

**SOCIAL SUPPORT FOR THE HIV+ CLIENT:
A COMPARISON OF THE EFFECTIVENESS OF TRADITIONAL
VERSUS VOLUNTEER CASE MANAGEMENT
INTERVENTION**

by

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This longitudinal repeated measures study was designed to evaluate and compare the effectiveness of volunteer support versus traditional case management for those with HIV in improving level of independent functioning. A non-random sample of one hundred and fifty-three clients (eighty-two in professional, seventy-one in the volunteer program) participated in the study. Evaluative tools utilized included a *Checklist of Needs* and *Level of Independent Functioning Scale* (LIF).

It was predicted that volunteer case managers would be more effective than professionals in improving the independent functioning of clients with HIV and mental health/drug and alcohol problems. It was also predicted that volunteers would be more effective than professionals in assisting clients with obtaining a greater percentage of outside needs (needs provided by other agencies and defined as more critical in increasing independence).

Multivariate analyses of data collected were used to test for relationships between two case management interventions (independent variables), time spent with clients (mediator) and two outcome (dependent) variables, level of independent functioning and percentage of outside needs met .

Results supported the prediction that clients of volunteers improved their level of independent functioning and had more outside needs met than clients in the professional group.

Path analyses revealed that increased time spent by volunteers (total time, number of contacts) partially mediated improvement in level of independent functioning. Face to face time, the most intense form of time, appeared to fully mediate the relationship between independent and dependent variables. However, the time variables did not mediate the relationship between type of intervention and outside needs met.

Recommendations were made for agencies to consider utilizing volunteers in a professional capacity. Also, the evaluative tools developed for this study may be useful to demonstrate outcomes to support lobbying efforts for increased funding. Future research could focus on further refining the LIF scale.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	XI
1.0 INTRODUCTION.....	1
2.0 THE IMPACT OF THE HUMAN IMMUNODEFICIENCY VIRUS (HIV)	5
2.1 POPULATIONS AFFECTED BY THE DISEASE.....	5
2.2 IDENTIFYING AND ADDRESSING UNMET NEEDS	12
2.3 CASE MANAGEMENT DEFINED	18
2.4 MEASURING SERVICE OUTCOMES	21
3.0 THEORETICAL FOUNDATIONS	23
3.1 STRESS AND COPING: A HISTORICAL REVIEW	23
3.2 THE IMPACT OF SOCIAL SUPPORT	26
3.3 PEER SUPPORT	29
3.4 LIVING WITH HIV: THE EFFECTS OF STRESS AND SOCIAL SUPPORT	32
4.0 CASE MANAGEMENT IN SOCIAL WORK.....	37
4.1 EVALUATION EFFORTS.....	37
4.2 MENTAL HEALTH AND DRUG AND ALCOHOL CASE MANAGEMENT RESEARCH.....	41

4.3	CASE MANAGEMENT FOR HIV POSITIVE INDIVIDUALS: GROWTH AND RESEARCH	45
4.4	HIV AND SOCIAL SUPPORT RESEARCH.....	57
5.0	STATEMENT OF RESEARCH GOALS.....	61
5.1	THEORETICAL MODEL	65
6.0	METHOD	69
6.1	RESEARCH DESIGN.....	69
6.2	PRELIMINARY STUDY.....	70
6.3	THE SERVICE SETTING	72
6.4	CASE MANAGEMENT PROGRAMS	73
6.5	DESCRIPTIVE STATISTICS: CHARACTERISTICS OF THE DROP-OUTS AND PARTICIPANTS.....	76
6.6	PROCEDURE	80
6.7	MEASURES	81
6.7.1	Independent Variables.....	81
6.7.2	Dependent Variables.....	81
6.7.2.1	LIF Scale.....	81
6.7.2.2	Checklist of Needs.....	85
6.7.3	Mediating Variables.....	87
6.8	DEMOGRAPHIC INFORMATION	88
7.0	BIVARIATE FINDINGS	90
7.1	DEMOGRAPHICS OF BOTH CASE MANAGEMENT INTERVENTION GROUPS	90

7.2	CHANGES IN LEVEL OF INDEPENDENT FUNCTIONING SCORE (LIF).....	94
7.3	PERCENTAGE OF OUTSIDE NEEDS MET.....	94
7.4	TIME AS MEDIATOR.....	96
8.0	MULTIVARIATE STATISTICS: PATH ANALYSES OF MEDIATION MODELS	99
8.1	CASE MANAGEMENT INTERVENTION AND THE DEPENDENT VARIABLES.....	99
8.2	PATH ANALYSES AND TEST FOR MEDIATION.....	102
9.0	DISCUSSION	112
9.1	RESEARCH RESULTS.....	113
9.2	RESEARCH LIMITATIONS.....	114
9.3	IMPLICATIONS FOR PRACTICE AND RESEARCH.....	118
	APPENDIX A: IRB LETTER	123
	APPENDIX B: CASE MANAGEMENT DEMOGRAPHIC COLLECTION INSTRUMENT	124
	APPENDIX C: CLIENT CHECKLIST OF NEEDS.....	125
	APPENDIX D: PITTSBURGH AIDS TASK FORCE (PATF).....	127
	BLIOGRAPHY	130

LIST OF TABLES

Table 1: Comparison of Demographics Between the Drop-Outs and the Participants.....	78
Table 2: Comparison of Volunteer and Professional Groups	91
Table 3: Service Needs and Service Needs Met	95
Table 4: Time Spent by Case Managers	97
Table 5: Time, Outside Needs Met and LIF Change Correlations	98
Table 6: Testing for Significant Demographics Utilizing the T-Test, Anova and Chi-Square (P-Values)	100
Table 7: Regression Analysis for Total Hours as Mediator and LIF Change as the Dependent Variable.....	104
Table 8: Regression Analysis for Total Contacts as Mediator and LIF Change as the Dependent Variable.....	105
Table 9: Regression Analysis for Face to Face Contacts as Mediator and LIF Change as the Dependent Variable	106
Table 10: Regression Analysis for Total Hours as Mediator and Percentage of Needs Met as the Dependent Variable	108
Table 11: Regression Analysis for Total Contacts as Mediator and Percentage of Needs Met as the Dependent Variable.....	109
Table 12: Regression Analysis for Face to Face Contacts as Mediator and Percentage of Needs Met as the Dependent Variable.....	110

LIST OF FIGURES

Figure 1: The Theoretical Model	66
Figure 2: Change in L.I.F. and Total Hours.....	103
Figure 3: Change in L.I.F. and Total Contacts	104
Figure 4: Change in L.I.F. and Face-to-Face.....	105
Figure 5: Percentage of Outside Needs and Total Hours.....	107
Figure 6: Percentage of Outside Needs and Total Contacts	108
Figure 7: Path Model for Percentage of Outside Needs and Face-to-Face.....	109

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1.0 INTRODUCTION

The rapid spread of HIV Disease to already disenfranchised populations is severely straining both case management (CM) resources and state and federal budgets (Desalu, 2005). Government funds have historically limited support services for those living with mental health and/or drug and alcohol issues to single mothers in poverty. Filling the role of service providers inhibit case managers' ability to assess, coordinate and meet the range of multiple needs for a growing client population.

In addition, the prevailing belief had been that those with HIV have a terminal illness and thus are not expected to live long enough to develop coping skills; however the development of combination therapies in 1995 have changed the status of HIV to that of a chronic disease (Kucera, 1998). Individuals with HIV now deal with living, and often without the social support of friends and families who have distanced themselves due to societal disapproval of homosexuality and drug use. Increasingly, individuals with HIV identify drug use and heterosexual contact as their risk factors for infection (Emlet, 1998).

As the disease becomes chronic and progressive, individuals struggle with cognitive impairment. Among asymptomatic people with HIV, 22% demonstrate significant cognitive dysfunction. By the time a person with HIV is in the advanced stages of the disease, cognitive impairment is found among 60-90% of individuals (U.S. Department of Health and Human Services, 1996). HIV not only causes brain damage as opportunistic infections spread, but also

psychiatric impairment. For those living with the disease, anger over the diagnosis, guilt and fear over social isolation, job and relationship losses and agonizing over the possible course of their disease results in a greater incidence of psychosis and mood disorders (Harvard Mental Health Letter, 1999).

Obtaining resources for populations with chronic health problems and a myriad of needs is challenging. Linking clients to appropriate, responsive and comprehensive services is daunting due to limited funding. With the exception of health care coverage for pregnant women and small children, the government has lobbied, over the past fifty years, to restrict health coverage and support services to the poor and disenfranchised (HIV/AIDS Bureau, 1996). And when the client population is also dealing with co-morbidity risk factors such as poverty, drug use and mental health problems, the federal government, driven by economics, has continued to restrict funds and services while focusing on giving responsibility back to the individual (HRSA, 2000).With the advent of medical advances, increased longevity has also increased both state and federal expenditures. Burgeoning case loads, and too little time to coordinate services with other providers, often result in clients living from crisis to crisis and burn-out for staff as they address daily emergencies. Providing crisis intervention prevents case managers from implementing a strengths-based approach that would serve to transform clients from passive recipients of services to managers of their own goals and lives. Because of the extent of client needs, fractured community programs that struggle to collaborate, dwindling social service dollars, agency turf wars, little or no social support from families, and waiting lists for mental health and drug and alcohol programs, the role of case manager has moved from assessing needs to providing direct services where gaps exist (Raiff & Shore, 1993).

In response to the growing pandemic and the number of deaths, Congress enacted the Ryan White Care Act in 1990. This act, combined with federal waiver programs, has provided funding for HIV case management. Many AIDS Service Organizations (ASO's) were created and operated by non-professional volunteers; however, federal and state funds have stipulated that services be provided by paid college-educated professional staff. In addition, federal funds, as well as foundation grants, now mandate the development of outcome measures, an overwhelming task for most agencies, let alone volunteer driven ASO's.

What constitutes an effective CM intervention for those with HIV and mental health/drug and alcohol issues has not been adequately addressed in research literature. While HIV case management is commonly employed, there have been relatively few published studies over the past ten years.

In her review of research articles, Chernesky (1999) found most studies to be descriptive. The few studies that addressed outcomes focused only on costs and whether a case management intervention reduced the number of hospital days. There has also been limited research that has examined the effectiveness of volunteer/ peer interventions, though a number of studies have shown the importance of social support for psychological functioning among persons with chronic illnesses (Husaini, 1982; Linn et al., Mueller, 1980; 1995; Rodgers, 1995).

The objective of this study is to examine whether a volunteer/peer driven social support model of case management is as, or more effective, than traditional professional case management in improving an HIV positive client's ability to live more independently. As the number of those living with the disease and mental health and/or drug and alcohol problems grow and government dollars and availability of staff dwindles, there is, and will continue to exist, a critical need to find an alternative intervention. Currently, few research efforts have

attempted to develop outcome measures and have focused on description or cost containment as a means of evaluation.

This study will determine if either a professional, or peer run, case management intervention that focuses on support and skill-building, accomplishes the ultimate goal of case management - helping the client to become more self-reliant.

2.0 THE IMPACT OF THE HUMAN IMMUNODEFICIENCY VIRUS (HIV)

2.1 POPULATIONS AFFECTED BY THE DISEASE

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), at the end of 2006, thirty-five and a half million people worldwide were estimated to have been infected with HIV. The Centers for Disease Control and Prevention reported that in the United States in 1996, it was estimated that 1 out of every 250 individuals were infected with HIV (Kucera, 1998), with over 40,000 new cases of HIV being diagnosed each year. This number only accounts for those individuals who have knowledge of being at risk and choose to be tested. In a radio interview on National HIV/AIDS Testing Day, (June 27, 2006, WAMO, Pittsburgh), the Executive Director of the Southwestern Pennsylvania AIDS Planning Coalition, Doyin Desalu, stated that nationwide, 25% of those infected with HIV are unaware of their status, and thus put others at risk.

Since 1981, close to one million cases of infection have been reported in the United States. And since only AIDS (end stage of HIV disease) is reportable, the number of those living with HIV is much higher. According to the National Institute of Health (2002), estimating those living with HIV, but not at the advanced stage of the disease, requires one to multiply the number of AIDS cases by a factor between 10-15.

Although deaths have fallen by 70% since 1995, and continue to decline due to advances in medical care and medication, AIDS is still the 5th leading cause of death in the United States for people between the ages of 25-44. But for African American males in the same age group, it is the leading cause of death (NIAID, 2005).

HIV also disproportionately affects African American and Hispanic women. Combined, they represent less than 25% of the population, but they account for more than 79% of all AIDS cases in women. By the end of 2005, the World Health Organization estimated that 17.5 million of the over 40 million infected with HIV worldwide are women. In 2003, two-thirds of U.S. AIDS cases in both women and children were African American (NIAID, 2006). And of all women newly infected with HIV, 68% are black. In comparison to their male counterparts, women are more likely to be single parents, head of households and the primary caretakers of their children. They represent a challenge that is unparalleled by any other illness (Hackl, et al., 1997; Land, 2000). Women, especially women of color living in an urban setting, are more likely to live in poverty, and have higher rates of HIV infection than their white counterparts. The combination of poor coping skills, limited financial resources, being marginalized by society due to race or mental health issues, and then shunned by family and friends due to having HIV, makes it difficult for women to get the needed care for themselves and their children. One study (HRSA, July, 2002), found that psychological distress presented a significant barrier as 31% of women delayed accessing care for 3 months after a diagnosis because of fear, depression and their anxiety. In addition, women often do not put their own medical needs first, focusing energy on their families' needs.

According to an article by Dr. Malebranche (2005), HIV is ravaging the Black community. It is estimated that one out of every 50 Black men in the United States is HIV-positive. He cites

a study done by the Centers for Disease Control as finding HIV prevalence in men at the rate of 46%. And while Black women only comprising 12% of the entire female population, they make up approximately 70% of all female HIV/AIDS cases.

In an article titled *Conspiracy Beliefs About HIV/AIDS and Birth Control Among African Americans* (2005), the authors examine the role that conspiracy beliefs (HIV is a manmade virus, and the government is trying to limit the Black population by encouraging the use of birth control) play in the prevention of HIV. Their research suggests that conspiracy beliefs influence sexual behavior and attitudes toward medical care and may significantly contribute to the disproportionate number of Black men and women infected with HIV.

In Southwestern Pennsylvania, Allegheny County is the epicenter for AIDS in the eleven-county region, having 71% of all those diagnosed in the region as residents. Since 1980, over 3,200 cases of AIDS have been reported in this region. Mirroring national statistics, since 1980 there has been a decrease in white male AIDS cases, and an increase in women and Blacks (Desalu, 2005), with the number of cases steadily increasing since 1998. Intravenous drug use as a risk factor for HIV infection has steadily increased from 1981 to the present. Less than 5% of those infected in Pittsburgh in 1981 cited drug use as a risk factor. But in 1999, over 46% of those living with HIV were drug users, and in 2005, 64% confirmed that they were either drug users or had been in a relationship with someone who injected drugs.

Despite advances in the treatment and prevention of this disease, the epidemic continues to affect large numbers of individuals. And though medical advances, such as protease inhibitors, have moved the disease from a terminal illness to one of a chronic disease, those living with both the infection and social and economic barriers confront enormous challenges in surviving the disease. Trying to access services and resources while dealing with a myriad of health/social and

economic issues is often an insurmountable task. Lack of these services can often result in premature disability and death.

While medically HIV is considered a chronic, manageable illness, from a socio-economic perspective, those living with the disease often die as a result of poverty, lack of access to medical care, or mental health and/or drug and alcohol problems. According to the *HIV Cost and Services Utilization Study* (HRSA, July, 2002), individuals who are HIV+ are poorer than the general population. They are half as likely to be employed or to have incomes above the poverty level. With lack of work, individuals generally go without health insurance, medical care, medication and proper nutrition. Without this critical support, individuals have a poorer quality of life and die years before those who have medical care and adequate food.

Inadequate schooling limits employment options and, with fewer funds, compromises health care (Emlet et al., 2002). “In the face of challenges to survival, such as poverty, domestic violence, high-crime neighborhoods, homelessness, and other difficulties in meeting basic needs, the management of HIV/AIDS-related needs easily becomes compromised, and such compromises can jeopardize the survival of women and their children” (Parrish, et al., 2003, p. 312).

Females typically present for medical care in a more advanced stage of the disease than do males, and are less likely to be insured (Katz, 1997). Besides the various socioeconomic barriers that often prevent access to services, these same barriers complicate adherence to medical regimes for urban women, especially those of color. Because HIV was originally considered a gay male disease (hence the original name of GRID, Gay-Related Immuno-Deficiency Disease), many research and clinical trials have historically excluded women as participants. Especially for African Americans, such biases are reminiscent of a history of unethical and dangerous research

experimentation on their race (Land, 2000) and contribute to lack of trust with HIV medical providers.

As the number of women, African Americans and especially IV drug users infected continue to climb, so do the rates of infection in adolescents. One-quarter of the 40,000 new cases diagnosed each year are under the age of 21 (HRSA, July, 2002). Lack of sex education, feelings of invincibility, experimentation with sex, drugs and alcohol contribute to their risky behavior. At their age, viewing HIV as a chronic disease versus a fatal illness due to new treatment does not discourage their risky behavior. Adolescents comprise a growing at-risk group for infection in large part due to medical advances, and drug and alcohol use. This behavior is understandable when it is commonly known that many adults smoke, drink, take drugs and over eat while ignoring the almost certain future health problems.

The progression of HIV disease not only results in multiple life threatening opportunistic infections and potential organ failure, but often compromises intellectual and emotional functioning. In one study of men who had tested positive for HIV, 40% developed at least one secondary disorder affecting the brain (The Harvard Mental Health Letter, 1999). Even before opportunistic infections or cancers appear, the human immunodeficiency virus gains entry into the brain. About 25% of people with AIDS show mild symptoms of dementia and 30-50% are somewhat cognitively impaired at the time of death (The Harvard Mental Health Letter, 1999). AIDS also has neuropsychiatric and psychological complications, with anxiety, depressive symptoms and suicidal ideation being the most common. People with HIV often have anger towards ineffectual medical treatment, discrimination, guilt about sexual practices or drug use, loss of significant others to the disease, the resulting social isolation and uncertainty and fear about the course of the disease. Central nervous system dysfunction and subsequent

neuropsychiatric impairment are common and are characterized by slowed mental functioning and psychomotor retardation that resembles depression. Marked global cognitive deficits, delusions and disorientation often ensue in late stages (Faulstich, 1987).

People living with HIV are increasingly affected by psychiatric impairment. There exists a greater incidence of psychosis and mood disorders. Poverty is more prevalent in this population as are histories of sexual and physical abuse, both as children and as adults (HIV/AIDS Mental Health Services Demonstration Program, San Francisco). And in general, people with chronic mental illness have rates of HIV infection that are more than twice as frequent as the general population. Data from some of the Mental Health Services Project sites have shown that 70% of clients report sexual abuse, and there is a reported high rate of victimization and violence as children and as adults. Of those sexually abused, 50% have a major psychiatric diagnosis and higher rates of substance abuse than those who have not suffered abuse. In one program, 90% of those with HIV with mental illness were also found to have co-occurring substance abuse problems.

Homelessness is common among people with chronic mental illness, and is itself a risk factor for HIV as individuals trade sex for drugs, food and a place to stay, do not have access to condoms, lack educational opportunities on risk reduction, and the very nature of their mental illness precludes their ability to understand and implement safer sex and clean needle use (Harbison, 1993). People suffering from mental illness are more sexually active, and much of that activity is of the riskiest kind-impulsive and forced sex, sex with injection drug users, sex with strangers and sex while drinking or taking illicit drugs without the use of condoms (The Harvard Mental Health Letter, 1999). Given these challenges, "...individualized and intensive

case management is an economical approach for providing effective medical and psychiatric treatment to people with chronic mental illness” (Harbison, J.D., 1993, p. 12).

In the United States, more than any other country, AIDS has become closely associated with drug abuse and addiction. The disease is contracted through contaminated injection equipment and unprotected sex with infected drug users. In this country, the proportion of injection drug users HIV infected is now twice as high as the number of gay men. Drug abuse accounts for about a quarter of deaths from AIDS, and at least a third of new cases in the United States (The Harvard Mental Health Letter, 1999).

Psychiatric disorders and drug abuse interact with the physical effects of HIV, which can make diagnosing their symptoms difficult (The Harvard Mental Health Letter, 1999). Clients are generally unwilling to seek help or to follow through with care. Delays or refusal to seek medical care means more emergency room visits and hospitalizations. In one study, researchers found that hospital stays were 40% longer and cost 40% more for injection drug users than for other men with AIDS (The Harvard Mental Health Letter, 1999). Providing social support, a community safety net, case management could serve to address their array of needs and help the individual client become more self-sufficient. While the federal government supported funding case management for those with mental illness and other disabilities, those living with HIV disease often did not have their service needs met as volunteer-based AIDS Service Organizations struggled for professional recognition and financial support.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 was a historical piece of legislation that has provided funding to improve and equalize service accessibility, quality and outcomes for different populations living with HIV. Since then,

federally funded studies have investigated the service needs and access barriers of those already receiving medical care.

2.2 IDENTIFYING AND ADDRESSING UNMET NEEDS

A 1996 study of HIV-positive clients receiving services in San Francisco explored the reasons why service needs were not met. Forty-five per cent stated they lacked information and 44% cited emotional barriers such as denial, fear and concerns about confidentiality. In addition, 54% of all clients reported having to be on a waiting list (HRSA, 2000). Findings of research funded by the Health Resources and Services Administration (HRSA) reported in 2000 that the receipt of supportive services significantly increases the likelihood of clients entering medical care and keeping regular medical visits.

Services most often cited as “unmet needs” include benefits advocacy (help obtaining health insurance and public income assistance), substance abuse treatment, counseling, dental care, with people of color being more unstably housed. Studies of access barriers have focused on client demographics (gender, race, health insurance status, etc.) rather than on the characteristics of the health care providers and the service delivery system. Although women, blacks, the uninsured/low income individuals and injection drug users often encounter more access barriers, studies did document the effectiveness of case management in reducing unmet service needs (HRSA, 2000).

Barriers cited most frequently by women in these studies were having to wait too long for service, fearing the loss of child custody, finding it hard to keep appointments due to lack of

transportation and affordable daycare and having difficulty communicating needs to service providers.

As a condition of receiving Ryan White Funds, each region in every state (Pennsylvania has seven regions) has been mandated to have a planning coalition. Coalitions serve as a network of organizations and individuals and helps them to assess, define, plan and stimulate the development of needed programs for those living with

HIV. To help accomplish this task, the coalitions conduct needs assessments, provide education to providers, advocate for additional funds as well as being responsible for distributing and monitoring the expenditure of funds allocated to ASOs. In Southwestern Pennsylvania, the regional coalition is the Southwestern Pennsylvania AIDS Planning Coalition (SWPAPC).

A meta-analysis of past needs assessments conducted by the SWPAPC in 2005 found that African Americans make up the majority of infected persons not seeking service and have a 68% higher risk of poorer survival than Whites. In addition, there are fewer women accessing resources, active substance use is a barrier to seeking services, and over one third go without needed mental health and drug and alcohol care. Studies further identified that behavioral health care providers are in need of training in order to better assist their clients in accessing programs. In all of the needs assessments, clients and providers cited lack of information as the number one barrier to care and resources. The Pennsylvania Department of Health, Bureau of Epidemiology, HIV/AIDS Surveillance Section, conducted a sub-analysis of the Medicaid Fee-for-Service claims database and found that the greatest number of AIDS diagnosed individuals living with unmet needs reside in Allegheny County (Desalu, 2005).

In 2002 and 2003, their needs assessment identified case management as the most utilized service, with the number of clients accessing services increasing approximately 30% each year.

In setting service goals for 2006/2007, SWPAPC has identified case management as its number one priority. An additional goal is to partner with mental health care and substance abuse providers in order to develop an integrated approach to service delivery. The assessments showed that mental health organizations lacked training and knowledge of appropriate resources. As the number of individuals living with HIV have, or develop, mental illness, both mental health and drug and alcohol agencies often refer clients to AIDS Service Organizations (ASOs) out of fear, general lack of knowledge and their own overburdened resources.

At the Pittsburgh AIDS Task Force, in 1990, this researcher observed that less than 10% of the clients presented with mental health issues. But in the year 2000, the number grew to over 65%, and has been climbing steadily (SWPAPC, 2005). As people live longer with HIV, serious and persistent mental illnesses are becoming more evident. This decrease in mental health functioning is due either to a pre-existing mental health diagnosis (putting the mentally ill at greater risk for contracting HIV due to poor judgment, trading sex for money, etc), or to infected individuals developing mental illness as a result of their diagnosis (brain infections, or the psychological impact of living longer with the disease).

Having a physical illness and mental health diagnoses presents significant challenges in accessing care as service programs typically work in isolation and are often located at some distance from each other. Fragmented support services do not historically communicate and coordinate services due to lack of training, unawareness of existing services, competition for clients and funding and confidentiality laws. Obtaining services often requires multiple bus trips, money, time, energy, good health, child care and a knowledge of the existing services. Instead of a one-stop shop where all services are made available, clients, especially women, often need to coordinate going to four different locations, with limited funds, time, inadequate

babysitting and on-going health issues. These barriers are often overwhelming and contribute to psychological distress.

People living with HIV deal with a multitude of stressors not often experienced by the rest of the population, which serves to exacerbate both physical and mental health functioning. Lazarus & Foreman (1984) identified three major stress stimuli that are experienced by those living with HIV on a daily basis; 1) major events outside of one's control (change in health, appearance, and discrimination), 2) major changes in one's life (loss of a job, friends, lovers, family, children, support and independence that often occur out of life sequence as the majority of those infected are between the ages of 30-49), while also trying to deal with abject poverty, mental illness, addiction and frequent hospitalizations, and 3) contending with the daily hassles of acquiring such basic needs as food, clothing, shelter and medicine made more difficult due to the disease. Individuals at risk for contracting HIV often live in poverty and struggle each day to meet their basic needs. Being diagnosed with HIV often makes it even more difficult to obtain needed resources due to discrimination. Regardless of race, gender or sexual orientation, or how one contracted HIV, this diagnosis makes it very difficult to obtain basic resources to live a quality life, such as employment, housing, medical care, food, transportation and social support. Resources are already limited to those impoverished, and living with a stigmatized illness creates barriers and instills fear among service providers.

Especially among women, who may be homeless, social supports are often non-existent. Due to the high incidence of intravenous drug (IV) use, much needed support systems and resources are often exhausted before the disclosure of HIV. Agencies, with limited funding, are generally overwhelmed by other populations in need of care. This factor, coupled with an

increasing number of people being diagnosed each year who are living longer, suggests there will continue to be a struggle obtaining basic services.

Discrimination, borne from a lack of knowledge and understanding, has served as a significant barrier for HIV+ clients accessing services in a timely fashion. Resources such as individual and group counseling and psychiatric medical care traditionally utilized by those with mental health and/or drug and alcohol problems, have been unprepared to treat those with HIV. Unfamiliar with this population, homophobic or AIDS phobic agencies have often refused services, or delayed them as the person was dying. ASOs were actually created out of response to discrimination. When working at the Pittsburgh AIDS Task Force, this researcher, along with many AIDS activists at the time, was compelled to file a number of law suits and complaints at the local, State and Federal level against nursing homes, personal care homes, home health care agencies, hospitals, dentists, funeral homes, schools, hairdressers, and transportation programs in order to address discrimination. Resolving complaints often took years and such sustained effort is often impossible as case managers are faced with burgeoning caseloads, and little personal or agency support to follow through with legal action in order to open doors for clients.

As a result of discrimination or lack of knowledge by many professionals and agencies, a critical component of case management services to those living with HIV disease is social support. Individuals living with this disease, alienated from friends and family and dealing with hostile service providers, often distance themselves from help due to societal disapproval of homosexuality and drug use. Unfortunately, as clients seek service at ASOs, too few staff and too many clients severely limit their ability to obtain emotional support and services.

As the client base grows, the challenge is to obtain funding for volunteer programs. State and foundation dollars have, over time, decreased their allotment to reimburse paid staff. To meet the growing needs of clients, many ASOs began focusing on training volunteers.

In response to this need, many AIDS Service Organizations created buddy programs (matching one client with one volunteer for a limited time period), but few of them moved this volunteer peer support into case management. Created in 1996, the C.A.R.E Program (Coordinating AIDS Resources for Empowerment) at the Pittsburgh AIDS Task Force utilized peer support. Trained volunteers provided all of the standard CM activities, but in addition, focused on teaching clients how to navigate through the maze of social services in order to help them better meet their own needs. In addition, the volunteers were often peers living with the disease and thus more understanding and empathetic.

While more client needs were being met, this source of intervention has not been funded, severely impacting an agency's ability to increase service capacity. To obtain and secure on-going funding, assessing the impact of professional CM services became a priority, but of even more importance was how to measure the changes that occurred in a client's status as a result of volunteer intervention. ASOs had few dollars to hire professional case managers, but many have, and continue, to look at their roots as a volunteer-driven organization. The question is how can an organization, created and run by volunteers, survive and continue to provide services to an increasing number of HIV+ clients while local and government monies decrease:?

2.3 CASE MANAGEMENT DEFINED

Historically there has existed professional skepticism in regards to the role of case management in social work. The intervention was often dismissed as lacking operational clarity, was subject to too many program interpretations, the term was often over-used, and used for interventions not related to case management, and the value, until recently, has been poorly understood (Raiff & Shore, 1993).

Case management has been described as grounded in social work tradition as a problem-solving activity, and as an intervention that mirrors the profession's values; respect for each individual, self-determination and equal access to services. The Case Management Society of America (2001) defined case management and its philosophy as a collaborative process which assesses, plans, implements, coordinates, monitors and evaluates the options and services required to meet an individual's health needs, using communication and available resources to promote quality, cost-effective outcomes. Case management serves as a means for achieving clients' wellness and autonomy through advocacy, communication, education, identification of service resources and service facilitation... Case management services are best offered in a climate that allows direct communication between the case manager, the client, and appropriate service personnel, in order to optimize the outcome for all concerned" (p.1)

The most common definitions of case management divides components into discrete, yet overlapping functions that include the following; initial client outreach and engagement; assessment of needs; development of a service plan, or goals for the client to obtain; linking clients to services and resources within the community; implementing the plan and coordination of effort to ensure services are obtained; monitoring and evaluating the services to ensure needs are being met; and reassessing for any future client needs (Raiff & Shore, 1993). It has been

proposed by Raiff and Shore (1993) that there exists among agencies a continuum of case management models, ranging from providing minimal services (outreach, assessment, planning and a simple referral) to more comprehensive programs that incorporates advocacy, developing natural support systems, providing education for self-care, teaching activities of daily living, crisis intervention and medication monitoring.

According to Raiff & Shore (1993), a new case management model has emerged over the past twenty years in response to increased need, escalating costs and decreased funding. The new case management has occurred in selected populations that have benefited from government and private funding. The intervention has focused on consumer rights, on a strengths-based approach (seeing the client as not having a problem or health issue, but on having strengths to resolve or adapt to their disability); stressing the importance of social support and peers and the need to respect cultural diversity. Now, in many programs, case management is considered a key or pivotal service, not an ancillary program playing a secondary role and has been promoted as a cost-containment intervention. The term used by Raiff & Shore, advanced case management, includes the idea that case managers extend their involvement with clients by spending more time with them (intensity), having a broader perspective on client needs (breadth), and remain involved with clients as long as the need exists (duration). The researchers define advanced case management as "... a specialized practice designed to bring together a vast array of services needed to sustain the most vulnerable and 'difficult populations' that are at the greatest risk" (Raiff & Shore, 1993, p.15)

Lehrman's (2002) review of HIV case management models throughout the country identified several CM definitions. A Seattle ASO defined HIV case management as "... an array of services designed to locate and identify persons with HIV infection who need services and

link them with the most appropriate resources. The goal of the program is to facilitate access to quality, cost effective care, and to enhance the client's quality of life" (Lehrman,2002, p. 31). Case management is predicated upon patient empowerment, realized through the identification of client needs and subsequent facilitation of access to appropriate services." (Lehrman, 2002 p.29). The largest ASO in the country, AIDS Project Los Angeles, has no definition for case management, making it difficult to assess its effectiveness. Their philosophy is to "...empower clients to utilize their own strengths and to take charge of their own situations..." (Lehrman, 2002, p.27).

For case management to be effective, this service delivery system must focus on providing skill building to clients, rather than using valuable time addressing each crisis and client need. Time and effort need to be focused on instructing clients on how best to meet their own needs, so that in the future, with developed skills, knowledge and self-confidence, they will be able to resolve their own problems and achieve their own goals With decreased federal and state funding, there will never be enough staff to address the needs of a growing community of HIV+ individuals unless those living with the disease are empowered to help themselves.

The goal of case management is to identify and provide access to services that not only serve to improve an individual's life, but encourages and enables them to function more autonomously. The need is to identify or construct evaluative methods that could measure the extent to which this goal is reached, and the extent to which clients rely on their own strengths to better manage their lives. As those living with HIV confront daily, major and catastrophic stress, access to social/peer support may help to improve their ability to acquire services and increase their level of independence. Future research needs to measure the impact of social support on the functioning ability of those living with HIV.

2.4 MEASURING SERVICE OUTCOMES

Over the past decade, federal and state governments, along with foundations and the United Way, have required specific outcomes measures. While qualitative research, describing programs and using satisfaction surveys, has proliferated in the past twenty years, quantitative research has not kept up with the need for agencies to justify dollars spent. The ability to identify and create concrete and specific measures of any intervention with a client population is a challenge that researchers are currently addressing.

One of the functions of SWPAPC regionally is to assist providers with developing outcome measures as a provision of receiving Ryan White dollars to fund such services as case management. Methods of evaluation to date have included provider surveys, satisfaction surveys, the number of service units (15 minutes of service) provided and client chart audits. Disclosed in their strategic plan (Desalu, 2005) was a description of their quality management plan as “...rudimentary as we await technical assistance from the State” (p. 97).

Research has provided more questions than answers on how best to evaluate the outcomes of a case management program. Lehrman (2000) recommends examining the improvement in client lives and changes in client behavior as a result of case management intervention.

What constitutes effective case management, and the ultimate goal of this intervention, is to help the client become more independent. Over the past two decades, more individuals at risk for contracting HIV (heterosexuals, injection drug users, African Americans and women) are becoming infected at alarming rates, and with HIV potentially a chronic disease rather than a terminal illness (if one has access to services and support), the demand for case management has already surpassed availability. Decreases in federal funding and annual increases in diagnoses have resulted in those living with HIV waiting for case management and often dying before they

receive service. Case management has shown to increase accessibility to resources, which in turn improves compliance with medical care. Medical compliance, while an important outcome, does not predict the ability to function more independently.

The challenge for this research is to develop quantitative tools that could assess if case management is an effective intervention in helping those living with mental health and/or drug and alcohol problems function more independently. A primary focus of this research is to determine if peer support and increased hours available through the volunteer case management program significantly affects a client's level of independent functioning as compared to professional case management. While professional case managers are experienced and knowledgeable about community and government resources, their time with individual clients is often limited due to caseload size.

3.0 THEORETICAL FOUNDATIONS

3.1 STRESS AND COPING: A HISTORICAL REVIEW

Each person confronts stress on a daily basis. For some, the stress is dealing with the daily hassles of job, family and finances. For others, stress may include major changes in one's life such as illness or death of a loved one. Events not in one's control, such as a disabling or disfiguring illness or discrimination, cause significant stress. Those living with HIV, often Black, poor, dealing with mental illness and/or addiction as well as disabling opportunistic infections, deal with all of these stressors, often with little emotional and practical support.

The theory of stress has been extensively researched as far back as the 19th century and was recognized as a source of health problems. Stress defined refers to any environmental, societal, or internal demand which requires the individual to readjust his/her behavior patterns (Holmes & Rahe, 1967). This theory holds that stress serves to motivate efforts to cope when a crisis, small or large, occurs. As various stressors mount, which includes major life events, chronic strains and daily hassles, an individual's ability to cope becomes overwhelmed and his/her psychological and/or physical resources become depleted. Over 50 years ago, Selye (1956), who is considered to be the father of modern stress theory, focused research attention on various stressors on laboratory animals' physiological reactions. The study of stress flourished with Holmes and Rahe's (1967) inventory of major life changes and their associated magnitudes of

stress. Since the late 1970's, a variety of methods for measuring stress have been published (Brown & Harris, 1978; Dohrenwend et al., 1993, Pearlin & Schooler, 1978, Wheaton, 1991).

While stress and its damaging effects have been studied, less research has been devoted to the ways in which humans cope with stress (Monat & Lazarus, 1991). Over the past 40 years, according to Kaplan (1983), social support, as a mechanism for coping with stress has been addressed in terms of social bonds (Henderson, 1977), social networks (Mueller, 1980), meaningful social contacts (Cassel, 1976), and availability of confidants (Brown et al., 1975).

What has remained consistent throughout the research is the importance of human relations; the concept of social support has been the subject of considerable study among social scientists and psychiatrists. A central hypothesis of this theory is that a person's sense of well being is sustained by social contact. Lynch (1977) found that in relation to heart problems, there exists a biological basis for the need to form loving relationships or otherwise health is imperiled. Spitz (1946) found that developmental problems in children were due to maternal deprivation. Cobb (1976) focused his studies on the hypothesis that social support may be a buffer or mediator of life stress. Turner (1983) acknowledged that the concept of social support is used to make sense of the fact that people in what seem to be supportive environments are in better health than their counterparts without support.

While diversity has existed as to how social support is defined, most definitions in research have focused on the helping elements. In addition, social support has been viewed as accessible to the individual though social ties to individuals, groups and to the larger community (Turner, 1983). Gerald Caplan (1976) focused his research on social support within the context of crisis theory and mental health. He found that attachments serve to improve adaptation to short-time challenges and stressors. He emphasized the importance of more formal sources of social

support such as professionals and self-help groups. House (1981) identified 4 broad classes of social support: (1) emotional support, involving empathy, love and trust, (2) instrumental support, involving behaviors that directly aid the person in need, (3) informational support, composed of information useful in coping with personal problems within the environment, and (4) appraisal support, involving relevant and self-evaluation or social comparisons, exclusive of any effect that might accompany such information.

Interest in how individuals cope with stress has grown since 1966. In his conceptual analysis of stress and coping (Lazarus, 1966, Lazarus & Folkman, 1984), Lazarus argued that stress consists of three processes. *Primary appraisal* is the process of perceiving a threat to oneself, *secondary appraisal* is the process of bringing to mind a potential response to a threat, and *coping* is the process of executing that response. Lazarus maintained that these processes do not function as a linear sequence, but are interdependent. For example, realizing that a coping response is available may cause one to view a threat or a crisis as less threatening. In order to study the process of coping, Lazarus and his colleagues (Folkman & Lazarus, 1980) identified two general types of coping; the first, problem-focused coping, is aimed at problems, or initiating an action that would change the stress. The second type of coping, emotion-focused, is aimed at reducing the emotional upheaval that is a result of the stressful situation. In a review of Lazarus and Folkman's work, Carver et al (1989) cited that while the majority of stressors result in both types of coping strategies, problem-focused coping tends to predominate when people feel that they are in control, and can affect a change in the stressful situation. Emotion-focused, coping, on the other hand, surfaces when individuals experience a lack of control and feel they must endure the stressful situation.

According to Caplan (1998), the experience of stress creates emotional arousal, manifested by a reduced efficiency of cognitive functions. As a result, one becomes less effective at focusing attention on the environment for problem solving. “Social support compensates for perceptual deficits, reinforces the sense of self, and provides a monitoring of the person’s adequacy of functioning” (Walsh, 1998, p.56). Caplan stated that there are ten characteristics of effective support; nurturing and promotion of an ordered world view, the promotion of hope, the healthy promotion of timely withdrawal and initiative, the provision of guidance, the provision of a communication channel with the social world, the affirmation of one’s personal identity, the provision of material help, the containment of distress through reassurance and affirmation, the insurance of adequate rest and finally the mobilization of other personal supports.

3.2 THE IMPACT OF SOCIAL SUPPORT

In the area of physical illness, disabilities and social support, research literature is replete with both positive and negative outcomes. Dunn and colleagues (1999) described how a volunteer peer support service assisted women with breast cancer, decreasing social isolation and increasing optimism about the future. Dunn further recommended that volunteers be matched with patients most similar to them in way of life. Hirschman (2005) determined that a woman’s ability to navigate her new role as a breast cancer patient is impacted positively by the support she has available.

Aguero-Trotter (2005) examined the effects of stress management and coping skills of cancer patients. According to the author, a diagnosis of cancer, like a diagnosis of HIV, is considered to be a negative stressful event. As patients live longer with a once terminal illnesses,

their level of stress increases as they adjust to chronic illness and live with the fear of a recurrence or a decline in health. The intervention, a stress management coping skills training intervention compared to an unstructured support group, found that after the training, participants reported significantly lower levels of stress and depression.

Based on a computer search of Diabetes in health-related databases from 1980-2003, Van Dam et al. (2005) selected studies testing the effectiveness of social support interventions on health outcomes and found six controlled studies. Overall, the typical forms of support (spouse, family and friends) resulted in no improvement in diabetes management. However, specific forms of social support, (groups, internet and telephone-based peer support) may positively help improve the management of this disease.

Bartley (2005) found that with family support, cardiac patients improved adherence to their therapy. Frick and colleagues (2005) discovered that problematic social support is associated with poor survival following stem cell transplantation. Marmot & Wilkinson (Eds, 2006) published the second edition of the *Social Determinants of Health* (first published by the World Health Organization in 1998). This new edition focuses on the most recent research as it pertains to the effects of social support on various aspects of health. Reviewed in this compendium of research literature are the positive effects of social support on stress and health, early life development, poverty, social exclusion and minorities, old age, sexual behavior, vulnerability and ethnic and racial inequality.

Cooper & Tiknaz (2005) found that social support in the form of nurture groups made a significant impact in the areas of social and emotional development and behavior in school-age children. Appleyard (2005) examined the role of social support across childhood and adolescence in a high-risk population (maltreatment, life stress, level of maternal support).

Findings showed that those with increased social support functioned better at school and had fewer behavioral problems. Anschuetz (2005) found that among college students, their access to social support significantly improved college adjustment. Fry & Debats (2006) looked at the sources of life strengths predictors of late-stage mortality and survivorship. From their research, they found that, as hypothesized, an individual's sources of strength (perceptions of self-esteem, internal control, maturity, social contacts) are critical to the prediction of mortality of both men and women. For men, lower education and lower levels of perceived control, personal commitment and physical functioning are associated with the greatest threat to mortality, while for women, perceived low levels of social support and social engagement present the greatest risk to their mortality.

Sullivan and Poertner (1898) found that the long-term mentally ill had small social networks (Tse, et al., 2004). Caron (2005) favored interventions that focused on the development of social support for those with mental illness. An article by Snyder (2006) reported that social support networks that are developed through volunteering can act as a buffer against stress and illness and has been associated with good health and well-being. Those with a strong sense of their own effectiveness, coping abilities, social usefulness and who are socially active tend to have better health and lower mortality. Baker (et al., 1992) found that both availability and adequacy of social support was positively related to quality of life and functioning. Finally, Edwards (2005) found that for those with depressive symptoms living in a long-term facility, the presence of social support reduced depressive symptoms.

3.3 PEER SUPPORT

Over the past thirty years, participation in peer-run self-help groups has become an important way for people to help each other cope with various problems and crises. Approximately 7.5 million Americans belong to as many as 500,000 self-help groups, addressing a range of illnesses, addictions and disabilities (Lieberman & Snowden, 1994). Durman (1976) found that most self-help groups developed in response to the need for human interaction, quick availability in a crisis and a focus on helping members cope with difficult situations. Numerous studies have shown that participation in self-help groups can significantly help improve the quality of lives and reduce the need for medical care and hospitalization (Campbell & Leaver, 2003). Today, mental health agencies employ consumers to provide peer services such as case management and crisis intervention (Arntsen, et Al, 1995).

Since the beginnings of peer support, consumer providers have asserted that help is best received when the receiver has direct control over the help and there is reciprocity between the help givers and the receivers (Zinman, 1987). Empowering the client, central to the concept of peer support, cannot occur when given by those with greater power to those with less. Peer providers believe that a supported environment based on self-determination and empowering relationships is critical in helping those improve their ability to participate in the community. Peer-run services actively provide support in helping clients make choices about treatment, housing, education etc. Because clients are motivated by the hope that it is possible to lead a more independent life, peer support programs encourage self-determination by focusing on teaching skills needed to direct one's own life. Many programs have an educational component that teaches members problem-solving skills, coping skills and information on available community services (Silverman, 1997). To accomplish this, the skills of listening and

collaboration become crucial. Peer support allows time to get to know the person. Consumers with mental health problems have repeatedly stated that it is critical in their recovery that peers believe in them, stressing the importance of connecting emotionally with the peer provider (Campbell & Leaver, 2003).

In 1999, a report by the Surgeon General (U.S. Department of Health and Human Services) recognized peer support as an important adjunct to traditional mental health services and concluded that self-help programs serve as powerful agents for change in social service programs. As in the field of HIV, with growing numbers of consumers and reduced funding, peer-run support services emerged in a mental health system that is under-funded and that fails to reach the majority of those ill (Campbell & Leaver, 2003). And as with HIV-infected individuals, the lives of mental health consumers are frequently set apart by hostile or indifferent communities that reject, shun and sometimes attack them out of fear and ignorance. Stereotypes of persons with mental illness, as with HIV, are that those affected or infected are dangerous, unpredictable, incompetent, immoral and responsible for their own illness.

In the mental health field, there have been positive changes in the identification and delivery of more effective, evidence-based services. The Substance Abuse and Mental Health Services Administration identified, and provides funding, for services such as assertive community treatment, supported employment, family support, and integrated dual diagnosis treatment. But consumer leaders have found that such evidence-based practices often lack relevance to their everyday struggles for quality of life and are not always consistent with a recovery-based philosophy of treatment and service choice, mutual support and self-determination (Frese, Stanley, Kress & Vogel-Scibilia, 2001).

In regards to life stressors and support, the National Committee for Prevention of Child Abuse (1990) asserted that in a study designed to prevent abuse, a volunteer peer support program significantly improved parenting skills and coping strategies as well as being economically more advantageous than intervention by professionals. LePage (2006) found that patients who perceived more support had improvements in a number of lifestyle behaviors. Budde & Schene (2004) addressed the ever increasing interest of policy makers as well as practitioners in utilizing the support of friends, family and volunteer peer support groups. While these informal support interventions are flexible, responsive to individual needs, improve social support, reduce violence and save money, he concluded that rigorous and creative evaluations are needed in order to measure their effectiveness.

Clients living with HIV disease, and often with co-occurring mental illness, face barriers to accessing services due to illness, confusion and often discrimination. Without friend and family support, without a job and struggling to obtain basic resources, this most vulnerable population is at risk for untreated opportunistic infections and early death. It has been shown that emotional support helps improve the management of disease and increases access to support services. In Southwestern Pennsylvania alone it is estimated, from the number of AIDS diagnosed to date, that over 15,000 are living with HIV. Coupled with decreased state and federal funding, it appears to be critical that peer support be expanded from the traditional Buddy programs to case management. Peer support has been successful in the mental health field, and the concepts of self-empowerment and teaching problem solving and coping skills could serve to increase the level of independent functioning for those with HIV.

Because case management entails the development of a close working relationship between manager and client, it provides the opportunity for identification in much the same way

as a therapeutic relationship (Harris & Bergman, 1987). The danger with case managers providing emotional support while addressing client needs is that without promoting independence and skill-building, dependency on staff to manage their lives often results in their inability to obtain services and resources on their own.

3.4 LIVING WITH HIV: THE EFFECTS OF STRESS AND SOCIAL SUPPORT

Thoits (1995) stated that literature on stress showed that members of disadvantaged social groups such as those living in poverty, single mothers, individuals with mental or physical disabilities, and those at greatest risk for contracting HIV, are especially vulnerable to stress. Those living with the disease must deal with catastrophic illness, daily crisis, economic deprivation, social isolation and discrimination, losing friends and family to the disease, and an uncertain future, as multiple opportunistic infections attack their compromised immune system.

While one cannot generalize from existing studies that social support would improve functioning for HIV+ individuals, a vast amount of literature suggests that social support plays a vital role in how people cope with physical and emotional disasters.

One of the few studies to look at the psychosocial outcomes of HIV disease (Linn et al., 1995) demonstrated that a sense of control and a sense of coherence lead to a belief that life has meaning and is predictable despite having a catastrophic illness. This sense of control is dependent upon receiving resources from social relationships that help facilitate successful problem solving. A dissertation by Doroon (2003) found that HIV+ women who utilized support from friends, family and professionals adjusted better to their diagnosis. Another dissertation by Derlaga (2002) found that clients who sought social support coped better with the diagnosis of

HIV. Halleret and colleagues (2003) found that clients living with HIV had a higher rate of suicide if they lacked stable personal relationships and had a restricted social environment. Rodgers (1995) found in her study that HIV+ individuals who perceived themselves to have higher levels of social support made better adjustments in their lives than those with less perceived support. Haas (2002) studied how particular sources of social support affected the maintenance of gay couples in which one has HIV, and found that family members and friends provided a high level of support. For couples dealing with a chronic illness, his findings suggest that illness-related social support also serves to help maintain and support the couple's relationship. Harvey & Wenzel (2002) reviewed literature as it relates to the improved coping strategies of those with HIV, and found that how they view their close relationships forms an important basis for giving meaning to their lives. Saunders & Burgoyne (2001) studied factors associated with requests for professional services at an AIDS Service Organization. Those that requested practical support services reported having significantly fewer friends, less social support and more health issues, and those that requested emotional support reported significantly lower positive social interaction compared to those who did not request it.

In 2002, Leslie and colleagues studied the impact of emotional distress and social relationships on health related outcomes of parents living with HIV, as mediated by active and passive coping styles. Social support was significantly associated with higher levels of coping. Overall results indicate that interventions to enhance coping skills could lead to improved health-related outcomes for HIV+ parents. Song & Ingram (2002) examined the relationship between the perceptions of the availability of social support and perceived non-supportive social interactions relative to anxious and depressive moods among African Americans. They found that greater satisfaction with the availability of social support was associated with lower levels of

mood disturbance. Results also indicated that the level of HIV-related unsupportive social interactions was positively related to the use of the coping strategy of disengagement and denial, which in turn was associated with greater mood disturbance. Stewart and colleagues (2005) found social support was positively associated with mental health status, and that the health status of those living with HIV may be improved by assessing and addressing social issues such as social isolation and life stressors. A literature review by Walsh (1998) found that persons who are depressed often isolate themselves from others, that depression can be alleviated with social support, and that all individuals tend to function most effectively with available supports from several sources.

According to Greene et al. (2002), researchers have begun to turn their attention to the study of social and personal relationships. Among those researchers, Leslie, Stein and Rotheram-Borus (2002) surveyed 295 HIV positive parents about their coping style, emotional distress, conflict, social support, and health outcomes. Their findings show that active coping was related to higher levels of social support, greater health satisfaction and less substance abuse. The researchers argue that interventions focusing on enhancing coping skills could improve health outcomes for those with HIV.

Ashton et al. (2005) examined the social support and maladaptive coping behaviors as predictors of HIV-related health symptoms. Individuals reporting more satisfying social support were more likely to report a lower incidence in their HIV-related symptoms, suggesting that social support is a strong predictor of health outcomes.

Computers connect an increasing number of isolated individuals, seeming to provide social support as well as anonymity. Routledge (2000) conducted a study to look at the impact of internet use on the coping skills of those living with HIV. The study revealed that the impact of

internet use on coping ability involved three themes: the internet promotes empowerment, augments social support and facilitates helping others. A group of researchers (Flicker, et al., 2004) even looked at social support through the internet and found that for youths age 12-24 who were living with HIV, the internet provided an additional source of positive social relationships.

Patterns of HIV-status disclosure and social support were examined by Kalichman et al. (2003). Results showed that rates of disclosure were associated with social support. Friedland et al. (1996) found in their study of coping, social support and quality of life, that close friends provided most types of support, and that although the participants indicated high levels of satisfaction with support, they expressed a need for more emotional support.

An article by Greene et al., (2002) introduced the issue of HIV within the context of personal and social relationships. The authors highlighted four major themes: (1) the changing nature of HIV to a long-term chronic illness, (2) the importance of personal and social relationships, (3) the effects of HIV on the personal and social relationships of minorities and women, and (4) the continuing stigma, and coping with the stigma, that affects the lives of those living with HIV. “Individuals with HIV infection, besides living with a potentially life-threatening and long-term disease, face many social challenges, including the impact of the disease on their personal relationships with intimate partners, friends, family of origin or choice, neighbors, co-workers, health care professionals and acquaintances. In turn, the nature and quality of those relationships (e.g., the extent to which they provide social support) may influence how well one copes with HIV...” (Greene, et al., 2002, P. 221). Although social and personal relationships have been important for those living with HIV, the shift to long term disability makes existing relationships even more important. Martin, et al (2005) surveyed HIV+

clients living in the Los Angeles area and found that many were in need of support in order to re-enter the workforce due to experiencing significant obstacles.

Those living with HIV not only face the ravages of a disease, but may also lose friends and family to the illness, suffer the loss of their job, self-image, house, health, physical appearance and ability to care for themselves and meet their basic needs. Each day they live with the worry of contracting a new infection that may disable or disfigure them. And with each new infection comes a decline in health and the potential for death. While these struggles are in themselves overwhelming, those living with HIV must also contend with discrimination as a result of their diagnosis in addition to their race, gender, sexual orientation, financial status or mental health and/or drug problems. These stressors are compounded by the fact that many with the disease are abandoned by friends and family out of fear and disapproval.

Studies have demonstrated the importance of social support in improving a sense of well-being, health, ability to better adjust to stress and giving back to the individual a sense of control. In the mental health field, research has shown that peer support provides skill building, problem and emotion-focused coping strategies, self determination and empowerment. Peer support is not only a strong predictor of health outcomes, but enables clients to become more self-reliant.

Despite considerable theorizing about how social support works to reduce physical and psychological ill health, relationships among various psychosocial coping resources remain understudied (Gore, 1985). Unlike mental health, there has been little research in the field of HIV that has demonstrated the impact of peer support. This study will serve to begin to examine the effectiveness of a specific model of social/peer support on an individual's ability to function more independently-that of a peer driven volunteer intervention that provides training, encouragement, validation and skill building.

4.0 CASE MANAGEMENT IN SOCIAL WORK

4.1 EVALUATION EFFORTS

Case management (CM) as an intervention in the field of social work was poorly studied until federal policies in the 70's mandated programs for the elderly and the mentally ill. Previously, case management models of care were not developed until after World War II when the focus of care was on treating the elderly and the mentally ill (Netting, 1992). Cohen and Cesta (1991) describe CM as a creative response to providing less expensive care in a restrictive environment. Case management is generally viewed as a way to decrease fragmentation of services, encourage and support self-care, decrease cost and enhance quality of life for individuals with multiple problems and complex needs (Benjamin, 1988). Interventions for achieving these outcomes include integrating and coordinating services, monitoring client health and compliance with care, anticipating and prioritizing needs and working closely with other service providers.

Case management reflects various core social work principles of problem solving within a client's environmental context and achieving change in the person, the environment, or both (Gant, Green, Stewart, Wheeler, & Wright, 1998b; Greene, 1992; National Association of Social Workers, 1991). In order to assure that services are appropriate to the needs of each individual client, goals need to be client-oriented and client-driven based on both client strengths as well as weaknesses. Case managers provide a comprehensive assessment, monitor to ensure access to

services and resources as well as compliance, support the clients' caregivers as well as serving as bridges between numerous institutional and community based care systems. And while these are the generalized goals of case management, Beatrice (1991) asserted that "Case management is therefore neither inherently nor definitively defined. It derives its definition in large part from the nature and needs of a system whose component parts it will be coordinating and integrating... It must be a creature of its environment, tuned to the specific characteristics and needs of its host system, if it is to be effective" (p. 124).

Bryant and Bickman (1996) described the heterogeneity of case management programs and the frequent failure of authors to adequately describe case management, making it difficult to interpret any evidence as to its effectiveness. Brekke and Test (1992) asserted that a detailed description is needed of the services in order to determine if they are delivered as planned before being able to study their impact. As with any case management program, there tends to be general agreement as to its primary components; identification, assessment, planning, linking and referral, coordination of referrals, monitoring of the clients status and evaluation and, at times, advocacy (Melville, Kiber, & Haddle, 1977). For each component of the case management process, specific activities should be described and will vary with the population being served.

Case management has been described in the literature as both a micro and macro approach in that both individual practice and community practice are integrated, with the case manager needing to interact within a variety of social layers. Case management programs vary along a number of dimensions, each of which can affect both program effectiveness and client outcomes. Financial reimbursement, professional versus lay staff, the political environment of the community, the quality of the referral base, whether an individual or team approach is utilized,

caseload size, the timing of the intervention as well as the intensity of the client-case manager relationship all will affect client outcome and need to be factored into any evaluation.

Historically, outcome research for case management intervention has focused on reducing hospital costs. But evidence that case management services reduces costs by reducing hospitalizations is mixed. In some studies with the elderly and chronically ill, costs decreased, while in other studies, the same populations used both case management and in-patient services, thus increasing costs (Twyman & Libbus, 1994). A study by Arnold (1996) found that initiating case management services before clients become acutely ill improves satisfaction, outcomes and appropriate use of services. Other studies show that case management improves the quality of life for individuals and their families, increases compliance with medical care and reduces health care costs (Harrel, Lamperti, & Reich, 1995).

As acute healthcare is being managed increasingly by large health care organizations instead of by healthcare providers, case management for chronically ill populations is under greater scrutiny. To remain funded, case management must have qualitative and quantitative measures of outcomes (Bulger & Feldmeirer, 1998). Case managers believe in the value of their service for improving client's quality of life while decreasing health care costs. But beyond defining the functions of case management and implementing satisfaction surveys, programs must develop a method of demonstrating the impact of their services.

Applebaum & Austin (1990) assert that case management programs have historically failed to take into consideration the impact of the program within which case management services are delivered. The majority of research studies have focused on either quality assurance, the structural process of service delivery (what information is gathered and when), or the process of how a service is delivered (staff meeting face to face or making phone calls), and not on

outcomes (what happens to the client after the service has been provided), or on program impact evaluation. The latter, according to Applebaum & Austin (1999), is designed to answer the question of whether CM affects clients differently from an alternative model of care.

To address this issue, case management as a service delivery system was tested in fifteen federally sponsored demonstrations between 1973 and 1985. Federal waivers under the Medicaid Program have permitted reimbursement for case management in waiver-funded programs operating in over forty states. These waivers encourage the delivery of case management services as a way to contain costs for more expensive in-home or nursing home care. In addition, case management has been a primary focus in recent demonstration projects such as the Social/Health Maintenance Organization, the Medicare H.M.O. Projects and the Robert Wood Johnson Hospital Initiatives in Long-Term Care.

These studies suggest that the role of case management will continue to expand and take on greater importance in providing critically needed community-based care to the aging and the disabled (Applebaum & Austin, 1990). But despite the proliferation of case management programs and the completion of many demonstration programs, Applebaum and Austin (1991) assert that there is limited information on how best to monitor and evaluate the impact of case management services. Demonstration projects often are setting-specific, utilizing their own terminology and standards. In assessing the effectiveness of any case management program, Applebaum and Austin (1991) contend that it is important to differentiate between quality, evaluation and quality assurance. In addition, they believe that while the goal of any case management intervention is to provide quality services to those most in need, quality care is evidenced through quality assurance (typically focused on client satisfaction, or the amount of time it took to obtain services) and evaluation.

In evaluating a program, the key question is whether the services delivered or provided had the intended effect. Does the client function more independently, have decreased hospitalizations or show other positive outcomes? To demonstrate that a particular outcome is achieved over time, the case management service and its components must be operationally defined and standards as well as assessment tools need to be developed.

In a comprehensive review of case management articles, the majority of measurements of case management programs are descriptive (Chernesky, 1999). These measures are easy to define, and most agencies are able to collect basic data without employing an individual with substantial evaluation experience. Peer review, independent experts examining sample case reports, client and case manager interviews as well as reviewing client records tend to assess the structure and process of the case management approach (what services were obtained, how long did it take to acquire the services), but do not provide definitive evaluative information about the program's impact on client outcome

4.2 MENTAL HEALTH AND DRUG AND ALCOHOL CASE MANAGEMENT RESEARCH

Research regarding the effectiveness of case management for psychiatric clients has shown mixed results. Cousins, et.al.(2002), reviewed available process evaluation literature and found that only a small number of published studies examined the assessment of mental health case management programs, and that in fact, few even attempted to evaluate CM programs.

According to Bryant & Bickman (1996, P. 121), case management has often been likened to a Rorschach test with interpretation depending on individual perspective. "The heterogeneity of case management programs and the frequent failure of authors to describe case management

make it difficult to interpret evidence of its effectiveness” (Bryant & Bickman, 1996). Some studies showed improved outcomes while others reflected a decrease in client satisfaction and functioning which may be the result of the role of the case manager (Twyman & Libbus, 1994). A longitudinal experimental design (Morse, Calysn, Allen, Templehoff & Smith, 1992) was used to study three treatment programs for the mentally ill and homeless. The effectiveness of traditional out-patient care was compared to care at a drop-in site with continuous intensive case management. After twelve months, those clients receiving case management had more contact with personnel, were more satisfied with care, accessed more community resources and had fewer days when they were homeless. A study by Huxley and Warner (1992) showed that psychiatric clients who received case management described an improved quality of life, although the number of contacts with a case manager was negatively associated with satisfaction with treatment (Twyman & Libbus, 1994).

As noted in general case management studies, the methodologies of their reviewed studies focused on the descriptive characteristics of case management. In addition, they tended to evaluate the process characteristics in terms of whether or not a case management component was present, and the research was time limited, rather than examining integrated services on an on-going basis. The authors of the review felt that these limitations restricted the extent to which the methodologies could be used to identify the critical ingredients of the case management intervention that contributes to client outcomes.

Effective case management can enhance an individual’s ability to cope and function in the world. Bond, Miller and Krumweid (1988) demonstrated in an experimental study that psychiatric clients receiving an intensive case management approach that focused on their wide spectrum of needs decreased the need for hospitalization. A major study of the provision of a

continuum of care to military dependent children in the Fort Bragg Child and Adolescent Mental Health Demonstration Project (Bickman, Bryant, & Summerfelt, 1993; Bryant and Bickman, 1996), found that this case management intervention was based on the following principles: case management service must be described, evaluation should be guided by theory, a multimethod technique should be used in order to obtain a rich description and the criteria for assessing the quality of the intervention should be clearly stated. For this study, measures flowed from program theory, examining and detailing the processes and components of case management. The multimethod approach included questionnaires, observations, chart reviews, and case managers completing logs to describe their activities, and interviews. The authors concluded that more descriptive research is needed in order to identify the basic structures and processes in case management before being able to assess any outcomes. They recommended that the attributes of quality case management be operationalized, and that data collection tools must be created and refined.

A dissertation by Schaedle (1999) sought to identify some of the attributes of case management with a review of current literature, and by interviewing case managers in the mental health field. According to the author, there are nine interdependent principles that foster a positive relationship between case manager and a client with mental health issues. He also asserted that these principles could provide direction for outcome research. The nine principles of case management are;

- An agency that supports services
- Clients having access to care without financial or geographical barriers
- Providing a full array of services
- Services must be individualized

- Service must be flexible to meet individual needs
- Other agencies must work together in a continuum of care
- Each client needs the opportunity to develop a relationship with a case manager
- The client needs to participate in the creation of his/her treatment plan
- The services must be culturally sensitive.

While substance abuse and psychiatric disorders often occur concurrently (Stewart, Zuckerman & Ingle, 1991), case management programs for those addicted have only recently come into existence and too few studies exist. The importance of considering a variety of measurements to assess the effectiveness of case management for those with drug and alcohol issues has received increased attention (Sullivan, et al., 1992). Although the reduction and/or elimination of substance use is critical, it is also important that interventions result in improved overall functioning. The degree to which alcohol and drug use is related to functioning in various life domains has been the subject of debate, and unfortunately too little research. Case management as an intervention can serve to provide a continuum of care, but too few programs fund drug and alcohol case management and so services tend to be limited. While a recent review of substance abuse treatment programs in Los Angeles revealed that the majority provided some form of CM services, little was found about who is case managed and by whom. McNeese-Smith (1999) extensively reviewed CM research in the field of drug and alcohol, and found that there have been both positive and negative results. A study by Morse and colleagues (1997) found that community-based CM was most effective with the outcomes of stable housing, increased income and greater client satisfaction. Veterans with substance abuse issues receiving CM services worked more days (Seigal et al, 1996), and women formerly incarcerated and mandated to receive CM were more likely to complete treatment (Berkowitz, et al., 1996).

On the other hand, Grella and colleagues (1997) found no re-hospitalization differences in those with mental health and drug and alcohol problems (MH/DA) as compared to a control group. Of the three interventions employed by Grella and his researchers, skills-training was found to be more effective in reducing costs, in improving functioning and in reducing substance abuse. In addition, the intervention decreased psychiatric symptoms.

Another study (Braucht et al., 1995), found that CM did not improve service quality or outcomes. In reviewing fourteen studies that used CM for substance abusers, McNeese-Smith (1999) found that seven showed positive results (clients better able to access housing and supportive services) while seven showed the same or worse results than other interventions. However the programs in the study did not describe how CM was being used, making it difficult to assess its direct impact. Bongjae (2005) found that social support, a component of case management, had a direct impact on an alcoholic's health and well-being, while Klingemann (1991) found that social support motivated individuals to stop using alcohol and heroin.

4.3 CASE MANAGEMENT FOR HIV POSITIVE INDIVIDUALS: GROWTH AND RESEARCH

In a study by Lehrman (2001) of the HIV/AIDS case management process in New York City, the researchers found that case managers played a critical role in the lives of those living with HIV. They described the case management process as a direct service in which the case manager and client relationship enables case managers to assist and support clients as they manage their illness while attempting to live independently.

Lehrman (2001), reviewing case management programs at ASOs cross the country, found gaps in evaluating services for alcohol and drug abusers, as there was missing data. In addition,

she (2001) found that there were no specific case management programs for mentally-ill/chemical abusers (MICAs). There also appears to be a lack of data about the numbers of MICAs served, as information was missing about the demand for services by this population. Lehrman suggested that logic dictates that the majority of MICAs would benefit from help navigating the system. Care for those with mental health and/or drug and alcohol problems have typically fallen upon ASOs as other providers cite HIV, and not MH/DA, as the presenting issue. In order to address all of their issues beyond dealing with a disease, it is crucial to have on-going support.

Case management as an intervention for people with HIV has only been adopted since the mid-1980's. Community based AIDS Service Organizations (ASOs) were quickly established around the country in response to the complex specialized needs of those living with HIV, as well as to the fear and discrimination that existed among service providers. An important event in the development of a case management service delivery system occurred in 1986 when the Robert Wood Johnson Foundation established nine demonstration projects, the AIDS Health Services Programs. In 1991, the National Commission on AIDS referred to the value of case management as a critical intervention strategy for persons with HIV/AIDS. The Commission acknowledged the benefits of case management for cost savings, reducing the number and length of hospitalizations, coordinating complicated care as well as enhancing satisfaction and quality of life. "The rapid proliferation of HIV case management programs resulted from the 1990 Ryan White Care legislation and funding, because the legislation did not mandate service provisions, program models, or case manager qualifications, each locality was able to design its own service delivery system. Consequently, there is little consensus about what HIV/AIDS case management

is and describing HIV/AIDS case management as it is actually practiced has become a research challenge” (Chernsky & Grube, 2000, p. 4).

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in August 1990. Federal dollars provide funds for an array of support services, including case management. The CARE Act is administered by the HIV/AIDS Bureau, Health Resources and Services Administration (HRSA), and the Department of Health and Human Services. Nationally, almost 18% of Ryan White CARE Act funding has been expended on HIV/AIDS case management (Shulman, 1995). These funds support the provision of medical care, support services, case management and the Special Projects of National Significance (SPNS).

Because of the success of the Ryan White CARE Act (this legislation has allocated more money to HIV/AIDS in the United States than any other federally mandated program over the past 15 years), Congress reauthorized the program in 1995 and in 2000. The next reauthorization in September 30, 2005, provided continued funding with only a ten million dollar increase for 2006 (Henry J. Kaiser Family Foundation, 2005). These funds were allocated for reimbursement of medication and not for direct services. Along with the funding for 2006, there was to be only a 3.7% increase in funding annually from 2008 to 2011, with 75% of the CARE Act funds to be used for medical services and not case management and other support services. In December 2006, Congress rewrote the Ryan White Care Act allocating funding to previously under funded regions further reducing dollars for case management. While the population of those HIV infected continue to grow at 40,000 new cases each year, and those with the disease are living longer, funding has not increased to keep pace and in fact, for support services, has decreased (The New York Times, 8/1/07).

In distributing the limited CARE funds, programs need to "...evaluate the effectiveness of a service or program in achieving its intended results." (HRSA & HIV/AIDS Bureau, 1998, p.1). Although the Act does not define "effectiveness", the interpretation of providers has been that programs need to reach the right people and make a difference at a reasonable cost (HRSA & HIV/AIDS Bureau, 1998). And while the CARE legislation stresses the importance of program evaluation and accountability, making a difference has been up to the individual agencies to determine. A white paper prepared by the Bureau of HIV/AIDS has encouraged service providers to assist with the development of performance indicators and to participate in local studies that increase knowledge about outcome effectiveness (HIV/AIDS Bureau, 1996). And according to a joint report issued by HRSA and the HIV/AIDS Bureau (2000), when evaluating accessibility, quality and outcomes of HIV services, researchers need to consider the following; knowledge, attitude, experience and training of staff, ease of location and operational hours as well as the wait time for services (HIV/AIDS Bureau and HRSA, 2000).

Lehrman (2001) stated that the vast majority of existing HIV/CM studies have tended to focus on processes (e.g., the completeness of the documentation, types of activities undertaken) and not on outcomes. "Although process evaluation is valuable-it can help pinpoint ways to improve CM-in and of itself it does little to justify program continuance." (p. 4). According to Lehrman, (2001) additional outcomes which could be examined, but have not been extensively evaluated, include improvement in clients lives, and changes in clients' behavior.

According to HRSA and the HIV/AIDS Bureau (1998), an outcomes evaluation assesses the effectiveness of a service or program in achieving its intended results. In contrast to cost-effectiveness analysis, outcomes evaluation does not assess the value of a service relative to its cost, but instead focuses on the degree to which goals and objectives are met. Standard

measurements for evaluation with most agencies have been process measures, assessing the way in which services are delivered. In addition, to meet CARE funding requirements, most AIDS Service Organizations (ASOs), including the Pittsburgh AIDS Force, used outputs instead of outcomes. Quarterly reports focused on the number of service units delivered (e.g., the number of trips to a food pantry, how many bus tickets given, hours spent with case manager, the dollar amount of financial aid that was allocated etc.), rather than the results of the specific intervention or service. The question that had not been addressed was how did the number of case management hours, the dollars given, the amount of food or bus tickets provided serve to improve the quality and functioning level of the client?

Abramowitz et al. (1998) assessed the efficacy of a study that measured differences in case management activities when working with families versus individuals working with those living with HIV. Here again, the study did not focus on the effect of the intervention but instead described the activities of the case manager (assessment, linkage, phone calls, etc), as well as the amount of time spent obtaining the services and how these variables differed based on family versus individual, client needs, HIV status and family history. What was found was that case managers spent more time with families, especially if more than one family member had HIV, and spent more time accessing services for those with end stage disease.

In the field of HIV case management, few studies have documented the effectiveness of case management intervention. A review of social work and psychology abstracts, as well as thirteen other databases found that there were articles that studied people living with HIV, case management as an intervention, but none that addressed research or outcome measures for this population. Reviewing the same databases found no articles on drug and alcohol CM, but there were over 12,000 articles on mental health research. Of the over 1.6 million digital dissertations,

982 dealt with HIV/AIDS but only 3 studies addressed CM, and none utilized any measurement tools.

In *The Case Manager's Handbook* (Mullaby,1998), the majority of articles focused on public sector case management, i.e., in regards to workman compensation claims, hospitalizations, and containing costs for insurance and health care programs. There was only one mention of working with HIV infected clients, two paragraphs on working with those with drug and alcohol issues and only one article even addressed the needs of those living with mental health problems. Not one article identified an outcome measure.

According to a press release issued in June, 1998, The National Institute of Mental Health stated that “Research is urgently needed to adequately respond to the AIDS epidemic among people with persistent and recurrent psychiatric disorders such as schizophrenia, depression, or bipolar disorder” (p.1). Since research into the magnitude of the AIDS epidemic in persons with severe mental illness did not begin until the early 1990’s, in part due to the focus of sexual activity and drug use of this population being a risk factor, “...there is a paucity of research on HIV infection in persons with severe mental illness” (p. 2).

Lehrman (2001) in reviewing ASO’s, found those with substance abuse and mental health problems were least likely to be connected to HIV social services, lacked the knowledge of how to access services, had difficulty keeping appointments, and lacked social support, often contributing to delaying access into care.

A study by Emler & Gusz (1998) examined service utilization of clients enrolled in an HIV case management program. Besides identifying that the number of injection drug users rose consistently over a five-year period, service utilization also increased in the area of in-home services and case management hours. Harrell, Lamperti & Reich (1995) found that case

management for HIV positive women and their families improved the quality of life, improved compliance with medical care and reduced health care costs by providing early intervention. Compton's study (1996) demonstrated that by providing access to a coordinated system of community care with a focus on planning, an HIV+ individual's ability to cope with the challenges and manage the crises presented by the disease improved. This system of care significantly reduced the number of times clients needed to access case management.

However, despite the growth of case management, research has focused more on the physical outcomes as it pertains to; accessibility, quality and outcomes of HIV services for vulnerable populations (Palacio, et. al, 1999; Shiboski, et. al, 1999); Comparing social-economic characteristics and knowledge and use of HIV-related resources between men and women (Davidson, et.al, 1998); examining attitudes of African Americans and Latinos towards HIV (Kaiser Family Foundation, 1998); determining whether race is associated with health care coverage (Kass, et. al, 1999); looking at the participation rates of women, injection drug users and people of color in clinical drug trials (Stone, et. al, 1997); and determining the level of hospice use among injection drug users (Cox, 1999).

One of the first to examine case management for those living with the disease, Lehrman et. al (2001) studied HIV services in New York State. The purpose of her study was to help fill the gap of so little research by examining CM outcomes and processes. The research focused on linking clients to needed services and had as its' goal to answer the following questions:

- To what extent is CM successful in identifying clients' needs?
- What is the nature of clients' needs?
- To what extent are arrangements made to meet clients' needs and to what extent are services utilized once they are arranged?

- Do the needs identified and utilized vary according to demographics?
- When are service needs identified?
- How long does it take to arrange the service?

According to Lehrman (2001, p. 483-484), “The number of client needs identified, and the extent to which needs were arranged (i.e. the case manager completed all necessary arrangements required for the client to use the service) and utilized formed the primary dependent variables for the study.”

As evidenced from the questions, the focus of this research was on identifying client needs and the length of time it took for a case manager to meet those needs. As with other evaluation efforts, the researcher stopped short of asking the question if the service needs met made a difference in the functioning level of the client.

Employing chart reviews and client/case manager interviews, the authors were able to determine how long it took to obtain a particular service, which services were more frequently accessed and utilized by the identified agency over another, and differences in service needs based on gender. In a follow-up study done in 2002, Lehrman et. al identified a variety of needs and whether the case manager was able to meet those needs. Still, neither study addressed whether the met need resulted in increased independence of the client.

Chernesky (1999) reviewed the research results of nineteen case management programs. Her review found that case management for HIV+ youths is extremely time intensive (Tenner et al., 1998); older adults with HIV are less likely to use emotional support and mental health services (Emlet, 1996), and case management was observed to be a promising intervention for substance abusers (Schwartz, et al., 1993). Indyk et al., (1993) found that community-based case managers, more than hospital based staff, worked to empower clients and to teach them to take a

more active role with their service providers. Other studies (Cruise & Liou, 1993, Crusie ,1997), found that case management is the third most frequently offered service at ASOs. Dunn (1997) and Stoskopf et al. (1996) discovered that the Medicaid AIDS Waiver Program, a program providing for reimbursement of CM services, reduced Medicaid costs due to better access to services and decreased hospitalizations. These studies demonstrate that research often describe needs, unmet needs, the programs themselves or how costs were reduced, but not whether the programs helped the clients function more independently. However, these studies suggest that case managers, more than other professionals, may play an important role in supporting and empowering people living with HIV.

Current on-going studies include the HIV/AIDS Mental Health Services Demonstration Project (a collaborative effort of the Center for Mental health Services, the Bureau of Health Resources Development and the National Institute of Mental Health), the first federal initiative to allocate funds to address the mental health needs of people living with HIV. The program was created to develop experience with, and obtain empirically based knowledge about, the delivery of mental health and related services for those with HIV. The eleven participating service delivery projects tested a variety of mental health service interventions. Funded in 1993, the five year grant evaluated the effectiveness of the programs. The goals of the program were to describe client characteristics, assess their service needs, improve access to comprehensive, integrated mental health and support services, create HIV/AIDS mental health care models that can be replicated elsewhere and to develop data collection methods. But here again, this demonstration project provides descriptive information on case management, but does not identify, create, or evaluate outcomes.

However, these studies have shown that there is poor or no coordination among various specialty agencies, and few resources for obtaining psychotropic medication from psychiatrists experienced with HIV. In addition, adult and children services are often at different sites, affecting the compliance of care for women. Services are often physically scattered throughout the community and have different eligibility requirements, service philosophies and policies. Coordinating these services is usually impossible for clients whose mental illness can preclude handling paperwork, keeping appointments, and obtaining transportation. The funded sites have structured all programs that provide a quick response, are client-focused, have one-stop shopping, and combine medical, mental health and supportive services as well as substance abuse treatment. Even where programs and services exist for those living with multiple issues, staff often lack critical knowledge concerning the care and treatment of HIV disease, existing resources and even risk factors that would compromise the health of their clients and expose others to infection.

The Special Projects of National Significance (SPNS) is a federally funded effort that focuses on developing outcome measures for the range of physical and mental health services for those with HIV. This Project is administered by the Office of Science and Epidemiology of the Bureau of Health Resources Service Administration (HRSA). The goal of the SPNS Program is to advance knowledge about the care and treatment of persons with HIV. HRSA provided guidelines to various programs for evaluation, emphasizing the importance of using both qualitative and quantitative measures in order to evaluate HIV related outcomes. Evaluation data have been collected and analyzed by the Measurement Group, an agency that specializes in the application of scientific methods of program evaluation to help health and social service programs record their activities, quality of services, client satisfaction and outcomes. One of the

initiatives funded in 1996, the Integrated Service Delivery Model, supports the development of models of care that create linkages and integrates health and support services, including housing and mental health and substance abuse services for those living with HIV (The Measurement Group, 1997).

Lehrman et al. (2001) asserted that in order to be credible to the public, outcomes must be reasonably attributable to provider actions. Many of the most valued outcomes of case management, particularly that of client empowerment, are difficult to measure. In addition, agencies, especially volunteer driven ASOs, have not been traditionally structured to facilitate outcomes assessment. Computer use at social service agencies has not kept up with the technology in tracking services, and a research consensus regarding what are appropriate outcomes has proven a daunting challenge at the local, state and federal level. But probably most glaring is the fact that social service agencies and ASOs generally lack the technical knowledge and training in how to collect, evaluate and use outcome data.

The majority of AIDS Service Organizations (ASO's) were created by activists lacking professional degrees as an alternative to traditional health care. Consequently, staff and volunteers have not possessed the education and skills necessary to assess their interventions. Social service agencies often lag behind for-profit companies in possessing computer resources and programs that collect client information. ASOs, created by volunteers with little funding, have been unable to afford the research staff to collect the data. Growing caseloads have prevented case managers from having time to collect outcome data.

According to Lehrman et al. (2002), research consensus regarding appropriate outcome measures has proved to be challenging at the federal, state and local level. She further states that current literature suggests outcomes selected for review need to be meaningful to the case

managers, to the funders and that clients need to be involved in their development. She recognized that agencies have not been traditionally structured to facilitate outcomes assessment. This concern holds true for mental health and drug and alcohol agencies, whose funding and staff are limited.

Creating an outcomes assessment program, and having staff participate, is often daunting to agencies that lack even the basic skills and training in program development, creating assessment tools and in statistical methodology. Lehrman et al. (2002) postulated that outcomes for those living with HIV could be affected by a number of factors including staffing, location of service delivery, and the availability of peer support as it affects improvement in their lives. Questions posed by Lehrman for future research are:

1. Has CM improved the clients' lives in regards to mental health functioning, activities of daily living, and ability to obtain social support?
2. Has CM support resulted in clients showing increased self-responsibility in their ability to secure services and resources?

It is clear that the focus of research to date has been to explain the role of the case manager and the importance of obtaining, as well as providing, service. But for many agencies, as well as for many researchers, the difference between effectiveness and efficiency needs to be differentiated. Effectiveness addresses how well clients progress in a case management program and is tied to goal attainment, while efficiency has to do with how long it took for the case managers to obtain services for clients (Frankel & Heft-La Porte, 1998). Geron and Chassler (1994) point out the difficulty in creating standards for CM because standards outline performance expectations which have corresponding effects of specific improvements in client

outcomes. “However, little evidence has been found that specific client outcomes are the result of specific case management activities” (Bulger & Feldmeier, 1998, p.100).

4.4 HIV AND SOCIAL SUPPORT RESEARCH

There exists research pointing to both the positive difference, as well as the lack of impact, social support has on the functioning of those with physical health concerns, dealing with other life stressors, as well as those living with mental health/drug and alcohol issues. A vast amount of research on stress suggests that support plays a vital role in how people cope with physical and emotional stress, and that perceived control is critical (Monat & Lazarus, 1991). Further studies have shown that people living with HIV cope better when they have control over their own health (Jue, 1994).

Improving the quality of life is a central issue to the care and support of people living with HIV. Care and support that generate hope and confidence will have widespread effects not only on the well-being of the person themselves, but will be disseminated to their family, community and society in general (Skevington & O’Connell, 2003). Studies (WHO and UNAIDS, 2000) show that the needs of those living with HIV go well beyond clinical care and treatment and include social support. As Lehrman (2001) asserted, “certainly from the client’s perspective, ‘actions speak louder than words.’ For a person living with HIV disease the reality of case management is not found in definitions and models, but in human interactions and the impact of those interactions on their lives” (p.4).

A survey of Pennsylvania’s Targeted Case Managers conducted by the Pennsylvania Case Management Project (1999) sought to identify some of the attitudes of case managers regarding

their roles and the nature of their work. Of those case managers who returned surveys, 89% believed the role of the case manager is to provide emotional support to consumers. One hundred per cent (100%) stated that the role of case manager is to be an advocate and to educate the consumer about available resources. The two most important contributions managers felt they made when working with their clients was providing resources and referrals and providing emotional support.

According to Gutheil and Chernesky (1999), individuals living with HIV, like other vulnerable populations, require a network of formal and informal services and supports for quality independent functioning. “Many can extend their survival and enhance their quality of life if they can rely upon a supportive environment. Yet, these supports are frequently inadequate, highly complex, and difficult to access ” (Chernesky, 2000, p. 3).

To better meet the needs of those living with HIV/AIDS who for years experienced social isolation and discrimination due to either their diagnosis or their risk factor, AIDS Service Organizations identified the unmet need and created ‘Buddy Programs’. These programs were designed to match a client to a volunteer/peer based on demographics and interests. Often, Buddies were their only source of social/emotional support and they stayed with the client until they died. Over the years these programs have provided social support, but no descriptive or research articles evaluating the effectiveness of this intervention have been found.

In examining the role of case managers, Kucera (1998) determined that case management goals must not conflict with the client’s goals, and should include the promotion of independence, and the empowerment of the client so that informed decision making can take place and that social rejection and feelings of isolation are minimized.

Chernesky & Grube (1999) found that research to date has suggested that the purpose of CM is to "...provide those living with HIV the support necessary to ensure that they are able to maintain a reasonable quality of life. This involves being there for the clients, helping them to develop essential skills, and teaching them what they need to know as they manage their disease and the environmental stressors they face" (p.26)

In much of the literature on HIV/AIDS CM, case managers play a pivotal role in providing both practical, but especially, emotional and social support. In reviewing two studies that examined the CM system of care for those living with HIV/AIDS living in the New York tri-state region, Chernesky & Grube (1999) focused not on the referral activities of case managers, but on their perception that they need to provide support necessary to ensure that clients can maintain a quality of life. During focus group meetings, the case managers were clear about their role. According to the authors, the case managers saw themselves primarily as supporting clients in order to make it possible for them to withstand the stressors they faced. They identified their role as; supporting clients, teaching clients, empowering clients, helping them, by education, to manage their disease, and linking them to need service.

According to Chernesky, (1999), while evaluating the effectiveness of case management is becoming more of a research focus for a variety of populations, this has not been the case for those living with HIV. She cites in her review of outcome research that there is evidence that case management is effective in helping physically and mentally impaired individuals. However, "There has been, in fact, no research on either the social adjustment or quality of life of persons infected with or affected by HIV/AIDS who are receiving case management services" (Chernesky, 1999, p. 111).

Outcome-based research for those living with HIV needs to examine the role of the case manager, and to ask the questions of what the case manager provides and does it make a difference in improving a client's ability to live more independently.

This research focuses on defining the role of a case manager as providing needed services to clients. In theory, case managers skilled at meeting services needs would aid clients in becoming more independent. This study will examine whether a volunteer-peer driven intervention that focuses on accessibility, support and skill-building is as, or more, effective than professional case managers who, due to caseload size, are unable to spend time with clients providing support and teaching them to help themselves. Similar to the advanced case management model, this study will look at a program whose volunteers are able to spend more time on the phone and in person with a client potentially resulting in clients obtaining more needed services. The number of services met will be compared between both case management programs. But most important, this research will evaluate if peer support and services obtained through skill-building results in an increase of independent functioning. If volunteer/peer CM have the ability to spend more time with clients, providing support as well as the ability to address a multitude of client needs, then reasonably, clients may be able to function more independently within a shorter period of time. Not only could volunteers be utilized effectively in case management, but with their help, the role of social workers might change from procurers and providers of services to teachers and mentors.

5.0 STATEMENT OF RESEARCH GOALS

The past twenty years have challenged social workers with the task of developing effective interventions for those living with HIV, and challenged social scientists with assessing their effectiveness. Lacking social service support, people living with this disease now exist in every stratum of our society; the elderly, children of infected parents, individuals with mental health and drug and alcohol problems, the homeless, adolescents practicing unsafe sex, gay and lesbians who continue to deal with discrimination and often remain closeted, sex workers who are prosecuted and heterosexual women. For many African Americans, there are the additional challenges of acknowledging homosexuality within their community and trusting medical treatments.

There has been a rapid growth of HIV CM programs since the funding of the 1990 Federal Ryan White Act. However, federal and state governments did not legislate funding to evaluate the services, only to provide them. Consequently, HIV case management programs in every state have developed their own structure of service delivery and their own definitions of case management services, making it a monumental challenge for any researcher in this field to assess outcomes and to interpret any findings if they exist. And, while the concept of case management has not been clearly defined, the literature suggests that outcome criteria for programs must be driven by the needs of the population they serve.

A review of research literature has shown that assessing the effectiveness of any HIV/AIDS case management intervention is still in its infancy stage, with quality assurance (satisfaction surveys) or descriptions of services dominating current research efforts. A paucity of information exists that describes how best to monitor and evaluate the impact of case management intervention. Both providers and clients have identified support as the most important component of case management, but few studies have assessed its impact. In addition, few if any non-profits such as AIDS Service Organizations have the financial resources, staff time and personnel skilled in research methodology to not only implement, but track over time, the effectiveness of any CM intervention.

This study examines two types of case management intervention: a volunteer case management program that focuses on providing emotional and practical support (more intensive contact for support and education to promote self-help), and the traditional government funded professional case management program whose goal is to meet client needs by staff directly providing or securing the services.

This research will examine whether differences exist between the two case management interventions in the intensity and amount of time spent with clients and if either correlate with improvement in independent functioning. In terms of time, the total number of face to face hours (more intensive than time spent on the phone), the total number of hours (combining face and phone time) as well as the total number of face and phone contacts will be compared between the volunteer and professional case managers. Utilizing path analyses, the intensity and amount of time will be tested as possible mediators. Theoretically, increased time as well as face time spent with a client would result in additional practical and emotional support. This support may better

assist clients who are physically, mentally and emotionally stressed with acquiring more services and improving their LIF score.

The theory of stress maintains that stress can often serve to motivate efforts to cope when a small or large crisis occurs. But as stress accumulates, the ability to cope is diminished, psychological resources are depleted and illness, or a decline in health, can result. In numerous physical and mental health-related studies, the damaging effects of stress have been studied (Monat & Lazarus, 1991). Consistent throughout the research is the importance of human relations and the concept of social support as a coping mechanism when situations in life become overwhelming. How individuals cope with mounting stress has been a special focus of study in the field of mental health. A multitude of studies have shown that participation in peer-run self-help groups provides support, information, reduces the need for medical care and instills a sense of self-determination as skill-building and coping strategies are employed. Research across the spectrum of social issues has identified social support as a key element in not only facilitating change, but helping to improve the quality of life. Those living with HIV experience stress in their physical, financial, social, emotional, and mental realms of life. Monat and Lazarus (1991) affirmed that access to social support increases coping skills, thereby decreasing physical and mental health symptoms.

The concept of social support is reflected in the mediators and may provide a sound basis from which to develop both the data collection tools and the outcome measures. According to Lazarus and Caplan, professionals such as case managers and peers such as volunteers play a critical role in reconstructing an emotional/practical support network where none exists for the client (due to poverty, alienation, discrimination, loss, etc.). This theory directs attention to

examining the relationship between the client and case manager; the amount of time spent, the type of contact and whether it was with a peer or a professional case manager.

In addition, any examination needs to look at the effect of contact case managers have with clients over a period of time.

Historically, definitions of case management focused on the role of staff in assessing for, and providing, necessary services and resources. The Case Management Society of America (2001) defined the very structure of case management as assessing, implementing, coordinating and evaluating the effectiveness of obtained services. The assumption of traditional case management was, and is, that clients will improve their ability to function independently when they get the services they need. Raiff and Shore (1993) identified the emergence of an advanced model of case management that focuses on providing peer/social support in helping consumers with multiple health issues help themselves. Rather than clients being viewed as helpless and in need of rescuing by a case manager, this model, supported by volumes of literature addressing the impact of social support for those with mental and physical disabilities, stresses the importance of clients becoming more self-reliant. Independence thus begins with clients' efforts to secure their own services.

Any intervention needs to reflect the key social work values of addressing client problems within the context of the environment in which they live, and helping to facilitate change. Goals are to be client-focused, based on client strengths and weaknesses, not on the goals of the case manager. In focusing on the strengths-based approach, a growing body of literature has identified skill-building as an important component, with volunteers and peers playing a critical supportive role for those living with multiple physical and mental health issues. Since so little research exists that focuses on outcome measures, researchers have agreed that there exists a

need to first identify the structure of case management and its integral parts before any data collection tools can be created.

Providing social, emotional and practical support beyond referring clients to services requires time. Many case management programs, with large caseloads and too few staff, do not have the luxury of spending extended time with each client. The volunteer/social support model of case management was structured to allow time for support, education and self-empowerment.

5.1 THEORETICAL MODEL

The theoretical foundations for the present study come from the theory of stress and coping as an important mechanism in dealing with adversity. In addition, this study looks more closely at peer support as a coping strategy, and the role increased face time has on improving one's ability to deal better with stress. A proposed model appears in Figure 1. According to Lazarus and his colleagues, individuals cope in two ways: problem-focused coping aimed at problem solving or taking some action to relieve the source of stress, and emotion-focused coping aimed at reducing or better managing the emotional burden that is associated with the stressor(s). Individuals often employ both coping strategies as problem-focused coping is goal directed while emotion-focused coping serves to provide support when a stressful situation cannot be altered or changed (Carver et.al, 1989). While those living with HIV are able to problem solve and obtain services, thereby reducing their stress, Caplan (1976) focused on the importance of social support. He placed importance on not only formal support, such as case managers, but on peer support in the form of self-help groups.

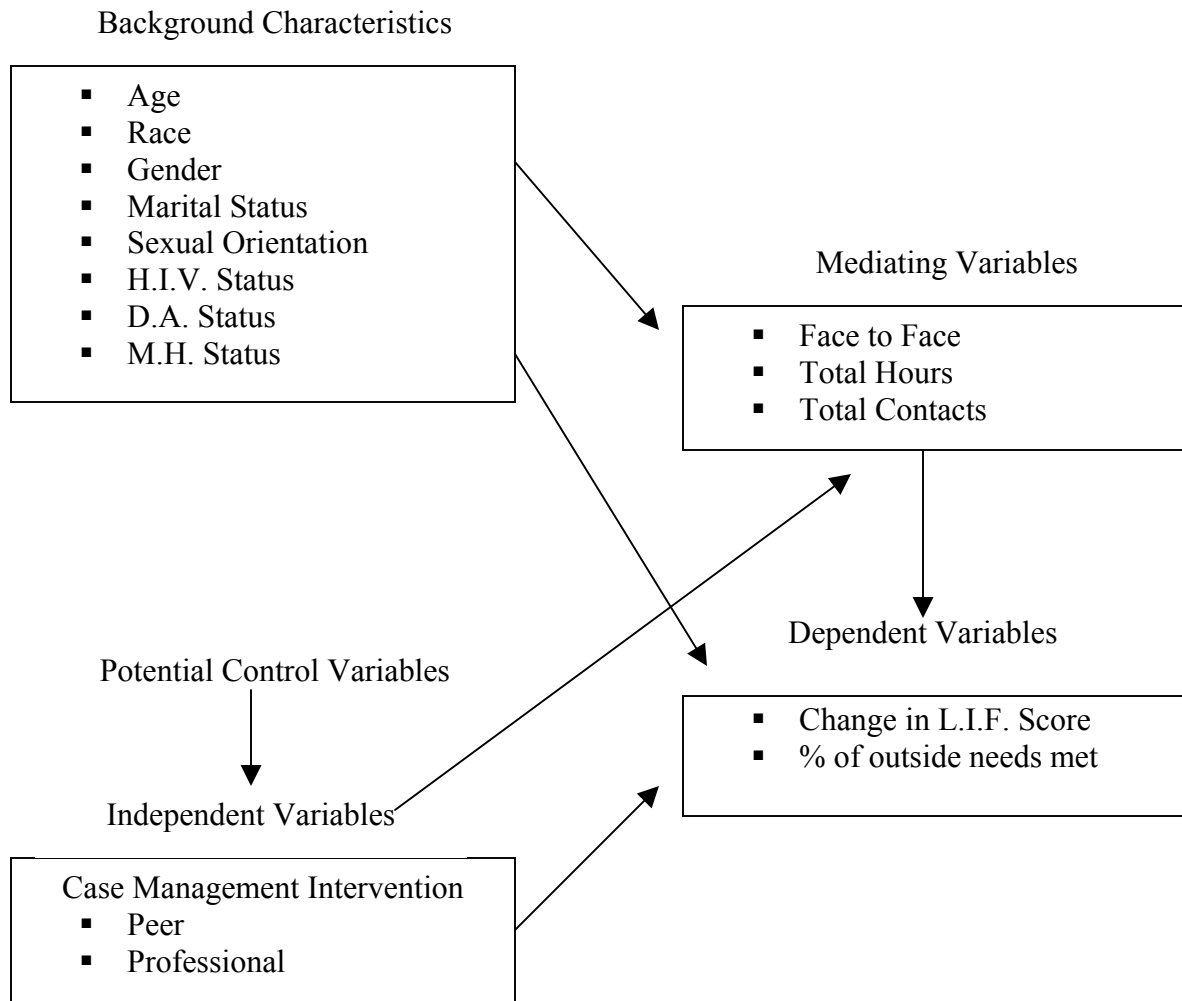


Figure 1: The Theoretical Model

According to Lazarus (Carver et.al, 1989) everyone lives with a wide range of stressors, and how one copes can positively or negatively affect ones' ability to deal with life. It has been shown that those living with HIV disease confront a myriad of minor, major and catastrophic stressors on a daily basis. How that support is provided, by whom (professionals or peers), and

how much time is given may impact not only on how many services clients may obtain to help reduce their stress, but may impact the very quality of their life by helping them to become more independent.

A potential mediator is time, not only the amount of time (in terms of quantity of hours and contacts), but also the differences in the intensity of time provided-face to face versus phone calls. As previously stated, a key difference between volunteer case managers and professionals is their ability to spend more one on one time with their clients.

According to Raiff & Shore (1993), the goal of any case management program is to build upon client strengths, encourage and promote empowerment and independence and to eventually ensure that clients are no longer in need of case management services. The challenge for case managers working with HIV positive clients who also have mental health and/or drug and alcohol problems is how best to provide them with needed support while discouraging dependency and encouraging independence.

In order to achieve this goal, the following two hypotheses will be explored and addressed in this research study:

1. A Volunteer/peer driven social support model of case management will be more effective than traditional case management in improving the independent functioning of clients living with HIV and mental health and/or drug and alcohol issues
2. A Volunteer/peer driven social support model of case management will be more effective than traditional case management in assisting clients with obtaining a greater percentage of outside agency needs (needs latter defined as more critical to increasing a clients' independence and obtained from other agencies) after nine months of intervention.

The demographic variables in the study are age, race, gender, marital status, sexual orientation, severity of HIV diagnosis, severity of mental health and drug and alcohol issues. Intensity of intervention (face-to-face versus phone contact), the number of total hours spent with each client and the number of total combined contacts (face to face and phone) are potential mediating variables in this study.

The following additional research questions will be explored in this study:

1. Do volunteer or professional case managers spend more time (face to face and phone time) with clients at the end of 9 months of CM intervention?
2. Do volunteer case managers spend more intensive time (face to face versus phone) with clients than professional case managers?
3. Do volunteers have more contact with clients (number of phone contacts plus number of face to face contacts) than professional case managers?
4. Does the accumulative amount of time spent with a client correlate with proportionately more needs being met at 9 months?
5. Is there a correlation between changes in LIF score, number of needs met and the amount/type of time case managers spend with clients?

The key responsibility of any case management program is identifying needs and obtaining the resources for clients. As clients secure services, they should have decreased needs, be less dependent on the case manager for assistance and better able to function more independently.

6.0 METHOD

6.1 RESEARCH DESIGN

The design of this research is that of a longitudinal design taking baseline measures on two groups of people, exposing each group to a different case management intervention, and collecting follow-up data at four different points in time. Clients who came to the agency requesting and/or were assessed to need case management had both programs explained to them. Clients chose which program they wanted, so there was no randomization of participants.

Due to a large drop-out rate of 49%, two separate studies were combined, each study tracking participants for nine months. The first study was completed in 2000 and the second ended in 2001. Both research projects were identical in structure, design and implementation.

After each case management intervention was thoroughly explained, clients chose to work with either a professional case manager or to enroll in the volunteer/peer program. Both studies utilized the same measurement tools and all clients were assessed at the same time intervals (baseline and after 3, 6 and 9 months of service). For the combined total of 153 participants (82 clients working with professional case managers and 71 clients working with the peer/volunteer program), complete information on each measurement tool and for every time period was obtained.

The three measurement tools used were created by this researcher and served to (1) gather demographic information, (2), identify needs, and (3) assess Level of Independent Functioning (LIF). At baseline, during the first meeting with the client, basis demographics were obtained.

In addition to the self-report data of the participants and assessments by case managers, volunteers and supervisors, additional information was culled from medical records that helped to determine the severity of HIV disease, as well as the history and current level of mental health and/or drug and alcohol impairment. Identification of needs came from both clients and staffs' assessment. Based on existing medical/psychiatric records, client statements, demeanor, collateral information and staff observations, an initial LIF score was created.

After three, six and then nine months of case management service, the checklist of needs was updated at each time period to report when services were acquired, and at each time period, staff assessed how well the client was functioning and assigned a score using the LIF scale. The amount of time and type of time (face to face and phone calls) as well as the number of total contacts case managers provided to each client were also tracked.

6.2 PRELIMINARY STUDY

This researcher was able to gain a unique insight into the multiple needs and challenges of those living with HIV as a result of having worked in the mental health/drug and alcohol field for fifteen years, and then having served as the Director of Client Services at the Pittsburgh AIDS Task force for eleven years.

In 1997, I examined the relationships between the type (face to face versus phone contact), and amount of time staff spent providing case management services and its correlation with both

number of services obtained and level of client satisfaction. In addition, I looked at the correlation between the amount of time spent with a client and the number of services obtained with the severity of the client's mental health, drug and alcohol and HIV status. Predicted was that the more intense the intervention (face to face versus phone contact), and the total number of hours spent, the more services a client would receive, resulting in a higher satisfaction score. In addition, the severity of an individual's mental health/drug and alcohol problems, and not the stage of their HIV disease, would predict both an increase in staff time and the number of service needs met.

With a convenience sample of sixty-eight clients, (as clients came to the agency for services, the first sixty-eight clients who agreed to participate became a part of the study), time spent and services obtained were tracked for nine months. While the results demonstrated that the relationship between the intensity of the intervention and the increased number of service needs met approached a level of significance when an individual had both severe mental health and drug and alcohol problems, it was the total number of hours spent that very strongly correlated with the number of services obtained, and neither the amount of time spent nor the services obtained affected client satisfaction. In addition, clients with severe psychiatric impairment and/or drug use and not an AIDS diagnosis spent more hours with case managers. This study confirmed the experience of staff at the Pittsburgh AIDS Task Force (PATF) that more time was being spent with clients who had severe behavioral rather than physical health concerns. But it could not be inferred from the findings that the clients with severe behavioral issues, whose needs were met, functioned better in the community as a result of spending more time with a case manager. Concern existed, not only at the Pittsburgh AIDS Task Force but with AIDS Service Organizations (ASOs) statewide, that staff were spending valuable time addressing the

needs of clients who were not getting their needs realized at mental health and drug and alcohol facilities. Those living with AIDS, the target population for ASOs, often had to wait for service. In order to avoid a waiting list, this researcher created the first volunteer/peer case management program in Pennsylvania. But since no outcome research existed as to the effectiveness of volunteer intervention, this program went unfunded.

6.3 THE SERVICE SETTING

The Pittsburgh AIDS Task Force (PATF), the largest ASO in Southwestern Pennsylvania located in Wilkinsburg, provides services, support and referrals to anyone living with HIV in an eleven-county area. As the largest provider of services in the region, the agency has struggled to adhere to a policy of no waiting lists for clients and struggled to work with every client as they walked in the door or called for services. The client services department provides information, education on safe practices, referrals, buddies for emotional support, food, nutritional supplements, legal assistance, advocacy and transportation assistance. The service most requested, case management, is provided by five experienced staff. Services can occur at the office, home, hospital or any location requested by the client. All services are free and there is no eligibility criterion for case management.

6.4 CASE MANAGEMENT PROGRAMS

With a staff of five professional case managers (minimum bachelor's degree and three years previous case management experience), an intake case manager with 9 years at PATF, and a supervisor with twenty years in the field, the agency served over 900 clients in 1999, with an average 10% increase for each subsequent year. For both studies, clients would either call, be referred by a friend, family member or other provider, or simply walk in requesting any number of services or information. Staff would initially talk to the prospective client and make an assessment of need. If staff determined that the individual presented with physical and/or mental health/drug and alcohol problems, or had serious financial need (homeless, no income or utilities or medical coverage etc.) they would arrange for the intake case manager to meet with the individual for a more thorough assessment of history and current needs. The intake case manager would contact previous providers and obtain medical/psychiatric records. After explaining the role of a case manager (having regular contact with a client until needs are met, making referrals, helping with applications, advocating for services) the client could choose case management and would then be referred to a case manager for follow-up. Regular contact with a client would be dependent on a number of factors:

- ability to contact the client, as many had no phone service or would frequently move
- clients in and out of the hospital or jail
- clients absent due to mental health/drug and alcohol, financial or health issues
- severity of their need (staff would need to prioritize helping someone with a housing issue while someone needing utility assistance might have to wait)
- the size of a case manager's caseload

- the ability of the client to come into the office
- how far the client lived from the office.

As caseload sizes grew, trained social work interns from six area colleges and universities functioned as assistants to the case managers and facilitated making appointments and completing paperwork.

Professional case managers provided intervention and support until 1996, when volunteers were moved into case management. Historically, volunteers have been key in providing educational and practical support for clients and staff at ASOs. The first program created at many AIDS Service Organizations focused on recruiting volunteers to become buddies, providing one on one emotional support to clients at end stage in the disease. ASOs were the first to develop comprehensive screening and training programs for volunteers who worked with those living with HIV.

Revolutionary in 1993 (and met with opposition within the organization), volunteers were recruited and trained to provide the same case management services as their professional counterparts; assessment, referrals, advocacy, helping the client set goals, practical assistance in completing paperwork and above all listening and providing support. Over a quarter of the volunteers had either been clients or had friends/significant others who were living with HIV.

Case management volunteers were provided with two weeks of intensive training that focused on teaching case management activities, modeling listening skills, providing empathy, setting limits, educating the client on how to access various programs, encouraging the client to self-advocate, providing positive support, dealing with mental health and drug and alcohol problems and the importance of accessing supervision. Weekly supervisory group support and

on-going training was mandated. Teams of volunteers shared a caseload of fifty clients. Initially, volunteers proactively called clients on a regular basis in order to assess how well they were doing. When clients called, they would be directed to their volunteer. Since some had no phones and it was impossible to determine health status and functioning ability over the phone, the program expanded into the C.A.R.E Program in 1998. Coordinating AIDS Resources for Empowerment (C.A.R.E.) was a drop-in clinic open Monday through Friday from 9-4. Volunteers would staff the clinic and clients would either call or drop-in without an appointment, and could come as often as needed. The forty-six possible client needs that had already been identified were detailed in fact sheets-how to access the service, who to call, eligibility requirements if applicable as well as the applications. Volunteers focused on encouraging the client to complete the work or make the phone calls. Social work interns provided assistance and professional case managers rotated service in the clinic in order to provide oversight and to problem-solve. At any time, a client could choose to request assignment to a professional case manager, or a client being seen by a professional case manager could move to the C.A.R.E. Program. Only those clients who stayed in the program they chose were followed in this research study. The twenty-six clients who had elected to change CM programs were not tracked.

The case management interventions differed in two key aspects-time and focus. Professional case managers, while having the flexibility to travel to a client's home or to the hospital, often were constrained in how much time they could spend with each client due to caseload size. Even with interns providing support, time spent with a client would out of necessity focus on the need and how best to quickly meet that need. While volunteers only provided services over the phone or at the office, they were not constrained by time as several

volunteers staffed the clinic each day. Volunteers could then focus on providing emotional support and taking the time to teach the client how to help themselves.

6.5 DESCRIPTIVE STATISTICS: CHARACTERISTICS OF THE DROP-OUTS AND PARTICIPANTS

The primary goal of this study was to determine the effectiveness of two case management interventions for clients living with HIV disease and mental health and/or drug and alcohol issues. As the demographics have changed, with those mentally ill or addicted at high risk for the disease, an increasing number of clients accessing services at the Pittsburgh AIDS Task Force presented with these co-morbidity factors. At the time of both studies, over two-thirds of clients living with HIV had either mental health and/or drug/alcohol problems and 71% of all who contacted the agency for service requested case management.

In the first study in 2000, there were initially 165 clients who had chosen either professional case management or the volunteer/peer case management program. In 2001, 135 clients comprised the second study. Of the 300 clients from both studies, a total of 147 clients, or 49%, dropped out due to the following reasons:

1. Clients moved or they died (12%)
2. \Clients went into the hospital (9%)
3. Clients went to jail (17%)
4. The most common reason was that clients dropped out and could not be located (58%)
5. Clients chose not to remain in the program and did not want to complete the Paperwork. (4%).

Of those who dropped out in 2000, twenty-three clients had chosen professional CM and forty-eight had picked volunteer/peer CM. In 2001, of the clients who did not return for follow-up, thirty-eight had worked with professional case managers and thirty-nine with the volunteer/peer program. Table 1 presents a comparison summary of the demographics of those who did not complete the study (n =148) and those who remained (n =153).

In reviewing the demographics, located in Table 1, there were no significant differences between these groups on any of the variables examined. While the drop-out group had somewhat more Blacks than Whites, this difference was not statistically significant. Approximately two-thirds in each group were males, but again, no significant difference between the drop-out group and the research sample on gender. Both groups had more clients that were heterosexual than gay, and the majority of clients served in both groups were single. So for both sexual orientation and marital status, there was no significant difference between the two groups.

When looking at HIV status, for both groups, close to half the clients were diagnosed asymptomatic, less than half were AIDS diagnosed and the smallest percentage had no health issues related to HIV. For clients diagnosed with mental health issues, almost half presented with some issues, less than half had chronic concerns and about the same percentage of clients in both groups had no current or past issues. Only the category of drug and alcohol approached .05 significance with those who dropped out of the study having had more issues than the participants, and those who remained in the study had less drug and alcohol involvement than those who dropped out.

Table 1: Comparison of Demographics Between the Drop-Outs and the Participants

Demographics	Drop-Outs N=148		Participants N=153		Chi-Square	Sign
	Frequency	Percentage	Frequency	Percentage		
Race						
White	56	38%	69	45%	1,633	.201
Black	92	62%	84	55%		
Gender						
Females	49	33%	53	35%	.079	.779
Males	94	67%	100	65%		
Sexual Orientation						
Heterosexual	97	65.5%	84	55%	4,886	.087
Gay/Lesbian	51	34.5%	69	45%		
Marital Status						
Single	122	82%	128	84%	.081	.777
Married/Committed	26	18%	25	16%		
HIV Status						
Asymptomatic	15	10%	21	14%	1.11	.574
Symptomatic	70	47%	73	48%		
AIDS	63	43%	59	38%		
Mental Health						
No Issues	19	13%	14	9%	1.94	.379
Some Issues	77	52%	75	49%		
Chronic Issues	52	35%	64	42%		
Drug and Alcohol						
No Issues	46	31%	61	40%	5.801	.055*
Some Issues	52	35%	35	23%		
Chronic Issues	50	34%	57	37%		
Professional						
Case Management	61	41%	82	54%	4.622	.032**
Volunteer						
Case Management	87	59%	71	46%		
		Mean		Mean	T-Score	Sign
Age		30.5		32.6	-.202	.84

* Drug and Alcohol approaches significance at .05

** Significant

Both the drop-out group and the research sample were very similar in age, with the average age for drop-outs being 30 and for the research participants, 32. But when choosing professional or volunteer case managers, a significantly higher percentage of clients in the drop-out group had chosen volunteers, while a larger percentage in the research sample had chosen professional case managers. In addition, a larger percentage of clients who dropped out were Black (62%) while 55% of Blacks remained in the study. The larger drop-out rate for those in the volunteer program maybe a result of the volunteer case management program having been in the process of being developed and refined. Lack of adequate program development and volunteer training may, in part, account for a larger number of those clients dropping out. In addition, neither case management program had African American staff, which may account for some Black clients not returning for service. And those clients most severely physically and/or mentally ill may not have been able to return to work with the volunteers. But while this difference was significant it does not appear to be a huge difference, as the large total sample size of 301 allows for small differences to reach significance. In summary, the sample that dropped out and the research sample were demographically similar in almost all variables that were explored.

An important observation when comparing both groups is that for both the drop-out and research samples, there were significantly more Blacks than Whites (over 55% in both groups). And while there were more males than females, women accounted for over a third in both samples. Unlike the beginning of the AIDS pandemic when less than 5% were women and 10% were Black, these group statistics represent the growing number of females and Blacks that are increasingly becoming infected with HIV

6.6 PROCEDURE

For both combined research studies, clients who contacted the agency for service and presented with physical, mental/emotional or financial needs, were given a detailed description of the professional and volunteer/peer case management programs. Clients in need of case management services were offered a choice of programs. Clients were informed of the research and of what information would be gathered over a nine month period. It was explained that no personal information that could identify them would be collected, and choosing not to participate would in no way affect their service. They were told that should they agree to participate, they could elect to drop out at any time. Each client who agreed to be part of the study was asked to sign a release form which contained full disclosure as to what the study involved. Client data sheets were then coded to protect the identity. The Institutional Review Board of the University of Pittsburgh gave permission to use the client data for this dissertation.

At baseline, an initial level of functioning score was obtained, the checklist of needs was completed and demographic information was gathered. After 3, 6 and 9 months of service, the level of functioning was reassessed. In addition, a comprehensive list of needs was updated at each interval to reflect if the services were obtained.

6.7 MEASURES

6.7.1 Independent Variables

The independent variable of this study is the two types of case management interventions, professional case managers and the volunteer-peer case management program. A total of 5 professional case managers (mean years of case management experience- 3.6 years), an intake case manager with 9 years experience and a supervisor with 20 years of experience comprised the professional case management program. There were a total of 26 volunteers, with 3-4 staffing the C.A.R.E clinic each day. Volunteers went through a rigorous two week training, were supervised daily by the intake case manager and met weekly with the supervisor for problem solving and additional training. The only demographic information that was obtained for staff and volunteers was that staff and volunteers did not personally know or have any relationship with any of the clients.

6.7.2 Dependent Variables

6.7.2.1 LIF Scale

In this study, there are two dependent variables 1) The level of independent functioning, (LIFS) score, which measures the change in functioning level of a client in seven areas of life at 9 months and 2) the percentage of outside needs met at 9 months.

For the first dependent variable, to assess a clients' level of functioning before and after the intervention, a Level of Independent Functioning (LIF) scale was modified based on the Acuity Assessment Tool created by Action AIDS in Philadelphia (please refer to Appendix E for a copy

of the LIF scale). In a review of existing case management outcome measures by Lehrman, Gentry & Gantz (1996), only the scale created by Action AIDS was identified as having a theoretical basis with prior testing. The triaging tool developed by Action AIDS was designed primarily to distribute clients evenly among case managers based on their overall functioning score. Their tool measured 3 categories of client needs (medical needs, mental health and drug and alcohol needs, and life management needs such as housing, food and transportation). Within each of these three categories of needs, there are three levels of independent functioning. As an example, for medical needs, a client maybe medically stable (a score of 1), may have some opportunistic infections (a score of 2), or may be seriously ill (a score of 3). So a score of 1-3 ranges from most stable to severe. In addition, Action AIDS created a level of risk category that is also scored from 1-3. They identified three areas in a clients life that would put them at little to great risk (score of 1-3) of not following through with obtaining services. The three risk areas are ability to commit to working with case managers, if the client has existing support in their life, or if the client has to deal with children or a significant other who may or may not be HIV infected. The studies completed by Action AIDS focused solely on determining a client's total acuity score (totaling the numbers in each of their 6 categories, three categories that were needs and three categories that were risks) to give an overall score of functioning ability in order to assure equitable client assignments among case managers based on how well the client functioned.

Finding Action AIDS' acuity tool to have potential in assessing changes in a clients' ability to function over time, this researcher worked for three years to complete clinically accepted modifications. The goal in revising the tool was to take their work one step further. If the tool could assess a client's level of functioning, then theoretically the score could show improvement (a decrease) over time if clients were working with case managers and their needs were being

met (assuming that needs being met would improve someone's functioning level). Beyond just utilizing the tool at different time periods, it became important that the categories of needs mirror the range of critical needs clients presented, and that the risk factors were more comprehensively categorized. Case managers could then more easily give each client a score that reflected how well they were functioning in their day to day life. Based on staff input as they assessed clients, an additional category titled life management skills was created. This category assessed the clients' ability, again at three levels; from having skill, (1), to no skill, (3) in the areas of ability to budget, to parent and make and keep appointments and take medication as prescribed (of critical concern as non-compliance could worsen symptoms and further compromise the immune system, and not taking certain medications such as protease inhibitors can cause the virus to mutate or become immune to therapy). Therefore, the higher an individual's score, the less skill they possess in taking care of their needs.

To re-design the tool for use in outcome studies, five case managers and a case management supervisor used the tool and provided feedback during four separate trials of use over a six month period. For each trial, a random pool of twenty clients was obtained from a master client list. After receiving training on the structure and purpose of the form and how to complete it, the case managers completed the functioning scale for each client. Upon completion, the case managers were interviewed as to the validity of the content and if the scoring of the scale corresponded to the perceived functioning level of the client. The supervisor completed the scale for the same clients for each trial and a number of revisions were made as responses were compared for inter-rater reliability. During trial two and three, with less than 80% agreement between the case managers and supervisor, additional training was provided in terms of clarifying the terminology (what constitutes severe illness, no budgeting skills etc.).

For the fourth and final trial, a sample of twenty-eight clients was used. With the supervisor also assessing the client on the functioning scale, a 92% match was found. Five case managers agreed with the supervisor 92% of the time in assessing clients' scores. Feedback from the staff indicated that they "loved the tool", found it to be a helpful gauge of the client's functioning and suggested no further changes.

The twenty-one item LIF scale is intended to measure the extent to which one is able to function independently. Three areas measure risk (risk defined as likely to function more poorly due to how much they lacked support, how often they kept in touch with a case manager, and how many, and who within their immediate family members were also infected with HIV). The remaining four areas measure current need; medical needs, mental health and addiction issues, life management needs (such as obtaining benefits, housing, food and transportation), and life management skills (ability to budget, to parent, to make and keep appointments and taking medication as prescribed).

Three categories exist for each of the seven areas, with 1,2, and 3 points are assigned to each category. One point indicates either low risk or a high level of independence, while a score of three in a risk category indicates the highest risk or the least ability to function independently due to lack of social support or family stressors. In the needs section, (separate from the Checklist of Needs which identifies each specific need a client has), a score of one would indicate no need or need had been met in a general needs category, and a score of three would mean that the client is without a basic resource needed to function more independently.

The scores on the LIF scale ranged from 7-21, with someone with the lowest score, a 7, needing less support and able to function more independently. As the score increases for a client, there is less of an ability to function independently.

Before volunteers used the LIF, they were provided with training. Each day when utilizing the scale, they were given supervision and confirmation of the assessment by a supervisor or the intake case manager.

To the best that staff could assess functioning level at baseline, a score was provided. Each client in both programs was then assigned a score at 3 months of service, 6 and then after 9 months of case management by either staff or the volunteers. For this research project, only data at baseline and at 9 months for the LIF and Checklist of Needs was utilized. Baseline information was used for the demographic information.

6.7.2.2 Checklist of Needs

The second dependent variable is the number of outside needs met (needs not provided by PATF). Since there are a number of services offered at the Pittsburgh AIDS Task Force, case managers have more control over obtaining those identified needs, or inside services, more quickly. These inside services are; providing information, food, nutritional supplements, vitamins, transportation, referrals, a buddy, a pet buddy, payment of utilities and crisis counseling. Negotiating for community, or outside services, is more difficult and time consuming. Success in securing these services often hinges on the knowledge of staff, the amount of time they can spend on each client, the relationship staff have with providers, how quickly application is made, as well as the tenacity and ability of the case manager to advocate for the client and to complete the referral process. Outside services identified on the Checklist of Needs used in this study fall under the following categories; housing, medical, psychiatric and dental care, medical supplies, nursing support, furniture and clothing, state and federal programs such as welfare and disability, mental health and drug and alcohol support and job training. Not only does it take more time and effort to acquire these services, but it is apparent upon

comparison of the two, that the outside services are more critical than the inside services in helping to increase the level of independent functioning. The services that are provided by other agencies, the outside services, are specific to securing housing, mental health services, drug and alcohol care, medical coverage and income and extended health care support. These very services are more critical in providing a network of support that increases independence than those provided by PATF-transportation, food, legal and nutritional support, information on health and safety issues and limited emotional support with Buddies.

One critical tool for gathering information, the Checklist of Needs, is a comprehensive compilation of services created by this researcher to aid staff when helping clients identify their needs. This list differs from the LIF scale in that it identifies forty-six possible needs a client may have and can identify at the time of intake. While the checklist identifies a variety of needs, the LIF scale evaluates how well a client functions in six key life skill areas. Theoretically, as client needs are being met, their LIF score should improve in one or more of the six areas.

Created in 1992, the list of service needs went through dozens of revisions before a total of forty-six were identified. These needs are listed under the following categories; medical, home care, housing, transportation, nutrition, mental health treatment, drug and alcohol treatment, risk reduction and a category for other services such as applying for benefits or disability, legal help, advocacy, clothing, job training, information on treatment and care and getting someone to help care for pets.

A case manager's primary function is to identify and meet client needs. Clients come to case managers because they lack an important service or resource. Clients may end up depending on friends or family or they simply go without the service/resource. As their needs are met, they would reasonably be able to function more independently.

Content validity was achieved with focus groups comprised of professionals who had worked with an HIV population for at least five years. Twenty-three providers in the field of HIV, mental health and drug and alcohol reviewed the list of needs and made additions. Also, client files were reviewed over a three year period of time and that helped to identify additional services that had been requested. Out of this came an exhaustive list of needs. This checklist of needs had also been used for two years by staff at the Pittsburgh AIDS Task Force and consensus existed that the list was comprehensive. The Pennsylvania Department of Health, HIV/AIDS Bureau, accepted the checklist as a tool to be used throughout the state.

At baseline, both the client, professional and volunteer staff jointly completed the checklist of needs, identifying every need. At 3 months, clients and professional and volunteer staff reviewed the checklist and marked the needs that were met. This occurred again after 6 and 9 months of service.

6.7.3 Mediating Variables

In this research study, time is considered to be a potential mediator. A critical benefit and goal of peer support CM intervention is that volunteers are able to spend additional time with clients in order to assist them with securing their own services. Traditional case management has had to sacrifice this level of intensive support in order to quickly meet the needs of growing caseloads and funders who mandated results. As a result, historically, clients were seen but had fewer needs met and would depend on case managers for their help. More time, especially more intensive face to face time with a client should theoretically result in a client obtaining more services, being less dependent on a case manager and thereby increasing their level of independence.

There were three mediating variables in this study; 1) The amount of total time (face to face and phone) a professional or volunteer case manager spends with a client; the number of face to face hours (more intense) versus phone hours (less intense), and 3) The total number of contacts (face to face and phone). The number of hours staff or volunteers spent with a client, the type of contact (face to face versus a phone call) and the total number of all contacts were collected and totaled after nine months of CM service. Any or all of these variables could affect the direction and strength of the relationship between the case management interventions and the change in LIF score and/or the percentage of outside service needs met.

6.8 DEMOGRAPHIC INFORMATION

A demographic information sheet was created with staff feedback after they utilized the form for over two years. This sheet included gender, race, age, marital status, sexual orientation, a measurement of the severity of HIV disease, (asymptomatic, symptomatic or AIDS diagnosed garnered from medical records), severity of mental health and drug and alcohol issues (as with HIV, each has three categories, ranging from no history to chronic issues). This information was gathered from medical records, client interviews, and an assessment by a supervisor with more than seventeen years experience in mental health and drug and alcohol and was completed at baseline. In addition, severity of the combination of HIV/mh/da was separated into 2 categories- less severe (total score 3-6) and more severe (total score 7-9). The separation of severity of HIV/mh/da was based on each physical/mental health category having a score from 1-3 (less to more severe). When combining the scores for all three health issues, the lowest possible score would be 3 and the highest score would be a 9. Clients were categorized as having less severe

multiple health issues if they had at most, only one score of 3. Therefore, a total score from 3-6 was assigned the category of less severe. A score of 7-9 was assigned to those clients with the most severe multiple health problems.

7.0 BIVARIATE FINDINGS

7.1 DEMOGRAPHICS OF BOTH CASE MANAGEMENT INTERVENTION GROUPS

Of the initial 300 clients in both studies, 153 remained and all paperwork was completed for each and every client at baseline, 3, 6 and then 9 months after receiving either professional or volunteer case management services. A total of 82 clients were followed in the professional case management program and 71 chose the volunteer program. Complete data was gathered for each of these clients for every time period.

The t-test and chi-square test were used to identify any significant variations between the clients in the professional and volunteer case management program. The demographic variables that were tested were; age, gender, race, marital status, sexual orientation, severity of HIV diagnosis, severity of mental health, and severity of drug and alcohol. Also tested were the number of inside needs (needs the Agency supplied) and the number of outside needs (needs outside agencies provided) at baseline. Lastly, the change in Level of Functioning (LIF) was tested, comparing baseline scores to scores after 9 months for both the professional and volunteer case management intervention groups.

The results for testing the differences between the 2 case management programs are found in Table 2. Using the Pearson chi-square test, the results showed that the demographic variables of race, gender, sexual orientation, marital status, HIV diagnosis and severity of drug and alcohol

are not significantly different between the two case management groups. In addition, using the independent t-test, there was no significant difference in age between the 2 groups. However, there was a significant difference between the groups in the area of severity of mental health and the type of intervention. Chi square of 6.57 demonstrated that professional case managers worked with more severely mentally ill clients than did the volunteers.

Table 2: Comparison of Volunteer and Professional Groups

Demographics	Demographics of the Sample N=153				Chi-Square	Sign
	Volunteer Program N=71		Professional Program N=82			
	Frequency	Percentage	Frequency	Percentage		
Race						
Black	36	50.7%	48	58.5%	.943	.332
White	35	49.3%	34	41.5%		
Gender						
Male	51	71.8%	49	59.8%	2.45	.117
Female	20	28.2%	33	40.2%		
Sexual Orientation						
Heterosexual	37	52.1%	47	57.3%	.416	.519
Gay/Lesbian	34	47.9%	35	42.7%		
Marital Status						
Single	61	85.9%	67	81.7%	.493	.483
Married/Committed	10	14.1%	15	18.3%		
HIV Status						
Asymptomatic	14	19.7%	7	8.5%	4.287	.117
Symptomatic	33	46.5%	40	48.8%		
AIDS	24	33.8%	35	42.7%		
Mental Health Status						
No Issues	7	9.9%	7	8.5%	6.57	.037*
Some Issues	42	59.2%	33	40.2%		
Chronic Issues	22	31.0%	42	51.2%		

Table 2 (Cont'd)

Demographics	Demographics of the Sample N=153				Chi-Square	Sign
	Volunteer Program N=71		Professional Program N=82			
	Frequency	Percentage	Frequency	Percentage		
Drug and Alcohol						
No Issues	28	39.4%	33	40.2%	.353	.838
Some Issues/In Recovery	15	21.1%	20	24.4%		
Actively Using	28	39.4%	29	35.4%		
Severity of HIV/MH/DA						
Less Severe (Scores 3-6)	36	50.7%	34	41.5%		
More Severe (Scores 7-9)	35	49.3%	48	58.5%		
	Volunteers N=71		Professionals N=82			
	Mean		t score		Significance	
Age	32.85	32.39	t=-.334		.739	
LIF score at baseline	14.73	14.96	t=.502		.616	
No. of needs for inside services at base	10.32	10.77	t=-1.23		.221	
No. of need for outside services at base	4.97	6.26	t=-2.86		.005**	

* Significant at .05

** Significant at .01

As can be seen from this table, both groups were comparable on race and gender, with each having over 50% Black clients, and 30% in each group were women. Both groups were also similar in sexual orientation and marital status with over 50% being gay/lesbian and over 80% being single. When reviewing HIV status, both the clients in the volunteer group and those in the professional group were similar in the percentage of those who were symptomatic (having some health problems) but differed when it came to being asymptomatic and AIDS diagnosed. Twice as many clients who had no physical health problems (asymptomatic) were in the

volunteer group, while a larger percentage of those with AIDS were followed by professional case managers. However, these differences were not significant.

Comparability existed for clients who had drug and alcohol problems, with both CM programs have similar percentages in the three categories of no history of drug use, some and chronic use. However, when it came to mental health concerns, there was a significant difference, with groups having roughly the same percentage of clients with no problems and some history of mental illness. But when it came to the clients who were assessed to be mentally ill, the professional case managers worked with a larger percentage of clients. The clients in the volunteer and professional case management group were comparable in their mean age, their LIF score at baseline and their need for inside services. And possibly due to a significantly greater percentage of clients with chronic mental health issues being served by the professional case managers, individuals in the professional group expressed a significantly greater need for outside services (services that included mental health therapy and support groups).

When examining the combined severity of HIV disease, mental health and drug and alcohol issues, there were no significant differences between the two groups.

In comparing the effectiveness of both professional and volunteer case management programs, two hypotheses will be explored. The first hypothesis asserted that volunteers would provide more effective case management than professional case managers as evidenced by an improvement in clients' LIF (Level of Independent Functioning) score. Inherent in this assumption is that volunteers would spend more time (a mediating variable) with clients providing emotional support, education and instruction in helping clients obtain their own services, thereby increasing their ability to function more independently.

With the use of the independent t-test, the change in LIF from baseline to 9 months was compared as was the type and accumulative amount of time provided by both intervention groups.

7.2 CHANGES IN LEVEL OF INDEPENDENT FUNCTIONING SCORE (LIF)

The LIF score ranges from a low of 7 (highest functioning) to the least ability to function at 21. At baseline, the mean for clients in the professional case management group was 14.96, and 14.73 for those served by the volunteer/peer case management group. As can be seen when comparing the means, both groups were comparable in their average LIF scores. After receiving case management services for 9 months, the mean score for those in the professional group was 12.01 while for clients in the volunteer/peer group the score was significantly lower at 10.28. While clients in both groups experienced improvement in functioning after the CM intervention, clients who worked with the volunteer/peer group experienced a greater decrease in their LIF score (increased independent functioning) than did clients who were being followed by the professional group.

7.3 PERCENTAGE OF OUTSIDE NEEDS MET

The second hypothesis asserts that volunteer case managers will be more effective in securing a larger percentage of outside needs (those needs already defined as more critical in increasing independence and provided by agencies outside of the Pittsburgh AIDS Task Force).

Table 3 identifies that at baseline, clients in the professional case management program had significantly more needs than did clients in the volunteer program (mean of 17.36 for professionals, 15.45 for volunteer clients). The total number of needs met after 9 months of service for both intervention programs was comparable with a mean of 13.8 for the professional group and 13.7 for the volunteer. It was apparent during data entry that both case management programs were meeting the majority of inside needs, needs the agency directly provided.

The decision then was made to separate needs into two categories-inside and outside needs. A review of inside needs at baseline shows that both professional and volunteer client numbers were comparable. And while the percentage of needs met was shown to be statistically significant at .05, upon examination of the means, it is clear that both programs, professional at .94 and volunteers at .96, have met almost 95% of all inside needs. There is no significant difference between the two groups as there is no variability between the means. However, there is a difference between the two groups with outside needs. At baseline, there is a significant difference with clients in the professional group expressing more of a need for outside services. But in looking at the percentage of outside needs met, the volunteer case managers significantly met, or provided support, in helping clients obtain more outside needs.

Table 3: Service Needs and Service Needs Met

	Professional Case Managers		Volunteer Case Managers		t-score	Sign. Level	r
	Mean	SE	Mean	SE			
No. Needs Base	17.36	.49	15.45	.43	2.87	.01**	.24
No. Needs Met at 9 Months	143.80	.41	13.7	.35	.18	.85	.01

Table 3 (Cont'd)

	Professional Case Managers		Volunteer Case Managers		t-score	Sign. Level	r
	Mean	SE	Mean	SE			
Inside Needs at Baseline	10.76	.26	10.32	.25	1.21	.23	.13
% of Inside Needs Met at 9 Months	.94	.010	.96	.007	-1.97	.05*	.22
Outside Needs at Baseline	6.25	.32	4.95	.31	2.83	.01**	.21
% of Outside Needs Met at 9 Months	.622	.034	.81	.027	-4.37	.001***	.43

*** P<.001

** P<.01

* P<.05

As for the answer to the second hypothesis, volunteer case managers, more than professional case managers, assisted clients in obtaining a significantly higher percentage of the more critical outside services.

7.4 TIME AS MEDIATOR

When looking at the amount of time case managers spent with clients, located on Table 4, the concept of time was operationalized into three different measures; the total face to face hours and phone hours is labeled *total time*, *face time* is the hours spent face to face with a client and the *total number of contacts* is the number of face to face contacts plus all phone contacts.

As evidenced from Table 3, volunteers spent significantly more total time, face to face time and total contacts than did the professional case managers. When looking at the effect sizes, face

to face time (more intense and personal time than phone calls) has the largest size effect at $r = .65$, with the differences between the volunteers and professionals substantial for all three time measures.

Table 4: Time Spent by Case Managers

	Professional Case Managers		Volunteer Case Managers		t-score	Sign.Level	R
	Mean	SE	Mean	SE			
<u>Total Time</u> (Face plus Phone in Hours)	33.74	1.43	42.77	1.65	-4.41	.001	.34
<u>Face Time</u> In hours	13.9	.84	27.3	.96	-10.66	.001	.65
<u>Total Contacts</u> (Total no. of Face and Phone Contacts)	33.73	1.4	44.49	1.51	-5.21	.00	.42

In addition to the two research hypotheses, five additional research questions were posed:

1. Do volunteer or professional case managers spend more time (face to face and phone time) with clients at the end of 9 months of CM intervention?
2. Do volunteer case managers spend more intensive time (face to face versus phone) with clients than professional case managers?
3. Do volunteers have more contact with clients (number of phone contacts plus number of face to face contacts) than professional case managers?
4. Does the accumulative amount of time spent with a client correlate with proportionately more needs identified at baseline being met at 9 months?

5. Is there a correlation between changes in LIF score, number of needs, and the amount of total time and total number of contacts case managers spend with clients?

From Table 3, for research questions 1-3, volunteer case managers spent more total time (face plus phone time), more intensive face to face time and had more total contact (face contacts plus phone calls).

Table 5 details the correlations between time spent, number of outside needs met and change in LIF score. For research question 4, at .01 significant level, the amount and type of time spent with a client (total contacts, total hours and face to face time) all correlate with an increase in number of outside services obtained. In addition, for research question 5, more time spent correlates with both more outside services obtained and an improvement in LIF score.

Table 5: Time, Outside Needs Met and LIF Change Correlations

	Total Contacts	Face Time	Total Hours	LIF
No. of Outside Needs Met at 9 Months	.327**	.234**	.333**	.379**
LIF Change	.428**	.450**	.412**	
Total Contacts		.814**	.854**	
Face Time			.844**	

** P<.01 level

Utilizing path analysis, it will be determined if face to face time, total hours and total contacts served as mediators, not only for the percentage of outside needs met, but also for the change in client LIF functioning and the two CM interventions.

8.0 MULTIVARIATE STATISTICS: PATH ANALYSES OF MEDIATION MODELS

The following discussion of the research findings is organized to follow the theoretical model upon which this study was based (see Figure 1). The path analyses to be examined tests for possible mediation of the effect of the two case management interventions on both dependent variables are,- change in LIF score and the percentage of outside needs met through three possible mediators associated with time: face to face contact, total hours and total contacts.

The path analyses only included those control variables that are significantly related to both the independent and dependent variables. Upon review of Table 6, only mental health status was significantly related to both the dependent and independent variables and will be included in the path analyses as the control variable. The clients in the professional CM program had more chronic mental illness.

8.1 CASE MANAGEMENT INTERVENTION AND THE DEPENDENT VARIABLES

The first hypothesis posed by this research asked the question, are volunteer case managers more effective than traditional case managers in improving the level of independent functioning (LIF) of clients?

As evidenced from the bivariate correlation results, at baseline, clients served by the professionals had a mean LIF of 14.96, and the clients in the volunteer group had a comparable LIF score of 14.73. After nine months of case management intervention, however, the clients followed by professionals had a mean LIF of 12.01, while those in the volunteer group had a significantly improved score of 10.28. Both groups appeared to benefit from case management intervention, but the clients in the volunteer CM program experienced a greater decrease in their LIF score (increased independent functioning). Therefore, volunteer case managers appeared to be more effective in improving the level of independent functioning of their clients than did the professionals.

Table 6: Testing for Significant Demographics Utilizing the T-Test, Anova and Chi-Square (P-Values)

	Dependent Variables	
	Change in LIF Score	% of Outside Needs Met
Sex	.414	.894
Sexual Orientation	.092*	.990
Race	.553	.141
HIV Status	.516	.445
Mental Health	.003***	.000***
Drug and Alcohol	.048**	.000***
Marital Status	.202	.772
Age	.186	.357
Independent Variable		
Case Management Intervention		
Sex		.117
Sexual Orientation		.519
Race		.332
HIV Status		.117
Mental Health		.037**
Drug and Alcohol		.838
Marital Status		.483
Age		.739
* P<.1	** P<.05	*** P<.001

The second hypothesis asserts that volunteer case managers would be more effective in securing a higher percentage of critically needed outside resources than the professional case managers. Theoretically, the more critically needed services a client receives, the more likely their ability to function independently would increase. Again, from the bivariate results, clients in the professional CM group had more outside needs than did the clients in the volunteer group (mean of 17.36 for professionals compared to 15.45 for volunteers), however, the volunteer case managers did obtain a higher percentage of outside needs, at a mean of .81, while professional case managers averaged .62. This result is tempered by the fact that clients in the professional CM group had more outside needs, in part due to serving more severely mentally ill clients. Client with more severe mental health issues were often not to secure the mental health resources.

To address the research questions posed by this study as well as to test the theoretical model, multivariate regression analyses were done for the two dependent outcome measures. The first of these was designed to test whether a particular case management program improves the LIF score of clients. As the key difference in the structure of the two programs was the amount of time case managers spent in providing emotional support and education, the three aspects of time (amount of time, intensity and number of contacts) were tested as possible mediators.

Figures 2, 3 and 4 present the path analyses for each of the three potential mediators of time—total hours, total contacts and face to face contact. Tables 7, 8 and 9 are the corresponding tables for the path analyses.

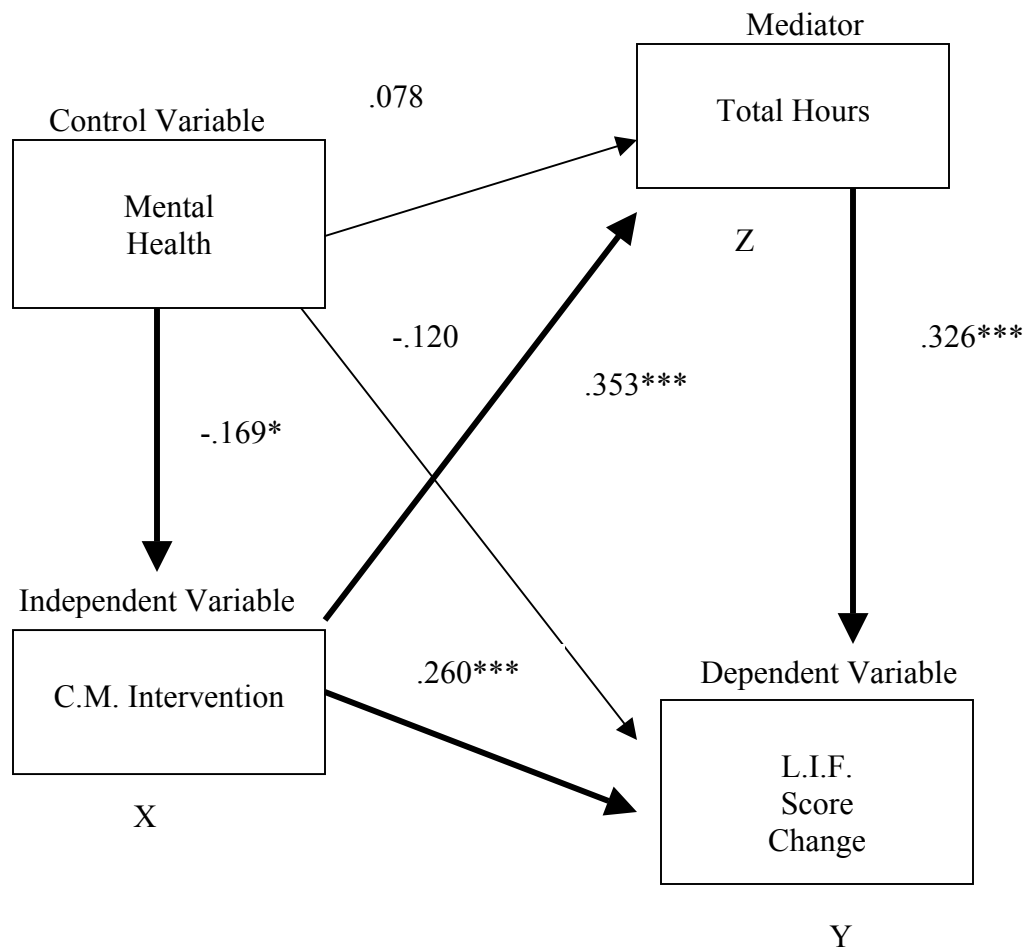
8.2 PATH ANALYSES AND TEST FOR MEDIATION

When looking at changes in LIF and the potential role of total hours case managers have with clients, the path analysis in Figure 2 shows that CM intervention is strongly correlated with total hours ($\beta=.35$), and total contacts is strongly correlated with LIF score ($\beta=.32$). From the path coefficients, total hours appears to mediate the relationship between CM intervention and change in LIF score.

The Sobel Tests for significance of the indirect effect of X on Y through the mediator variable. It must have a significantly large Z score with a p-value less than .05 in order for there to be at least partial mediation. If the relationship between X and Y remain significant when the mediator is controlled then partial mediation occurs. When the relationship between X and Y is markedly reduced and not significant there is full mediation (Barron and Kenny, 1986).

For total hours, a Z score of 2.72 indicates that there appears to be at least partial mediation- volunteer case managers appear to have a greater impact on helping to change the LIF score for a client due in part to their spending more hours with a client.

Figure 3 shows the path analysis for LIF and total contacts. A review of the path coefficients shows that CM intervention is strongly correlated with total contacts ($\beta=.40$), total contacts is strongly correlated with change in LIF score ($\beta=.33$). From the betas, total contacts would also appear to mediate the relationship between CM intervention and change in LIF. The Sobel Test scores shows that a Z score of 3.34 supports the expected mediation- volunteer case managers help improve LIF scores through having more contact with clients than do professional case managers. For both total hours and total contact, the p value was less than .01.



* P<.05
 ** P<01
 *** P<.001
 → Correlation

Figure 2: Change in L.I.F. and Total Hours

Table 7: Regression Analysis for Total Hours as Mediator and LIF Change as the Dependent Variable

Dependent Variable	Predictor	B	SEB	B	p	R squared	Adj. R. squared
CM Intervention	M.H. Diagnosis	-.133	.063	-.169	.036	.029	.022
Total Hours	CM Intervention	10.038	2.210	.353	.000	.121	.109
	Mental Health Diagnosis	1.734	1.736	.078	.320		
LIF Change	Total Hours	.044	.010	.326	.000	.255	.240
	CM Intervention	1.006	.296	.260	.001		
	Mental Health Diagnosis	-.365	.219	-.120	.097		

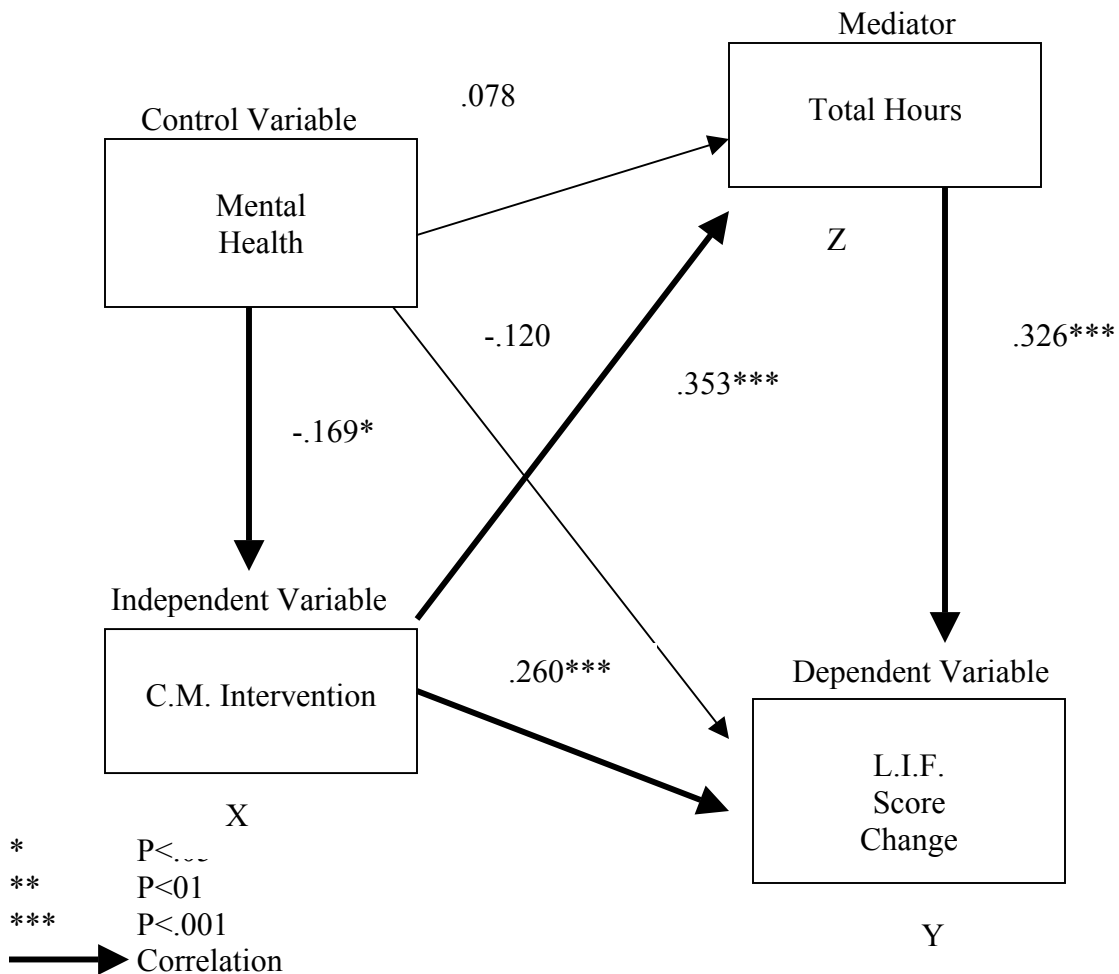


Figure 3: Change in L.I.F. and Total Contacts

Table 8: Regression Analysis for Total Contacts as Mediator and LIF Change as the Dependent Variable

Dependent Variable	Predictor	B	SEB	B	p	R squared	Adj. R. squared
CM Intervention	M.H. Diagnosis	-.133	.063	-.169	.036	.029	.022
	Total Hours	11.139	2.094	.404	.000	.159	.022
LIF Change	Mental Health Diagnosis	1.753	1.645	.081	.288		
	Total Contacts	.047	.011	.336	.000	.257	.242
	CM Intervention	.925	.303	.239	.003		
	Mental Health Diagnosis	-.371	.219	-.122	.092		

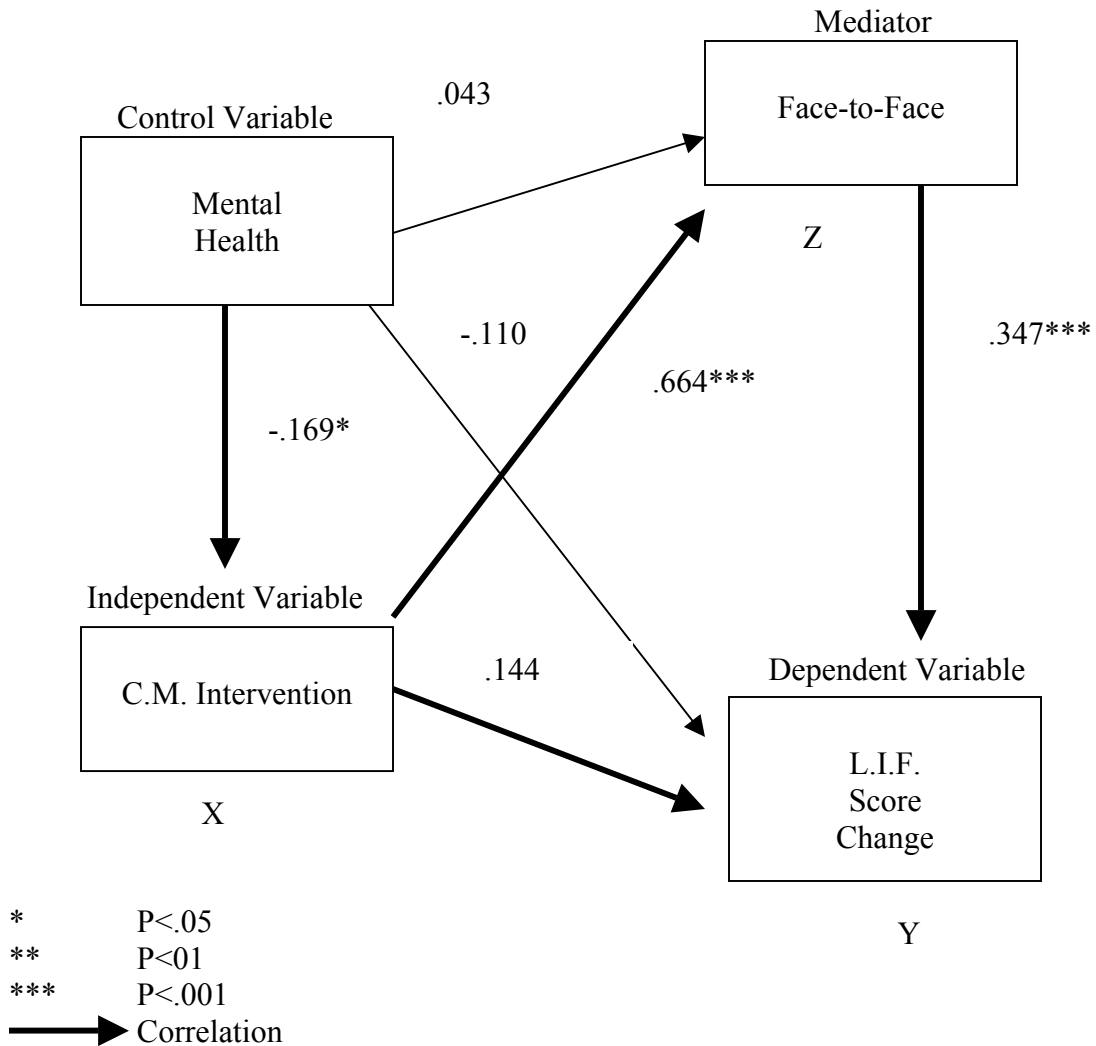


Figure 4: Change in L.I.F. and Face-to-Face

Table 9: Regression Analysis for Face to Face Contacts as Mediator and LIF Change as the Dependent Variable

Dependent Variable	Predictor	B	SEB	B	p	R squared	Adj. R. squared
CM Intervention	M.H. Diagnosis	-.133	.063	-.169	.036	.029	.022
Face-to-Face	CM Intervention	13.793	1.294	.664	.000	.434	.426
	Mental Health Diagnosis	.703	1.017	.043	.491		
LIF Change	Face-to-Face	.065	.018	.347	.000	.230	.214
	CM Intervention	.558	.374	.144	.139		
	Mental Health Diagnosis	-.334	.222	-.110	.135		

For the more intensive contact, face to face, a glance at Figure 4 shows that CM is strongly correlated with face to face contact ($\beta=.66$) and face to face contact is strongly correlated ($\beta=.35$) with the change in LIF score. The significant difference with this path analysis is that CM intervention is no longer correlated with changes in LIF score once face to face contact is entered. A review of the Sobel Test scores for face to face contact shows a Z-score of 3.44 with a p value of less than .001. This, combined with the fact that the CM intervention is no longer correlated with changes in LIF score, after entering face to face contact, provides a case for full mediation. Volunteer case managers spent significantly more face to face time with clients than did professional case managers, and this type of contact fully mediated the change in LIF score.

Figures 5, 6 and 7 present the path analyses for each of the three mediators of time and percentage of outside needs met. Tables 10, 11 and 12 correspond to the path analyses. For percentage of outside needs met and face to face contact (Figure 4) the strongest correlation with case management and changes in LIF, there is no correlation ($\beta=.05$). For changes in percentage of outside needs met at 9 months with total hours, (Figure 5), there is no correlation ($\beta=-.04$). And for percentage of needs and total contacts, (Figure 6) there is again no correlation ($\beta= -.05$).

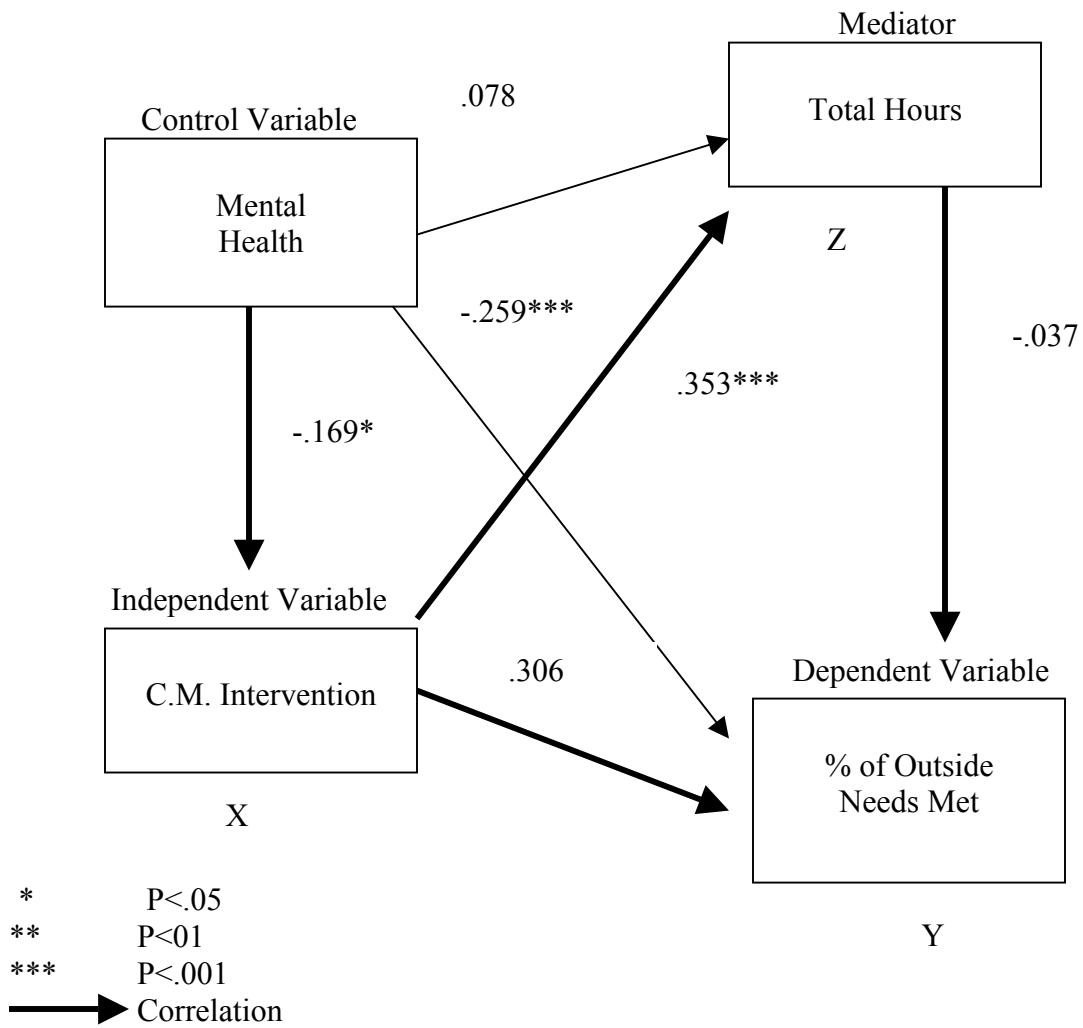


Figure 5: Percentage of Outside Needs and Total Hours

Table 10: Regression Analysis for Total Hours as Mediator and Percentage of Needs Met as the Dependent Variable

Dependent Variable	Predictor	B	SEB	B	p	R squared	Adj. R. squared
CM Intervention	M.H. Diagnosis	-.133	.063	-.169	.036	.029	.022
Total Hours	CM Intervention	10.038	2.210	.353	.000	.121	.109
	Mental Health Diagnosis	1.734	1.736	.078	.000		
% Outside Needs Met	Total Hours	-.001	.002	-.037	.642	.182	.165
	CM Intervention	.177	.046	.306	.000		
	Mental Health Diagnosis	-.118	.034	-.259	.001		

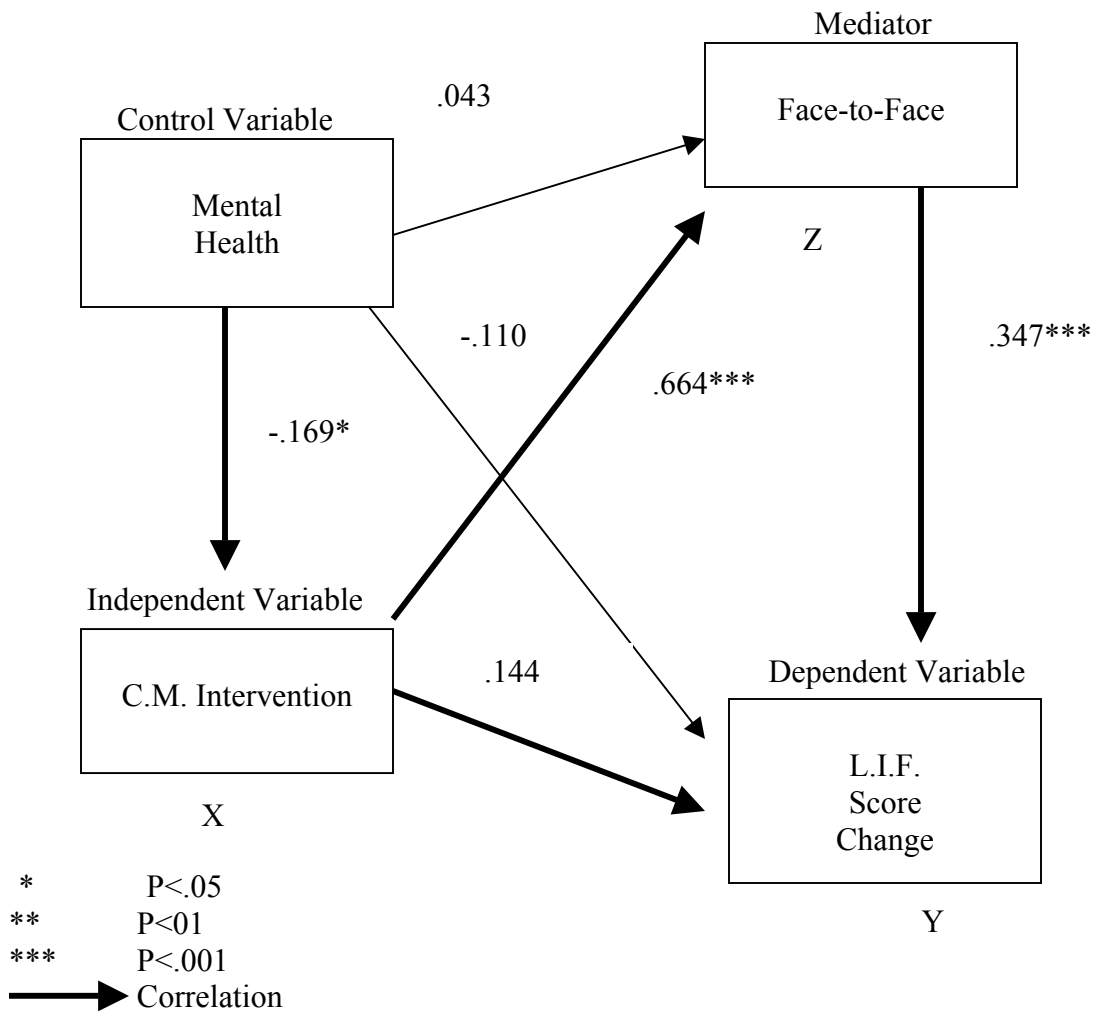


Figure 6: Percentage of Outside Needs and Total Contacts

Table 11: Regression Analysis for Total Contacts as Mediator and Percentage of Needs Met as the Dependent Variable

Dependent Variable	Predictor	B	SEB	B	p	R squared	Adj. R. squared
CM Intervention	M.H. Diagnosis	-.133	.063	-.169	.036	.029	.022
Total Contacts	CM Intervention	11.139	2.094	.404	.491	.159	.148
	Mental Health Diagnosis	1.753	1.645	.081	.000		
% Outside Needs Met	Total Contacts	-.001	.002	-.038	.643	.182	.165
	CM Intervention	.179	.047	.309	.000		
	Mental Health Diagnosis	-.118	.034	-.260	.001		

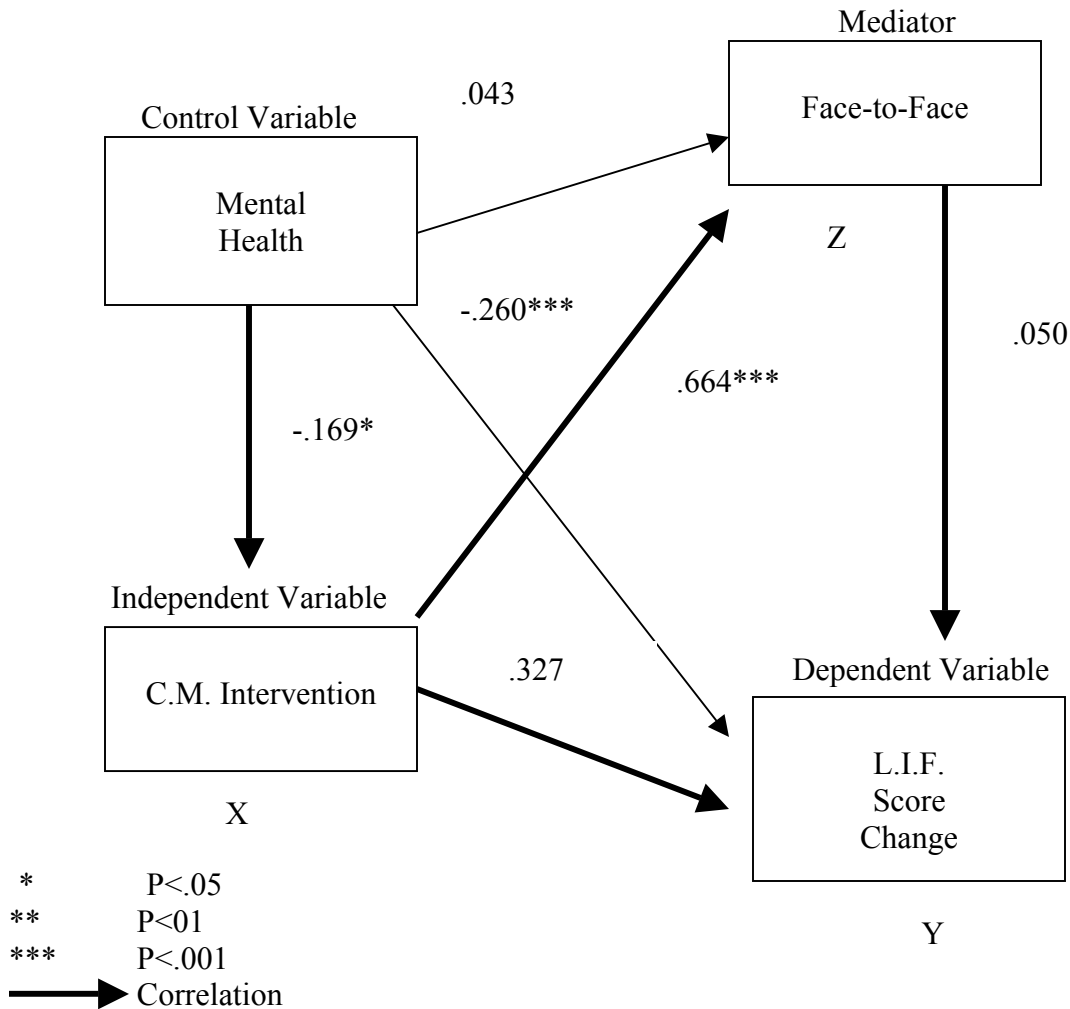


Figure 7: Path Model for Percentage of Outside Needs and Face-to-Face

Table 12: Regression Analysis for Face to Face Contacts as Mediator and Percentage of Needs Met as the Dependent Variable

Dependent Variable	Predictor	B	SEB	B	p	R squared	Adj. R. squared
CM Intervention	M.H. Diagnosis	-.133	.063	-.169	.036	.029	.022
	Face-to-Face	13.793	1.294	.644	.000	.434	.426
% Outside Needs Met	Mental Health Diagnosis	.703	1.017	.043	.491		
	Face-to-Face	-.001	.003	-.050	.611	.182	.165
	CM Intervention	.189	.058	.327	.001		
	Mental Health Diagnosis	-.118	.034	-.260	.001		

In testing time mediating the relationship between the two case management programs and percentage of outside needs met, the mediator must correlate with percentage of needs met and this does not occur with any of the mediators for time. And in conducting the Sobel test for mediation, the Z-scores of .51 for face to face contact, .46 for total hours and .64 for total contacts all had p values greater than .61.

From the path analyses and the Sobel test, the increase in time spent significantly mediates the relationship between the case management intervention and LIF score but not in the percentage of outside needs met and LIF.

In answer to the research questions posed by this study, volunteer case managers did spend more total time (face to face meetings plus phone calls), had more total contacts and provided more intensive face to face time with their clients than did the professional case managers. And as hypothesized, there was partial mediation with the amount of total contacts and total hours spent and improvement in clients' LIF score. Face to face time, the most intensive contact, appeared to fully mediate the type of CM intervention and LIF. Clients in the volunteer CM

intervention program experienced an improved level of functioning in part due to having more contact and time with staff and in large part, to having more one on one, face time with the volunteers.

For the second hypothesis, this research found that volunteer case managers assisted clients with obtaining a higher percentage of more critically needed outside needs. In addition, the percentage of outside needs met did strongly correlate with improvement in LIF score. However time- total contacts, total hours and face to face contact-did not mediate this correlation. While volunteer case managers spent more time with clients, and did help clients obtain a higher percentage of outside needs, the amount of time provided did not significantly impact the percentage of services received.

9.0 DISCUSSION

This study was designed to determine if either a traditional/ professional or volunteer self-help case management program was superior in helping clients live more independently and be self-reliant. While the responsibilities of a case manager varies from agency to agency, *The Case Manager's Handbook* (1998) was clear in defining the role; "The focal point of case management in all of its roles is to empower clients, giving them and their families access to a greater understanding of their disability or disease, a larger voice in the delivery of their care, and more personalized attention to their particular needs." (p.5).

Evaluating the effectiveness of CM intervention at the Pittsburgh AIDS Task Force (PATF) was accomplished by modifying an existing acuity scale that measured the level of independent functioning in seven key areas of life. At the beginning and then at the end of nine months of case management, clients' level of functioning was assessed and given a score. How much the score changed, and whether clients scores improved or worsened served to measure the effectiveness of both case management programs. In addition, it was theorized that volunteer case managed clients would have a larger percentage of their outside needs met after nine months. The results show that while volunteer case managers met a greater percentage of outside needs, those in the professional group had more needs as a result of more clients being severely mentally ill.

9.1 RESEARCH RESULTS

The research findings for the first hypothesis, in which volunteer case managed clients experienced greater improvement in their functioning level, is consistent with the theory of stress and coping that focuses on the importance of social support. Lazarus (1980) identified problem and emotion-focused coping as mechanisms to deal with stress. House (1981) cited emotional and informational support as critical when helping others. What has remained consistent throughout research on stress and coping is the importance of human relationships. Research addressing the impact of peer support has found that empowering clients motivates them to lead a more independent life by increasing problem solving and coping skills and giving them needed information (Silverman, 1997). As hypothesized for the volunteer group, there was partial mediation with the amount of total contacts and total hours spent and improvement in clients' LIF score. Face to face time, the most intensive contact, appeared to fully mediate the relationship between the volunteer case management intervention and change in LIF. Clients in the volunteer CM program spent more time, had more contacts and met with clients in person more than the professional staff. This, theoretically, enabled volunteer staff to spend more time supporting and educating clients to help themselves.

For the second hypothesis, this researcher found that volunteer case managers assisted clients with obtaining a higher percentage of more critically needed outside needs. While the percentage of outside needs strongly correlated with improvement in LIF, time (total contacts, total hours and face to face contact) did not mediate this correlation. Volunteer case managers spent more time with clients and helped them secure a higher percentage of outside needs, but the amount and type of time spent did not play a role in obtaining services. One factor that may account for time not being correlated with percentage of needs met is the number of clients who

were severely mentally ill. The professional case managers had a higher number of clients with severe mental illness than did the volunteers. Mental illness and CM intervention were correlated with percentage of needs met, and CM was already shown to be correlated with time. But time was not a mediator, due in part, to clients with severe mental illness having had more needs and those needs were often unmet at the end of nine months.

9.2 RESEARCH LIMITATIONS

When reviewing any research study, it is important to consider design flaws, discrepancies or constraints that could affect the results. Knowing this would serve to help improve future research. Following are a list of concerns that arose during this study. Of most importance, clients were not randomly assigned but had the right to choose their CM program. Clients who were healthier both physically and mentally may have been more apt to choose the volunteer program that required them to travel to the office for service. In reviewing the means of each group, the volunteers had fewer clients who were AIDS diagnosed and fewer who were severely mentally ill. Mental health services were the most difficult to obtain and often were never realized. This would affect LIF scores, and, impede the ability of professional staff to obtain services for clients, since they worked with more severely ill clients.

Those in the volunteer group may have been more motivated and ready to help themselves, thereby increasing the likelihood that they would experience a greater improvement in their LIF score. In addition, clients who switched programs were not tracked. Clients who experienced a decline in either their physical or mental health may have dropped out of the volunteer program or moved to the professional program because of inherent obstacles in getting to the office.

Economics as a demographic variable was not examined and may have played a role in the interventions chosen. Time, both in terms of number of contacts and total hours, included phone calls. Clients in financial straits often could not afford phones which would compromise their ability to talk to staff or follow-up with various applications for services. Clients, then, with better resources, may have been more likely to choose the volunteer group.

Though not significant, the professional group had more women (40.2%) than did the volunteer group (28.2%). Women choosing the CM intervention may have been more interested in choosing the professionals because of travel and daycare concerns. Many of the women had children and, while PATF provided transportation and daycare, they still had to gather the children, get on one or two buses (or a cab) and travel to the office. And having children generally placed women at the bottom of the economic scale, and could have made it more difficult for them to follow through with application requirements.

Other demographic information that was collected but not analyzed was age. Certain age groups might have self-selected specific interventions. Older clients may have been in social service systems longer and chose a volunteer program based on their past experiences with professional staff. They may have sought additional time and support because of accumulative stress and losses due to the disease. Because of lack of outreach at PATF, there were no clients under the age of eighteen in either group.

And though PATF served clients in an eleven county area, the majority of the participants lived in urban areas so the needs of clients in rural areas were not adequately reflected.

For the measurement tools:

Demographic Information Sheet,

1. Assessing medical (HIV) status as well as drug and alcohol and mental health issues relied on the case manager and/or supervisor securing the appropriate data and making an informed judgment. While the supervisor was trained to assess and judge this information, it was not always clear if staff/volunteers provided comparable assessments, or if all pertinent data were in the charts.
2. Under marital status, an important component missing in assessing level of social support are those clients who had been divorced, separated or lost a loved one, or who may have lived with extended family.
3. Under drug and alcohol use, when identifying level of severity, the number of years of drug/alcohol use or of sobriety were not documented. In addition, drug use and alcohol use were not separated. There would be a perceived difference in severity for someone who smoked pot, to someone who drank for three years or to someone who had been addicted to heroin for ten years. The level of severity was not differentiated.
4. Another possible concern with obtaining information on drug and alcohol use is that clients would lie in order to secure services. Many programs, including Welfare, deny benefits if a client is addicted.
5. The same concern exists for those with mental illness in terms of not identifying the number of years clients lived with severe illness, and if that mental illness pre-dated a diagnosis of HIV disease (making it more chronic).
6. One piece of information not collected was whether the client had other forms of support such as a counselor or case manager from other agencies.

The Level of Independent Functioning Scale (L.I.F.) appears to be a good diagnostic and evaluative tool in assessing changes in independent functioning. For future research it is recommended that certain modifications be made to some of the categories:

- 1) Under the section for risks/needs, need for transportation was in the same category as someone who has unstable housing. As both of these diverse issues were weighted (given the same score), consideration needs to occur when modifying this tool to make the categories comparable in need and severity. When looking at the need for emotional support category, it did not include the loss of friends/family due to HIV.
- 2) It is not generally possible to assess a client's commitment to case management (category 1) at baseline as the client generally does not have a history with the agency.

For the Checklist of Needs:

- 1) The majority of needs were identified at baseline, but if needs arose at 3, 6 or 9 months, they were not documented.
- 2) For future studies, it would be helpful to know how long it took to obtain certain services. Knowing this could assist an agency in lobbying a particular service provider to deliver their services sooner. For example, if it took nine months to obtain mental health or drug and alcohol care, as was often the case in this research, then ASO's could address this gap in service with the those agencies.

Other constraints of the study included the fact that the client data was six years old and the current demographics and needs of clients may have changed.

Demographic information was not obtained for the volunteer or professional case managers. Identifying their race, sexual orientation, whether or not they were HIV positive or knew someone who was, or were in recovery for drug and alcohol or mental health issues could speak

volumes in terms of their ability to build rapport with clients. It is known that there were no African American case managers in either program despite the fact that over half of the clients in each were Black. This could, in part, account for not only the large dropout rate (49.2%), but also for how much contact they had with staff and how many services they received.

Due to HIV related opportunistic infections steadily declining as a result of new retroviral therapy, less than 14% of participants in the drop-out and research group were asymptomatic. Individuals living with more advanced HIV may have dropped out due to the incapacitating effects of AIDS. Additional follow-up demographic

information was not gathered for those who dropped out. Clients who did drop out of the study may have been too ill to follow-up with services, but were most in need of them.

9.3 IMPLICATIONS FOR PRACTICE AND RESEARCH

It is clear from the results that volunteer case managers were more effective than professional case managers in providing more time and more intensive time that resulted in an improvement in their ability to function more independently. While a major role of case managers has always been to help secure services, it is the goal of affecting a clients' ability to function more independently that is most critical in defining successful case management. And while obtaining more services did correlate with improvement in LIF score, it was face to face time that had the strongest relationship with positive changes in independent functioning.

A volunteer/peer CM program would greatly reduce the caseloads of already overburdened professionals within a number of social service agencies. But most importantly, volunteer/ peers, who have the ability to spend quality time educating and supporting clients,

may be better able to help dependent clients obtain their independence and self-esteem. Funding volunteers who work more closely with clients might encourage clients to volunteer for others once their life has stabilized. This mentor model might garner support from mental health and drug and alcohol facilities. In addition, the ability of clients to connect with volunteers, some of whom may have shared their experiences, might result in the more fragile of clients with multiple MH/DA issues feeling connected and supported, less likely to drop out of care, end up in jail or die.

The volunteer/peer case management model could be replicated in other social service venues-mental health, drug and alcohol, adolescent and family programs, those with mental and/or physical disabilities, etc. This model could also demonstrate that clients receiving support and care from volunteers would more likely access medical care, thereby reducing hospital costs.

These demonstrated results serve to not only bolster efforts to secure funding for targeted case management services provided by volunteers and interns, but may help to reinstate funding for more intensive intervention. As policy, the Pennsylvania HIV/AIDS Bureau limits state funding for less intensive contact due to a lack of demonstrable results, and reimburses only case managers who are degreed and have experience. The ability to evaluate effectiveness of CM intervention may enable HIV/AIDS coalitions to better lobby for an increase in dwindling Ryan White dollars. Increased funding would theoretically result in no-waiting lists at AID Service Organizations. No waiting lists would mean that clients could obtain needed services more quickly and live a better quality of life. Foundations and the United Way may also be more amenable to funding a non-professional case management program.

This research study also tracked services obtained by women (a special carve-out funding initiative for Ryan White dollars in which increased dollars became available). Providing

evidence that women obtaining more services and functioning more independently could help to increase funding federal monies. Any future study also needs to explore if either CM intervention is more effective for women.

Perhaps the fastest growing population, and those most in need most in need of comprehensive services, are women, and specifically Black women. This population accounts for 68% of all newly diagnosed cases but historically they delay their own care in order to focus on their children.

Future research may show that the measurement tools identify what services are needed and how long it would take to secure them specific to race and gender. The Checklist of Services could help identify any special needs for specific groups of individuals. If, for example, women had difficulty obtaining mental health services, or day care, these issues could be addressed at an agency level. Knowing the needs of a specific population, identifying any barriers, including length of time it took to meet the need, would give valuable information in helping case managers provide more gender specific and culturally sensitive services. The ability to identify when and if a client receives a specific service could enable agencies to address deficiencies within their own service structure. In addition, gaps in critical service needs could then be discussed with other agencies.

National demonstration programs (The Measurement Group) have shown that multiple services, a one-stop shop approach, eliminates barriers to care. Currently in Southwestern Pennsylvania, as elsewhere, HIV and mental health/drug and alcohol programs are separate agencies with poor if any coordination (Desalu, 1998). Faster access to mental health care would likely serve to decrease dependence by improving functioning.

As those infected live longer, the incidence of mental health issues, due either to infection or catastrophic life changes, has been on the rise. This is reflected in the fact that clients with mental health issues comprised over 85% in each group. Nationally, Blacks account for 13% of the population but over 50% of all new cases, and in both groups studied here, the percentages of Blacks exceeded this percentage. Since 1999, a growing number of those infected cite drug use and heterosexual sex as their risk factor. Both group statistics confirm this trend, with over 60% having some or chronic drug/alcohol problems and over 55% in both groups being heterosexual. It is critical that future research examines more closely the needs of populations with these emerging profiles.

The research tools utilized in this study would provide agencies with the means to evaluate the effectiveness of staff in improving the independent functioning of their clients. But most importantly, this research demonstrates the vital role volunteers/peers CM play in helping clients transition from dependency to independence. With Blacks becoming infected at eight times the rate of whites and having AIDS as the number one cause of death, it is important to compare whether one CM program is more effective than others in providing support and services than others (NIAD,2005). Heterosexual women, as one of the fastest growing populations infected with HIV, and who experience the most service barriers, are perhaps in the greatest need for an intervention that serves to meet their lack of resources and supports their ability to be more independent in caring for themselves and their children. And while historically gays have had greater access and support at predominantly gay-founded ASOs, heterosexuals are becoming infected at alarming rates but typically have not felt comfortable going to an agency where the majority of the clients are homosexual. A CM program providing time and support to heterosexual clients, the fastest growing population, would be invaluable.

And lastly, future research needs to evaluate if more time spent by volunteers results in educating clients in helping themselves, or just provides staff with more time for them to secure the needed resources. Client assessment of the degree to which a case management intervention served to empower them, and a closer look at the process by which clients become more self-reliant would be an important component to add when evaluating any intervention designed to facilitate independence.

Despite the flaws of the study, this research is one of a very few that compared two case management programs over time. While most evaluative research has examined client files, hospitalization rates or client satisfaction, few, if any, focused on defining a component of successful case management in such a way that it can be measured. In an area that has been understudied, this research has contributed to not only creating measurement tools, but also looking at expanding the role of volunteers beyond providing peer support.

APPENDIX A

IRB LETTER



University of Pittsburgh *Institutional Review Board*

Exempt and Expedited Reviews

University of Pittsburgh FWA: 00006790
University of Pittsburgh Medical Center: FWA 00006735
Children's Hospital of Pittsburgh: FWA 00000600

3500 Fifth Avenue
Suite 100
Pittsburgh, PA 15213
Phone: 412.383.1480
Fax: 412.383.1508

TO: Ms. Mary Ann Fisher

FROM: Sue R. Beers, Ph.D., Vice Chair *Sue R. Beers*

DATE: August 29, 2006

PROTOCOL: Social Support for the HIV+ Client: A Comparison of the Effectiveness of Traditional Versus Volunteer Case Management Intervention

IRB Number: 0607114

The above-referenced protocol has been reviewed by the University of Pittsburgh Institutional Review Board. Based on the information provided in the IRB protocol, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(4).

- If any modifications are made to this project, please submit an 'exempt modification' form to the IRB.
- Please advise the IRB when your project has been completed so that it may be officially terminated in the IRB database.
- This research study may be audited by the University of Pittsburgh Research Conduct and Compliance Office.

Approval Date: August 29, 2006

SRB:kh

APPENDIX B

CASE MANAGEMENT DEMOGRAPHIC COLLECTION INSTRUMENT

Age: _____ Client ID: _____
 Sex: Male: _____ Female: _____
 Sexual Orientation: Heterosexual _____ Gay/Lesbian _____ Transgender _____
 Race: Caucasian _____ African American _____ Other _____
 Marital Status: Married/Committed _____ Single _____

Amount of Phone time	
Number of Phone Contacts	
Amount of Face-to-Face Time	
Number of Face-to-Face Contacts	
Total Amount of Time Spent	

Total Number of Service Needs _____

Total Number of Service Needs Met _____

Mental Health:

No Problems _____ Some Issues _____ History of Chronic Problems _____

Drug and Alcohol

Never Used _____ In Recovery/Treatment _____ Actively Using _____

HIV Status

Asymptomatic _____ Symptomatic _____ AIDS Diagnosed _____

APPENDIX C

CLIENT CHECKLIST OF NEEDS

Client ID _____

Baseline: _____ 3 Months: _____ 6 Months: _____ 9 Months: _____

Service	Need Now	Need Met	Need Not Met
Medical			
HIV medication			
Psych meds.			
Other medication			
Medical Supplies			
Dental care			
Refer to Dr.			
Medical Coverage			
Home Care			
Homemaker services			
Home health aide			
Nursing care			
Respite care			
Hospice			
Day care			
Housing			
Short-term			
Long-term			
Phone Hook-up			
Utility assistance			
Moving assistance			
Furniture			
Transportation			
Bus tix/MATP			
Access			
Van Service			
Bus Pass			
Yellow Cab			
Gas Vouchers			

APPENDIX C (cont'd)

CLIENT CHECKLIST OF NEEDS (cont'd)

Client ID: _____

Baseline: _____ 3 Months: _____ 6 Months: _____ 9 Months: _____

Nutritional Needs	Need Now	Need Met	Need not Met
Food			
Referral to pantries			
Nutritional Supp.			
Vitamins			
Nut. Counseling			
Food Stamps			
WIC			
Mental Health TX			
Crisis inter. (1x)			
Crisis inter (several)			
St.-term Counseling			
Lg.-term counseling			
Ongoing counseling			
Support Groups			
Drug/ Alcohol TX			
Counseling			
Rehab			
Support groups			
Methadone			
Risk Reduction			
Safer sex			
Food/Water safety			
Pet Safety			
Cleaning needles			
Other Services			
Apply for Welfare			
Apply for Disability			
Legal/Advocacy			
Buddy			
Pet Buddy			
Clothing			
Job/Training			
Info. on HIV TX			

APPENDIX D

PITTSBURGH AIDS TASK FORCE (PATF)

Level of Independent Functioning (LIF) Scale

(Modified version of Action AIDS Acuity Assessment Tool)

Client's ID Number: _____

Baseline: _____ 3 Months: _____ 6 Months: _____ 9 Months: _____

Level of Risk

Category	3 Points	2 points	1 Point
I. Need for CM Commitment to CM and treatment goals	Frequently does not return CM calls Often misses appointments and follow-up activities Not invested in treatment plan Unaware of services and resources	Occasionally does not return CM calls Sometimes misses appts. and follow-up activities Some investment in treatment plan Not always aware of needs and resources	Usually returns CM calls Keeps appts., good follow-up with activities Invested in Treatment Generally aware of needs and resources
II. Support Systems	Absent or overburdened support system Needs CM structure to get basic needs met	Inconsistent or undependable support system	Intact support system
III. Households with dependent children and/or significant other HIV	Presence of one or more dependent children under 18 years of age Children HIV negative Significant other is HIV+ but stable	No minor children Significant other is HIV negative	No minor children Significant other is HIV negative

APPENDIX D (cont'd)

PITTSBURGH AIDS TASK FORCE (PATF)

Level of Independent Functioning (LIF) Scale (con't)

Level of Current Need

Category	3 Points	2 points	1 Point
IV. Medical Needs	Numerous medical needs Frequently misses medical appts., medications or treatments In hospital in past 30 days In denial of HIV status Needs help with daily needs	Intermittent need for medical care or supplies Needs supportive transportation Occasionally misses medical appts., medication or treatment Active O.Is Needs some help with daily needs	Monthly monitoring to ensure access to health care Medically stable All basic medical needs met Attends all appointments and takes medication
V. Mental Health	Active chaos or disruption due to violence/abuse Recent death in family/support system Acute dementia/psychiatric problems Active DA abuse, non-compliance with Treatment Requires significant emotional support	Sporadic chaos or disruption due to violence/abuse Intermittent dementia/psychiatric problems Sporadic Drug and alcohol abuse Occasional emotional support needed	Stable Mental health No drug or alcohol issues No violence/abuse issues Minimal emotional support needed
VI. Life Management Basic Needs	Basic benefits incomplete, applications needed Homeless No or poor access to food Needs transportation	Benefit applications completed/pending Unstable housing Inadequate food supply Inconsistent transportation	Benefits intact Stable housing Food needs are met Adequate transportation
VII. Life Management Skills	No budgeting skills Deficient in parenting skills CYF involvement Overwhelmed and needs prompting Depressed/addicted and needs prompting Needs memory aids to complete tasks	Inconsistent budgeting skills Inconsistent parenting At times overwhelmed/confused and needs prompting Needs prompting due to MH or DA issues Inconsistent with taking medication	Good budgeting skills Good parenting skills Able to handle own appts. Able to take medication as prescribed

APPENDIX D (cont'd)

APPENDIX D

Pittsburgh AIDS Task Force

Level of Independent Functioning (LIF) Scale (cont'd)

Scoring Grid

Section	Maximum Points	Score
I. CM availability/Treatment Plan involvement	3	
II. Support Systems	3	
IV Household Demographics	3	
IV Medical Needs	3	
V Mental Health/Drug and alcohol	3	
VI Life Management Basic Needs	3	
VII Life Management Skills	3	
ACUITY SCORE TOTAL	21	

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