Integrating Community-Based and Hospital-Based Case Management
Debbie Indyk, PhD, MS and Kathy Wade, MSW

Over the past 25 years, high-tech, hospital-based care proved that it could improve and prolong the lives of the elderly, victims of traumatic accidents, and severely impaired newborns. In response to these advances, case management was developed as a strategy to provide to these patients chronic and sustained follow-up and management in the community. The success of case management is demonstrated by the local systems of care linking hospital and community-based social services for the elderly. Its failure is evident in the epidemic of homelessness among the mentally ill, who were deinstitutionalized into communities that were unprepared to supply the resources to support the multiple social and psychiatric needs of this population.

But case management has the potential to work in other settings. As HIV infection shifts from an acute and rapidly fatal condition to a chronic disease, case management is proving to be the best approach for developing the sustained primary support and linkages between hospital and community providers that HIV-related care requires. In fact, case management may be the only approach responsive to the burgeoning HIV epidemic in inner cities.

Case management approaches health care by developing “a web of linkages,” a network of medical and social services that permit the provision of predictable, routinized, and timely care by appropriate caregivers in appropriate settings. The main goals of case management are to: ensure individualized, coordinated, comprehensive, quality care; promote optimal physical, social, and psychological functioning of clients while maximizing their independence in the community; and provide cost-effective services that avoid duplication and fragmentation. This article examines case management theory, its application to HIV-related hospital and community care, the barriers to its successful implementation, and methods for fostering HIV-related case management networks and the work of frontline hospital- and community-based organizations.

The San Francisco Model and The Inner City Challenge

Managing the care of people with HIV disease is seldom predictable or routine. It requires a flexible approach to effectively assess, monitor, and respond to the changing nature of the disease, its manifestations, its treatment, and its impact on the individual, the family, and support systems. The successful application of HIV-related case management has been limited by fragmented social and health care systems, an environment of increasingly scarce resources, and variations in the availability of community support across the country.

In addition to these societal obstacles, several other factors determine the content and form of case management and complicate the approach. Among these are: the locus of HIV-related case management (community- or hospital-based); the pre-existing system of prevention and care in the community; the size of the service area; the prevalence of HIV infection; pre-existing problems such as mental health, child welfare, and substance abuse that affect HIV-related care; the pool from which case managers are drawn; the difficulty of maintaining reasonable case loads for case managers; and the ability to track patients and maintain them in the system.


Editorial: Juggling with Entropy
Robert Marks, Editor

It is an axiom of physics that all matter and energy tend toward entropy, the ultimate state of disorder. While such a powerful image may seem grandiose when describing health care systems, it is a useful metaphor to express the chaos of needs, services, and entitlements that comprise HIV-related care.

Case management refers to the process by which care organizations—ranging from hospitals to emotional support agencies—are linked and their service provision coherent and efficient. Like a juggler negotiating with gravity to keep balls spinning in the air, the case manager negotiates with entropy to make service provision coherent and efficient.

It is truly a magic act to pull together such disparate elements as private hospitals, public assistance, non-profit AIDS service organizations, child care, housing, food bank agencies, and all the other services that define HIV-related care. Case management, as Debbie Indyk and Kathy Wade describe in this issue of FOCUS, can organize this disorder, but it is dependent on the willingness of service organization personnel to work together to create order in the whole system.

The juggler makes the circuit of baton, torch, knife, and ball appear to be a solid ring, the image of one object blurring into the next. Yet these objects maintain their distinctions even as they appear to the audience to have lost their separate identities. So too must the case manager make the organizations of the network move together—quickly and efficiently—to “fool” clients into believing that the system is one; so too must he or she recognize the different abilities, attitudes, and approaches of these organizations.

Case management is infinitely more complex than juggling, and case managers cannot be expected to manipulate services with the same ease as accomplished jugglers handle balls or batons. If case management is to work, service agencies must do more than the juggler’s inanimate objects. They must also take on the juggler’s role—helping to break down barriers so that services and disciplines appear as one. HIV-related care has always been about crossing boundaries and taking on new roles. Mental health and health practitioners, who sit on the sidelines watching as services are distributed to their clients, can be cast as the juggler’s assistants, working with case managers and service providers to hold the network together, acting as the juggler’s students as well as his or her appreciative supporters.

As the performance ends, the juggler disappears from the lives of spectators. In the world of AIDS, however, a little of the juggler remains in all of us, and practitioners must be alert to the times when they too must perform what they know of the magic of case management.

As early as 1986, HIV-related case management in San Francisco arose out of the particularly cohesive and well-organized community of predominantly White gay men who had contracted HIV infection through unsafe sex. This community was able to respond by developing a continuum of community-based services and the networks to support them. City government in turn was highly responsive to these initiatives.

But the early model did not anticipate the non-linear nature of the disease as it moved back and forth through asymptomatic, acute, chronic, and terminal phases; this shifted the locus of care back and forth from community to hospital. Nor was it easily adapted to inner city African-American and Latino communities, which required culturally sensitive prevention and care.

The San Francisco model also was predicated on the notion that case management could be achieved by coordinating and expanding existing community-based supports and services. These are almost non-existent in the inner cities, and given the fragmentation of social and health care systems in the U.S., this situation is unlikely to change. HIV-related case management is further complicated by two factors: care does not fall within the purview of a single medical specialty or social service; and it is increasingly common for HIV-infected people to present with chemical dependency and tuberculosis, and to have children and other family members with significant problems.

The impact of poverty, substance abuse, and HIV disease, and the physical and mental health issues they raise, is particularly acute in the inner city and requires integrated services from agencies that have traditionally functioned apart. But the shared communication and resources that must cross between settings is often inhibited by untrained or ill-equipped staff, inadequate funding, unrealistic case loads, and boundaries among disciplines, hospital departments, community-based organizations (CBOs), and government agencies.
Additionally, patients are often socially isolated, disenfranchised, and appear to be non-compliant and manipulative. They often use more than one health care facility, compromising the benefits of continuity of care and making it difficult for CBOs to verify medical information.

The challenge for case management then is to be able to shift between hospital and community and to manage effectively the multiple and complex needs of families: schooling, housing, legal services, financial support, and the medical care of more than one HIV-infected person in a family, including treatment for mental illness, chemical dependency, and tuberculosis.

### An Integrative Model of Case Management

The successful integration of hospital and community systems requires a structure to link networks of care. New York State’s Department of Health, through its AIDS Institute, has been working closely with providers to develop criteria, training guidelines, and tracking systems for case management programs.

Local case management networks vary dramatically with respect to size, HIV incidence, availability of services, and history of interagency experience. In New York State, an HIV Care Network can encompass many counties. In New York City, an HIV Care Network often encompasses a single neighborhood, such as East Harlem in Manhattan or Mott Haven in the Bronx.

In East Harlem, within an epicenter of the epidemic, the Mount Sinai Medical Center (MSMC), a state Department of Health-designated AIDS Center, has worked with individual CBOs to develop and link community and hospital case management systems. This is occurring through: weekly interdisciplinary inpatient and outpatient rounds at MSMC; monthly interagency rounds at the community network level; a weekly HIV and substance abuse work group comprised of community and hospital practitioners; and ongoing analysis of individual cases by members of MSMC’s Department of Community Medicine.

The MSMC AIDS Center provides a full range of HIV-related services and case management to over 700 patients. Teams composed of a social worker, a physician, and a nurse meet weekly, to follow in- and outpatient cases. Interdisciplinary rounds, attended by approximately 40 primary and specialty providers are held to discuss patient care issues, expand the clinical knowledge of providers, and receive support.

Using a case management model, the “identified” patient is seen within the context of a family system. The following case provides an example of this approach.

Joan S. is a 34-year-old African-American woman with AIDS known to the adult AIDS team. Her HIV-infected 3-year-old daughter is followed by the pediatric team and her 15-year-old son, who is not

### The Role of the Case Manager

The activities of case managers are largely determined by the structure, mission, and function of their service settings. The needs of their clients tend to be perceived within the limits of the services case managers can offer. The role of the HIV case manager includes performing the essential functions of intake assessment, referral, service planning and delivery, monitoring, reassessment, and discharging. The case manager must be broker, facilitator, communicator, advocate, and friend—interacting with providers in the community to coordinate care of clients seeking services and entitlements from a number of sources.

Community-based case managers—who may be social workers or specially trained paraprofessional staff—are often linked to several care networks but have few sustained professional supports. They often work in small agencies without access to clinical expertise in the areas of HIV infection, chemical dependency, and mental health, yet their work regularly requires “clinical” assessment and the navigation of complex medical, social and judicial systems. In urban areas, they must often forge a complex web of community-based, primary supports for their clients.

HIV disease usually requires multiple hospitalizations entailing complex medical and psychosocial services. Hospital-based case managers—who may be nurses or doctors but generally are social workers—orchestrate interdisciplinary HIV-related care and bridge hospital and community services. They also cross boundaries to integrate family-based care addressing issues for child, teenage, and adult HIV-infected family members.

### References


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The future of case management is dependent upon improving connections among agencies and case managers. While, in some middle and low HIV prevalence areas, standardized assessments, documentation, and client tracking across agencies facilitates communication among case managers, this has not yet occurred in inner cities.

Isolated community-based workers, often without access to information, formal training, or structural ties to the systems they must access for their clients, need to be supported at many levels through case management networks. For instance, a short but intensive training program, funded by the AIDS Institute and developed by Hunter College, teaches the techniques required to function as a case management technician. This program must be complemented by ongoing formal supervisory and peer support.

To cope with the AIDS epidemic, individual providers and agencies are being forced to develop working alliances across practice settings and disciplines. To create such alliances, communities must develop both formal and informal mechanisms to raise and solve problems related to patient care, and medical and social service systems. The purpose of these alliances will be to: monitor complex cases in which multiple providers from different settings and disciplines interact; identify gaps in services; assure a more rational division of labor; identify opportunities to develop shared resources (such as liaison nurses who bridge hospital- and community-based agencies); and identify system barriers that can be resolved either through collaborative efforts or policy changes in the health care system.

**Conclusion**

Forums and case rounds are critical to the development of interagency linkages and systems. They are also critical as support groups for workers who, because of the stress and complexity of AIDS work, require education and nurturing. Resources must be allocated to fund staff to run these groups and to allow for release time of workers to participate in them.

In arriving at a rational approach to case management, providers must depend on an accumulation of individual cases, where the collected wisdom of many providers is incorporated into practice. Feedback provided by each case serves to guide and inform the definition and implementation of community-based, family-centered case management.

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**Clearinghouse: Case Management**

**References**


Case management has long been used to deliver social and mental health services. As the health care community seeks to decrease HIV transmission and provide medical and psychosocial services to underserved populations, intensive community-based case management is being used to reach and treat HIV-infected substance abusers. These programs, because of the nature of substance abuse, differ from traditional case management approaches and, because of the nature of HIV disease, differ from common substance abuse treatment protocols.

Substance Abuse and Recovery

Substance abuse is the loss of control over the use of a substance that leads to health, work, and psychosocial problems. Most abuseable substances alter judgment, cause acute and chronic changes in mental status, may affect memory and concentration, and may lead to chronic organic brain damage. The substances themselves or their routes of administration may also cause medical problems.

Abuse usually includes: tolerance for the substance used, which means that the body needs progressively more of the substance; craving or withdrawal symptoms when the substance is not used; and a preoccupation with the substance. Abuse may evolve into overwhelming addiction and lead to the neglect of most areas of life.

Substance abuse is defined as a disease, not as a moral deficit or lack of willpower. This illness model eliminates guilt or judgment about substance use. It also puts into perspective three central aspects of substance abuse theory. Addiction is permanent; those with an addiction can never return to controlled substance use. Getting into “recovery,” or learning to live clean and sober, is emphasized as the primary treatment goal. Relapse, or the episodic return to substance use, is seen not as a treatment failure but as part of the disease and ongoing recovery.

Many people begin to use alcohol or drugs as “symptom relievers,” that is, attempts to stop emotional or physical pain. Once in recovery, the same symptoms, whether depression, stress, or physical pain, may lead to relapse. It is crucial in recovery not only to stop using, but to learn to live clean and sober using alternatives to symptom relieving substances.

In addition, the environment of many substance abusers may not encourage recovery. Unstable living arrangements, single parenting, relationships with using partners, family members, or friends, inadequate health care options, an increased risk of tuberculosis, and meager financial resources all complicate attempts to live clean and sober.

These attempts are further complicated by barriers related to the community response to substance abusers. Among these barriers are: apathy and hostility towards substance abusers; short and inadequate hospital stays; limited medical inpatient detoxification programs; limited residential substance abuse treatment beds; and limited treatment appropriate to the needs of people of color, women—especially those with children—youth, transsexuals, homeless people, and disabled people.


Contacts

Debbie Indyk, PhD, MS, Mount Sinai Medical Center, AIDS Center, Box 1009, One Gustave Levy Place, New York, NY 10029, (212) 241-7863.


Clint Nix, MSW, AIDS and Substance Abuse Program, UCSF AIDS Health Project, San Francisco General Hospital, Building 1, Suite 203, Room U2, 1001 Potrero Avenue, San Francisco, CA 94110, (415) 206-6158.

John Piette, MS, UCSF Institute for Health Policy Studies, Box 0936, San Francisco, CA 94143-0936, (415) 476-1197.

Kathy Wade, MSW, Columbia Presbyterian Medical Center, Harkness Pavilion 2N, Department of Social Services, 622 West 168th Street, New York, NY 10032, (212) 305-3081.

See also references cited in articles in this issue.
The Course of Case Management

The experience of San Francisco clinicians treating substance abusers with HIV disease has uncovered one central theme: the combination of HIV disease and addiction renders clients all but unable to negotiate the health and recovery bureaucracies. Intensive case management rather than mere referral and linkage provides comprehensive service coordination through an ongoing therapeutic relationship. The case manger is one person on whom the HIV-infected substance abuser can rely to address the hallmark defense mechanisms of addicts—denial, projection, and fear of suffering—to assist in dealing with the uncertainty of HIV disease, and to provide advocacy and linkage to substance abuse treatment and HIV-related services.

The risk of this model is that case managers may end up doing more for clients than clients are willing to do for themselves. This may raise issues of codependency, enabling, and boundary maintenance, which, in turn, may lead to continuing substance abuse, relapse, and guarded or dishonest communication with case managers. To avoid these problems, the ideal case manager would have experience working with substance abusers and have consistent and careful clinical supervision.

After assessment of an HIV-infected substance abuser establishes the need for services, case management runs the following course. At the first meeting, the case manager develops rapport, explores the nature of the case management relationship, further assesses the needs of the client, and establishes the treatment plan. The client signs a basic contract agreeing to: attend regularly scheduled meetings during which the client is not “loaded,” inform the case manager of contacts with other service providers and any change of address or telephone number, maintain confidentiality related to other case management clients, and abide by program rules. Rules include: prohibitions against threats or acts of violence, and against borrowing, lending, or exchanging money.

Over time, the treatment plan is reviewed and modified as the client’s needs evolve. Treatment planning involves establishing long-term and short-term goals and setting time frames within which those goals will be accomplished. Common long-term goals include: a clean and sober lifestyle, linkage and compliance with primary medical care, stable housing, and enrollment in needed and appropriate entitlement and support services. Short-term goals are task-orient-

Comments and Submissions

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Editor, FOCUS
UCSF AIDS Health Project, Box 0884
San Francisco, CA 94143-0884
Treating the Elderly and HIV-Infected People


While case management has increased satisfaction with and use of community services by chronically ill elderly clients, it has had little effect on client health, hospital usage, or cost of care, according to a comprehensive review of research on care for the aging. These findings raise questions about the assumptions that AIDS care advocates commonly make when promoting the expansion of community-based services and case management. Among the goals of AIDS care policy makers are reducing hospitalizations, limiting nursing home use, expanding community care options such as hospice and home care, and coordinating delivery by case management. Research among the aged demonstrates that case management approaches like these are effective in meeting client needs, building confidence and satisfaction among caregivers and clients, and increasing use of community services. These solutions, however, do not produce significant drops in hospital utilization or cost of care: older patients use community services in addition to and not as a substitute for institutional care.

Moving care out of institutions and into the home and using friends and family to provide care shifts the cost of care to these informal providers. Community care provided by volunteers needs to be priced out in order to fully understand the actual costs of this approach. It has also not been demonstrated that volunteer care can be sustained over time or that sufficient social support networks exist for all populations affected by HIV disease.

Analysis of Community Case Management

Mor V, Piete J, Fleishman J. Community-based case management for persons with AIDS. *Health Affairs.* 1989; Winter: 139-153. (Brown University.)

A preliminary analysis of nine community-based AIDS service projects in 11 sites throughout the United States identified several key challenges facing AIDS case management systems.

Researchers visited Robert Wood Johnson Foundation-supported sites between February and July 1988, and collected and analyzed data on 9,015 clients. All sites had burgeoning case loads, and programs generally lacked an organized approach to monitoring client needs over time.

Large numbers of people with HIV disease were living alone making them particularly vulnerable to institutionalization. But a shortage of formal providers and limited social support networks within some populations hindered attempts to prevent institutionalization by providing care at home.

The projects failed to develop substantial housing options for their clients. Volunteers provided a high volume of services, but were concentrated at sites where gay and bisexual male clients were in the majority. Typically, volunteers worked outside of the case management system without central coordination of their services, and some sites were severely constrained by a lack of all services.

Researchers made several recommendations to improve case management of HIV-related services including: communities should develop housing options; case managers should have access to volunteer and general health service information about clients, and volunteer services should be coordinated by case managing agencies; special long-term care facilities should be developed in areas where clients with minimal financial and social support live alone; in communities with good existing home health services, case managers should be located in communities rather than in hospitals; and the role of case manager needs to be clarified and well-defined before used on a large scale.

Hospital- and Community-Based Care


A large survey of case management programs throughout the U.S. found that the type of case management—hospital-based or community-based—had a direct impact on the structure, content, and efficacy of services provided.

Researchers surveyed 75 community-based organization (CBO) case managers and 93 hospital case managers in the 27 U.S. cities with the highest incidence of
AIDS. The questionnaires, collected from November 1988 to April 1989, surveyed case load characteristics, functions performed, and difficulties experienced linking clients with services.

While the median case load across organizational type was 50, the case mix varied: hospitals saw more injection drug users; CBOs worked primarily with gay or bisexual men. Clients seen through hospitals needed more residential placement, long-term care, transportation assistance, and counseling. Clients working with CBOs required more legal advice, volunteer support services, and assistance with financial entitlements.

Hospital case managers had higher educational levels and more years of experience and their interventions included more counseling and more effective navigation of health and social services. They were more likely than CBO case managers to serve as intermediaries between clients and service providers and more often provided psychological counseling. CBO case managers functioned more actively as advocates for greater client independence and assertiveness in their interactions with care providers.

Although both types of case manager commonly saw clients in the hospital, hospital case managers rarely interacted with clients outside the hospital. In contrast, CBO case managers visited more than half their clients at home and spent time with clients during unscheduled evening and weekend hours.

Hospital case managers were more able than CBO case managers to secure important services including residential and outpatient drug treatment, entitlements, home health care, and homemaker services. However, hospital case managers had more difficulty than CBOs in arranging volunteer services. Both had difficulty securing subacute residential placement, housing services, and long-term care.

Care for Multi-Problem Clients


A Multi-Service Network (MSN) in Vancouver was successful over two years in improving coordination, reducing costs, and restructuring the lives of its 56 “multi-problem” clients who, in the past, had consumed large amounts of service and frustrated caregivers. The program stressed communication among human service agencies affected by clients with serious mental illnesses and substance abuse problems.

During a 27-month period, the network maintained an open case load of 56 clients, chosen from 160 people who had been referred by mental health, alcohol and drug, corrections, forensic services, social services, and housing agencies. Clients were accepted if three agencies reported difficulty with them, that is, “having behavior and characterological problems that make them unwelcome or unsuccessful” in using agency services. MSN staff coordinated case conferences among agencies that resulted in individual plans of care. Common features of the plans included administration of social assistance, one-to-one case management, thorough diagnostic assessment, legal advocacy and support, and elimination of duplication of services.

Two commissioned studies of MSN found that the program produced some reduction in cost. In addition, community agencies reported that more knowledge about clients and other agencies improved agency functioning and resulted in better options for dealing with difficult clients. Case reports showed that by introducing more structure through interagency cooperation, clients’ lives improved.
ABOUT UCSF AIDS HEALTH PROJECT PUBLICATIONS

The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.htm.

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