Case Management for Adults Living with HIV/AIDS: A Qualitative Study of Social Workers’ Perceptions and Lived Experiences

Dissertation

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Abstract

Multiple health and psychosocial needs are associated with the Human Immunodeficiency Virus (HIV) infection and Acquired Immunodeficiency Disease Syndrome (AIDS). Persons living with these medical conditions are in need of assistance in many areas of their lives. Therefore, case management services are utilized to support most of this population. Although several studies have reviewed case management service delivery, most of these studies focus on conceptualization of case management and clients’ outcomes rather than the actual practice of case management. Yet, within the health and social service delivery system, case managers play crucial roles in assisting the diverse needs of persons living with HIV/AIDS (PLWHA). This research, therefore, was done to explore the perceptions and lived experiences of social work case managers offering services to PLWHA. Qualitative research methods in a grounded theory approach were used to collect data through semi-structured interviews with thirteen adult social work case managers of the Ryan White Care Program in one public health setting, one hospital, and two community based organizations in a metropolitan area of a Midwest state. Themes that emerged from the analysis of data were: 1) defining the role of the case manager; 2) challenges with clients; 3) challenges with formal organizations; 4) recommendations for improving case management service delivery; and lastly, 5) satisfaction and rewards of the job. The results have implications for improvement of case management service to PLWHA.
Dedication

Dedicated to my husband Kumi

Dedicated to my children Naa, Selina, Labi Kate, and Asieduaa

Dedicated to my sister Christiana
Acknowledgments

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Chapter 1: The Problem

Human Immunodeficiency Virus (HIV) infection is a chronic condition that affects the human immune system, reducing its ability to fight infections and diseases (CDC, 2009). In its later stage, HIV infection develops into Acquired Immunodeficiency Disease Syndrome (AIDS); at this point, the virus begins to destroy the human body’s immune system. The body then becomes prone to infection by disease-causing viruses, fungi, and bacteria that may have catastrophic effects because of the subject’s weakened immune system (CDC, 2009).

Demographic trends and the nature of HIV/AIDS infection present challenges both to persons’ living with the disease and to care providers, including case managers. The chronic nature of HIV/AIDS, the susceptibility to other infections and diseases, the likelihood of other sexually transmitted diseases afflicting persons living with HIV/AIDS (PLWHA) resulting in co-morbidities, are some of the issues that present challenges to persons living with the disease. Rothman and Sager (1998) stated that such challenges make PLWHA particularly vulnerable, in need of multiple kinds of assistance for the remainder of their lives. Case management services have been utilized to offer support and care to many of these people.

Several studies have reviewed problems associated with living with HIV/AIDS, yet little is documented about the perceptions and lived experiences of persons who provide services to PLWHA, including case managers.
Case management is considered an approach that involves planning, facilitating, and advocating for options and services to meet an individual’s health needs by using communication and available resources to promote quality cost-effective outcomes (http://www.cmsa.org/Home/CMSA/WhatIsACaseManager/tabid/224/Default.aspx). Case management practices are common across a wide array of service delivery models, especially in the health and social services sectors. Case managers play a key role in the health care delivery system, providing a broad range of services including education, counseling, assistance with medication management and adherence, nutrition support, monitoring, and help with housing.

Several studies have reviewed case management practices, especially within the health and social services sector. However, whether they are evaluating principles, concepts, or outcomes of the service, the exclusive focus of many of these studies is on the clients, not the case managers who deliver service. Very few studies have reviewed case management service delivery based on the perceptions and experiences of the case managers themselves. The purpose of this study was to address this gap in the existing research by exploring the perceptions and lived experiences of social work case managers regarding service delivery to PLWHA, with the goal of developing localized knowledge of case management service delivery to this target population.

Flaskerud and Miller (1999) have observed that HIV infection generates a unique series of stresses both for the affected person and for others providing care to persons living with the disease. Emerging demographic trends, as well as physical and psychological health issues associated with HIV/AIDS, are some areas that may pose challenges to social work case managers delivering services to this target population.
Problems associated with living with HIV/AIDS are well-documented; not much is documented on the issues confronting case managers.

The Changing Face of HIV/AIDS

HIV/AIDS was first discovered in the United States in 1981, and in spite of breakthroughs in treatment, HIV/AIDS presents one of the most serious challenges to public health both nationally and globally (UNAIDS, 2007). The global status of HIV/AIDS indicates that 6,800 persons become infected and 5,700 persons worldwide die every day of HIV (UNAIDS, 2007). Of the world’s 6.6 billion population, it is reported that at the end of 2007, an estimated 33.2 million of the world’s population lived with the disease (UNAIDS, 2007). In the same year, some 2.5 million people became newly infected and 2.1 million died of AIDS.

The HIV/AIDS epidemic has spread across almost every country on the globe. Africa is the worst affected continent in the world with more than two-thirds of all PLWHA living in the sub-Saharan region. Even though sub-Saharan Africa has only an estimated 10 percent of the world’s population, this region is the home of 68 percent of the world’s total people living with the disease (UNAIDS, 2007). It is also reported that an estimated 1.7 million of the persons newly infected with HIV in 2007 occurred in this region (UNAIDS, 2007).

The Centers for Disease Control and Prevention (CDC) report that out of nearly 303 million people, approximately one million persons are now living with HIV/AIDS in the US (http://www.cdc.gov/hiv/topics/surveillance/united_states.htm). An estimated 24-27 percent of persons in the US who are infected with the disease remain undiagnosed and unaware (http://www.cdc.gov/hiv/topics/surveillance/united_states.htm). This
suggests the spread of the disease should those infected continue to engage in compromising behaviors that promote the spread of the disease. In fact, the CDC reports that each year, about 40,000 new cases of HIV/AIDS infection are identified in the United States (CDC, 2007; CDC, 2006).

Besides numbers, the profile of the population infected with HIV/AIDS also changed over the years (UNAIDS, 2004; UNAIDS, 2006; UNAIDS, 2008). For example, in contrast to notions held during the early years after the discovery of the disease affecting primarily white gay and bisexual men, persons with hemophilia, and/or Haitian immigrants (Ungvarski & Flakerud, 1999), the demographic profile of the population infected with HIV/AIDS now reflects diversity by gender, age, ethnicity, and socioeconomic status (CDC, 2009). In the United States, for example, data on newly diagnosed HIV infection cases show increasing new trends among African Americans and Latinos as opposed to trends among Caucasians (CDC, 2009). It must be noted that these data may include both African Americans and other persons of African descent, including immigrants to the United States.

The discovery of antiretroviral drugs has also brought change to the face of HIV/AIDS by prolonging life and reducing mortality rates among PLWHA (CDC, 2007 CDC, 2007UNAIDS, 2006). Either because of the suppression of the body’s immune system or the common route of HIV infection and other diseases, PLWHA must deal not only with the health concerns of the disease, but also with those of other infections such as hepatitis, tuberculosis, and pneumonia (Portillo, Holzemer, & Chou, 2007). For example, studies have shown that there are increasing liver-related diseases among PLWHA (Peters, 2007; Raymond, 2004; WHO, 2004). Thus, PLWHA must receive
treatment for the disease as well as for other morbidities and must deal with the side effects of their various medications (Portillo, Holzemer, & Chou, 1994). Thus, services by health care providers working with PLWHA extend across other disease domains.

Because of the damage caused by HIV infection to the human body’s immune system, a high standard of nutrition is vital for PLWHA (Duran, Almedia, Segurado, & Jaime, 2008). Case managers link their clients to resources such as food banks, food pantries, and food vouchers as well as professionals offering nutrition education.

There are also complex psychological issues related to HIV/AIDS infection (Hoffman, 1991; Treisman & Angelino, 2004). Treisman and Angelino (2004) report that “HIV has become a psychiatric epidemic.” Psychiatric disorders associated with HIV are either caused by the HIV infection or are pre-existing conditions that hinder prevention and treatment (Treisman & Angelino, 2004). Studies have shown that PLWHA also suffer from various forms of mental health conditions, including anxiety, depression and adjustment disorders (Hoffman, 1991). PLWHA also have to deal with other social issues such as stigma, loss of employment (Hoffman, 1991), and other internal deficits such as lack of information about the disease, lack of coping skills, and low self-esteem (Rothman & Sager, 1998). Rothman and Sager (1998) suggest that such internal deficits need to be balanced by strong external supports. Case managers render support by advocating for clients, linking them to resources, and coordinating other services used by them.

Psychiatric issues related to HIV/AIDS may also pose challenges to PLWHA in the areas of adherence to medications and treatment. This calls for counseling PLWHA (Hoffman, 1991), but Hoffman (1991) notes that few counseling psychologists are trained
to work with the wide array of complex psychosocial issues related specifically to HIV infection. In the absence of trained counselors, case managers assume roles as counselors to PLWHA. There is a gap in research into the experiences of case managers offering psychiatric counseling services to PLWHA that needs to be investigated.

The stigma associated with HIV/AIDS occurs at the individual, family, community, and societal levels, impacting on treatment of the disease (UNAIDS, 2007). Case managers must not only deal with the complex and far-reaching issues of stigma but also serve as support systems for their frightened and ailing clients.

The multiplicity of the needs of PLWHA means that case managers working with this population need to deal with other professionals who also provide services to this target population. Although case managers serve as coordinators for service delivery to meet the varied needs of PLWHA, there remains a gap in research into their lived experiences of improving coordinated services.

**Significance of the Problem**

HIV/AIDS continues to spread, and while medications have been effective in treating the disease, HIV/AIDS continues to present new types of clientele with chronic disease, with symptoms affecting their quality of life, thus making them vulnerable and dependent in many areas of their lives. These persons need assistance with a wide range of health, human services, and therapeutic interventions for managing the disease (Portillo, Holzemer, & Chou, 2007), and case management services are being utilized to meet these needs.

The increase in the number of PLWHA implies an increasing ratio of clients to case managers and/or an increasing number of case managers. In the same way, diversity
in the population of PLWHA presents a need for case managers to know how to deal with persons of diverse backgrounds, especially immigrants from different countries. Case managers’ experiences and coping mechanisms in dealing with increasing and diverse populations need to be explored.

Changing trends with HIV/AIDS have implications for case management service delivery, yet very little research has been conducted in this area. Emlet and Gutz (1998) have stated that there is a relationship between increasingly complicated social and economic factors and the use of case management services. Flaskerud and Miller (1999) have also observed that HIV infection “. . . generates a unique series of stresses” (p.225) not only for the affected person but also for others including health care providers. These include case managers who also play key roles as coordinators of health care for PLWHA.

Chernesky and Grube (2000) state that HIV/AIDS has been identified as a stressor that makes individuals utilize case management services. Because of the multifaceted nature of the needs of PLWHA, case managers provide a broad range of services directly or indirectly to clients. Yet even though problems associated with living with HIV infection are well-documented, not much is documented on the perceptions of case managers on their service delivery to PLWHA.

There is a gap in research on case management services based on the perceptions of case managers and this gap results partly from a lack of qualitative research in this area. As noted by Angell and Mahoney (2006), “Previous studies on case management borrow concepts and measures from psychotherapy research and may therefore overlook very important differences in tasks, settings and clinical roles across settings” (p.172).
These differences, according to Gursansky, Harvey, and Kennedy (2003), may impact differently on work performance and outcomes. Gursansky, Harvey and Kennedy (2003), therefore, call for research into the concept of case management for knowledge about case management practice in various settings. Such knowledge can be gained from the case managers who provide services.

**The Research Project**

The goal of this research was to explore the lived experiences of case managers to generate theory through identification of variables relating to case management service delivery to PLWHA. Specifically, this study focused on case management services and the views of social work case managers relating to the integration of services for PLWHA. Two main research questions guided the study:

- How do social workers perceive case management service delivery to PLWHA?
- What are the lived experiences of social work case managers with integration of services to PLWHA?

This was a qualitative study; participants were adult social work case managers working with PLWHA in a metropolitan area. Data were collected using semi-structured interviews with thirteen licensed social workers with at least six months of work experience with the target population. Data were collected according to Charmaz’s (2006) stance on objectivist grounded theory that allowed the researcher to use the constant comparative method as well as open and focused coding to generate themes that emerged from the data collected during the interviews.

Charmaz’s objectivist stance on grounded theory views data as already in existence, not as something created by the research process. The unbiased researcher
distills theory from data with the application of a systematic analytic process (Charmaz & Hendwood, 2008; Charmaz, 2002). This view also assumes that research participants can and will relate facts about their situations (Charmaz, 2002). Researchers distance themselves from participants’ reality and maintain objective views about the facts in the data. Researchers also report and offer objective analyses of participants’ situations (Charmaz, 2006; Charmaz, 2002), building knowledge that can be generalized and applied to similar situations (Charmaz & Hendwood, 2008). Objectivists assume that theories developed with this approach are transferable and applicable to similar situations (Charmaz & Hendwood, 2008). Objectivist grounded theory was chosen to analyze data for this study because it offers guidelines for developing localized knowledge within actual human experience.

In this research, the concept of services integration, defined by Khan and Kamerman (1992) and by Austin (1997), is used as a framework for understanding case management service delivery to persons living with multiple issues, specifically persons diagnosed with HIV infection or AIDS. In inter-organizational relations, the concept of services integration is based on the notion that several links exist among organizations, between service providers and their clients, and between clients and their environment. These links can be strengthened to improve outcomes of service delivery. The perceptions and lived experiences of case managers were explored to understand the strengths and challenges faced by case managers in delivering services to PLWHA. Findings from this research have implications for social workers and other professionals, as well as for the policy makers who define services, plan programs, and make funding available for HIV/AIDS treatment and services.
Chapter 2: Literature Review

Services provided to persons living with HIV/AIDS (PLWHA) are interrelated and span across several agencies. An integrated system of care is suggested as a way to facilitate human services delivery for improved outcomes (Austin, 1997). In this literature review, the researcher discusses the concept of service integration as a model of case management services delivery looking at definition, theoretical framework, strengths, challenges, applications, and the role of social workers in promoting integrated services.

What is Case Management?

Case management is a system of care that involves the delivery of multiple interrelated services (Gursansky, Harvey, & Kennedy, 2003). The Commission of Case Management Certification (CCM) defined case management in 1996 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” (p. 6).

Case management services delivery has been applied to various settings, especially in the health and human services sectors. The principles of case management application may be similar, yet approaches toward delivery may differ across agencies and programs. Within the human services sector, the services of case managers are
utilized to provide a broad range of services including education, counseling, assistance with medication management and adherence, nutrition support, and help with housing, as well as monitoring, evaluation, and linkages to resources to improve treatment outcomes. Case management involves delivery of multiple, interrelated services. Case management services are applied on a continuum of care in regard to ongoing needs of clients within or across settings (Gursansky, Harvey and Kennedy, 2003). Case managers interact with professionals involved in a client’s system of care, such as family, employers, service providing organizations, and other health care providers. Case managers coordinate treatment interventions that may directly or indirectly impact a client’s health.

**Case Management and Integration Models**

The concept of integrated systems has been applied to many disciplines, and service providers have used the concept at different levels of delivery. Integrated case management service is important in managing care for clients with chronic, complex conditions that require support at different levels extending over time (Coleman, 1999; Rothman & Sager, 1998). Kahn and Kamerman (1998) have noted that since the outbreak of HIV/AIDS, integrated programs have been used to provide systems of care for those living with the disease. The basis for integrated services is that clients have multiple needs that are interrelated, thereby making possible the engagement of the services of several professionals. Clients are also connected to other systems in their social and cultural environment, and meeting the needs of one client may mean meeting the needs of many others. The interrelatedness of clients’ needs and clients’ relationships to their social environment has resulted in a social service system that is fragmented, with several organizations offering programs to target populations with similar needs. Because of the
similarities in the needs of clients, most of these organizations use similar information systems, planning strategies, implementation, and evaluation of programs. They may even source funding and other resources from the same points. A fragmented services delivery system may pose problems to clients in their attempt to gain access to services. In order to reduce fragmentation and improve client outcomes, several writers have called for a more coordinated system that will be beneficial to both clients and service providers (Reitan, 1998; Austin, 1997; Morgan, 1995).

Several agencies within human services operate as autonomous bodies each with its own system of administration, rules, bureaucracy, and system of delivery. Usually, these agencies have narrowly defined professional disciplines (Reitan, 1998), with programs often targeted to clients who may have similar or multiple needs. Several writers have suggested integration of services as a better way to address the multiple needs of clients (Fine, Pancharatnam, & Thomson, 2000; Khan & Kamerman, 1998; Reitan, 1998). This will help organizations to focus on building external relationships and how these can be used to enable clients’ easy access to services, to learn from each other, to complement each other, to build upon the strengths of success, and to provide a more holistic service delivery.

In the theory of inter-organizational relations, the concept of services integration is based on the notion that several links exist among organizations, between service providers and clients, and between clients and their environment. Through collaboration and networking, these links can be integrated to provide a more coordinated delivery system that will reduce fragmentation and duplication, as well as cost, and make services more accessible to clients.
Definition of Services Integration

Services integration has been defined as a structure, (Khan & Kamerman, 1992; Austin, 1997) or as a process (Walter & Petr, 2000; Habert, Finnegan & Tyler, 1997). Other writers have defined it in terms of physical location where a network of services is situated in one place (Austin, 1997; Walter & Petr, 2000).

Khan and Kamerman (1992) define services integration as: “. . . a systematic effort to solve problems of services fragmentation and of the lack of an exact match between an individual or family with problems and an interventive program or professional specialty” (p. 5).

Integrated services delivery is a way of enhancing delivery through a system that permits the values of collaboration, prevention, and measurable outcomes (Habert, Finnegan, & Tyler, 1997). Kahn and Kamerman (1992) have observed that services integration may mean different things but its strength lies in its ability to reduce fragmentation and address programs with holistic approaches involving family and community participation to meet multiple needs.

Terms such as “collaboration,” “interagency collaboration,” “coordination,” and “one-stop shopping” have sometimes been used interchangeably to define the concept of services integration (Habert, Finnegan, & Tyler, 1997; Walter & Petr, 2000). The relationship among cooperation, coordination, collaboration, and integration has been likened to a continuum (Walter & Petr, 2000) where organizations progress from being autonomous actors to the point where they begin to establish cooperative links, coordinate their activities, and then collaborate to initiate steps of integration. At one end of the continuum, agencies exist and act as autonomous bodies with little or no reference
to one other (Walter & Petr, 2000), even though these organizations may be working with the same clients or may be using similar information systems or strategies in service provision. At the other end of the continuum is the point where organizations integrate strategies and programs for better outcomes.

**Steps Toward Services Integration**

The first step toward integration occurs when autonomous organizations begin to identify common needs, begin to establish links of cooperation with each other, and begin to show their willingness to work together to achieve common goals (Konrad, 1996). The organizations establish communication processes and begin to identify common problems and goals. The willingness of staff to work together is very crucial at this point. Coordination is a step further from cooperation. This involves initiation of joint activities. However, participating members maintain their own sets of goals, expectations, and responsibilities. Formation of task forces and interim committees are some of the steps that may be initiated at this point. The appointment of a coordinator who will initiate steps such as scheduling meetings, creating linkages among group etc., is very essential at this stage. The next step toward integration is collaboration. At this stage, autonomous organizations undertake joint initiatives, and joint planned activities with well-defined goals that are mutually beneficial to all parties are put in place to bring about change (Mattessich & Monsey, 1992). The goal of cooperation, coordination, or collaboration is to have an integrated services delivery. Achieving this goal means putting in place a comprehensive system that is more efficient and effective. Once a comprehensive system is put in place, it is important for organizations to maintain it through ongoing monitoring.
and evaluation, openness to discussions, and willingness to loosen boundaries to avoid disintegration.

O’Looney (1997) has observed that factors that may impede the smooth progression toward integration include: lack of time, lack of clear definitions and identifiable starting points, lack of leadership, lack of a positive cost-benefit ratio, and threat to security. In order to achieve the goal of services integration, Waldfogel (1998) has suggested the following steps: 1) identifying of clients’ needs; 2) adjusting of services delivery; 3) removing of possible barriers to integration, and 4) taking positive steps to facilitate integration.

The human factor in these relationships is very important. For it is staff members who determine the levels at which steps toward integration should occur (Ragan, 2003). It is also important to remember that levels of integration may differ among agencies and within programs. In some situations, integration at the level of cooperation or coordination may be sufficient, and in other situations, full integration may be needed. With yet others it is better to allow organizations to operate as separate entities without integration.

**Forms of Integrated Services**

Different viewpoints are presented on what forms integrated services should take. Fine, Thompson, and Graham (2000), for example, suggest that integration can be achieved with the creation of a new autonomous agency such as managed care services or units as in hospitals. Khan & Kamerman (1992), on the other hand, hold the view that services integration is not an end in itself but a way of searching for the best possible model for delivery of fragmented services.
Services integration may take place between departments within a single agency providing multiple services (intra-agency). For example, at a human services agency it may be possible for integration to take place among programs providing maternal health, housing, and HIV/AIDS services.

Integration can also take place between different agencies (inter-agency) providing services to the same target population (Hassett & Austin, 1997). For example, agencies providing services to dual-diagnosed women may include mental health agencies, agencies that provide drug and alcohol treatment, drug treatment residential facilities, housing agencies, parole offices, and/or children services. Integration among these agencies is encouraged given the fact that their services are targeted to clientele with similar diagnoses and problems. Kahn and Kamerman (1992) have observed that varieties of social problem areas develop their own ways of coordinating, collaborating, or integrating. Service integration may mean different things in different settings, but its main strength lies in the appeal of dealing with fragmentation and addressing programs with holistic approaches involving family and community participation to meet multiple needs (Kahn & Kamerman, 1998).

Various authors have also written about the different aspects of services integration. Writings on the concept include levels at which integration may occur, models of service integration delivery, steps toward integration, and evaluation of services integration programs. Integration may occur at different levels. Sometimes services integration is viewed at the administrative or organizational levels; at other times it is geared toward cases and techniques of services delivery and sometimes both. For
effective services delivery, it is important to identify the levels at which coordination may be effective.

Writing on the levels at which services integration may occur, Fine, Pancharantnam, and Thompson (2000) identified three major levels: macro, mezzo, and micro. Macro level integration occurs at the federal, or state government level and involves policy issues, planning, and administration of different programs and service types. At this level, state and national governments outline policies backed by acts of legislatures or laws to support integration initiatives. Here, integration is more mandatory than voluntary. At this level, political support plays a crucial role in the successful implementation of services integration initiatives.

The mezzo level involves initiation efforts between organizations at the regional and local level. Integration efforts center on administrative issues and focus on decentralization and empowerment of local service providers. Links between the two levels of services delivery are strengthened for improved outcomes. Middle-level integration identifies relations among organizations.

The micro level involves interpersonal relationships between different service staff and clients. Use of techniques such as case plans, common systems of delivery, and information sharing are hallmarks at this level of delivery (Agranoff, 1991). Various organizations work together to remove duplication, and overlapping of programs and make services more accessible to clients through referral and other services.

Details of integrated systems involve local planning, and no one set of integration features can apply to all situations (O’Looney, 1994). However, several features have been identified with integrated systems: a focus on families rather than individuals, co-
location of services and staff, cross-training of staff, joint referral systems, reduction of barriers to information sharing, joint programming, and a system level of evaluation (O’Looney, 1994; Bruner, 1997).

Morgan (1995) suggested two models for viewing services integration: from the policy perspective or from the program perspective. Efforts toward integration based on the policy model focus on the integration of systems within the community and how to create linkages, reduce duplication, and establish accountability. Programmatic models of service integration, on the other hand, target certain populations and how to offer comprehensive approaches in service delivery by concentrating a number of services in one place. Services integration efforts designed from a programmatic perspective use collaborative and inter-professional service efforts to correct fragmentation. A program model does away with obstacles such as boundaries and bureaucracies that keep organizations separated and encourages closer relationships between clients and professionals and also among professionals to enable them to meet the needs of clients better (Morgan, 1995). A policy model, on the other hand, deals with improvement of overall policy for funding, supportive infrastructure, and quality (Morgan, 1995).

Bruner (1991) outlined three approaches to interagency collaboration that may lead to services integration: first, second, and third generations. The first generation approach generally involves the establishment of interagency groups such as task forces, commissions, committees or councils to address issues. Such groups exist with various degrees of formality. The second generation approach is involvement of policy makers who authorize organizations to plan together to address needs. This approach also involves increased state intervention in integration of effort. State involvement comes in
the form of the provision of financial assistance, guidelines, and technical assistance to
local collaborative initiatives through multi-site pilot demonstration projects. The third
generation approach involves building on experiences of multi-site demonstration
projects (Hassett & Austin, 1997). At this level, policy makers design comprehensive
statewide structures to support integration.

Khan and Kamerman (1992) also suggested the formation of clusters of programs
in implementing service integration initiatives. This model offers three areas for
integration:

Cluster #1: Programs offering financial and means tested programs such as
Medicaid, General Assistance, and Food Stamps.

Cluster #2: Services for adolescents

Cluster #3: Services for families with children under age 12

Khan and Kamerman’s focus on integration is a bit narrow in the sense that it is
limited to services to means tested programs, and services to adolescents and families
with children under 12 years of age. However, the cluster model has been used in
programs in some places. For example, Williams (1982) studied three counties in New
Jersey that used the cluster model. The goals of the study were to explore the existence of
clusters and to establish the relationship among funding sources, geographic and cultural
characteristics, characteristics of clients, and types of services to clusters. Findings from
the study showed that clusters existed among the agencies, and factors such as common
funding source, common geographic area, common clients, or common services were
some of the factors that facilitated integration efforts.
The developmental model of collaboration has also been used to explain the process of inter-organizational integration (Gary, 1995). This model stipulates that integration is achieved through a process with conditions to be met at different stages. He identifies the stages toward integration as: the problem setting stage, the direction setting stage, and the structuring stage. The problem setting stage involves the identification of stakeholders and issues of common concern and the discussion of interdependence. The direction setting stage is where stakeholders begin to identify common goals, set out values, and identify common means of working together. At the structuring stage, parties begin to put in place structures for long-term problem solving activities.

Also, a systemic approach can be used to achieve integration (Looney, 1994). This model describes collaboration as involving systems that are interdependent and have links that interact and positively or negatively reinforce one another (O’Looney, 1994). Four key elements for positive interdependence are: 1) common wishes and goals; 2) shared values and attitudes; 3) joint tasks and rewards; and 4) fair distribution and exchanges. Each of these elements forms part of a whole with each part reinforcing the others, and failure to complete any of these tasks affects the entire system (O’Looney, 1994).

Services integration may also be described as “loosely coupled” or “tightly coupled” (O’Looney, 1993). Loosely coupled integration involves independent organizations interacting as the need arises but without any formal ties. This system tends to be more responsive to individual and community needs and maintains a high degree of reliability (O’Looney, 1994). Tightly coupled integration, on the other hand, involves centralized independent organizational units acting in a coordinated or collaborative way.
Successful implementation of services integration efforts depends on the strategies used. Several strategies have been suggested, and these can be broadly categorized into administrative versus operational ones (Ragan, 2003). Administrative strategies involve steps toward changing structures, such as decisions on the number and types of service providers, “blending funding streams,” sharing data on clients, sharing information systems (Ragan, 2003, p. 17). Strategies at this level include consolidating governance structures and integrating funding streams, collaborating in planning, management and oversight, and integrating formal and informal systems. Operational strategies are involved more with direct practice and affect casework practices and client-related processes as well as location of programs (Ragan, 2003). Factors such as co-locating of staff, integrating intake and assessment, consolidating of staff functions, creating cross-program teams, and consolidating case management are critical for success (Ragan, 2003).

Hoge and Howenstine (1997) have also suggested eight strategies as potential tools for system managers in accomplishing the goal of services integration by a local mental health authority. These are: creating an umbrella organization; integrative task groups; participatory management; strategic planning; boundary spanners; team building; resource sharing; and multi-agency programming. The creation of an umbrella organization enables more than one agency to take charge of services delivery. Such consortium allows a new system-wide identity and can be useful in sponsoring activities such as task groups and conferences without dealing with turf issues. Hoge and Howenstine (1997) cite the example of the Greater New Haven area when the local
mental health agency decided to become identified as the Mental Health Network of South Central Connecticut.

The second strategy is to form a task force to allow staff from different agencies to work together to manage and regulate delivery systems. This will enhance communication and foster development of shared perceptions. Hoge and Howenstine (1997) identify three levels at which such a task force can be formed: 1) the executive level, which involves senior managers and agency directors who would deal with policy monitoring and evaluation; 2) the middle management, who would be involved in managing service delivery on a day-to-day basis; and 3) treatment planning level, which involves direct service personnel.

Another approach to promoting services integration involves implementation of a strategic planning process (Adams & Nelson, 1997). This approach involves bringing together all stakeholders and engaging them in discussions about their perceptions, strengths, weaknesses, and directions for the service. Services integration involves organizations working beyond their boundaries. It involves assigning individuals who work for different agencies to work at organizations other than their own. It involves team building, resource sharing, investing time and money in continuing education, and the willingness to share resources.

**Evaluation**

Evaluation of programs is one of the effective ways of identifying factors to guide steps for improvement of integrated services, yet it remains one of the challenging endeavors of collaboration (Habert, Finnegan, & Tyler, 1997; Kagan, 1991; O’Looney, 1997). Just as there is no one specific approach for implementing integration efforts, so
also there is no one specific framework for evaluating (Habert, Finnegan, & Tyler, 1997). Researchers design evaluation tools to fit specific initiatives. Evaluation can be done using the systemic approach based on the components of context, process, and outcomes, or it can be done using the developmental model (Habert, Finnegan, & Tyler, 1997) based on needs assessment, direction setting, and structuring of initiatives. Evaluation based on the context of the program looks at how stakeholders move through the process of collaboration and whether or not the desired outcomes are achieved. Evaluation based on the process model looks at successful progression through the phases of the collaborative process, and completion of process-associated tasks determines whether outcomes have been achieved and the types of outcomes achieved. Outcomes may differ depending on the phase of the collaborative process that is being evaluated. The developmental process of evaluation of services integration involves assessment of the phases of collaboration at the formative, implementation, and outcome levels of integrated efforts. At the formative level, one looks at products of collaboration such as mission, goals, and contractual agreement. At the implementation phase, it is appropriate to look for outcomes in terms of changes in the services delivery system or broader systems changes. Outcomes may differ depending on the phase of collaboration.

**Application of Services Integration**

There are reports on case studies of the application of the concept of services integration. These reports reflect the application of the concept to child welfare, education, mental health, substance abuse, and many more. Some of the studies are based on qualitative methods of research, and some are based on quantitative methods that
identify variables and their interrelationships and how these impact service integration efforts.

One of such studies was done in New Hampshire. In the study, O’Hare and Printz (2003) report on services integration initiatives between Early Head Start and Family-Centered Early Supports and Services in New Hampshire using the program model. The goal of the study was to explore how collaboration at the program level of Early Head Start (EHS) and Early Supports and Services was helping families of infants and toddlers in New Hampshire to receive appropriate services. The research was based on surveys and conversations focused on collaborative practices with specific emphasis on information sharing, joint services to families, and challenges to working together to support families. The study also wanted to find out the potential benefits of additional collaborative efforts such as joint training, cost sharing, areas-wide case managers, and joint release of information from parents. Findings of the study indicated that the directors of the two agencies reported their interest in working together to explore opportunities to create administrative structures and policies that would enhance services integration for families and reduce redundancy. The report also noted that families, staff, and administrators all admitted that of all of the service integration activities, the avoidance of turf issues was the most important factor. Staff found the support they received from one another and the confidence they had in each other’s skills very useful. Administrators found joint planning and collaboration with community groups to be essential for services integration at the program level. Some general recommendations were made based on the information gathered: 1) increasing activities such as having reciprocal advisory board members participate in joint staff meetings and attending
transition meetings with families to coordinate and streamline services for families without increasing the budget; 2) holding joint staff gatherings and trainings, joint intake and screening, and 3) evaluation procedures to improve integration efforts.

Lindner (2003) reports of how Vermont’s Agency of Human Service (AHS) used the cluster model to initiate the Integrated Services Delivery Cluster. At the background of the study were the increasing number of trauma cases and their trickle down effects that caused the agency to develop strategies to provide coordinated assistance to clients served by it. Clusters under the integrated services included: policy coordinated case management; coordinated approach to home visits; crises and family stabilization services, integrated service delivery across the system; coordinating the caregiver process; high risk pool: strengthening the safety net and connecting better with communities.

A study conducted by Fine, Pancharantnam, and Thomson, (2000) at the Camberwell Health Authority in inner London, United Kingdom, assessed the needs of PLWHA. The goals of the study were to gather respondents' views on their individual roles and those of the organizations they represented as well as the health and social needs of PLWHA and the extent to which these needs were being met by current service provision and the coordination of services for PLWHA. Data were collected from respondents drawn from 47 key service providers from the local health services, local social services departments, and a number of locally active voluntary organizations and individuals involved in the care and support of PLWHA in the Camberwell Health District. Findings from that study showed, among other things, that PLWHA reflected a wide variety of health and social care needs and also utilized a broad range of services.
The majority of respondents felt that some of the needs of PLWHA were similar to those of persons living with other chronic illnesses (such as cancer). However, they also identified a number of problems that were either unique to or more severe for persons with the virus. Services for persons with HIV/AIDS were generally felt to be poorly coordinated, and a number of areas of overlap and gaps in service provision were identified.

**Strengths and Challenges of Services Integration**

The advantages of integration of services cannot be overemphasized. Both clients and organizations benefit when services are integrated (Kahn & Kamerman, 1992; Martinson, 1999). Integration makes care available in a more comprehensive and coordinated manner, especially in the areas of intake, referrals, etc. (Kagan, 1991). This enables clients to have easy access to services. It provides a better fit between clients and community needs, and a wider array of services is made available because of more coordination in planning, information sharing, and pooling of agency funds (Bruner, 1991). This, in turn, eliminates duplication and reduces total transaction cost. It enables organizations to have improved access to clients, and increased efficiency, especially in the use of resources, resulting in enhancing clients’ and funders’ outcomes (Fine, 1997; Ragan, 2003). Again, a coordinated service delivery system allows direct service workers to be more knowledgeable of the entire array of services available and equips them with the capacity to deliver these services. It allows workers to acquire other skills through information sharing that will enable them to deliver services that would otherwise have been delivered by a number of different organizations (Fine, Pancharantnam, &
Thomson, 2000). Integration efforts such as referral processes may reduce cost and time associated with accessing services (O’Looney, 1993, O’Hare & Printz, 2003).

Integration of services gives clients access to a wider range of services than would otherwise have been available to them; and allows clients access to diverse services at one location (Bruner, 1991). This helps to reduce the stigma that may be attached to some welfare and health services. At a service hub location, it may not be easy to identify which services persons who walk through the door are seeking.

Even though integration of services is considered beneficial to both clients and professionals, it has its limitations. Transaction costs have been identified as one area that may pose challenges to efforts toward integration (Fine, Pancharantnam, & Thomson, 2000). According to them, it may be cheaper to provide service within an organization that deals with complex ongoing needs of clients, such as the hospital setting. However, this can be challenging where clients have difficulties with compliance to treatment. One of the major challenges to the application of this concept is the difficulty of measuring the impact of integration. It is not easy to find out whether changes that occur result from integration of services or other resources, such as funding that may moderate effects (Fine, Pancharantnam, & Thomson, 2000).

Other barriers to service integration include bureaucratic procedures and turf issues, different philosophies and missions, differences in performance measures and obtaining credit for service and results, and different eligibility procedures (O’Hare & Printz, 2003). Collaborative efforts toward services integration may fail because of a lack of time, clear definitions and/or identifiable starting points, state and/or local leadership, or a positive cost-benefit ratio (O’Looney, 1997).
In spite of these challenges, the concept of services integration continues to gain recognition in the human services arena. This is because bureaucratized, categorized, fragmentized policies and programs lack the holistic capacity to meet the complex needs of individuals and families. Ultimately, most writers agree that services integration is not an end in itself but a continuous process to achieve better service delivery (Khan & Kamerman, 1998; Fine, Finnegan, & Tyler, 2000).

Social work case managers play a crucial role in bridging the gaps between fragmented services and clients’ lack of knowledge of medical and community resources to improve their health status. Also, social work case managers provide ongoing clinical and community services to clients. As social workers, they understand the patterns of interaction that generate or perpetuate problems that may involve multiple systems, such as families, neighbors, and school systems, and intervene to change them.
Chapter 3: Methodology

This was a qualitative study using a grounded theory strategy to collect and analyze data on case management to adults living with HIV/AIDS. One of the basic premises of qualitative inquiry is that individuals or groups give meaning to the world around them, and these meanings can be described, analyzed, and explained (Denzin & Lincoln, 2008). In addition, the qualitative researcher gathers information from the persons who live the experience under study. Therefore, case managers who work with adults living with HIV/AIDS were the participants, the source of data on case management with this population.

Grounded theory is a qualitative strategy that uses systematic methods to learn and develop theory about the worlds we study. Charmaz’s (2006) objectivist stance on grounded theory strategy was applied. This approach views data (information gathered through interviews, observations, field notes etc.) as already in existence. An unbiased researcher discovers knowledge and theory with the application of a systematic analytic process (Charmaz & Hendwood, 2008; Charmaz, 2002) by interviewing research participants who can and will relate information about their situations (Charmaz, 2002). The researcher distances himself from participants’ reality. Objectivists assume that theories developed with this approach are transferable and applicable to similar situations (Charmaz & Hendwood, 2008). Objectivist grounded theory was chosen for this study.
because it offers guidelines for developing localized knowledge. That is knowledge that is rooted in actual human experience.

**Sample and Sampling**

Participants for this research were purposefully selected because they all had professional experience in the phenomenon being studied (Charmaz, 2006). Participants were chosen based on their ability to contribute to the building of knowledge and development of theory in a specific area. Rubin and Rubin (2005) suggest that “. . . finding interviewees with the relevant, firsthand experience is critical in making results convincing” (p. 64). Thirteen social work case managers working with the Ryan White CARE program were recruited to participate in the study. The Ryan White Care Program is a nationally funded program through which funds are made available to assist persons living with HIV/AIDS (PLWHA). These programs employ case managers who have been educated as social workers in accredited bachelor’s and master’s programs and are licensed in their respective states.

Criteria for purposive sampling were as follows: adults age 21 or older, who held at least a bachelor’s degree in social work, were state licensed as social workers, and had at least six months experience as case managers to PLWHA. The minimum period of participants’ experience was six months. This time interval excluded the three-month orientation period that newly hired case managers undergo. Thus, a case manager with six months experience had also undergone three months of training/orientation where he/she understudied an experienced case manager and had a chance to work directly with clients. It was assumed that during six months of professional experience, plus three months of orientation, case managers would have gained adequate experience on the job.
Furthermore, selecting participants who held at least a bachelor’s degree in social work was a way to ensure that the participants had received appropriate education and training for the role they performed. Also, holding a state license in their field of practice ensured that their practice was supervised by a professional body and was regulated by the laws of the state.

Participants were recruited from four sites in a metropolitan area in the Midwest. One of the sites was a public health setting, one was a hospital, and two were community-based organizations. One of the community-based agencies provides services only to AIDS/HIV positive persons and the other provided services to clients with mental health and drug and alcohol addictions. The use of four different agencies rather than one was a method called triangulation that allowed the researcher to collect information from case managers from different sites and settings. Triangulation of sites and settings was a way of ensuring rigor of this qualitative research project (Padgett, 2008).

In recruiting participants, the researcher contacted the administrative heads of the selected organizations and sought their permission to use the sites to collect data for the research. The administrative heads gave their approval and offered private space for conducting interviews. Lists of contact information for the case managers were provided to enable the researcher to contact the case managers employed by these agencies. The researcher personally contacted the participants by telephone to introduce herself and explain her research project. The researcher then checked to see whether each potential participant met the established criteria for purposive sampling. Individual case managers who expressed interest were recruited and interviewed. See Table 1 in Chapter 4 for a description of the participants in this study.
Data Collection

Data were collected using a semi-structured interview schedule. Main questions in the interview schedule were open-ended and exploratory. Each interview lasted between one and one-half to two hours. (See Appendix A for a copy of the interview guide). During the interviews, the researcher used the interview guide but also formulated specific questions to probe for additional, specific, and clarifying information.

Interviews were audio-tape recorded and labeled with the date and an anonymous name to protect the identity of each participant. The researcher, however, kept a master list of the actual names of participants. Interviews were transcribed by a paid professional. Data, including transcribed notes, written memos, and electronic storage devices such as a home computer, CDs, pen drives, etc., used for this research were kept under lock and key in the researcher’s home office and were accessible only to the researcher, her doctoral adviser, and the professional transcriptionist as needed.

Data Analysis

In analyzing data, the researcher read through the transcribed interviews three times in order to understand statements within their context. The following steps were used in analyzing data for this research: initial line-by-line and focused coding to generate categories to construct themes. Finally, the themes were integrated in writing the research report.

The researcher generated initial codes (open codes) from the data. Codes are units of meaning derived from data. Codes generated at this stage were provisional and open to possible changes or the emergence of new codes in the course of the analysis. At the
stage of generating codes, the researcher wrote short, analytic notes termed memos to explain the decision making process in generating the codes (Padgett, 2008).

After the initial coding, the researcher identified and focused on the most frequent codes that appeared in the initial codes across segments of data (Charmaz, 2006). These focused codes enabled the researcher to sort and compare large amounts of data (Charmaz & Henwood, 2008; Charmaz, 2006) to generate categories and themes. Advanced memos were written on the identified categories. This involved documentation of the definition of each category, how each category emerged and/or changed, identification of the assumptions supporting the changes, identification of the researcher’s viewpoint as well as the participants’ view-points of participants, and how the categories differed from the various points of view, as well as the placing of categories within an argument (Charmaz, 2006). In constructing themes, the researcher integrated excerpts from the interview transcripts to illustrate concepts explicitly. Such excerpts from participants were the evidence to support and justify each theme, as well as the overall research findings.

The emergence nature of grounded theory allowed the researcher to constantly compare data from the participants to clarify and refine the categories of emerging data (Charmaz, 2006). This continued until the categories were saturated and no new properties emerged. The researcher at this stage identified several themes that emerged from exhaustive analysis of the data. These themes formed the major headings in the report in Chapter 4.
Rigor

According to Padgett (2008), rigor in research is a way of ensuring that research is conducted in an ethical manner and that findings come as close as possible to experiences (Padgett, 2008). She further notes that, in qualitative research, the concept of trustworthiness comes close to capturing this phenomenon. Trustworthiness is a way of ensuring that qualitative research is ethically conducted and findings represent as closely as possible participants’ views about the phenomenon under study. The following strategies suggested by Padgett (2008) were used to ensure trustworthiness in this study: triangulation of sites and settings, peer debriefing, and an audit trail.

Triangulation of sites and settings was a way of ensuring rigor for qualitative research by collecting data from four different agencies instead of one (Padgett, 2008). Data for this research was collected from four different sites: a hospital, a public health clinic, a community based organization that offers services to only PLWHA and another community-based organization that offers mental health services. Even though all the agencies from which data were collected for this research offered services under the Ryan White CARE funding, all the agencies operated in diverse settings and differed in focus and expectations.

Peer debriefing, also referred to as external audit, involved ongoing supervision and discussion with the team of the researcher’s academic advisors. This ensured the quality of the data collection process and helped guard against introducing any biases.

The audit trail is the clear documentation of the steps taken in collection and analysis of the data in qualitative research (Padgett, 2008). This offers an opportunity for other researchers to confirm the findings of a study. It makes the steps of the research
process and the researcher’s decision-making transparent to readers. The audit trail relies on field notes, audio tapes, and interview transcripts as well as the memos to document steps and decisions on steps taken during data collection, coding, and analysis.

Human Subjects Considerations

To ensure protection of the rights and confidentiality of the participants, the researcher adhered to the guidelines for Human Subjects Protections provided under the Institutional Review Board on Human Subjects (IRB) of an accredited university. Steps taken in this direction included completing training on human subject considerations in research and obtaining approval of the research from the IRB. To ensure that participants were well informed before they voluntarily consented, the researcher also shared information on the goals, possible benefits, and any possible risks involved with the research. Participants signed the IRB-approved consent form only after they had been provided the above information. (See Appendix B for IRB forms for this research).

Limitations of the Study

The research elicited rich data from participants. However, the study was limited to case managers in the Ryan White Care funded program for PLWHA in one metropolitan area in a Midwestern state. The study did not include case managers in other ASO’s that are not funded by Ryan White Care. Additionally, all participants in this study had degrees in social work. Therefore, it would be advantageous to interview case managers in the above mentioned ASOs, case managers in other metropolitan areas in the U.S., and case managers with no formal education in social work. One cannot assume that their perceptions and lived experiences are necessarily similar.
Additionally, the participants in this study worked in urban settings, albeit four different care settings. However, case managers working in agencies in suburban and rural settings were not included. It would be helpful to learn through qualitative inquiry what the lived experiences of case managers in these types of locales are. The social structures of these communities differ from cities, and some different data may emerge.
Chapter 4: Results

The researcher collected data from 13 participants. Pseudonyms were used to hide the identity of the participants. Participants’ demographic profiles were identified by gender, number of clients, age, ethnicity, level of education, and length of years in case management. Participants were identified as females (n = 11) and males (n = 2). Nine were Caucasians, two were Black and African American, and two identified as “other.” Eleven of the participants had graduate degrees and two had bachelor’s degrees.

The participants were drawn from one hospital (n = 2); one public health clinic (n = 2); one community-based agency that provided HIV/AIDS services (n = 5); and another community-based agency that provided mental health services (n = 4).

Table 1 below depicts participants by pseudonyms, gender, age, level of education, type of population served, number in case load, and number of years as a case manager. Case managers assigned to predominant groups of clients showed: African females (n = 1); African males (n = 1); gay white men (n = 1); women/children young adults (n = 2); newly diagnosed adults (n = 2) and general adults (n = 5); and mentally ill clients (n = 1). The average caseload of the participants ranged between 60 and 100 clients. Two participants whose case loads were 30 and 40, respectively, worked part-time. The rest of the participants worked full-time. The number of years of participants’ experience as case manager varied: two participants had one year of experience as a case manager to PLWHA. Eight of the participants had practiced case management to
PLWHA from three to ten years. Two of the participants had seventeen and nineteen years of experience respectively. One case manager had experience of twenty years.

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Degree</th>
<th>Type of population</th>
<th>No. in Caseload</th>
<th>No of Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ruby</td>
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<td>30s</td>
<td>MSW</td>
<td>African females</td>
<td>69</td>
<td>1</td>
</tr>
<tr>
<td>Mercy</td>
<td>F</td>
<td>40s</td>
<td>MSW</td>
<td>Gay white men</td>
<td>74</td>
<td>17</td>
</tr>
<tr>
<td>Carlos</td>
<td>M</td>
<td>30s</td>
<td>MSW</td>
<td>African males</td>
<td>79</td>
<td>9</td>
</tr>
<tr>
<td>Tango</td>
<td>F</td>
<td>40s</td>
<td>MSW</td>
<td>General adults</td>
<td>82</td>
<td>19</td>
</tr>
<tr>
<td>Augustina</td>
<td>F</td>
<td>30s</td>
<td>BSSW</td>
<td>General adults</td>
<td>40</td>
<td>3</td>
</tr>
<tr>
<td>Catherine</td>
<td>F</td>
<td>40s</td>
<td>MSW</td>
<td>Mental health/Drug and Alcohol</td>
<td>82</td>
<td>5</td>
</tr>
<tr>
<td>Traci</td>
<td>F</td>
<td>40s</td>
<td>MSW</td>
<td>Women/children, young adults</td>
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<td>20</td>
</tr>
<tr>
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<td>F</td>
<td>40s</td>
<td>MSW</td>
<td>Newly diagnosed</td>
<td>60</td>
<td>4</td>
</tr>
<tr>
<td>Grace</td>
<td>F</td>
<td>40s</td>
<td>BSSW</td>
<td>Newly diagnosed</td>
<td>54</td>
<td>1</td>
</tr>
<tr>
<td>Jane</td>
<td>F</td>
<td>30s</td>
<td>MSW</td>
<td>Women/children, young adults</td>
<td>54</td>
<td>3</td>
</tr>
<tr>
<td>Helena</td>
<td>F</td>
<td>40s</td>
<td>MSW</td>
<td>General adults</td>
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<td>9</td>
</tr>
<tr>
<td>Philip</td>
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<td>20s</td>
<td>MSW</td>
<td>General adults</td>
<td>85</td>
<td>4</td>
</tr>
<tr>
<td>Esther</td>
<td>F</td>
<td>30s</td>
<td>BSSW</td>
<td>General adults</td>
<td>80</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 1: Description of participants by pseudonyms, gender, age, level of education, type of population served, number in caseload, and number of years of experience.

The perceptions and lived experiences of the case managers are presented through five themes that emerged from the data: (1) defining the role of the case manager, (2) challenges with clients, (3) challenges with formal organizations, (4) recommendations for improving case management service delivery, and lastly, (5) satisfaction and rewards.
Theme One: Defining the Role of the Case Manager

All of the case managers defined their roles as primarily focusing on provision of services to ensure adherence with medical treatment and to enhance overall health status. In addition, they provide services based on the specific characteristics and needs of clients and the specific foci of their agencies. They all acknowledged that clients’ needs extend beyond medical issues and are interrelated and closely linked to HIV/AIDS care. All of the participants used the term “medical case management” to refer to prioritizing clients’ medical needs. These needs included referral to infectious disease doctors, assistance with coverage for the cost of treatment, primary health and dental care, as well as taking care of other health conditions that are related to clients’ HIV/AIDS health status. Brenda, who works in a hospital, stated that provision of medical care services supersedes any other roles of case managers: “The focus is medical care instead of other things . . . so even though you do other things for them, if a person does not go for the medical appointments, you are not accomplishing the medical piece.”

The participants also acknowledged that their roles extend beyond provision of medical care services because clients have pressing needs other than the medical. The goal is to assist clients to eliminate any barriers that will impede their success in treatment of HIV/AIDS. For example, Jane, who works at a hospital, observed that “. . . some of the clients are homeless, to them housing is more of a priority than HIV and you can only get them into medical care after you meet their housing needs.” Ruby, Catherine and Helena work at a community mental health organization. They describe their
population as generally adults and noted that they address clients’ mental health and drug and alcohol addictions in order to enhance client’s participation in medical care. Tango works in a hospital setting and her case load consists predominantly of women, children and youth. She describes her role as “holistic and well-rounded.” Carlos, who works with Africans and other immigrants in a community-based agency, sees his role as “well rounded,” and “a little bit of everything . . . .”

Esther works in one of the community-based agencies. Her case load is predominantly adults. She works with clients who transfer from the public health setting, where they received six to twelve months of initial services, to the community-based agency for long-term care. Some of her clients are located in outlying counties and rural areas near the metropolitan area. Some of them, after the initial treatment, prefer to maintain services in the metropolis instead of transferring to services in their local communities. Esther said that she drives outside the metropolis to visit them. Some clients in the rural areas are linked with infectious disease (ID) doctors in their area. Esther said she visits one clinic once every month to see those clients.

In addition, participants defined their roles as case managers to PLWHA in relation to the agencies they are affiliated with and clients’ characteristics. Brenda and Grace, who work in a public health clinic, define their role as “early interventionists” who work with newly diagnosed clients for a short period of time lasting between six months and one year before transferring the clients to other agencies for long-term care. Their primary responsibility is to ensure that newly diagnosed clients begin treatment as early as possible. Their office is located near a sexually transmitted disease clinic (STDC) that does testing for HIV/AIDS. Because of their proximity to the STDC, they are often
called upon to do pre- and post counseling to newly diagnosed clients to help them gain increased knowledge about HIV/AIDS. Grace said they do a lot of counseling to help clients “through the emotional stresses of initially receiving the news of HIV.”

Case managers serve specific client populations. Traci works in the public health setting and offers long-term care predominantly to women and children. Mercy describes her role as working predominantly with gay white men. Ruby said her “...population consists of African women.” Catherine also works for the same organization. Her case load is made up predominantly of clients with mental health, drug, and alcohol problems.

Case management positions can be created to meet specific needs. Carlos, himself an immigrant who works with a community AIDS organization, stated that his position was created to meet the needs of immigrants. Recently there has been an influx of African and Hispanic immigrants into the city. It was noticed that a lot of these immigrants were “falling through the cracks” and not utilizing available services. Positions were created for case managers with cultural competency skills to work with clients who are immigrants. These case managers did not receive any formal training on cultural competence skills. It is assumed that the status of the case managers as immigrants enables them to understand clients who are immigrants well.

**Theme Two: Challenges with Clients**

One of the goals of case management is to assist clients to reach a point where they can self-manage their health and related conditions. Therefore, clients are expected to participate in treatment by keeping appointments, providing proof of eligibility for certain resources in a timely manner, and adhering to medications, among other things. Clients’ failure to participate fully in treatment presents challenges to case managers.
All of the participants identified several reasons for clients’ poor participation in treatment that included, but were not limited to: stigma, homelessness, drug and alcohol abuse, lack of family support, difficulties with adherence to medications, and language and communication problems, especially with immigrants. All of the participants identified stigma as a major challenge to clients’ participation in treatment. Stigma is also closely associated with fear of ostracizing; it causes some clients to relocate, isolate themselves, or fail to join support groups. Stigma also causes some clients to live in constant fear, always anticipating repercussions from the attitudes of other people towards persons with HIV/AIDS. Mercy, whose case load is made up predominantly of gay white men and a few black males, noted that because of the stigma associated with HIV/AIDS, most of her clients “. . . move from smaller towns to bigger towns or from one state to the other to get farther away from family members who stigmatize them.” She further stated that African American gay men fail to disclose their HIV positive status to members of their families for fear that family members will share the information with others who need not know about the client’s health status.

Carlos, whose case load is predominantly African and other immigrants, observed that stigma impacts more deeply on African immigrants than their counterparts from the United States or other regions. He noted that because of stigma and fear of ostracizing, efforts to get African clients into support groups are not wholly successful because “. . . they were afraid that other Africans in the support group will talk to the other members of the communities.” According to Carlos, the African clients explain that this will lead to ostracism and will make it difficult for them to “acculturate themselves in a strange
country.” Again because of stigma, African clients are cautious about their choice of doctors and agencies where they want to receive services. Carlos continued:

> They do not want anybody from their communities find to out; they make sure that that whichever doctor they go to, there are not any other . . . African immigrants, whether they are working as interpreters or as janitors. They just don’t want to be seen in the space because of the issue of stigma.

Philip confirmed the same with his clients. He said some of the clients in his case load also face stigma with visiting the agency. He said “. . . one client said to me: ‘you don’t have any idea how difficult it is for me to walk into his building to see you’ . . . .” Philip said the client’s statement drew his attention to how clients struggle with stigma with HIV/AIDS.

Jane also noted that clients who visit their clinic find it difficult to return to the hospital to attend to support group or other activities held in the hospital. She stated that the clients said once they leave the hospital they do not want to have anything to do with the building.

Some African clients have communication problems. According to Carlos, some fail to use interpreters because of stigma and fear of others knowing about their status. Tango noted the use of interpreters presented other barriers as well. For example, female clients found it difficult to talk about their sexual issues when working with male interpreters.

Dealing with homeless clients posed the greatest challenge to all of the participants. Tango observed that homeless clients are not consistent with treatment. They “drop in and out of treatment”; Augustina described the homeless clients as “hard to
engage” in treatment; Ruby stated that “it is very time consuming trying to get hold of them”; and Carlos described them as persons who “are hard to motivate.” They miss appointments and cannot be contacted to continue treatment. According to Mercy, they move often and constantly change their telephone numbers, making it hard for case managers to keep in touch with them.

In addition, the majority of homeless clients have multiple issues, such as mental health, or behavioral issues including drug and alcohol addiction. Carlos stated that clients with mental health issues may not be in the right frame of mind to understand what case managers explain to them. Catherine’s caseload consists predominantly of clients with mental health issues and drug and alcohol addictions. She noted that frequent incarceration and hospitalization are major barriers to clients’ continuous participation in treatment. She also stated that when clients are using drugs and alcohol, they fail to take their medications as prescribed. Carlos also noted that sometimes clients decide to do “what they want to do . . . making choices in their lives that are very harmful to them.” This means they make choices not to go to their doctors’ appointments, have blood tests done, or take their medications as prescribed.

When clients miss appointments, they present problems for both doctors and case managers because their large case loads often make it difficult for them to schedule new appointments for clients. Five of the participants stated that some of the doctors decide not to see clients again after clients have missed appointments three times. All of the participants admitted that clients who drop out of treatment usually come back later to continue treatment; but return when they are experiencing serious health problems that require immediate and intensive management.
All of the participants used the word “frustrations” to describe their feelings about dealing with clients who are homeless or have mental health or addiction issues. Ruby’s case load is made up clients with mental health issues and drug and alcohol addictions. She noted that “. . . those people are few but they can really wear you down;” and Carlos stated that “. . . it is very hard to motivate someone who doesn’t want to be motivated.”

Family support is seen as an important component in clients’ treatment; therefore, clients who lack family support face a lot of challenges. Mercy observed that a lot of her clients who have moved away from their families lack skills for managing their lives because they have always depended on others to take care of things for them. She stated:

I do find that some of my male clients lack some of those skills. They can sometimes be a little helpless, but I really think that has to do with how society sees that. You know, it's not necessarily something that men take care of or even pay attention to as they are growing up because their moms always do it.

Not only do some clients depend on others to do things for them, but, as Tango noted, some of them have “trust issues.” They don’t trust family members enough to share information about their HIV/AIDS health status. Some clients therefore use the agency as “a place for venting about their HIV.”

Sometimes, such clients turn to case managers for support, but these choices often place an extra burden on case managers. Brenda acknowledges that “gay men have their own support systems” within their own communities. Ruby stated that support systems among clients can sometimes be unhealthy, especially when they exist among the homeless and those with addiction and behavioral problems.
Theme Three: Challenges with Formal Organizations.

HIV/AIDS care involves working with organizations at the federal, state, and local levels, as well as coordinating work among the various organizations. Some organizations provide funding to support HIV/AIDS care, others offer treatment, while others offer direct care to PLWHA. Augustina and Tango described organizations involved in working with persons living with HIV/AIDS (PLWHA) as “a system.”

There are advantages to working with several organizations; it assists clients to have easy access to services (Martinson, 1999; Khan & Kammerman, 1998); allows providers to learn from each other, compliment each other, build upon the strengths of success, and provide a more holistic service delivery (O’Hare & Printz, 2003). However, integration of services also presents challenges to service delivery.

The main source of funding for HIV/AIDS care is Ryan White CARE. This program emerged after the enactment of The Ryan White Comprehensive AIDS Resources Emergency Act, usually referred to as Ryan White CARE legislated in 1990 to provide funds for HIV/AIDS care (Rowan & Honeycutt, 2010). Through this program, grants are made available to cover a series of programs to assist PLWHA. Funds for Ryan White CARE are provided from either federal or state governments or a combination of both to public and private providers (http://hab.hrsa.gov/law/leg.htm). In addition, organizations working with PLWHA solicit grants from other federal, state, and private sources to supplement funds for the Ryan White CARE program.

There are guidelines on eligibility and use of funds. Carlos stated that guidelines with private funding are more flexible than guidelines on funds from federal or state governments, which are stringent. Traci described the guidelines with Ryan White Care
as “red tape,” while Tango described the setup for using the grants as a “bureaucratic system” that “requires a lot of paperwork.” All of the case managers noted that dealing with the guidelines for Ryan White CARE and other funding is very “stressful.” It is time-consuming, reduces direct care to clients, changes often, and case managers are not informed about changes in a timely manner. These realities impact negatively on clients and cause clients to vent their frustrations on case managers who are at the front line of service delivery.

All of the participants further explained that following the various guidelines is time-consuming and takes away time that case managers would prefer to spend on clients. Tango summed up participants’ frustrations regarding the system for HIV/AIDS care:

I'd say the bureaucracy of the way that the system is set up. There are huge numbers of rules and guidelines and a lot of paper. A huge amount of paperwork that's required for our funders. And that really is a big obstacle with providing services because you're spending so much time providing documentation of different things that it takes away from actual face-to-face time with clients, which is pretty counterproductive.

Health Resources and Services Administration (HERSA) is the department responsible for overseeing Ryan White CARE (http://hab.hrsa.gov/law/leg.htm). Ryan White CARE has been re-authorized over the years since its enactment in 1990, and several changes have taken place at the federal level about how funds are to be used (Rowan & Honeycutt, 2010). State governments also have the flexibility to change how Ryan White CARE funds are disbursed (Chernesky & Grubbe, 2001). During the early years after Ryan White CARE was introduced, the program covered several services.
Mercy, Tango, Carlos and Helena who have worked with the Ryan White CARE for nine years and longer noted that there have been changes to services the program covered over the years. Initially, the program allowed the provision of several services including provision of gas cards, food vouchers, payment of rent, etc. There were no restrictions on services the program could cover. Additionally, there have been changes to the face of HIV/AIDS and also the Ryan White CARE program over the years. Mercy, Tango, Carlos, and Helena noted that PLWHA were then not expected to live long but now, with the advent of effective medications, the life span of PLWHA is prolonged. Moreover, the number of newly diagnosed PLWHA continued to increase over the years. These changes affected funding of Ryan White CARE and resulted in changes over services the program could cover. Tango noted: “. . . over the years the focus has narrowed to medical and dental care, taking away a lot of services that are not directly related to HIV/AIDS care. Ruby confirmed this saying: “. . . we’re no longer allowed to give bus passes or gas cards or any type of transportation services to any one of our clients, unless it’s an HIV-related medical appointment or dental appointment.”

In 2006, the Ryan White Treatment Modernization Act (RWTMA) was passed. RWTMA focuses more on medical care and mandates states to use at least seventy-five percent of funding to provide medical care for PLWHA (Rowan & Honeycutt, 2010). Guidelines of RWTMA allow use of the funds to cover HIV/AIDS care and related services (Rowan & Honeycutt, 2010). Ruby also noted that it is not very easy to draw a line between what is a HIV infection-related condition and what is not. She cited conditions such as methicillin resistant staphylococcus aureus (MRSA) and meningitis. She said these may be classified as not HIV infection-related, meaning cost for treatment
may not be covered under Ryan White CARE. However, according to Ruby, “... these are very serious conditions,” and several laboratory tests must be done before it can be ruled out as not HIV-related but the costs for running these tests may not be covered by the grant.

Several of the participants also noted their concerns about other changes to the Ryan White CARE program. Mercy, Ruby, and Augustina, noted that apart from the frequent changes to the guidelines for Ryan White CARE, the timing for changes to take effect raises concern for case managers. For example, Ruby noted that case managers are not notified early enough about changes to “the rules.” She noted that sometimes they get emails in the middle of the month about changes and the changes take retroactive effect. When this happens, it is the case managers who face the brunt of clients’ frustrations.

All of the participants acknowledged that clients who have been in the system for a long time usually find it difficult to accept removal of services because of their experience of having received a lot of services earlier. Such clients have a “sense of entitlement,” and usually vent their anger at their case managers. Ruby, however, noted that the African immigrants in her case load usually do not become angry when informed about removal of services. According to Ruby, “They are appreciative and would say: ‘I don’t have a problem with you, it is not your fault.’ She noted that the American-born clients in her caseload are different, they have “... a huge sense of entitlement.”

Tango observed that case managers are not given enough time to learn the new guidelines and become familiar with their use before they need to prepare for audit at the end of the fiscal year. Sometimes other providers such as doctors may not be aware of changes that have resulted in the removal of certain programs from coverage. They may
order a service only to be informed by a case manager that it can no longer be paid for. Mercy said there have been times when she found herself offering education to doctors about changes to coverage of Ryan White CARE. She also stated that “can be a touchy thing to do when you are talking to a doctor.”

Some clients who have been HIV/AIDS positive for over 15 years are vocal and can sometimes take their complaints about denial of services to the Department of Health that oversees the disbursement of Ryan White CARE in the state. Grace and Mercy cited instances when they received directions from the Department of Health directing them to offer certain services. This was after clients had made reports to the department about denial of certain services. They said in both instances the pleas of these clients were not responded to because case managers go by the rules of the grants. Mercy acknowledges that at the state level there are few instances where exceptions can be made to the rules to allow coverage of certain medical costs. There are forms that case managers must complete to that effect.

Involvement of case managers in decision making on changes to Ryan White CARE is very minimal. Mercy commented: “It doesn’t really matter sometimes what case managers think. What matters is what’s being funded and what HERSA decides is going to happen.” Mercy further noted: “the rules are brought down to the state level and we are the ones on the frontline implementing the changes in the rules.” Even when case managers are given the opportunity to offer suggestions, Mercy noted that their suggestions do not really matter. She noted that sometimes after audit case managers are made to write their suggestions, but then said that “. . . it doesn’t really matter sometimes what case managers think.”
Apart from Ryan White CARE, AIDS services organizations (ASO) source funding from federal, state and private funders to provide care to PLWHA. Brenda who works at the public health clinic mentioned that she had been involved in writing grants for her agency. Several of the participants expressed their views on the demands of working with funded programs. Information required from case managers on how funds are used is repetitive and providing these is time-consuming and reduces time spent with clients. Tango puts it: “So you're completing the same information time after time after time because you're accessing multiple funding sources to pay for some things, so that's - it's pretty frustrating.” Several of the participants stated that going through Ryan White CARE audit puts a huge stress on them. Tango and Traci noted that failing the audit could cause case managers to lose their jobs.

Agencies offering services to PLWHA also work closely with an HIV/AIDS advocacy organization in the metropolis. This organization consults with policy makers and advocates for the rights of PLWHA. It also organizes conferences and training programs for both case managers and PLWHA. For example, once every year, it organizes a statewide Leadership Conference that offers opportunities for case managers and clients to obtain updated information about treatment and care of HIV/AIDS through presentations, workshops, and seminars. The conference also offers case managers opportunities to learn about resources and service delivery strategies. All of the participants noted that such conferences are very helpful avenues for “learning,” “socializing,” and “interacting” with their colleagues. It also offers case managers the opportunity to consult others about issues of concern. However, the reality that this
conference occurs only once a year is viewed as inadequate to meet the needs of case managers.

Within the framework of health care for PLWHA, case managers work with different physicians, including infectious disease (ID) doctors, primary care physicians, dentists, and other doctors with varied specialties. Some ID doctors are practicing primary health care physicians while others focus only on infectious diseases. Augustina noted that “even within the HIV medical field, there is just a disconnect” among providers. Furthermore, staff at doctor’s offices do not consistently follow through. Traci shared her experience about a client she worked with. According to Traci, at the point of referral, the client looked healthy and strong. Traci referred her to a doctor at one of the major hospitals in the metropolitan area for follow up. Even though the client kept the scheduled appointment, her medications were not ordered. Traci said she saw the client again after three months and the client was very weak and unable to walk without the assistance of a walker. Traci said: “I said to myself, is this not the lady who looked so strong the last time I saw her.” Traci said she became very angry and called to doctors’ office to find out what had happened. To her surprise the nurse who talked over the telephone hung up on her. Traci said she wanted to report the case to the state, but upon second thought she decided to drop it. She did not have the time to follow through with it.

Communication with federal agencies also presents obstacles with grave consequences for clients. Catherine mentioned an instance when one client died before his benefits were approved. Tango confirmed that she experienced a similar situation with one client. Esther narrated her experience with DJFS when one of her clients was denied Medicaid benefits.
She said:

I encouraged the client to request a hearing. I accompanied the client to the
appointment for the hearing. . . The adjudicator was in the room when we arrived
but the case manager handling the client’s case was not around. She never showed
up at the meeting even after she had been paged several times through the internal
communications system. The adjudicator reviewed client’s case and informed us
that client was never denied benefits; the person who keyed in the information did
so wrongly. I asked how would the client have known if he had not appealed his
case? I also wondered: what if the client had not requested for a hearing; what if I
did not accompany him to this appointment? So after that incident, I made up her
mind to appeal on behalf of any client who is denied benefits.

Clients with mental health and behavioral issues are referred to agencies that offer
programs to assist such clients. Therefore, organizations offering services to PLWHA
collaborate with other community-based organizations to offer such support for clients.

The participants expressed their appreciation for the presence of a communication
network among HIV/AIDS case managers and others in the local service delivery system.
They share information among themselves about clients’ issues, available community
resources, and updates on treatment. Mercy noted: “The good thing about that is, is that
you don’t always feel like you’re doing everything alone. You feel like you do have
another team of people out in the community to address some of your client’s needs.”

Helena works with one of ID clinics in a rural town. She visits the clinic monthly to
provide services to clients. She mentioned that the ID doctor and staff are resourceful and
helpful at assisting her to the needs of clients.
Augustina, Catherine, Miriam, Jane, and Ruby however, noted that it is sometimes difficult working with staff from state entities. They complained that it is difficult to get hold of and talk to a staff person on the phone, and phone calls by case managers are often not returned, making it difficult for both clients and case managers to call to schedule appointments. Augustina summed it up when she stated: “. . . many a time a client needs something above and beyond HIV care, then I feel like there is a challenge because nothing comes easy when you are involved in a multi-system situation.”

**Theme Four: Recommendations for Improving Case Management Service Delivery**

The multiple needs of PLWHA call for multiple interventions as well as use of multiple resources in service delivery. All of the case managers acknowledged the involvement of numerous professionals in the provision of services to PLWHA. They also noted that there is very little integration among providers. They therefore call for integration of services among professionals and providers in the field. Augustina stated:

The whole problem including HIV is that each different agency is trying to address one small issue and what we really need to do is to have the team to come together . . . because there is little integration between agencies, between social services. In my experience as a case manager with child welfare, that was one of the greatest strengths because I was able to have a treatment team that we would meet together as system to plan together for the goals of that particular child that we were dealing. But with HIV/AIDS, I didn’t see that relationship. It seemed like the one hand will do something, then the other hand didn’t know what the other hand was doing. So there is not a lot of integration.
All of the participants observed that the emphasis on meeting guidelines for grants involved spending more of their time doing paperwork than they would have liked. They expressed their concern about the negative impact this has on clients. More time is spent on doing paper work and this takes time away from “actual face-to-face” time spent with clients.

Social work training at both the bachelor’s and graduate levels prepares social workers to assume case manager positions. Attendance at conferences, seminars, and training programs, which is part of continuing education, helps case managers to enhance their knowledge and practice competence. All of the participants noted that training specifically tailored to meet the needs of case managers is needed for improved service delivery. Ten of the participants recommended that special training focusing on case management training should be organized for case managers.

Emotionally, case managers experience challenges. These challenges affect their health, social lives and relationships. Tango, Carlos, Catherine, Traci, and Phillip made note of the emotional impact of their jobs.

Phillip noted that case managers suffer secondary trauma from listening to clients’ traumatic experiences: “... you sit before clients who narrate in detail their experiences and as you go home, you think about those experiences. It is like you are traumatized, I mean case managers suffer secondary trauma.” Phillip said that he had gotten to the point that when he left work he did not want to listen to the news, watch television, or even to talk to anybody. He noted: “This can have serious effects on your relations.”

Carlos also talked about his experiences about emotional issues. He stated there were times that after meeting with clients he felt so drained emotionally from what clients
told him. He would say to himself: “Oh my God, this is so exhausting. I’m so emotionally tired. It was just like taking on the weight of whatever the client was telling. Sometimes you walk the same way they were feeling.” He highlighted how he struggles with drawing a balance between expressions of empathy toward clients and keeping his personal emotions under control. He said:

It’s really hard to walk that balance because it’s like I don’t want to get too emotional that I start crying every time they tell me a sad story, but I don’t want to be so cold that I stare right at them while they tell me the most horrible things in their lives.

Stress and emotional issues can also impact negatively on case managers’ health. Tango had this to say about the relationship between case managers’ stress and health conditions. She stated:

I mean we have case managers that have all different kinds of health issues that are caused by stress, honestly. . . . I mean headaches, stomach aches, you know, just all different kinds of things that are definitely tied into the higher stress times we're having at the agency or the higher stress times people are having with their caseloads. They're having more symptoms . . . . I think people's immune systems don't work as well. I mean, obviously, we talk to our clients about that all of the time, but I think you can see it in the case managers. I mean on any given week we'll have people that are out sick. And, you know, in all honesty, a small number of us that there are, I think it's probably related to our immune systems don't work as well because we're constantly under a pretty high level of stress.
All of the participants noted that taking time away from the routine of work and attending programs such as retreats provide avenues for dealing with case manager stress. Tango noted that the mental health day given once every month for staff at the community-based agency is helpful in reducing the stress of the job for case managers. Tango, Ruby, and Miriam suggested that more training should focus on stress reduction for case managers.

Overall, the participants felt a great need for better methods and resources to address the major stresses that they experience in the performance of their jobs with persons with HIV/AIDS.

**Theme Five: Satisfaction and Rewards of the Job**

All of the participants reported that they experience satisfaction and feel rewarded in some ways by their jobs. They attributed their satisfaction to their personal inner strength and choice of being in a helping profession. Also, the participants feel rewarded when clients show improved health and are able to self-manage their lives.

Mercy draws inspiration from her late mother who used to serve on the governing board of an HIV/AIDS advocacy group formed in a small community in the late 1980s. She stated that initially, she did not want to “have anything to do” with persons living with HIV/AIDS (PLWHA) because her impressions about them were that they were dying and it made her feel uncomfortable. She said, she had a change of attitude when she witnessed the death of her own mother. She was holding her mother’s hand when she passed away. After that incident, any fears of working with persons who were dying vanished. Mercy said she made a decision to carry on with what her mother had done previously with the HIV advocacy group in their community.
Mercy added that she feels satisfaction when clients who discontinue treatment return and she notices improvement in their health. She stated: “... the most satisfying part of my work is when I have a client who begins to call me after a couple of years of really not following through with medical care” and this client gains improved health status.

Grace stated that it was her interest in working with the HIV/AIDS population that motivated her to obtain training in this area in graduate school. She secured her current position when the opportunity arose. She stated: “I already had the interest and I needed a job, so when the chance came, I took advantage of it.” Grace said the most satisfactory part of her job is when she sees a newly diagnosed client “who does not have a clue about what HIV is” go through treatment and have his/her health improve. She stated that any time she sees this improvement, she will say to herself: “OK, this is why I am doing this.”

Carlos said he likes what he does. He likes the clients he works with. The atmosphere at his job is “good.” He further noted that attrition among case managers at his job is high, but his “passion” for what he does has kept him going over the nine years he has been at this job. He feels satisfied whenever he sees a client “accomplish a goal because it is something they work hard for.”

Tango confirmed Carlos’ observation regarding the high attrition rate among case managers. When a case manager leaves a job, his/her case load is re-assigned to another case manager. Tango noted that frequent changes of case managers have a negative impact on clients. They have to start over to learn to relate and become accustomed to a new case manager. This is difficult for clients who desire to have one case manager
throughout the course of their treatment. Ruby noted that it is hard for clients to have to
tell their stories over and over again to different case managers. Tango stated that she
made a decision to stay a long time at her current job when during her first year, one of
her clients who was very ill and had mental health and drug and alcohol issues
approached her and asked if she “will also leave like the others did.” She had this to say
about this client:

. . . so she knew at some point she was really going to need the support, and she
knew she was going to die, and she said, ‘I really hope that you're going to stay
here long enough.’ And that just really stuck in my mind that how awful that
would be to think what if you had to go through a succession of people that you
don't know and you're getting closer to that point that you know you're going to get
to, to have to get used to someone new. And I thought . . . I was going to stay here
to see her through that; and I did, and I think it meant a lot to her.

Tango further noted that she derives satisfaction from seeing clients overcome the
initial distress from their HIV/AIDS diagnosis, obtain treatment, gain improved health,
and go “back to work,” “school,” or begin to do the things they did before they became
sick. She again cited a case to demonstrate this:

I had a client—I still work with her, but she's all stable and doing well—who had
mental retardation. She was using substances. Was in a domestic violent
relationship and she had been living outside in a tent for three years with her
abuser. And she had not been in medical care and she was having all these medical
issues. I mean you name it, she was experiencing it. And I was able eventually to
get her into housing. She's not with the abusive partner anymore. She's in medical
care. Healthwise she's doing great. She found a substance abuse treatment. She got into mental health counseling. At this point in time, she really is stable and doing well. And looking back on where she was, I mean you could have never predicted that that would be the outcome.

Brenda has approximately twenty years of experience in child welfare. She compared her current job to what she did previously. Unlike her former job, where she worked with clients for a long time, she now works with clients for only one to twelve months before referring them to long-term care. As an early interventionist, she can identify outcomes within the short period of intervention. She noted that she “. . . did not get into social work to make money but to give care.” She is happy when she sees clients “move on with their lives.” She cited the case of a client whose progress in treatment made her happy. The client had a master’s degree, but at the onset of treatment, he was homeless, did not have a job, and was not motivated to obtain one. He appeared to have low self-esteem. According to Brenda, she encouraged the client to “get over” his HIV diagnosis and “move on” with his life. Within six months of intervention, she observed that the client was able to cope better with his emotional issues and was motivated enough to return to work.

Ruby said she derives her satisfaction from her position as a helper and supporter of others in need. She acknowledged that some clients come into treatment feeling “down,” and “all they need is someone to talk to about their disease.” Sometimes all a case manager does is just listen to clients. She also said the good working relationship between her and her clients makes it possible for her clients to share their feelings with her. For example, a client will say: “I didn't have anybody else I could talk to about my
disease and you really saved my life.” Ruby said she does not expect any rewards from her clients beyond a verbal expression of their appreciation. She said “just a thank you from them” gives her much satisfaction.

Venting is used as an avenue for both clients and case managers to voice and get rid of pent-up feelings. Case managers serve as avenues for their clients to vent, while case managers use their colleagues and supervisors as avenues for venting. All of the participants noted that they often use their colleagues or supervisors as avenues for venting emotions. Under these circumstances, the supervisor may do nothing more than listen to the case manager. Traci said she will go to her supervisor any time she feels hurt by a client. Most of the time her supervisor will say: “I can’t believe the client said that to you.” She said it feels good to have someone with whom she can express her feelings honestly.

When case managers get time for a break, it offers them time away from the routine of work. At one of the community-based agencies, case managers are given one day in a month to as a “mental health day”. All the case managers in that agency said they take advantage of that opportunity.

In 2007, a three-day retreat was organized for the Ryan White case managers. Ruby, Mercy, Kim, Traci, Grace, and Miriam participated in the retreat. They all voiced their appreciation for that opportunity. “It was a time for relaxation,” “socialization,” and “interaction” with colleagues. Someone was brought in to teach case managers how to de-stress. Mercy, for example stated: “. . . that attending the retreat was by far . . . one of the best things I’ve encountered in this job.” It’s a good time, relaxing them, but it’s also
informative.” Unfortunately, that program has not been repeated, and all who participated in it stated that they wished there were more of similar programs.
Chapter 5: Discussion of Results

In this chapter, findings of the research are discussed and integrated into the concept of services integration with the goal of building localized knowledge on case management service delivery to persons living with HIV/AIDS (PLWHA). The perceptions and lived experiences of social work case managers with the Ryan White CARE program are used to understand and define in reality a model of case management service delivery to PLWHA and also to identify strengths and challenges faced by these case managers. Implications for further research are also addressed.

Various writers have noted that defining a case management model for PLWHA is a challenge (Rowan & Honeycutt, 2010; Chernesky & Grube, 2000). This is partly because of the multidimensional issues related to HIV/AIDS. The medical case management model, as defined by the Ryan White Treatment and Modernization Act of 2006 (RWTMA), leans more toward disease management; yet there are social, behavioral, environmental, and other needs that present barriers to a client’s HIV/AIDS treatment and management. A model of case management service delivery that addresses the multiple needs of PLWHA is therefore suggested as a preferred alternative.

The participants in this research defined their roles primarily as medical case managers. They also acknowledged providing services beyond medical care in order to eliminate barriers to HIV/AIDS treatment. The medical case management model of service delivery to PLWHA is in line with the guidelines of RWTMA that mandates case
managers to focus only on the provision of core medical services for HIV/AIDS
treatment and related services. Under RWTMA, core medical services are defined as
outpatient and ambulatory health services; laboratory tests and AIDS pharmaceutical
assistance; oral health care; early intervention services; health insurance premium and
cost-sharing assistance for low-income individuals; home health care; medical nutrition
therapy; hospice services; home-based health services; mental health services and
substance abuse outpatient care; and medical case management, including treatment
adherence services (Rowan & Honeycutt, 2010).

The medical case management model is also tied to federal and state funding of
the Ryan White CARE program. Changes in the funding amounts result in changes to the
guidelines for appropriation of funds. In 1990 when the Ryan White CARE was
introduced to provide services to PLWHA, it did not mandate service provisions and
program models, and AIDS service organizations (ASOs) designed their own programs
based on identified needs of clients (Chernesky & Grube, 2000). The 2006 RWTMA,
however, mandated a medical case management model. Social work case managers, in
compliance with this mandate, now focus primarily on medical care.

Also, the 1990 Ryan White CARE program was described as comprehensive; it
offered a wide range of services including the provision of gasoline cards, food vouchers,
and payment of house rent for PLWHA (Rowan & Honeycutt, 2010; Chernesky &
Grube, 2000). The 2006 RWTMA has resulted in the removal of certain services or
limited funding available for payment of certain medical costs and services including rent
and transportation.
Services are provided based on the specific needs of clients. Clients have issues with stigma; language and communications problems, especially with immigrants; homelessness; drugs and alcohol use; lack of family support; and difficulties with taking medications. All present barriers to clients’ participation in treatment. In order to assist clients to participate fully in treatment and maintain their improved health, case managers offer services beyond the confines of medical case management. Thus, the medical case management model falls short of providing comprehensive care based on the needs of the client. Findings from this study are consistent with observations of previous writers who have identified this gap and have called for a comprehensive case management model for PLWHA (Rowan & Honeycutt, 2010; Lemmon & Shuff, 2001; Chernesky & Grube, 2000; Indyk, Belville, Lachapelle, Gordon, & Dewart, 1993). An integrated case management model that incorporates clients’ social, behavioral, and economic conditions is suggested as a preferred alternative to the medical case management model.

Services to PLWHA are also provided based on location and specific focus of ASOs. For example, the site within the hospital setting provided services predominantly to children, women with families, and young adults. Because of the proximity of this site to the main hospital, clients of case managers had access to other services within the same location. The case managers also maintained a close network with other providers within the hospital to which their clients were referred. For example, clients received nutrition information, primary health care, and obstetrical/gynecological services within the same location. Also, clients receiving services at the public health site had access to other services within the setting. The case managers at this setting networked with other providers in the setting to help their clients’ access multiple services at one location.
Service delivery within the two health care settings represented a “one-stop-shop” model of services integration where clients receive services at one location instead of being referred to other providers, outside the agency (Walter & Petr, 2000; Hasset & Austin, 1997; Austin, 1997). This model promotes interagency collaboration; fosters communication among service providers and enhances service delivery (Habert, Finnegar & Tyler, 1997). It saves clients’ time from moving from one agency to another to receive services. Boundary and turf issues are also reduced. For example, social work case managers of the Ryan White CARE program at the public health setting were sometimes called upon to offer education and counseling to clients at the sexually transmitted clinic located in the same site.

Collaboration in Services Integration

Collaboration involves identification of common needs by organizations and their willingness to work together to achieve common goals. Autonomous organizations undertake joint initiatives and activities that are mutually beneficial to all parties (Mattessich & Monsey, 1992) to bring about change (O’Conner, 1997). This goal is achieved when specific changes believed to make a system more efficient, effective, and comprehensive are put in place (O’Conner, 1997). Once this goal is achieved, it is expected of organizations to work toward maintaining the process to avoid disintegration. Links of collaboration among organizations can be described as strong or weak depending on the organizations’ openness to how systems work, and their willingness to loosen boundaries to achieve common goals.

Several links of collaboration were also identified among cases managers at different settings; case managers and other health providers; case managers and ASOs;
case managers and providers of community resources; and case managers and federal government agencies, etc. These links of collaboration help case managers refer clients for appropriate services and have easier access to resources for clients.

Strong links of inter-agency collaboration exist among all of the case managers in the Ryan White CARE program. All the case managers from the four agencies on the Ryan White CARE program collaborate to provide services to PLWHA. The program has a central referral system headed by a network coordinator. All new cases are directed to the network coordinator who assigns cases according to clients’ characteristics and needs. Clients who sign on to the program consent for release of their information among all the Ryan White CARE providers. Case managers hold case conferences during monthly meetings to discuss service provision and clients’ needs. The research also found that there was smooth flow of information among the case managers. This allowed all of the case managers to have information on clients and to share information on any resources that can benefit clients. Additionally, it helped to eliminate duplication of services.

Generally, all of the case managers noted that collaboration with other health care providers helps case managers to keep track of clients’ follow-up with treatment and adherence to medications. They, however, complained that sometimes this process can be challenging depending on how quickly doctors’ offices respond to requests case managers make on behalf of their clients.

The research further identified strong links of collaboration among ASOs in the metropolitan area. Among these organizations were the Ohio AIDS Coalition (OAC), an HIV advocacy group and Project Open Hand, an organization that runs a food pantry and offers nutritional education to PLWHA. These ASOs hold monthly meetings to discuss
service delivery and efficient use of resources for better outcomes. Clients are invited to
attend these meetings to provide input. All of the case managers noted that these
meetings also offered a platform for case managers to network with other providers to
promote easy access to resources by clients.

HIV/AIDS diagnosis is identified as a factor that brings together people who have
been independent of government assistance for the first time; it also results in having
people who receive government assistance return to obtain further support (Chersensky &
Grube, 2000). Clients usually need assistance in the areas of income, health and housing.
Funding is made available for these services by federal and state governments to assist
eligible individuals and families. State governments are responsible for administering the
funds. State government agencies whose services case managers frequently access are:
Social Security Administration (SSA), the Department of Jobs and Family Services
(DJFS), and the Metropolitan Housing Authority (MHA) for assistance with client’s
income; health and welfare; and housing benefits, respectively. Because of complex
bureaucratic systems of the application process of these benefits; clients’ poor health
conditions; and clients’ characteristics, all of which create barriers to client’s easy access
to these benefits, case managers need to obtain benefits or advocate for those denied
assistance. Case managers therefore, interact a lot with staff at these state agencies.
However, all of the case managers in community-based agencies stated that they
encountered difficulties in dealing with state agencies that administered federal/state
funding. This is consistent with Morgan and Printz’s (2003) observation that bureaucratic
procedures, boundary issues, differences in mission and philosophies of organizations
present challenges to integration of services. Tango, Miriam, Traci, Augustina, Catherine,
Esther and Philip all complained about poor collaboration links with federal government agencies. Catherine complained about difficulty with communication. She mentioned instances where she made several calls to SSA and never received any response from that office. Such delays in communication may have serious repercussions when clients are in crisis.

Case managers leave their jobs in order to accompany clients to appointments. Usually, case managers sit with clients through the appointments. This puts a lot of pressure on case managers’ time. Helena stated: “They treat us like they do with clients.” She further stated: “We understand that the stress of their jobs due to the high case load, but we all are also stressed. It looks like they are at one side and we are at the other.”

Collaboration between case managers and federal agencies can be improved through improved communication. Helena suggested that one way of doing this could be to have discussions between the agencies to allow each of the parties gain education about services provided, look at ways to address challenges, and loosen boundaries to allow case managers easier access to services. For example case managers can have access to emergency telephone lines to assist clients in crisis situations.

**Recommendations for Improving Service Delivery**

Participants voiced their satisfactions with their roles. Some of the participants mentioned that the attrition rate among case managers was high. For those who had stayed on job for several years, their inner strengths, support for one another, as well as motivation and personal attachment to their roles have kept them long at their jobs.

Human resources are very important in services integration. Within the social services system, case managers serve as coordinators in services integration. They coordinate care
for PLWHA; promote networking among providers and link clients to appropriate
resources. Philip described stress experienced by case managers as “secondary trauma.”
Tango noted that stress at the job impacts on their health, resulting in “headaches and
even reduction of their immune systems.” Also, all of the participants noted that unlike
clients whose needs are addressed by others including case managers -- case managers do
not have formal avenues where they address their emotional and training needs. Tango
mentioned a workshop she attended that addressed stress management for caregivers. She
noted that she learned a lot of stress management principles from that experience. The
workshop, though, was not organized by an agency in HIV/AIDS care but by an agency
that offers services to the elderly.

All of the participants in this research recommended that, periodically, retreats
and training programs should be organized to offer the opportunity to address the needs
of case managers. Mercy, Tango, Carlos, and Brenda who attended a retreat organized for
case managers in 2007 voiced their satisfaction with it. Even though they look forward to
another one, lack of funds prevented the organizers from holding it again.

Again all of the case managers also mentioned the lack of formal training for the
job. Tango, Ruby, Catherine, Augustina, Jane, Helena, Philip, Carlos and Mercy all noted
there was no formal training on how to perform case management for HIV clients. Philip
noted that his supervisor told him that “you learn as you go.” Tango talked about how she
was just handed the list of her case load and was asked to begin work: “. . . I mean they
just handed me a case load of 75 clients and said ‘Good luck,’ that was it. I have to learn
on my own.” Tango suggested the development of a training manual to assist case
managers especially those who newly take the job. She acknowledged though, that this
can be challenging because of the diverse nature of what case management covers. Mercy also confirmed this when she said that guidelines on funded programs often change making it difficult to have blueprint that will suit all programs. Philip referred to courses he took at graduate school and noted that some were not related to his work as a social work case manager. He, therefore, suggested that social work professors could design courses that can be practically applicable. He suggested development of courses on time management, and dealing with multiple tasks as examples.

Persons in the social service professions now address the needs of clients who are on medications. Several of the case managers noted that they did not have in-depth knowledge about HIV/AIDS at the time they took the job. Brenda who worked several years in child welfare services noted that one of her main challenges at the onset of the job was learning about the HIV/AIDS. She said she had to learn about HIV/AIDS by herself in order to equip herself with information to help her clients. Augustina and Helena noted the same. Like Brenda they said they use the internet a lot to obtain information on HIV/AIDS treatment and care. Learning about the HIV/AIDS can be challenging especially in the areas of medications.

It is apparent that there are multiple areas in which social work case managers need to improve their knowledge and skills. These needs are currently not addressed well or at all in the various organizations where they are practicing. This research strongly recommends that in-service and continuing education be tailored to meet such needs. Local, state, and federal organizations must provide programming. Even schools of social work and pharmaceutical companies can serve in this capacity.
The role of social workers in promoting the idea of integration of services cannot be overemphasized and their engagement in the delivery system is hereby advocated. It is suggested that social workers form part of the services integration management team (SIMT). The strength that social workers bring to the team is that by their education and training, social workers acquire the knowledge and skills that enable them deal with the multiple needs of clients. Social workers are able to handle the multiple areas in service delivery such as education, counseling, linkage to support systems, empowerment, and stigma management, among others. Social workers have broad insights on social issues that enable them to cover diverse facets of the complex issues that the team may tackle. By basing practice on the concept of integration, social workers may be able to define ways of collaboration by assisting organizations to loosen boundaries, improve upon information sharing, and enhance resource development for improved outcomes.

**Implications for Further Research**

The body of this research also suggests significant areas for further research. Integration of services to PLWHA is important due to the multiplicity of clients’ needs and use of multiple professionals in meeting these needs. Shuff (1994) suggests that, at the minimum, HIV/AIDS care requires integration of three treatment teams in the areas of: primary health, mental health and care coordination services. Case managers play an important role in coordinating care to PLWHA. This research identified collaboration among HIV/AIDS care providers.

Several areas for further research are identified. First, mixed method studies may identify variables related to integration of services. Additionally, quantitative research can be conducted to identify levels of collaboration among HIV/AIDS providers and how
collaboration at these levels impact service delivery. Moreover, further research to investigate the dimensions of collaboration among ASOs and how these impact case managers may prove helpful. Esther and Helena, who have experienced working with PLWHA living in rural areas, identified several differences among PLWHA in urban settings and those in rural settings. It is suggested that further qualitative research can compare the multiple realities of case management service delivery to PLWHA HIV/AIDS in urban settings to that in suburban and rural settings.

Case managers in this research noted that even though they focus primarily on medical case management, they also provide services well beyond what the guidelines of the Ryan White CARE stipulate. Participants in this research noted they experienced stress associated with feeling overwhelmed by their responsibilities and the many demands of their jobs. Some of the participants noted that stress at the job impacted negatively on their health. Further studies are needed on the stressors affecting case managers as well as the interventions that may alleviate them.

Overall, there are many implications for further research into various facets of case management to PLWHA. Over time, the role of case managers has undergone changes as the AIDS epidemic and society’s response to it has evolved. However, if competent and efficient professional care is to continue, and PLWHA are to benefit, then current needs of case managers and case management practice cannot be ignored.
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Appendix A

Semi-Structured Interview Schedule

1. How would you describe your role as a case manager working with adults living with HIV/AIDS?
2. Please describe the population you provide services for.
3. What barriers, if any, do you identify in providing case management services to people living with HIV/AIDS?
4. How do these barriers pose challenges to your work as a case manager?
5. Please describe the most satisfactory part of your work.
6. What has been the most frustrating part of your work?
7. Tell me how you deal with issues of confidentiality in working with people living with HIV/AIDS.
8. Could you describe existing structures that are helpful to you in providing care?
9. How would you feel as a case manager working with adults living with HIV/AIDS?
10. How do you manage your time as a case manager?
11. How would you describe your work with other professionals who also provide services to your clients?
12. Are there any other thoughts that you want to share about your work as a case manager for people living with HIV/AIDS?
Appendix B

The Ohio State University Consent to Participate in Research

Study Title: Case management for adults living with HIV/AIDS: A qualitative study of social workers’ perceptions and lived experiences.

Researcher: Bette Speziale, MSW, Ph.D.

Sponsor: None

This is a consent form for research participation.

It contains important information about this research and what to expect if you decide to participate.

Your participation is voluntary.

There will be no penalty if you decide not to participate in this research. You can decline to answer questions during interviews, and may stop participating at any time, without any penalty.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:

The purpose of this study is to use a grounded theory strategy to build knowledge on social work case management services to adults living with HIV/AIDS.
Procedures/Tasks:
Data will be collected using a semi-structured interview schedule guided by main questions that are open ended and exploratory. Each interview will last between two to three hours. During the interview, the researcher will also formulate specific questions to probe for additional, specific, and clarifying information. A follow up interview of one to two hours may be necessary for clarification. Interviews will be audio taped, recorded, and labeled by date and with use of anonymous names to protect identities of participants.

Data, including transcribed notes and electronic storage devices used in this research will be kept under lock and key in the researcher’s home office and will be accessible to the researcher, her doctoral adviser, and a paid transcriptionist as needed. Three years after the completion of this study electronic data from interviews will be destroyed.

Duration: The research will last between Fall 2009 and Spring 2010.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

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Relationship to the subject
Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent

Signature of person obtaining consent

______________________________ AM/PM
Date and time