LIFE AT A LOCAL HIV/AIDS COMMUNITY OUTREACH PROGRAM: EXPLORING COMMUNITY RELIANCE IN THE FACE OF FINANCIAL INSTABILITY

By

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ABSTRACT:

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The positive association between poverty and ill health is one that is supported by a number of variables. More specifically, the association between poverty and the contraction of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) is one that sticks out in recent literature but frequently goes unacknowledged within mainstream society as a result of heavy stigmatization. After interning at a local HIV/AIDS community outreach center for several months, I have witnessed this stigmatization firsthand and recognize the value of educating others about this crucial topic.

In my thesis, I explore the personal struggles of clients and employees at this local HIV/AIDS community outreach center. Through face-to-face interviews with all of the employees at the Center, I have been able to provide a more in-depth analysis of what it takes to run a community outreach program of this nature and the types of resources that they provide to their impoverished clients on a regular basis. The resources that the clients rely on in the absence of outside support and the community that has been built at the Center emphasize the degree to which community reliance in the face of financial instability holds true with these programs. The purpose of this research is to raise awareness about the HIV/AIDS virus, promote the importance of community outreach programs, and hopefully combat some of the associated stigmatization.

TABLE OF CONTENTS

CHAPTER 1:
INTRODUCTION

Importance of HIV/AIDS Community Outreach Programs

The essential value of community outreach programs for individuals infected with or affected by the HIV/AIDS virus has been well documented throughout recent literature (Parker 2001; Lune 2007; Rhodes et al. 2010). These kinds of programs aid the community by providing necessary tangible resources (food, informational pamphlets, methods of birth control) that might otherwise be unattainable for clients who are struggling financially. In addition to these tangible resources, community outreach programs frequently also provide a therapeutic aspect through discussion with individuals going through the same struggle, support groups, and other beneficial workshops.

One component of many HIV/AIDS community outreach programs includes the concept of community-based participatory research. This kind of research allows for collaborative participation among HIV-positive individuals, activists, and academic researchers as a way to "improve community health and well being through multilevel action, including individual, group, community, policy, and social change" (Rhodes et al. 2010: 174). Community-based participatory research also serves to better establish connections throughout respective communities in the hopes of raising awareness and reducing stigmatization.

Through raising awareness in recent literature, a number of scholars have cited poverty as one of the key variables contributing to ill health and, more specifically, to the HIV/AIDS epidemic (Stillwaggon 2006, Stratford et al. 2008). For impoverished individuals who are infected with or affected by HIV/AIDS, the reliance on community

support in the face of financial instability plays a big part in coping with the impact of societal stigmatization. I was able to witness this firsthand during an internship over the past several months at a local HIV/AIDS community outreach center. I am grateful to now have the opportunity to share some of the knowledge that I have gained as a result of this experience in later chapters of these thesis project. By looking more closely at the way that HIV/AIDS community outreach organizations operate and the resources that they provide for their clients, the variables that stand in the correlation between poverty and ill health and poverty and HIV/AIDS become evident.

Breakdown of the Chapters

In this thesis, the completed project includes four chapters and each chapter is broken down into smaller sections as a way of better organizing the information at hand. This first short chapter includes a quick glimpse at the aim of the project and serves to introduce the information that will be discussed throughout the later chapters. The second chapter provides a review of the literature on the correlation between poverty and ill health, the correlation between poverty and HIV/AIDS, and a brief discussion about community outreach programs for PLWHA (People Living With HIV/AIDS). The third chapter presents the 'Herald Center* Story' – an overview of my firsthand experiences during an internship over the past year at an HIV/AIDS community outreach program; this chapter also includes three specific background stories of individuals who work and/or volunteer at the Center, along with each of their inclinations about the clients' reliance on community support in the face of poor health and financial hardship. The fourth and final chapter includes the conclusions that have been drawn as a result of the

crucial information presented in the literature review and through the firsthand experiences taken away from time spent at an HIV/AIDS community outreach program. This final chapter also includes a quick glimpse at the HIV/AIDS epidemic on a broader level (in sub-Saharan Africa) and a look at some of the potential solutions and contributions for the continued existence of community outreach programs and for the reduction of stigmatization throughout society.

CHAPTER 2:
LITERATURE REVIEW

[A]. Poverty and Ill Health

The positive association between poverty and ill health is one that is supported by many variables. However, while these variables are frequently tied to a number of resulting health concerns, the connection between poverty and the increased risk of ill health is not often discussed at public health interventions (Stratford 2008). The longer this correlation between poverty and ill health goes unacknowledged, the longer it will take for society to come to terms with it and do something progressive. Nguyen & Peschard (2003) and other scholars elaborate on the way in which individuals are subjected to a vicious cycle that circulates around the inability to stay healthy in the face of financial hardship, which subsequently leads to a struggle with maintaining any kind of financial stability in the face of ill health. The components of this continuous cycle of poverty and ill health include: lack of food and other resources, poor education, unemployment, homelessness, drug abuse, incarceration, and a lack of community/family support; each one of these is important to examine separately. As several scholars present these variables in the literature, it is clear that they are important and it is crucial to continually raise awareness about this topic in the hopes of keeping as many individuals as healthy as possible.

Lack of Food and Resources

Individuals living at or below the poverty line do not typically have enough money to splurge on food of a certain quality or quantity. Unfortunately, they are frequently unable to even purchase enough food to comfortably feed themselves and their

families. Due to their lower socioeconomic status, these individuals who are not getting enough of the nutrients the nutrients that they need are more prone to ill health (Elo 2009). These individuals who are suffering from financial instability are also struggling with a lack of accessible resources (ex: clean water, energy, stable living environment and shelter, etc).

Without sufficient food and resources, these individuals who are already struggling with external (material) problems will quickly find themselves struggling with internal (health) problems. Nguyen & Peschard (2003) discuss the lack of resources accessible to individuals in impoverished communities as an association with the fact that "fewer investments are made in infrastructure and social services" (451) in these respective communities. This inequality fuels a cycle in which the rich get richer (greater investment in their resources) and the poor get poorer (due to the lower investment in their resources).

Another aspect of this inequality shines through when scholars look at health concerns as a result of individuals living at or below the poverty line. Guruswamy (2011) elaborates on the notion that poverty leads to an inability to access energy per capita which therefore leads to a limited human capacity for self-growth. With a limited capacity for self-growth, these impoverished individuals ultimately struggle with development and are more likely to suffer with health issues without essential resources.

Poor Education

Individuals living in impoverished communities – especially individuals with health issues and high medical costs – are more likely to experience difficulty when it

comes to obtaining a decent and well-rounded education. The relationship between poverty, ill health, and poor education is cyclical and unnerving. Elo (2009) discusses educational attainment as a consistent SES measure with a high correlation to ill health. Individuals who have reached higher levels of educational attainment are more likely to maintain their health and live longer than individuals who have not reached the same levels of schooling.

Individuals who reach higher levels of education also typically receive better job offers and higher paying jobs. With better job offers and higher paying jobs, these individuals would be more financially stable and would not have to worry as much about medical costs if they were to become ill. However, in impoverished communities where individuals are struggling just to get by and may not be able to rank education as a top priority (cannot afford particular levels of education or must use the money that they have for basic resources), certain levels of employment are likely to feel unattainable. Many individuals in these communities with low socioeconomic status and lower levels of schooling may struggle with finding a decent job, in general. As a result, a good portion of these individuals are likely to remain financially unstable and, in this way, are more prone to falling subject to ill health and medical costs.

Unemployment

Seemingly related to poor education, unemployment stands as an important variable in the relationship between poverty and ill health. In today's workforce, the higher the level of schooling an individual has received has an impact on the likelihood of a potential employer to feel that the individual is qualified for a given position. Thus,

individuals living in impoverished communities without access to higher education must frequently settle for lower-paying jobs in undesirable fields or remain unemployed. These lower-paying jobs or a lack of jobs in general only continue to fuel the financial hardship that these individuals are struggling with. Elo (2009) describes the way in which a curvilinear relationship shows the impact that poverty in the workplace has on low-income individuals [as compared to high-income individuals] and that small steps towards financial stability will help these low-income individuals maintain healthier lifestyles and will lead to a decline in mortality rates. In this sense, the stress that comes along with not holding a steady well-paying job has a negative impact on health outcomes.

Elo (2009) also points out that individuals in higher status jobs tend to experience less anxiety about their socioeconomic status and are less likely to be living at or below the poverty line. Individuals who are living at or below the poverty line are often more frequently subjected to stressful events, such as unemployment, throughout their lives. These individuals feel unprepared and out of control while stuck in these situations and are not always able to successfully 'bounce back' due to lack of resources. Thus, individuals who have increased access to education and increased access to job opportunities are more likely to avoid some of the negative health outcomes (ex: anxiety, lack of resources and higher risk of infection, etc) connected with these variables.

Homelessness

As a variable for the correlation between poverty and ill health, homelessness is often associated with unemployment – both being frequently tied with the notion of

social exclusion (Mabughi & Selim 2006). The cyclical relationship between these variables and social exclusion brings us back to the cyclical relationship between poverty and ill health. More often than not, homeless individuals are experiencing an extreme financial crisis - one that has caused them to live on the streets as a result. Without access to crucial resources (shelter, clean water, healthy food, etc), these individuals are much more at risk for a variety of health concerns. As they are unable to afford proper medical care – both for prevention and/or treatment – the homeless population faces additional obstacles when trying to stay healthy. The fact that they are frequently unable to pull themselves out of their tough financial situation while unemployed and living on the streets continues to fuel the correlation between poverty and ill health.

Similarly, individuals who are not necessarily homeless but are impoverished nonetheless, are at a higher risk for many of the same issues. Kling et al. (2007) touch upon the idea that lower-income individuals living in financially unstable communities typically struggle with a range of health issues. These scholars emphasize that, when compared with higher-income neighbors in nearby communities, these lower-income individuals were more likely to be living in poverty and experience worse health outcomes.

Drug Abuse

In general, regular illicit drug usage is detrimental to an individual's health. For impoverished individuals who are unable to afford costly drugs such as cocaine and heroin, the sacrifice of other essential resources in order to obtain their 'fix' comes into play. Additionally, the very drugs that these individuals are making sacrifices for are

inevitably going to have a long-term negative impact on their health and well-being. Campbell & Shaw (2008) discuss the fact that the Drug Abuse Act of 1988 included a section that said that no federal funding would go towards the distribution of clean needles in exchange for used ones. Congress believed that denying support of needle exchange would help decrease the spread of disease and help decrease drug abuse. The government also believed that providing addicts with a safer way of doing drugs would only lead to increased usage.

Though, what the government did not anticipate is the fact that withholding clean needles would not lead to a decline in drug abuse as they had hoped (Campbell & Shaw 2008). As long as addicts are able to somehow access their drug of choice, they frequently continue using regardless of any consequences. By denying support of needle exchange in the hopes of avoiding further drug usage, the Drug Abuse Act of 1988 simply put the drug-using population at a higher risk of contracting infections by sharing used needles. In this way, impoverished drug users who cannot afford an unlimited supply of needles and must resort to re-using or sharing them, are the ones who are much more likely to suffer from ill health.

Incarceration

The number of individuals in the United States prison system has been steadily increasing over the decades. The National Research Council (1993) discusses the fact that a great deal of the incarcerated population is comprised of poorer individuals coming from urban areas (frequently minority groups). As the number of impoverished incarcerated individuals has increased over the past few decades, the health status of

these individuals has subsequently declined. It is important to acknowledge that many of these individuals suffer with health issues once they have been released from the prison system – often because they are unable to quickly adjust to the outside world again.

Also, scholars explain that there are a number of additional variables tied to the effects of incarceration on impoverished individuals. Schnittker & John (2007) explain that the effects of incarceration are frequently associated with lower wages or unemployment and social exclusion when an individual is attempting to integrate back into their community. As all of these variables are closely related to ill health, they further emphasize the connection between poverty, incarceration, and health concerns.

Lack of Community / Family Support

Impoverished individuals who experience a lack of community and family support are likely to experience even more anxiety and stress, which often leads these individuals to be more prone to health risks and concerns. Kling et al. (2007) discuss the way in which individuals living in impoverished communities experience a much lower level of community/family support than individuals in more affluent neighborhoods seem to have. This lack of support ties back to the other variables associated with the correlation between poverty and ill health. Without sufficient resources and a decent level of education, it is likely that these impoverished communities have different priorities that may not fall in line with the respective societies' expectations for social behavior and support.

Also, if individuals feel that they are inferior to others living in their community, they are likely to be more at risk for ill health. Nguyen & Peschard (2003) explain that

these feelings of inequality lead to a lack of social cohesion and inclusiveness, which ultimately leads to potential isolation, feelings of anxiety, and subsequent health concerns. It is entirely possible that many individuals will be able to avoid these health issues by placing a heavier emphasis on other variables, such as focusing on educational attainment or putting a halt to their drug abuse. However, in the long run, a lack of community/family support does have a significant impact on these impoverished individuals and puts them more at risk for ill health.

[B]. Poverty and HIV/AIDS

Over the past few decades, several scholars have dedicated much of their time to researching the topic of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (ranging from medical facts to prevention techniques to quality of life, etc). While there are several factors that are linked to poor health and the risk of contracting Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS), poor socioeconomic status is one that sticks out in recent literature. While the relationship between poverty and ill health is highlighted in Part A of this chapter, the more distinct association between poverty and HIV/AIDS will now be highlighted in Part B**.** A number of scholars acknowledge that poverty is deemed one of the key variables fueling the epidemic and emphasize that poverty-eradication programs are an important resource for HIV/AIDS-affected individuals (Stillwaggon 2006, Stratford et al. 2008). Thus, it has become apparent that there is a strong relationship between poverty and HIV/AIDS.

Lack of Food and Resources

Surprisingly, there does not appear to be a significant amount of scholarly work dedicated to the association between lack of food/resources and HIV/AIDS. In addition to their every-day living expenses, individuals living with HIV/AIDS must pay for costly medications and frequent doctor visits. These regular and substantial medical costs are typically not a part of any individual's planned budget - especially not individuals living at or below the poverty line (for whom figuring out what they can and cannot afford is a day-to-day scramble). These medications, which are required in order to attempt to keep these individuals' HIV/AIDS virus from spiraling even more out of control, introduce additional costs that may lead other potential necessities - such as sufficient amounts of

food - to fall by the way side. Malnutrition plays a catalytic role in many diseases, but for individuals living with HIV/AIDS, it represents lower levels of strength and higher levels of susceptibility to infection – issues that are already continuous obstacles for these individuals' failing immune systems.

Another major obstacle for individuals living with HIV/AIDS comes along with every-day resources needed to maintain good health (such as, heat or air conditioning, general electricity, and good hygiene). Guruswamy (2011) elaborates on the notion that access to electricity and various kinds of energy leads to better health care. Any individual experiencing a cold winter without heat or a hot summer without air conditioning is going to struggle; for impoverished individuals living with HIV/AIDS, these uncontrollable temperatures can be too much for their weakened immune systems and can lead to additional illnesses. It is essential that these individuals have access to electricity in order to monitor their body temperatures and health. Similarly, the ability to practice good hygiene (by having access to clean water, cleaning products, etc) typically enables individuals living with HIV/AIDS to get fewer infections that would be even more detrimental to their worsening health. In terms of resources, access to energy includes access to refrigeration, which HIV/AIDS patients frequently need to keep their medications cold.

In general, improved energy infrastructure can provide impoverished communities with access to hospitals (increased access to various medical treatments or machines) and school systems (increased access to resources for improved educational attainment). These opportunities and resources that would otherwise be unavailable to individuals living at or below the poverty line allow for superior medical care and

increased awareness within society regarding health concerns among other things. While a lack of food and resources represents a variable in the correlation between poverty and HIV/AIDS, a lack of access to various levels of schooling also signifies a variable in the relationship between poverty and HIV/AIDS. Increased access to resources may lead to more educational opportunities, which places individuals at a lower risk of contracting HIV/AIDS.

Poor Education

Just as poor education stands a crucial variable in the linkage between poverty and ill health, it also stands as an important variable with the more specific correlation between poverty and HIV/AIDS. As stated in Part A [‘poor education’ section], without access to education, individuals have fewer occupational opportunities and limited access to information regarding healthy ways of living (Elo 2009). However, when it comes to the correlation between poverty and HIV/AIDS, the limited access that impoverished communities have to information about this disease represents a serious issue concerning lack of prevention and overall awareness. For example, Guruswamy (2011) discusses the importance of access to energy as a catalyst for HIV/AIDS prevention programs. In order to reach at-risk impoverished communities through educational programming, these communities must be able to listen to the radio or watch television (both devices require access to energy).

Similarly, access to television programming in the classroom provides a more well-rounded education for children who respond more to what they see in an educational setting than to a wide range of varying ideas that they hear from individuals in the

community. Individuals living in impoverished communities frequently do not have access to the same quality of education as individuals living above the poverty line. Without financial hardship, parents are likely to have the opportunity to send their children to private schools [or well-run public schools], where they will receive a good education. By obtaining a good education, individuals are more aware of health risks and are more likely to practice caution and avoid situations that will result in ill health. Specifically, by learning about the risks associated with sexual behavior and drug usage at an early age, children are more aware of the health consequences and prevention techniques associated with HIV/AIDS (Elo 2009).

Many scholars put a heavy emphasis on the importance of sex education in the hopes of raising awareness for HIV/AIDS prevention. Parker (2001) elaborates on the association drawn between "risk related sexual behavior and the knowledge, attitudes, and beliefs about sexuality that might be associated with the risk of HIV infection" (164). By working to ensure that all individuals receive a proper sexual education and general education, these individuals would at least be aware of the possible consequences of their actions and would be able to make more of an informed decision before engaging in any kind of sexual behavior.

From a young age, children who obtain a better education are generally better protected from various risks throughout the community (Stillwaggon 2006). In impoverished communities, there is generally more street crime and drug usage. By staying in school, these children will be safer throughout the week and are more likely to make safer decisions regarding their activities on the weekends. Also, children who have

had access to a sufficient education will be more likely to secure employment opportunities and less likely to put themselves at risk for contracting HIV/AIDS.

Unemployment

In general, HIV/AIDS is a disease that is associated with a large amount of stigmatization. In greater detail, the National Research Council (1993) discusses the fact that individuals who are HIV positive are more likely to experience discrimination in the workforce, receive lower incomes, and possibly lose their job altogether. While this specific information is from nearly two decades ago, it still holds true today. Many impoverished HIV-positive individuals find that they have fewer occupational opportunities and are more likely to struggle with social networking if they feel that they are unaccepted within society.

Mrus et al. (2006) also address unemployment (as a result of lower levels of education and past lower incomes) as an important variable associated with the impact that poverty and HIV have on health-related quality of life. Thus, due to the lack of access to education and difficulty coping with other inequalities present in impoverished communities, individuals are frequently unable to utilize social networking skills and acquire employment options that will allow them to excel. Also, while unemployment represents a variable in the correlation between poverty and HIV/AIDS, the inevitable struggle to find and hold on to decent affordable housing in the face of poverty stands as another crucial issue.

Homelessness

Individuals living with HIV/AIDS often struggle with homelessness as a result of living at or below the poverty line; many are unable to afford their medications and support their previous uninfected lifestyle. Stratford et al. (2008) discuss the notion that homelessness, like several other variables associated with the correlation between poverty and HIV/AIDS, can be addressed and partially alleviated through the introduction of a variety of economic empowerment programs. By working to do something about their financial situation (situation typically involves struggling to stay employed, as discussed in the previous subsection), these impoverished homeless individuals will put themselves in a better position to stay healthy and are more likely to avoid situations in which they might contract HIV/AIDS. For example, by securing some form of shelter, these individuals will have more sanitary living conditions and will generally be at a lower risk for infection.

Bell et al. (2007) discuses the way in which many HIV positive individuals must relocate as a result of the cost of their disease on their physical and social well-being (ties back in with social exclusion). In addition to citing homelessness, these scholars also acknowledge "change of residence" and "refusal of entry into public places" (Bell et al. 2007, 118). Without financial stability and social inclusion, these individuals living with HIV/AIDS are much more likely to experience difficulty when attempting to hold on to a clean and affordable place of residence. In a cyclical nature, without a clean and affordable place of residence, these individuals are placed at higher risk for HIV/AIDS.

Drug Abuse

Another issue that places individuals at higher risk for contracting HIV/AIDS is drug abuse. Illegal drug usage, specifically drugs that require injection, represents a variable that is frequently associated with the transmission of HIV/AIDS. Chambré (2006) discusses the way in which heroin addicts represented a large portion of the HIV/AIDS-infected individuals at the beginning of the epidemic. By sharing needles to shoot up the heroin that they craved, these individuals – many of whom were unaware of their HIV-positive status – shared their disease with one another. Campbell & Shaw (2008) also touch upon the fact that many heroin users portrayed themselves as "ethical subjects" by claiming that they always diligently wash their syringes with bleach after shooting up. However, once these individuals are in the position to clean their syringes, the drug is already working its way through their bodies and they are likely to not want to ruin their high by going through the motions of cleaning. Similarly, many of these individuals are likely to forget to clean their syringes and needles altogether once they have come down from their high – an act of laziness which ultimately puts the next user at high risk for contracting any infection that the prior user may have if the individual chooses to share their syringe.

In an attempt to avoid having to inject and deal with syringes or needles with heroin, many drug users turned to smoking other various drugs. At the beginning of the AIDS epidemic, a large number of impoverished women were addicted to using crack (Chambré 2006). While crack was not a drug that required needles (typically smoked or snorted as opposed to being injected), these women ran into trouble when it came to obtaining enough crack to get their fix. While cheaper than heroin or pure cocaine, crack

is still an expensive commodity for individuals living at or below the poverty line. Unfortunately, in a scramble to get their share of crack, many women chose to sell their bodies in return for drugs. By choosing to have sex for drugs, these women put themselves at a much higher risk for contracting HIV/AIDS. In general, by choosing to inject illegal drugs, both men and women are more prone to infection and other health concerns tied to HIV/AIDS.

Incarceration

Drug abuse is an issue that often lands many individuals in jail (regarding drug use, dealing, etc). While most correctional facilities have implemented some sort of HIV prevention education for both prisoners and staff, the system must still accommodate inmates who arrive for their sentences already infected with HIV/AIDS. Prisoners living with HIV/AIDS represent an additional funding issue to prison systems that are already up against financial struggle. Jaffe (2004) discusses how, about a decade ago, about 2 percent of prisoners residing in state prisons and about 1.2 percent of prisoners residing in federal prisons were HIV-positive. These prisoners with HIV/AIDS have special treatment needs and are especially prone to infection – resulting in frequent segregation from other prisoners in an attempt to avoid any further health concerns or transmission of the disease to other inmates.

Even before these individuals are incarcerated, many of them have struggled with poverty, drug abuse, and lack of access to medical and therapeutic care that put their health at risk on an every-day basis (National Research Council 1993). Once incarcerated, these issues that already represent a struggle for individuals living with

HIV/AIDS seem to be heightened by the conditions of the prisons and the further lack of access to necessary medical treatments.

Lack of Community / Family Support

Community support - especially throughout impoverished communities - is an essential factor surrounding the lives of people living with HIV/AIDS. Rhodes et al. (2010) describe the way in which HIV is frequently associated with other "stigmatizing, disempowering, and marginalizing conditions that contribute to health disparities" (178). These scholars emphasize that a sufficient amount of community and family support represents a positive coping approach for these individuals and may essentially lead to a reduction or even elimination of various health issues. This focus on poverty as a contributing factor concerning HIV/AIDS and other health related issues ties back into the need for increased awareness and education with community support.

From the beginning of the AIDS epidemic, activists have strived for a combined effort among community members to promote healthy lifestyles in an attempt to lessen the burden that comes along with the disease (Rhodes 2010). In terms of social impact, HIV/AIDS frequently has the largest effect on impoverished individuals who are frequent victims of social segregation. Nguyen & Peschard (2003) address this topic in their discussion of structural violence in our society where the rich are growing richer and the poor are growing poorer. Without any flexibility, social inequality has fueled both poverty and wealth, but has resulted in the poor being more prone to infection and HIV/AIDS.

In an effort to tackle some of these issues, a number of scholars have looked to prevention programs as a positive aid. One scholar, Parker (2001), emphasizes the importance of HIV/AIDS prevention and how essential it is for prevention to be viewed as part of a larger process, not only geared towards reducing infection. In this sense, prevention must also be used as a tool for tackling the issue of structural violence, which has been associated with an increased risk of contracting HIV/AIDS. Another scholar, Jaffe (2004) discusses an additional challenge associated with prevention as HIV-status awareness. The low number of individuals who are actually aware of their HIV infection status is alarming as they may be unknowingly transmitting the virus to other individuals – none of which (including themselves) will be receiving treatment for the disease. Lastly, Jaffe (2004) discusses how "AIDS case rates are 10 times higher in African Americans than in white Americans" (1243). In these impoverished communities primarily comprised of African American individuals, there is frequently a lack of community support if the support does not include ties to the high rates of crime or drug usage (Jaffe 2004). In addition to this lack of support, other variables tied to these high rates of infection include poverty, sexually transmitted diseases which lead to HIV, and inability to access and use necessary health care.

In an attempt at offering solutions to impoverished individuals living with HIV/AIDS, a number of community outreach programs have been established across the country.

[C]. Community Outreach Programs for PLWHA

Community outreach programs offer some solutions to the problems that arise among impoverished individuals living with HIV/AIDS. Soon after the HIV/AIDS epidemic began in the 1980s, it became apparent that a reliance on the surrounding community and the introduction of respective community-based organizations was necessary. In New York State, the AIDS Institute (AI) was developed in 1983 – at the very beginning of the epidemic – as an organization meant to fund scientific research and facilitate the development of HIV/AIDS community outreach programs throughout the surrounding area (Chambre 2006). The fast-paced development of the AIDS Institute organization and several others stood as evidence that "the community-based mobilization of affected peoples in response to HIV/AIDS has been remarkable and nearly unprecedented" (Lune 2007: 4). This quick expansion of outreach programs involved a dependence on positive social interaction among the infected and affected individuals and support from respective activists.

Certain earlier community-based organizations involved more medical framework [with various drugs and treatments being tested] and emphasized community support as a way to increase compliance and improve physician-patient relationships. In this light, the AIDS community served as an important jumpstart for taking a closer look at the drug approval system throughout the country. While non-compliance and low enrollment were two large problems with these earlier primarily medicine-based organizations, things began to shift gears and developed into a more inviting environment as the organizations adopted a more therapeutic community-based approach (Chambre 2006). By adopting this approach, HIV/AIDS community outreach programs have stood their ground

throughout the country and will hopefully become even more prominent in areas with the greatest need for their services.

Three main goals for these community-outreach programs include: providing necessary resources that might otherwise be unavailable to HIV/AIDS community members who are living at or below the poverty line, offering therapeutic support in the face of both emotional and physical stress, and raising awareness about prevention techniques & the disease itself. By aiming to accomplish these three goals, the individuals who work tirelessly to fund and run community-outreach programs are striving to provide the tools for a better future for individuals infected with or affected by HIV/AIDS. These organizations are also working to educate the surrounding community about the virus in the hopes of prevention and reduced stigmatization.

Resources Available

While HIV/AIDS is still a disease that carries a certain stigma, many more resources have become available to the infected population over recent years. Some of these key resources include: increased public access to education (sex education and general education), increased access to addiction treatment, new health initiatives, and community outreach programs (Jaffe 2004). For individuals who are living in poverty, access to these otherwise unavailable resources is essential. More specifically, community outreach programs often provide additional resources necessary for prevention (ex: condoms to encourage safe sex, food to increase nutrients, pamphlets to increase education/awareness, etc) and continued therapeutic support.

In discussing development programs for individuals living with HIV/AIDS, Stillwaggon (2006) further emphasizes the importance of improving water systems and latrines, bolstering immune systems with nutrient supplements, keeping children in school, extending health care services, increasing mass communication for health information, changing the status of women at work, eliminating trafficking of women/children, engaging in blood screening, and reuniting families. All of these different elements serve as resources that can either help in the prevention of HIV/AIDS or help facilitate necessary steps for extended treatment of the disease. By utilizing these resources and obtaining therapeutic support, HIV/AIDS-affected individuals are able to better cope within mainstream society.

Therapeutic Support

Individuals living with HIV/AIDS are in need of a substantial amount of medical care; however, what people do not always realize is how essential therapeutic support is as well for long-term effective coping. This idea of the importance of therapeutic support improving health outcomes goes back to the last section of "Part B" – which focused on the lack of community/family support as a variable in the correlation between poverty and HIV/AIDS. Without community/family support as a means of therapy, these individuals living with HIV/AIDS [who are already experiencing a great deal of anxiety associated with their medical treatments and expenses] are likely to experience increased stress. This increased stress is ultimately detrimental to their health, and thus, this relationship between the medical aspects of the disease and the therapeutic aspects represents another cycle.

In this sense, regardless of their disease progression or other influencing medical variables, therapeutic support is extremely important and necessary for individuals living with HIV/AIDS. Any kind of group – support based or education based – has the potential to truly benefit these individuals with their continual treatment and help them strive towards a higher level of self-actualization (Willinger 2003). By following through with these groups and receiving other opportunities for therapeutic support (ranging anywhere from meaningful conversation to exercise to massages), individuals living with HIV/AIDS will be more likely to develop coping methods for both their medical and emotional needs.

Raising Awareness

Raising awareness about HIV/AIDS within our society stands as the beginning of a solution to educational inequity. By providing pamphlets and other forms of helpful material at community outreach centers, individuals infected with and/or affected by HIV/AIDS may begin to learn important medical strategies, new emotional coping mechanisms, etc. Rhodes (2010) highlights one approach for raising awareness in his descriptions of Community-Based Participatory Research (CBPR). By using this approach, activists and scholars ensure equal participation among the community members (including individuals who are affected by HIV/AIDS) and researchers who are strictly studying HIV/AIDS and working to improve community health access and awareness.

Another crucial issue to raise awareness about involves sex education and sexual power dynamics. While condoms have the potential to protect sexually active individuals

from exposure to infection, they can only do so if the individual in the respective relationship has the power to demand that they are used (Stillwaggon 2006). In this light, it is important to raise awareness pertaining to equality in sexual relationships and work on helping individuals in these relationships avoid situations in which they are subjected to undesired unprotected sex. Thus, raising awareness about all of these contributing factors (by providing additional resources, therapeutic support, etc) is a crucial aspect for successfully functioning community outreach programs.

CHAPTER 3:
THE HERALD CENTER* STORY

The Herald Center* is a community outreach program for individuals living in the Cedar City* area that are either infected with or affected by the HIV/AIDS virus (both the name of the Center and its location have been changed for confidentiality purposes). Most of the clients who come to the Center are living at or below the poverty line and are constantly struggling with both physical and emotional stress. The employees who run the Center work to ensure that the building is well kept and stocked with resources that will enable the clients to improve their day-to-day lives (meals each day that the Center is open, access to support groups, free contraceptives, etc). As a community outreach program, the Herald Center has aided the lives of many over the years and stands as an extremely important outlet for the Cedar City HIV/AIDS community.

While there are a number of other similar programs in the area, many of them are too far away for clients who do not own a car or cannot always afford public transportation. As emphasized in the literature review, the correlation between poverty and HIV/AIDS is one that is supported by a number of variables (including lack of food and resources, lack of community and family support, etc.). Unfortunately, what I am leading up to is a story in which the hardships associated with HIV/AIDS and lack of funding are only exacerbated. The story that I am going to tell is one in which the Cedar City Herald Center, a much-needed program, came up against a multitude of obstacles and has had to make several adjustments accordingly.

So the story begins…

I have interned/volunteered at the Cedar City Herald Center for about a year now, actively observing the way in which an HIV/AIDS community outreach center functions. My initial proposition for this senior thesis project was to interview clients at the Center about their everyday lives [being infected with or affected by the HIV/AIDS virus] in the face of financial instability, with a focus on their reliance on community support. As the months went by at the Center, I witnessed first-hand multiple turnovers in staff, an increase in lack of funding, a cut-back on the number of days that the Center remained open each week (went from 5 days to 3 days), and a change in the overall attitude of the individuals who made up this small community.

I started my internship at the Herald Center as a necessary component of my Anthropology of Poverty class during the spring term of my junior year at Union College. When I first began going to the Center with two other Union students in April 2011, the head director at the time, Stan*, was extremely laid-back and seemed to be very open and connected with the clients. Stan had explained the constant financial struggle due to lack of government funding and gave us some more information about the HIV/AIDS virus. He spoke with us about the overall goals of the Herald Center program: trying to ensure that individuals infected with or affected by the HIV/AIDS virus have a reliable community within the area, providing free meals for clients, and offering support groups that allow the clients to open up about their struggles in a safe environment. While I understood that these were the goals and values of the program, I did not hear much talk about the HIV/AIDS virus during my first couple visits to the Center; I barely even spoke

with the clients. The majority of what I did those first couple visits was cleaning the Center, organizing informational pamphlets [about substance abuse, safe sex, HIV/AIDS, etc] for visitors, and helping to cook/serve the meal of the day.

I was initially very frustrated about not speaking with the clients. As the Center was a community outreach program, I had originally hoped to help with some of the support groups and speak with the clients about their daily struggles. It took a few weeks for me to understand that I was a complete outsider, coming into an extremely confidential community and trying to act like I deserved their trust simply by being there. I had signed a confidentiality form during my first visit, stating that I would not tell anyone about any details about the clients' personal lives that were discussed while at the Center (the reason why all of the employees' and clients' names were changed for this project – the * next to each name the first time it appears in the story represents a name change). While the confidentiality form may have served an administrative purpose, I needed to realize that the form alone was just a piece of paper and didn't mean that any of the clients believed that I was trustworthy enough to listen to their personal stories and keep them to myself.

After working there for a few weeks, Stan opened up to us about his own HIV/AIDS diagnosis in his mid-20s and the huge impact that it has had on his life. I had not known that Stan was living with HIV/AIDS and was surprised by the news, as he looks like a very healthy young man in his late 20s. Unfortunately, HIV/AIDS does not discriminate among age groups and there are currently no known cures for the virus; once an individual is exposed to the virus (whether through unprotected sexual intercourse,

sharing of needles, etc), the individual will be infected throughout the remainder of their lifetime (antiretroviral drugs can be used to 'manage' the virus, but they will not cure).

Once Stan had opened up about his diagnosis and several clients overheard us speaking about his condition, the somewhat awkward dynamic between me and the clients began to fade and the clients began to open up to me about personal struggles throughout their daily lives with the HIV/AIDS virus. Towards the end of May 2011 (after about a month of being 'on the outside'), I began to feel like more of an accepted member of the community. As an insider, I was able to witness more of the aspects of what a makes a community outreach program like the Herald Center such a crucial resource for a struggling population.

I began to notice certain clients who were heavily reliant on the free meal that the Center offered each day. When I first began volunteering, the Herald Center was open 5 days a week (2 days for lunch and 3 days for dinner). I spoke with clients who came every single day for the meal (especially clients with small children) and openly admitted that they would not have been able to afford sufficient food for the week otherwise. Back in the spring of 2011, there were also a number of individuals who came straight from work to pick up lunch during their lunch breaks and bring it back with them. While the individuals who simply came and took food with them were not necessarily utilizing the 'community aspect' and the therapeutic resources that the Center offered, they still relied on the Center a few days a week for a meal that they might not have been able to afford on their own.

Unfortunately, during the time that I was home from school over the summer of 2011, Stan left the Center to pursue other endeavors. When I returned to pick up on my

volunteering and work on my thesis project in September, I found a new interim director (Andrea*), new volunteers (including Anthony* and John*), and many new clients. The new faces were not the only things that caught me off guard – the overall atmosphere at the Center itself had changed. It quickly became apparent that the lack of funding was a much bigger issue than Stan had ever mentioned in the spring. Stan had always been working on budgets and going to City Hall to propose ideas for grants, so I had not previously realized how tight money was for the Center or [at times] how unevenly he had chosen to distribute the funding that we had secured.

As the atmosphere at the Center had always been so laid back, neither the clients nor I were aware of how quickly the program would change once a new group of individuals came in to take over and allocate resources correctly. Many of the clients were extremely frustrated with the changes that had been made and openly expressed resentment towards Andrea, the new director, as a result. Throughout October 2011, I witnessed more hushed conversations among clients and more arguments between clients and staff than I had ever seen during my time at the Center a few months prior. Fewer clients were coming on a regular basis and the ones who were coming rarely ever stayed for group therapy sessions or activities that they used to plan their weeks around.

Throughout the fall of 2011, there were several meetings held at the Center about the changes that were going to be implemented in the coming months. Some of the big changes included: the Center would only be open 3 times a week (on Tuesdays for lunch and Wednesdays/Thursdays for dinner) as opposed to 5 times a week (twice for lunch, three times for dinner), the clients would no longer be allowed to come and take away bags of food with them – they would have to sit down and eat at the Center if they

wanted their free meal, and the introduction of a new 'membership program' (where each client would have to submit their full name and some other personal information about being infected or affected with HIV/AIDS in order to receive a membership card) which would serve as a way of ensuring that random individuals were not just able to come to the Center and use its resources without proof of any connection to the organization.

During these meetings in October, clients were able to openly express their concerns after being told about the changes. While I was not actually in attendance at the meetings, I heard a detailed description of them from both the clients and the staff after the fact. Overall, the clients were very frustrated with the changes and many expressed that they were going to stop coming to the Center altogether. Unfortunately, over the next several weeks [as I was supposed to begin my interviews for my thesis], the clients held true to their word and a number of them supposedly began going to another local Center.

I hit my biggest roadblock when Jen*, the initial assistant director who had worked alongside Stan, stopped working at the Center the day before our scheduled interview was set to take place. After this setback, the whole process took a turn for the worst. In attempting to secure interviews with the clients who had initially been open and even excited about the idea, I ran into unexpected trouble. I felt that I had built a strong rapport with these clients and, for one of the first times at the Center, I felt the heavy stigmatization of the HIV/AIDS virus as they told me that they were no longer comfortable sharing all of their personal information with me on record; while they want their voices to be heard, they are anxious about who will care enough to listen and whether or not they will be judged. As the Center has gone through a number of changes over the past several months due to changes in management and a lack of funding, the

once laid-back community [comprised of clients and volunteers alike] has become more anxiety-ridden.

Thus, while I first intended to solely focus on interviews with the clients about their personal struggles with the HIV/AIDS virus in the face of financial instability, my project has taken a significant turn. Ultimately, my project has become a case study – telling the story about the struggles of one specific community outreach program, but recognizing that the things that I observed could happen with any program. The short appendix – which is found after the final chapter of this project – includes the informed consent form, interview questions, and debriefing statement that were approved by the Human Subjects Review Committee before pursuing interviews for this study. My hope is to raise awareness about how essential it is to provide as much support as possible for these programs, and most importantly, to take a look at a small population within the HIV/AIDS community – a population that I believe frequently goes unacknowledged.

Andrea's Story

I spoke with Andrea* on January 19, 2012 about her personal background and her experiences thus far while working at the Cedar City Herald Center. Andrea grew up in Brooklyn and classifies herself as a big city girl. She grew up with a lot of siblings: five sisters and one brother. She was the second oldest of her siblings and due to the fact that her eldest sister was an intravenous drug-user, she had to quickly adopt a care-taking role at a young age (she did her best to care for herself and the rest of the children).

Andrea explained that growing up in a big city has made her a people person. She likes being around and working with all different groups of people – something that has

believes has better prepared her for her work as the Director of the Herald Center. She believes that growing up in a big city, surrounded by people prepared her to deal with all different kinds of people on a much more personal level. Andrea even went on to stress that her background has made communicating with the clients at the Center much easier for her.

When I asked Andrea what she looks forward to the most about coming to the Herald Center each day, she immediately said “making change”. She hopes to make positive and social changes for the clients. She is currently working on a membership program for the Center. Many of the clients are opposed to it, but she believes that it is very important for the organization to have more rules and regulations in order to continue to flourish in Cedar City. With the enactment of this membership program, each client will have to obtain a card that they will show each time that they come to the Center.

As of right now, a big issue has been lack of awareness about the clients’ conditions. As HIV/AIDS is heavily stigmatized, many individuals do not openly discuss whether or not they have the disease upon walking into the Center and it is likely that a number of individuals have used the Center over the years for its resources (free meals, etc) when they are not infected with or affected by the virus. As Andrea explained, “No one’s asking questions right off the bat because they don’t want to cross any boundaries. But… it’s important. How are we supposed to get more funding if we don’t have a concrete program with membership and rules? It’s important.”

The lack of funding for community outreach programs is a very large problem, overall. However, the clients’ resistance to change at the Herald Center has posed an

additional obstacle that Andrea and the other employees must work to combat. During our interview, Andrea expressed her frustration with the clients and explained that it mainly just stems from her strong desire to help people that don't always seem to accept her help. In the face of financial struggle, Andrea is working tirelessly with other crucial members at the Cedar City Inner City Ministry to ensure that the Herald Center will still be around for the clients even after she has given up her position as Director (which will occur in March 2012, as she has another project that begins at that time).

In terms of the clients who are still coming regularly, Andrea does believe that a lot of them rely on the Herald Center as a source of food and other resources. However, she also believes that they rely on the Center as a place of comfort – a place to come and talk with the friends that they trust. Many of the clients have known each other for a very long time and have built a trusting community at the Center. The clients feel comfortable speaking with each other about their illnesses, but do not necessarily open up as much to the employees (or at least not as much as they used to when Stan was serving as the Director in 2011).

When I asked Andrea why she believed that the clients did not feel as comfortable opening up to her as they might feel opening up to other clients, she was hesitant to respond. This slight hesitation alone serves to further emphasize the stigmatization surrounding the HIV/AIDS virus (even while working at a community outreach program). Andrea explained that she believes that several of the clients resent anyone who isn't personally infected with or affected by the disease. Though, she also spoke a bit about the clients' resistance to the administration. Andrea stressed: "I also don't think they like me because I'm in charge. It's the authority thing. But you can't have everyone

like you… and someone's got to do this job and make sure that this facility is still here, you know? But, at the end of the day, I do think that the clients come here and feel comfortable talking with other clients about their virus. They see it as a safe space. The confidentiality is so important to them."

While the clients may not always feel comfortable discussing the intricate details of their personal lives with the employees (an issue that I ran into myself when struggling to obtain more in-depth interviews), it is essential that they feel comfortable with the other clients at the Center. In addition to being able to sit and talk with their trusted friends, the clients are also given the opportunity to participate in several free support programs offered by the Center. During our talk, Andrea spoke highly about both the programs that are currently in place and the programs that she is working to start up at the Center. She explained that, "We're going to have a lot of… a lot more opportunities to educate those affected by the virus… in terms of prevention. Lots of prevention programs in addition to the support groups. I'm hoping that the new membership program will make clients more comfortable about signing up their families and ensuring their spot at the Herald. Like I said, I want to make positive change here. I'm fighting for more funding and further church support and I want it to make a difference in the clients' lives. We've already had to cut back on the number of days we're open… I don't want the clients to have the Center fade out… to lose it completely."

Andrea's dedication to the Center over the past few months has been crucial. She has done a lot of behind the scenes work and has been fighting for funding and positive change, while dealing with a lot of resistance from the clients (who like things the way that they are and do not want to see any further rules or regulations enforced). As stated

earlier in this section, Andrea will be leaving the Center in March 2012 to pursue another project. She does not plan to return to the Herald Center afterwards, but has stressed on multiple occasions the overall impact that this working experience has had on her. She has learned so much about the HIV/AIDS virus and has learned what it takes to organize this kind of a program. Working for, especially running, a community outreach program is a lot of work and Andrea has utilized her human relation skills over the past several months. She hopes that the Herald Center will continue to exist as a resource for the HIV/AIDS community within Cedar City and she "hopes the best for the people there, regardless of whether or not she continues to be a part of their lives". In this light, the Cedar City Herald Center will continue to have an impact on Andrea and other individuals who have been a part of the organization (either as employees *or* clients). As a whole, Andrea's story is one that represents the importance of raising awareness about the HIV/AIDS virus and the coping community. By working to aid this community outreach program for less than a year, Andrea developed a new, less-stigmatized and more informed perspective about the HIV/AIDS virus and the individuals who struggle with it on a daily basis. With this new perspective, Andrea [and others like Andrea] will now be able to spread her awareness further (to her friends, family, and others) and hopefully keep the fuel under the fire for the Herald Center as a community outreach program.

John's Story

I spoke with John* on January 12, 2012 about his personal background and experiences while volunteering at the Cedar City Herald Center. John grew up in a small

town in Iowa and said that there were not many activities to do there so he really needed to find his own friends and “make his own fun”. John described himself as being the odd one out in his family as he was “never horribly adept at sports or academics”. Though, through a one-year volunteering program, he has landed himself halfway across the country volunteering for a community outreach program through the local Church – which is, in itself, doing something bigger than he ever imagined he would back in Iowa.

When asked what kinds of things he looks forward to the most each day, John explained that he just wants to get through it in a positive way. He doesn’t feel that he necessarily needs to change the world on a daily basis, but sees the Herald Center as a good way of giving back; the Center provides him with the opportunity to get to know people that live differently than him and offer a different perspective (and vice-versa for him explaining his life circumstances to the clients). To John, the Herald Center stands as a place that is “doing at least some kind of good in the world and not a whole lot of people do. Granted it’s not huge or widely known, but it gives people with a very serious illness a place to call their own so to speak”.

In terms of the Herald Center having to cut back the number of days that it is now open to the community, John believes that it has had an impact on the clients’ continued attendance (many have not come as regularly as in the past). Though, in the hopes that it will get the Center back on track, the cut back on the number of days will hopefully allow for more grounded programs, a potential solidification with membership, and the possibility of more consistent funding. It is essential that the clients continue to have a free safe space to discuss their personal struggles with the HIV/AIDS virus.

John explained to me that he has overheard several clients discuss their expensive medications and their anxiety about paying for them on a regular basis – something that requires them to constantly prioritize what they need for them and their families to get by in addition to their costly medications. The majority of the current Herald Center clients are living at or below the poverty line and many of them have been struggling with financial instability since their childhood (John says that he has unfortunately seen many situations in which poverty traveled from generation to generation).

While the clients may discuss these financial and social qualms amongst themselves, they are not as likely to bring up these topics with the Center employees. For the most part, John has never really had an open conversation with any of the clients about their health, however, he believes that the clients would be comfortable discussing HIV/AIDS with him if he was mature about it and asked in an educational manner. John did not know very much about the disease prior to volunteering at the Herald Center and his experiences with the program have helped to reduce a lot of stigmatization that he once associated with the individuals infected with and affected by the HIV/AIDS virus.

After several months of being at the Center, John feels comfortable with the community that has formed there. Something that really stuck out to me as I continued to discuss John's experiences at the Center were his pre-conceived notions about the supposed dangers of being around other individuals with the disease. John said himself that: "If you know someone's got AIDS, you think Oh my gosh they must be some kind of leper and if I touch them, I'm going to get it and I'm going to start falling apart". Though now, after his time at the Center, John has settled on the fact that "It's a perfectly normal disease. These are real people, with feelings, that we're dealing with".

It is extremely important with any community outreach program to focus on the therapeutic support aspect as well as the provided tangible resources for the clients. In this light, spending time with the individuals at the Herald Center had a similar impact on John's thinking [just as it had with Andrea's outlook on the HIV/AIDS virus and the program, as a whole]. If the Center could only secure some more consistent funding, they would be able to provide additional therapeutic resources for the majority of the clients who are struggling financially, as well as physically.

Anthony's Story

I interviewed Anthony* on January 12, 2012 about his personal background and experiences thus far as the new Assistant Site Coordinator at the Cedar City Herald Center. Anthony was born in Florida but grew up in Cedar City. He was in an improvisational acting troupe at Cedar City High School that received a good portion of their funding from the Herald Center (this fact alone serves as evidence that the Herald Center was not always struggling so severely with funding). With the allotted funding that Anthony's troupe received, each member of the troupe promised to dedicate him or herself to volunteer at least one night a week at the Herald Center.

As a teenager, Anthony chose to volunteer two or three times a week at the Center. When he graduated from Cedar City High School, he moved back to Florida. Then, as of October 11, 2011, he came back and started volunteering at the Herald Center again, upon which he was granted the position as Assistant Site Coordinator. Anthony explained that working at the Herald Center and connecting with the clients has given him a totally new sense of direction. The HIV/AIDS virus hits close to home and has a

bigger meaning for Anthony, as his mother was infected with the virus and passed away when she was only 46 years old. While his mom was sick, he felt the stigmatization that she felt and witnessed the struggle that she went through physically and financially while trying to afford medications, support him and his siblings, and keep her health up. Anthony's decision to come back to the Herald Center and work to support the clients had a lot to do with carrying out his mother's memory – something that several clients who have lost loved ones are sure to do each time that they take part in support groups at the Center.

When I asked Anthony what the Herald Center meant to him as a whole, he seemed to get a little bit emotional, which serves to further indicate the level of importance that he associates with the Center as a community outreach program. Anthony explained that, "… it means the world to me to know that there are places designed for people with the statute to be able to go to… a home away from home. To actually sit down and get out of their house… to go to a home that's… where they can feel free to express themselves… to speak about their illness or speak about their condition openly. You know, not trying to hold anything back from their children or loved ones, but to openly speak about their situation to other people that are concerned about their needs and how they're feeling and how they're doing".

In this light, Anthony went on to emphasize the importance of community reliance in the face of financial instability. In addition to working at the Herald Center, he also volunteers for another agency called the Matilda* House, which is a homeless shelter. When comparing the two organizations, Anthony stressed that they are both essential community outreach programs for the Cedar City area, but that a big difference

that he felt set the two apart was the size of the programs. The importance of confidentiality at the Herald Center is one factor that has led to a much smaller group of clients and a much more close-knit community. In this sense, Anthony has chosen to describe the clients at the Herald Center as more of a 'family' than anything else he has seen while working with other organizations.

And back to the story…

These three individual experiences that I have just highlighted help to outline the mentality behind running and/or volunteering at a community-outreach organization. The personal details give outsiders a better idea of what the Cedar City Herald Center does for the surrounding HIV/AIDS community and how it serves to impact the lives of both its clients and its employees. As the Center has undergone many changes over the past year, it is important to look at both the positives and the negatives that have come out of these adjustments. In the hopes of providing a well-deserved sense of hope in the face of struggle, I will begin with the negative aspects and will then present the multitude of positive outcomes.

Over the past several months [after the transition from Stan to Andrea as the Center's Director], I have unfortunately witnessed firsthand the Center's ever-present struggle with its lack of funding. Andrea has continued to work on grants and has looked for other opportunities to allow for additional resources, but as far as I am aware, there have been no significant donations or increases in allocated funding during the time that I have volunteered at the Center. This fact alone presents a constant problem for an

organization that strives to provide resources for impoverished individuals while it is struggling with its own financial instability.

As discussed in the beginning of the story (prior to the presentation of the three individual experiences), this struggle with a lack of funding led to the Cedar City Herald Center having to cut back on the number of days that it is now open to the public. By only remaining open for 3 days [as opposed to the original 5], the number of individuals who have come to the Center on a regular basis has decreased. While some of the clients who are no longer coming to this local Center have resulted to going to a different HIV/AIDS community outreach center in Oak City* (which is larger and has still been able to maintain its 5 days a week for the public), others have moved to new [typically smaller] apartments in neighboring towns or simply resorted to seeking their necessary resources elsewhere. Many of the clients resented the ongoing changes and implementation of new rules and preferred going to the Oak City Center as it supposedly operates the same kind of way that the Cedar City Center used to run under Stan's direction.

For the clients who were more willing to accept the positive social changes that Andrea pushed forward, the positive outcomes in the face of financial struggle began to shine through for the remaining Cedar City community members. The membership program that Andrea is currently working on will allow for a more assured sense of confidentiality throughout the Center – everyone will know that each individual in attendance [aside from volunteers and employees] is definitely infected with or affected by the HIV/AIDS virus. A big concern for both clients and employees alike has been the inability to determine whether or not each individual who comes to the Center is coming

for the ‘right’ reasons; it is likely that several individuals who have no association with the virus have come over the years to get free meals and have ultimately posed a confidentiality breach for the clients who are coming to the Center to open up about their personal health struggles.

The introduction of Andrea’s membership program will also allow for more assurance for the various churches that provide food donations and volunteers on a weekly basis. With a guaranteed list of clients who have obtained membership cards by providing background information about themselves and their HIV/AIDS status, the employees at the Center will be able to give the churches more information that will prove how important their continued donations are for the clients and what a difference they are making for the Cedar City HIV/AIDS community.

Another positive change that I have seen at the Cedar City Herald Center over the past year comes with the increased awareness about funding and how that money is being distributed for various projects. When I first began volunteering at the Center in the spring of 2011, I was completely unaware of the financial struggle and random allocation of funds. While Stan was constantly going to City Hall to advocate on the Center’s behalf [in the hopes of increasing funding], he never discussed with me or anyone else just how much the Herald Center was struggling – alongside its clients – in the face of financial instability.

From what I have witnessed at the Center over the past several months, everything is much more out in the open now. The relationship between the employees and the clients is such that the majority of the administrative information that is available to the employees is now available to the clients, as well. Instead of trying to hide any

potential funding problems or changes being made for the framework of the organization (something that I believe occurred in the past without any of the clients or other volunteers, including myself, taking much notice), Andrea has held several meetings to continually update the clients about both the existing struggles and the gradual accomplishments. During these meetings, the clients have been given the opportunity to openly speak their mind about the changes. While the majority of the clients expressed frustration and resistance to change, it is essential that they recognize that these changes are what is now necessary to keep the Herald Center open and operating the way that it needs to in order to provide the best possible care and resources within the HIV/AIDS community.

The last thing that these clients – individuals who are living at or below the poverty line and rely on the Center as a source of food and other resources – need is for the Cedar City Herald Center to have to close its doors for good. In my mind, the increased awareness about the Center's ongoing struggles has been a positive thing because it has enabled many of the clients who were initially against any kind of deviation from their 'norms' to consider the new possibilities and opportunities that these social changes may bring. In addition to the increased awareness within the community itself, the Center has begun to become more widely known around the Union College campus (with both fundraisers and general discussion). While it is crucial to acknowledge the Center's struggles and negative aspects from a realistic perspective, it is even more essential for the surrounding community to focus on the positive changes that the Herald Center has undergone as an organization and the otherwise unacknowledged community that has begun to gain less stigmatized recognition within the Cedar City area.

CHAPTER 4:
CONCLUSION

Strengths and Weaknesses of the Project

While there were several obstacles that I ran up against throughout the duration of the project, each one of them provided me with a more realistic outlook towards community outreach programs and the problems that their employees and clients must face. In this light, I view the fact that I was working at the Cedar City Herald Center during the time that significant change was being implemented as a strength; if I had been interning at the Center at a different time, I would never have learned this story and might not have been as aware of the serious lack of funding that the employees are working to offset. Similarly, I would never have been able to raise awareness as effectively without these obstacles to overcome. The constant fight to hold on to necessary resources and the small sources of funding that the Center still receives is a greater topic of interest for most individuals than a stigmatized HIV/AIDS community outreach program in which things are running smoothly; the increased awareness about the Center needing constant help has made individuals more likely to ask questions, get informative discussions going, and try to make a difference.

While I am looking at these obstacles in a positive light, it is also important to acknowledge the weaknesses that came along with certain kinds of social change for the organization and my switch from planned interviews with clients to an overall case study of the Center. With these changes, I was unable to provide the intended clients' perspective of their reliance on HIV/AIDS community outreach programs and their financial struggles associated with the virus. These limitations led to a different outlook –

one in which the Cedar City Herald Center is more one-sided than I would have hoped; I had to trust that my firsthand observations and employees' perspectives on the clients' background and reliance on the community formed at the Center were accurate.

One other one-sided weakness of the project is the fact that it only provides detailed information about one specific HIV/AIDS community outreach program and does not assess the epidemic, along with community support, on a broader level. While my smaller study does relate to the broader picture (ex: stigmatization as a constant in most societies, community reliance throughout those infected with or affected by the virus), it does not provide an in-depth analysis of the effects of the epidemic on communities in other areas (such as Sub-Saharan Africa, where the virus affects so many individuals). The main reason for this exclusion of additional information is the fact that it could lead to another whole thesis – unfortunately, the line must be drawn somewhere. However, it is extremely relevant and important information. Thus, in the next short section, I will provide a conclusive quick glimpse at some of the discussion found in recent literature about the HIV/AIDS epidemic on a broader level.

Looking at Things on a Broader Level

In sub-Saharan Africa, the HIV/AIDS epidemic is still a very pertinent and serious issue at hand. While prevention education is a part of HIV/AIDS community outreach programs around the world, prevention involves a much more specific outline in sub-Saharan Africa – one that is frequently unattainable for many of the individuals who are struggling just to get by. One important aspect to take note of for the sub-Saharan HIV/AIDS community is the hope for the inclusion of "treatment for parasitic and

infectious diseases (including bacterial STDs)" specifically addressed within the realm of prevention for this area (Stillwaggon 2006).

The much higher rates of HIV/AIDS in sub-Saharan Africa [as compared to the other countries] cannot be explained by one defining variable. While many scholars acknowledge the high rates of unprotected sex and sex trafficking in these poor populations as a contributing factor, it cannot be pinpointed as a main cause for transmission by any means. In addition to these risks that arise as a result of unprotected sex, many scholars also discuss the dangers associated with the frequent drug usage that is most likely done with unsterilized needles in these impoverished areas. Though, when looking at the bigger picture, recent literature emphasizes the overall lack of resources and programs that could offer prevention techniques in sub-Saharan Africa as the main issue (Stillwaggon 2006).

Just as the literature review in the first chapter of this thesis discussed [lack of resources and] poor education as a variable in the correlation between poverty and HIV/AIDS, lack of access to education represents an important variable in the discussion of the high rates of HIV transmission in Africa (National Research Council 1993). In the refugee camps, urban slums, and suburban shantytowns that many of the impoverished individuals in sub-Saharan Africa occupy, the living conditions have not improved as the spread of infectious disease has increased. The inadequate clean water supply and sanitation in these areas frequently lead to further malnutrition, drug usage in times of hardship and, in many cases, the spread of diseases including HIV (Stillwaggon 2006).

In this light, it is evident that the HIV/AIDS communities in sub-Saharan Africa have dealt with and are still dealing with many of the same hardships that the infected

communities here in the United States are struggling with on a regular basis. Unfortunately, it appears as though one large difference lies in the further lack of access to resources in sub-Saharan Africa that might serve as ways of preventing future HIV transmission and ways of treating already infected individuals. Without adequate resources and access to education, these impoverished communities are struggling through an epidemic that frequently goes unacknowledged within our society here in the U.S, as many individuals have chosen to view the introduction of antiretroviral drugs as a solution. While the majority of this thesis project discussed the struggle with HIV/AIDS and community outreach programs here in the United States, I am hopeful that this quick glimpse at HIV/AIDS on a broader level [in sub-Saharan Africa] re-enforced the value of raising global awareness and stressed the unfortunate reality that the epidemic is far from being over.

Potential Solutions and Contributions

While it is evident that there is no 'quick fix' for the HIV/AIDS epidemic, it is important that our society continues to raise consciousness in the hopes of promoting prevention education and reducing stigmatization. As HIV/AIDS is no longer considered an automatic death sentence and there are antiretroviral medications that individuals who are infected with the virus can take (as long as they can afford them), many people believe that the epidemic is essentially 'over' (Mortensen & Trzcianowska 2001). A survey done by the Kaiser Family Foundation shows that only eight years ago, 36% of Americans deemed HIV/AIDS as the second most urgent health problem in the country (ranking second only to cancer). Though, even with a little over a third of society

acknowledging this urgency, overall anxiety and activism regarding the virus has declined in recent years (Jaffe 2004).

Without continued activism and awareness, prevention education is lacking and thousands of additional individuals become infected with the virus each year. Prevention education is not anywhere near a full-fledged solution to the epidemic, however, it is a step towards making strides to reduce the number of new infections and encourage people to get tested on a regular basis. Individuals who are unaware of their HIV/AIDS status are much less likely to be concerned about potential transmission (through unprotected sex, sharing of needles, etc) and will not be apt to receive the treatment required to manage [but not cure] the virus.

For individuals who are aware of their HIV-positive status, the most important thing for them is to focus on maintaining the healthiest lifestyle possible and reaching out to others to offer and receive support. By going to HIV/AIDS community outreach programs, these individuals who are frequently struggling financially are able to access resources that might otherwise be unattainable. They are able to speak openly and honestly with other individuals who are struggling to cope with the same issues. Most importantly, they are able to escape societal stigmatization in the comfort of a close-knit confidential community.

Throughout my research and internship at the Cedar City Herald Center, one thing has become very clear: the continued existence of these HIV/AIDS community outreach programs is essential. These individuals who frequently feel as though they have been shunned by society for their HIV-positive status, deserve to have a place where they feel like they belong – a place that will help them to be the healthiest that they can be under

the circumstances. In order to continue operating organizations like the Cedar City Herald Center, we must find a way to combat the lack of funding that these community outreach programs receive. Introducing membership programs at these Centers in order to have concrete evidence for donors to see where their allotted money is going is a great start, but it is not a conclusive solution for the programs' consistent financial struggle.

Unfortunately, there appears to be a stigma attached with the HIV/AIDS virus that the individuals who become infected have 'done it to themselves' (Jaffe 2004). In this light, many people within our society view HIV/AIDS as an avoidable virus and frequently have less sympathy for the individuals who contract the virus. In order to begin to fight some of these impressions and reduce this stigmatization, it would be beneficial for these community outreach programs to do more local fundraisers and events within their respective communities.

As a result of lack of awareness and education about the virus, I have heard many people say that they believe that HIV-positive individuals will look a certain way or will be able to infect them on sight. By striving to integrate more with the HIV/AIDS community, it is my hope that unaffected individuals will abandon their pre-conceived notions and begin to recognize that these HIV/AIDS-affected individuals are real people with feelings, just like themselves, fighting their own battle. With collaborative fundraisers and increased education, these kinds of HIV/AIDS community outreach programs will hopefully be able to obtain and hold onto the continuous financial support that they so desperately need.

APPENDIX

A). Informed Consent Form

My name is Amanda Greenberg and I am a student at Union College. I am inviting you to participate in a research study. Involvement in the study is voluntary, so you may choose to participate or not. A description of the study is written below.

I am interested in learning more about community support and financial struggles among individuals affected by HIV/AIDS. You will be asked to answer an assortment of questions pertaining to your background and experience with HIV/AIDS. The risks to you of participating in this study are: possible emotional stress as a result of discussing personal experiences. These risks will be minimized by the voluntary nature of participation and the fact that the depth of the stories and information that you choose to share with me is entirely your decision. If you no longer wish to continue, you have the right to withdraw from the study, without penalty, at any time.

All information will be kept anonymous and confidential.

I understand that even though all aspects of the research study may not be explained to me beforehand (e.g., the entire purpose of the study), during the debriefing session I will be given information about the study and have the opportunity to ask questions.

All of my questions have been answered and I wish to participate in this research study.

_____ _____

Signature of participant date

_____

Print name of participant

_____ _____

Name of investigator date

B). Interview Questions

1). Where did you grow up? Tell me a little bit about how your hometown has shaped you as a person.

→ *follow-up: How would you describe early experiences with your family (parents & siblings) and friends?*

2). What was your favorite thing about your childhood?

→ *follow-up: What are your favorite activities now? Hobbies? Sports?*

3). What kinds of things do you look forward to the most each day?

→ *follow-up: What do you look forward to the least?*

4). Are you currently employed? If so, where do you work/what do you do?

→ *follow-up [if applicable]: Would you say that the clients rely on the Center for food and other resources?*

→ *follow-up: Has the Center having to cut back the number of days it is open to the public had an impact on you and/or the clients both emotionally and financially?*

5). What does the Center mean to you?

→ *follow-up [if applicable and participant seems comfortable]: Do you feel that people who come are actually open to talking about HIV/AIDS?*

6). Over the next few years, do you think that you will continue working at the Center? Why or why not?

→ *follow-up: Do you feel comfortable with the community that has formed here?*

C). Debriefing Statement

Thank you very much for participating in my research study about community support among individuals affected by HIV/AIDS. In addition to looking at the community aspect, I am also exploring the impact that financial instability has on this same group of individuals. It is likely that a number of your responses will be used to support or undermine ongoing research for my senior thesis project; however, your name (& the names of your family members, hometown, etc) will be changed in order to protect your identity. My main goals in all of this are to spread awareness about HIV/AIDS throughout the community and to explore the connections between HIV/AIDS, community support, and poverty. Once again, I thoroughly appreciate your participation and would be happy to provide you with any additional information regarding the progression and/or results of this research study.

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