HIV Case Management:

A Review of the Literature

The Massachusetts
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A Brief History of Case Management

The practice of case management originated in the early 1800s with a social movement to identify and address the needs of the poor, as described by Fleisher and Henrickson in their historical overview of case management (2002). With a significant population shift from rural to urban areas during this time, social organizations began to recognize an increasing level of social problems plaguing the disadvantaged. Programs were developed to identify and meet the needs of such populations though direct services and coordinated interagency efforts. The settlement house movement at the turn of the century shifted care to a more centralized model of service delivery and marked the beginnings of the social work discipline.

Over the next several decades of the 1900s, however, the delivery of case management services through a social model fell into disuse as the Freudian psychotherapeutic model of care prevailed. Instead of receiving care through community-based agencies, individuals with social service and mental health needs were often admitted to large mental institutions. But by the 1960s, the treatment focus shifted once again with the movement towards deinstitutionalization. Care delivery moved from state psychiatric hospitals to community-based programs and social work again emerged as the primary method of service delivery to vulnerable populations.

During the 1970s, it became clear that case management services were highly fragmented and unable to handle the diverse, multiple needs of clients in the community. A series of legislative and policy initiatives in the late 70s and early 80s, such as the Omnibus Budget Reconciliation Act in 1981, recognized case management as a cost effective means of helping vulnerable populations navigate the social service system and

obtain the care that they need. Later, the Ryan White Care Act of 1990 mandated HIV case management to ensure service coordination and continuity (Fleishman, 1998). Such federally mandated acts specified the need for community-based case management programs, but left the definition of these services quite broad, which allowed funders considerable latitude in determining the functions of the case management role.

Today, case management is viewed as, "the coordination of care across a system of service providers to meet the needs of a particular client or client group" (Fleisher and Henrickson, 2002). Although service providers in various disciplines generally agree on the basic functions of case management, particular paradigms of care are complex and varied, and are tailored to meet the specific needs of their target populations, making it difficult to establish a comprehensive definition of the discipline. Case management for HIV-infected individuals is particularly unique in that clients most often present with a multitude of psychosocial, medical, and financial challenges, including substance use, chronic illness, poverty, and discrimination (Fleisher and Henrickson, 2002). Much of the work of an HIV case manager is population-driven. Programs are designed to respond to the unique needs of the client population they serve, rather than to fit academic or theoretical models of care, resulting in a wide variation in program functions. But despite the spectrum of program-specific nuances in HIV case management, several defined service delivery models have emerged.

Models of Case Management

Several models of case management have been described in the literature over the past several years. Such models are typically classified according to several factors, including target population, setting, role of the case manager, and scope of services

provided. The most prevalent models that have emerged in the field of HIV case management include: the broker model, the rehabilitation model, the full support model, and the strengths model (Williams et al., 1998 as cited in Fleisher and Henrickson, 2002).

The broker model focuses on linking the client to needed resources, usually external to the agency. In this model, the relationship between the case manager and the client is limited. The main role of the case manager is to identify the client's needs, then connect the client to the appropriate providers through a referral process. Case ratios are usually high under this model, and case managers are typically responsible for both conducting the client assessment and for carrying out the treatment plan.

The rehabilitation model uses the relationship between client and case manager as a mechanism to obtain services for the client. By identifying the strengths and weaknesses of the client, the case manager works to remedy a wide spectrum of barriers that prevent the client from functioning independently in the community. When the barriers that hinder the client's self-sufficiency have been addressed, the relationship between the case manager and client is significantly reduced or terminated.

The full support model builds upon the fundamental principles of the rehabilitation model by utilizing an integrated, multidisciplinary team of treatment providers, such as case managers, client advocates, and medical professionals, among others. This model differs from the others in that it often relies on in-house treatment team rather than referrals to outside agencies. Most services are provided to clients in one location. The case manager's role in this model is to not only coordinate care, but also provide a certain level of clinical support and life skill training. Research has demonstrated that his model reduces patient hospitalizations and is most effective in

working with clients who have long-term service needs, but the model is also difficult to evaluate and determine when care should be terminated with the client.

A newer model of case management, the strengths model, has emerged in the literature in recent years. Rather than assessing a client's needs based on their deficits or problems, this model builds a service plan based on the client's strengths. The role of the case manager is to assist the client in developing and attaining client-specific goals. The success of this model of case management depends on the level of outreach and follow up that is conducted with the client to ensure that they are obtaining needed services and care as identified through service planning.

Objectives and Core Tasks of Case Management

Although there is limited agreement on one definition or model of HIV case management service delivery, several key objectives of the discipline have emerged, including:

1) facilitate the provision of comprehensive, cost-effective health and supportive services to people with HIV disease;
2) establish services based upon a model of coordinated, comprehensive health care; and
3) demonstrate that care can be provided humanely and with cost-effectiveness. (Gant, 1998)

While it is critical for programs to work towards such objectives, Kucera (1998) notes the importance of focusing on specific client needs to improve quality of life. "Case management goals must not conflict with the client's goals, and they must be individualized and appropriate for the client." These goals should include promotion of independence, empowerment of the client to facilitate informed decision-making, and minimize societal rejection. Other case management goals may include prevention of

HIV transmission to others, wellness management, improved nutritional status, decreased hospitalizations, appropriate utilization of community resources, and decreased stress.

To achieve program objectives and meet the needs of the client, case management programs must define their core tasks and develop a model through which these functions can be performed. Although there is some variation among various programs in the key functions of their HIV case managers, the Centers for Disease Control (1997) have identified six core tasks that form the basis of most of HIV case management programs. These core tasks include:

1) client identification, outreach, and engagement;
2) medical and psychosocial assessment of need;
3) development of a service plan or care plan;
4) implementation of the care plan by linking with service delivery systems;
5) monitoring of service delivery and reassessment of needs; and
6) advocacy on behalf of the client (including creating, obtaining, or brokering needed client resources).

Again, each individual case management program may define their core tasks slightly differently, depending on the needs of their clients and the mission of their agency. For example, many programs identify discharge planning as a critical feature of their program, while others do not mandate it as a key task. Some agencies highlight the importance of aggressive follow-up on referrals to ensure clients receive the care they need, while other programs mandate that case managers focus on connecting their clients to a primary care provider. Broker models of service delivery focus on obtaining the widest range of services for their clients, but managed care models emphasize considering cost implications of service delivery and work to minimize excessive utilization. Case management programs also vary in their emphasis on psychological evaluation of clients, provision of services related to substance use, opportunity to

conduct home visits, utilization of a multidisciplinary team rather than individual case managers, caseload size, and criteria for use of a triage model, among many others. But, despite such variations in core tasks of case management, all involve the main themes of intake, assessment of need, service planning, referrals to needed services, and monitoring.

Standards of Care

The Ryan White Care Act of 1990 mandated that states initiate HIV case management to ensure service coordination and continuity, but left the definition of case management relatively broad, allowing states to develop case management programs that meet their population's needs. As a result, states have created HIV Case Management Standards of Care that vary in their scope of service provision mandates. The Massachusetts Department of Public Health (DPH) Standards of Care recognize that HIV-infected individuals face a complex service delivery system, and highlight the importance of providing a comprehensive range of services to case management clients with the goal of enhancing their independence and increasing their quality of life. While the Massachusetts DPH Standards of Care include many of the same functions as other case management programs across the country, there are some important differences that should be noted.

In a review of 15 Title I and Title II funded HIV case management programs from throughout the United States, at least 11 programs, including Massachusetts, include a standard related to the following categories: client advocacy, intake, needs assessment, financial resources assessment, housing assistance, transportation, support system assessment, legal assistance, substance abuse assistance, assessment of mental health needs, reassessment, on-going service planning, referrals to medical and support services,

monitoring and follow-up. Although the requirements vary across standards of care, most programs also specify guidelines for personnel training and professional qualifications/experience. These are fundamental services and guidelines that form the foundation of most HIV case management programs.

There are, however, several service categories and functions which the majority of other Title I and Title II programs include in their Standards of Care, but which Massachusetts excludes. More than two-thirds of the programs reviewed include a requirement in their standards for crisis intervention and counseling, assessment of functional status or activities of daily living, and assessment of risk behavior. Massachusetts' standards do not include these service mandates. The delivery of these services is often associated with more clinically based models of case management and requires clinically savvy case managers for implementation. Since Massachusetts promotes a more social service model of case management and does not require utilization of a medical or mental health clinical model of service delivery, the omission of these services from the Standards of Care is perhaps consistent with program goals.

Other service mandates that more than two-thirds of reviewed programs include in their Standards of Care, but Massachusetts omits, include: assessment of cultural, language, or ethnic issues, on-going quality assurance, and identification of service gaps and resources within the community.

Process Measures

HIV case management is a complex component of the health care system that is not easily measured or evaluated. How can we universally measure successful case management or efficient delivery of services when working with such a diverse

population with such a wide spectrum of needs? As described by Fleishman (1998), conducting research on the outcomes of HIV case management is problematic because the intervention is so multi-faceted and complex that it is difficult to decipher which components of the intervention, or combination of components, contributed to any change that has occurred for the client. Furthermore, agencies represent a wide spectrum of ideologies and approaches to HIV case management that shape the delivery of services to clients, making universal measurement of program outcomes a challenging task. Finally, the clients themselves have such a diversity of needs and backgrounds that they respond differently to the various aspects of case management. While one intervention may greatly enhance quality of life for one particular client, it may result in no improvement for another client.

Because outcomes of HIV case management are so difficult to measure, the vast majority of evaluations have focused on model descriptions and system appraisals, rather than individual client outcomes (Gant, 1998). But, despite the many challenges of outcomes evaluation of HIV case management, there are some measurable processes that may provide insight about program effectiveness. The Health Services and Resources Administration describes six process measures of HIV case management (Cozen, 1998):

1) Frequency of contact with client
2) Mode of client contact
3) Caseload size
4) Relationship of location of service site to types of problems
5) Tasks performed by case managers
6) Outcome measures for evaluating successful case management

HIV case management programs can be evaluated on these measures, among others, in an effort to understand the relationship between the process of case management service

delivery and client outcomes. Since all federally funded HIV programs are required to document progress towards specific measurable objectives (HRSA, 2001) evaluation of outcomes is critical for continued funding and program support.

Outcomes

Process measures such as frequency of client contact, mode of contact, and tasks performed by case managers may have a direct impact on outcome variables that have been shown to respond to HIV case management services, including (Fleishman, 1998):

1) Utilization of ambulatory medical services
2) Unmet needs for medical or social services
3) Quality or appropriateness of medical care
4) Measures of psychosocial adjustment or quality of life
5) Duration of survival from time of AIDS diagnosis
6) Costs of providing medical and social services
7) Degree of service coordination

Although there is a lack of research that demonstrates an improvement in health outcomes for HIV-infected individuals engaged in case management services, some studies suggest that case management tends to reduce the level of barriers many clients face in obtaining appropriate medical care.

A 2001 study evaluating HIV case management outcomes in New York State (Lehrman, 2001) explored the process of identifying client needs and the extent to which clients were connected with needed services by their case managers. The study also examined utilization of services once they had been arranged for the client and how this varied based on client or organizational characteristics. Clients from 28 agencies funded by the New York Department of Public Health participated in the study. All programs were required by the state to adhere to their standards of care and process guidelines that outlined how case management services should be provided. Only agencies that had

stable HIV case management programs and had been in existence for at least three years were included in the study.

After careful review of more than 588 client charts, and interviews with both case managers and clients, the following results were found. The most prominent client needs identified included housing, transportation, food, financial/entitlement needs, and medical needs (both primary and specialist care). Across all services, case managers were able to arrange services for their clients 72.3 percent of the time, but clients failed to actually utilize these arranged services 12.9 percent of the time. An important finding of the study was that services provided directly by the case management agency were both arranged by the case manager, and utilized by the client, at a significantly higher rate than those services arranged outside of the agency, suggesting a potential advantage to in-house service delivery rather than outside referrals.

Another interesting finding of the study was that although the arrangement of services by the case manager did not vary across any demographic characteristics, the actual utilization of these services varied considerably by one critical client characteristic – place of residence. Clients within New York City utilized services less frequently (60.4 percent of the time) than those living in other areas of the state (66.5 percent of the time). It was also found that it took an average of 2.3 months from the time a client's need was identified until the time the arrangements were met and they actually received the service. One notable exception to this was the provision of medical care, which was arranged in the significantly shorter timeframe of 1.5 months. Service needs that typically took longer to arrange for clients included legal services (5 months), housing (4.4 months), and job training/placement (3.8 months).

Overall, almost 60 percent of client needs were not identified within the first three months of a client's engagement in a case management program. Once a need was identified, it took an average of over two months to arrange services and meet the need. These findings suggest that short-term case management programs may be limited in their effectiveness of meeting client needs unless clients are triaged into short term programs because their needs are such that they can be met within a short time frame.

Another HIV case management outcomes study (Katz, 2001) measured the association between case management and unmet need for supportive services and utilization of medical care among HIV-infected individuals. Of the over 200,000 study participants, it was found that women, non-white individuals, injection drug users, those with less education, lower income, public or no insurance, and lower CD4 cell counts were more likely to have contact with case managers than other populations. Sustained contact with a case manager was strongly associated with a decrease in unmet needs for supportive services. "By linking clients with income assistance, health insurance, home health care, and emotional counseling, case managers improve the economic, social, physical, and emotional well-being of HIV-infected persons" (Katz, 2001). Results also indicated that case management decreased the likelihood of clients becoming unstably housed and increased utilization of HIV medications. This may be attributed to case managers working with clients to overcome fears about treatment and help them adhere to medication regimens, as well as assisting them in attending medical appointments more regularly.

In another study of case management outcomes in Miami (McCoy, 1992) a public health agency participated in a one-year demonstration project that revamped their case

management program for HIV-infected injection drug users. The newly designed program included assignment of individual cases to specified case managers, a screening process to identify needs, regular, on-going HIV prevention education about knowledge and skills required for behavior change to reduce HIV transmission, access to medical, mental health, social, economic, and addiction treatment services, monitoring patient utilization of services and compliance every two weeks, and reassessment of needs. Participants in the study were assigned to either the case management group or a control group, and case manager caseloads were less than 35 clients. Those in the case management group were assigned to a case manager and were linked with services to meet their specific needs, primarily financial assistance, outpatient medical services, and transportation services. They also received education related to AIDS 101 and HIV risk reduction. The participants in the control group were not assigned a case manager, but may have received health and social services from the agency upon their request and on an as-needed basis.

The results of this study indicated that engagement in medical care increased for those enrolled in case management programs. Participants in both groups also reported decreasing their drug and sex risk behaviors. Perhaps the most dramatic difference between those in case management and those not in the program was the number of different people with whom the individual injected drugs with and had sex with during the study period. This number was significantly lower for those in case management. The overall findings of the study suggested that although providing case management services to injection drug users was both time and labor intensive, the benefits for the client were significant. The study also indicated that engagement and interaction with a

client was a critical task for case managers working with the often-alienated HIV-infected injection drug using population.

The connection between case management and increased utilization of medical care services was further demonstrated in an outcomes study of the impact of ancillary HIV services on engagement in medical care (Messeri, 2002). This study of 577 HIV-infected adults in New York City demonstrated that individuals in high need who received any of three models of case management (medical referral, counseling, or social service planning) were are more than twice as likely to engage in appropriate medical care than those not receiving any case management services.

Discussion

In summary, the literature on HIV case management focuses primarily on theoretical models and program descriptions. To the extent that case management programs collect data or have been evaluated, most evaluations focus on process measures such as the number of visits types of referrals made. More recently, several outcome evaluations have measured the association between case management and unmet social service needs or HIV medical care. Most of these evaluations have documented an association between case management and specific social service or medical care outcomes.

However, none of the outcome evaluations were designed to examine the link between a particular model or application of case management and the outcomes of interest. The Katz study, conducted as part of the national Health Care Service Utilization Study (HCSUS), was a national probability sample of over 200,000 people across the country who were likely enrolled in many different models of case

management services. Likewise, the Messeri study in New York reported on the combined outcomes of three different case management models. Thus, more research is required to investigate the association between particular case management models and practices and the social services and medical care outcomes of interest to policy-makers.

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