The Importance and Cost of Non-Reimbursable Support Services and Care Coordination for People with HIV/AIDS

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INTRODUCTION

As the population affected by the HIV/AIDS epidemic continues to shift toward intravenous drug users, the mentally ill, the homeless, and the poor, the need for support services and care coordination is increasing. Recent advances in HIV/AIDS treatment, such as highly active antiretroviral therapy (HAART), have profoundly decreased morbidity and mortality among people living with HIV/AIDS (PLWH/A). However, significant socioeconomic barriers often impede access to life-saving medical care.

In order to provide high quality care for HIV/AIDS patients, the socioeconomic barriers must be addressed through the integration and coordination of social support services with medical, mental health, and substance abuse treatment. Unfortunately, many of these support services are not reimbursed by standard health insurance. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and other grant funding sources provide the primary means to finance these critical services.

The HIV/AIDS program at East Boston Neighborhood Health Center (EBNHC), a large New England community-based organization, uses these support and coordinating services to reduce barriers to accessing care. Through a detailed program description and analysis of service use and costs at EBNHC, we demonstrate the importance of support and coordinating services to PLWH/A and the need to maintain funding of these services.

Need for Integrated Services

The profile of people infected with HIV is changing as the epidemic continues. Increasingly, poor women of color are becoming infected with HIV (HRSA, 1999). Commonly the primary caretakers of their children, infected women need to deal with issues such as guardianship, food access, housing access, transportation, day care, respite care, and insurance coverage for their entire families. HIV/AIDS service providers are also managing the care of patients with co-morbidities, such as addiction and mental illness, as well as social problems, including poverty and homelessness (Acuff et al., 1999; Kunches et al., 1999; National Health Care for the Homeless Council, 1998).

People challenged by these problems access primary medical care less frequently and are more likely to be diagnosed with HIV at a later disease stage than people with more stable lifestyles (Bozzette et al., 1998; Shapiro et al., 1999). Consequently, upon diagnosis of HIV infection these individuals are often already sick. They are then suddenly confronted with the formidable tasks of learning to negotiate an unfamiliar and complex medical system while concurrently dealing with daily survival issues. Frequently, the immediate survival issues of food, shelter, and transportation must be addressed first before sufficient stability can be achieved to access and benefit from medical services on an ongoing basis.

In order to provide quality care to this high need population, medical care must integrate and coordinate psychosocial services with primary, subspecialty, home, and inpatient

care. In addition, given the need for strict adherence to HAART, individualized interventions that address a patient's specific barriers to adherence are also essential aspects of care.

EBNHC and the Project Shine Model of Care

East Boston Neighborhood Health Center was formed in 1970 by the East Boston Community Health Committee and the Department of Health and Hospitals of the City of Boston in response to a shortage of practicing physicians in the immediate area. East Boston is geographically isolated from the city of Boston proper by Boston Harbor, and therefore a full-service health care facility within the community was needed to serve its residents. EBNHC filled this need by providing community-based care close to residents' homes and eliminating the inconvenience of traveling to Boston hospitals.

The EBNHC service area includes a predominantly working class to poor population of approximately 120,000 people residing in the communities of Chelsea, Revere, East Boston, and Winthrop. An older Italian population and newer Central American, Brazilian and Asian groups reside in this ethnically diverse area.

In 1994, EBNHC received a Ryan White CARE Act Special Projects of National Significance (SPNS) grant to fund an innovative model for its HIV/AIDS program, Project SHINE (Support, Health Care, Intervention and Education). Project SHINE's model of care includes a multidisciplinary team that provides comprehensive, patient-focused care and links multiple services. The service links include medical management, addiction and mental health treatment, family support services, referral to entitlements, and other support services.

The team of providers is individualized to fit the needs of each patient, but at a minimum includes the primary care physician (PCP), the HIV clinical nurse specialist, and an infectious disease specialist. The social services case manager and mental health care manager are often members of the team. Other providers may include the HIV psychiatrist, substance abuse specialist, nutritionist, and pastoral care intern. The multidisciplinary team meets on a weekly basis to review patients' care from medical, psychosocial, and addictions perspectives and to develop care plans.

In addition to SPNS funding, other sources of funding for Project SHINE include Massachusetts Medicaid, Medicare, private insurance, Massachusetts Free Care Pool, Ryan White Title I and Title III funding, and grants provided by the Massachusetts Department of Public Health and the City of Boston.

EBNHC's HIV/AIDS case mix reflects the ethnicity of East Boston. Approximately 50 percent of the EBNHC HIV/AIDS patients are people of color, including a substantial number of new immigrants from Central America. The case mix also reflects the increasing incidence of infection among women and intravenous drug users (IDUs). Of the 138 people enrolled in the program from October 1, 1994 to December 31, 1998, 39 percent were female. Forty-three percent reported intravenous drug use, 30 percent

heterosexual contact, and 26 percent men who have sex with men as primary risk factors for infection. Insurance coverage at enrollment characterized the poor socioeconomic status of Project SHINE patients. Sixty-two percent were covered by Medicaid, 24 percent had no insurance, 9 percent were privately insured, and 5 percent had Medicare coverage.

Non-Reimbursable Services

In this section we will describe key positions within the EBNHC model of care that are not funded by major health insurance and their importance to providing comprehensive care. Three multidisciplinary team members, the HIV clinical nurse specialist, the social services case manager, and the mental health care manager work in close partnership to coordinate medical, social, and mental health/substance abuse treatment services.

The HIV clinical nurse specialist is the medical care manager whose role is to ensure the implementation of the medical aspects of the care plans developed by the multidisciplinary team. She performs a variety of functions including intake assessments of new patients; scheduling the initial visit with the PCP and other providers as indicated; providing 24-hour telephone on-call service for patients; performing triage when patients call or present in need of services; providing education and counseling about HIV infection and HIV medication administration, side effects, and adherence strategies; and promoting preventive care by ensuring patients' full immunization and by monitoring and facilitating patients' routine health maintenance. The HIV clinical nurse specialist works in collaboration with the providers at affiliated hospitals to ensure continuity of care when a patient is hospitalized and with other multidisciplinary team members at EBNHC to secure medications, detoxification beds or emergency mental health care, and appropriate home-based services when needed.

The social services case manager is crucial to the success of the Project Shine model of care because he/she facilitates access to critical social services, such as public benefits, free legal services, transportation programs, housing programs, and insurance coverage. Almost every patient in Project SHINE needs help obtaining some type of social service.

The social services case manager obtains a complete record of the patient's support networks, legal issues, housing status, financial resources, benefits, mental health and substance abuse history, and immigration status. Frequently, one of the case manager's first tasks is to help the patient become eligible for health insurance. However, many new patients are not eligible for health insurance because of undocumented immigrant status. In these cases, the case manager helps the patient pursue citizenship. In the interim, the patient is enrolled in the programs that do not require documentation of legal residency. The case manager also refers patients to the health center's social workers when more intensive counseling is necessary.

The mental health care manager is the third key position providing non-reimbursable services within the Project Shine model of care. This staff member is a social worker in EBNHC's Department of Mental Health and Social Services Collaborative Care

Management Program (CCMP), which is funded by a second Special Projects of National Significance (SPNS II) grant.

The goal of CCMP is to provide intensive counseling and care management services to PLWH/A who also have chronic substance abuse and/or mental health problems. In order to accomplish this goal, the care manager develops and maintains a network of mental health and substance abuse providers in the community. These relationships facilitate a comprehensive and seamless continuum of care by removing barriers to access for mental health and substance abuse services while providing a link back to primary care. The care manager also develops a comprehensive long-term care plan for each patient and provides counseling and crisis intervention.

The care manager provides both reimbursable and non-reimbursable services. Formal counseling characterized by insurance companies as "medically necessary" is the only reimbursable service provided by the care manager. However, in order to fully coordinate and manage care, numerous other non-reimbursable services are essential. For example, informal meetings with patients outside the definition of therapy are key to the care manager's role. These meetings may occur as often as two or three times a week during a crisis intervention or implementation of an important part of the care plan. This frequent face-to-face contact combined with telephone contact enables the care manager to provide the informed guidance and support that ultimately keeps the patient engaged in treatment for substance abuse and/or mental health problems, thereby facilitating access and adherence to medical care. The care manager also coordinates care through telephone calls and meetings with network providers, which are also non-reimbursable services.

The positions of medical director and administrative director of EBNHC's Department of Mental Health and Social Services are partially funded by the SPNS II grant. The medical director contributes to the CCMP team by providing medical psychiatric advice on issues such as psychopharmacology. The administrative director's duties include administration and clinical supervision of CCMP. In these roles, he/she frequently assists the care managers in crisis intervention and care plan implementation. Additionally, the administrative director assists the care managers in developing formal relationships with outside providers, such as alcohol and drug rehabilitation programs, to whom CCMP patients are frequently referred.

Several other positions that provide non-reimbursable services to EBNHC's HIV/AIDS patients include Project SHINE's medical director and a second infectious disease specialist. These two physicians are central to the model of care because they provide infectious disease expertise for other primary care providers at EBNHC. Some of this work is non-reimbursable and must be supported with grant funding. Other integral services they provide that are not reimbursable by health insurance include monitoring the delivery of HIV/AIDS primary care by internists, developing and updating the HIV Medical Standards of Care, and implementing the quality improvement assessment.

EBNHC's outreach, counseling, and testing program is also partially subsidized with CARE Act funding as well as funding from the Massachusetts Department of Public Health. Outreach, counseling, and testing are key to fulfilling Project SHINE's mission of providing HIV education, prevention, and treatment to the community. In addition, outreach provides an important source of referrals for the HIV program and is a critical link in ensuring that people who test positive for HIV are connected to HIV primary care services.

A part-time substance abuse specialist position is also covered by CARE Act money. The substance abuse specialist is a representative from a local substance abuse day treatment program. He/she provides consultation services to the CCMP social workers by participating in weekly staff meetings and facilitating joint meetings with patients and the CCMP mental health care manager. When a patient needs a referral for more intensive substance abuse services than can be offered at EBNHC, such as day treatment, the substance abuse specialist provides continuity of care by linking providers at a local network day treatment program with EBNHC staff.

Finally, CARE Act money funds the positions of a part-time pastoral intern and a full-time administrative assistant/patient care coordinator.

METHODS

In order to quantify the impact of non-reimbursable services and highlight the importance of grant funding to the model of care, we calculated the total cost to EBNHC of providing non-reimbursable services to its HIV patients. Total cost for non-reimbursable services was calculated by summing together the multidisciplinary team's salaries, fringe benefits, and other direct and allocated costs. In the case of several providers whose salaries were covered in part by money received from the provision of reimbursable services, only the grant-funded portion of their salaries was included in the analysis. Fringe benefits were calculated at a rate of 16.62 percent of the annual salary covered by the grant funding. Other direct and indirect costs were obtained from the EBNHC Department of Mental Health and Social Services 1999 Projected Budget, divided by the number of departmental FTEs to obtain a departmental cost per FTE, and then multiplied by the total number of FTEs providing non-reimbursable services to EBNHC's HIV/AIDS program.

Total costs for these non-reimbursable services were then analyzed on a per capita basis utilizing a per member per month (PMPM) methodology. As the health care industry continues to move toward a managed care environment, it is essential to analyze costs using per capita rates because they are central to the concept of managed care.

Total number of member months was calculated by counting the number of months each individual was enrolled in Project SHINE during the 1998 calendar year and then adding up the total months of all the individuals enrolled in that year. Costs PMPM were obtained by dividing total costs by total member months.

RESULTS AND DISCUSSION

Using this methodology, the total cost in 1998 for providing non-reimbursable services to EBNHC's HIV patients was $328,880 and the per capita cost was $331 PMPM. Below is a summary of the costs.

Annual Salaries Covered by Grant Funding	Fringe Benefits	Other Direct Costs	Indirect Costs	Total Cost
$ 276,650	$ 45,979	$ 3,939	$ 2,312	$328,880

Member Months (MM)	994
Cost Per Member Per Month	$ 331

It is important to note that this PMPM cost was an underestimation of support service costs because these figures did not include costs related to CARE Act funded support services provided to Project SHINE patients by other local providers. These services included transportation, childcare, supported housing, and peer support.

In order to put these per capita costs for non-reimbursable services into perspective, we compared them to the per capita costs associated with reimbursable services. In 1994, EBNHC's HIV/AIDS program received a SPNS I grant to conduct an evaluation of reimbursable service use and costs in order to determine the feasibility of accepting a capitation payment under a managed care contract. This study found that in 1998 it cost $471 PMPM to provide comprehensive medical care for patients with HIV/AIDS, excluding pharmacy, home health care, and durable medical equipment.

A comparison of the relative costs of these two types of services was striking. The cost/PMPM for non-reimbursable services was more than 70 percent of the cost/PMPM for reimbursable services. Clearly, costs for non-reimbursable services comprised a significant portion of the true total cost of providing PLWH/A with all the services necessary to access and receive quality medical care.

CONCLUSION

HIV infection is not solely a medical condition. Given the epidemiology of the infection, it is a complex mix of medical and psychosocial issues that requires an integrated, coordinated approach by providers of multiple disciplines. Care management throughout and across these disciplines is essential. However, as we have described, much of this service provision and all of the care coordination are not reimbursable by insurers. In fact, we have demonstrated that at least an additional 70 percent of the total reimbursable costs of care are required to fund these services and support the infrastructure of care that permits care coordination. This proves the need for funding sources such as the Ryan

White CARE Act. It is this grant funding that fills the gap left by insurance companies so that the multiple and complex needs of all PLWH/A can be met.

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