea that Connections is able to provide sources of support that the families of the women I interviewed cannot. It would

be helpful to compare levels of adherence and perceived levels of support among the two groups in order to better understand the role that holistic outreach programs have in providing support for patients.

I also think it would be interesting to vary the sample of participants by age. The age of my participants played a significant role in my interpretation of the data and as a result I am curious to see if a comparison between younger single women, mothers and grandmothers would yield different family structures and perceptions of support. By better understanding who the groups consider supportive and why, I might begin to verify some of my interpretations and determine whether or not the perceptions of loneliness and alienation, which are so significant in my analysis, are really unique to the participants I interviewed because of their age.

The results of my study, while diverse, indicate that the effect of support on medication adherence should be studied as a variable that is influenced by of a complex set of social factors which all contribute to how women experience that support. Research that simply seeks to answer the question does support matter will miss out on the vast array of intricate situations which would lead a woman to claim that it does or does not. Further research, however, is necessary to better study the range of variables, such as age, wealth and stigma, that this study only begins to investigate and which certainly affect the experiences women have with familial support and adherence to antiretroviral therapy.

Appendix A

Consent Form for the Study of Qualitative Analysis of the Effect of Perceived Social Support on Antiretroviral Therapy Adherence among Women in Hartford, Connecticut

I, _____ (please print name) hereby consent to my participation in this research project.

The purpose of this research project is to better understand the connection between perceived social support and adherence to antiretroviral therapy in women with HIV. As such, I understand that I will be asked questions that I might consider sensitive or personal. These include to whom I have disclosed my HIV positive status to and what their reaction was. I understand that my participation in this project is completely voluntary and that I am free to withdraw my participation at any time or refuse to answer any questions that I do not want to answer without any penalty. Upon completion of the study, I will be entered into a raffle to win a gift card to Stop & Shop for my participation.

I understand that use of a recording device is not required for participation in this study and I am free to request that a recording device is not used during my interview. If I choose to allow a recording to be made of my interview, I understand that I am free to request that the recording device be turned off at any point. I further understand that Hayley Berg, the principal investigator, will be the only person who will have access to these recordings. They will not include my name and, upon completion of the interview; they will be immediately transferred to a secure server and deleted off of the recording device. I understand that these recordings will be used for research purposes only and any transcripts will change all names that I mention and omit stories that could lead to my identification.

There are no anticipated benefits involved with this study. Potential risks involved with this study include the chance of disclosure of my HIV positive status. However, I understand that all of my responses in this study are completely confidential and will be used for research purposes only. I understand that the only record of my name in connection with this study is this consent form, which will be kept in a locked file cabinet separate from records of my interview. To preserve confidentiality I understand that my name will not be included in any notes or recordings of my interview. I further understand that every effort to maintain confidentiality in any published materials of this research will be made, which includes changing any names that I mention and omitting any stories that might lead to my identification.

If I have any questions regarding this project or wish to have further information, I am free to contact Hayley Berg, a student in the Anthropology Department at Trinity College, (603) 203-3741, hayley.berg@trincoll.edu.

Signature

Date

Appendix B

Semi-Structured Interview Questions

General, Pre-Interview Questions: Before we begin I'd love to know a little about you? Where are you from? What do you like to do in your spare time? Etc.

Brief Introduction to the Study

Adherence/Program Questions:

How long have you been a member at Connections? How is the program helping you...? What services do you find most useful?

How long have you been taking HIV medication?

What kind of medication are you taking right now? Do you know the names of your meds? Any side-effects?

How often do you miss doses? How well do you feel you comply with your drug regimen? Tell me more about why you feel that way? What factors do you think contribute to either complying well or poorly?

How often do you miss appointments?

Has your doctor/health care provider suggested you make a life change?

Have you made it?

Do you ever take too much medication? Too little?

Does compliance = ordered life

Leading Interview Questions:

Is there someone in your life who is supportive?

If not: What's it like? What are the challenges?

Questions that Should be Answered:

What members of your family are present in your life?

Who do you see most often?

Do any of your family members know that you are HIV positive?

So tell me about your relationship with ... How involved in your life are they?

What was their reaction to finding out you have HIV?

How do they help you take your medications?

Do find them to be supportive in other ways? (examples: financially, can you talk with them? Etc.)

If you're not feeling well are there any family members you could go to? What would you go to them for?

Do any of your family members go to appointments with you?

- If so do you find this helpful?
- If not do you wish someone would go with you?

Are there any family members who haven't been supportive?

How has this affected your relationship with them?

Has this affected your ability to take your medication? (have you missed/skipped doses in order to hide your HIV positive status from family members)

If the participant has not disclosed their HIV positive status to a family member: Why have you elected not to tell them you are HIV positive?

How has keeping this secret affected your relationship with them? What measures do you take to keep this secret? Have there been situations where keeping this secret affected your ability to take your medication?

Do you have any family members that you don't consider to be a part of your life? Why are they not a part of your life?

Leading Interview Questions (socioeconomic status):

Who are you living with? By yourself?

How do you pay your bills? What kind of assistance do you use to pay your bills?

How do you pay for your medication?

If you need to see a doctor, where do you go?

How do you get there?

Are you working or not?

Do you feel as though you have enough, etc.

How reliant on other people do you have to be?

Prompts

- Sometimes people say that not having enough money is a really important problem in managing medication – do you have any comments on that?
- Imagine things haven't been going well for you, maybe you've lost your job or have to move, how might that influence how you take your medication?
- Now imagine you have enough money to get your basic costs covered how would that influence how you take your medication?

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