

January 2012

## Occupational Stressors Among Providers of HIV Prevention and Support Services

Mackenzie Kaye Rapp  
*University of South Florida*, [mackenzierapp@gmail.com](mailto:mackenzierapp@gmail.com)

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Occupational Stressors Among Providers of HIV Prevention and Support  
Services

By

Mackenzie Rapp

A thesis submitted in partial fulfillment of the requirements for the degree of  
Master of Arts  
Department of Anthropology  
College of Arts and Sciences  
University of South Florida

Major Professor: Nancy Romero-Daza, Ph.D.  
Heide Castañeda, Ph.D.  
Elizabeth Bird, Ph.D.

Date of Approval:  
March 5, 2012

Keywords: HIV/AIDS, political economy, burnout, social services

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## **Abstract**

Much literature has documented the high levels of burnout, stress, and grief in HIV physicians and nurses due to the challenging nature of the chronic, fatal disease with which they deal on a daily basis. Providers of social and HIV prevention services face similar challenges while working with stigmatized, terminally ill clients. However, since these latter occupations deal with social, rather than clinical interventions, their experiences may differ from those of medical personnel. Through open-ended interviews with HIV counselors, educators, case managers, and outreach workers, this exploratory study assesses the occupational stressors of providers of social and HIV prevention services in the Tampa Bay area. By addressing the factors that contribute to stress in HIV prevention work, coping strategies and structural interventions are recommended to an AIDS service organization to combat the ill effects of these problems.

## **Chapter One**

### *Introduction:*

After thirty years of the HIV/AIDS epidemic, we have witnessed affliction, solidarity, and exciting advances in medicine. Today many people infected with HIV can become 'long-term survivors,' thanks to highly active anti-retroviral therapy. People today are living longer and healthier lives due to improvements in both treatment methods and medications. A less recognized corollary to this history is that many providers of HIV services have been around since the beginning of the epidemic, and may also be considered 'long-term survivors' as they have no doubt endured personal hardship and witnessed extensive suffering throughout the years (Miller 2000).

HIV/AIDS will persist as a major health problem in the coming decades, so it is imperative that the needs of health workers in this challenging field are examined and addressed. Indeed, experienced, committed, caring service providers are a vital resource in the fight against the virus. While, the problem of occupational stress and burnout addressed in this manuscript focuses on HIV/AIDS, the findings are also relevant and applicable to health and social professionals in other fields (e.g., oncology, Alzheimer's).

The costs of occupational stress are substantial. The United States industry lost approximately 550 million working days annually in the 1980s due to absenteeism, with an estimated 54% of these lost days being stress-related (Elkin and Rosch 1990). Work stress has been linked to increased alcohol and drug use, marital dissatisfaction, obesity,

and other serious health conditions (e.g., coronary heart disease, hypertension, migraines, asthma, and mental illness) (Cooper and Davidson 1987).

What exactly causes stress at work? According to Cox and colleagues (1993), a stressful work situation is one in which coping resources are not well matched to the level of demand placed upon them; where coping has constraints placed upon it, including lack of social support; and where the person has consequent negative emotions which chronically diminish well-being. In an early study of occupational stress, Frazer (1947) identified numerous factors that were associated with increased stress in the work environment. Some of these included: work without variety, work requiring constant vigilance, very light or sedentary work, boring and disliked work, or domestic factors such as reduced leisure time and restricted social contacts. In contrast, Locke (1976) identified several factors related to work satisfaction, such as mentally challenging work, personal interest in the work, high personal self-esteem, rewards that fit the person's aspirations, and working conditions that enable satisfactory completion of the work.

Recently, considerable emphasis has been placed on burnout among health care workers, particularly on its impact on the quality of patient care, efficiency, and effectiveness of health services (Marine et al. 2009; Felton 1998). However, much of the previous research focus has been limited to the high levels of burnout, stress, and grief in HIV physicians and nurses due to the challenging nature of their work environment (Benevides-Pereira and Alves 2007; Brown 2006; Saag 2006). Another significant workforce, the HIV prevention and social support providers, face similar hurdles. Since these occupations deal with social, rather than clinical interventions, the experiences of social service providers are significantly different from those of medical personnel.

In this thesis I will approach the above topics by exploring the work-related experiences of HIV prevention and social services in Tampa, FL. Using information gathered from interviews with providers of social and HIV prevention services, I will outline what motivates providers to work in HIV prevention, the factors that participants see as stressful, and the participants' reported responses to their work environment.

The first two chapters in this manuscript provide a framework for the research presented here. Chapter 1 focuses on previous literature relating to occupational stress and burnout among health care providers, specifically those in the HIV/AIDS field. The chapter begins with an introduction to occupational stress then moves to an outline of burnout in HIV/AIDS work.

Chapter 2 describes the research setting and situates HIV social services in Tampa within a broader context of HIV/AIDS in Florida and the United States. Service providers in the Tampa Bay area must also tackle regional-specific issues such as housing shortages, fluctuations in caseloads due to seasonal migration, and a bilingual client base.

Chapter 3 describes the methodology used to address the research questions. The evidence upon which I draw my arguments is based on participant observation during a Fall 2011 semester-long internship working in HIV services and open-ended interviews with providers of social and HIV prevention services in Tampa Bay. In total, 18 interviews were conducted with case managers, educators, and outreach workers in the HIV field.

Chapter 4 describes the results of the study. It illustrates providers' motivations for entering and continuing in the field, factors that contribute to occupational stress, and providers' responses to stress in their work environment. I will attempt to demonstrate



with my results that political and economic factors such as the recent economic downturn and funding for HIV services contribute to participants' stress. Other stressors include factors that are intrinsic to the job and relationships with clients, coworkers, family, and friends.

Chapter 5 ties the results of the study back to the previous literature and the context of HIV social services in Tampa, showing how structural factors intensify occupational stress and burnout for HIV service providers. It illustrates that many aggravators of occupational stress are outside service providers' control, such as the economic downturn and available funding for HIV services. I argue that these structural factors severely constrain service providers' efficacy, and therefore, amplify their levels of occupational stress. This chapter includes a discussion of specific recommendations to address the issues presented by participants and related research. These include structural, organizational, and individual level interventions aimed to reduce occupational stress. Finally, this section also discusses recommendations for future research.

*Previous Research:*

Much of the research conducted on the impact of HIV has focused on patients living with HIV/AIDS or those at risk of contracting the disease. Less research has considered the impact of HIV on providers caring for these patients. However, it is important to examine and analyze the behavior of providers in the HIV field because health care workers are at risk for harmful psychological effects (Speakes-Lewis 2011; Myers et al. 2007; Reece et al. 2007; Bennett and Kelaher 1993). Effective interventions can reduce the effects of grief, stress, and burnout, and in turn reduce associated variables such as absenteeism and staff turnover (Bennett and Kelaher 1993). Indeed, AIDS

burnout research can benefit all fields of health care. As noted by Miller (1996), we must take the needs of health workers seriously if we are to provide the best care possible.

Various health professionals are at risk for burnout, including nurses, social workers, dentists, care providers in oncology and AIDS-patient care, emergency staff, mental health workers, speech and language pathologists, among others (Felton 1998). In previous research, the symptoms of burnout have been most consistently described as the combination of emotional exhaustion, depersonalization, and reduced sense of personal accomplishment (Benevides-Pereira and Das Neves Alves 2007). In a study by Visintini and colleagues (1996), staff working in the specialties of surgery, oncology, and intensive care demonstrated that overwork, managing dying people, and inadequate preparation to cope with the emotional needs of patients were major causes of occupational stress. A study by Kleiber, Gusy, Enzmann and Beerlage (1992) initially examined the fields of HIV/AIDS (n=360), oncology (n=78), and geriatric care (n=155) to compare factors and stressors associated with psychosomatic and other occupational reactions. The researchers found no significant differences in burnout rates between the three health fields. However, in the second stage of research, Kleiber and colleagues found that specific occupations within the HIV/AIDS field generate stress on their caregivers at different levels. Psychologists and social workers had higher levels of burnout than nurses and clinicians (Miller 1992).

There are additional studies that compare the social impact on workers in HIV/AIDS occupations with that of providers in other fields. Miller and Gillies (1996) compared the effects of occupation on the domestic and social lives of oncology and HIV/AIDS staff. They found few differences, but discovered that HIV workers were less

likely to discuss their work socially, and more likely to have a family member who had suffered a chronic or life-threatening illness. Bennett, Michie, and Kippax (1991, cited by Barbour 1994) found that AIDS nurses did not suffer emotional exhaustion as often as did oncology nurses, but they were prone to greater intensity of emotional exhaustion when it did occur. It has also been suggested that burnout in the AIDS field manifests more sharply and more strongly than in other fields such as oncology (Bellani et al. 1996). These differences could be due to AIDS-specific stressors such as fear of contagion, issues of sexuality, stigma, exposure to alternative lifestyles, and issues of confidentiality (Barbour 1994).

According to the literature assessing the experiences of physicians and nurses working with HIV/AIDS patients, clinical providers in this field are at increased risk for grief (Bennett and Kelaher 1993), burnout (Demmer 2004), and occupational stress (Miller 1992). Studies have demonstrated that caring for people with AIDS is associated with unique demands from providers due to the nature of the chronic, stigmatized, terminal illness (Miller and Gillies 1996; Barbour 1994). When combined, burnout, stress, and grief have significant effects on clinicians can prevent them from providing the highest quality of care. The overload of work demands manifests itself physically, behaviorally, and cognitively in symptoms such as physical exhaustion, lack of sleep, apathy, cynicism, depression, and increased use of drugs and alcohol (Demmer 2004; Bellani et al. 1996).

Individual factors such as age, seniority, and gender may also affect susceptibility to emotional exhaustion, depersonalization, and a reduced sense of personal accomplishment. The age of health workers is an often-examined factor in studies

looking at vulnerability to stress (Miller 2000). For example, in a study by Ulrich and FitzGerald (1990) younger oncology physicians were the most fatigued, and stress reduced as staff aged. In addition, Cordes and Dougherty (1993) found that younger people consistently report higher scores on each of the Maslach Burnout Inventory (MBI) subscales: emotional exhaustion, depersonalization, and personal accomplishment. In another study, older nurses with more experience had significantly lower emotional exhaustion (van Servellen and Leake 1993).

Gender may also impact burnout. According to research by Erickson and Ritter (2001), women are more likely to experience burnout. However, more contemporary research to date does not consistently differentiate the experiences of work stress according to gender (Miller 2000), noting that although the attributes of individual health workers may affect levels of health worker stress and burnout, it is *mainly* due to the structures and processes of health care organizations.

In additional studies, researchers have demonstrated high turnover rates and levels of burnout in HIV/AIDS volunteers and social workers (Held and Brann 2007; Ross et al. 1999; Maslanka 1996). This evidence suggests a need for research examining the factors contributing to occupational stress and burnout in providers of social and HIV prevention services. Piemme and Bolle (1990, as cited in Bennett and Kelaher 1993) explain that nurses working with AIDS patients (and also oncology patients) face “bereavement overload” from exposure to several terminally ill patients over a short period of time. There is no time for these providers to grieve. This may cause providers to feel like they are ineffective at making a difference in the patient’s care. The chronic nature of HIV/AIDS creates problems for both patients and caregivers. These include numerous

remissions and relapses; increased financial, social, physical, and emotional pressures; long-term family disruption; progressive decline in health; elaborate treatment regimens and their debilitating side effects; and recurring dilemmas surrounding decision making and treatment choices (Walker et al. 1996). Stress and burnout can have effects on personal lives. In a study of HIV workers in Italy (n=67), Miller and Gillies (1996) found a surprisingly high number of participants with problems in their domestic lives (35-56%). However, research has not addressed these issues as they pertain to other care and prevention workers. Because counselors, educators, outreach workers, and case managers must also deal with high workloads, low budgets, and a stigmatized, disenfranchised client population, it is important to assess these issues in their workplace.

Employees of AIDS service organizations face a dual threat of stressors: social work-related stressors (such as a heavy workload, poor pay, unpleasant working environment, and bureaucratic restrictions) and AIDS stigma-related stressors (fear of contagion and disapproval from friends and relatives) (Kerr et al. 2011). Furthermore, providers of HIV prevention and social support services may experience the secondary stigmatization of working with a stigmatizing disease (Miller 2000). A recent study (Reece et al. 2007) demonstrated that HIV prevention workers experience social stigma due to their work in HIV. Workers in the HIV field experience job stress from emotional strain, excessive demands, time pressure, social stigma, and identification with groups who are most affected (Miller 1992).

Burnout is a syndrome that may occur if stress is not recognized and addressed in these populations (Miller 1992). According to Miller and Gillies (1996), if life outside of work fails to relieve job stress, somatization can result in headaches, tiredness, irritability,

neck and shoulder pain, a tendency to cry, and loss of appetite. Burnout syndrome is the combination of emotional exhaustion, depersonalization, and a reduced sense of personal accomplishment of employees (Miller 1992). When people say they are “burnt out,” they mean work has lost meaning for them, they are disillusioned, rundown, not approaching their life goals, or they are being stretched too thin (Felton 1998).

The combination of burnout factors can lead to reduced staff satisfaction, increased staff turnover, and result in loss of valuable staff (Bennett and Kelaher 1993). The 1998 Northwestern National Life of Minneapolis Survey of 600 American workers indicated that burnout resulted in lowered production, and increases in absenteeism, health care costs, and personnel turnover. Significant burnout occurred when employee benefits were cut, when corporate ownership changed, when frequent overtime was required, and when the work force was reduced (Felton 1998).

Another potential source of stress is personal identification with, or emotional involvement with, clients who may have the providers’ own sexual orientation, or substance use difficulties. Many gay professionals will over-identify with people with AIDS and will push themselves too hard to provide care (Bennett and Kelaher 1993; Barbour 1994). Providers of services may share a background and similar experiences as clients and, due to prolonged contact, staff often form close relationships with clients (Bennett and Kelaher 1993). In a study conducted by Bennett (1992), identification with HIV/AIDS patients was found to be an important factor contributing to grief. Where the majority of patients are gay, it would be expected that staff members affiliated with the gay community would show greater identification with patients. According to Selwyn

(1995), identification with patients can result in loss of perspective, a failure to set limits, and an increasingly heavy burden for providers.

Service providers facing occupational stress and burnout are in need of effective models of stress management and prevention (Miller 2000). Miller and Gillies (1993) divide such models into four categories: *professional supervision*; *emotional support/therapeutic counseling*; *stress reduction/management*; and *context management*. In *professional supervision*, a supportive supervisor monitors a provider during daily tasks such as reviewing case files and then provides an evaluation of procedures and skills. The authors note that this intervention could increase the confidence of the provider, but in some cases it could also be stress-inducing because it exposes the provider to peer criticism. In *emotional support* or *therapeutic counseling* interventions, the intention is to relieve the health worker through individual or group sessions such as support groups. Regular expression of suppressed feelings can help providers avoid burnout. In *stress reduction or management* interventions, the providers employ active relaxation techniques or develop skills to prevent stress from arising. Lastly, *context management* interventions are aimed at the organizational level rather than the individual level, and involve structural or environmental initiatives. Examples of this type of intervention include limiting allowable work hours for staff or providing quiet rest areas for staff.

However, it is important to note that evidence of the efficacy of these interventions is inconclusive (Briner 1997). Reynolds and Briner (1994, as cited in Miller 2000), state that, “beliefs about the value of occupational stress in the workforce have gone unchallenged, and they are based on simplistic views of organizations and

individuals that simply do not match the complexities of causes and consequences identified in the burnout literature” (page 193). They add that interventions are too often aimed at individuals as the agent of change rather than organizations. Furthermore, burnout is a consequence of chronic processes and should not be treated with acute interventions such as one-time workshops or seminars (Bennett et al. 1994). While empirical evidence has not proven the effectiveness of the various models of staff support, it is evident that organizations should treat service providers as valuable resources and consider their needs (Miller 2000).

*Study Goals:*

This exploratory study aims to delineate the experiences of HIV social and prevention work and to examine how they compare with the experiences of clinicians in the field. Specifically, this thesis will examine service providers’ motivations for working in HIV prevention, factors that cause stress at work, and their personal responses and coping strategies in a stressful work environment. The research will begin to address the literature gap regarding HIV social and prevention workers experiences on the job. A significant amount of literature documents the prevalence of burnout, grief, stress, and stigmatization of HIV nurses and physicians (Felton 1998; Miller and Gillies 1996; Barbour 1994; Bennett and Kelaher 1993). While these clinicians work with the same disenfranchised population served by providers of HIV prevention and social services, the nature of social and prevention work is much different. Social service providers face the challenges of social work and AIDS stigma simultaneously, which includes poor pay, bureaucratic restrictions, disapproval from relatives and friends, and heavy workload (Kerr et al. 2011). Rather than addressing the clinical manifestations of HIV and its many



opportunistic infections, these providers must address the social aspects of living with HIV/AIDS. They regularly help clients address psychosocial issues such as adherence to medication regimens, financial insecurity, and loss of medical benefits. Instead of treating the physical manifestations of HIV/AIDS, these providers must undertake the social and emotional effects of the illness. Accordingly, the service providers' experiences of stress at work may differ from those of clinicians.

This study will explore factors that contribute to the stress of HIV social service providers and recommend coping strategies to administrators and staff at AIDS service organizations. If staff members are informed about the manifestations of extreme job stress, such as headaches, lack of sleep, resentment, helplessness, and alienation, they can better observe the symptoms in themselves and others. This could prevent negative outcomes such as anxiety, depression, and antagonistic relationships with colleagues, and negative attitudes towards patients. Workers can employ effective coping strategies to deal with occupational stresses if they are informed and aware of the symptoms and of the implications of ignoring them.

These improvements could be significant for administrators who face high employee turnover, absenteeism, and low quality work. Administrators can utilize proven strategies such as workplace support groups, or provide personal coping resources to their staff. Providing a supportive work environment could improve staff relations and enable the organization to provide better care.

## **Chapter Two**

### *Introduction*

Approximately 583,000 Americans have died since the onset of the AIDS epidemic in the 1980s (HRSA 2010). Each year, it is estimated that 56,000 Americans become infected with HIV, and more than 1.1 million Americans are living with the HIV virus today (HRSA 2010). In 1990, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act to improve the quality and availability of care for populations that lack health insurance and are disenfranchised from the health care system. This program was named after Ryan White, an HIV-positive teenager from Indiana, who fought stigma and helped bring HIV/AIDS issues to the mainstream public. The CARE Act was reauthorized as the Ryan White HIV/AIDS Treatment Extension Act of 2009 to provide services for an estimated 529,000 people each year who do not have sufficient coverage or resources to cope with HIV (HRSA 2010).

This federal funding, coupled with monies from states, provides the bulk of funding for HIV/AIDS services in the United States. HIV prevention and social service providers utilize grants allocated from these sources to participate in the local community planning process and work with local entities such as clinics for primary care, mental health and substance abuse treatment centers, AIDS Service Organizations, community-based organizations, correctional or jail facilities, schools, housing agencies, homeless shelters, and local media outlets. Many services can be accessed without a referral, but case managers help clients navigate the system of care. This is generally accomplished by

assessing clients' specific needs, developing a case plan, providing information and referrals to other agencies, and monitoring the progress of the client through the continuum.

Numerous factors complicate and constrain the ability of service providers such as case managers to provide quality services. For instance, salary levels continue to be low, which impact the retention of staff (RWCH/ASP 2008). Staff turnover hinders agencies' effectiveness and negatively influences client retention. Moreover, differing eligibility determination processes and requirements create additional administrative overhead and reduce time that case managers can devote to clients (RWCH/ASP 2008). Yet, the foremost problem for providers of HIV/AIDS prevention and social service providers is arguably funding and the availability of resources.

### *HIV/AIDS Funding and the Political Economy of Health*

The political economy of health framework attempts to understand health-related issues by examining the macro-level forces that shape the occurrence and distribution of disease. This approach is concerned with the social production of illness and the impact of economic and political factors on the production, distribution, and consumption of health services (Baer 1982). Using a political economy of health framework, this chapter illustrates the structure of HIV/AIDS funding and service delivery and explains how the structure itself constrains the ability of HIV prevention and social service providers to adequately serve the needs of their clients.

Since its onset, the HIV/AIDS epidemic has been inextricably linked to economic and political structures of society. For example, Singer (1993) states that the AIDS

epidemic is a product of the interrelationship of social and environmental factors, such as unequal access to status, resources, and power. Through his use of the political economy of health approach, Singer (2004; 1993) has significantly contributed to an understanding of the relationships between social inequality and health outcomes. In his work with drug users in the United States (2005), he illustrates how political, economic, and social factors related to gender, age, and race increase risk of HIV infection associated with drug injecting. He argues that decreasing HIV risk for injecting drug users necessitates policy efforts that consider the motivations associated with injecting drug use. Most notably, Singer developed critical medical anthropology (1995), an anthropological approach that seeks to uncover causes of poor health as they relate to capitalism and neoliberal economics while examining health structures on a macro and micro level.

Indeed, politics and economics have influenced HIV/AIDS since the beginning of the epidemic and continue to act as major cofactors in risk and treatment efforts (Whelehan 2009). Economic and political factors shape the epidemic in several ways: 1) by influencing which groups have increased risk for contracting the virus; and 2) by determining the rate and type of prevention, testing, and treatment programs that are developed, which in turn constrains the allocation of resources for portions of the population and their utilization of available health services (Whelehan 2009).

First, the reality that individuals with fewer resources have increased health risks as a result of poor nutrition, higher rates of infectious disease, and less access to health care is well documented (Wiley and Allen 2009; Maternowska 2006; Farmer 1996). In the 1960s and 70s, the Whitehall cohort studies examined the social determinants of health among thousands of British civil servants (Marmot 1994, as cited in Dressler

2010). This research found a strong association between levels of civil servant employment and mortality rates for a wide variety of diseases and health conditions. Men in the lowest levels of employment had a mortality rate three times higher than that of administrators. Lower level civil servants had higher rates of smoking, high blood pressure, coronary heart disease, and a greater risk for heart attacks. Clearly, there is a relationship between social position and health. Poverty is thus a central cofactor in HIV risk; indeed, today the majority of people living with HIV/AIDS are poor (Whelehan 2009; Farmer 2006; Singer 2005). Inequality and poverty create complex forces that affect health in a multitude of ways. Those without adequate resources are not able to pay for healthcare, proper nutrition, sanitation, safe housing, transportation, and education – all of which can have profound impacts on health. For example, an individual without an automobile relies on the schedule and quality of public transportation to travel to work, to the grocery store, to appointments, etc. Clients may face the hardship of taking several different buses across town to attend a doctor’s appointment between their two jobs. In this way, lack of resources pose major challenges for individuals at the bottom of the social ladder.

Of course, income is not the only way in which society is divided; other significant divisions include race, gender, national origin, religious belief, sexual orientation, and language. Race and gender categories cannot be wholly separated from socioeconomic status because these factors exacerbate each other. Minority groups also have less power and are disadvantaged politically in society, which increases the chance that their health and social needs are disregarded by those in power. For example, President Ronald Reagan did not publicly acknowledge the existence of the AIDS

epidemic until 1987, when more than 20,000 Americans had already died from the virus – arguably because the disease mainly affected marginalized groups such as drug users, homosexuals, minorities, and the poor (Wiley and Allen 2009). The conservative ideology of those in power did not condone certain sexual behaviors or the use of drugs and saw those first affected by the epidemic as societal deviants. As a result, the government was slow to act because those in power made moralistic judgments regarding marginalized populations and associated behaviors. Failing to acknowledge the threat of HIV in a timely fashion undoubtedly affected the rate of its initial spread into the population. Today, political and economic factors continue to impact risk. If individuals are judged as immoral, sinful, or undeserving based on their behavior or membership in a group, shame and stigma will drive the behavior underground and discourage people from seeking help (Whelehan 2009).

Second, political and economic factors determine the rate and type of prevention, testing, and treatment programs that are developed and funded. For instance, in 2001, President George W. Bush reinstated the Global Gag Rule, originally enacted by Reagan, which withdrew United States funding for reproductive health services from international agencies that mentioned or provided abortion services (Wiley and Allen 2009). This policy cut funding from non-governmental organizations (NGOs) that provide much needed services for millions of people in developing countries. Policy impact studies now show that the Global Gag Rule increased the negative impacts of HIV/AIDS and contributed to the deterioration of women's health around the world (Global Gag Rule Impact Project 2006, as cited in Whiteford 2009). In another example, the President's Emergency Plan for AIDS Relief (PEPFAR) provides approximately \$5 billion per year

to countries experiencing the gravest effects of the HIV/AIDS pandemic – although, under the Bush administration, PEPFAR subsidized US-based pharmaceutical giants and directed at least one-third of prevention funds to anti-condom projects run by faith-based organizations (Schoepf, 2004). These moralistic policies not only ignore the reality of human sexual behavior, but also limit the availability of desperately needed health services.

HIV prevention and treatment programs in the United States are also impacted by politics. For example, the use of federal funds for needle-exchange programs is currently banned in the United States (Szalavitz 2009), even though their harm reduction approach has proven effective in slowing and preventing the transmission of HIV in injecting drug user populations (Kermode et al. 2010; Buchanan et al. 2004). Injecting drug users can exchange used and potentially contaminated syringes and injection equipment for new sterile supplies, and thus reduce their chance of infection. However, there is political opposition to providing clean needles for drug addicts on moral grounds, despite the scientific support for needle exchange (Kermode et al. 2010; Szalavitz 2009). Due to this political opposition, needle exchange programs are criminalized and even targeted by police (Buchanan et al. 2004). Again, this is an example of the impact of economic and political structures on the development of HIV prevention, testing, and treatment options for the public.

So how do the structures of political and economic factors relate to providers and their ability to adequately serve the needs of their clients? Robust economic stability and a favorable political climate provide an infrastructure for intervention efforts, including prevention, production and availability of treatments, and provision of medical care

(Whelehan 2009). Without stable funding for services, providers are left without the resources necessary to tend to their clients, who are themselves at increased risk for ill health due to homelessness, unemployment, and poverty. The following sections illustrate the structure of HIV/AIDS funding and service delivery and explain how the structure itself constrains the ability of HIV prevention and social service providers.

### *The Ryan White Program*

Today, the Ryan White Program remains the single largest federal program designed specifically for people with HIV/AIDS (HRSA 2010). The program functions as a “payer of last resort” for individuals and families that have no other source of coverage. Administered by the Health Resources and Services Administration (HRSA), the program remains the third largest source of public financing for HIV/AIDS care in the United States, after Medicaid and Medicare (Kaiser Foundation 2007). The Ryan White program is comprised of several parts, and the types of entities eligible vary for each part. The majority of funding is provided to states (59%) followed by cities (29%), while the remainder goes directly to organizations (Kaiser Foundation 2007). The major parts of the Ryan White Program are (HRSA 2010):

**Part A** targets cities disproportionately affected by HIV. Today 56 grantees made up of Eligible Metropolitan Areas (EMAs) and smaller Transitional Grant Areas (TGAs) are funded. At least 75% of the funds must be spent on core medical services such as outpatient and ambulatory services, medications, hospice, mental health, and medical case management. EMAs are required to establish Planning Councils to deliver care and develop priorities to allocate funds. The 2010 fiscal year appropriation was approximately \$680 million.



**Part B** funds all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and five other territories. These funds include Base and Supplemental grants to states, AIDS Drug Assistance Program (ADAP) grants, and Emerging Communities grants. At least 75% of these funds must be spent on core services. ADAP is the largest component of Part B spending today due to increasing costs of pharmaceutical treatment. The state ADAP provides medications to low-income individuals with HIV disease who have limited or no cover from private insurance or Medicaid. The FY 2010 Part B appropriation was \$1.25 billion, of which \$835 million went to ADAP.

**Part C** awards contracts directly to organizations and service providers to support HIV early intervention services and ambulatory care. At least 75% of these funds must be spent on core medical services. The FY 2010 Part C appropriation was approximately \$206 million.

**Part D** funds private and public organizations to provide family-centered and community-based services. In the 2010 fiscal year, Part D appropriations were \$77.8 million.

**Part F** funds AIDS Education and Training Centers (AETCs), the Minority AIDS Initiative (MAI), and Special Projects of National Significance (SPNS). The 2010 fiscal year appropriations for Part F were over \$73 million.

The Ryan White Program will continue to play a critical role for people living with HIV/AIDS in the United States. Unfortunately, because the program is a discretionary federal grant program, its funding depends on annual appropriations by Congress (Kaiser Foundation 2007). Therefore, funding levels do not necessarily correspond with the number of people who need services or the actual costs of services.

Consequently, some states and communities are unable to meet the total needs of people living with HIV/AIDS. According to a recent report by the National Alliance of State and Territorial AIDS Directors, ADAPs need an increase of \$360 million in 2012 to maintain their programs and correct structural deficits that have built up (NASTAD 2011). However, the federal share of ADAP funding has decreased from 72% in FY 2003 to 49% in FY 2009 (NASTAD 2011).

Regrettably, funding issues may continue to worsen as individuals are losing their jobs and insurance in the recession. Due to the economic downturn, a record number of people are in need of safety net services. As 56,000 new HIV infections occur annually in the United States, there is a relatively constant demand for new treatment spots (Ryan White 2010). Furthermore, individuals with HIV/AIDS are living much longer with the help of highly effective antiretroviral drugs. As a result, individuals may require programs like ADAP for a lifetime. Mercifully, funding increases have continued. At \$2.29 billion, appropriations for the Ryan White Program were the largest in history for the fiscal year of 2010 (Ryan White 2010).

Relying on federal funding creates problems for states, communities and organizations trying to provide consistent services for vulnerable clients. A delay in the disbursement of federal Ryan White funds in 2011 forced some community-based groups to temporarily reduce their services. Congress took far longer than usual to approve the federal budget for fiscal year 2011, and a miscalculation in Ryan White funding allocations to several cities and states by the Health Resources and Services Administration (HRSA) created further delays (Washington Blade 2011). The disbursement problem was resolved by September, but the HRSA acknowledged that

delays might have adversely impacted hundreds of community-based organizations and as many as 500,000 people living with AIDS in the country (Washington Blade 2011). Many entities serving HIV-positive clients depend on the consistent and timely delivery of federal funding to operate. Large-scale structural problems like delays in funding disbursements create instability in organizations providing much needed services to clients and interrupt the continuity of care for people living with HIV and AIDS.

### *Florida HIV: History, Statistics, and Trends*

In 1981, Florida reported its first AIDS case. Active surveillance of AIDS cases began in 1984, and in July of 1997 Florida began reporting new HIV cases (Florida SCSN 2009). Cases of AIDS peaked in 1993 when the United States expanded the definition of AIDS, but have been declining thereafter. Florida ranked second among all states in the number of reported AIDS cases, and first among all states that reported HIV cases in 2000 (Florida SCSN 2009). In that same year, two major metropolitan areas in Florida – Miami and Ft. Lauderdale – were in the top ten for number of reported AIDS cases in the United States. Miami had an even higher case rate at that time than New York City at 58.0 per 100,000 compared with 56.6 per 100,000 (Florida SCSN 2009). The state of Florida has consistently reported 10 to 12% of the national AIDS morbidity, and the Department of Health estimates that 125,000 people, or approximately 11.7% of the national estimate of 1,185,000 HIV cases, are currently found in Florida (Florida SCSN 2009). In 2010, the rate of HIV cases was 31.8 per 100,000 in Florida (FloridaCHARTS 2010). The HIV/AIDS epidemic is widespread in Florida, but the highest rates of HIV occur in several urban areas. Seven Florida counties represented 73% of Florida's total HIV reported cases in 2007: Broward, Duval, Hillsborough,

Miami-Dade, Orange, Palm Beach, and Pinellas. Miami-Dade County ranked the highest in the state with 25% of HIV cases, while Hillsborough, the study county, ranked fourth with 7% of Floridian HIV cases (Florida SCSN 2009).

Advantageously, Florida has a high (roughly 90%) completeness of reporting diagnosed cases and good timeliness of reporting, with 87% of AIDS cases reported within six months and 73% of HIV cases reported within two months of the positive test (Florida SCSN 2009). According to an HIV surveillance employee, Florida tests more people than any other state (surveillance coordinator, personal communication). In addition, Florida was the first state to establish voluntary, confidential HIV counseling and testing at all county public health units in 1987 (RWCH/ASP 2008).

#### *Florida Funding and Resource Allocation*

Federal and state sources provide funding for Ryan White Part B consortia, patient care networks, and county health departments. Specific programs funded in the 2008-2009 service period include Ryan White Part B Consortia, AIDS Insurance Continuation Program (AICP), AIDS Drug Assistance Program (ADAP), General Revenue Patient Care Networks, County Health Departments General Revenue –Direct Patient Care Networks, Housing Opportunities for People with AIDS Program (HOPWA), and special contracts (Florida SCSN 2009). These entities coordinate to provide medical care, pharmaceuticals, dental services, mental health and substance abuse counseling, medical case management, and numerous other support services. Total allocation for patient care services in the 2008-2009 service period was roughly \$165,376,000; HOPWA's allocation was \$4,066,000 (Florida SCSN 2009).

The allocation of services is determined by the Bureau of HIV/AIDS and Departments of Health and then presented at an annual public forum during Florida's Patient Care Planning Group meeting. Resource allocation is subject to change year to year depending on variables such as: percentage of HIV/AIDS cases in geographical areas, the amount of unexpended funds from previous years, and the amount of appropriation for Florida's program (Florida SCSN 2009).

#### *Florida's ADAP Waiting List*

Beginning June 2010, the Florida AIDS Drug Assistance Program (ADAP) joined other states in instituting a waiting list to ensure availability of HIV medications for all ADAP clients who were currently enrolled. State ADAPs are partnerships between federal and state governments and the pharmaceutical industry. ADAPs receive the best prices in the country through agreements negotiated with manufacturers (NASTAD 2011). In 2009, it was estimated that ADAPs nationwide served one-quarter of people with HIV/AIDS receiving care (NASTAD 2011). However, the creation of waiting lists poses critical risks for patients in some states. Patients may become resistant to effective HIV drugs if a treatment regimen is interrupted; so precise adherence is crucial once a medication regimen begins (Freidland and Williams 1999). Unfortunately, waiting lists delay the onset of some clients' course of therapy, which leaves them vulnerable to illness and opportunistic infections.

By May of 2011, there were 8,300 people on waiting lists in 13 states, with Florida accounting for roughly 50% of the total waiting list with 3,938 people (Tampa Tribune 2011; NASTAD 2011). Many states even reduced client eligibility requirements

and removed expensive drugs from their formularies to contain costs, so the reported numbers underestimate true need (Tampa Tribune 2011). The number of clients needing assistance has increased during the economic downturn as people are laid off and lose their insurance coverage. Furthermore, the recession has also limited the states' ability to fund these programs.

The U.S. Health Resources Services Administration places blame on the Florida Health Department for low state funding and failing to recognize the potential for increases in demand. For example, Florida contributes only nine percent toward ADAP programs compared to the national average of 19% by other states (NATAP 2011). In 2011, the state turned to charity to pay for the medications. In February 2011, the state made an agreement with Welvista, a South Carolina-based nonprofit pharmaceutical assistance program, to provide six weeks of funding for medications for more than half of Florida's ADAP program (Tampa Tribune 2011). Pharmaceutical companies also voluntarily paid for \$23.8 million in medications in the spring to reduce the list. By December, Florida's list was reduced to 806 people with the help up \$9 million in Ryan White and \$6.9 million in federal emergency relief funds (ADAP 2011; Florida Independent 2011a), but inched back up to 1,070 people by the end of the month (Florida Independent 2011b). Florida's Bureau of HIV/AIDS believes that the waiting list will continue to be a problem in 2012, but hopes that President Barack Obama's December announcement of \$35 million in additional ADAP funds may lessen the state's burden (Florida Independent 2011b). In the meantime, many people living with HIV/AIDS in the state of Florida wait and remain vulnerable to poor health. The postponement of needed

health care allows patients' condition to worsen, and adds to the responsibilities of health care providers once care is eventually reached.

*Structure of HIV Service Provision in Florida*

The 67 counties of Florida are divided into 14 geographical Ryan White Part B areas, which act as planning bodies and are responsible for planning and prioritizing the delivery of HIV/AIDS services. Figure 1 illustrates the 14 Ryan White CARE Act Part B Service Areas and Planning Bodies. The federal Ryan White Program and state General Revenue fund these services, in part. Each of the 14 planning consortia meets once a month to discuss the needs of clients in the area, and an elected member of each consortium participates in the Statewide Florida Comprehensive Planning Network to represent their area (Florida SCSN 2009).

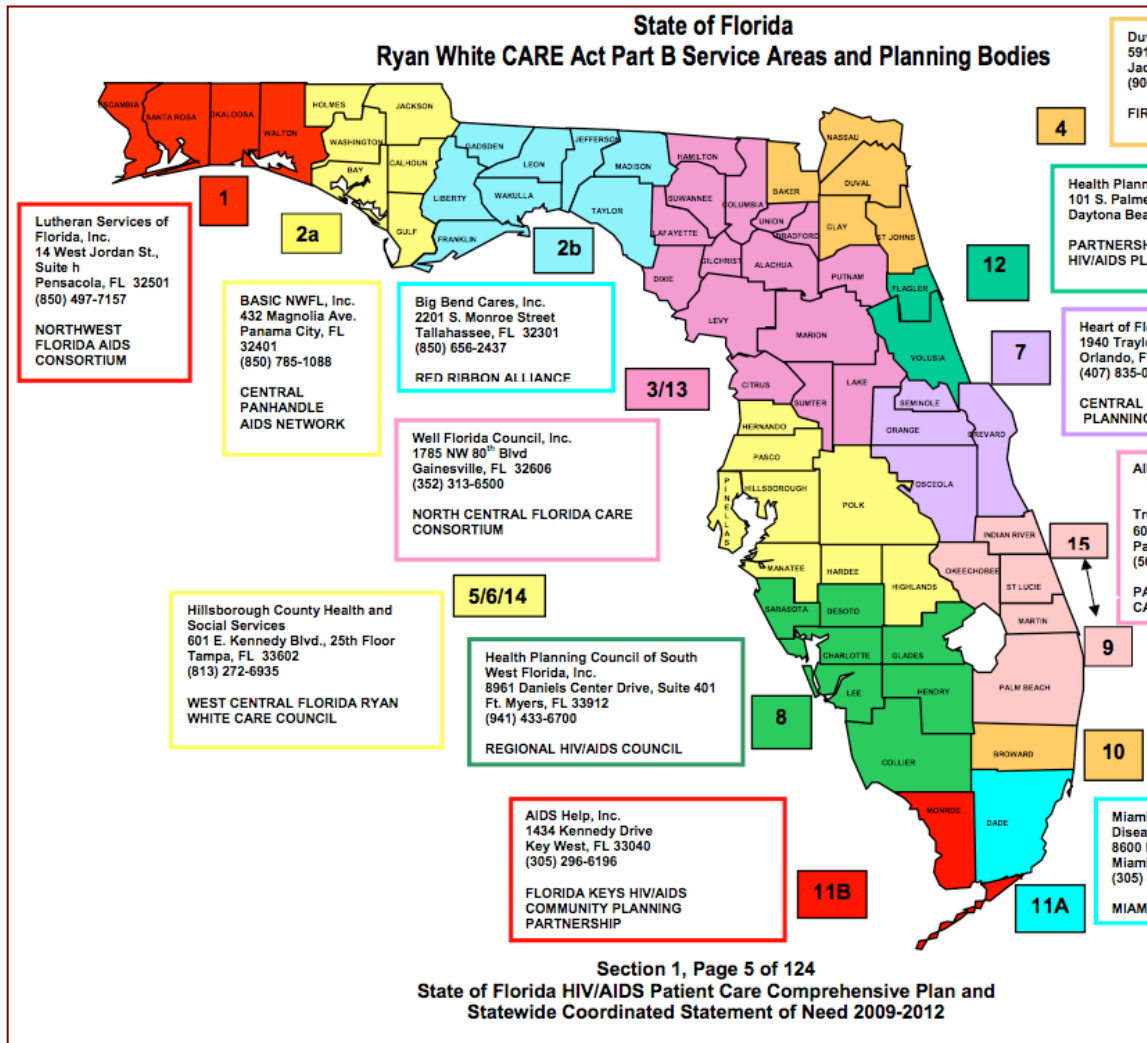


Figure 1. Ryan White CARE Act Part B Service Areas and Planning Bodies  
(Florida SCSN 2009)

### *Florida-specific Client and Geographical Challenges*

Providers of HIV prevention and social support services in Florida face specific challenges due to their client base and geographical location. For example, Florida has more inward migration than other states because many people living with HIV/AIDS come to Florida for the climate or to live near their retired parents (Florida SCSN 2009). As many as 5% of reported cases could have originated in other states, which means the



true number of people living with HIV/AIDS in Florida could be higher than reported (Florida SCSN 2009). The allocation of Ryan White funding does not compensate for interstate migration, so Florida does not receive any additional money (Florida SCSN 2009). Seasonal fluctuations in population also occur throughout the year due to seasonal migrant laborers and people who reside in Florida for only part of the year. Therefore, the demand for services varies because of the ebb and flow of populations. Furthermore, because migrant workers may lack citizenship and have immigration concerns, many are never eligible for Medicaid or other programs and remain dependent on Ryan White funding for services. Moreover, this population faces high rates of poverty, lack of transportation, lack of insurance, and the need to coordinate care during work travel, which increases their costs of care (Florida SCSN 2009).

Poverty, mental illness, substance abuse, homelessness, and lack of insurance are problems faced by numerous people living with AIDS in the state. Seventeen percent of Floridians were living below 100% of the poverty level according to the 2000 US Census, and 23% were without insurance (United States Census 2000). The increasing number of individuals without health insurance is a concern when planning for public funded services. In 2008, the Florida Bureau of HIV/AIDS identified 1,504 people living with co-occurring HIV/AIDS and mental illness issues, and 9,621 individuals with substance abuse co-morbidities (Florida SCSN 2009). The Bureau identified substance abuse treatment as a major challenge for the state as many areas report waiting lists for these services. In the same year 1.5% of people living with HIV/AIDS reported to be homeless (Florida SCSN 2009). The Florida Department of Children and Families estimates that on any given day there are 59,036 persons in Florida who are homeless

(RWCH/ASP 2008, 2008 Annual Report on Homelessness Conditions in Florida).

Transient homeless populations seek warmer climates during winter months and may have numerous health issues requiring treatment. Interestingly, in the 2009-2012 State of Florida HIV/AIDS Patient Care Comprehensive Plan and Statewide Coordinated Statement of Need, all 14 HIV/AIDS planning areas cited poverty, homelessness, drug use, lack of transportation, lack of private insurance, lack of knowledge about services, *perceptions of some staff as lacking compassion*, and co-morbidities to be critical issues (Florida SCSN 2009, emphasis added).

These client demographics create added challenges and costs for service providers, which create the need for capacity building and increased funding. Unfortunately, because of economic decline – particularly in the housing market – the Bureau of HIV/AIDS projects that state tax revenues will continue to decrease and require cuts at the state level (Florida SCSN 2009). This will undoubtedly reduce the budget for a variety of HIV/AIDS programs.

Finally, Florida's proximity to the Gulf of Mexico and the Atlantic Ocean leave Floridian citizens vulnerable to hurricanes. In severe weather, normal business operations can be interrupted for days or even weeks and disrupt continuity of care. In previous years, hurricanes have negatively impacted service delivery and capacity (Florida SCSN 2009).

### *Regional Structure of HIV Services*

Hillsborough, the study county, belongs to the Area 6 HIV/AIDS planning body, along with Hernando and Manatee counties. Areas 5, 6, and 14 combined forces in 1999

and now operate under the West Central Florida Ryan White Care Council based out of the Hillsborough County Health Department (RWCH/ASP 2008). Figure 2 illustrates areas 5, 6, and 14, the Total Service Area of the West Central Florida Ryan White Care Council. Combined, the Total Service Area (TSA) includes Hillsborough, Hernando, Manatee, Pasco, Pinellas, Hardee, Highlands, and Polk counties. Four of these counties, Hernando, Hillsborough, Pasco, and Pinellas are a part of the Eligible Metropolitan Area (EMA), while the remaining rural counties are considered non-eligible metropolitan area counties (non-EMA). The EMAs receive Ryan White Part A funds while all counties in the TSA can access Ryan White Part B funds. Population densities in the area range from 43 people per square mile in Hardee to 3,384 people per square mile in Pinellas – the most populated county in Florida (RWCH/ASP 2008). The metropolitan areas of Tampa, St. Petersburg, and Clearwater have multiple health care resources and “pockets of high poverty” (RWCH/ASP 2008).

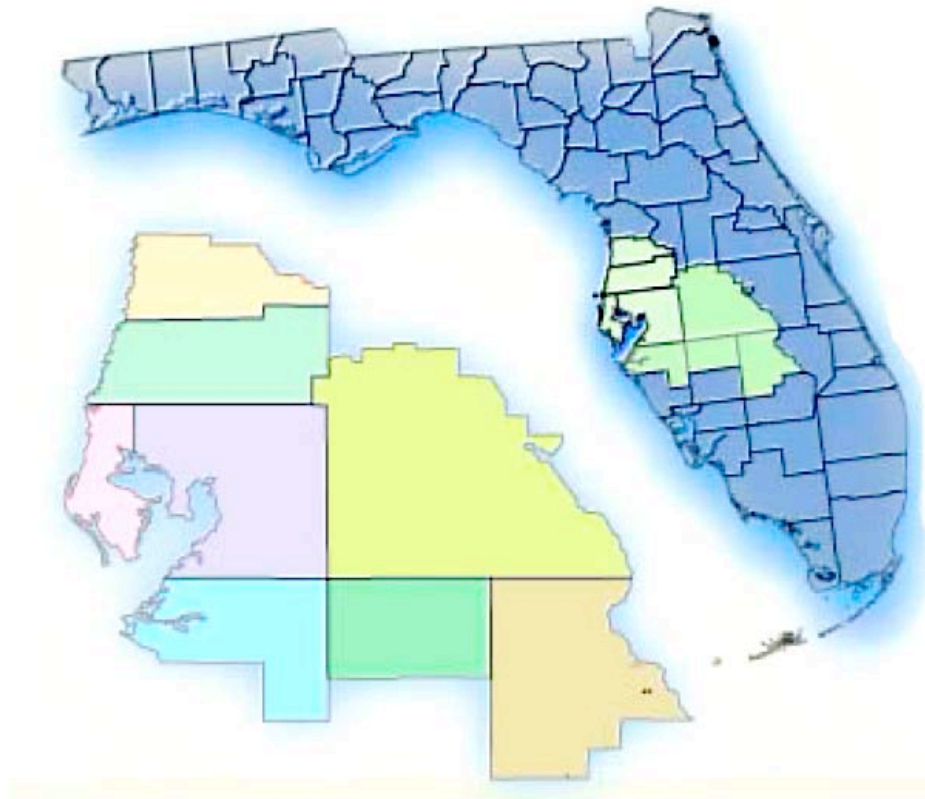


Figure 2. The Total Service Area of the West Central Florida Ryan White Care Council  
(RWCH/ASP2008)

### *Regional HIV Statistics*

The Total Service Area (TSA) serves a population of 3,771,367 – roughly 20% of the state’s population (RWCH/ASP 2008). It is estimated that approximately 21,600 individuals are homeless, 10.7% live in poverty, and 15.9% are uninsured (RWCH/ASP 2008). The total living cases of HIV and AIDS in the TSA are 12,113 accounting for 14% of cases in Florida (RWCH/ASP 2008). In 2010, the rate of HIV cases per 100,000 people was 33.5, higher than the state rate of 31.8 (FloridaCHARTS 2010). Hillsborough, the study county, has the largest percentage of people living with HIV and AIDS in the TSA at 44% and 46% respectively (RWCH/ASP 2008).

### *Regional Funding and Gaps in Care*

The West Central Florida planning body has funded “core” services (outpatient/ambulatory, pharmaceutical, hospice, medical case management) at greater than 80%, but had to discontinue funding to some support services such as housing, legal, and rehabilitation services (RWCH/ASP 2008). From 2001 to 2008, HIV/AIDS prevalence increased by 67% while Ryan White funding has only increased by 4.5% (RWCH/ASP 2008). The gap between funding and increases in HIV/AIDS prevalence has continued to grow, and at this rate it remains impossible to keep up with the demand for services.

In the eight-county Total Service Area (TSA), Medicaid accounts for 65% of total funding, which includes Medicaid Project AIDS Care Waiver (PAC) funds. The AIDS Drug Assistance Program (ADAP) represents 12% of funding and Ryan White Part A funds another 9% of service area expenditures. HOPWA (Housing Opportunities for Persons with AIDS) and General Revenue from County Health Departments and Networks account for 4% and 3% of funding. General Revenue funds can come from annual allocations to each health department or allocations to each geographical “Network” – in this case the Suncoast General Revenue Network, which includes the same eight counties that comprise the TSA. Ryan White Part B represents 2% of funds, while Parts C, D, Ryan White Minority AIDS Initiative (MAI), AIDS Insurance Continuation Program (AICP), and the combined county governments of Hillsborough, Manatee, and Pinellas represent 1% of funds each (RWCH/ASP 2008).

In the 2008 fiscal year, support services received \$651,562 – approximately 5% of funding. Of this money \$180,000 was distributed for non-medical case management, \$344,757 for food bank and home-delivered meals, \$110,100 for medical transportation services, and \$16,705 for direct client services (RWCH/ASP 2008). Service gaps in the region were assessed by a client survey during a three-year needs assessment process. Some barriers to care cited by residents in the survey include: lack of transportation, distance to service sites, dealing with other health problems, need for an evening/weekend appointment, length of wait for an appointment, and lack of knowledge of where to go or how to apply, and not wanting people to know about their HIV positive status (RWCH/ASP 2008). The 2009-2012 West Central Florida Ryan White Comprehensive HIV/AIDS Service Plan states, *“It is increasingly difficult to provide high quality, comprehensive services to eligible individuals due to expanding caseloads, rising health care costs and clients in need of more supportive services to help them enter and remain in care”* (2008, page 23).

#### *Regional Client Demographics*

As cited in the 2010 US Census American Community Survey, Hillsborough County has an estimated 16.6% of individuals living below the federal poverty level (US Census ACS 2010). Many residents have been negatively affected by the recent economic conditions. The U.S. Bureau of Labor Statistics reported that Tampa-St. Petersburg had 10.3% unemployment in October 2011, somewhat higher than the national rate of 8.5% (U.S. Labor Statistics 2011).

To make matters worse, the cost of housing has increased in the Tampa Bay area, and many lower cost alternatives are being demolished to make room for more expensive properties (THCDDH/AHP 2007). Accessing the remaining affordable housing has become nearly impossible for individuals with a criminal record, poor credit, and substance abuse issues. In some areas, public housing programs have waiting lists longer than four years (RWCH/ASP 2008). In 2011 the state of Florida had the fifth highest foreclosure rate in the nation – with one in every 130 Florida housing units with a foreclosure filed during the second quarter (RealtyTrac 2011). In the same quarter, Hillsborough County ranked fifth highest in the state with 4,343 foreclosures (RealtyTrac 2011).

The City of Tampa Housing and Community Development Division HIV/AIDS Housing Plan (2007) reported that affordable housing units were available for merely 12% of people living with HIV/AIDS in the Tampa metropolitan area. Additionally, only 23.4% of HIV positive survey respondents reported that were receiving a rental subsidy or living in public housing. This lack of stable housing can hinder an individual's ability to adhere to medication regimens and access treatment. Homeless individuals face even greater challenges as they lack proper storage and refrigeration for medications and experience poor nutrition, exposure to the elements, greater stress, and poor hygiene (RWCH/ASP 2008). This increases their susceptibility to illness and the cost of treatment when care is eventually accessed.

One issue faced by HIV/AIDS Area 5/6/14 is a significant amount of immigration. The TSA attracts tourists from around the world and is home to many retirees from other states. In 2007, the Tampa-St. Petersburg area had 633 cases that originated

out of state, which represents more than 5% of the total HIV/AIDS cases in the area (RWCH/ASP 2008). These cases are eventually captured when individuals convert to AIDS, but because they are not counted in initially funding allocations, they cause a serious impact on available resources. Some of these individuals may include migrant labors, farm workers, and other minority groups that reside in rural areas of Hillsborough County. There are an estimated 50,000 migrant workers and their families in TSA, attracted by farm worker employment in the winter season (RWCH/ASP 2008). Because English is not the primary language for roughly 20% of the client base, bilingual medical staff and health information materials are necessary (RWCH/ASP 2008).

Clients in the TSA also have limited access to transportation assistance. Hillsborough County has a widespread, but somewhat disorganized bus system, which can result in several hours of travel to and from appointments. Monthly bus passes have recently been discontinued in favor of single-day passes meant for medical and social service appointments (RWCH/ASP 2008). There is no assistance available for other travel needs such as grocery shopping or attending support groups. The limited mobility of some clients severely constricts their ability to coordinate work schedules, childcare, various appointments, and other important errands like grocery shopping.

Finally, all eight counties in the TSA are designated as Health Professional Shortage Areas and Medically Underserved Areas (RWCH/ASP 2008). According to the Florida Health Insurance Study (2005), 15.9% of the TSA population under the age of 65 is uninsured. Moreover, it is estimated that 30% of HIV-positive people in the region who are aware of their status are not receiving care (RWCH/ASP 2008).



## *Summary*

Undoubtedly, HIV service providers in Hillsborough County confront many obstacles outside their realm of control that inhibit their abilities to provide effective services for clients. Macro-level forces such as the recent economic downturn and the structure of funding have significant impacts of HIV prevention and social service delivery on the ground. Federal funding, often the greatest share of available funding, is determined by annual appropriations by Congress that do not necessarily reflect need or the cost of services. Resource allocation from the state can also change from year to year depending on variables such as: percentage of HIV/AIDS cases in geographical areas, the amount of unexpended funds from previous years, and the amount of appropriation for Florida's program.

Due to the recent economic recession, a record number of people are in need of safety net services, and less money is available to provide them. There is a constant need for new treatment spots as 56,000 new HIV infections occur annually in the United States. Furthermore, advances in therapy such as highly active antiretroviral medications allow individuals to live much longer, and therefore require expensive pharmaceuticals and treatment for years.

Many community-based organizations that employ case managers, educators, and outreach workers depend on funding from federal and state grants, and are therefore subject to fluctuations in resources. This surely inhibits their abilities to provide dependable services to clients in dire need of consistency.

In addition to expanding caseloads and rising health care costs, service providers in Hillsborough County must also tackle regional specific issues such as housing

shortages, fluctuations in caseloads due to seasonal migration, and an English-limited client base. On top of everything else, Hillsborough and surrounding counties have a shortage of qualified health professionals and are considered medically underserved. Combined, these problems generate gaps in care and significantly add to the burden of local HIV prevention and service providers. Macro-level issues related to a poor economy, funding, and structure of the HIV/AIDS field unquestionably contribute to the daily stress of Hillsborough County providers in HIV/AIDS care. This chapter provides a contextual background for the participants' responses to questions of occupational stress in their daily HIV/AIDS work. Chapter four will report results of interviews with social service providers, which illuminate how structural factors negatively impact HIV/AIDS prevention and care staff and contribute to their perception of work-related stress.

## **Chapter Three**

### *Methods*

The overwhelming majority of previous research on occupational stress and burnout has used surveys, which raise two procedural issues: 1) surveys often involve the administration of self-report, self-administered questionnaires, and 2) participants must select stressors from a predetermined list (Miller 2000). Barbour (1995: 522) argues that, “Scant attention... has been paid to contextualizing AIDS-related work”. The needs of particular staff support groups cannot be recognized without a detailed understanding of the work environment and contexts in which they arise (Miller 2000). Therefore, observational and interview data are needed. While questionnaires may not identify meanings attached to participant responses, interviews can more precisely describe individually experienced occupational stressors (Gillies 1991). It is therefore worthwhile to ask HIV/AIDS providers to identify and define their own stressors. Miller (2000) argues for a conscious attempt to allow subjects to describe their own perceptions of stressors in the workplace because at present, “the true nature of identified occupational stress cannot be placed in a clear context of health work” (Miller 2000:106). As a result of this stance, open-ended interviews were used in this study to allow providers to describe their individual experiences at length.

During the fall of 2011, I completed a 10-hour a week internship in HIV Services at a large behavioral health service provider in downtown Tampa, FL. The organization was selected as an appropriate internship setting due to its significant presence in the

community and implementation of outreach and prevention programs. Through this internship position, I networked with providers of social and HIV prevention services at the organization and other similar AIDS service organizations in Tampa. These social connections enabled me to make contacts in the HIV prevention field. Through open-ended interviews with HIV counselors, educators, case managers, and outreach workers, this exploratory study assessed the occupational stressors of providers of social and HIV prevention services in the Tampa Bay area. In total, I completed 18 interviews with HIV educators, counselors, and outreach providers. My research questions were:

*Question 1*

What motivates individuals to enter such a stressful field or work environment?

*Question 2*

What factors contribute to stress for employees in HIV social and prevention work?

*Question 3*

What are service providers' coping mechanisms and personal responses?

*Study Sample*

A total of 18 individuals were interviewed in order to address the two main research questions. Fifteen of the 18 individuals were female prevention workers. The participants ranged in age from 25 to 53, and nine confirmed receiving some sort of formal training outside of their agency regarding some aspect of HIV testing or prevention. Various trainings ranged from HIV 500 and HIV 501 pre- and post-test classes offered by the health department to Ryan White Case Management training. The range of HIV prevention experience varied from three months to 21 years in the field.

One of the participants was one of the first AIDS case managers in the study county. The participants occupied a variety of different jobs in the HIV prevention and education field. Some of these jobs included: Director of Client Services, HIV Specialist, Disease Intervention Specialist, Case Manager, Peer Advocate, Program Manager, and Housing Specialist. All participants were employees of five different AIDS Service Organizations in Tampa Bay. Several (N=8) had previously worked at other agencies before their current position. The goals and missions of these organizations varied from providing supportive services to HIV+ clients to helping people become self-sufficient. Because HIV/AIDS organizations in Tampa work together to provide services for patients, I used snowball sampling to recruit participants. The HIV/AIDS network in Tampa is small and interconnected, so individuals were able to suggest many other potential participants at theirs and other AIDS Service Organizations. At the end of each interview, I asked participants for additional contacts that fit the study criteria. These contacts were then telephoned or emailed to invite them to participate in the study. This sample represents a considerable proportion of the HIV service providers in the area, which are estimated to number around 45 in the study city (personal communication with service provider).

### *Study Design*

In early October of 2011 I began an internship at a behavioral health services organization located in downtown Tampa, FL. This well-established organization is one of Florida's largest community-based providers of behavioral health services. Through its various services, this organization addresses substance abuse and mental health issues. Its comprehensive programs work toward healthy living, job productivity, and overall family

stability. While the primary purpose of the organization is to treat substance use disorders, it specializes in providing treatment to individuals with a co-occurring mental health disorder. These emotional or psychiatric illnesses may include depression, trauma, grief, anxiety, bipolar disorder, ADHD, or sleep disorders.

This Tampa-based behavioral health organization aims to improve family cohesion and overall communication; reduce the likelihood that youth and adults will engage in risky behavior; improve individuals' relationships at home, school, and work; promote engagement in community and neighborhoods; reduce the incidence of substance abuse; and engage and empower individuals and families. Substance abuse and mental health disorders are treated through outpatient and residential program settings. Other supportive services include HIV testing and counseling, adult education/GED, primary healthcare, day care, and affordable housing.

For a semester I interned with the HIV Services department involved with HIV/AIDS prevention under the umbrella of specialty services. Substance users, particularly those who inject drugs, are at high risk for HIV/AIDS (Purcell et al. 2001). The onsite Project Care program provides current information, testing, counseling, and notification services. All clients receiving treatment at the facilities are provided with HIV/AIDS education, and free, confidential testing. The organization not only offers conventional HIV/AIDS testing services, but also the OraQuick<sup>®</sup> Rapid HIV-1 Antibody Test. This provides immediate test results, eliminating the two-week wait associated with other testing. Having access to adequate nutrition is also critical for those living with HIV/AIDS. Therefore, the organization has established an onsite food bank program that provides gift cards to local grocery stores and cooperatives for those who meet eligibility

guidelines. In addition to monetary assistance, a dietician from the community provides nutritional workshops to individuals in the Food Bank Program.

This internship lasted the remainder of the Fall 2011 semester and provided me with rich participant observation experience. For ten hours a week I observed the day-to-day responsibilities and challenges faced by the HIV Services department. Throughout the semester I also attended group HIV education sessions and worked at larger prevention events such as presentations by motivational speakers and World AIDS Day. During the three months I spent working in the HIV Services department, I made observations of the goals, tasks, and relationships involved in HIV prevention work. These observations were recorded during and shortly after each five-hour work shift.

Through this position I learned about organizational structure and operations, the client services offered, the network of HIV prevention in Tampa, and personally experienced work in an HIV/AIDS service setting. In my internship position I focused on client education, risk reduction, and outreach activities. My job duties included the development of HIV/AIDS prevention materials, the coordination of prevention events such as World AIDS Day activities, and the use of social media to spread educational messages. In this position I learned the intricacies of client progress notes, the vastly important role of documentation, and how to bill for Ryan White case management services. Additional job duties included updating client case files, filling out discharge documents, and promoting events with signs and online social media. I created information packets for educators on HPV and Hepatitis C to be used during group HIV education sessions. Through this internship I was also able to establish connections with

employees of other AIDS Service Organizations to recruit additional participants for this study.

Interviews commenced on September 28<sup>th</sup>, 2011 and continued until November 28<sup>th</sup>, 2011. The open-ended interviews ranged from 40 to 80 minutes and were audio recorded. Brief notes were recorded during the session and interviews were transcribed within two days of the meeting. The data were collected with individuals from a total of five AIDS Service Organizations. The participants chose the meeting location, and thus interviews were most often conducted at the participant's worksite. Three participants chose to meet at nearby coffee shops. An exploration of occupational stressors included gathering information regarding initial and continued motivations for working in the field, the causes of occupational stressors, the effects of daily stress, and personal responses to the work environment. The questions were modeled based on previous literature regarding burnout, grief, and stress in HIV clinical work, but due to the exploratory nature of the study, the interview structure was open-ended. Follow up questions were asked if pertinent information was revealed from a particular question, and the participant's responses directed question order and time spent on each topic.

Upon completion of the interviews, the transcripts were coded to observe common responses. Throughout transcription recurring responses were noted in order to prepare a list of codes for data analysis. Twenty codes were used under four broad themes of 1) environment and setting, 2) relationships, 3) effects on workers, and 4) personal responses and coping. Responses were organized by corresponding code and then compared. The frequencies of certain responses were noted and compared. Surprising responses that differed from the majority were also examined. Specific data such as the



number of people tested each year by the state of Florida were corroborated with official reports and news articles.

The main components of the interviews were 1) demographic information of participants including age, educational background, and years of experience. These data were self-reported by the participants (n=18). Following, the participants were asked to discuss 2) details of their job duties, agency goals, and personal motivations to work in the HIV/AIDS field. Participants were asked to describe a typical day on the job and their usual job responsibilities. Questions regarding motivations were asked in order to assess the participants' expectations, thoughts, and ideas of the field in the past and in the future. The bulk of the interview questions attempted to elucidate 3) job experiences of the participants related to stress, burnout, stigma, and grief. These sections included questions such as: what activities at work cause you stress? And, how has your family reacted to your work in this field? Finally, questions related to 4) coping strategies were asked in order to evaluate the personal responses of the participant to occupational stress. This section included questions on support groups and overall perceptions of work in the HIV field.

Throughout my internship, participant observation allowed me to observe the daily happenings of HIV prevention, testing, education, outreach, and social services. As an intern, I observed and participated in HIV prevention group education sessions, staff planning meetings, community outreach initiatives, HIV testing sessions, and the preparation and implementation of World AIDS Day events. This allowed me to ascertain the standard of care at this location, the expectation of staff, and goals of the agency. During the month of October 2011, I was also able to tour several facilities at other AIDS

Service Organizations. These experiences helped me gather information about the structure and role of the various players in the HIV field in Tampa. This was important for building a context in which to understand the comments of participants in their interviews. The participant observation allowed me to gain a more in-depth understanding of HIV services in the region as a whole.

Before the study commenced, ethical approval from the University of South Florida Institutional Review Board (IRB) was obtained (IRB #5665).

#### *Participant Confidentiality*

The names of the participants were not connected to their responses to interview questions. All written and audio data will be destroyed after five years per recommendation of the USF IRB. All data were stored on a secure, password-protected computer or under physical lock and key.

## **Chapter Four**

### *Results*

As stated previously, the aim of this study is to identify providers' motivations for working in the HIV field, factors that contribute to stress in HIV prevention and social service work, and the participants' reported responses to their work environment. In understanding the above objectives, a more complete picture of the work environment at AIDS service organizations can be gained. Furthermore, in evaluating the perspectives of individuals who provide HIV social and prevention services, additional perceived barriers to serenity and effectiveness can be identified and eliminated in order to promote a healthy and supportive working environment.

### *Demographics*

The study participants ranged in age from 23 to 53 years old. Of the 18 participants, one third (n=6) were between 20 and 29 years old. One third of participants were between 30 and 39 years old. And the final third of participants were between 40 and 53 years old – four in their forties and two in their fifties. Previous research has suggested that age may affect the perceived stress of HIV service providers (Handy 1987; Bennet et al. 1994). In a study of paramedical staff and social workers, younger age predicted HIV/AIDS-related burnout (Egan 1993). Figure 3 reports the time the participants have held their current position. Figure 4 displays the participants' years of experience in the HIV/AIDS field.

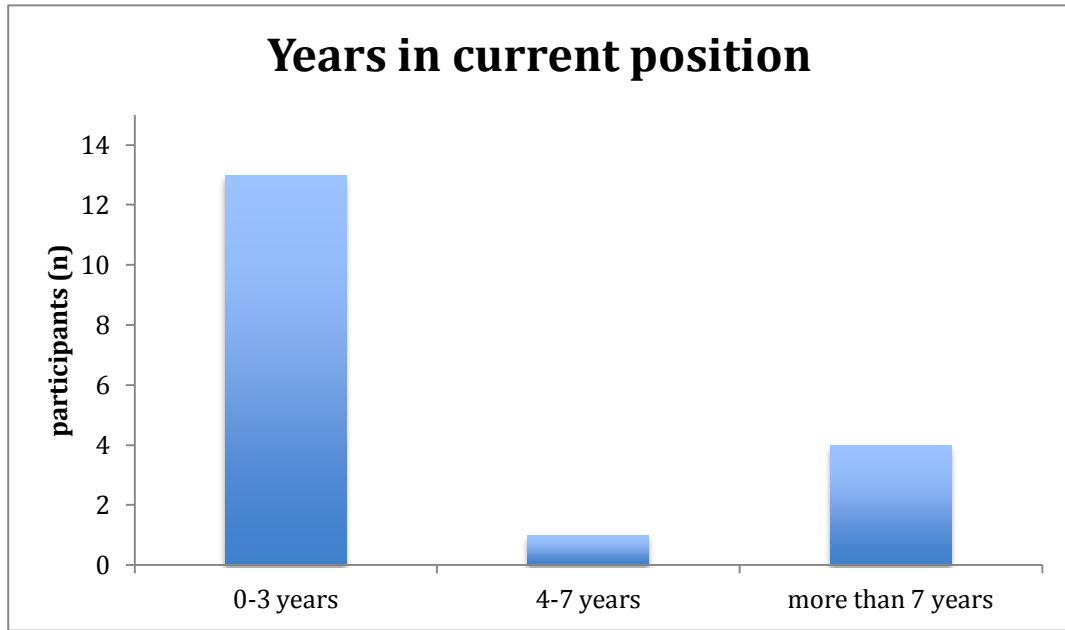


Figure 3. Participants' years in current position (n=18)

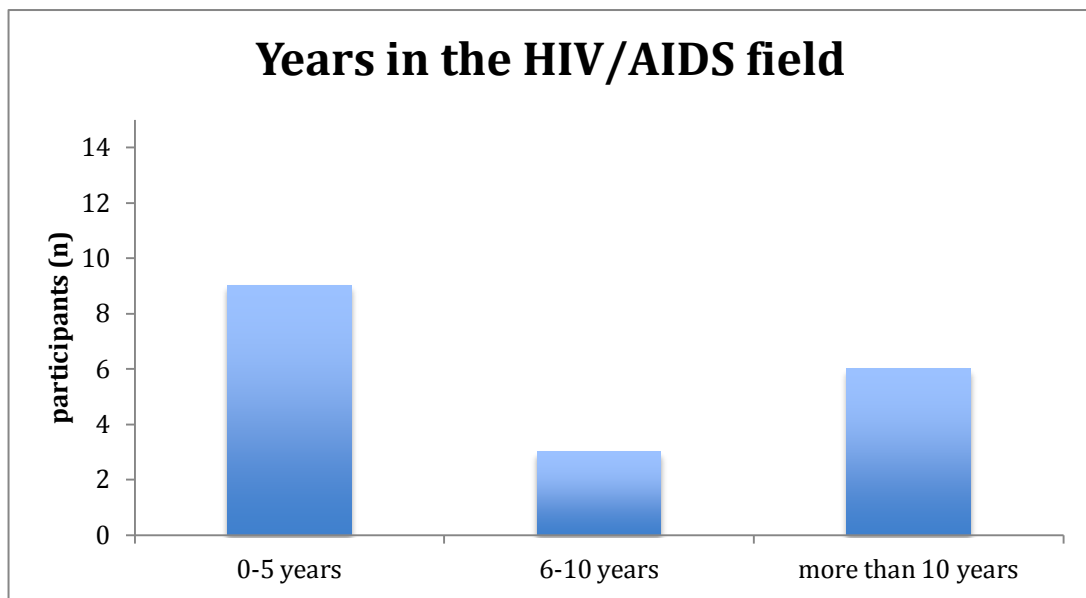


Figure 4. Participants' years of experience in the HIV/AIDS field (n=18)

Studies of HIV clinicians have suggested that length of time in the field may also affect the levels of stress in providers (van Servellen and Leake 1993). Three of the study

participants were male, while the remaining were female. Interestingly, two participants reported that they were HIV positive. This important factor will be discussed in further detail in subsequent sections.

### *Motivations for entering the field*

Figure 4 displays participants' reported motivations for entering the HIV field. There has been little consideration of providers' motivation for becoming involved in HIV/AIDS care and how this relates to stress and burnout. Barbour (1994) argues that

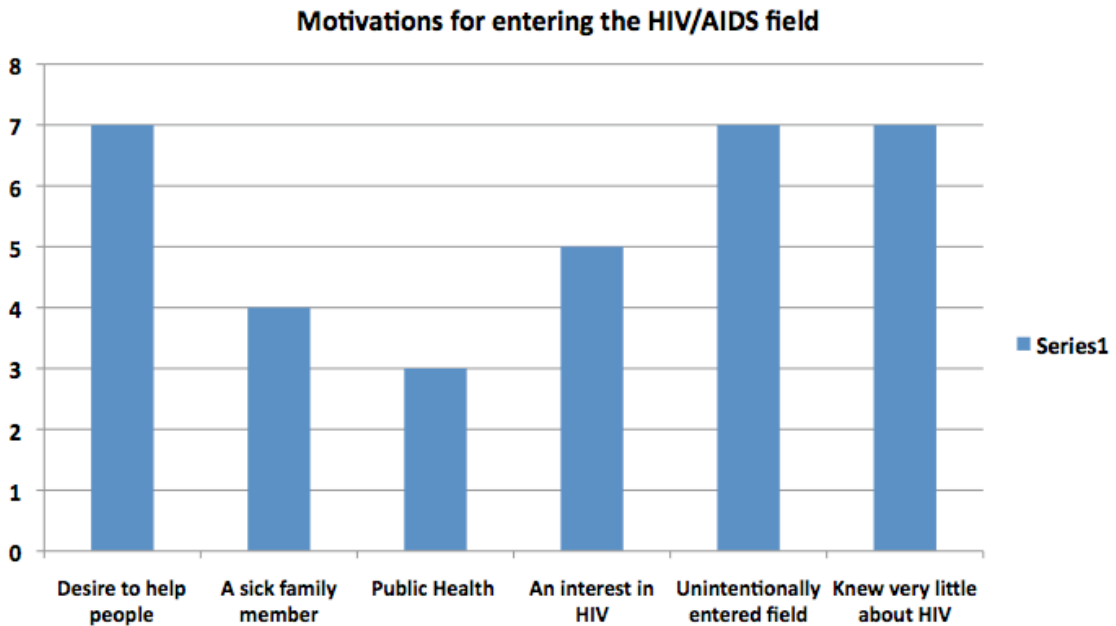


Figure 5. Participants' motivations for entering the HIV/AIDS field (n=18)

motivations for HIV/AIDS work are critical in answering why people become stressed. Specifically, previous job experience, and whether or not staff chose to enter – rather than being deployed in – HIV/AIDS care could help explain providers' reactions to stress.

When asked about their motivations for entering HIV/AIDS work, seven study participants discussed the general desire to help people. More specifically, a sick family member prompted four participants to enter HIV prevention. According to Pasacreta and Jacobson (1989), personal experience has an important role in career choice. For instance, the personal experience of a death of a loved one has been recognized as a factor pre-disposing individuals to hospice work (Patrick 1987; Paradis et al. 1987), and could be applicable to work in HIV/AIDS. A 30-year-old female housing case manager reported:

My uncle was diagnosed when I was thirteen. And he just collapsed at work one day. It was kind of a shock to the family. Since then I was like, I want to work with people who have HIV – just because I saw the difficulties he had and ignorance. It's gotten better, but of course this was back in the 90s, and we were starting to talk about it in schools. And people would be so ignorant about it. And I would be like, "Well my uncle has HIV, and I hug him and see him all the time. And it's fine." So that's kind of what led me in this direction.

Three participants reported a background in public health, and mentioned it as an impetus to work in the field of HIV/AIDS. In addition, five participants entered the field of HIV prevention and social service work because they were specifically interested in HIV. It is notable that seven participants reported entering the HIV/AIDS field somewhat inadvertently or unintentionally. A fifty-three-year-old female case manager said:

[I]t was actually that for my externship I kept getting directed to the field of HIV and AIDS. And not knowing much about it at the time I had a fear of working in the field. Um, I finally just said, okay I need to do what I need to do to finish my Associates Degree. And um, I started to work in the field and I loved it.

A thirty-year-old female program manager added:

Well, the social work field has always appealed to me because I grew up very poor and I had a lot of social workers in my life. So I always wanted to do something with people who lived in poverty or struggled. So then I started off with homeless families with disabilities. And then, as I've been

with the agency, I've been promoted up to oversee the HIV/AIDS population... It kind of just happened. It was a huge learning curve. I had to go out and get some books and learn, you know, like medicines, T-cells, viral loads, and detected/non-detected. So when I talked to the clients, I knew what they were talking about, and I didn't seem completely dumb. Likewise, seven participants mentioned they did not know anything about HIV and went into the field "a little bit blindly." One stated, "I didn't have specific interest in HIV. To be honest, I didn't know too much about it either." A fifty-one-year-old female housing specialist responded:

So one day I was just looking in the newspaper, and I saw an advertisement for an AIDS case manager. Well, like I said, this was in 1990. I knew nothing about HIV and AIDS. I didn't know what A.I.D.S. stood for, or whatever. So I applied for the position and got an interview. And the lady taught me, she was telling me [about HIV/AIDS]. I was thinking, oh gosh. I don't know if I want to do this. But I didn't say nothing.

These responses confirm that not all providers opted into HIV/AIDS care, which could affect their reactions to work stresses (Barbour 1994). Barbour (1994) explains that individuals who initially chose a career centered on homelessness or drug use may not have anticipated how HIV would alter the focus of their work. Therefore, it is important to consider the motivations of individuals involved in HIV/AIDS work as providers may have different reactions to stressors depending on their attitudes towards their work and toward their clients.

### *Factors that contribute to occupational stress*

#### *Chaos and variability of job duties and daily schedule*

Nearly all participants (16 out of 18) discussed the variability of their job duties and the chaotic nature of their daily schedules. Some of the numerous responsibilities mentioned include: planning outreach activities and events; hosting focus groups;

communicating with other agencies and coworkers; running onsite programs such as a food bank; researching available services and opportunities for clients; obtaining housing, transportation, and medical care for clients; grant writing; facilitating educational or support groups; conducting HIV and other sexually transmitted infection (STI) testing; managing other employees; and documenting all services rendered. A female program manager (age 30) stated:

Every day is different. I come in and look at my calendar and think, oh it's not going to be so bad. And then, it's totally out of whack... Because some days I will just come in and do paperwork. Or I am working on a grant or working on a report. Or I'm in the middle of that, and all of a sudden an emergency happens where one of our ladies have gotten sick, and we have to call 911. And we've had a fire here one day. So there is nothing typical.

Within the discussion of variability, nine participants discussed feeling a lack of control in their position. When asked about her working conditions, the same participant stated:

[W]hat is the most stressful, and we go through that a lot, is when somebody is in need. And you're not able to fix it right away. There's some things that you don't have control over, and that is frustrating. I think most social workers or social services people that you talk to might be like, "Yeah I want to have control over the situation." And they don't always have it.

This lack of control was often discussed in relation to the availability of services for clients. Fifteen participants felt that funding trends have made this especially challenging in recent years. Funding trends and providers' perspectives of funding will be discussed further in subsequent sections.

"Crisis" events caused workdays to be particularly stressful for providers. A "crisis" might involve a medical emergency or a client in dire need of services when none are immediately available. One participant reported, "[Y]ou just never know. You never know what phone calls you are going to get, or who is going to walk in the door, or if there is going to be a crisis." When asked what a crisis might entail the participant



replied, “Well I’ve had clients who are in the hospital, and they are about to be released from the hospital with nowhere to go. You know? Or if their lights are going to be turned off tomorrow, what are they going to do?” During a discussion of her daily experiences on the job, a female case manager (age 35) explained:

It’s challenging when there is something urgent, or when there is a crisis occurring. And by the nature of this job it is crisis after crisis. Everyone here is having some sort of personal crisis. Like, oh the clients are going through a lot of issues. And maybe to them it seems more of a crisis than it actually is. It’s a challenge to just remain levelheaded and just do things in a timely manner and not get carried away with the urgency of every situation that comes up.

It seems that a persistent sense of chaos and lack of control contributes to the daily stress of providers working in this environment.

### *Documentation*

Documentation and paperwork were reported as major sources of stress for HIV service providers. A twenty-six-year-old female participant quipped, “I don’t think I have any stress at work besides the 50 million charts I have to look for.” From the beginning to end of their workdays, social service providers are expected to record their actions. While chaos and variability are the norm, providers reported that they loathed detailed documentation for its monotony and tedium. These employees must take notes on any conversations, referrals, appointments, applications, or progress on cases. There may be different paperwork for admissions, medical history, service plan goals, referrals, confidentiality agreements, billing, discharges, and funding reports. These forms may differ for each agency or funding source, which causes an added burden of correctly filling out the numerous forms for each organization. These necessary forms report accounts of services provided to clients for funding agencies and help protect client

confidentiality, but are often overwhelming to service providers. When asked about the stressful aspects of her job, a twenty-eight-year-old female substance abuse counselor replied:

Documenting everything. Because you end up doing so many different things, a lot of times something new comes up before you are able to document the previous thing that happened. A lot of times it will be time to go home and you realize, I didn't have time to write any of this down. I'm going to have to do it tomorrow. And tomorrow comes with its whole new set of issues... You have to be very disciplined to get everything done.

A female client services director (age 40) aptly summarized this job responsibility:

Paperwork. There is just so much paperwork, so much documentation. But those are the things you have to do. And everybody learns this I am sure. If it is not written down, it didn't happen... You really have to protect the confidentiality. And we have an audit every year, several every year, from every funding source. And we actually have one tomorrow with Ryan White. So they come in and they make sure you are doing your work. But they even need a release from the client. So when you are working with a client we say, "We need a release so Ryan White can review your file to make sure I am doing my job." Some clients can refuse that too. It's just there are a lot of checks and balances to protect the client's confidentiality.

A thirty-five-year-old female case manager wished for less daily paperwork:

Um, sometimes the documentation is a lot. Because you have to be so detailed in the documentation. You might have a note that's over a page long. And that's the thing that takes up a lot of time it seems. Sometimes I do wish that there was less documentation to the job. But I know it is very important. So, I understand why we need to do it. But sometimes I wish it didn't have to be so much.

The simple task of filing paperwork takes up valuable time that could otherwise be used for direct client contact or other needed tasks. A participant explained that at times, completing paperwork forced them to take time away from appointments with clients.

## *Funding*

Unfortunately, funding limitations constrain the ability of HIV service providers to assist their clients. Participants saw funding as a major factor contributing to stress in their work environment. Of the 18 participants, 15 discussed funding challenges – many focusing on recent funding trends. One participant exclaimed, “Sometimes the funding deals with you!” Without funding to provide services, service providers are left to tell clients they are on their own. This constrains the ability of service providers to effectively do their job, and as discussed previously, lack of control over situations contributes to providers’ stress. A female housing case manager, age 30, discussed her frustrations about funding at length:

When someone has an issue I like to help them take care of it, but sometimes it’s just not there. And you just have to tell them, “I’m sorry there is just no funding. I don’t know what to do.” That’s really, that’s really difficult. When I first started in 2005, I was an intern. There was so much more funding. Under Ryan White we had legal services. We had financial assistance. We had good transportation dollars. And every year it just gets cut back and cut back and cut back. So now we are down to like the bare bones. And it has been difficult for clients to adjust to that because they are used to having the supports there. And it’s been difficult for us to adjust to that because you know, we talk about the good old days. We were like, “Oh you need your rent paid? Okay.” And it’s just not like that anymore.

Participants also seemed to be concerned with their job security. Six study participants brought up job security during the interviews. Fear of losing one’s position could undoubtedly cause stress for employees (Whittington et al. 1993). A female peer advocate, age 30, speculated on the reasons for the recent funding trends:

When HIV first came out and they put all this money into it. And now they think people are aware and this and that. You know, social services as a whole has been cut because this doesn’t seem to be a priority to people. When the economy is struggling, the first things to get cut are always education and social services. So even in the last year we have seen huge cuts in our financial funding. It’s very frustrating. We’ve lost hundreds of

thousands of dollars this year for certain programs. So I was just talking to a coworker. I've applied for eight grants this year. And two, no three of them were first time grants just to try to make up for the money that we lost. And we go to county commissioner meetings to fight for money, and it's very frustrating.

Nine study participants brought up the economy in their discussions of work frustrations and funding challenges. "Politics and bureaucracy" and "changes in the HIV field" were also cited by 10 and 7 participants respectively as reasons behind the recent funding trends.

### *Stigma*

The stigmatization of people living with HIV/AIDS remains a continuous problem and major focus of public health interventions and awareness campaigns (Mahajan et al. 2008). Stigma is social shame or disgrace caused by myths and misunderstandings that can lead to discrimination. Stigma is a sign of HIV's social unacceptability and may limit the availability of housing, employment opportunities, or social interaction for people living with HIV/AIDS (Mahajan et al. 2008). Participants saw stigma as a persistent problem faced by their clients. Service providers attempt to alleviate stigma in their client's lives. One participant explained, "Sometimes I have to have one-on-ones with my client's family members that just don't understand or whatever. They think that they can't eat or drink behind this person." When asked about the stigma of HIV, a twenty-eight-year-old female substance abuse counselor replied:

Oh my gosh. It is still where people think it's a gay disease, or people are dirty or druggies. And that's just not, that's just not the case. The stigmas still exist, and that's the way it is. We still try to educate people in that you can touch your cousin, you know? You can hug them and kiss them... You are not going to catch it by someone sneezing. You know those [ideas] are still are out there.

Yet, less well-known are the stigmas faced by those providing social and HIV prevention services. Eight of the 18 study participants reported that they themselves have been stigmatized because of their work. A study in 2007 (Reece et al.) demonstrated that HIV staff experience social stigma due to their work in HIV. Barbour (1994) found that 41% of HIV health staff in her study had received negative comments regarding their HIV-related work. Levels of adverse comment were greater if the staff member had opted into HIV care. Furthermore, upon learning of their work in HIV/AIDS, others may assume the providers are HIV+ themselves. One participant explained, “Or people ask me, ‘Well you work with people who have HIV. Does that mean you have HIV?’ So they don’t get the whole, you can’t contract it by just hugging someone or by working with them. Or that must mean I have it because I am willing to be around people with HIV.” These circumstances have led other health care workers, such as nurses (Blumfield et al 1987), to deny their work with HIV to those outside of the workplace.

Unfortunately, other types of stigma may occur as well. A 1990 study found that 38% of participating physicians felt that having HIV patients might affect perceptions of their own sexuality (Taylor et al. 1990). A thirty-one-year-old male program manager reported being asked about his HIV status, but his sexual preferences were also questioned. HIV/AIDS was (and by some still is) perceived as a gay man’s disease. In 1892 during the early stages of the epidemic, the disease was named gay-related immune deficiency (GRID) or informally “gay plague” after public health officials noted a cluster of Kaposi’s sarcoma and Pneumocystis pneumonia in gay males in Southern California and New York City (Khan 2009). Many gay males volunteered as companions for people with AIDS or became advocates in the fight for HIV/AIDS patient rights. Because of the

continued contribution of the gay community, males in the field today are subject to discrimination based on assumptions about their sexuality despite their sexual orientation.

Due to the various stigmas involved in HIV/AIDS work, service providers may also face disapproval from relatives and friends. These loved ones may not know the pathways of HIV transmission or understand the conditions of the social service and prevention work environment. In a study of HIV/AIDS clinicians, 53% of respondents described their families' reactions to their work as "supportive/positive", 19% as "equivocal/fearful", 15% said their families were "intolerant" of their work, and 13% said the matter was so controversial, it could not be discussed with families (Miller and Gillies 1996).

Nine participants in this research study dealt with negative reactions from their family members because of their work in HIV/AIDS. Surprisingly, a participant reported, "Um, it's weird because even my family members who are in the health field – like nurses – were worried about me when I first told them I was going to be working with the HIV population." When asked about her family's reactions, one thirty-five-year-old female case manager replied, "Well, my mother doesn't like this. She has let me know. She is afraid that I am going to get HIV by just having casual contact with someone. And I told her that that is not how you get HIV, but she still thinks that I am going to get HIV."

Of the 18 participants, six others experienced supportive reactions from their family while three faced mixed reactions from their relatives. A fifty-one-year-old female housing specialist with 21 years of experience in the field told a compelling story of how her family eventually accepted her work. The participant introduced her family to

one of her favorite clients, a charming and handsome man in recovery from a heroin addiction, without telling her family the details of this man's past or how she knew him. The client, assumed to be the participant's friend, won over her family quickly. One night when invited over for dinner the client revealed his HIV+ status. The participant continued the story:

My shocked family replied, "You mean you have AIDS?" He said, "Yes I do. I've been sick for so many years." He went into his story about how he got infected because he used to shoot heroin and all this kind of stuff. All they did was hug him and embrace him. So that was maybe like six months after I had been working there. They were totally okay with it. That's how I changed their minds.

Reactions from friends were overall more supportive than those of relatives. Only two participants reported mixed or negative reactions from friends. The providers often attributed the different responses of friends and family to the nature of their close friendships. Eight participants explained that their close friends were also social service providers who either worked alongside them or with similar populations. One participant summarized this effectively, "Well, my close friends are here. And my best friend actually used to do this. And she is actually a case manager in another field now. And everyone knows and has sort of done this thing before so it is not really a big deal."

### *Hostility, Verbal Assault, and Unsafe Settings*

Reports about verbal attacks from clients or dangerous situations arose from the interviews as an unforeseen factor contributing to a stressful work environment. Seven participants mentioned instances of verbal assault by angry or distressed clients. Participants told stories of being cursed at, screamed at, or threatened by clients. At times clients become upset about the availability of services or decisions made by providers.

Certain clients can be violent and may be dealing with mental health issues or drug and alcohol abuse.

In addition to verbal attacks, home visits comprise a critical risk for some service providers. Home visits may require some service providers to enter unsafe neighborhoods or volatile homes. A fifty-three-year-old female case manager relays a story of a frightening home visit:

I've dealt with clients who are out of control, and I've had to ban people from here for being violent. I remember being at a client's home, and she was in the middle of kicking her boyfriend out of the house. I was just sitting there doing paperwork with her. And all of these men came in. She was like screaming at him, cursing at him. "Get the hell out of here. Get the hell out of here!" And I was like what do I do? I just want to leave. So I was like quickly, "Sign this. Sign this. Sign this." because I didn't want them to come back. And I heard them outside saying, "I will pistol whip you. I will get my pistol. I got my gun," and stuff. And I also heard one of them say, "You need to be quiet. You are going to scare the white lady." I've been in some weird scary places in this job, but that was the only time where I was actually really, really scared... You go to scary parts of town. You go to some questionable homes... I always make sure I have an exit. I always park my car, if I can, on the street so I don't get blocked in. And I always make sure I can see the door. And I always have my cell phone on me. And I leave my purse in the car. I usually put it in my trunk. When I go to home visits I don't wear my ring. That's all you can do.

While not all job positions require providers to visit clients at their residence, home visits constitute an acute risk for those that do.

### *Relationships with Clients: Attachment, Identification, and Loss*

In nearly all of the interviews, participants told stories about particular clients that stood out. Some providers have direct contact with clients over an extended period of time, which sometimes results in the development of personal relationships. Providers may meet the client's families, work with them in their home, and act as their system of



support. Consequently, some providers become quite attached to their clients. Eight participants spoke of their attachment to or relationships with particular clients. Some study participants even spoke of clients as “extended family” or as “loved ones.” A fifty-one-year-old female case manager elaborated, “[It’s] hard for me to get my composure back and know that there’s all these other people that’s counting on me. It really affects you like you lost someone in your family. Because they are your extended family.” A female peer advocate, age 31, added, “It is kind of like being a parent almost. If you are in a situation, there is no time to be scared. You have to make sure everyone else is okay.” A female disease intervention specialist, age 33, also described her role as parenting, “Some of these women are old enough to be my mom. I switch the role with them quick. I say I could be your daughter, but this time I am going to switch and be your mom today and we are going to do this.”

Other participants spoke of losing sleep from distress over a particular client, or praying for a client at length. It is evident that some social service providers go out of their way to comfort clients. A twenty-eight-year-old female counselor explained that several of her clients who are ill and stuck at home call her at work when they are feeling lonely. She explains, “I’ve spent a lot of time with the phone just to my ear, literally, just while I am doing my notes. And just have them talk about whatever they’ve done that day.” She doesn’t say much, but just having someone listen to him or her comforts clients.

In some cases emotional attachment made it incredibly difficult for providers to deal with the death of a client. Nine participants told stories about dealing with the loss of clients. A female case manager, age 53, spoke of a client she felt particularly close to:

I actually had one client that I was there the day that he died. I was there at the hospice center in Sun City, Florida. And I traveled after work hours and would go sit and read to him. Talk to him. See him until like eight or nine o'clock at night, forty minutes going, forty minutes back. And I would do that so many times a week. And I was there when his family turned against him. And I was there right until he took his last breath. And I didn't want to be there when he took his last breath because it emotionally affects you, but it was like he needed me. And that's, that's a hard thing. And honestly I have to say that, that particular client, that took something out of me.

The participant was working on redecorating a room in her house when this client passed away. When he died, she discontinued her project saying, "I was frozen in my heart to complete it." And for one whole year the participant did not enter that room in her home.

In addition, identification with clients can increase the emotional strain felt by participants (Bennett and Kelaher 1992). For example, where the majority of patients are gay, it would be expected that staff members affiliated with the gay community would should greater identification with patients. Two of the study participants revealed their HIV positive status. This could certainly affect their relationships with clients and contribute to emotional strain and grief. Eleven participants disclosed that they relate to different aspects of their clients experiences and suffering. According to Selwyn (1995), identification with patients can result in loss of perspective, a failure to set limits, and an increasingly heavy burden for providers.

In general, participants were aware of the precarious balance between empathizing with clients and maintaining emotional distance. Twelve participants spoke of personally distancing themselves from clients. In a thirty-five-year-old female case manager's words:

You don't want to get too emotionally attached. I mean you want to have sympathy and empathy for their situation, but if you get too emotionally attached, it will definitely be a detriment to your work and to yourself really. I've seen case managers cry after they visit a client or after they

talk to a client and you just can't do that. Because it's on your mind all day, and how are you going to help someone else that needs your help if you are just emotionally stuck on one client? You just can't do it. Other participants spoke of maintaining a "provider/client boundary" and putting up a "barrier" between themselves and clients. These responses indicate that providers are conscious of the emotional vulnerabilities of attachment to clients and varied in their ability to maintain boundaries to protect themselves.

*Relationships with coworkers:*

Relationships with coworkers also arose as a contributing factor to employee stress. Thirteen participants elaborated on experiencing "agreeable" or "satisfactory" social support from their fellow employees. These providers spoke of feeling like a "tight knit group" or an "integral part of the team" rather than "replaceable" or "taken for granted." Others equated their fellow coworkers to family. A female eligibility specialist, age 25, explained the importance of coworker support, "When you get along with them you work better. You communicate better. You don't come into work feeling miserable... This is something you are going to experience every day for eight hours a day, and it is really important to feel comfortable." On the other hand, seven participants discussed "insufficient" levels of social support either at their current or a previous position. In some cases, the providers even left these prior places of employment due to poor coworker rapport.

A female case manager, age 30, explained:

"When I had my first HIV case management job I left that agency. Not because I didn't like the job, but because I didn't like the people running it. You know, which I don't go around telling people that because I have to deal with that agency. I just felt like we were all a target, and they were, they didn't care. Like we were replaceable. And that kind of stuff, when

you don't have a good solid foundation, that stuff eventually trickles down to the clients."

Another female case manager, age 23, discussed the environment at her previous agency, "You're frustrated. You have no one else to go to. I mean it was hard to find who you could trust because people are competitive because there is a lack of funding and everyone wants your job. So you have to really trust who you are talking to, and I had to learn that the hard way." These providers took extreme action and left their previous places of employment because they did not feel adequately supported by their agencies and coworkers.

Participants also discussed poor relationships with bosses or coworkers. A twenty-five-year-old female eligibility specialist stated, "It was much more stressful when we had coworkers that I didn't necessarily get along with. That's way more stressful than any other time in my work ever." A female substance abuse counselor, age 28, explained, "I had a supervisor, and I won't say which department... I couldn't wait to leave. I was like, man I need to look for another position. And when it's like that, you can't do your work." When asked about relationships with her coworkers, a female disease intervention specialist, age 28, said:

I have talked to a lot of people in social work that have issues with their bosses, and it makes their job that is already really difficult, like ten times more difficult... I get along with all of the coworkers here really well. It wasn't always like that. There was gossip in the past. Or I had heard that I was being gossiped about in the past by one of the coworkers. So luckily they ended up leaving.

A twenty-six-year-old female disease intervention specialist explained that it wasn't the nature of the job that created stress, but the work environment itself. She said, "Without the right support it just adds that much more emotional stress."

### *Consequences of stress factors*

As discussed previously, the multitude of factors contributing to stress in HIV service providers has effects such as burnout, which consists of emotional exhaustion, depersonalization, and reduced sense of personal accomplishment (Benevides-Pereira and Das Neves Alves 2007). This could have significant effects on providers and prevent them from providing the highest quality of care. Five participants spoke about burnout directly. A male coordinator, age 47, who has worked in HIV/AIDS for twenty-one years compellingly verbalized:

After doing counseling and testing for three years, I think I ended up telling 150 people they were HIV+... I just couldn't care less anymore. I just truly lost the compassion. Basically all it was for me was more work. I knew I was burned out because I didn't care to tell them they were HIV positive. They could cry. They could do whatever. It just didn't matter to me.

While this testimony alone illustrates the need for a comprehensive examination of occupational stressors and burnout in providers of HIV social and prevention services, these responses taken as a whole substantiate providers' environment, relationships, and position responsibilities to be critical areas for future research.

### *Personal Responses and Coping Strategies*

Participants discussed the strategies they employ when they are feeling overwhelmed. In some interviews the participants were asked directly about their coping

strategies, while in others the discussion regarding responses to stress began unprompted. Figure 5 illustrates the types of coping strategies brought up by participants and the number of participants who mentioned them. Fourteen participants stated they talked, vented, or joked with others – coworkers, family, or friends – when they were feeling overwhelmed. Discussing their workday with others helped to “work through problems” and “get advice from people with experience.” Another four participants used physical activity to relieve stress. Activities mentioned by participants included yoga, running, yard work, and hitting at the batting cages. A twenty-eight-year-old female case manager explained the importance of physical activity, “Something that has been really helpful for stress relief has been for me to feel better physically... I do yoga like once a week. Sometimes I go jogging. I have a few friends that I go jogging with.”

Twelve participants took time off or “escaped” when they were feeling overwhelmed. The length of the break varied from person to person. For some, escaping meant a short errand during the workday. In one participant’s words, “I come up with reasons to leave the office. I’ve got to run down to the bank – just to get away from everyone for a little bit. Or I run to Starbucks or whatever.” Or, the participants took a few days off from work when they were feeling overwhelmed. One provider used personal retreats a couple times of year to take a break. These involved several-day solitary trips with a good book and a cheap hotel in the surrounding area. Whether they were “five-day weekends” or “ten-minute sunshine vacations,” taking breaks appeared to help providers relieve some stress.

Lastly, some providers used their religion or spirituality to lighten the burden of stress. Nine participants spoke about spirituality or religion as a coping strategy. A thirty-

five-year-old female case manager explained, “I am living as a Christian. I feel that is the source of my strength. I totally rely on like prayer coming in to work. Usually I come into work and listen to motivating or spiritual music.” Another female case manager, age 25, elaborated, “Sometimes it can be really easy to get frustrated with the clients. Um, but spirituality, it helps me to remember to be a little bit less self-centered. So it helps me to remember that they have a lot more problems.”

Through conversations with coworkers during my internship in HIV services I discovered that some agencies have acknowledged the need for stress relief and employee support. Staff at some agencies have access to employee assistance programs (EAPs) through their insurance. These EAPs may provide counseling sessions or other venues of stress relief to staff members. One HIV service organization even provides a weekly yoga class for staff. More commonly, my coworkers and providers at other agencies sometimes used staff meetings to vent about a particularly difficult client or to relay a sad story of another client’s experiences. In this way, staff meetings often functioned as an informal support group. During these meetings, I saw that providers were able to share their experiences and voice concerns. If staff members do not have access to employee assistance services they may find creative ways to relief stress at work. For example, employees at another agency divulged that they use the onsite kitchen to bake cookies for one another when the workday is especially challenging. Comically, a female director revealed that she performs a dance from a Saturday Night Live skit to cheer up her fellow coworkers on bad days.

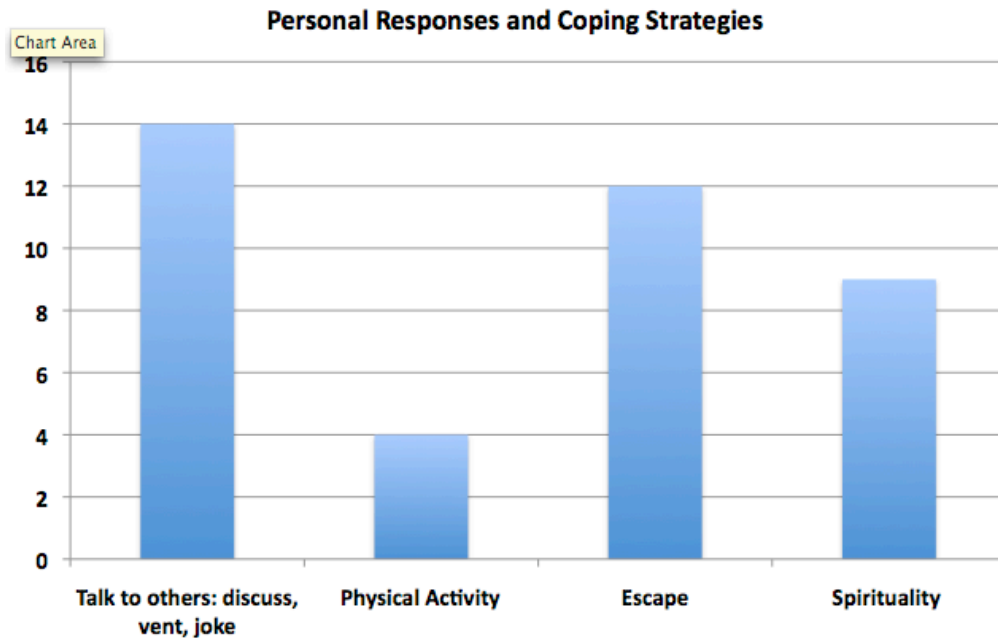


Figure 6. Participants' personal responses and coping strategies (n=18)

*Motivations for continuing in the field*

While the discussion above focuses on factors that contribute to stress in HIV prevention work, the remainder of the chapter will examine the motivations of providers of social and HIV prevention services for remaining in the field. What encourages providers to persist in such a taxing environment? A twenty-eight-year-old female substance abuse counselor expressively conveyed its attraction:

It's a very inspiring field of work. There is just a lot of truth that comes with working in HIV, a lot of truth about suffering and joy and hope. It's just like an everyday thing that I deal with or hear about. It better equips me to talk with some sort of authority to people who are suffering. This is what I have seen. This is what I have heard. This is how people have found joy. This is how people have found hope in the midst of everything that they are dealing with. And if they can do it, then of course so can I, and then so can you. It's definitely a field that has given me a lot of personal strength.



Three main themes arose from the responses concerning motivations: the necessity of the work, the desire to help others, and a sense of pride and privilege.

Seven participants spoke of “seeing the need” for their work in HIV/AIDS. Many specifically spoke of the need to continue and expand testing and education initiatives, but also to continue providing social services for clients. A thirty-five-year-old female case manager stated, “Sometimes we joke around and say, ‘What would the clients do without us?’ but it really is the case for some people. Where would people be without us?” Another participant spoke of the need for the work and her duty as a Christian to serve, “This is what the Bible says when it says the lowest of the low – people that in every way in society have been outcasts, or marginalized. And um sometimes I am very overwhelmed in a way, but... I feel very fortunate and I hope that somehow I am a blessing. That’s at least my prayer. Sometimes the need is really apparent.”

A general desire to help others was discussed by 13 participants. These providers stated their clients were a driving force for their work. A forty-seven-year-old-male coordinator elaborated, “I am so lucky to get up every day and come here. I truly feel blessed. The clients motivate me every day to come here. They are incredible people who face so many things.” In her discussion of helping other clients through obstacles, an HIV positive service provider exclaimed, “I feel like I am doing something I should have been doing before I even became positive... Oh I love my job. You are getting me all emotional. I *love* my job.” She concluded with, “It’s difficult, but it is very fulfilling helping people.”

Throughout the discussions of motivations and future work in the HIV field, a widespread sentiment of pride and privilege surfaced. Of the 18 participants, nine

asserted a sense of honor about their experiences in the HIV/AIDS field. A fifty-year-old female housing specialist elaborated, “Well, I am honored. And I feel rewarded to be able to do [work] for others, especially when things come together in a good way. I set out to do something for somebody and I am able to do it without having to come back and say that I can’t. That really just makes me feel, like really great.”

Therefore, despite many factors contributing to occupational stress, providers of social and HIV prevention services find their work rewarding, necessary, and honorable. The satisfaction of helping others in need and providing essential services offsets the grueling aspects of the HIV/AIDS field.

### *Summary*

Study participants discussed several dynamics that affect their levels of work-related stress. A few issues such as funding, the economy, and the threat of job loss are structural and concern the field of HIV as a whole. A number of topics discussed such as stigma, paperwork, verbal assault, and lack of control over resources are intrinsic to the occupation or specific work environment. The remaining stressors involved negotiating relationships with clients, coworkers, or friends and family not involved in HIV/AIDS care. These service providers may or may not have purposefully entered the HIV/AIDS field, and may have differing individual perceptions of stressors. To offset the effects of a taxing workplace, providers employed a variety of coping strategies such as discussion with others, physical activity, escape, and spirituality. By and large, participants remained motivated by the apparent need for their work, the overall desire to help people, and the sense of pride and honor they felt from making a difference in clients’ lives. The

following chapter will include a thorough discussion of these findings, recommendations for HIV service providers and their organizations, and suggestions for future research.

## **Chapter 5**

### *Discussion*

The AIDS epidemic has impacted the lives of countless individuals and families over the last thirty years. Today, it is estimated that more than 1.1 million Americans are living with the HIV virus (HRSA 2010). Providers of social and HIV prevention services have remained key actors in the fight against HIV/AIDS over the years. Efficacy and quality of HIV/AIDS prevention and care can be maintained by protecting the health of this essential workforce. In order to plan and implement effective interventions aimed to alleviate stressors, service providers must self-identify the factors that influence stress in their workplace environment.

The participants in this study mentioned several structural factors that aggravate their levels of stress, such as the economic downturn, funding for HIV services, and the threat of job loss. Using a political economy of health framework, it is easy to see how macro-level factors such as these can influence levels of stress for service providers. AIDS Service Organizations rely on federal funding from the Ryan White Program, grants, and also funding from state governments to provide their array of services. Depending on the priorities of an administration, funding allocations ebb and flow during each term. This funding structure creates uncertainty in the HIV/AIDS arena because organizations are unable to create long-term plans. They may not know if the current staff is going to get paid during the next fiscal year, if they are going to receive sufficient grants to provide care for their clients, or if they will be forced to cut services. The

capacity of each organization may fluctuate greatly from year to year. One participant explained that her Tampa-based agency started with three staff members, rose to 12 staff members, was currently employing six staff members, but was faced with firing three once a grant ended in two months. This same organization applied for eight different grants – five that they usually receive and three new grants – and only received three of them.

Grants also force competition between agencies as many local HIV/AIDS organizations are applying for the same money. One participant explained that if an agency was expecting to receive a grant and did not, it was probably because another local agency received it instead. He explained that this often worked in a cyclical fashion, with grants rotating from certain agencies to others. And in some cases, staff members might even move from agency to agency, depending on who has received money. According to the participant, the competition for grant money creates tension between the local agencies.

As an intern in HIV services this semester, I had several conversations with coworkers about recent funding cutbacks. These providers revealed that they were looking for additional work and educational opportunities within and outside of the agency in case their position could no longer be funded. My coworkers knew that certain agency programs are being cut in the coming months and are worried about their personal job security but also about the availability of services for their clients.

The recent economic downturn has greatly impacted funding availability for social services in Tampa such as HIV/AIDS prevention and care, and has therefore affected local service providers. When levels of funding decrease, agencies are forced to

accomplish their objectives with fewer resources or scale back their efforts. The providers themselves must work longer and harder or tell clients, “There is nothing I can do.” In conversations with co-workers during my HIV services internship, I learned that certain client services such as a monthly food bank would no longer be available in the forthcoming months. Many clients in Tampa are already struggling with homelessness, unemployment, poverty, and other serious health conditions, but there may be truly nothing that service providers can do. In either scenario, providers may experience elevated stress levels from increasing workloads or lack of control over the outcomes of their clients’ issues. This may cause providers to lose their sense of efficacy and become cynical and discouraged. My coworkers at the agency felt an unmistakable sense of uncertainty about their work in the coming months. As stated previously, one of the symptoms of burnout is a reduced sense of personal accomplishment, along with depersonalization and emotional exhaustion. It is clear that loss of crucial funding could constrain providers’ efficacy and thus cause a reduced sense of personal accomplishment.

The study participants also mentioned social work-related stressors such as unwieldy loads of paperwork and required documentation. During my internship in HIV services this semester I spent hours completing and filing paperwork for clients’ files and can attest to its enormity. At my agency, these files included summaries for each appointment with a client, notes on what topics were discussed in each group therapy and education session, and copies of any faxes sent between service agencies. This extensive amount of paperwork and documentation is required by federal and state funders, and is meant to ensure that grant money is used appropriately and effectively. Each funding source completes regular audits, so agencies must keep immaculate records in accordance

with the rules of several different funders. In addition to disliking the overwhelming enormity of necessary paperwork, participants lamented that the simple task of filing paperwork takes up valuable time that could otherwise be used for direct client contact or other needed tasks. It seemed that an entire position could be created for the sole purpose of filing the required documentation for each client. This would certainly free up experienced case managers or outreach workers for more critical tasks.

Research has demonstrated that health professionals may not have empathetic attitudes towards people living with HIV/AIDS (Blumenfield et al. 1987, Link et al. 1988). Studies on U.S. clinicians found that portions of mental health and substance abuse staff (Dow and Knox 1991) and orthopedic surgeons (Arnold et al. 1989) did not consider it unethical to refuse to care for AIDS patients. Another study found that nurses felt they should not be required to work with AIDS patients (Sherer and Haughey 1988). A number of studies found that some health professionals would choose not to care for AIDS patients if they had the option to do so (Dworkin et al. 1991, Gordin et al. 1987, Dow and Knox 1991). While these studies focused on health professionals rather than social service providers, it is possible that some case managers and prevention staff may not have intended to work in the field of HIV/AIDS or may hold inhospitable attitudes towards people living with HIV/AIDS.

The study participants also discussed AIDS-specific stressors such as stigma. Service providers endeavor to lessen the impacts of stigma faced by their clients, and are thus subject to harsh stigmas themselves. Uninformed individuals may have adverse reactions to the work environment of service providers, which may fracture valued relationships with family and friends. In other cases, assumptions are made about service

providers' HIV status or sexual preferences. This conjecture may have serious consequences for service providers as HIV-positive individuals and homosexuals face discrimination and condemnation.

The remaining stressors involved negotiating relationships with clients, coworkers, or friends and family not involved in HIV/AIDS care. In general, participants were aware of the precarious balance between empathizing with clients and maintaining emotional distance. In some cases emotional attachment made it incredibly difficult for providers to deal with the death of a client. Other participants spoke of maintaining a "provider/client boundary" and putting up a "barrier" between themselves and clients. These responses indicate that providers are conscious of the emotional vulnerabilities of attachment to clients and varied in their ability to maintain boundaries to protect themselves. Unfortunately, cases of either extreme could have negative consequences. Intense emotional attachment to clients could exacerbate emotional exhaustion. On the other hand, maintaining a sense of distance or implementing boundaries with clients could relate to a sense of depersonalization. Both emotional exhaustion and depersonalization are symptoms of burnout; therefore, negotiating work-related relationships could contribute to burnout.

Evidence of heightened occupational stress and potential burnout in HIV prevention and social service providers is plainly presented in the study results. Factors that contribute to occupational stress were either structural, intrinsic to the job, or relating to relationships between coworkers, clients, or family and friends. In general, participants remained motivated in such a stressful work environment by the apparent need for their work, the overall desire to help people, and the sense of pride and honor they felt from



making a difference in clients' lives. However, as discussed previously, stress and burnout can have significant effects on providers and prevent them from providing the highest quality of care. Some participants already employ coping strategies when they are feeling overwhelmed by work-related stress. These include discussing issues with others, venting, joking, physical activity, taking a break or escaping, and religion or spirituality. Yet, improved personal coping strategies and organizational changes are necessary to buffer and prevent stress.

### *Recommendations*

A key limiting factor in the scale up and sustainability of HIV care and treatment programs is the global shortage of trained health workers (Rajaraman and Palmer 2008). Therefore, burnout as the central factor affecting the quality of work in the area of health care has theoretical and practical importance (Bellani et al. 1996). Participants in this study were asked to self-identify their perceived sources of stress because understanding the specific stressors of HIV prevention work can lead to improved personal coping strategies and larger-scaled workplace improvements. Occupational stress and burnout appear to be caused largely by structural and organizational conditions rather than by differences in individuals. However, strategies often target changes at the individual level. While individual coping strategies can act as an important buffer against perceived stress, it is important to recognize that changes in structural or organizational factors that cause stress can have more impact.

Certainly, the most effective strategies to bolster the HIV/AIDS field involve sizeable increases in funding or stable, reliable sources of funding to alleviate the

structural factors that constrain effective treatment and prevention. The virus cannot be defeated without considerable investments in research, treatment, and prevention.

Unfortunately, instead of scaling up efforts, recent funding trends have shown decreases due to the economic downturn as social services are often first to be cut in times of economic crisis.

Surprisingly, on December 1st of 2011, World AIDS Day, President Obama announced \$50 million in additional funding for AIDS treatment in the US (New York Post 2011). The money will include \$15 million for the Ryan White Program and \$35 million for state AIDS Drug Assistance Programs (ADAP). This much needed funding will hopefully be used to augment and reinforce effective HIV/AIDS care and prevention efforts. However, \$50 million may not adequately sustain care and prevention efforts in the United States, and there are likely to be funding fluctuations in the future as priorities shift. Funding may or may not reach agencies in need, and the allocation of federal funding for the HIV/AIDS field remains outside of service providers' control. While activists have had great success in advocating for the HIV/AIDS field in the past, many providers are already overworked, underpaid, and do not have time to get involved with political activism outside of work. However, workplace-specific strategies can be developed to improve issues at an agency level.

For example, models of effective staff support are urgently required (Miller 1992). Procedural or organizational initiatives might include: limiting working hours; providing training in stress recognition and management; enabling expression of work successes; enabling expression of initiative and work variation; and giving increased control over work tasks (Miller and Gillies 1993). Occupational stress research can also provide the

information necessary to design organizational interventions such as workplace support groups, therapeutic counseling, and stress reduction workshops (Miller and Gillies 1993).

Several studies have documented the beneficial effects of support groups for HIV staff and volunteers (Held and Bran 2007; Grossman and Silverstein 1993). In a study by Grossman and Silverstein (1993) HIV provider support groups were specifically created to assist participants in several areas: (1) reduce and manage stress and prevent burnout associated with AIDS care, (2) continue working with people with HIV/AIDS, (3) work compassionately with people with HIV/AIDS, (4) maintain a rational perspective so that they can cope appropriately with professional issues such as suicide ideation, (5) identify the effects of stress on their colleagues and supportively bring it to their attention, and (6) establish and maintain professional boundaries. Common problems expressed by participants in support groups included coping with death and dying, work overload, identification with clients, feelings of depression, dealing with suicide ideation by clients, and anger with family reactions to their relatives with HIV/AIDS.

These support groups, with their focus on awareness, shared experiences, supportive and helping relationships, and the emotional consequences of working with people with AIDS, help professionals manage stress and enhance their capacity and effectiveness to work with these clients (Grossman and Silverstein 1993). In addition, support groups help participants to feel less isolated and to share feelings regarding issues such as death, anger, helplessness, and loss. Support groups helped professionals to obtain the emotional strength necessary to continue working with people with AIDS. Participants in the Grossman and Silverstein study said groups should be an ongoing activity for people who work with HIV/AIDS clients because it helps them alleviate

stress, feel less isolated, share difficult feelings, and raise concerns (Grossman and Silverstein 1993). Support groups may be effective for some AIDS service organizations to decrease high turnover rates and absenteeism in their overworked staff.

In some cases, formal support groups may not be necessary. During my participant observation as an HIV services intern, I learned that staff meetings could function as informal support groups. My co-workers were able to vent about their frustrations, share stories about their clients, and ask each other for help in difficult situations. Supervisors can facilitate this process by dedicating a portion of the staff meeting to this activity and encouraging employees to participate. However, in order for this method of stress relief to be effective, staff members must feel comfortable sharing in front of their co-workers and know they will not be penalized for revealing their vulnerabilities. Therefore, it is important to foster a supportive working environment.

While many factors aggravating occupational stress are caused by structural or organizational conditions, personal coping responses are strategies within the realm of providers' control and may act as an important buffer to stressors. Martin (1990) found that coping styles that involved disengagement were associated with higher burnout and greater intentions to discontinue working in the AIDS field. Previous research on HIV physicians and nurses has demonstrated that internal coping strategies that did not focus on fixing the source of the problem are more effective. These may include: expression of feelings; patience and persistence; optimistic attitudes; and time-out coping techniques (Demmer 2004; Dorz 2003). Several participants in this study demonstrated internal coping strategies such as discussing issues with others and taking a break or escaping from work-related stress. External coping strategies are less effective for HIV service

providers because they have no agency to externally cope or eliminate HIV/AIDS.

External strategies may include: negative expectations; fatalistic attitudes; dependence on faith, prayers and miracles; and avoidance of difficult situations (Demmer 2004; Dorz 2003). Effective, internal coping strategies should be recommended to HIV prevention workers to decrease the chronic fatigue, frustration, and desperation they may feel from their work.

Before implementing organizational interventions, it is crucial to communicate with staff about what they want and need from such interventions. If interventions are instead imposed on staff, they may perpetuate rather than reduce stress (Miller 2000). In addition, it is important to recognize that burnout is a problem caused by chronic stress, and acute interventions that last for a few days will have little impact on staff. Alleviating burnout will require a commitment to effective staff support – a good investment for agencies because staff who are cared for provide the best quality of service. Therefore, staff should be treated as a valued and expensive resource (Miller 2000).

### *Study Limitations*

This research study is not without its limitations, most notably of which is the small sample size. A larger sample size would have made statistical analysis of the results possible. Overall, this research functions as an exploratory study of the occupational stress and work environment of HIV prevention and social service providers, and the small sample size allowed for a more in-depth study. Future studies should seek to obtain larger sample sizes in order to verify and strengthen the results of the findings reported here.

Furthermore, it should be noted that the findings of this study could not illustrate the complexities of time involved in the perceptions of stress and personal experiences acquired over many years of working in a dynamic field such as HIV and AIDS. The field of HIV/AIDS has changed dramatically since the early days of the epidemic when providers might lose several patients a month. Therefore, providers who have been working in the field for twenty-one years – as some of the participants in this study have – surely have quite different personal experiences than individuals who have recently entered the field. In addition, individual perceptions of stress may fluctuate depending on personal workload at a particular time. Unfortunately, I was only able to meet each study participant for one interview, and cannot speculate on participant perceptions of stress over time. Burnout is a chronic process and cannot be analyzed completely from a single interview. Furthermore, my internship in HIV services only lasted one semester, and therefore, can only speak to the work environment of the agency during that interval of time. Future research should carefully consider the effects of time on the evolving HIV/AIDS field and on the personal experiences of individual providers.

A final important limitation to note is that each provider was not directly asked their opinion on what stress-related interventions they would prefer or think would work for them. It is just as important to ask providers what kind of interventions interest them, as it is essential to ask providers to self-define the factors that cause work-related stress, as Miller (2000) argues. As provider preferences could vary significantly by age, years of experience, agency, or environmental factors, a solid understanding of staff interest is necessary. This is also something supervisors or managers should consider at their particular agency before instituting an intervention.

### *Future Research*

Miller (2000) has suggested that much occupational stress among providers of HIV prevention and social support services is a result of structural or organizational factors rather than differences in personality or characteristics of individuals. Indeed, study participants cited many structural and organizational factors that influence their levels of stress. Anthropologists are well suited to explore the problem of occupational stress and burnout in the HIV/AIDS field. Anthropological approaches such as the political economy of health and critical medical anthropology can connect macro-level influences like federal funding to micro-level effects such as a reduced sense of personal accomplishment in a service provider. These theoretical approaches can change the rhetoric of personal responsibility and remove blame from individual providers by illustrating the political and economic barriers to their goals.

This research study suggests occupational stress and burnout are in fact potential problems for providers of HIV prevention and social services and are influenced by service providers' environment, specific occupation, and relationships within and outside of the HIV/AIDS arena. Future research studies are needed to assess the prevalence of burnout in HIV prevention and social service providers and further contextualize the condition. Larger sample sizes will be necessary to accomplish this goal, but surveys are not sufficient to address this research question and should be supplemented with data from participant observation and interviews. Interviews can provide details of work contexts and reveal original opinions and ideas.

In addition, there is a need for continued attention to burnout in providers of HIV prevention and social services. Because HIV/AIDS is a dynamic field, information gathered at one point in time may not reflect changing conditions or trends. With the advent of anti-retroviral therapy and technological advances, working in the HIV/AIDS field today is incredibly different than during the first years of the epidemic. Trends and changes in the HIV/AIDS field must be considered in future research studies. Also, burnout is the result of a chronic process and should be examined in individuals over time.

### *Conclusion*

In conclusion, a combination of structural, occupational and relational factors contribute to the stress of HIV prevention and social service providers. From a political economic standpoint, macro-level structural forces like the economy and funding availability in conjunction with specific social work-related and AIDS-related stressors shape the work environment for providers of HIV prevention and social services, and therefore impact their occupational stress. I am in agreement with Miller (2000) who argues that, "In an age where work-related stress and distress are treated as expressions of individual pathology, we need to shift the burden of responsibility back on to working structures that actually generate stress, rather than blaming the individual for experiencing stress that workplaces create (Miller 2000, page 220).

These service providers may or may not have purposefully entered the HIV/AIDS field, and may have differing individual perceptions of stressors. To offset the effects of a taxing workplace, providers employed a variety of coping strategies such as discussion



with others, physical activity, escape, and spirituality. By and large, participants remained motivated by the apparent need for their work, the overall desire to help people, and the sense of pride and honor they felt from making a difference in clients' lives. Care must be taken to prevent high levels of occupational stress and burnout in these individuals in order to ensure the highest quality of service provision for clients.

To improve the workplace conditions and prevent burnout, a multi-level approach including structural, organizational, and individual strategies must be implemented. Some possible interventions include: additional funding allocations from federal and state governments to increase financial support for AIDS Service Organizations; support groups to help providers alleviate stress, feel less isolated, share difficult feelings, and raise concerns; and internal personal coping strategies such as taking adequate breaks from work. Only with this kind of multi-level approach can burnout be prevented.

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