

8-1-2011

Strong Ties and Strong Influences: Social Networks and HIV Prevention

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STRONG TIES AND STRONG INFLUENCES: SOCIAL NETWORKS AND HIV
PREVENTION

Nicole M. Wengerd

81 Pages

August 2011

This research builds on the social-oriented literature of HIV-risk behaviors in Gondar, Ethiopia by investigating influential social networks and why individuals would deviate from the norms established by their community.

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The objective of this research is to build on the literature, further understanding the social nature of HIV risk behaviors. The first research question investigates what social networks people are part of and then looks at which of those networks are considered most influential concerning HIV- related risk behavior. The second question explores why-- or in what situations-- a person would deviate from the norms established by their community again as it relates to HIV risk behavior. The study analyzes data collected from ten interviews as well as three focus groups from a local PLWHA (People Living with HIV/AIDS) Association in Gondar, Ethiopia. The first question was addressed through narrative storytelling and direct questioning which indicated that there were eight social networks, and of those the family was unquestionably the most heavily talked about. Contrary to my expectation, during the direct questioning the majority of respondents indicated that the religious community was most influential in their lives concerning HIV prevention while only 10 percent mentioned anything about the family. The focus groups were set up to explore the second research question in more depth and the overwhelming amount of discussion revolved around the economic conditions, which were later broken down into two subsections: economics and basic needs. From these

findings two conclusions have been made. First, there are underlying structural issues, such as poverty and gender inequality, which our current regime of behavior change prevention programs do not and cannot address alone. Second, this research suggests that social-oriented interventions that utilize the social influence process by addressing the social environment-- such as social networks and norms-- can potentially be more affective, affect a greater number of individuals, and have a more sustainable impact on behavior change.

APPROVED:

Date Frank D. Beck, Chair

Date Gina I. Hunter

Date Virginia T. Gill

STRONG TIES AND STRONG INFLUENCES: SOCIAL NETWORKS AND HIV
PREVENTION

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

MASTER OF ART

Department of Sociology

ILLINOIS STATE UNIVERSITY

2011

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AND HIV PREVENTION

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ACKNOWLEDGMENTS

The author wishes to express sincere appreciation to Professors Gina I. Hunter and Virginia T. Gill for their assistance in the preparation of this thesis. In addition, a special thanks to my committee chairman Frank Beck for the dedicated time and effort he has put into guiding me throughout this entire process. I truly would not have been able to accomplish all that I have without your help.

N.M.W.

CONTENTS

	Page
ACKNOWLEDGEMENT	i
CONTENTS	ii
TABLES	iv
CHAPTER	
I. INTRODUCTION	1
AIDS Prevention	1
Statement of the Problem	3
Objective of the Study	4
Background	5
Expected Findings	10
Significance of Study	10
II. REVIEW OF LITERATURE	12
Introduction	12
Shifting Interventions: The Case for Africa	15
At Risk: Women and the Poor	19
Norms and Networks	25
Rationale	32
III. METHODOLOGY	34
Background Setting	34
Data Source	34
Data Collection	36
Methods of Data Analysis and Coding	41
Implications	42
IV. FINDINGS	44
Introduction	44
Narrative Findings	45
Interview Question Findings	52

Focus Groups Findings	55
Analysis of Findings	64
V. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	69
Summary of Research Problem, Methods, and Findings	69
Concluding Remarks	73
Recommendations	74
REFERENCES	76
APPENDIX A: Interview Questions	81
APPENDIX B: Focus Group Questions	83

TABLES

Table	Page
1. Interviewee Demographics	38
2. Most Influential Social Networks	53
3. Most Influential Social Networks in HIV-Related Risk Behavior Choices	54
4. Religious Community Examples	56
5. PLWHA Association Examples	57
6. Economic Difficulty Examples	59
7. Basic Needs Example	60

CHAPTER I
INTRODUCTION

AIDS Prevention

Over the last three decades AIDS-prevention researchers have drawn two simple and uncontested conclusions; we've made progress and we can do better. The world's first major HIV prevention campaigns targeted gay and bisexual men in US cities and were primarily focused on individual or small- group behavioral change. The campaigns began in the early 1980s and were run by non-governmental organizations such as the San Francisco AIDS Foundation, AIDS Project Los Angeles and Gay Men's Health Crisis in New York. These community-based groups had for some time been teaching people about AIDS and how it was most likely acquired, but they found that this was not enough. Even men who saw friends suffer and die of AIDS found it difficult to make long-term lifestyle changes (Avert 2010).

While the behavioral approach celebrated some success in its infancy, as these prevention efforts crossed international borders the shortcomings became evident. Among its most established limitations include: 1) the failure to change contextual and structural influences on HIV infection, and 2) a lack of attention to culturally specific influences, which are frequently omitted from most individual-level theories of behavior change (Trickett 2005). No continent has felt the impact of these shortcomings more than Africa. A poster-child for adversity, many countries in Africa continue to endure the

struggle to survive. The 2009 UNAIDS global report noted that 67% (22.4 million) of people living with HIV/AIDS and 72% of AIDS deaths are in sub-Saharan Africa. For decades there has been a great deal of speculation as to why HIV rates in sub-Saharan Africa are so high. Among academics, some of the most widely discussed reasons include: concurrent partnerships (more than one sexual partner at a time), poor sexual health (i.e. high STI rates which increase the likelihood of acquiring HIV), and frequent unprotected sex (Mojola 2010). The identification of these causes led to a frenzy of interventions aimed at changing individuals' sexual behavior.

Probably the most widely used example of this is the ABC (abstinence, be faithful, condom use) approach. The slogan appears to have first been adopted by the Botswanan government in the late 1990s. Seen on billboards around the country, it optimistically declared:



(Photo by Petkun 2000)

For years, this simple message was supposed to encompass the complex interworkings of individual motivation and social relations. In Africa especially, the individual-focused approaches ignored the importance of social ties, the influence of the

extended family, and the inequalities of gender relations. In short, the oversimplification of the problem led to the oversimplification of the solution.

Most interventions were developed in the US and Europe, a world away from the African countries where they were being implemented. The miscommunication and misunderstandings have been epic. Let me give an example. In the US waving ‘bye-bye’ to a small child means ‘goodbye’. In Ethiopia that same hand gesture means ‘come here’. Over time you could teach the children that know you that where you come from that hand gesture means ‘goodbye’, but you’d probably be more effective if you learned what it meant there and adapted the way *you* say goodbye. This is only a simple word-to-gesture association. One can imagine the miscommunication struggles that would arise when teaching women how to correctly use condoms in a country where women don’t have the authority to use them.

Statement of the Problem

The 2010 UNAIDS Global Report, reference book that provides comprehensive analysis on the AIDS epidemic and response, opened with ‘a new vision’. This vision stated that to meet our goals “will require a hard look at the societal structures, beliefs and value systems that present obstacles to effective HIV prevention efforts” (Global HIV Prevention 2008: 12). The report went on to talk about the effects that poverty, gender inequity, discrimination and unequal resource pathways have on the HIV response, and how we need to help “to provide social environments that are effective against the spread of HIV and promote more general mental and physical well-being” (Global HIV Prevention 2008: 12). While there has been increasing recognition of the need for a social-level HIV intervention agenda, much like the Global Report, the

underlying theories and methodologies of interventions have largely remained individual-oriented, limiting the potential of social avenues of intervention for behavior change (Trickett 2005). For example, according to the 2010 Ethiopia Country Progress Report, in Ethiopia, Behavior Change Communication (BCC) remains one of the key national strategies for HIV prevention. Much like the Botswanan message posted over 20 years ago, the prevention messages explicitly promoted being sexually abstinent, delaying sexual debut, being faithful, using condoms consistently, and engaging in safer sex (FHAPCO 2010).

For years, researchers and program implementers have looked for fault in the noncompliance of individuals when trying to pinpoint the reasons for inconsistent success in HIV prevention interventions instead of evaluating the intervention strategy itself (Farmer 1997). If we look at models of behavior change being employed in HIV prevention they tend to be highly cognitive, emphasizing risk perceptions, attitudes, and beliefs, diverting attention from the social and economic contexts that we know help shape these cognitions (Trickett 2005). But we are learning that without a socially supportive environment, individual-oriented interventions tend to lack sustainability, with most HIV behavioral change decaying 3 to 6 months after intervention (Trickett 2005).

Objective of the Study

While a good deal of scholarship continues to emphasize the individual, the present study builds on two critical areas related to the social nature of HIV risk behaviors. It first inventories and analyzes social networks in Gondar, Ethiopia both in daily life decisions and those that influence individuals' choices regarding HIV risk

behaviors. Secondly, it helps to untangle societal norms surrounding HIV prevention and motivating factors that shape behavioral decisions.

My research questions are as follows:

- 1) What social networks are people in Gondar, Ethiopia part of and which of those networks influence HIV related risk behavior?
- 2) Why--or in what situations--would respondents deviate from the norms established by their community (social networks) as they relate to HIV risk behavior?

Background

AIDS in Ethiopia

Ethiopia has been battling the AIDS pandemic since the mid-1980s. The adult HIV prevalence rate in 2009 was estimated to be between 1.4% and 2.8%, which at first glance would give the illusion that Ethiopia should be a low priority country when compared to some of its sub-Saharan counterparts (FHAPCO 2007). However it is estimated that over 1.1 million people in Ethiopia are living with HIV, which is one of the largest populations of HIV- infected people in the world. Furthermore, women accounted for 59% of the HIV-positive population, 57% of new HIV infections and 57% of AIDS-related deaths in 2007 (FHAPCO 2007: 6). In addition, to date, a staggering 750,000 children under the age of 18 years were orphaned due to AIDS-related deaths (Red Cross 2010).

Initially, researchers attributed the spread of HIV in Africa primarily to a lack of correct information, or to myths and rumors circulated informally (Helleringer and Kohler 2005). However, if we look specifically at Ethiopia's situation, the 2006

Ethiopian HIV/AIDS Behavioral Surveillance Survey (BSS) indicated an increase in basic HIV/AIDS information but a decline in behavior change nationally. The new view is that the severity of the AIDS epidemic in Africa is due to social and cultural barriers that inhibit behavioral change despite widespread knowledge about the consequences of the disease and about recommended methods of prevention (Helleringer and Kohler 2005).

Poverty and Religion

For those that have had the opportunity to spend any length of time in Ethiopia there are two realities of daily life that become apparent quickly: poverty and religion. This contextual background is essential in understanding Ethiopia's social world.

As most can probably recall, Ethiopia's unveiling to the international world came in the form of despair and desperation during the famine of 1984. Images of fly-covered faces and a never ending sea of starvation inundated the hearts and lives of millions around the world. The first reporters described the famine as "the closest thing to hell on Earth," which had been induced, and later perpetuated, by the persistence of drought, unstable security conditions, and the government's inability or unwillingness to provide relief (BBC 2000). Even today the event serves as a reminder of the fragility of a country where 84 percent of population continues to live in rural areas as sustenance farmers (Red Cross 2010).

Comparatively speaking, modern-day Ethiopia is generally viewed as on the right trail but far from out of the woods. Ranked 157 out of 169 countries on the 2010 Human Development Index, Ethiopia remains one of the poorest countries in the world. With the second largest population in Sub-Saharan Africa and an annual population growth of 2.5

percent, even in the best of farming seasons Ethiopia is only able to produce 70 percent of its food requirements, leaving the country to continuously rely on foreign aid (Red Cross 2010). Ethiopia's health services, although improving, are considered to be among the weakest in the world. Ethiopia is also plagued by: high illiteracy rates, poor educational systems, gross violations of human and children's rights, and an environment plagued by erosion, overgrazing, and deforestation (Red Cross 2010).

These conditions create what author Eileen Stillwaggon calls an "environment of risk" (Stillwaggon 2006; 69). From a physiological standpoint, the conditions of poverty--worsening nutrition, chronic parasite infection, and limited access to medical care--make people more susceptible to all infectious diseases, including HIV (Stillwaggon 2006). Based on our knowledge of infectious disease, we should expect the HIV epidemic to develop differently in a region with widespread malnutrition and other host factors known to contribute to disease susceptibility. Furthermore, from an economic and social standpoint, poverty and underdevelopment impose constraints on people's choices (Stillwaggon 2006).

The second aspect of Ethiopian culture that is important to note is religion. In Ethiopia's last census (2007); approximately 62 percent of the population was counted as Christian, 34 percent as Muslim, and the remainder are of traditional faiths (Abbink 2011). Data for this research was collected from the Amhara region which is predominately Christian and so the background information and findings will reflect that. The religious history of Ethiopia is long and rich. The Ethiopian Orthodox Church is the oldest sub-Saharan African church, and Ethiopia is the second oldest Christian state in the world (Ethiopia 2011). The Christian religion was adopted in the mid-fourth century,

around 333 A.D., by the Axumite king, Ezana, and the Axumite kingdom left a legacy that religion should have a central role in society. This legacy has not only been an important element that has shaped Ethiopia's history but continues to influence the lives of modern-day Ethiopians. Even today, people's public identity is becoming more religiously dominated (Abbink 2011). Although there is limited academic literature on the topic, in my time spent in Ethiopia I can attest to a palpable, daily religious presence. Before the sun comes anywhere close to breaking the horizon, the humming of multiple church speakers pierces the morning silence. A symphony of dogs barking at the men and women shuffling down dirt paths on their way to church soon follows. From church service to weekly fasting, the ritual of religion is something that can be easily seen in the lives of Ethiopians.

Abbink looks beyond the ritualistic duties of religion in Ethiopia and delves into its deeper daily social influences emphasizing that religion is very present in the public sphere in Ethiopia and functions as a key framework for community life (Abbink 2011).

Religion is actively and assertively constructed by communal leaders and religious entrepreneurs as the normative, dominant identity of citizens. This connects to its unmistakable social role as a source of community feeling and spiritual consolation, as well as a legitimate alternative focus of collective identification. (Abbink 2011: 274)

Abbink makes two important points here. The first is how the 'dominant identity' of citizens is constructed by communal leaders and religious entrepreneurs. The second is collective identification. As this pertains to HIV prevention and this research, the religious leaders and religious community can play a key role in the social influence process. Abbink hits this point precisely with the above passage. Furthermore, Abbink elaborates that given the strife of Ethiopia's political and economic insecurities, the

appeal to religion as the dominant element of personal and communal identity will grow (Abbink 2011). These are all important points to consider as we delve into the social environment of Ethiopia and its relation to HIV/AIDS related behaviors.

Gender, Networks, and Norms

According to the 2008 UNAIDS report, women bear a disproportionate burden of HIV infections in sub-Saharan Africa, accounting for nearly 60% of HIV infections (Magadi 2011). This research will touch on some of the contributing factors to this disparity and the important difference between women and men in the underlying mechanisms of HIV infection. Examples include the socially constructed gender differences between men and women in roles and responsibilities, access to resources, as well as decision-making power (Magadi 2011). Magadi some of the other factors contributing to increased vulnerability of women to HIV infection include gender-based discrimination and violence, economic dependence, and the inability to negotiate sexual encounters (Magadi 2011).

These inequalities are often fostered and sustained through social and environmental structures (Glanz et. al 2008). As Latkin and Knowlton note, social networks serve as a main source of social-environmental information received by individuals for monitoring their behaviors. Social network members have been found to have powerful influences on individuals' behaviors through not only social comparison and social control processes, but also by fear of social sanctions (Latkin and Knowlton 2005). One mechanism by which networks affect individual behavior is the social norms generated among network members (Trickett 2005). Empirical research in a number of countries indicates that social norms are strongly associated with HIV risk behaviors.

Expected Findings

After living in Ethiopia for over two years I have made many observations exploring the facets of Ethiopian culture and had numerous conversations pertaining to the hardships of everyday life with students, co-workers, and friends. Given that Orthodox Christianity is the dominant religion in the region I collected my data, I expect that most respondents will emphasize the influence of the religious leaders and the religious community when talking about social networks and HIV. Regarding the second research question, I expect poverty to play a strong role in the discussion. Ethiopia is one of the poorest countries in the world. Low economic status can lead to risky behaviors therefore; I expect poverty to play a central role in the motivation (or lack thereof) to violate social norms as they relate to HIV risk behaviors.

Significance of the Study

Research suggests that social-oriented approaches to behavior change can potentially be more effective--affecting a greater number of individuals, and have more sustainable effects on behavior change (Trickett 2005). This study aims to move the social-oriented agenda forward by addressing the social nature of HIV risk behaviors. The study does this in two ways. First it examines which social networks people find to be most influential in their lives as it relates to HIV risk behaviors. As program implementers look to make an impact at the social-environmental level, they will need to know who will be the key groups to use as a vehicle for HIV prevention. Second, it explores the situations that would motivate a person to deviate from norms related to HIV risk behavior—engaging in behavior that puts one at risk for disease and goes against what is culturally accepted. By having ideas of what social and/or environmental

problems are considered influential, interventions will be better able to address the root of the HIV epidemic in Ethiopia instead of the aftershock.

CHAPTER II

REVIEW OF LITERATURE

Introduction

In 1854 John Snow observed that residents in the vicinity of the Broad Street pump in London had a much higher mortality rate from cholera than did residents in other areas. It was clear to Snow that an individual behavior- drinking from the pump- was leading to the deaths of many people in that neighborhood. But he also observed that the population near the Broad Street pump had a higher mortality rate than populations with similar behavior in the vicinity of other pumps. He recognized the risk of individual behavior in the context of proximity to a particular water source. Snow's framing of the problem, as an environmental one, led to his choice of policy intervention. He did not go door to door, recruiting volunteers to be trained as peer educators who would advise their neighbors to cease drinking from the pump. Nor did he recruit businesses to train their managers to talk to the workers about their drinking problem and distribute water purification tablets in the workplace to be used when the workers got home. Snow presented his results to the authorities of the parish, and the next day they dismantled the pump. He altered a significant part of the risk environment, and mortality in the neighborhood dropped quickly, even without enlisting the active cooperation of residents. (Stillwaggon 2006: 161)

While fixing the figurative 'pump' in HIV prevention is more complex than dismantling a water source, Snow's idea of taking an individual behavioral problem and addressing it through altering the environmental risk was revolutionary at the time and continues to be something we struggle to do even today. In this literature review I briefly review our initial responses to the HIV epidemic and, more importantly, I look at what societal elements have taken on the function of the 'pump'.

In the beginning of the epidemic, there were serious tensions regarding the strategic approaches to HIV prevention. Some individuals felt that HIV/AIDS should be tackled

primarily as a public-health problem with an emphasis on shorter term, behavioral interventions such as condom promotion and social marketing, sex education of youth, voluntary counseling and testing (VCT), and treatment of sexually transmitted infections (STIs) (Merson et al. 2008). While others believed that the pandemic could best be controlled with a longer-term development approach that addressed structural determinants that increase vulnerability to HIV infection, such as gender inequality, human rights, poverty and overall community development (Merson et al. 2008). This dichotomy has in the past and continues today to impede our ability to harmonize efforts (Merson et al. 2008). Our inability to address both agendas has left prevention efforts woefully insufficient in the countries most devastated by HIV around the world.

It is no secret to those who work in the field that the foundation for most HIV prevention efforts worldwide has been individual-level behavioral interventions, leaving structural determinants to the wayside (UNAIDS 1999). Given that HIV is sexually transmitted it wasn't completely illogical to first address HIV from a behavioral standpoint. As author Eileen Stillwaggon points out, there were some valid reasons for the emphasis on behavior. The first reason was that in industrialized countries, behavior-modification programs were quite successful in slowing the spread of HIV (Stillwaggon 2006). Second, population-control groups were the first on the scene addressing the emerging crisis—whose focus and methods are behavioral (Stillwaggon 2006). And third, a behavioral emphasis seems to offer a quick solution. In a time of fear and uncertainty policy makers saw distribution of condoms and AIDS education as the quickest barriers they could place between people who were infected with HIV and those who were not (Stillwaggon 2006).

As sociologists we know this approach to be incomplete, not wrong but incomplete. There are two arguments on which I want to touch briefly -- explaining why an individual-level behavioral intervention is inadequate. The first is our assumptions about personal agency. As described by Bandura, one of the key constructs of personal agency is perceived control, which he describes as one's perceived amount of control over behavioral performance, determined by one's perception of the degree to which various environmental factors make it easy versus difficult to carry out the behavior (Glanz et al. 2008). Existing models of individual-level behavioral interventions are often based on various cognitive theories that assume an individual will take steps to avoid risks if they are fully informed and sufficiently motivated- that is, that they can exercise personal agency in the context of HIV-associated risk (Global HIV Prevention 2008). However, as we know, there are social reasons why individuals have imperfect information and individual behavior is often more heavily influenced by broader socioeconomic, cultural, and environmental factors that I will discuss later in this section.

Another shortcoming of the individual-level behavioral intervention is the ability for people to sustain, or not sustain, behavior change over the long term. Strangely, few clinical trials for behavior interventions have followed participants for more than 12 months; but emerging evidence suggests favorable behavior changes seen in individuals during the first year following exposure to a prevention intervention can fade over time (Global HIV Prevention 2008). Positive behavior changes often fail to endure because these changes require a collective change in norms and the creation of a supportive social environment (Epstein 2008). A large part of creating a supportive social environment that helps individuals maintain behavior change is related to social networks and norms.

Shifting Interventions: The Case in Africa

Today Africa is the continent worst affected by AIDS, and because most new infections occur during unprotected heterosexual sex, the primary goal in HIV prevention in Africa has been to persuade people to change their sexual behavior – to delay first sex, decrease casual relationships, and increase condom use (Avert: 2010). For nearly three decades individual-oriented approaches to behavior change have governed the prevention world, both domestically and internationally. In sub-Saharan Africa programs focusing on individual risk behavior are unlikely on their own to achieve the level of success needed to reverse the epidemic. Although individual behavior change programs and initiatives that target groups at highest risk retain an important place in the region's HIV prevention continuum, meaningful reductions in HIV prevention levels will require major population-wide changes in social norms with regard to sexual and relationship norms and gender equity (Global HIV Prevention 2008).

As mentioned previously, existing models of behavioral interventions are often based on the premise that individuals can exercise personal agency in the context of HIV-associated risk and that risk behaviors are conscious decisions, the result of rational choices (Latkin et al. 2005: 120 and Global HIV Prevention 2008). What author Nancy Krieger calls a 'blame-the-victim' approach emphasizes individuals' responsibility to 'choose' so-called 'healthy lifestyles' and to cope better with 'stress', instead of addressing economic and political determinants of health and disease, including structural barriers to people living healthy lives (Krieger 2001: 669). The difference between three decades ago and today however is that we now know that individual-oriented approaches

are inadequate and we are getting closer to understanding how to improve prevention methods.

Despite the growth of this knowledge, Stillwaggon says one of the major barriers remains our narrowed focus. She explains that relatively few researchers stray across the boundaries of their narrow sub-disciplines. For example, most social scientists and policy makers do not read much of the biological scientific literature related to the spread of HIV. Consequently, our understanding of the AIDS pandemic is disproportionately influenced by notions that derive from sometimes unsupported but familiar preconceptions about behavior, a field in which social scientists feel more at home (Stillwaggon 2006: 31). Eileen Stillwaggon's book, *AIDS and the Ecology of Poverty*, is one of few that looks well beyond the behavioral perspective of HIV. Stillwaggon writes that the HIV/AIDS epidemic in sub-Saharan Africa is not an isolated phenomenon. It is a predictable outcome of an environment of poverty, worsening nutrition, chronic parasite infection, and limited access to medical care (Stillwaggon 2006: 69). Stillwaggon argues that such co-factors make people more susceptible to all infectious disease, no matter how they are transmitted; suggesting overtly that the spread of HIV is more complex than sex. While her text focuses heavily on the nutritional and biomedical side of HIV transmission, she talks at length about the 'environment of poverty' and its complexities, including economic and social factors.

Utilizing the term social epidemiology, Mojola (2010) also breaches the 'behavior bubble'. The term can be defined as the "study of the role of social factors in the etiology of disease"; in effect, social epidemiology calls for a marriage of sociological frameworks and epidemiological inquiry (Krieger 2001). The field emerged in the early

20th century and was later applied to the HIV crisis to address underlying social and structural determinants of HIV/AIDS, in what Epidemiologist Jim Koopman calls epidemiology's "transition from a science that identifies risk factors for disease to one that analyzes the systems that generate patterns of disease in populations" (Poundstone et al. 2004: 29). Much like Snow's pump, early studies of HIV/AIDS focused on what author, Krieger refers to as "biomedical individualism" which focused on individual characteristics and behaviors in determining HIV risk (Poundstone et al. 2004: 22). The interventions at this level focus on individual behavior change to prevent HIV transmission. On the contrary, the social epidemiology perspective examines *how* persons become exposed to risk and under what social conditions individual risk is related to disease (Poundstone et al. 2004). This perspective suggests that particular forms of social-level factors situate people in positions of high risk of disease above and beyond their individual choice and behaviors (Mojola 2010). In agreement with Mojola, Latkin and Knowlton affirm that risk behaviors are not randomly distributed, but rather are generated and perpetuated through socially or environmentally structured social interactions.

With growing awareness of the role social-level factors, both structural and environmental, influence HIV risk behaviors, structural-focused interventions have become increasingly advocated. Broadly considered, the phrase structural and environmental factors often refer to those forces outside of the individual that may affect risk behaviors; what Gupta et al. would describe as—social, economic, political, and environmental factors (Latkin and Knowlton 2005 and Gupta et al. 2008). The aim of a structural approach is to address these underlying factors and seek to change the root

causes or structures that affect individual risk and vulnerability to HIV (Gupta et al. 2008). Falling within the structural approach genre, Krieger also discusses this research theme from what she termed an eco-social perspective, which focuses on the guiding questions of “who and what drives current and changing patterns of social inequalities in health” (Krieger 2001: 672). Gupta et al.’s article, “Structural approaches to HIV prevention,” elaborates on Krieger’s guiding questions of ‘who and what’ by explaining the details of a structural approach. Put into plain words, Gupta et al. explains that a structural approach can result in activities or services being delivered to an individual, however the approach is different from an individually-focused behavior change intervention because it addresses *factors* affecting individual behavior, rather than targeting the behavior itself (Gupta et al. 2008: 768). Gupta et al. goes on to give an example about microcredit. A microcredit program may be offered as a direct service to an individual woman, providing them with capital to start their own income-generating activities (IGA), however by doing so they can operate structurally by addressing the broader issue of women’s economic dependency that contributes to their HIV vulnerability (Gupta et al. 2008: 768).

At Risk: Women and the Poor

Mirroring what Stillwaggon suggested earlier when talking about the ‘environment of risk’, Mojola writes that social epidemiology takes as its starting point the idea that the distribution of disease in society is non-random and reflects intersecting systems of inequality such as income and gender (Mojola 2010: 4). Gupta et al. also specifically mentions poverty and gender in their discussion of structural factors that shape or constrain individual behavior. For many people, the simple fact that 90% of the world’s

HIV infections occur in developing countries is evidence enough that social, economic, and political structures drive risk behaviors and shape vulnerability (Gupta et al. 2008: 765).

Gender Inequality

It is widely accepted that women are at risk for HIV because of their gender and social standing (Shisana 1999). Gupta et al. use a detailed diagram I've copied below to show, in this case an example about condom usage, the causal pathway of how gender inequality can put women at a higher risk for HIV. Shisana et al. found that the epidemic they studied in their area was characterized by gender inequalities and that young women were more likely to be HIV infected. For example, if gender inequality manifests violence against women, which in a local community results in women's fear of retribution, it reduces their ability or willingness to negotiate condom use (Gupta et al. 2008). Or alternatively, if gender inequality manifests financial dependence it hinders a woman's independence and again her ability or willingness to negotiate condom use. According to Shisana et al., in many societies women tend to be dependent on men in many ways outside the financial realm as well, making it difficult for them to protect themselves from HIV infection (Shisana 1999).

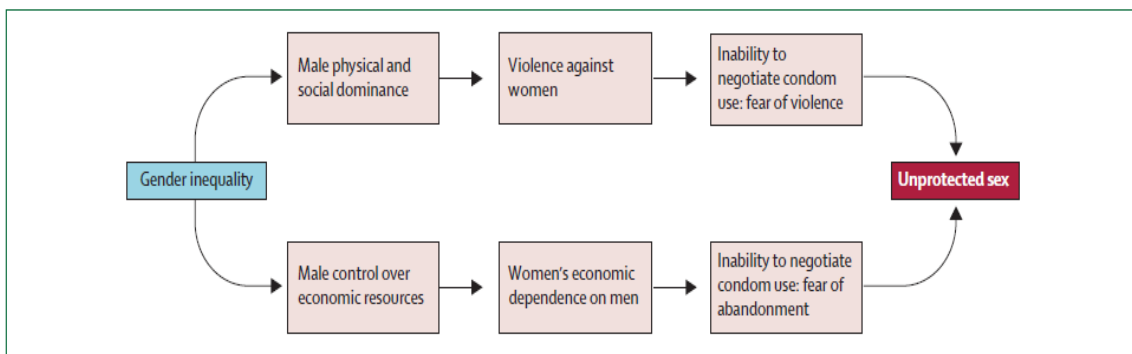


Figure 2: Different causal chains can link the same distal structural factor (gender inequality) and HIV risk behaviour (unprotected sex)

(Gupta et al. 2008: 768)

The Population Council in Addis Ababa, Ethiopia released a report in 2009 that looked at three towns, Addis Ababa, Bahir Dar, and Gondar (Population Council 2004). The article outlines many of the reasons why from a young age women are set up to be dependent and inferior to men. The list is lengthy: lack of education, type of work and earnings available to women, social isolation, migratory patterns to find work, and early marriage customs (Population Council 2004). The list could go on. Among many other things, the report discusses gender norms and self-perceptions at length with Ethiopian girls (Population Council 2004).

Additionally, Erulkar and Ferede talk about how connectedness to family, schools, voluntary groups and peer groups, and the social norms governing these groups were thought to be factors in young people's risk-taking behavior (Erulkar and Ferede 2009). The discussion on social isolation points specifically to domestic workers in this case, as nearly half (48%) of the group from which they collected data were performing domestic work (Erulkar and Ferede 2009). All working females worked extremely long hours for very little pay; domestic workers reported an average of 63.3 hours in the previous week and were paid roughly half of what females in other types of work - on average US \$8.20 per month versus other workers US\$19.00 per month (Erulkar and Ferede 2009). In this particular study 98 percent of domestic workers had migrated to the area, which the authors found to be associated with early sexual initiation and coerced sexual debut (Erulkar and Ferede 2009). Likewise, being socially excluded was associated with both negative outcomes. Additionally, because domestic workers are most often migrants, with few friends or relatives in the vicinity, they usually have no one to turn to for assistance or support; they may not understand or know whom to report

abuse or difficulties, and the very people they depend on for sustenance may be the ones exploiting them (Erulkar and Ferede 2009).

Poverty

Poverty and disease are involved in a vicious downward spiral, each aiding and abetting the other making poverty a chronic consequence and cause of ill health (Klugamn 2002). Diseases of poverty increase poverty, and poverty, in turn, increases the chances of developing the diseases of poverty (Singh and Singh 2008). The World Health Organization calls them ‘diseases of poverty’ because they primarily affect the poor, and they worsen poverty’s toll (Results 2007). Primary diseases of poverty like TB, malaria, and HIV/AIDS and often the ever-present malnutrition take their toll in helpless populations in developing countries (Singh and Singh 2008). Singh and Singh note, for example:

1. Nearly 95% of almost 40 million victims of AIDS live in developing countries, with over 28 million in Africa alone (UNFPA State of World Population 2007a). Its impact is greatest among the poor, who have no economic cushion and the weakest social support of any group; it is the leading cause of death in sub-Saharan Africa and the world’s fourth biggest killer (ibid).
2. 98% of the world’s active TB cases are in developing countries (Results, 2007)
3. 90% of deaths due to malaria occur in Africa, south of the Sahara, mostly among young children (RBM, 2007: RBM means Roll Back Malaria).

(Singh and Singh 2008: 190-191)

Historically, attempts to explain the dual link between poverty and HIV/AIDS have employed either of the following approaches: the behavioral or lifestyle approach and the material or structural conditions approach (Whiteside 2002). Today the arguments have

become more refined as author Alan Whiteside outlines. He first talks about the relationship of poverty and HIV from a biological perspective, which looks at mechanisms that specifically connect malnutrition and parasite infestation that depress immune responses by weakening the effectiveness of cells in the immune system (Whiteside 2002). In other words, poor people are more likely to be food insecure and malnourished. Conditions such as protein-energy malnutrition, iron-deficiency anemia, vitamin-A deficiency, and many others are known to weaken the immune system, which in turn may lead to a greater risk of HIV transmission in any unprotected sexual encounter (Gillespie et. al 2007).

Sawers and Stillwaggon elaborate on Whiteside's argument noting that the poor are also more likely to live in dwellings that do not protect against disease and may reside in communities with inadequate sanitation, and are thus burdened with high rates of infectious and parasitic disease (Sawers and Stillwaggon 2010). Field studies and trials as well as laboratory research have found substantial evidence for a connection between the transmission of HIV and several diseases highly endemic in Africa (Sawers and Stillwaggon 2010). Living in a country where one is surrounded with disease raises the likelihood that any mosquito bite or contact with ground water will bring an infection. To the extent that some of those diseases promote the transmission of HIV, HIV is a disease of poor countries (Sawers and Stillwaggon 2010). Sawers and Stillwaggon stress that for otherwise healthy adults in developed countries, HIV has relatively low rates of transmission however for most of Africa the majority of the population is not "otherwise healthy" (Sawers and Stillwaggon 2010).

Although most proximate causes of being infected with HIV are biological, a person's sexual behavior is next in line as it determines the number and type of sexual encounters he or she will have (Whiteside 2002). Whiteside says the sexual behavior is in turn determined by economic, social and cultural factors, which is the second approach to examining the relationship between poverty and HIV (Whiteside 2002). Singh and Singh say that the social dimension of poverty can hardly be discounted. No social phenomenon is as comprehensive in its assault on human rights as poverty (Singh and Singh 2008).

Whiteside gives an example of this:

For example, a truck driver on any of the major routes in Africa may be away from home for long periods. He might have sex with a commercial sex worker because he is bored, he feels his job is dangerous and he deserves some compensation, he is frequently away from his wife and family, he experiences peer pressure from his fellow drivers to engage in this activity and he has the necessary money. The commercial sex worker, on the other hand, is driven by poverty and the need to feed her family (Whiteside 2002: 317).

The United Nations Development Program's reiterates this point in their concept paper 'Conceptual shifts for sound planning: Towards an integrated approach to HIV/AIDS and poverty'. "The argument states that sexual behavior does not occur in a void but is influenced by external factors in the social, political, economic and technological environment, and that in many instances ... the freedom of choice regarding sexual behavior is circumscribed by external factors such as social norms and values and one's socio-economic position in the society" (UNDP 2002: 4). Lerato Sonia Tladi's research take this one step further when she argues that although cultural, societal and religious norms have an influence on sexual behavior, a person's sexual behavior is mostly influenced by their education levels and financial situation, both usually low in situations of poverty, thus leading them to behave in ways that they would not in the absence of

poverty (Tladi 2006). As applied in Tladi's study, the theory holds that poverty does influence HIV/AIDS infection rates because poverty deprives people of the necessities of life, e.g. food and shelter, thus causing them to respond in ways that, although harmful, will ensure that they obtain these necessities (Tladi 2006).

Furthermore, and probably one of the most overlooked points of HIV prevention, Singh and Singh talk about the effects of life's fluctuations and "society's callousness" that allows the poor to accept their fate and sink further into the tangle of poverty, disease and deprivation (Singh and Singh 2008: 192). Reduced self-esteem, with a feeling of being trapped in a helpless situation, with no relief in sight, adds to the crippling effect of poverty, disease, deprivation of human existence (Singh and Singh 2008). Poverty is not just income deprivation but capability deprivation as well (Sen, 2001).

There is a distinction between lack of income and lack of capacity (Sen, 2001). Poor people acutely feel their powerlessness and insecurity, their vulnerability and lack of dignity. Rather than taking decisions for themselves, they are subject to the decisions of others in nearly all aspects of their lives. Their lack of education or technical skills holds them back. Poor health may mean that employment is erratic and low-paid. Their very poverty excludes them from the means of escaping it. Their attempts even to supply basic needs meet persistent obstacles, economic or social, obdurate or whimsical, legal or customary. Violence is an ever-present threat, especially to women (UNFPA State of the World's Population 2007b: 21).

Millions of people living in developing countries are constrained by the denial of elementary freedom, imprisoned in one way or another by economic poverty, social deprivation, political tyranny, or cultural authoritarianism (Singh and Singh 2008). As we move forward we will look at what role the social environment plays in the constraints and release of those freedoms, and how it all ties back into improving HIV prevention.

Norms and Networks

While gender inequality and poverty are two important structural elements in the spread of HIV it's only looking at part of the story. In order to understand the issue of where gender power relations evolve and are perpetuated, or why those that live in poverty may be driven to risky behaviors we have to take a closer look at the social environment, networks and norms. Consistent with the social ecological perspective Latkin et al. describe, norms can be considered the rules and procedures that facilitate adaptation to social environments. They also note that one appealing aspect of norm change interventions is that often norms are self-maintaining and, hence, the common problem of decay or relapse is avoided (Latkin et al. 2009). Social norms have been found to be associated with numerous health behaviors, including smoking, alcohol consumption, exercise, dietary practices, substance use, and an area more directly associated with HIV risk, sexual behaviors (Latkin et al. 2009).

The influence of norms on sexual behavior has been reviewed extensively in the scientific literature (Bauermeister et al. 2009). Wellings et al. suggest that possibly the most powerful influences on sexual behavior are the social norms that govern its expression (Wellings et al. 2006). Morals, taboos, laws, and religious beliefs used by societies worldwide circumscribe and determine the sexual behavior of their citizens. In some societies, for example, homosexual behavior is celebrated in public parades of pride; in others it carries the death penalty (Wellings et al. 2006). In some countries condoms are available to young people in schools; in others their possession is a criminal offense. To reiterate what Latkin et al. touched on previously, Wellings et al. emphasizes that behavior change interventions will be transient if participants continually return to an

environment that does not intrinsically reward that behavior or actively opposes it (Wellings et al. 2006).

Elaborating on Wellings et al.'s observation, small deviations from norms may produce strong negative reactions from social network members, which means initiatives must persuade social groups to examine and alter sometimes long-established values, assumptions, and behavioral patterns (Global HIV Prevention 2008). Furthermore, in developing interventions, a central question should be how to make adoption of HIV risk-reduction practices more socially acceptable, or how to potentially link them to behaviors that are socially rewarded. Latkin et al. writes that the goals of behavioral intervention are often to promote behaviors that violate prevailing social norms and how interventions should be developed to address possible social reactions to norm violation (Latkin and Knowlton 2005). A critical issue in altering health behaviors is how individual-level behavior change can be leveraged into group- or community-level change.

One conceptual approach to community-level change is through social diffusion, wherein prominent individuals within a group, known as early adopters, first embrace a new behavior and move closer to creating new norms (Rogers 2003). It has been hypothesized that successful social diffusion early adopters lead others to change their behavior. In this manner, the new behavior is diffused through the community (Latkin et al. 2009). Rogers discusses a public health service in Peru that attempts to introduce innovations to villagers to improve their health. For example, they might encourage people to install latrines, burn garbage daily, control house flies, or in this case boil drinking water. A two-year water-boiling campaign was conducted in a peasant village of about two hundred families in the coastal region of Peru. A local health worker, Nelida,

was given the task of persuading housewives to add boiling water to their daily behavior. Rogers' explains that even with the aid of a medical doctor, she was only able to convince eleven housewives to boil their water. The diffusion campaign was viewed as a failure. To understand why the campaign failed Rogers listed three examples of women the worker encountered and their response (Rogers 1995).

Mrs. A: Custom-Oriented Adopter:

Mrs. A is about forty and suffers from a sinus infection. The Los Molinas villagers call her the "sickly one." Each morning, Mrs. A boils a pot full of water, which she uses throughout the day. She has no understanding of germ theory, as explained by Nelida. Her motivation for boiling water is a complex local custom of "hot" and "cold" distinctions. The basic principle of this belief system is that all foods, liquids, medicines, and other objects are inherently hot or cold, quite apart from their actual temperature. In essence, the hot-cold distinction serves as a series of avoidances and approaches in such behavior as pregnancy, child rearing, and the health-illness system. Boiled water and illness are closely linked in the norms of Los Molinas. By custom, only the ill use cooked, or "hot" water. Villagers learn from early childhood to dislike boiled water. Mrs. A drinks boiled water in obedience to local norms, because she perceives herself as ill. She adopted the innovation, but for the wrong reason.

Mrs. B: Persuaded Adopter:

The B family came to Los Molinas a generation ago, but they are still strongly oriented toward their birthplace in the high Andes. Mrs. B worries about lowland diseases that she feels infest the village. It is partly because of this anxiety that the public health worker, Nelida, was able to convince Mrs. B to boil water. Mrs. B not only boils water but has also installed a latrine and sent her youngest child to the health center for a checkup. Mrs. B is marked as an outsider in the community by her highland hairdo and stumbling Spanish. She will never achieve more than marginal social acceptance in the village. Because the community is not an important reference group to her, Mrs. B can deviate from the village norms on health innovations. With nothing to lose socially, Mrs. B gains in personal security by heeding Nelida's advice. Mrs. B's practice of boiling water has no effect in improving or damaging her marginal status.

Mrs. C: Rejecter:

This housewife represents the majority of Los Molinas families who were not persuaded by the efforts of the change agent during the two-year water-boiling campaign. In spite of Nelida's repeated explanations, Mrs. C does not understand germ theory. How, she argues, can microbes survive in water that would drown people? Are they fish? If germs are so small that they cannot be seen or felt, how can they hurt a grown person? There are enough real threats in the world to worry

about - poverty and hunger - without bothering about tiny animals that one cannot see, hear, touch, or smell. Mrs. C's allegiance to traditional village norms is at odds with the boiling of water. A firm believer in the hot-cold superstition, she feels that only the sick should drink boiled water.

(Rogers 1995: 1-5)

Rogers goes on to explain in his article that the campaign failed because of cultural beliefs, which are a key component to existing social norms (Rogers 1995). Had the health worker understood the local knowledge systems she could have taken a different approach when introducing the topic. In many ways implementing HIV interventions around the world has faced the same challenges as the health worker in this story. As Latkin notes, the meanings given to environmental information is critical for adaptation, and potential modification, of behaviors. Therefore, for behavior change to be maintained it is critical to understand how a new behavior may be made socially acceptable and meaningful, i.e. normative (Latkin and Knowlton 2005).

Social norms created by opinion leaders will ideally have a strong effect on behavior. Diffusion of Innovation Theory asserts that changing behavior will more likely happen if the new behavior is compatible with accepted social norms of a specific social network, is simple to do, and has observable outcomes (Kalichman 1998). One's social network can be a source of emotional and instrumental support and a reference that establishes social norms (UNAIDS 1999). In its most simplistic form social networks can be defined as "our connections with other people" (Donath and Boyd 2004). For this study, I will use the following definition of a social network: "...consist[ing] of interpersonal ties to a group of people who can be relied upon to provide emotional sustenance, assistance, and resources in times of need, who provide feedback, and who share standards and values" (Asher 1984: 349).

Studying social networks is not a new phenomenon. In the early 1930's a US social scientist named Dr. Jacob Levi Moreno developed a diagram that showed points and lines to represent relations among persons called a sociogram (Roos 2009). This tool was the first formal measure of social networks and was used to identify social leaders, outsiders, and what Moreno referred to as the "sociometric star," the person to whom all others are connected (Roos 2009). In the mid-1950's Professor J. A. Barnes officially coined the term "social network," influenced by his work in a Norwegian fishing village where he studied social ties, and eventually concluded that "the whole of social life could be seen as 'a set of points, some of which are joined by lines to form a 'total network' of relations" (Roos 2009).

Although they may have been a starting point, the importance of social networks moves far beyond a set of points and lines. Social networks consist of complex relationships that manifest themselves in varied forms of social interaction. As we know, social interactions play an essential role in forming individuals' perceptions and influencing decision-making. Akerlof, author of "Social Distance and Social Decisions" sums up why this is: social decisions have social consequences. Conventional decisions such as which fruit to buy at the food store have no effect on friends and relatives. However, they will be affected by my educational aspirations, my attitudes and practices toward racial discrimination, my involvement with drugs, or whether I get married or divorced (Akerlof 1997). Akerlof elaborates:

All of these activities will affect who I am in an important way, and thus how I associate with my friends and relatives, as well as whom those friends may be. As a consequence, the impact of my choices on my interaction with other members of my social network may be the primary determinant of my decision, with the ordinary determinants of choice (the direct additions and subtractions from utility due to the choice) of only secondary importance. A proper theory of social

decision then must first spell out their consequence for social exchange. (Akerlof 1997: 1006)

In summary, when making decisions that will fundamentally change who an individual is and more importantly how they will relate to the world around them, an individual would be more likely to hold the opinions and judgments of those around them in higher regard.

A recent study examined how social norms of HIV risk behaviors are structured within social networks and how these norms may be linked to subsequent risk behavior (Latkin et al. 2009). The article says that a critical issue in altering health behaviors is how individual-level behavior change can be leveraged into group- or community-level change (Latkin et al. 2009). Network analysis can provide insights into how behavior change among a few network members may diffuse to others and become the norm within the network. In mathematical modeling of networks, Kincaid found that network structure, especially the bounds of networks, had a strong influence on the network members' adoption of new behaviors (Latkin et al. 2009). The network structures help explain why the behaviors of a small minority within a network could lead to a behavior change within a sub-network with strong links to the minority (Latkin et al. 2009). In this study, Latkin and Knowlton examined how HIV risk behavior norms are structured within social networks. More specifically, they examined the relationship between perceived norms, risk behavior, and the actual behavioral norms of drug network members in a cross-sectional study of injection drug users in the United States and Thailand (Latkin et al. 2009). The results documented that norms of several HIV risk behaviors of sharing injection equipment are clustered within social networks. There are several important implications from this finding; one is that because norms are clustered by networks it may be feasible to identify groups of individuals who endorse and promote

norms of high-risk injection behaviors through network sampling. And two, the results show that social networks may be a useful vehicle for sustained behavior change which has been the end goal of HIV prevention from the start (Latkin et al. 2009).

In sum, we know individual behaviors and the spread of HIV are not explained solely by biology or psychology. We know that social factors matter. It's clear that gender inequality and poverty play a role in the distribution of HIV and we have a better understanding of how our interventions need to shift in order to address those issues. There is also strong evidence showing how the social environment, such as networks and norms, relates to the social influence process. This study documents how networks, norms, gender, and poverty are associated with individual behaviors and the risk of infection.

Rationale

While there is a great deal of literature discussing HIV risk behavior modification, a small percentage of researchers are specifically addressing the underlying issues that influence or even promote individual risk behaviors. Consequently, HIV interventions are not concentrating on these issues on the ground. My study fills this gap in the literature by moving the social agenda of HIV prevention forward in two ways. First, by addressing the importance of social networks and norms as they relate to HIV. The social influence process is something that has entered the health arena; however, there have been few that have made the leap to HIV. By looking at social networks we can look at who the most practical groups are in terms of influence, and by looking at norms we can better address what approach will be most effective without asking people to violate local custom. Second, my study uniquely focuses on what circumstances would push an individual to

violate norms established by their community regarding HIV risk behavior. This is key when addressing root issues within the decision-making process. With this knowledge researchers can look at how to better address way to prevent those situations from happening.

Another gap in the literature is specific to Ethiopia. The academic literature on social issues surrounding HIV in Ethiopia is extremely limited. Despite the uniqueness and diversity of the country, weak structural systems and harsh conditions make for spotty and incomplete research. My study, although only sampling a small pocket in Gondar, offers solid data that provides a foundation for further research in Ethiopia. Furthermore, the research questions are such that they could be applied over vast cultural and regional differences in Ethiopia and still provide valuable information in the fight against the HIV epidemic.

CHAPTER III

METHODOLOGY

Setting Background

Ethiopia is located in Eastern Africa, bordered by Djibouti, Eritrea, Kenya, Somalia, South Sudan, and Sudan. Slightly less than twice the size of Texas, Ethiopia's population in 2011 was just shy of 91 million people (CIA 2011). As mentioned in the introduction, accounting for almost 85% of total employment, Ethiopia's economy is based primarily on agriculture (CIA 2011). According to the Ethiopian Federal HIV/AIDS Prevention and Control Office (FHAPCO), the national HIV prevalence rate in 2009 ranged from 1.4-2.8%, directly affecting over 1 million people (FHAPCO 2010). The country is divided into 9 ethnically-based administrative regions and two chartered cities (Addis Ababa and Dira Dawa). Research for this study was collected in the town of Gondar which is located in the Amhara region, which is located in the Northern highland territory (CIA 2011).

Gondar is just one chapter in Ethiopia's long history, but it is an important one. The city sits at 7,500 feet, surrounded by mountains and speckled with magnificent castles and churches from its rich past. In 2005 the Central Statistical Agency estimated that the total population of Gondar to be 194,773 of whom 97,625 are men and 97,148 are women, which is representative to the rest of the country (CSA 2011). 83.31% adhere to Ethiopian Orthodox Christianity, and 15.83% of the population said they were Muslim

(CSA 2011). There is also a sizable number of Ethiopian Jews living in Gondar, although many have fled to Israel. Historically, Gondar was the fourth capital of Ethiopia beginning in 1635 by Emperor Fasilados. Fasilados was given the throne after violent persecution was inflicted against thousands of Orthodox Christians, which resulted in a revolt against his predecessor. Fasilados was able to repair the damage done and successfully reunited the church and state, bringing peace back to the kingdom and inspired religion as the central focus of society. Gondar lasted two centuries as a capital, cultural and political center. Today Gondar serves as a popular tourist attraction because of its historical interest and architectural destinations such as the castle of Fasilidos and various churches and monasteries (Reed 2011).

Data Source

The group I worked with for this research is the Fre-Hiwot PLWHA (People Living with HIV/AIDS) Association. In my time in Gondar I had the privilege of working very closely with this group and the chairman of the association, Berihun. Our relationship began when I contacted him to be a guest speaker at a three-day HIV prevention program to talk about the importance of social support in HIV prevention and care. Berihun has been openly HIV positive for nearly nine years and was happy to share his experience and thoughts with the 40 orphans and vulnerable children (OVCs) at the training. The OVCs cheered and applauded at the end of his inspirational session. Following my first contact with Berihun, I frequently found myself invited for tea and conversation at the association office and soon was learning more and more about the association itself--how they supported each other and what services were offered to members. I was impressed with the organization and social support system they had

constructed for one another and equally impressed to discover that most members were openly HIV positive in their community for over five years. With discrimination against HIV positive people still an issue in Ethiopia, this association allowed PLWHA to bond and find comfort in their openness with each other.

It is important to note why I chose to work specifically with an openly-HIV positive population, meaning open about their HIV positive status to others. The first reason was to avoid having the participants regurgitate answers that fit into common stereotypes or to limit their answers to only those that are socially acceptable. For example, it's commonly believed in many areas of Africa that HIV is a punishment from God and that only immoral people become infected. These kinds of responses often limit open discussion and don't present fruitful data concerning the authentic reasons why Ethiopians contract HIV. I feel the frankness and openness of this population allowed respondents to engage in meaningful discussions and collect data reflecting the reality of the HIV epidemic in Gondar. Aside from data collection, the other reason I focused on this population was because it allowed the PLWHA to transform the trials of becoming HIV positive into solutions for improving HIV prevention for their community.

Data Collection

Because of the language barrier the recruitment process was primarily facilitated by Berihun and my interpreter, Kassahun. We discussed together what methods were available for recruiting participants and decided that an announcement at the next Frehiwot Association meeting would be the best venue. After the announcement those who were interested in participating contacted Berihun directly. Those who chose to participate in the interviews were given an allotted day and time slot and those interested

in the focus groups were placed in one of three groups based on their availability. The interviews were held in a small office nearby to the Frehiwot Association grounds. There was limited electricity so the door and window were left open for light; however, the office sits in a gated compound far from the road to ensure privacy. The focus groups were held in a classroom on the Frehiwot grounds and had a similar setup to the interview office to again maintain privacy for respondents.

Every interview and focus group was verbally read a translated version of the informed consent and then given the opportunity to sign in agreement (or stamp their finger print if not able to write). The interviews and focus groups were both recorded on a digital recorder and later my interpreter translated data in English. Again because of the high frequency of power outages, Kassahun used headphones to listen to the interviews and focus groups and wrote out the translated data by hand. That hand written data was then given to me and kept safely locked in my house until my departure. Following translation the Amharic recordings were deleted.

To fulfill the objectives of the study, qualitative data was gathered from members of the Fre-Hiwot PLWHA. The ten personal interviews included demographic questions, a narrative portion, and direct questioning. From the demographic questions I was able to gather some of the following information found in Table 1.

Table 1: Interview Demographics

Respondent	Age (yrs)	Gender	Education (grade completed)	Employment	Monthly Income (1 USD=about 13 Birr)
1	34	F	12	Not working	250 Birr (From Aid)
2	37	F	8	Not working	None
3	40	M	None	Sells small commodities	150 Birr

4	25	F	N/A	N/A	N/A
5	35	M	6	Sells lottery tickets	150 Birr
6	36	F	12	Small business	100 Birr
7	30	F	None	Not working	180 Birr (From Aid)
8	30	F	10	Not working	None
9	30	F	8	Small business	N/A
10	24	F	8	Not working	320 Birr (Husband income)

All respondents at the time of the interviews lived in the town of Gondar in the Amhara region and were between 24 and 40 years old. Eight females and two males participated, and of the ten interviewees there were three people that had no modern education or were illiterate- which means they had no formal schooling, one person that reached grade 6, three people finished grade 8, one completed grade 10 and two completed grade 12. In my experience and based on this information, I did feel that this group was a good cross-section of the PLWHA Association. In addition I conducted three focus groups ranging from six to eleven people in each group. Though I did not formally gather demographic data on focus group participants, the majority of the participants were female and fell in the same age range as the interviewees.

Following the basic demographic questions, which can be found in the appendix, respondents were asked to provide a life history. More specifically, they were asked to tell me about the time period from as far back in childhood as they could remember up until the point they found out they were HIV positive. The guidelines were very vague; respondents could talk about anything they remembered including people they interacted with or places they lived, jobs, teachers, etc. I collected data using specific components of narrative inquiry, which in its most simplistic form is the process of collecting

information for the purpose of research through storytelling. As Czarniawska notes, “Telling stories is far from unusual in everyday conversation and it is apparently no more unusual for interviewees to respond to questions with narrative if they are given some room to speak” (Czarniawska 2004: 650). This method was very fitting in Ethiopian culture and I think was a very non-threatening way to gain insight into the culture and lives of my respondents, especially when talking about a sensitive issue such as HIV/AIDS.

This method of data collection attempts to understand how people think through events, as well as what and who they value through an examination of how people talk about events and whose perspectives they draw on to make sense of such events (Riley and Hawe 2004). A researcher can break a story down both structurally and/or linguistically, depending on what information s/he is looking for. A structural analysis would be interested in, for example, the sequential order of a story, as it relates to human experience (Franzosi 1998). Whereas a linguistic approach might focus on whether the language in the narrative was descriptive or if an action was habitual or infrequent. The methods are not mutually exclusive and are often best used together. For the purposes of my research I primarily focused on, what is called “the supporting cast.” By focusing on the supporting cast, or the “actors” or “characters” of the story, I was able to look at who was mentioned in the telling of events and who was absent (Riley and Hawe 2004). As a supporting cast member, each person has a purpose or reason for existing in the story, but as Riley and Hawe point out, the most important point about who is mentioned is that it reveals the people or organizations that are most significant to the person telling the story.

Although there are many benefits to this method there are also limitations that are important to note. First, the local and cultural context is a key tool in understanding the gaps or the parts of the story I will not hear. Although, I lived in Ethiopia for over two years, being a foreigner means that there will always be a distance in perspective and interpretation from that of my respondents. Second, there will still be some social desirability factors. It is difficult for people to admit when they were wrong. It is likely that in potentially embarrassing or challenging situations or relationships people will leave some information out and/or try to make themselves look like the ‘good-guy’. Because of this, I decided to add six questions at the end of the narrative that directly address the information I will interpret from the life stories.

To elicit the most useful and diverse information within the association, conversations with three different focus groups were conducted over the course of two days. For most of our participants the concept of a focus group was beyond foreign. The interpreter used a set of guiding questions to help participants engage in and continue discussion. The hope was that conversation among the participants would revolve around the second research question, why someone would deviate from the norms of their network—thereby exposing themselves to HIV/AIDS, but our participants elaborated far beyond my expectations.

Methods of Data Analysis and Coding

Each section of the data was coded using different methods. The first section, the narratives, was coded first by word repetition. The first goal of the narratives was to look at what social networks people were part of, so the first reading strictly identified social networks that were mentioned. For example the sentence, “It was my mother who was to

take care and look after me” would be labeled under *family* because she was talking about her mother and so on. After all of the social networks were listed, I then went back and counted how many times each of those networks was mentioned in each individual narrative. For example, narrative 1 might look something like this: family-10, friends-3, school teachers-2. From this I would determine that the family social network was discussed the most, meaning the family is an influential social network in that respondent’s life. After going through this process with each narrative, I then took all of the results from each of the narratives and determined which social network had the greatest influence. For example, if narrative 1, 2, 4, 6, 7, and 10 all mentioned family the most, based on a ranking system, I determined that out of the ten narratives family was the most influential social network. I also directly asked respondents what social network they felt was most influential in their lives generally and with respect to HIV related behaviors specifically.

In the focus groups the interpreter would introduce a question to the group and then allow them to discuss it. When the conversation came to a halt he would introduce the next question. Because of this I first read all the responses and pulled out major themes for each of the questions that were addressed by highlighting key words, and then within each question grouped the information into categories relevant to the specific discussion. For example, if the question asked why a person might deviate from the social norms ascribed to HIV risk related behavior, I first inventoried all of the responses categorizing by major theme (ex. economic status, gender) for each focus group. Next I combined the data from the three groups based on those themes, and then further evaluated the content and group responses together. For example, within the responses

focused on economic status there might also be a group that specifically made reference to basic needs. That data would be pulled out in order to further analyze what is most representative of the groups.

Implications

I feel strongly that it was the methods used in collecting the data that allowed for such rich and abundant discussion and answers. The narratives not only allowed me to quietly assess what social networks existed and which are influential, but also provided a rare look into the contextual background of the respondents' daily lives. The direct questions after the narratives also provided a unique opportunity to compare how respondents would answer questions first when they didn't know what I was looking for and then how they answered when asked directly. Additionally, the focus groups cultivated meaningful discussion and participants did an exceptional job at both challenging and complementing each other's arguments. All methods exceeded my expectations by bridging the gap between an academic world of questions and the practical world of poor, rural Ethiopian's answers.

I would like to note here that for the purpose of better comprehension in the following Findings section I have altered some of the grammar and word confusion in the examples. The content and context have been maintained to the best of my ability.

CHAPTER IV

FINDINGS

Introduction

The findings are broken into three sections. The first section addresses the narrative findings. Participants were asked to lead us through their life story from childhood up until the point they learned they were HIV positive. I started with the narrative for two reasons; first, to allow respondents an opportunity to provide some contextual background to their answers. There is a lot of information that can be lost not only in linguistic translation, but in cultural translation. The narratives allow respondents to fill in some of the missing cultural context that I feel would otherwise be missed for the reader. Second, the narratives allowed one to indirectly observe which social networks had a strong presence in the respondent's lives by noting the frequency with which they were mentioned.

The second section will focus on the findings from direct questioning. This section will look at the most relevant information to my two research questions; what social networks people are part of and which of those networks influence HIV related risk behavior. In addition, this section will discuss any consistencies or lack thereof between the narrative findings and direct questions.

The third section will examine the data from the three focus groups. The focus groups looked more closely at the last research question pertaining to why- or in what

situations- a person would deviate from the norms established by their community related to HIV risk behavior. Particular attention is paid to economic status and gender.

Narrative Findings

There were eight social networks identified in the narratives. Listed from most frequently discussed to least: family, friends, government/military (in context these two should be grouped together), work related, health workers/center, neighbors, PLWHA Associations, and traditional doctors. The network that was most predominantly discussed was the family. Because of the overwhelming amount of discussion about the family compared to any other network my narrative findings will be focused primarily on family.

Tesfaye's story is a good introduction and representation of the family in Ethiopian culture. As in many other African countries the focus of Ethiopia's social system remains the extended family. In chapter 3 of the Ethiopian Constitution it states that "The Family is the natural and fundamental unit of society..." (Rights 2011). It isn't unusual to have three generations living under one roof. Typically a family is 6-12 people and consists of the father, mother, children, servants, as well as extended family members (Nguyen et al. 1998). The family is responsible for teaching the children cultural and religious values and the skills necessary to become self-supporting adults (Nguyen et al. 1998). Once a child has become a self-supporting adult there is tremendous pressure to support those extended family members that are having difficulty even if they no longer live in the same town or country. Family needs are put before all other obligations.

Tesfaye is a 40 year old man that grew up in the town of Gondar. He buys and sells some small commodities for profit making, about 11.50USD a month. He has no

modern education but participated in Ethiopia's literacy campaign years ago. As he walked into the office the afternoon rains were just starting to rumble in the distance. As he sat down to start the interview, Tesfaye's demeanor was respectful yet strong. He kept his hands folded on his lap the entire time and spoke calmly and clearly.

Tesfaye's Story:

"I don't know exactly when I was born but I think it was in 1955 E.C. (Ethiopian Calendar) and the place was Lay Armachiho Woreda in Tikil Dengay. During my childhood I helped my parents look after the animals, we had a sheep and cowherd. When I grew up I used to farm for them. Then I used to farm for other families for hire. Before farming I even looked after domestic animals for others for money. My parents were not very wealthy. I had to support them during that time. These people were giving me different kinds and amounts of cereals from the product which was directly forwarded to my family or parents. This happened up to 18 years of age.

After I was fed up of farming for others I returned to my parents. My parents were living with one of our grandmothers who had enough farm land. I started farming on this farm land for house consumption. After I stayed two years of serving my family, I married a wife according to our culture. The marriage ceremony was fantastic. My wife and I stayed with our family for one year but after that we started living in our own house. A farmland was shared to people according to the number of family members. While I used to live with my parents and grandmother, my wife and I were included in the family. The head for the family was my grandmother. After I started living by my own with my wife, I asked my grandmother to use at least our own share from the farmland which was supposed to be for the whole family.

In the meantime, my wife's father wanted his daughter and I to live in a place where he was living. We had no any alternative and we move there. My grandmother couldn't give me my share from the farmland through negotiation. I appealed to the Woreda court about the case but I was not successful. I think she had bribed the judges and they decided that the land should belong to my grandmother. We couldn't live long with my wife and we separated.

I went to another place and married my second wife. We lived together for 6 years. After this I joined the army and went to Ogaden. I spent three years around that area. Then, we moved to Ambo. In 1983 E.C. the military force I joined was displaced by the EPRDF government. It took me 6 days to travel from Ambo to Addis Ababa on foot. I have started smoking while I was in the military. Finally I went back home, slept only for one day with my second wife. The situation was she did not look good. She had sold all the property we had. I left her and moved to Janifenkera, to my father's relatives. Being persuaded by my aunt, I married my third wife there.

During I spent the night with my second wife, we had sex relations and my first daughter was conceived. I was able to have two more children from my

third wife. One of them died and the other still lives. At that time, I was not feeling well. Sick now and then, I went to the clinics for treatment repeatedly and also used Holy-water but no solution was found. I was getting weaker and weaker. Finally, I came to Gondar to be examined. After some time I was treated against TB but at the end it was proved that I was (HIV) positive. I really don't know from whom I was infected.”

Tesfaye's story is a great example of a typical rural Ethiopian family. His experience growing up and supporting his family in a time of need is an expectation that is well understood in Ethiopian culture. The social bond between families is a unique agreement of mutual support. In times of crisis, the family will take full responsibility for the family member's problems, whether it is financial, health or social (Molakign 1996). From my own observations, the balance is quite remarkable, not many people ever excel enough financially to get themselves out of poverty, although not many people ever go unsupported in times of need. Even in business, maintaining a social tie can and often is more important than making a profit for the day. It's also important to note here that support isn't always monetary. For example, as Tesfaye mentioned about his payment being different kinds and amounts of cereals that were directly forwarded to his family or parents.

Tesfaye's story is representative of the male perspective, however as we move forward to our next example it's important to note some of the important gender differences in Ethiopian culture. The division of labor for families in the rural areas tends to be more distinctive than urban areas. The women start their day at dawn, get the water, make the coffee (which is a bit more of a process than turning on a coffee maker), prepare the grains for the day's meals, do the washing for the family, and care for the children (Ethiopia 2011). The men till the soil, tend to the livestock, harvest the grain crops, and if necessary, are expected to defend the homestead in times of danger

(Ethiopia 2011). If both parents work outside the home it's not uncommon for parents to depend on servants and extended family members to look after the children (Nguyen et al. 1998). As children, boys are trained by their fathers from a young age to prepare land, plant, sow and care for livestock. Girls, on the other hand, are expected to help their mothers with household chores- washing, sweeping, fetching water, and cooking (Nguyen et al. 1998). As children grow older the gender role division becomes more dynamic. As we will see in Tigist's story, most girls will stay under her family's control until they get married, at which time her husband will likely be in control of the finances and any important household decisions.

Tigist is a 34 year old woman that grew up in the town of Gondar. She completed the 12th grade and lives on roughly 30USD a month, with some additional but unreliable funds from selling bread on the street. Before the interview she sat meekly in the chair next to the recorder, her eyes averted until the interpreter greeted her. There was no electricity that day so the window was open, allowing a single beam of light to fall on her tattered dress. Like a good deal of Ethiopian women, her frame was tiny and frail and she spoke softly.

Tigist's Story:

"I was born in a place called Kemkem-Libo in 1958 Ethiopian Calendar (E.C.). I came to Gondar very early and had grown up here in Gondar. As my mother had come from a village, she had an economical problem. She came to Gondar not only with me but also with my older and younger brothers. Her first reason to bring us here was my older brother's sickness. She wanted to get him examined and treated in the hospital. By the way, he has died. He was shot by the Derg officials. My younger brother also was a soldier and he has died too.

When I was 13 I was engaged to a husband very early. We did not start living together. We had an agreement to stay separately for some years. But in between, that time was not good for the youth and he simply joined the army. Everyone was being expected and sometimes killed as an outlaw. He didn't turn up again; he died there during a fight.

After some time I got a job in the Kebele Administration. Some friends used to ask me to be their girlfriend while others said I should marry someone. Then I married my first husband, who died later, during my early stage in 1973 E.C. He died after we have two children in 1983. We lived together for ten years. After that, I had decided not to marry anybody but to look after my two children only. I couldn't continue with my decision. I said to myself that I had to marry again and live with him and with my children. Then I married my second husband.

As I said earlier, I used to work in the Kebele Administration first as a 'messenger' and then as a secretary. I had a responsibility to help and support my children and mother. My first husband and I went to Estie Wereda because of his job assignment there. We didn't live long and we came back to Gondar. In 1977 E.C. he was also assigned to go to Metema, a place chosen to be the draught affected farmer's resettling area. He came back to me being sick and finally this was the cause for his death.

...As I said earlier, I was married with my second husband and lived with him for nine years (from 1989 to 1997 E.C.). He had an affair with another woman was the news I heard from my friends. I had checked myself and it was true. Then I divorced him in 1997 E.C. He married that woman and they lived together. After some time, that woman became very sick and then died of her illness. People told me that the cause for her death was HIV. This time I asked his mother if she had known cause for son's wife death. She also told me that the cause was HIV. Then I immediately decided to give my blood test and to know myself. After the blood test, I was told that I was HIV positive in 1998 E.C."

Tigist's story highlights some of the hardships of growing up as an Ethiopian girl and hones in on the struggles of gender relations in a marriage. Ethiopia has one of the most severe crises of child marriage in the world (Population Council 2004:1). In 2005 over 30 percent were married by age 15, and more than half of girls were married by age 18 (Ethiopia 2006: 82). The Amhara region has had the lowest median age at first marriage for the last 25 years, ranging from 13.6 to 15.2 (Ethiopia 2006: 83). At just 13 years old Tigist was engaged to be married. Today the legal age of marriage in Ethiopia for men and women is 18 (Molakign 1996). Prior to a law passed in the year 2000, the acceptable age of marriage for rural girls was 12-14 years old (Molakign 1996). While the urban areas widely acknowledge the law, reinforcement of such laws in the rural areas is almost impossible. Marriages are still typically arranged by the bride and groom's

families and the age at which those arrangements happen remains blurry in some areas. After a woman has married, it's likely she will be considered subordinate to her husband. In some cases, as we saw with Tigist, the powerlessness women face can result in a deadly outcome.

Tigist and Tesfayes' stories were highlighted here because they are particularly representative of the situations and trials that Ethiopians face. However, the data gathered from the remaining narratives are also important to note. One theme mentioned through multiple respondents was discussion on the absence of one or both parents due to illness and the "economically weak" situation parents were in that sometimes influenced precarious work and/or living arrangements for them as children or even later in life. As was mentioned in the literature review and will be addressed in more detail later in this chapter, poverty can and does contribute greatly to creating an environment of risk. Children are particularly vulnerable and helpless to the lack of financial support from family and often in Ethiopia means the continuation of the generational poverty cycle. Similarly, if one or both parents pass away due to disease or illness, the child often becomes the burden of other family members that are most likely struggling themselves. Another theme that was addressed was education. Several female respondents pointed out that after marriage or having children, their education was discontinued and they "simply became a housewife" which in my observations has a very specific role mostly confined to the house or market. This leads to another theme among the female respondents, the absence of their spouse. For a variety of reasons- army, work, etc. - men tended to be out of the house for long periods of time. The interesting side note to this is that chronologically looking at the narratives, women primarily became infected with HIV

after their spouse had been away from the house for a length of time and then came back. In addition, several women noted that their spouse openly lied to them about being HIV positive even though they had been tested and knew their status. Most of these themes go hand-in-hand with the discussion about the inferiority of women in Ethiopia and the gender inequality discussed in more detail later this chapter.

Narrative Findings Summary

In terms of the research questions, overall the narratives yielded two pieces of noteworthy data. The first, as noted earlier, is the overwhelmingly large amount of discussion of the family. Even taking into account that the family would be mentioned more during childhood, the family was talked about far more than any other social network. The second was the complete lack of discussion regarding the religious leaders or the religious community. My expectation was that the family would play a central role in the lives of my respondents; however, I also expected some discussion of the religious community. As mentioned earlier, part of the motivation for collecting the narratives was to have an indirect view of what social networks are important based on the frequency and emphasis within the narratives. While the sample is too small to generalize to a larger population, it is nonetheless worth noting that when respondents were not asked directly, there was no mention of the religious community.

Interview Question Findings

Following the narratives, respondents were asked a series of direct questions. There were two questions in particular that yielded data relevant to the research questions. Those two questions are listed below followed by the findings and two tables listing examples pulled from the data.

- 1) Which group of people would you say have been most influential in your life?
- 2) In terms of behavioral decisions (as they relate to HIV risk) what group would you say has been most influential in your choices?

In Table 2 and Table 3 you will find examples from respondents with percentages indicating the percent of respondents that felt that group was most influential.

After the strong presence of the family in the narratives I expected that to be reflected in the first question. However, as you will find in Table 2, only 1 out of 10 respondents mentioned anything about the family, which was the same percentage as health workers, friends, government and the media. This is again particularly striking given that those groups had little or no mention in any of the narratives. Furthermore, “no group” respondents- people that felt there was not any group that was influential in their lives- came in above family at 2 out of 10 respondents. However, one of the “no group” respondents did mention that her time with the militia (army) group “might have been (influential)” but only “a bit influential” as she put it. The other “no group” respondent was also in the army and said it was not groups of people that influenced him, but experience. For example, he elaborated on a story about how seeing their neighbor shot by the Derg (Ethiopian military responsible for civil war) and their brother being killed in the war was what motivated him.

Meanwhile 4 out of 10 of respondents, noted that the religious community has been the most influential in their lives, which was again a group that was not mentioned in the narratives. It’s important to make note here that responses were varied in how they addressed the religious community. Some, for example talked about the leaders of the

religious community and the education they received, - “The most influential part in my life was my religious community, I mean the education I learned from this community.” Others focused more on the followers-“The group of people that I would say have been most influential in my life are the religious leaders and the religious community that I am part of.” For the purposes of this study, both responses were grouped together.

Table 2: Most influential in life

Percent	Example
4/10 Religious Community	I1: “The group of people that I would say have been most influential in my life were leaders of the Orthodox Church and the community (its followers).”
2/10 No Group	I3: “There is no one or no group of people that has been most influential to my life. Self-awareness and self-decisiveness was and is still influential to oneself.”
1/10 Family	I2: “My family has been the most influential in my life. The way I was treated during my childhood was a role model for me to lead a family.”
1/10 Health Workers	I4: “The health workers are the most influential group of people in my life before and after my HIV case.”
1/10 Friends	I6: “Although it was not that much, the group of people that I would say have been most influential in my life are friends of the same age.”
1/10 Radio Programs- Government Media	I5: “The group of people that I would say have been most influential in my life is nothing else but the programs which were and are being transmitted or broadcasted through the Ethiopian Radio programs. Different programs through Ethiopian radio. Programs which were horrified for people were destructive rather than being constructive.”

The aim of the second question was to focus more on which of those groups are most influential to behavioral decisions as they relate to HIV risk behaviors. Again, one of the immediate findings that jumped off the page was the low incidence with which the family was mentioned. As Table 3 indicates, the majority of respondents felt that health workers are the *most* influential; however, I think it is important to note here that 7 out of

10 respondents did also mention the religious community in their answer, and 6 out of 10 said the religious community did have an influence on their daily behavioral decisions. Even respondents that said they didn't think the religious community played an important or influential role in their decisions still made comments such as, "Of course, the religious community and especially the religious leaders have the key in their hands to do as they are expected to, but they still have to do more."

Another interesting point here was the high response for health workers. This raises some important questions about which social network people trust in terms of information and which social network influences daily behavior. The Ethiopian government has made a huge push in the last decade to get health workers out to the more rural health clinics where there usually are no doctors and very little medical support or education.

Table 3; Most influential in HIV-related risk behavior choices

Percent	Example
4/10 Health Workers	I1: "The group of people that I would say has been most influential in my choices in terms of behavioral decisions which is related to HIV risk are health workers who give enough education about the prevention methods of abstinence and secondly if this is difficult for some of them, using condom should be the next alternative."
2/10 Religious Community	I2: "In my opinion, the education which is given by well awarded religious leaders is the most influential group. My religion teaches not to steal, not to have sex besides your spouse, to love and respect your friend. So, it was influential to me."
1/10 HIV Positive People	I3: "Learning from the very near HIV positive people is the most influential in someone's behavioral decisions."
1/10 Family	I4: "The groups that I would say have been most influential in my choices in terms of behavioral decisions (as related to HIV risk) are: 1. My family, and 2. My religious leader. I strongly believe that someone's family can be, and really are his/her role model from his/her choices either in a positive or negative way. In addition to this good religious fathers (like mine) are most

	influential in someone's choices right from the very beginning and throughout his/her life.”
1/10 No Group	I5: “There was no group that I would say had been most influential in my choices in terms of behavioral decisions as I said earlier.”
1/10 Teachers	I6: “As a student, I would say that teachers have been most influential in my choices in terms of behavioral decisions as related to HIV risk. One of my teachers used to advise me and my friends as well how to concentrate on our subject matters and keep away bad behaviors from us. I might not have understood him that time but still his words are influential to me. The pressure that was put on me by my friends and some neighbors for my first and early marriage and because of this marriage to my HIV status is something which is always in my mind as an example for bad people.”

In conclusion, the discrepancy between the narratives and the interview questions over the influence of religion and religious groups suggests there could be an important link between who people say are influential and which people are actually influential. As I mentioned before, the sample size for the interviews was small nonetheless this could be an important avenue for Ethiopia to pursue in looking at effective intervention strategies.

Focus Group Findings

After completing the interviews, three focus groups were conducted. After such mixed results from the narratives to the direct questions I wasn't sure what to expect. The opening question posed to the groups was very similar to the question asked in the direct questioning portion of the interviews: “Which group of people would you say has been most influential in terms of behavioral decisions concerning HIV prevention education?” One of the most widely mentioned responses was the religious community. The discussion touched on one main theme, and that is that the religious leaders and community are a fundamental figure of society. Although some may disagree with the

church at times, their word is respected and largely unquestioned by a majority of the population despite the fact that there may be counter evidence. Table 4 lists some examples regarding the influence of the religious community.

Table 4

Religious Community Examples

F1-“But what I meant was religion is entirely related with beliefs and it is stronger than others. People especially who live in villages respect their religion and listen carefully to what they are told from their religious fathers. If there is someone who does sex other than his wife, he will be condemned by his religious father. He will never do it again.”

F2- “I will say that it is the religious leaders. Because they are always in the church what they said will be accepted. The community (religious) is always with them every morning and every evening. Therefore, I believe that they are influential.”

F3-“As to me, I will say that religious leaders are the most influential group concerning HIV prevention education. I can give you an example. Previously, some of the Orthodox Christian leaders said that using holy water was the only solution for HIV problem. Many of us accepted what they said and we stopped taking our tablets. I didn’t use my tablet except the holy water for some time. Then, some of the leaders changed their mind and said that we could use both the holy water and the tablet. I accepted what they said and I started taking my tablet. You can understand from myself and from my friends act that how influential the leaders were.”

With almost equal mention and discussion, the next most commonly mentioned influential group was PLWHA (People Living with HIV/AIDS) and the associations of which they are members. A lot of the discussion, as you can see in the examples listed below, touched on two important details about this group’s effectiveness. The first is that openly HIV positive people are living amongst their peers and have the opportunity to advocate their message through their daily actions. Respondents felt that one of the most effective ways to disprove a myth is with action and evidence. The second point is that it can be a jolting experience to hear the stories of how PLWHA became HIV positive or

how it has changed their lives. The people of the PLWHA associations either were victims or at some point made a risky decision that resulted in their HIV positive status.

Table 5

PLWHA Association Examples

F1-“As the first speaker said, we, HIV positives are the most influential group. In 1996 and 1997 E.C. the degree for stigma and discrimination was very high. I was not allowed to wash my clothes in some one’s washing bowl. They were not allowing me even to touch it. But afterwards, I could change more than ten people’s mind. Due to my lesson, they gave their blood for HIV test and they were found to be positive. Because of their medication, they are still living and they always say ‘thank you’ to me. People will give their attention to us more than others. This is the reality that we ourselves have proved.”

F2-“The government, the church, and other groups give lessons to the society concerning HIV prevention They always tell people what they must do and what they shouldn’t. But we see people doing what they were told not to do and the other way round. A person who was taught to abstain or to be faithful and to use condom will be seen doing sex with any individuals even without using condom. A person who is told not to drink will be seen drinking too much. In this case the decisiveness of self-determination should not be forgotten. We, HIV positive people are in one way or the other an example of this type of people. In this case, the lesson that we give to people goes from the real source (from us) and no doubt for its acceptance. Therefore, our associations are the most influential group for HIV prevention education.”

There were two other groups also mentioned to a much lesser degree. The first was governmental organizations (GO) and the second was non-governmental organizations (NGO). In both cases respondents talked mostly about the “necessary role” they play in HIV prevention and how they are working in a wide range of areas. One of the more well-known GOs in Ethiopia is an office called HAPCO (HIV/AIDS Prevention Control Office). They’ve been around for over a decade and primarily work to support, network, and advocate for other organizations that are implementing HIV prevention in the community.

On the other end of the spectrum Ethiopia also has an abundance of local and international NGOs working all over the country. NGOs are the main sources of aid to alleviate rural poverty (Ethiopia 2011). The Swedish International Development Agency was the first NGO in Ethiopia in the 1960s, focusing on rural development. Drought and war have been the two biggest problems in past years, although today most NGOs focus on development and preventive health care issues; including, food, clean water, HIV, Malaria, and TB.

Barriers

One of the last questions posed to the focus groups addressed the second research question; to explore why- or in what situations- would a person deviate from the norms established by their community related to HIV risk behavior? The purpose of the question is to better understand what situations push people past rational choice. It is true that some people *choose* to put themselves at risk with the choices they make, however, if we can better understand what underlying issues affect those choices then we are in a better position to address those issues.

Economic Status

The overwhelming response to the question about reasons for deviating from the norm was because of economic difficulty. Respondents repeatedly touched on scenarios that put people in desperate situations that led to risky behavior. Table 6 shows some examples of these situations. The second point worth noting here digs into the core of what a lot of Ethiopians deal with as a daily part of life; the struggle to meet basic needs. It's no news flash that as humans we can endure a great deal of struggle, but that becomes

more and more difficult if a person's basic needs are persistently unmet. Table 6 looks at a few examples from respondents touching on basic needs.

Table 6

Economics

F1- "Some people are forced to do something against their religious rules because of economic problems and other reasons. In order to be faithful, you must have a friend or wife. And to have a friend or wife, you must have money. If you don't have any money you will be forced to one or more of the wrong doings. So economic problem is the main problem."

F2- "Some people make mistakes because of economic problem. They may live in towns renting a house. Sometimes they may not have enough money to pay their rent. At this condition, they will do anything as far as there is a possibility to get money."

F3- "A man with a low income will be unable to marry a wife and because of this reason, he will make sex with little amount of money with prostitutes. On the other hand, women who don't have enough money for their living will choose to be prostitutes. Their economic problem is the main reason for these two groups to be out of the rules of their religion..."

F4- "I will say that being rich or poor by itself plays a major role to be forced to act as our internal feelings. We observe young adults whose families are rich living in a relaxed way, just spending money for unnecessary things. This happened because they have the money. You can compare two young adults who are different in their economic status. You will see the one who is rich having a boy or girl friend and spending his time in unnecessary places while the poor shining shoes or selling vegetables to earn money for his living."

One issue that the examples in Table 6 touch on is marriage. It's not surprising that respondents made the connection between people that struggle economically and marriage. In Ethiopia marriage is viewed as a rite of passage and plays an important role in their culture. As mentioned in the narrative section, arranged marriages are the norm, although this practice is becoming less common, especially in urban areas. The elders are typically very involved in the proposal and ceremonial processes and both the bride and grooms families prepare a great deal of food for the occasion (Ethiopia 2011).

Furthermore, a presentation of a dowry is often made from the male's family to the female's family (Ethiopia 2011). The amount is not a set amount and varies with the wealth of the families; the dowry may include livestock, money, or other socially valued items (Ethiopia 2011). In addition to the money needed for food and dowry from the family, a man would be expected to be able to provide minimal basic needs for his family since he is likely to be the breadwinner.

Table 7

Basic Needs

F1- "Take myself as an example, I was not educated but I served my country being a soldier for 11 years. After I retired, I couldn't have a job which means no money. Then how can I respect my religious rules? I know that my wrong act contradicts with these rules, but behind this, there is economic problem. The government itself has a contribution to the spread of HIV as my understanding. There are many retired soldiers who don't have jobs like me. Especially who are HIV positive are neglected. Because of this, we lose hope very easily and will do unwanted things. If I'm not able to fulfill my primary needs, how can I respect other rules?"

F2- "One of the reasons, I think is economic problem. Shortage of money. If I am living in a poor condition, I will do anything in order to eat and then to live. I know that no one supports my wrong doings but I will do it."

F3- "It is easy to respect the rules of our religions, but our economic problem will give us a push not to obey for some of them. If for example, one of our friend's husbands died and if that woman doesn't have anything to feed her children, she will try what she thinks is the means for their survival. She may soon marry another husband or do sex with others for the sake of money. This is because of her economical problem."

Mirroring what the respondents in Table 7 are saying here Singh and Singh say that poverty goes beyond income and capability deprivation, but also means what they call *optimism deprivation*. Which means, the will or motivation to fight poverty, the urge to escape its shackles, the hope that the fight will succeed one day (Singh and Singh 2008: 193). This optimism is lost due to subsistence living and the daily fight for survival.

The poorest use what resources they have, and considerable resourcefulness, in their struggle to survive. For the poor, innovation means risk, and risk can be fatal (UNFPA State of the World's Population 2007b).

If we cross interdisciplinary lines briefly and look at Maslow's hierarchy of needs there are three parts of his pyramid that are particularly relevant here. The first is the base or foundation level (physiological needs) and the second is the next level up (safety needs). For the majority of Ethiopians, they will spend their entire existence working to provide their physiological and safety needs. Before anything else the need for water and food is a matter of survival (Sorensen 2006). When a person is hungry the area of consciousness is filled with the desire to eat and all the other needs fade into the background and in a way become non-existent until the need has been fulfilled (Sorensen 2006). The future perspective seems to change according to the present need (Sorensen 2006). When that need is met a new and higher need arises and that need will now dominate the conscious, when that need is gratified a new will emerge and so on (Sorensen 2006). Provided food and clean water are taken care of, Maslow's next level talks about security in shelter, the family, health, and resources. All of these things are central to the everyday struggle of life in Ethiopia.

The conceptualization of HIV behavior change sits at the highest need in Maslow's hierarchy, which is self-actualization. Maslow writes the following of self-actualizing people: "They embrace the facts and realities of the world (including themselves) rather than denying or avoiding them" (Sorensen 2006). For those who are struggling to meet their basic needs it seems a stretch for them to make the leap to the top of the pyramid and make behavioral changes based on information.

Gender

Throughout the narratives there was an unspoken sympathy for a woman's place in Ethiopian society. It's not discussed; it's understood. Women are considered inferior to men in Ethiopian society. This of course isn't always the case, there are women in Ethiopia living in cities, towns, and occasionally in a rural village that have earned the respect of an equal, and not every man in Ethiopia feels the need to exert his dominance over all of woman-kind. However, the important observation here is that for the vast majority of women in Ethiopia the option of being independent and self-sufficient is slim if not non-existent. The two examples below have been pulled from the interview narratives and exemplify the realities and vulnerability of many women living in Ethiopia today.

Example 1:

Etenesh is an illiterate woman that was born in the Gojam area and later moved to Gondar. She tells us that she is 25 years old but later explains that she doesn't really know how old she is and that's her best guess.

"I don't really remember each step of my grown up process during my childhood. I was born in Gojam-Burle. I was not lucky enough to grow with my parents as they were separated during my early stage. It was my mother who was to take care and look after me. She was living in a poor condition. As she was economically weak, I had no chance to be supported by her but rather to do labor work for others as a maid servant even during my childhood. I ate and slept in the house I worked but my mother used to collect and use my monthly wage for herself. It was 20 birr (1.50 USD) a month.

After serving different individuals in different times for more than three years, a teacher, whom I had known him as a neighbor, advised me to leave the house I was serving and to move with him to Bahir Dar and then to serve him. He said he would pay me a better wage. I was convinced by his advice and moved with him to Bahir Dar. I as a maid servant used to cook his meal and did laundering and other household chores for at least four months. One night, he forced me to have sex with him. We did it.

Soon after we had sexual intercourse for only that day I heard that his previous wife had died because of HIV case. I was shocked and couldn't continue to serve him. I left his house immediately and came to Gondar. I continued giving service to different houses as a maid servant until I finally entered in Sister Eniyish's house. She was a very kind and a special woman for me. After I stayed three months with her, I was not feeling well. I had become sick now and then. Because she was a nurse, she was treating me at home as well as in the hospital. I was getting weaker and weaker. One day, I told her that I had a sex with the teacher only once and the rumor I heard about his late wife. Eniyish advised me to give my blood test and to know myself."

Etenesh's story is not an uncommon one. A worker for Save the Children-Sweden once commented that, "Child domestic work (in Ethiopia) is not only widely accepted but often considered as a better alternative for children coming from poor families (IRIN 2011). Due to poverty, lack of schooling in rural areas, and an increasing number of orphans, children- especially girls- are often pushed into domestic labor (IRIN 2011). In Etenesh's case, her family's economic situation and Etenesh's lack of education played a substantial role in her having to help support her mother through domestic work. More than one third of domestic workers do not go to school, and instead work exhausting 11-hour days, seven days a week (IRIN 2011). In addition, almost half do not actually get paid, working instead for accommodation and food (IRIN 2011). The worker from Save the Children later added a startling statistic, according to NGOs, 84 percent of child domestic workers in Addis Ababa are girls, many of whom, like Etenesh, are subjected to sexual abuse by their male employers (IRIN 2011).

Example 2:

Miriam a is 24 year old housewife that is completely dependent on her husband's small monthly income of 320 birr (about \$25 USD) he earns being a guard at a fuel station. She grew up in the Amhara Region and has completed the 8th grade.

“I was born in a village called Mehin-Abo at Lay Armachiho Woreda. I started my education there at early ages. I am the eldest child in my family. I completed grade 6 at Mehin Abo and moved to Tikil-Dengay to continue my 7th and 8th grade lessons. I remained in grade 8 twice. Although I was not matured enough to lead a house, due to a push from friends and neighbors and losing hope in my education, I married a husband at Tikil Dengay. He had served the military force for some years but that time he was learning leaving the army. I thought I would pass my 2nd national exam and both of us would help each other. Unfortunately that didn’t happen. I was detained as I said earlier.

He continued his education but I didn’t. I simply became a housewife. He had started a business while he was learning. I spent most of my time selling goods to customers. Soon after some months, I gave birth to my first child. When my baby son was around 1 year old, his father (my husband) became sick. Three of us (my husband, son and I) were using holy-water at Tikil Dengay. No improvement in his sickness was seen or observed. I didn’t know really what the cause for his illness was. But he secretly had been investigated and had known himself that he was positive. He even became a member of Mahibere Hiwot without letting me know about his case. At the end, leaders of the Mahirbere Hiwot convinced him to take me to a hospital for investigation. He brought my son and I here in Gondar hospital and gave our blood for HIV test. From the test, our son was told HIV free while I was found to be HIV positive.”

Miriam’s story is also, unfortunately, very common. As mentioned before, gender inequality is still prevalent in Ethiopia. The patriarchal structure of society is reflected in the stress on education for boys over girls (Ethiopia 2011). Especially in the rural areas the belief still exists that females are less competent than males and that education is a waste of time and resources (Ethiopia 2011). We saw in Miriam’s situation that her husband’s education was prioritized while she was expected to take on the domestic activities. Also representative of gender differences in Ethiopia was her social engagement outside the home. Men often spend more time socializing outside the home, while women take care of the household, which makes it difficult to know, such as in Miriam’s case, what information is being neglected.

Analysis of Findings

Throughout the findings section the data addresses several overriding patterns that speak to the research questions. These patterns are an important indicator of how we could be addressing HIV prevention from a socially-focused perspective and allow us a glimpse into the world of the Ethiopian AIDS epidemic.

The first research question asks what social networks people are part of. Throughout the narratives, although several networks were mentioned, the resounding response again and again was the family. The two narratives that were chosen were representative of this; however, it's important to note that these examples were in no way uncharacteristic of the rest of the respondent's stories. It wasn't surprising that the family was so widely discussed given its central role in the daily lives of Ethiopians. However, what was surprising was the lack of mention of the religious community. Given the importance of daily religious ceremony in Ethiopian culture, I expected the religious community to have a stronger presence in the narratives.

This finding was also interesting given the substantial references in the interview portion and the focus groups to the religious community as an influential social network. The discrepancy between the two raises the interesting question of why. Why was the family so heavily discussed in the narratives, while the religious community wasn't mentioned at all, and in the interviews and focus groups the family was rarely commented on while the religious community was repeatedly talked about? Based on my experience in Ethiopia, I have reached one possible theory on this issue, and that has to do with a social desirability bias. During the narratives respondents didn't know we were going to be looking at social networks that are influential but in the interviews and focus

groups the question was asked directly. As discussed earlier, there is a societal obligation to the family, but there is a much stronger social desire to be viewed as religious. Even if you are not following the rules of the church, there is a need to appear as though you are to that community. For example, all three focus groups were asked what would happen if someone openly disagreed with the teachings of the church. Every response was some version of the example below:

“Previously, people with the virus, like us, died without taking the tablet as it was not available in Ethiopia. But now, with God’s will, we are using it. Someone who believes the medicine is helping him should continue with this belief and the other who believes with holy water should continue with what he believes. To come to the point, if I say that holy water won’t help in front of them (the church), I would have immediately been neglected from the society and be penalized by the church.”

The responses show the pressure to maintain a relationship with the religious leaders and community. Furthermore, it allows us a window into understanding why a respondent might respond differently when asked directly which group is most influential in their lives.

The second part of the first research question specifically looks at which network is most influential when addressing HIV risk behavior. In the interviews the most widely discussed group was the religious community. The teachings of the church are clear and consistent, abstinence until marriage and then faithfulness to your partner. If these rules are followed there shouldn’t be a need for condoms. The church openly denounces the use of condoms. As one respondent commented:

“Our religious leaders condemn the use of condom. They usually say to us, ‘You believe that condom or a plastic is important for living but it is only Jesus Christ who gives you life!’ Therefore if I oppose what they say, no doubt that I will be condemned and reject by both religious leaders and the community.”

Similarly the focus groups also listed the religious community as one of the most influential groups in terms of behavioral decisions; however, PLWHA and the associations they are part of were not far behind. One of the respondents summed the two groups up nicely,

“NGOs and other organizations have tried their best on HIV prevention. But, the problem still exists. In order to be effective on the prevention work both of the religious groups and these associations have to work hard together. These groups are the most influential groups. Most people respect their religious organizations. They also listen to what we are telling them. If we two work together interactively, the lesson we teach will be accepted easily.”

When discussing groups specifically related to HIV risk behavior the family was again absent. In my experience the topics that surround HIV risk behavior- primarily sex- are topics that are somewhat taboo to discuss. A recent article published by the BBC World Service Trust talked with Elsabet Samuel, producer of a health radio show called Abugida. Elsabet insisted the problem isn't a lack of information, but rather the problem is that people don't talk about it. "Conversations just don't happen" she says. "Mothers are too embarrassed to talk to their daughters, girls are shy, even friends don't talk about it." (Miller 2011) Another producer from the show went on explaining that bombarding young people with more information isn't the answer. "What they really need is communications skills," says Frehiwot Guangul. "They need to learn how to talk about sex, how to talk to their parents, negotiate with their partners, talk about contraception." (Miller 2011)

And finally one of the last questions posed to the focus groups addressed the last research question; to explore why- or in what situations- a person would deviate from the norms related to HIV risk behavior that had been established by their community. The

overwhelming amount of discussion pertaining to the economic condition of respondents was to a certain degree expected considering Ethiopia is one of the poorest countries in the world. On a recently released publication by the United Nations Population Fund (UNFPA 2009), they noted that “the impact of AIDS on poor households is clearly disproportionate” (UNFPA 2009). The participants from the focus groups continually painted a picture of a poor Ethiopian, male or female, taking risks because of limited choice. This participant uses the example of housing below:

“Some people make mistakes because of economic problem. They may live in towns renting a house. Sometimes they may not have enough money to pay their rent. At this condition, they will do anything as far as there is a possibility to get money.”

These limited choices can force many to leave home in search of work, which increases the chance of risky behavior, or can create vulnerable circumstances for impoverished girls and women that can lead to early marriage or insecure power dynamics between men and women (UNFPA 2009). In the data collected respondents talked at length about cultural repercussions of being poor for men in terms of marriage and how continuously unmet basic needs can alter a person’s ability or willingness to conform to social norms regarding risky behavior.

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary of Research Problem, Methods, and Findings

At the start of the HIV/AIDS epidemic, there was a split consensus on how interventions should address prevention. Some felt it was a public health problem that should be dealt with emphasizing shorter-term, behavioral interventions. While others believed the pandemic could be best controlled with longer-term development approaches that focused on the structural determinants that increase vulnerability to HIV infection (Merson et al. 2008). From early on the public health approach gained popularity, manifesting in individual-focused behavioral interventions that addressed what appeared to be the central problem, sex. Today probably the mostly widely used and recognized example of this is the ABC (abstinence, be faithful, condom use) approach.

While the behavioral interventions celebrated some success, as the epidemic crossed international borders the shortcomings were highlighted in more detail. Two of the most prominent inadequacies of the approach deal with personal agency and sustainability. Existing models of individual-level behavioral interventions are often based on various cognitive theories that assume an individual will take steps to avoid risks if they are fully informed and sufficiently motivated- that is, that they can exercise personal agency in the context of HIV-associated risk (Global HIV Prevention 2008).

However, as we know, there are social reasons why individuals have imperfect information and individual behavior is often more heavily influenced by broader socioeconomic, cultural, and environmental factors (Glanz et al. 2008). Another shortcoming of the individual-level behavioral intervention is the ability of people to sustain, or not sustain, behavior change over the long term.). Positive behavior changes often fail to endure because these changes require a collective change in norms and the creation of a supportive social environment (Epstein 2008). A large part of creating a supportive social environment that helps individuals maintain behavior change involves social networks and norms.

The fact that about 90% of the world's HIV infections occur in developing countries is strong evidence that social, economic, and political structures drive risk behaviors and shape vulnerability (Gupta et al. 2008). And it is here that the social sciences thrive in contributions. The most widely acknowledged perspectives from the social science school of thought suggests that particular forms of social-level factors situate people in positions of high risk of disease above and beyond their individual choice and behaviors (Mojola 2010). In other words, risk behaviors are not randomly distributed, but rather are generated and perpetuated through socially or environmentally structured social interactions (Latkin and Knowlton 2005). This allows researchers and program implementers to address the intersecting systems of inequality- such as income and gender- that help support the individual behavior change needed.

The objective of this research set out to build on areas related to the social nature of HIV risk behaviors. The first research question investigated what social networks people are part of and then looked at which of those networks influence HIV related risk

behavior. While the second question explored why- or in what situations- would a person deviate from the norms established by their community (social networks) related to HIV risk behavior.

The first question was addressed in several ways. The first was through narrative storytelling with ten different respondents. In section of the findings I outlined the results which indicated that there were eight social networks identified, and of those eight the family was unquestionably the most heavily talked about. The other interesting note to the narrative findings was the complete lack of mention of the religious community. Given the importance of daily religious rituals in Ethiopian culture, I expected the religious community to have a stronger presence in the narratives.

Following the narratives I attempted to again address this same question while digging a bit deeper about which network is considered most influential as it pertains to HIV prevention messages. The findings were again baffling. The majority of respondents indicated that the religious community was most influential in their lives; only 10 percent mentioned anything about the family. Furthermore, pressed on the issue of influential networks regarding HIV risk-behaviors, the responses indicated that health workers were the most influential; however, as noted before, 70 percent did also mention the religious community in their answer. The discrepancy between the narrative findings and the direct questioning findings suggests there could be an important link between who people say are influential and which people are actually influential.

As mentioned previously, the focus groups were meant to explore the second research question in depth; why- or in what situations- a person would deviate from the norms established by their community related to HIV risk behavior. The overwhelming

amount of discussion revolved around the economic conditions, which was later broken down into two subsections: economics and basic needs. The economic section gave examples of how a person's economic situation can affect things like marriage and cultural responsibility. While the basic needs section talked about what happens when a person's basic needs are unmet and how that can affect their decision making in terms of deviating from communal norms surrounding risk behavior.

This study was able to fill two gaps in the current literature. The first was the connection between social networks, norms and HIV. While there is a fair amount of literature that talks about social networks and norms in regards to health, I found that there was very little specifically addressing HIV. This is important because it helps to move the social agenda of HIV prevention forward. By looking at social networks we can study who the most practical groups are in terms of influencing HIV risk behaviors, and by looking at norms we can better address what approaches will likely be adopted and sustainable. Second, my study uniquely focuses on what circumstances would push an individual to violate norms established by their community. This is key when addressing root issues within the decision-making process. The second wasn't as much as a gap in the literature; there was minimal literature. Academic literature on social issues surrounding HIV in Ethiopia is extremely limited. My study offers solid data that provides a foundation for further research on the topic. Furthermore, the research questions are such that they could be applied over vast cultural and regional differences in Ethiopia and still provide valuable information in the fight against the HIV epidemic.

Concluding Remarks

Given the current body of HIV/AIDS prevention literature and the findings of this research, there are two main conclusions and several recommendations for future research which I've outlined below.

The first conclusion is nicely summarized by author Eileen Stillwaggon which she points out on more than one occasion; the HIV epidemic is a development issue that is being treated as a behavioral problem (Stillwaggon 2006). As research and our findings suggest, there are underlying structural issues, such as poverty and gender inequality, which our current regime of behavior change prevention programs do not and cannot address. This leads us to the second conclusion, a fundamental shift in prevention efforts that will address the social aspects of the epidemic, not exclusively but in conjunction with individual behavior change. Although initially our response to the HIV pandemic has been focused on individual-oriented approaches to behavior change, research suggests that social-oriented can potentially be more effective, affect a greater number of individuals, and have more sustainable effects on behavior change (Trickett 2005).

While there has been increasing recognition of the need for a social-level HIV intervention agenda, the underlying theories and methodologies of intervention have largely remained individual-oriented, limiting the potential of social avenues of intervention for behavior change (Trickett 2005). This study aimed to move the social-oriented agenda forward by addressing the social nature of HIV risk behaviors. The first is by looking at which social networks people find to be most influential in their lives, as it relates to HIV risk behaviors. As program implementers look to make an impact at the social environmental level they will need to know who will be the key groups to work

with. The second is by addressing what situations would motivate a person to deviate from those respected norms. By having ideas of what social and/or environmental problems transcend social control we are able to address the root of the problem instead of the aftershock.

Recommendations

When I consider my experience in Ethiopia and the findings from this study, I have a few recommendations on how we could use this knowledge to better address the HIV epidemic. First let me answer this within the context of this study's findings. The two social networks that held particular importance were the family and the religious community. Experience shows me that the Ethiopian religious community (both leaders and followers) is a much more complex world than this study was able to reflect. The religious leaders in Gondar are a devout group that stands strongly for their morals and opinions. As HIV prevention has evolved the religious community has maintained their stance: abstinence until marriage and be faithful to your partner thereafter are the rules. While I may not always agree with their approach I think that trying to change the morals of Orthodox Christians is foolish. I propose to get the religious community more involved with the root issues that we have established have an impact on risk behaviors, such as the overwhelming economic difficulty. This seems to be a win-win. The religious community is well respected and has tremendous influence, in no way does this approach conflict with their moral obligations or teachings, and it helps address a critical issue related to fighting the HIV epidemic.

As for the family, I think this group can play a key role in the behavioral aspect of HIV prevention. Even after two years of living in Ethiopia I won't pretend to understand

the complexities of the family structure in Ethiopia. The dynamics of power and gender relations go far beyond my limited interaction; however, I do know that the best way to influence that dynamic is through long-term generational change and the greatest future impact will come with future generations. While the schools are trying to educate about disease and HIV risk, I think that needs to be reinforced in the home as well. Mothers spend the most time with children so my best guess would be to provide a support network for women and mothers with accurate health information and an outlet to ask questions.

Of course the most important recommendation I could give to fighting the HIV epidemic in Ethiopia is to ask Ethiopians. For so many years international aid agencies and foreigners have *told* people how to fight the HIV epidemic, but how many times have we asked them their opinions? Instead of inflicting our ideas, why not facilitate the development of the local perspective? In my time teaching in Ethiopia one of the most fruitful assignments I gave my college students was for them to design their own HIV prevention intervention. I asked them which social network they would utilize and what they would do. I was blown away by their creative responses. Their ability to think locally with an understanding of the cultural constraints more than altered my international perspective. That being said I do think that the international world plays an important role in drawing those ideas out and facilitating resources to put interventions on the ground. Additionally, I think research like this study can be a helpful tool in guiding those beginning discussions and giving an interdisciplinary perspective. HIV does not live in a vacuum, neither should our prevention strategies. Both in research and on the ground we need to start thinking outside the box.

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APPENDIX A
INTERVIEW FORM

Demographic Survey:

- 1) Is participant _____ Male _____ Female?
- 2) Participant age _____.
- 3) What region of Ethiopia did you grow up in?
- 4) In what region of Ethiopia have you lived the longest?
- 5) What is the highest education level you have completed?
- 6) Are you currently working?

If yes, proceed to question 7. If no, skip question 7 and proceed to question 8.

- 7) What is your own monthly income?
- 8) What are your monthly expenses?
- 9) If any, what financial support do you receive?
- 10) From whom does this financial support come?
- 11) What is your current marital status? (married, divorced, widowed)
- 12) How long have you known of your HIV positive status?
- 13) Have any of your family members died of HIV?
- 14) What is your religious affiliation?

Life history:

This section will be categorized into three broad sections; childhood, youth, and adult.

The interpreter has been informed to merely facilitate the participants' story. However, the following questions have been mapped out to help initiate discussion by the participant:

Childhood-

- 1) Where did you spend most of your time as a child?
- 2) Describe your surroundings; house, compound, neighborhood.
- 3) Who is actively part of your life at this stage?

Youth-

- 4) Where did you spend most of your time as a youth?
- 5) Describe your surroundings; house, compound, neighborhood.
- 6) Who is actively part of your life at this stage?

Adult-

- 7) Where did you spend most of your time as an adult?
- 8) Describe your surroundings; house, compound, neighborhood.
- 9) Who is actively part of your life at this stage?

Direct questions:

- 1) Which group of people would you say have been most *influential in your life?

*Influential meaning-whose opinions do you value? Who would you listen to?

- 2) In terms of *behavioral decisions (as they relate to HIV risk) what group would you say has been most influential in your choices?

*Behavioral decisions in this case include any behavior that could put you at risk for HIV; for example, abstinence, being faithful, or condom use.

- 3) Do you feel that the religious community you are part of plays an influential role in your daily decisions?
- 4) Do you feel that the religious community you are part of plays an influential role in your behavioral decisions?
- 5) Before your HIV positive status did you have any HIV prevention education? If yes, what did that education include?
- 6) What HIV prevention strategies do you feel would be more effective in today's interventions?

APPENDIX B

FOCUS GROUP QUESTIONS

- 1) Which group of people would you say have been most influential in terms of behavioral decisions concerning HIV prevention education in Ethiopia?
- 2) What do you think about the role played by religious organizations concerning HIV prevention education?
- 3) Do you believe that HIV prevention education given by religious leaders or groups is important? Why?
- 4) Do you believe that there is pressure from the religious community to be or to appear to be a follower of the teachings of the church (in terms of HIV prevention education)?
- 5) Do the teachings of the church (in terms of HIV prevention education) occasionally contradict the actions of community? If so, what are some of the reasons that a person might contradict those teachings?
- 6) What would happen to an individual if they openly opposed the teachings of the church (in terms of HIV prevention education)?