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BUREAU OF PRIMARY HEALTH CARE

Over $1 Billion in grants awarded to serve over 7.3 million people

Provide comprehensive high quality primary health care services that are community based, family oriented and case-managed

Increase access to health care services for the underserved and the most vulneralbe populations

Build capacity for the provision of health care services at the local level by involving the community in health care planning

Focus on health promotion and disease prevention

Support the training and placement of health professionals in underserved communities

COMMUNITY /MIGRANT HEALTH CENTERS

Support 574 primary care programs in over 1500 sites throughout the US

Located in inner city and rural areas

Offer integrated systems of comprehensive primary care including a wide range of services for a wide range of health care needs; e.g. mobile vans for Mammogram screening, education about the hazards of substance abuse on the street, health services and education to children in schools, translation services, dental, mental health as well as medical services.

HEALTH CARE PROVIDER DEVELOPMENT AND DEPLOYMENT

(National Health Service Corps and Scholarship and Loan Repayment Programs)

Provides health care providers to communities via educational support to health professional students

Offers both scholarships and loan repayment plans to these students

Currently supports over 360 scholarships, 320 loan repayers, 27 State loan repayment programs, and 11 State community scholarship programs.

NHSC currently has over 1200 health care providers in the field

PRIMARY CARE ACCESS PLANS

(State Primary Care Agreements and Primary Care Associations)

Goal- to develop a strategy to increase access to primary care by building a primary care infrastructure and capacity

Identifies areas in need of primary care services and the services presently available

Identify the location and capacity of Federal, State and local programs addressing medical underservice

Recommends how needs can be met by drawing on the spectrum of available resources

PROGRAMS FOR SPECIAL POPULATIONS

Addresses the special health care needs of populations at risk for poor health outcomes. The following are the major programs administered to serve the target populations:

Comprehensive Perinatal Care program, Hepatitis B Demonstration, Infant Mortality Program, Healthy Schools, Healthy Communities Program, Health Care for the Homeless, Homeless Children Program, Primary Health Care to Residents of Public Housing, Health Care Services in the Home Program, Pacific Basin Health Initiatives, Native Hawaiian Health Care Program, Alzheimer's Program, Integrated Primary Care and Substance Abuse Program, and the HIV Early Intervention Services Program

BPHC HIV ACTIVITIES

As of February 1994, BPHC supported 574 Community and Migrant Health Care Centers (C/MHC). Of the total C/MHC: 382 (67%) reported providing care to over 52,000 HIV clients. Of the 382 C/MHCs reporting HIV clients: 17 (4%) receive Title I funds, 5 (1%) receive Title II funds and 59 (15%) receive Title III(b) funds.

There are 140 (25%) C/MHCs in 34 Title I (EMAs) cities; 128 (91%) of these report serving HIV clients. Of the 128 C/MHCs in Title I cities reporting HIV clients,

seventeen (13%) receive Title I funds; 5 (4%) receive Title II funds, and 32 (25%) receive Title III(b) funds.

HIV EARLY INTERVENTION SERVICES PROGRAM (Ryan White CARE Act Title III(b)

Increases the capacity and capability of ambulatory care facilities to provide early intervention and primary care services as part of a continuum of HIV prevention and care services. Services include risk reduction counselling and testing, partner involvement in risk reduction, and transmission prevention.

Services for HIV positive clients include antiviral therapies, prophylaxis for opportunistic infections, standard and investigational therapies for clinical manifestations of HIV infections/malignancies as part of ongoing medical care. Also provided are dental and mental health services and case management.

Address the co-epidemics of HIV and TB, or substance abuse.

130 grantees throughout the US and Puerto Rico.

In FY 1993, 40% of clients were female, 20% were between the ages of 13 to 24 years.

Twenty-eight percent are injecting drug users or their sexual partners.

Sixty-two percent are racial and ethnic minorities: 31% are African-Americans, 25% are Hispanic, 2% are Asian-American, 3% represented other racial/ethnic groups, including Native Americans.

Fully 25% of HIV positive clients have severe immune impairment and advanced disease (CDC AIDS defining illness or CD4 count below 200) at entry into the program.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

BPHC FACT SHEET

BUREAU OF PRIMARY HEALTH CARE • DIVISION OF PROGRAMS FOR SPECIAL POPULATIONS • FEBRUARY 1994

Integrated Primary Care and Substance Abuse Treatment

Community-based primary care providers are well-positioned to identify and help patients who have drug abuse problems and are at risk for exposure to the HIV/AIDS virus.

To assist these providers, in 1989, the Bureau of Primary Health Care (BPHC) within the Health Resources and Services Administration entered into an intra-agency agreement with the National Institute on Drug Abuse (NIDA) within the Substance Abuse and Mental Health Services Administration (SAMHSA). The NIDA and BPHC launched a three-year $30 million demonstration program to assess the feasibility of linking primary care and drug abuse treatment to improve the effectiveness of drug treatment, and to slow the transmission of HIV. In 1992, 15 of the existing 21 programs were extended for a fourth year, in order to further analyze the cost of integrating drug treatment and community-based primary care services. The organizations receiving grants under this demonstration represented community and migrant health centers, drug abuse treatment programs, state and local health departments, criminal justice programs, and academic institutions.

In Fiscal Year 1994, the Integrated Primary Care and Substance Abuse Treatment Program began a new demonstration cycle through an intra-agency agreement with the Center for Substance Abuse Treatment (CSAT) within SAMHSA. Through a full and open competition, 18 programs were selected for a three-year award period to provide primary care, HIV services, substance abuse treatment, and mental health care. Eight of the existing 21 programs were selected to continue in the new demonstration program. These organizations will provide comprehensive health and drug treatment services to injection drug users, their sexual partners, and family members.

The Division of Programs for Special Populations, BPHC, has worked cooperatively with NIDA, CSAT, SAMHSA, and the National Association of State, Alcohol and Drug Abuse Directors in developing and implementing this program. The current intra-agency agreement will allow HRSA and SAMHSA to jointly administer programs which link primary care and HIV services with substance abuse treatment and mental health treatment. An evaluation of mental health services provided by the Integrated Primary Care and Substance Abuse Treatment programs in this demonstration is underway with results expected in mid-1994.

For more information, please contact the HIV and Substance Abuse Services Branch at 301-594-4444.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

BPHC FACT SHEET

BUREAU OF PRIMARY HEALTH CARE • DIVISION OF PROGRAMS FOR SPECIAL POPULATIONS • FEBRUARY 1994

HIV Early Intervention Services Program

The incidence of HIV infection continues to significantly increase, especially among low-income, medically underserved people. In the early stages of this epidemic, most HIV-related medical services were provided through AIDS specific clinics in tertiary care facilities. In an effort to effectively reach hard-to-reach populations and provide HIV early intervention services, an increasing public effort is being made to incorporate HIV-related care into the existing primary care system.

In response to this need, Congress passed the Ryan White C.A.R.E. Act of 1990 (Title XXVI of the PHS Act, as amended). Title III of the Act authorized a program to support outpatient HIV early intervention services. This program was an expansion of the existing Bureau of Primary Health Care (BPHC) effort to provide HIV early intervention and HIV-related primary health care at customary sources of care for underserved groups. The program specifically targets previously underserved populations, which have had limited access to care, including women, children, adolescents, people of color, and substance abusers.

Program Services

Title III(b) programs provide a continuum of HIV related services including risk reduction counseling and testing, partner involvement in risk reduction, transmission prevention, appropriate medical evaluation and clinical care. The services provided for HIV infected clients include antiviral therapies, prophylaxis for opportunistic infections, standard and investigational therapies for clinical manifestations of HIV infections/malignancies, as part of ongoing medical and psychosocial care. Case management is an important component of assuring access to services, and continuity of care. The HIV Early Intervention Programs address the co-epidemics that occur alongside HIV infection. These include the critical problems of substance abuse, and the increasing rates of tuberculosis infection.

Program Data

The 137 grantees represent a cross-section of community based organizations. They include 46% federally funded community/migrant health centers, 12% non-federally funded community health centers, and 13% city and county health departments. The remaining 29% of grantees are diverse community based organizations including gay/lesbian identified organizations, health care for the homeless centers, family planning agencies, and comprehensive hemophilia centers. Early intervention service programs have been successful in providing access for critical populations that traditionally have no access to health care.

During fiscal year 1993, services were provided to an estimated 150,000 individuals who were infected with HIV, or were identified as at-risk for HIV infection. An estimated 60,000 individuals who are HIV infected, received comprehensive primary care services through the Programs. Forty percent of the clients were women, 55 percent were ethnic/racial minorities, one in five clients were between the ages of 13-24. Twenty-eight percent (28%) were injection drug users or their sexual partners. Fully one-quarter of the HIV infected clients had severe immune impairment and advanced disease (CDC Classification Group IV) at entry into the early intervention programs. This indicates the extent of the delay that currently exists in gaining access to, and providing services for these critical populations.

For additional information, please contact the HIV and Substance Abuse Services Branch at (301) 594-4444.

MCHB TITLE IV EFFORTS TO SUPPORT HIV AFFECTED FAMILIES

During the 1980s, the Maternal and Child Health Bureau made a major commitment toward the development of family-centered care in settings providing services to children with special health care needs. As a result of these efforts, landmark legislative initiatives such as Part H of the Individuals with Disabilities Education Act, the Maternal and Child Health Block Grant Amendments of 1989, and the Ryan White Care Act define family-centered care and mandate family-centered policies and practices.

MCHB continues to implement family-centered care through Title V and Ryan White Title IV program efforts: operationalize the key elements of family centered care at the community level in hospitals, clinic, and other MCH settings; institutionalize family-centered care in statewide systems of care; support and assess the impact of family/professional collaboration on the delivery of services; support families in their involvement and collaboration with health care reform initiatives and managed care plans. In the past year Title IV has implemented efforts to support HIV family involvement in program planning and to foster peer leadership and support networks. Some specific examples of Title IV initiatives are as follows:

o Funding to the Institute for Family Centered Care provides technical assistance and training to families and professionals. Title IV projects have received technical assistance and on-site assessments on family-centered issues.

o Over 100 HIV affected families are involved in a national HIV affected family support network supported by regular meetings and a family newsletter.

o A focus group with HIV infected women was held on May 21, 1994 to discuss attitudes, issues, and recommendations related to ACTG 076. A preliminary report summarizing the results of the focus group was useful input to HRSA, CDC, and NIH expert meetings to develop recommendations on 076 follow up.

o A family and youth HIV leadership conference was convened in March, 1994 with 74 family/youth from 30 of the Title IV projects in attendance. The conference provided leadership skill building for families and planning for how to lead community-based family support efforts.

ADOLESCENT HEALTH AND HIV INITIATIVES

MCH Title V Block Grant and special projects of regional and national significance (SPRANS) funding support special State MCH programs for adolescent health, including school health and care for adolescents with special health care needs. In addition, the Ryan White Title IV program has placed special emphasis on developing comprehensive outreach and care for youth with or at risk for HIV/AIDS. Some of Title IV's adolescent initiatives are the following:

o Case studies of eight Title IV adolescent projects were published in February 1993 to serve as examples of best practices in reaching and serving adolescents. The eight adolescent projects studied fall into three broad and sometimes overlapping categories. Projects delivering comprehensive services to youth already infected with HIV; projects focusing on outreach and prevention; and projects studying legal and ethical issues.

o A report on a national workshop of experts in the care of HIV-infected adolescents was issues in 1994. This report examined the critical practice, research and policy issues affecting the care of youth affected by HIV.

o A joint MCHB/BHRD HRSA evaluation effort is underway to study issues of access to HIV care. Focus groups are being conducted with two groups of infected adolescents-- those who are not in care and those who are in care.

o Title IV, MCHB, in collaboration with NIH (National Institute of Child Health and Human Development and National Institute of Allergy and Infectious Diseases) are supporting a Adolescent Research Network. Applications for the cooperative agreements will be reviewed in July with funding decisions in FY 1994. The ultimate goal of this initiative is to study HIV disease progression and comorbidity in adolescents and the natural history, transmission and models of health delivery. Adolescents with HIV have not received adequate clinical and health services research and care attention in the past.

BUILDING PRIMARY CARE CAPACITY

FOR HIV AND OTHER CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

MCH provides leadership and technical assistance to the States for developing early intervention-related aspects of services for children with special health care needs and to strengthen primary care provider capability to provide community based care. For example, the Bureau has funded the Hawaii Medical Home Project to demonstrate a model of care where children with special health care needs have a medical home in their communities to coordinate all care. In addition the Bureau has collaborated with the American Academy of Pediatric to build pediatric capability at the community level through the CATCH program.

The Title IV program has also focused on the need to organize models of care that build on the important role of community-based, primary care providers in diagnosing and caring for children and families with HIV/AIDS. Over the past year, two program meetings have been held to develop consensus about the role of primary health care providers working in collaboration with tertiary care centers in order to strengthen community-based HIV care. A May 1994 Title IV meeting "Building Pediatric HIV Primary Care Capacity in the Community" had the following conclusions and recommendations:

o The vast majority of the health care needs of HIV-infected families are best met by primary health care providers in local communities supported by tertiary care centers. Guidelines to better define the role of primary care providers are needed. Given the vast differences in the needs and medical care systems in different geographic areas, neither primary nor tertiary care roles should be pigeon-holed--there needs to be flexibility built into models for local care systems.

o Expanded efforts are needed to ensure that primary care providers are adequately prepared and reimbursed to serve families affected by HIV. This includes finding methods for compensating the communication and consultation time provided by both primary and tertiary components. Medical school educators may need to re-evaluate their training goals to ensure primary capacity development.

o Demonstration Funding strategies should emphasize supporting models of primary care, recognizing that in the past, demonstration grant funding methods favor more sophisticated and offer tertiary centers over community based providers and organizations.

o There should be ongoing assessment and evaluation of various methods of providing primary care to families affected by HIV, including reviewing services delivery cost, utilization and effectiveness of primary care models.

MCHB Fact Sheet
Maternal and Child Health Bureau
Health Resources and Services Administration • Public Health Service • U.S. Department of Health and Human Services

Pediatric AIDS

Acquired immune deficiency syndrome (AIDS) in children was first described in 1982 when it became apparent that this then-mysterious disease could be transmitted by blood transfusions or the blood products used to treat hemophilia. Perinatal transmission from mothers infected through intravenous drug use or sexual contact was recognized at about the same time. Initially, it was difficult to distinguish AIDS from the rare and equally puzzling congenital immunodeficiency diseases in children.

By 1984, the numbers of children with AIDS began to escalate, especially in New York City, Newark, and Miami. That year, the Division of Maternal and Child Health (now the Maternal and Child Health Bureau) cosponsored the first National Meeting on Pediatric AIDS which concluded that AIDS did occur in children, that the number of children involved was undercounted in the Centers for Disease Control and Prevention (CDC) surveillance system, and that infected infants and children and their families were subject to discrimination and sometimes barred from basic services.

In 1986, at a second National Pediatric AIDS Meeting, physicians and other health care workers, social workers, and educators shared information about the clinical spectrum and treatment efforts. A new confidence resulted from the increasing knowledge about the etiology and transmission of AIDS. Moreover, it was recognized that most existing approaches to the treatment of children with special health needs were applicable to children with HIV infection.

A third national meeting in 1987, the Surgeon General's Workshop on Children with HIV Infection and Their Families, focused on prevention of human immunodeficiency virus (HIV) infection in children and on the difficulties of caring for children already infected. In addition to summarizing current knowledge about AIDS in children, workshop participants—who included clinical and research physicians, health providers, economists, educators, parents, members of the clergy, and media representatives—presented 82 recommendations for future directions in research, prevention, and services. These recommendations, contained in the workshop report, provide a useful framework for meeting some of the challenges presented by HIV infection in children.

In 1988, the Pediatric AIDS Health Care Demonstration Program was initiated, with funds appropriated under the Public Health Service Act. In 1994, the program is permanently authorized under Title IV of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The program is administered by the Maternal and Child Health Bureau, which now refers to it as the Pediatric/Family HIV Health Care Demonstration Program, reflecting the fact that projects serve families, not just children, that are infected with or at risk for HIV.

Incidence of Pediatric AIDS

- AIDS is transmitted in several ways: from infected mothers to their infants; through exposure to infected body fluids, primarily blood; and through sexual contact with an HIV-infected partner.
- 4,906 children with AIDS have been reported to CDC through September 1993. About one-third of these cases were reported since 1990 with perinatal transmission the risk factor in 90 percent. The epidemic among children has spread from large metropolitan areas to smaller cities and rural communities, particularly in the Southeastern United States.
- AIDS is already one of the leading causes of death for all children and the ninth leading cause of death among children 1 to 4 years of age.
- 1,167 adolescents with AIDS ages 13–19 years and nearly 13,000 young adults with AIDS ages 20–24 years have been reported to the CDC through September 1993.
- AIDS is the sixth leading cause of death in young people between the ages of 15 and 24 years.
- Women are the fastest growing segment of the AIDS population. The number of women infected with HIV, particularly within communities of color, continues to grow and spread beyond the large urban epicenters to smaller urban and rural settings.

- 40,702 cases of AIDS in female adolescents and adult women have been reported to the CDC through September 1993. Almost one-third of these cases (12,000) were reported in the past year. The majority of women are exposed to HIV through heterosexual contacts, and sexual contact with drug users.
- AIDS is the fifth leading cause of death in women in the United States and the leading cause of death in New Jersey and New York City.

The Pediatric/Family HIV Program

The purpose of the Pediatric/Family HIV Health Care Demonstration Program is to improve and expand the infrastructure of comprehensive care services in order to increase the access of HIV/AIDS-affected women, infants, children, and youth to a comprehensive, community-based, family-centered system of care. As a result of the transfer of the program to Title IV, the focus of the program is further expanded to develop innovative models that link systems of comprehensive community-based medical and social services for the affected population with the National Institutes of Health and other clinical research trials. Funds support innovative strategies and models to organize, arrange for, and deliver comprehensive services through integration into ongoing systems of care and support from appropriate financing mechanisms. The service delivery systems assure the delivery of high-quality care at the appropriate level, with an emphasis on ambulatory care services that may reduce unnecessary hospital stays.

Three categories of projects have been funded: Pediatric AIDS Projects which provide or coordinate comprehensive, family-centered health, social, and support services; Comprehensive Care Consortia with the unique requirement that private sector funding must match public funding; and National Issues Projects which provide information, training, and technical assistance to expand national resource capacity and impact national program development.

In fiscal year 1993, 44 projects were funded in 20 States, the District of Columbia, and Puerto Rico for a total cost of $20.9 million. Thirty-nine of the projects funded were AIDS demonstrations, two were consortia, and three were on national issues. Eighty-four percent of the projects' clients are from poor, minority families with limited access to transportation and housing. Currently, 39 percent are Hispanic and 43 percent are African American. In fiscal year 1994, the program is funded at $22 million.

Program Accomplishments

- The pediatric/family HIV projects have proven to be effective in their ability to organize and improve patient access to a comprehensive system of services. Between 1991 and 1992, the pediatric/family HIV projects have increased the unduplicated number of individual clients served by each project by 87 percent with a total of 28,738 clients served.
- The number of families served more than doubled each year between 1988 and 1990, indicating the program's commitment to maintenance of the family unit in the face of this devastating disease.
- Children in the majority of projects studied were able to participate in clinical trials that gave them access to state-of-the-art treatments. Access to state-of-the-art treatment is provided in coordination with primary medical, social, and family support services which are made available to family members of children served by all of the projects.
- The program has improved the capacity of health and social service professionals, community-based organizations, and families to address the demand of the growing epidemic. In each project, individual grantees have made efforts to strengthen provider capacity within their communities and States through education, training, and peer support.
- A recently completed National Issues Project grant has documented the cost of caring for children with HIV and AIDS, and has proposed reimbursement methodology appropriate to pediatric AIDS financing.
- Projects are identifying HIV-positive pregnant women through outreach, counseling, and testing. These efforts have resulted in earlier identification of both HIV-positive women and HIV-exposed newborns, with appropriate followup care.
- Two national resource centers have been funded by the program. The National Pediatric HIV Resource Center provides information and technical assistance, and has developed curriculum for multidisciplinary training programs for health administrators and care providers. The Institute for Family-Centered Care provides technical assistance to support families affected by HIV and AIDS.

For further information, contact the chief, Hemophilia and AIDS Services Branch, at (301) 443-9051. *1/94*

MCHB Fact Sheet
Maternal and Child Health Bureau
Health Resources and Services Administration • Public Health Service • U.S. Department of Health and Human Services

State Programs

The Maternal and Child Health Services Block Grant Program, first authorized in 1935 by Title V of the Social Security Act, has always operated as a Federal/State partnership. When the Title V program was converted to a block grant in 1981, seven categorical programs were consolidated into the single block grant. States were given considerable discretion, consistent with identified State needs, in determining how to use Federal funds to achieve the purpose of the legislation.

Amendments enacted as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA '89) introduced stricter requirements for the use of funds and for State planning and reporting. States still exercise considerable authority in priority setting, allocating funds, and delivering services to fit State and local needs and characteristics. They are required, however, to use at least 30 percent of Title V funds on preventive and primary care services for children and at least 30 percent on services for children with special health care needs. They may spend no more than 10 percent of Title V funds on administrative costs and must maintain the State contribution to at least the fiscal year 1989 funding level.

States receive about 85 percent of the Federal appropriation, which in 1994 amounts to $574.5 million, and are required to match 3 dollars for every 4 Federal dollars they receive, resulting in more than $1 billion available for maternal and child health programs at the State and local levels. Many States provide funds beyond their required match.

Program Administration

The maternal and child health (MCH) programs under the block grant are located in the department of health in every State and the majority of programs for children with special health care needs (CSHCN) are also located in the health departments. Nine State CSHCN programs are administered by other State agencies including human service or education agencies, or in universities. One State has established the CSHCN program as an independent commission. A list of the directors of the MCH and the CSHCN programs in the 59 States and jurisdictions is available from the Bureau.

State Title V programs implement their responsibilities by engaging in a range of core program functions, including: needs assessment; program planning and development; service delivery, coordination, and financing; standard setting and monitoring; technical assistance, information, and education; and reporting.

State Title V programs are required to coordinate with other related Federal health, education, and social service programs. For example, MCH programs have provided the technical expertise and the service delivery systems to ensure that expanded Medicaid eligibility and benefits result in improved access to services and improved health status of pregnant women and children.

Services

State Title V programs support—by directly operating programs or by funding local providers—such services as prenatal care; child health services including immunizations, well-child examinations, and treatment or referral; school health services and education programs; and specialized health services and family support for children with actual or suspected developmental disabilities or chronic illnesses. The services for children with special health care needs are most often provided through organization of specialty clinics and through purchase of private office or hospital-based out- and inpatient diagnostic, treatment, and followup services.

OBRA '89 mandated that State programs develop family-centered, community-based, coordinated care systems for children with special health care needs. State programs are also developing community-based networks of preventive and primary care that coordinate and integrate public and private sector resources and programs for pregnant women, mothers, infants, children, and adolescents.

Over 80 percent of State CSHCN programs provide case management, care coordination, and family support services for at least some portion of their target populations. Three-fourths of the State MCH programs have supported local "one-stop shopping" models integrating access to Title V, Medicaid, the WIC food program, and other health or social services at one site. All State Title V programs support some home-visiting services, although these services are extremely limited in many States due to funding constraints.

Title V-supported programs provide prenatal care to approximately 3.6 million women and primary health care to 8 million children, including 750,000 children with special health care needs who also receive specialized health and family support services.

For further information, contact the chief, Program Systems Development Branch, at (301)443-3163. *1/94*

MCHB Fact Sheet
Maternal and Child Health Bureau
Health Resources and Services Administration • Public Health Service • U.S. Department of Health and Human Services

Early Intervention for Children with Special Health Care Needs

Early intervention in its broadest sense is any planned, systematic program of services necessary to prevent and/or minimize the effects of disability on young children with special health needs and their families. The MCHB early intervention initiative, which emphasizes the relationship between health and education, has three primary components:

(1) Ensuring that the medical/health component of the early intervention system is in place for young children with special needs and their families;

(2) Creating the interdisciplinary/interagency partnerships necessary to ensure continuity of early intervention services; and

(3) Facilitating the development of community-based systems of early intervention services which are comprehensive, family-centered, and fully coordinated, in keeping with the objectives of *Healthy People 2000.*

Program Components

Ensuring the Medical/Health Component of Early Intervention

The Bureau provides leadership and technical assistance to the States for developing the early intervention-related aspects of services for children with special health care needs (CSHCN) supported by the Maternal and Child Health Services Block Grant (Title V of the Social Security Act). In addition, the Bureau supports numerous initiatives to ensure that necessary health services are available to, and utilized by, young children with special needs and their families, and that early intervention professionals are prepared to provide quality interdisciplinary and specialty intervention. The results of this MCHB support include:

- The Hawaii Medical Home Project. Models for providing comprehensive services to children with special needs through the medical home have been developed and demonstrated. This project, a collaboration between MCHB and the American Academy of Pediatrics, has made major strides in assuring access to and continuity of primary care for children with special needs.
- Demonstration of Neonatal Hearing Screening Using Evoked Otoacoustic Emissions. The cost-efficiency of the evoked otoacoustic emissions technology as a means of promoting early hearing screening for all neonates has been demonstrated.
- Leadership Development for Nurses in Early Intervention. A curriculum to prepare nurses to develop and implement early intervention services has been developed. In addition, standards of nursing practice for early intervention have been developed.

Creating Partnerships

While the specific focus of the MCHB effort is directed toward organization of the medical/health component of early intervention, collaboration with other agencies and service sectors is considered critical to the development of coordinated, community-based systems of early intervention services.

- Collaboration with Health Professionals. MCHB has a strong tradition of collaboration with the pediatric community. Recent collaborative efforts with the American Academy of Pediatrics have focused on jointly sponsored workshops, conferences, and projects such as the Integrated Services Project, Corporate Summit, and Communities Can.
- Family/Professional Collaboration. MCHB supports several initiatives designed to establish parent-to-parent networks, articulate principles of family-centered care, and increase representation of families in Federal, State, and local policy development. One such initiative, Family Voices, is designed to represent the viewpoints of families of children with special needs in regard to health care reform.

- Health/Education Collaboration. MCHB and the U.S. Department of Education, Office of Special Education and Rehabilitative Services, have worked closely together on the enactment and implementation of early intervention legislation. State Title V agencies serve as the lead agency for P.L. 102-119 implementation in many States. (P.L. 102-119 is Part H of the Individuals with Disabilities Education Act.) MCHB is also a member of the legislatively established Federal Interagency Coordinating Council (FICC). Major collaborative efforts with the Department of Education focus on joint sponsorship of early intervention projects (Family-Centered, Coordinated Early Intervention Services for Navajo Children and Families); publications (*Guidelines and Recommended Practices for the Individualized Family Service Plan,* 1991); and conferences (Partnerships for Progress). MCHB works closely with professional organizations in education to foster a health/education agenda that includes early intervention. The Interprofessional Education Commission, sponsored by the Association of Teacher Educators, and the Division for Early Childhood Family Day, sponsored by the Division for Early Childhood of the Council for Exceptional Children, are examples of this type of collaboration.

In addition, MCHB collaborates with a number of other professional organizations and voluntary agencies on early intervention activities in the areas of genetics, hemophilia, and AIDS.

Facilitating the Development of Community-Based Systems of Care

MCHB plays a leadership role in providing and promoting family-centered, community-based, coordinated care for children with special health needs, and in facilitating the development of community-based systems of services for these children and their families. The elements of this systems development initiative provide the basis for MCHB-funded activities in the area of early intervention. Major activities in this area include:

- The CSHCN Workgroup on Systems Development has produced several documents including *Developing Community-Based Systems of Services for Children with Special Health Care Needs and Their Families: An Overview,* as well as documents on the progress of Title V State CSHCN Programs in systems development.
- Coordination of early intervention activities with projects funded under the State Systems Development Initiative of Special Projects of Regional and National Significance (SPRANS) and the Community Integrated Service System (CISS) program.

Publications

National Early Childhood Technical Assistance System (NEC*TAS) and the Association for the Care of Children's Health (ACCH). (1991). *Guidelines and Recommended Practices for the Individualized Family Service Plan.* Washington, DC: ACCH.

Bureau of Maternal and Child Health and Resources Development and the American Academy of Pediatrics. (1989). *Establishing a Medical Home for Children Served by Part H of Public Law 99-457.* Washington, DC: Georgetown University Child Development Center.

University of Kentucky College of Nursing. (1991). *National Standards of Nursing Practice for Early Intervention Services.* Lexington, KY: University of Kentucky.

For further information, please contact the Habilitative Services Branch at (301) 443-2370. *1/94*

HIV/AIDS AETC

AIDS EDUCATION AND TRAINING CENTERS

FACT SHEET

Seventeen AIDS Education and Training Centers (ETC) have been established through a cooperative agreement program of the Health Resources and Services Administration, within the U.S. Public Health Service, Department of Health and Human Services.

The ETCs are a national network of centers that have a responsibility for designated geographic areas in which they conduct targeted, multidisciplinary education and training programs for health care providers. The goal of the AIDS ETC Program is to increase the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat and manage individuals with HIV infection, and to assist in the prevention of high risk behaviors which may lead to infection. The ETCs also serve as resource centers by coordinating warmlines for current, accurate information concerning HIV, and by making available information about HIV resources, drug trials, and referrals.

Each ETC incorporates the following functions:

- Training community primary care providers to incorporate strategies for HIV prevention into their clinical priorities
- Training selected trainees to serve as HIV educators of health care personnel in their local areas
- Emphasizing HIV training for minority providers and providers who serve minority populations
- Implementing needs assessments to better allocate resources
- Placing an emphasis on AIDS epicenters
- Establishing linkages with existing clinical trials groups

In addition, up to 10% of funds are set aside for rural centers. ETCs collaborate with Area Health Education Centers (AHECs), community-based HIV organizations, medical and health professional schools, local hospitals, health departments, community and migrant health centers, medical societies, and other professional organizations.

Current Roster of AIDS Education and Training Centers (ETCs)

Serving New York and the Virgin Islands

- New York/Virgin Islands AIDS ETC
  Columbia University School of Public Health
  600 West 168th Street
  New York, New York 10032
  Cheryl Healton, Dr.P.H.
  (212)305-3616, Fax(212)305-6832

Serving Washington, Alaska, Montana, Idaho, Oregon

- Northwest AIDS ETC
  University of Washington
  1001 Broadway, Suite 217 Mail Stop ZH-20
  Seattle, Washington 98122
  Ann Downer, M.S.
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AIDS TREATMENT COSTS DURING THE LAST MONTHS OF LIFE:

EVIDENCE FROM THE AIDS COST AND SERVICE UTILIZATION SURVEY (ACSUS)

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ABSTRACT

This study utilizes data from the AIDS Cost and Service Utilization Survey (ACSUS) to examine the volume and cost of services consumed by persons with AIDS (PWAs) during their last months of life. The ACSUS is the most comprehensive survey of the type and volume of medical services consumed by persons with HIV, and involves six interviews with approximately 2,000 respondents over an 18 month period from Spring 1991 to Fall 1992.

This analysis is restricted to PWAs who survived the fifth time period (an approximately three month period in the early spring and summer of 1992). The types and costs of services consumed during the fifth time period by PWAs who did survive (survivors = 79), and who did not survive (decedents = 609), the sixth time period are compared in this study. This study also examines characteristics of decedents that explain variations in their use of services during the fifth time period.

This study shows that the cost of treating decedents is more than three times the cost of treating survivors. Decedents experienced more than four times the number of home health visits and were hospitalized more than four times as many days as survivors. Both the average length of stay (19.3 for decedents and 10.3 for survivors) and the frequency of hospitalization during the fifth time period (.70 for decedents and .28 for survivors) were higher for decedents than survivors. The levels of outpatient care (including emergency room care) and of prescription drug use were similar for decedents and survivors.

AIDS TREATMENT COSTS DURING THE LAST MONTHS OF LIFE: EVIDENCE FROM THE AIDS COST AND SERVICE UTILIZATION SURVEY (ACSUS)

I. INTRODUCTION

The relatively long period from the time of diagnosis to the time of death for most diseases makes it difficult to estimate lifetime medical care costs. In an article that estimates the medical care cost of treating persons with AIDS, Scitovsky and colleagues state that, "Unfortunately, while there are data on annual medical care costs for some other diseases, there are no data on their lifetime costs."(Scitovsky et al., 1986, p. 3106)

Nonetheless, there is evidence that as the time of death approaches that the cost of treatment increases (Riley et al. 1987) Baker and colleagues have shown that the medical care cost of lung and breast cancer increases ten-fold during the time period immediately preceding death (Baker et al. 1991), and Lubitz and Riley have shown that between 27 and 30 percent of Medicare payments are attributable to persons in their last year of life.(Lubitz and Riley 1991)

Existing studies report that AIDS patients receive substantial amounts of health care services during the period immediately preceding death.(Scitovsky et al. 1986; Scitovsky and Rice, 1987;

Solomon et al. 1989; Lee et al. 1991; Merzel et al. 1991; and Solomon and Hogan 1992) There also is evidence that the cost of care immediately following diagnosis is high.(Scitovsky et al. 1986; Lee et al. 1989) The care received during the period of time between diagnosis and death is less intensive than the care received immediately following diagnosis or the care immediately preceding death because patients spend much of this time outside of the hospital. This results in a U-shaped cost curve.

Information from existing studies on the cost of treating persons with AIDS (PWAs) reflects patterns of care that existed several years ago; all existing studies of resource utilization for PWAs immediately preceding death reflect patterns of care before 1990 and are based on data obtained from a single geographic area or from a single insurer. This study examines the utilization and cost of medical services by persons with AIDS (PWAs) who were respondents in the AIDS Cost and Service Utilization Survey (ACSUS) which was conducted in 1991-199?.

This study compares the cost of services consumed by PWAs who at the end of data colection were still alive (survivors) to the cost of services consumed by PWAs who died during the last 3 months of the study (decedents). This study also examines characteristics of decedents that help explain variations in their use of services.

II. BACKGROUND

In one of the first studies of the cost of treating PWAs, Scitovsky and colleagues analyzed data on 201 AIDS patients who received all their inpatient and outpatient care at San Francisco General Hospital in 1984.(Scitovsky et al. 1986) They found that the lifetime cost curve for AIDS care was U-shaped. For those PWAs who were diagnosed in 1984 (n=83) the mean monthly charges were $2,617 ($12,040/4.6); for those who were diagnosed prior to 1984 and who lived all 12 months (n=30) in 1984 mean monthly charges were $586 ($7,026/12); and for those PWAs who died in 1984 (n=88) mean monthly charges were $3,660 ($23,425/6.4).

In a subsequent study, Scitovsky and colleagues analyzed the expenditures of seven PWAs who did, and seven PWAs who did not, receive AZT during a twelve month period from 1986 to 1987 at San Francisco General Hospital.(Scitovsky et al. 1990) Although the focus of this study was on the effect of AZT use on medical care costs the study revealed information about the level of spending during the months before death. All of the patients on AZT survived the twelve month study period and all but one of the patients who did not receive AZT died during this period. Thus, the cost of treating persons who did not receive AZT was essentially equivalent to the cost of treating decedents, and the

cost of treating persons on AZT was equivalent to the cost of treating survivors. The mean monthly charges for those receiving AZT were $1,873 and the mean monthly charges for those not receiving AZT were $4,793. The differences in these costs reflect the effect of AZT on the cost of care as well as the impact of death on the cost of care, and it is not possible to attribute the differences in costs between these two sources.

Solomon and colleagues analyzed data from Michigan Medicaid, the Michigan General Assistance Medical Program, and the Michigan Resident County Hospitalization Program for services provided on or after January 1, 1984 and before November 30, 1987 to persons with HIV.(Solomon et al. 1989) Information from payment records was received on 71 persons who died during this period. These persons were identified from a review of death certificates with AIDS listed as a cause of death. The authors found that HIV-related monthly payments grew from about $1,500 per month three months before the patient's death to more than $8,000 in the last month of life (Solomon et al. 1989). In a subsequent study of 149 decedents with AIDS who received services from Michigan Medicaid between January 1, 1995 and December 31, 1990 and for whom death records were available, Solomon and Hogan confirmed the finding that the cost of treating persons with AIDS climbs swiftly just prior to death.(Solomon and Hogan 1992)

In a longitudinal study of 322 enrollees in New Jersey's Medicaid

home and community-based services waiver program for persons with symptomatic HIV (the AIDS Community Care Alternatives Program -- ACCAP) who died between March 1, 1987 and February 28, 1989, Merzel and colleagues found that fifty percent of the expenditures were incurred during the last two months of life.(Merzel et al. 1991) ACCAP afforded reimbursement for services not normally covered by Medicaid including private duty nursing and personal care assistance services provided to enrollees in their homes.(Merzel et al. 1992) Expenditures during the last two months of life did not vary by exposure category (i.e. gay/bisexual men, injection drug users, women) but did vary by race and gender. Black enrollees and women enrollees incurred higher expenses during the last two months of life because they were hospitalized more often and had longer lengths per hospital stay.

In a subsequent study that employed data on all 801 enrollees in the ACCAP between March 1, 1987 and February 28, 1989, Merzel and colleagues found that nine percent of enrollees incurred costs in excess of $50,000 (these cases were termed "cost outliers"). (Merzel et al. 1992, p. 38) Of the group of decedents who were cost outliers, 92 percent were hospitalized during the two year study period; of the group of decedents who were not cost outliers, only 60 percent were hospitalized during the two year study period. This study also found that 92 percent of the cost outlier decedents received services from home health agencies and

60 percent of the decedents who were not cost outliers received services from home health agencies.(Merzel et al. 1992, p. 38) The reverse was true for services received from spouses. It was found that four percent of the cost outlier decedents received care from a spouse and 13 percent of the decedents who were not cost outliers received services from a spouse.

Based on an analysis of the computerized coverage and claims files from Blue Shield of California, Lee and colleagues found that medical care charges for PWAs were U-shaped over the course of the disease.(Lee et al. 1991) For patients who received most of their care in Los Angeles and were diagnosed with AIDS in 1989 the mean monthly charges for the three month time period immediately following diagnosis were $5,204 ($15,612/3); the mean charges for the 12 month time period immediately following diagnosis for those diagnosed in 1989 were $2,304 ($27,651/12); and the mean charges for the three month time period prior to death for patients who died in 1989 were $9,922 ($29,767/3). For patients who received most of their care in San Francisco these figures were $2,185, $1,570, and $6,423, respectively.

The study by Lee and colleagues used billed charges as a measure of costs. Yet, the amount received by providers of care may be substantially less than billed charges. The amount of the billed charges deemed "allowed" is often a better approximation of the amount actually received by providers. Yet, often the level of

allowed charges is viewed as proprietary by health insurers and is unavailable to researchers. The level of allowed charges was not available to the researchers in the study of Blue Shield of California's computerized claims files.

In our study, the level of billed charges also is used as a measure of costs. Thus, our study also overestimates the amount actually received by providers. Cost estimates derived using billing data overstate the cost of medical care to insurance companies, public insurers, and individuals. In addition, cost estimates based on billing data do not measure the cost to society (i.e., the "real" cost, or what economists refer to as the "opportunity" cost) because charges (whether billed or allowed) are not accurate measures of the real cost of resources.

III. METHODS

The contract to develop and conduct the ACSUS was awarded to Westat Inc., Rockville, Maryland. The ACSUS sample was obtained using a three stage sampling design (selection of cities, providers, and study participants). The ACSUS includes data on persons with HIV from ten cities (Baltimore, Maryland.; Chicago, Illinois; Houston, Texas; Los Angeles, California; Miami, Florida; Newark, New Jersey; New York City, New York;

Philadelphia, Pennsylvania; San Francisco, California; and Tampa, Florida).

A list of institutions (hospitals and freestanding clinics) as well as physicians that treat persons with HIV was obtained from the Centers for Disease Control and Prevention (CDC) National AIDS Information Clearinghouse and from local health departments, and estimates were made of the number of infected persons receiving care from each provider. In general, the providers in each area that treated the most persons with HIV were selected. Thirty-two providers were selected for the ACSUS sample, and 26 agreed to participate in the ACSUS. Of the 26 providers that agreed to participate, five were from New York City, three each from Newark, Tampa, and Miami, and two from each of the remaining cities.

The third stage involved selecting patients with HIV infection from each site. A systematic probability sample was drawn at each site that involved obtaining basic information (e.g. HIV status, gender, insurance status, likely route of infection, and symptoms) from all patients that received care at a site over a two to four month time period. Screening forms were distributed to 5,811 persons with HIV infection. The screener forms were distributed by study coordinators at each site. Patients who were not infected with HIV were automatically excluded from the sample.

The screener form did not have any patient identifying information other than a number that could be used to call back the patient in case they were selected for the sample. Using information in the screening form, the site coordinator placed each patient in a sampling stratum and an algorithm developed by statisticians at Westat, Inc., was used to select the sample. The sampling algorithm insured an adequate representation of persons by stage of illness (asymptomatic, symptomatic, and AIDS), exposure group (gay/bisexual, intravenous drug user (IDU), and other), and source of payment. Of those asked to participate in the ACSUS, 88 percent agreed. The lowest recruitment rate was 80 percent for asymptomatic homosexual men.

The ACSUS collected information on all services consumed by persons with HIV. Participants were interviewed every three months during an 18 month time period from Spring 1991 to Fall 1992. The first interview included questions about the use of services during the time period between March 1, 1991 and the date of the first interview, and the last interview included questions about the use of services from the time of the fifth interview through August 31, 1992. The short time period between interviews was selected to reduce recall bias. It is important for survey to HIV-infected persons as frequently as possible because persons with HIV may experience problems that affect memory.

At the first interview participants were asked to identify all providers of health care, and at each subsequent interview participants were asked to identify new providers. Participants were asked to sign release forms for each health care provider (e.g., physicians, clinics, hospitals, pharmacies, and nursing homes) so that billing and medical record data could be obtained.

ACSUS has been successful in following patients from interview to interview. During each of the six interview periods, only about seven percent of the persons interviewed during one time period were not interviewed the next time, and almost all of these either were determined to be dead or to have moved out of the area. Only about one percent of the participants were not re-interviewed in each period because their whereabouts were unknown or they refused to be re-interviewed.

This study uses data from the fifth wave of interviews, which were conducted during the spring and early summer of 1992. Respondents in the fifth wave of interviews were divided into those who did, and those who did not, survive the sixth time period. (Note, all of the data used in this study were obtained from respondents who survived through the fifth time period). Of the 688 PWAs interviewed in the fifth wave, 609 survived the sixth time period and 79 died during the sixth time period. If it assumed that the dates of death of these 79 PWAs were uniformly distributed across the sixth time period then the

average amount of time between the end of the fifth time period and the date of death is one-and-a-half months.

Billing records from hospitals, physicians' offices, clinics, home health providers, and pharmacies for all services received by respondents during the period between March 1, 1991 and December 31, 1991 were abstracted by a team of field workers between March 1, 1992 and July 1, 1992 during the first round of the provider survey. The second round of the provider survey collected billing data from providers for all services received by respondents between January 1, 1992 and August 31, 1992. This effort began in April 1993 and ended in July 1993. Data from the second round of the provider survey were unavailable at the time of this study. Data from the first round of the provider survey were used in this study to derive estimates of the average charge for a hospital day, an outpatient visit, and a home health visit as well as an estimate of the average amount spent on prescription drugs per respondent.

IV. RESULTS

Table 1 compares characteristics of PWAs who died during the sixth time period with those who survived the sixth time period. Table 1 shows that the proportion of decedents identified as

gay/bisexual men, injection drug users (IDUs), or other, is similar to the proportion of survivors identified as gay/bisexual men, IDUs, or other. The information on exposure category was obtained from the screener form and a large proportion of both decedents and survivors indicated that they were neither gay/bisexual men nor IDUs. It is likely, however, that some of those who indicated that they were neither gay/bisexual nor an IDU were not accurately reporting this information.

Table 1 also reveals that a lower proportion of decedents are women (11 percent) than survivors (17 percent), and that the proportion of decedents and survivors insured by private companies, Medicaid, or other public payers, and those without insurance is similar to the proportion of survivors in these categories. Fifty two percent of the survivors were covered by Medicaid while fifty eight percent of decedents were covered by Medicaid. Four percent of survivors and six percent of the decedents were uninsured.

The racial/ethnic composition of decedents and survivors also is presented in Table 1. White persons comprise 46 percent of both decedents and survivors, while black persons comprise 31 percent of decedents and 28 percent of survivors. Hispanic individuals comprise about 23 percent of decedents and 24 percent of survivors. Two percent of survivors were neither white, black, or Hispanic, and there were no persons in the "other" category

among decedents.

Seventy-one percent of decedents were hospitalized during the fifth time period and 28 percent of survivors were hospitalized during this time period. The average length of stay was 19.3 days for decedents and 10.3 days for survivors. The average standardized number of hospital admissions was .70 for decedents and .28 for survivors. The average standardized number of hospital days for decedents during the fifth time period was 13.6 and for survivors it was 2.9 (see Table 2). Numbers of hospital days and admissions are "standardized" to a three month time period because interview instruments collect information about service use between the date of the prior interview and the date of the current interview, and this time period is not always exactly three months.

Table 2 compares hospital use, ambulatory visits, emergency room visits, home health visits, and prescription drug use for decedents and survivors. The average standardized number of emergency room visits during the fifth time period was .4 for decedents and .5 for survivors. The average standardized number of ambulatory visits (i.e., community clinic visits, hospital clinic visits, and physician office visits) was 4.5 for decedents and 5.2 for survivors.

The average standardized number of formal home health visits

received by decedents during the fifth time period was 11.2; it was 2.7 for survivors. Formal home health visits include visits by physicians, nurses, social workers, case managers, therapists, and other paid helpers that provide medical care services. Formal home health visits do not include meals delivered or visits by persons who provide housekeeping services. They also do not include visits by friends and relatives who provide medical care services. Thirty percent of decedents and 11 percent of survivors received formal home health visits during the fifth time period.

The average number of prescription drugs taken by decedents during the fifth time period was 5.2 and for survivors it was 5.3. This number includes all drugs that were purchased by the respondent, that were given to the respondent free of charge by a physician or at a clinic, and all drugs that were refilled during this time period. This number measures the number of distinct medications and not the number of prescriptions.

Data on the estimated cost of care received by decedents and survivors appear in Table 3. Estimates of the cost of each service were obtained from the first round of the provider survey. The estimated cost is $216 for an ambulatory visit, $336 for an emergency room visit, $1085 for a hospital day, $125 for a home health visit, and $50 for each prescription drug. The utilization rates in Table 2 were multiplied by the per unit

costs to derive the estimated cost of services received during the fifth time period (Table 3). The estimated cost figures in Table 3 represent the cost of care for three months.

Table 3 reveals that the cost of treatment in the fifth time period for PWAs who died in the sixth time period was more than three times as large as the cost of treatment in the fifth time period for PWAs who were alive at the end of the sixth time period. The higher costs are attributable to a greater likelihood of being hospitalized, longer lengths of hospital stay, and greater use of home health services. The utilization rates of ambulatory care services, emergency room care, and drugs are similar for decedents and survivors. The average monthly cost of treating decedents during the fifth time period is $5,840 ($17,522/3), and the average monthly cost of treating survivors during the fifth time period is $1,680 ($5.041/3).

Thirty-one percent of the decedents utilized informal home health services, and 20 percent of survivors utilized informal home health services during the fifth time period. Informal home health care services include all health care related services (e.g., changing dressings, insuring that appropriate medications are taken at proper time intervals, cleaning and operating infusion systems, and taking the patient's temperature and monitoring other vital signs) provided by friends and relatives in the patient's place of residence.

Using data only from the sample of decedents it was discovered that decedents who had received informal home health services spent fewer days in the hospital. Decedents who received informal home health services spent an average of 7.5 days in the hospital whereas those who did not receive informal home health services spent an average of 16.2 days in the hospital. Conversely, it was found that decedents who received formal home health care services spent more days in the hospital (11.9) than decedents who did not receive formal home health care services (3.9).

Again, using data only from the sample of decedents it was found that whether or not a decedent died in the hospital was closely related to the number of hospital days. Death certificates and medical and billing records were scrutinized in order to determine the site of death for a random sample of 31 decedents. If the date of death for a decedent was the same of the date of discharge from the hospital then it was assumed that the person died in the hospital. It was found that 20 decedents died outside of the hospital and 11 died in the hospital. Decedents who died in the hospital spent an average of 27.3 days in the hospital during the fifth time period while those who died outside of the hospital averaged 12.5 days in the hospital during the fifth time period.

V. DISCUSSION

The cost of treating PWAs who survived a subsequent three month period was compared to the cost of treating PWAs who did not survive a subsequent three month period in this study. We were unable to obtain information about the use of services during the weeks immediately preceding death because interview data were not available from decedents for the sixth time period. If the dates of death for the decedents in our study are randomly distributed through the sixth time period then information about the utilization of services for an average of one and one-half months is missing. It is likely that if information about the utilization of services up to the moment of death were available that the differences in utilization between decedents and survivors would have been greater.

Nonetheless, this study suggests that the cost of treating PWAs rises rapidly as the time of death approaches. The cost of treating decedents was found to be about three times as great as the cost of treating survivors during the fifth time period. This occurs because decedents use disproportionately large amounts of home health and hospital services compared to survivors. There is no difference in their utilization of emergency room services, ambulatory medical visits, or drugs.

This study not only compares the composition and costs of care

between decedents and survivors, it also identifies factors that explain variations in the use of services among decedents. It is shown here that decedents who receive health care services from friends and relatives used fewer hospital services than decedents who did not receive health care services from friends and relatives. The reduced use of hospital services by decedents with strong social support systems (i.e., by decedents who received health care services from friends and relatives) may reflect both a greater resolve to remain at home as well as a greater capacity to remain at home. Furthermore, PWAs with strong social support systems who prefer to remain at home as long as possible may be less likely to demand an aggressive approach to treatment because it frequently entails long periods of hospitalization.

Data also reveal that decedents who use formal home health care services consume more hospital services than decedents who do not use formal home health care services. This was unexpected because home health care services (whether formal or informal) often are viewed as a cost-efficient substitute for hospital care.(Abramovitz, Michael, October 1991) To some extent, this finding may reflect the greater use of all types of health services by PWAs with poor social support systems. And to some extent, the greater use of both formal home health care services and hospital services by some decedents may reflect an aggressive approach to treatment.

It was also found that persons who died in the hospital were hospitalized more than twice as many days as persons who died at home. For some patients, the site of death may reflect an explicit decision about preferences concerning where and how to die. For patients without adequate support services at home, there may be no choice.

VI. CONCLUSION

Using data from a sample of 609 survivors and 79 decedents from the fifth wave of the ACSUS, this study shows that the cost of treating decedents is more than three times the cost of treating survivors. Decedents experienced more than four times the number of home health visits and were hospitalized more than four times as many days as survivors. Both the average length of stay (19.3 for decedents and 10.3 for survivors) and the frequency of hospitalization (.70 for decedents and .28 for survivors) were higher for decedents than survivors. The levels of outpatient care (including emergency room care) and of prescription drug use were similar for decedents and survivors.

Previous studies have demonstrated that the cost of treating persons with AIDS increases as the time of death approaches. Yet, this study is the first to include persons with AIDS covered

by different insurers and the first to included PWAs from a variety of geographic areas. It also is the only study that examines the cost of care since 1990 (this is important because treatment regimens for patients with HIV infection change rapidly (Hellinger, Fred, June 1993)), and the first to examine the use of emergency room care, outpatient medical office visits, prescription drugs, and home health care services by decedents and survivors.

This study includes a relatively small number of decedents (n=79) which makes it is impossible to estimate the impact of geographic variations on the use of services by decedents. A larger sample of decedents must be studied in order to obtain an estimate of treatment variations across geographic areas. In addition, a larger sample is needed to explore the influence of gender, exposure category, insurance status, and race, on the utilization of services by decedents.

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TABLE 1

Information on Study Population

	Decedents (N=79)	Survivors (N=609)
Exposure Category		
Gay/Bisexual	57.1*	53.6
IDU	19.5	18.3
Other	23.8	27.8
Gender		
Female	10.7	17.2
Male	89.3	82.9
Insurance		
Private	27.7	29.8
Medicaid	57.8	51.7
Other Public	8.4	14.6
None	6.0	4.0
Race		
White	46.4	46.1
Black	31.0	27.6
Hispanic	22.6	24.4
Other	0.0	2.0

*Figures are precentages of decedents (survivors) in each category. The percentages do not add up to exactly 100 due to rounding error.

Table 2

Utilization of Services for Persons with AIDS
During the Fifth Time Period

	Decedents (N=79)	Survivors (N=609)
Ambulatory Medical Visits (Excl. Emer. Room)	4.5	5.2
Emergency Room Visits	.4	.5
Home Health Visits	11.2	2.7
Hospital Days	13.6	2.9
Drugs	5.2	5.3

Table 3

Cost of Care for Persons with AIDS
During the Fifth Time Period

	Decedents (N=79)	Survivors (N=609)
Ambulatory Medical Visits (Excl. Emer. Room)	$972 (6)*	$1,123 (22)
Emergency Room Visits	134 (1)	168 (3)
Home Health Visits	1,400 (8)	338 (7)
Hospital Days	14,756 (84)	3,147 (62)
Drugs	260 (1)	265 (5)
Total	17,522	5,041

*Figures in the parentheses represent the percent of cost attributable to the service. The figures in the parentheses do not add up to exactly 100 due to rounding errors.

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The Use of Health Services by Women with HIV Infection

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Agency for Health Care Policy and Research

The Use of Health Services by Women with HIV Infection

Fred J. Hellinger

Objective. The purpose of this study is to determine whether women who have been diagnosed with HIV utilize the same volume of medical care services as men who have been diagnosed with HIV.

Data Sources. This study uses data from the first wave of interviews of the AIDS Cost and Service Utilization Survey (ACSUS) conducted between May and July of 1991. The first wave of interviews involved 1,949 adults and adolescents, of whom 359 were women.

Study Design. The ACSUS sample was selected from 26 sites (hospitals, clinics, and physician offices) in ten cities chosen from the 25 cities with the most AIDS cases. Cities are located throughout the nation, and in low, medium, and high prevalence areas. The sites in each city are generally those that treat the highest number of persons with HIV infection. Patients at each site were chosen using disease stage (asymptomatic, symptomatic, and AIDS) and gender as the selection criteria. Utilization equations are estimated for AZT use, outpatient care, and hospitalization.

Data Collection. The ACSUS involves six in-person interviews over an 18-month period. Interviews include questions about the use of medical and support services, insurance status, functional status, and barriers to care during the prior three-month period.

Principal Findings. A male injection drug user (IDU) with AIDS is 20 percent more likely to be hospitalized than a woman with AIDS, and the hospital cost of treating a male IDU with AIDS is $9,180 more per year than the hospital cost of treating a woman with AIDS.

Conclusions. This study shows that, even after being diagnosed and after having accessed the medical care system, women with AIDS receive fewer services than men with AIDS.

Keywords. HIV, AIDS, women with HIV/AIDS, access

BACKGROUND

This study uses timely data from a national survey to examine the relationship between gender and the use of health services by persons with HIV infection. The use of medical services (AZT, outpatient care, and inpatient care) by HIV-infected women is compared to the use of medical services by HIV-infected men after adjusting for stage of illness (asymptomatic, symptomatic, and AIDS), race, exposure category, geographic location, insurance status, and income. Data on the use of health services during a three-month time period in the spring and early summer of 1991 for 1,949 persons with HIV infection, of whom 66 percent did *not* have AIDS, are examined in this study. The vast majority of research into the cost of treating persons with HIV infection relates only to persons who have AIDS.

This study uses data from the AIDS Cost and Service Utilization Survey (ACSUS). The purpose of ACSUS is to provide a comprehensive data base on the types and cost of medical care services used by persons with HIV infection. Almost all existing cost studies of persons with HIV infection are limited to services covered by a single insurer or provided in a single hospital. These studies have been unable to link services provided by other insurers or services received at other hospitals to a specific individual. In order to acquire information on all medical services consumed by persons with HIV infection, a patient-based survey such as ACSUS must be conducted. Two patient-based studies have been conducted that analyze the economic cost of AIDS. Bennett and colleagues acquired data from 36 persons with AIDS in Los Angeles during the years 1987 and 1988 (Bennett, Cvitanic, and Pascal 1991), and Bennett and colleagues conducted a study in New York City on 38 intravenous drug users with AIDS in 1989 (Bennett, Pascal, Cvitanic, et al. 1992).

There is considerable evidence that women who are diagnosed with HIV exhibit a higher rate of serious infections than do men at entry into the health care system (Schoenbaum and Webber 1991; American Public Health Association 1991; Stein, Piette, Mor, et al. 1991; Caschetta 1990; and Harvard AIDS Institute 1991). The American Public Health Association states that "there is growing evidence

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that many women with HIV are not being diagnosed correctly and are not receiving care . . . many physicians who treat women do not expect to see HIV disease and as a result HIV-infected women may go undiagnosed until late in their disease." (American Public Health Association 1991, 8). Educational efforts regarding HIV are often directed at internists; yet many women receive their primary care from their gynecologist (Harvard AIDS Institute 1991, 11).

The proportion of women with AIDS is increasing, and there is evidence that this trend will continue. Eleven percent of the 230,179 AIDS cases reported to the Centers for Disease Control (CDC) through June 1992 were women (Centers for Disease Control 1992b). Yet 13 percent of all AIDS cases reported between July 1990 and June 1991 were women, and 14 percent of all AIDS cases reported between July 1991 and June 1992 were women. Data through May 1992 from the 19 states that implemented HIV surveillance prior to January 1991 reveal that 8.2 percent of all AIDS cases reported were women but that 15.6 percent of all HIV cases without AIDS were women (Fleming, Ward, Morgan, et al. 1992).

There are differences between women and men with AIDS in racial composition and risk behaviors. Although most men with AIDS are white (56 percent), only about one-quarter of women with AIDS are white (Centers for Disease Control 1992b, 12). In addition, a much smaller proportion of men (21 percent) with AIDS include intravenous drug use (IDU) as a risk factor than women (45 percent) (Centers for Disease Control 1992b, 8).

AZT

Existing studies suggest that women are less likely than men to receive AZT (zidovudine) even after controlling for a variety of factors (e.g., time since diagnosis, insurance status, exposure category, race, and disability status for Medicaid eligibility) (Moore et al. 1991; Solomon and Hogan, in press; Stein et al. 1991). Women with HIV infection who are pregnant may be less inclined to use AZT, and HIV-infected women are more likely to be poor and to use intravenous drugs than HIV-infected men (Minkoff and DeHovitz 1991). Both of these factors may contribute to lower rates of AZT use among women with HIV infection than among men with HIV infection.

A study based on persons with AIDS (PWAs) in Maryland indicates that women are less likely to receive AZT than men (Moore et al. 1991). Moore and colleagues used the Human Immunodeficiency Virus Information System (HIVIS) data set, which contains informa-

tion on Maryland residents with AIDS who were at least 17 years of age and were enrolled in Medicaid, Blue Cross and Blue Shield, the Maryland AIDS Drug Assistance Program, a clinical trial for AZT distribution sponsored by the Johns Hopkins University AIDS Clinical Trials Unit, or the Maryland Pharmacy Assistance Program. Of the 714 members of this cohort that were diagnosed with AIDS between April 1987 and June 1989, 53 percent of the men (313/596) and 33 percent of the women (39/118) received AZT.

Solomon and Hogan used Michigan Medicaid payment records generated between 1985 and 1989 to identify 783 people who were diagnosed with an HIV-related illness (Solomon and Hogan, in press). Payment records were merged with data from the Michigan Death and AIDS Surveillance registries. Of the 759 people identified, 59 percent of the males and 19 percent of the females had received at least one Medicaid paid prescription for AZT. This difference persisted even after eligibility criteria were taken into account. Women are more likely to be covered by Medicaid before an AIDS diagnosis. Most women qualify for Medicaid because they are on Aid to Families with Dependent Children (AFDC), and most men qualify for Medicaid because they are disabled. Thus, men on Medicaid are more likely than women to have AIDS and to be offered AZT. Of those who qualified for Medicaid in Michigan because they received AFDC payments, 38 percent of the men and 10 percent of the women had received AZT. Of those who qualified for Medicaid in Michigan due to a disability, 69 percent of the men and 46 percent of the women had received AZT.

The evaluation of the Robert Wood Johnson Foundation's AIDS Health Services Program (RWJF AHSP), conducted by researchers at Brown University, examined the use of health care services by women with HIV infection (Stein, Piette, Mor, et al. 1991; Mor et al. 1992). This evaluation used results from interviews of 939 clients of AHSP collected from November 1988 through April 1989 at ten hospital clinics and five affiliated community-based organizations (CBOs) in nine cities. Ninety percent of the 939 clients were male and 87 percent had AIDS. This sample provides some information about the use of services by women with AIDS, but it provides little information about the use of services by women with HIV infection without AIDS.

Using data from the evaluation of the AHSP, Stein and colleagues found that males were more likely to have been offered AZT than females (Stein, Piette, Mor, et al. 1991). This difference was most acute among the 87 persons with symptoms but without AIDS. In this population 65 percent of the men and 30 percent of the women were

offered AZT. This difference could not be explained by race (64 percent of white persons were offered AZT compared to 58 percent of nonwhite persons) or risk category (60 percent of IDUs were offered AZT compared to 61 percent of non-IDUs). Among persons with AIDS but without *Pneumocystis carinii* pneumonia (PCP), 88 percent of men and 68 percent of women were offered AZT. Among persons with PCP and AIDS, 95 percent of men and 89 percent of women were offered AZT. In a multivariate logit model that controlled for disease severity, IV drug use, insurance status, and race, men were three times as likely as women to be offered AZT.

OUTPATIENT AND INPATIENT CARE

In contrast to AZT use, existing studies indicate that most of the differences between women and men with HIV infection in their use of other health services may be explained by factors such as race, exposure category, insurance status, and stage of illness. These factors are important determinants of health service use, and their exclusion from studies of the relationship between gender and health service use may lead to biased estimates. For example, most studies have found that IDUs, once they have accessed the system, use more services than non-IDUs (Scitovsky 1989, 333; New York State Department of Health 1991, 147; Andrews et al. 1991, 1,046). Since the proportion of women with HIV infection who are IDUs is higher than the proportion of men with HIV infection who are IDUs, cost studies that do not adjust for exposure category may overestimate the impact of gender on the use of health care services.

Mor and colleagues explored the relationship between gender and the use of outpatient and inpatient care using data from the evaluation of the RWJF AIDS Health Services Program (Mor et al. 1992). The authors estimated a multivariate regression equation that controlled for gender, race, education, risk category, AIDS status, symptom intensity, and physical functioning. Dependent variables included the number of outpatient visits, use of the emergency room, and hospitalization during the three-month period prior to the interview. This study reports that white persons and non-IDUs were most likely to make outpatient visits, and black persons and IDUs were most likely to use the emergency room and to be hospitalized. Gender was not statistically significant in equations explaining the number of outpatient visits, use of the emergency room, or the likelihood of hospitalization.

A multivariate analysis of Medicaid enrollees with AIDS in New York state and California who died between October 1985 and Septem-

ber 1986 (681 on MediCal and 2,371 in New York) showed that women had 3 percent lower expenditures than drug-using males with no prior Medicaid enrollment (Andrews et al. 1991). The authors controlled for the diagnosis of PCP and Kaposi's sarcoma, eligibility status (medically needy only, Supplemental Security Income, and AFDC), age, drug use, and state (California, New York).

In a multivariate analysis of inpatient hospitalizations of 733 adult clients enrolled in a Medicaid waiver program (the New Jersey AIDS Community Care Alternatives Program or ACCAP) for functionally impaired persons with HIV infection, gender did not have a statistically significant effect on the number of hospital admissions or the number of hospital days (Merzel, Sambamoorthi, and Crystal 1991). This analysis adjusted for differences in race, exposure category, history of PCP, and time in the program. The data were from Medicaid claims for the period March 1987 through August 1989.

METHODOLOGY

The ACSUS is a study of 1,949 adults and adolescents in ten cities (Baltimore, Chicago, Houston, Los Angeles, Miami, Newark, New York, Philadelphia, San Francisco, and Tampa) and is funded by the Agency for Health Care Policy and Research (AHCPR). The ACSUS sample includes 359 women and 1,590 men. Participants were enrolled at 26 sites (e.g., freestanding clinics, physician offices, and hospitals). Data from the first (March–July 1991) of six waves of ACSUS interviews are analyzed in this study. ACSUS includes 422 asymptomatic persons with HIV infection and 840 persons with HIV-symptomatic illnesses (swollen glands, persistent fever, diarrhea, or slight weight loss), as well as 675 persons with AIDS.

The ACSUS sample was obtained using a three-stage sampling design. Initially, ten cities were selected from the 25 cities with most AIDS cases. These ten cities were selected based on geographic location (an attempt to include cities from all regions of the nation was made), prevalence of AIDS (a mix of low, medium, and high prevalence areas was sought), and the availability of a sufficient number of women (cities with large numbers of women with AIDS were given preference).

The second stage involved the selection of sites within each of the ten cities. A list of providers in each city was obtained from the Centers for Disease Control and Prevention's (CDC's) National AIDS Information Clearinghouse and from the local health departments. Thirty-two

sites were selected from the ten cities, and 26 agreed to participate in the study. At each site, approval was obtained from the institutional review board. In general, the sites selected were those that treated the most HIV-infected patients in the area. Two sites were selected from each city except for New York City where five were selected, and Miami, Newark, and Tampa where three were selected in each city.

The third stage involved selecting patients with HIV infection from each site. A systematic probability sample was drawn at each site; this involved obtaining basic information from all patients that received care at a site over a two- to four-month period. Screening forms were distributed to 5,811 persons with HIV infection at the 26 provider sites. The sample was collected by hiring a coordinator at each site to distribute to all patients during specified time periods a self-administered screening form. The screening forms contained questions about HIV status, gender, insurance status, and symptoms. Patients who were not infected with HIV were automatically excluded from the sample. The screening form did not have any patient-identifying information other than a number that was given to each patient after he or she filled out the form; respective numbers could be used to call back patients in case they were selected for the sample.

An algorithm derived by statisticians at Westat, Inc. was used to select the sample. The algorithm used disease stage and gender (women were oversampled) as the sample criteria. Those patients selected by the algorithm were then asked by the site coordinator to participate in the study and to fill out the informed consent forms. Of the patients who were asked, 88 percent agreed to participate in the ACSUS. As part of the first interview participants were asked to identify all providers of health care, and at each subsequent interview participants were asked to identify new providers. The purpose of the short time period between interviews was to mitigate errors due to poor recall. Because persons with HIV may experience problems that affect memory, it is important for surveys of HIV-infected persons to interview patients as frequently as possible.

Participants in the ACSUS were interviewed every three months during an 18-month period from spring 1991 to fall 1992. The first interview included questions about the use of services during the time period between March 1, 1991 and the date of the first interview. Participants were asked to sign release forms for each health care provider (e.g., physicians, clinics, hospitals, pharmacies, and nursing homes) so that billing and medical record data could be obtained. (Data from billing and medical records were not available at the time of this study.) In this study, the values for the two dichotomous dependent

variables (used or did not use AZT; and was or was not hospitalized) are not standardized. However, the variable representing the number of outpatient visits is standardized to a three-month period. This was necessary because March 1, 1991 was used as the reference date for all respondents, and most respondents were not interviewed exactly three months after the reference date.

All respondents were asked to report their utilization of services between March 1, 1991 and the date of the interview. When possible the interviews were conducted at locations (e.g., the sample site, a public place such as a restaurant, the respondent's home) suggested by the respondent. Westat, Inc. hired and trained interviewers at each site, and the data processing of the interview data was performed at Westat's headquarters in Rockville, Maryland.

The basic statistical techniques employed in this study are logistic multivariate analysis and linear multivariate analysis. The logistic model is used to examine a relationship where the dependent variable is binary (in this case, did or did not use AZT, and was or was not hospitalized). Coefficients in the logistic model are estimated using maximum likelihood techniques and are based on the assumption that the dependent variable equals one (i.e., the event occurred) only when an underlying response variable defined as $Y^* = a_0 + a_1x_1 + a_2x_2 + \ldots + x_n + u$ is greater than zero where u has a logistic distribution (Maddala 1983, 41–46).

Linear regression analysis is used to examine the relationship between outpatient visits and patient characteristics. Least-squares estimators are calculated for each coefficient in the linear model under the usual assumptions that the relationship between the dependent and independent variables is linear and that the error term is normally distributed with mean zero and constant variance (Johnston 1963, 107–142).

The coefficients presented further on (see Tables 2 and 4) for the logistic regression equations correspond to probabilities that the dependent variable is equal to one (i.e., that the event occurred). These coefficients are obtained by multiplying the logistic coefficients by $p(1 - p)$, where p is the average observed probability of the event occurring for persons in each equation (Kmenta 1971). Thus, the coefficient .19 for public insurance in Table 2 implies that a person with AIDS on public insurance (e.g., Medicaid) is 19 percent more likely than a person with AIDS without insurance (the reference category for this variable) to have used AZT during the three-month period covered by the first interview. Statistical significance is at the .05 level using a two-tailed t-test.

The utilization equations in this study include a combined gender and exposure variable. This variable has four categories (gay/bisexual, male IDU, women, and other). The gender and exposure categories are derived using information from the screening form, which asks the respondent to identify the most likely method by which he or she was infected (sex with gay/bisexual, intravenous drug use, sex with intravenous drug user, or other). Thus, persons with multiple risk factors are placed in only one category. About 7 percent of adults and adolescents with AIDS are identified as both gay/bisexual and intravenous drug users in CDC case reports (Centers for Disease Control 1992b, 8). Information about the date of a person's first positive test for HIV, race, ethnic background, medical history (e.g., whether he or she had PCP, Kaposi's sarcoma, herpes, or tuberculosis), and source of payment was also collected on the screener form.

The women category was not broken down by IDU status because in regression equations explaining AZT use, outpatient visits, and hospital admissions, the variable representing IDU status for women was not statistically significant. The "other" category includes men who acquired HIV through a blood transfusion or through heterosexual contact with a woman. The other category is the reference category for this variable. The AZT use variable is defined as one if the respondent reported taking AZT between March 1, 1991 and the date of the interview, and zero if the respondent did not take AZT during this period. The hospital use variable is similarly defined except that it is set at one if the respondent is hospitalized. The outpatient visits variable is defined as the number of ambulatory encounters with the medical care system between March 1, 1991 and the date of the interview.

The race variable has three categories (black, white, and other). The reference category for the race variable is the "other" category. The insurance variable is defined as public, private, and none. Those with no insurance constitute the reference category. The income variable represents before-tax income for 1990. Five income categories are defined ($0–$4,999; $5,000–$9,999; $10,000–$19,999; $20,000–$39,999; and $40,000 and above); and those with before-tax incomes between $0 and $4,999 constitute the reference category. In addition, there are dummy variables for each geographic location (i.e., providers were aggregated by city) except Baltimore. Baltimore is the reference category for the geographic variable.

RESULTS

Women in the ACSUS sample are poorer than men (see Table 1). Fifty-five percent of the women in the ACSUS sample had before-tax incomes of less than $5,000 in 1990, and only 1 percent had before-tax incomes greater than $40,000. Thirty-one percent of the men in the ACSUS sample had before-tax incomes of less than $5,000 in 1990, and 12 percent had before-tax incomes greater than $40,000.

Women in the ACSUS sample also are more likely to be black. Forty-eight percent of females in the ACSUS are black compared to 26 percent of the men. Alternatively, the proportion of females in the ACSUS who are white (21 percent) is lower than the proportion of males in the ACSUS who are white (47 percent). About the same

Table 1: Information on the Study Population

	Female	*Male*	*Total*
*Insurance**			
Private	29 (8)†	596 (38)	625
Public	279 (78)	706 (45)	985
None	51 (14)	258 (17)	309
*Income**			
<$5,000	194 (55)	474 (31)	668
$ 5,000-$ 9,999	89 (25)	331 (21)	420
$10,000-$19,999	44 (13)	297 (19)	341
$20,000-$39,999	21 (6)	264 (17)	285
>$40,000	4 (1)	187 (12)	191
*Race**			
White	74 (21)	733 (47)	807
Black	174 (48)	402 (26)	576
Other	113 (31)	440 (28)	553
Exposure Category			
Gay/Bisexual	–	1,059 (67)	1,059
IDU	134 (37)	354 (22)	488
Other	225 (63)	165 (10)	390
Disease Stage			
Asympto...atic	100 (28)	322 (20)	422
Symptomatic	154 (43)	686 (43)	840
AIDS	105 (29)	570 (36)	675

*The number of enrollees varies slightly among the three categories (insurance, income, race) because there were slightly different numbers of missing data fields for each question.

†The numbers in the parentheses are percentages calculated for each gender within each category (insurance, income, and race). Due to rounding error the percentages for each category range from 99 to 101.

percentage of females (31 percent) as males (28 percent) in the ACSUS sample are neither black nor white.

AZT

The proportion of persons in the ACSUS sample that received AZT during the preceding three-month period is similar across disease categories. Sixty-seven percent of PWAs, 65 percent of symptomatic persons, and 59 percent of asymptomatic persons used AZT during the study period.

Table 2 presents results from three logistic multivariate regression equations explaining AZT use. The coefficient for the gender variable in the asymptomatic equation is statistically significant and equal to −.20. This coefficient implies that an asymptomatic women is 20 percent less likely to receive AZT than an asymptomatic man in the reference category.

Table 2 also indicates that an asymptomatic male IDU is 26 percent less likely to receive AZT than an asymptomatic man in the reference category. The variables for public and private insurance are significant and positive in the asymptomatic equation. The coefficients

Table 2: Probability of AZT Use Based on Logistic Regression Analyses

	Coefficient†	t-*Ratio*
AIDS		
Female*	−.03	0.3
Public insurance	.19	3.0
Income ($10,000–$19,999)	.13	2.1
Income ($20,000–$39,999)	.18	2.3
Income ($40,000–)	.23	2.4
Symptomatic		
Female*	−.04	0.6
Asymptomatic		
Female*	−.20	2.2
IDU (male)	−.26	2.4
Private insurance	.35	4.0
Public insurance	.22	3.0

*All coefficients and *t*-ratios for the variable representing Female are reported here. Coefficients and *t*-ratios for other variables are reported only if they are statistically significant.

†All statistics are calculated from patient level data. Probabilities were obtained by multiplying logistic coefficients by $P(1 - P)$ where P is the average observed proportion of persons who used AZT within each disease stage. Thus, coefficients were evaluated at the mean value for each disease stage.

reveal that an asymptomatic person with private insurance is 35 percent more likely to receive AZT than an asymptomatic person without insurance, and an asymptomatic person with public insurance is 22 percent more likely to receive AZT than an asymptomatic person without insurance.

The gender variable was not statistically significant in the equation explaining the use of AZT for symptomatic persons or for persons with AIDS (PWAs). This implies that women who are symptomatic or who have AIDS are not more or less likely to receive AZT than men who are symptomatic or who have AIDS. The equation explaining the use of AZT by symptomatic persons did not have any significant variables.

Public insurance was positively associated with the use of AZT by PWAs. The probability that a PWA with public insurance received AZT is 19 percent more than for a PWA without insurance. The private insurance variable was not statistically significant in either the symptomatic or PWA equation.

Income is a statistically significant determinant of AZT use for PWAs but not for asymptomatic and symptomatic persons with HIV. The probability of a PWA with a before-tax income between $10,000 and $19,999 of receiving AZT was 13 percent more than for a PWA with a before-tax income less than $5,000, while a PWA with before-tax income between $20,000 and $39,999 was 18 percent more likely to receive AZT than a PWA with a before-tax income less than $5,000. A PWA with a before-tax income of $40,000 or more was 23 percent more likely to receive AZT than a PWA with a before-tax income less than $5,000.

OUTPATIENT SERVICES

The average number of outpatient visits incurred by a PWA during the standardized three-month period was 7.7. Symptomatic persons averaged 6.2 outpatient visits and asymptomatic persons averaged 5.6 outpatient visits during a three-month period.

Table 3 presents the results of regression equations explaining the number of outpatient visits incurred during a three-month period in early 1991. Data from the ACSUS reveal that women who are symptomatic or who have AIDS are more likely to use outpatient services than men in the reference category. Outpatient visits include emergency room, hospital clinic, community clinic, and private doctor office visits.

The regression equation for PWAs indicates that women had 3.8

Table 3: Linear Regressions of the Number of Outpatient Visits During a Three-Month Time Period

	Coefficient (Mean)	*t-Ratio*
AIDS		
Female*	3.8 (11.5)	3.2
White	3.1 (10.8)	2.4
Symptomatic		
Female*	3.1 (9.3)	3.6
White	2.3 (8.5)	2.9
Miami	2.4 (8.6)	2.4
Asymptomatic		
Female*	0.9 (6.5)	0.6

*All coefficients and *t*-ratios for the variable representing Female are reported here. Coefficients and *t*-ratios for other variables are reported only if they are statistically significant.

more outpatient visits than men in the reference category, while the regression equation for symptomatic persons indicates that women had 3.1 more outpatient visits than men in the reference category. The male IDU variable and the gay/bisexual variable were statistically insignificant in each of the three outpatient visit equations.

White persons with AIDS had 3.1 more outpatient visits than persons in the reference category (i.e., persons who are not white or black), and white persons with symptoms had 2.3 more outpatient visits than persons in the reference category. Symptomatic persons in Miami had 2.4 more outpatient visits than symptomatic persons in Baltimore. The variable representing black persons was not statistically significant in any of the equations explaining outpatient visits.

INPATIENT SERVICES

Table 4 presents results of the logistic equations explaining hospital admissions by PWAs and symptomatic persons with HIV. There is no logistic equation for asymptomatic persons with HIV because the SAS algorithm to estimate this logistic equation did not converge in 25 iterations. It is unclear exactly why the algorithm did not converge, but the fact that relatively few asymptomatic persons were hospitalized may have contributed to this problem. (Only about 8 percent of asymptomatic persons were hospitalized between March 1, 1991 [the reference date] and the first interview.)

Table 4 indicates that women with AIDS are less likely to be hospitalized than men with AIDS in the reference category. The coefficient for the gender variable is statistically significant and implies that

Table 4: Probability of a Hospital Admission Based on Logistic Regression Analyses

	Coefficient†	t-Ratio
AIDS		
Female*	-.05	2.0
IDUs (Male)	.15	2.8
Black	.08	2.1
Symptomatic		
Female*	-.05	1.2
Black	.09	2.9
Gay/Bisexual	-.10	2.7
Private insurance	.13	2.8
Public insurance	.11	2.7
Tampa	-.17	3.1

*All coefficients and *t*-ratios for the variable representing Female are reported here. Coefficients and *t*-ratios for other variables are reported only if they are statistically significant.

†All statistics are calculated from patient-level data. Probabilities were obtained by multiplying logistic coefficients by $P(1 - P)$ where P is the average observed proportion of persons who were hospitalized within each disease stage. Thus, coefficients were evaluated at the mean value for each disease stage.

the probability of hospitalization for a woman with AIDS during the observation period was 5 percent less than for a man with AIDS in the reference category. The coefficient for male IDUs is statistically significant and implies that the probability of hospitalization for a male IDU with AIDS is 15 percent greater than for a man with AIDS in the reference category.

The variable representing gay/bisexual men is not statistically significant in the logistic equation explaining hospitalization for PWAs. Yet the variable representing gay/bisexual men is negative and statistically significant in the logistic equation explaining hospitalization for symptomatic persons. The probability of hospitalization for a symptomatic gay/bisexual man during the observation was 10 percent less than for a symptomatic man in the reference category.

Both insurance variables are positive and statistically significant in the logistic equation explaining hospitalization for symptomatic persons. The probability of hospitalization for a symptomatic person with private insurance during the observation period was 13 percent higher than for an asymptomatic person without insurance, and the probability of hospitalization for a symptomatic person with public insurance during the observation period was 11 percent higher than for a symptomatic person with no insurance. The only statistically significant geo-

graphic variable was for symptomatic persons in Tampa. The probability of hospitalization for a symptomatic person in Tampa was 17 percent less than for a symptomatic person in Baltimore (the reference city in this category).

COST IMPLICATIONS

The probability of hospitalization for a woman with AIDS is 5 percent less than for a man with AIDS in the reference category (Table 4). In results not presented here, none of the gender/exposure category variables (i.e., gay/bisexual, male IDU, female, and other) was statistically significant in the regression equation explaining the average length of stay for a PWA. Thus, we deduce that a woman consumes $2,295 less for hospital services per 12-month period (.05 × $45,900) than a man in the reference category.[1] A woman with AIDS has an average of 15.2 (3.8 × 4) more outpatient visits per 12 months of life than a man with AIDS in the reference category (Table 4). A recent study indicates that the average cost of an outpatient visit for a PWA is $138 (New York State Department of Health 1991, 142). Using this figure for the cost of an outpatient visit implies that the annualized cost of outpatient care is $2,098 (15.2 × $138) higher for a woman with AIDS than a man with AIDS in the reference category. These calculations suggest that the annualized cost of treating a woman with AIDS is comparable to the annualized cost of treating a man with AIDS in the reference category—women with AIDS consume $2,295 less for hospital services and $2,098 more for outpatient services over 12 months. Our results also reveal that the difference in costs between treating a man in the reference category with AIDS and a gay/bisexual man with AIDS is *not* statistically significant.

Data from this study reveal that the probability of a woman with AIDS being hospitalized is 20 percent less than the probability of a male IDU with AIDS being hospitalized. (The female variable in the AIDS equation in Table 4 has a statistically significant coefficient equal to -.05 and the male IDU variable has a statistically significant coefficient equal to .15.) This suggests that a woman with AIDS incurs $9,180 (.20 × $45,900) less for hospital services than a male IDU with AIDS during 12 months of life. A woman with AIDS consumes $1,711 (3.1 × 4 × $138) more in outpatient expenses than a man with AIDS in the reference category, and the difference in outpatient use between a man with AIDS in the reference category and a male IDU with AIDS is not statistically significant. Thus, our findings suggest that the cost

of treating a male IDU with AIDS is substantially greater than the cost of treating a woman with AIDS.

DISCUSSION

In any discussion of the findings from this study, it is essential to underscore the study's limitations. First, the information used here was obtained through interviews and is self-reported. Although some responses were verified during the interviews (e.g., persons who indicated that they received Medicaid benefits were asked for their Medicaid cards), most responses were not verified. Second, the data may not reflect patterns of care outside the ten cities in which the ACSUS was conducted. And third, a relatively small number of women (359) were interviewed. In order to derive better estimates, it is necessary to collect data from more women in more geographic locations (including rural areas), and to verify as many responses as possible using information obtained from other sources (e.g., provider bills, medical records, and insurance records).

As noted above, the generalizability of the ACSUS sample is limited because it includes only respondents from ten cities and excludes persons with HIV infection who receive all of their health services in places other than these urban areas. Thus, the ACSUS data base is not nationally representative, and data from ACSUS are best suited to explore the relationships between variables. This study uses data from ACSUS to examine the relationship between characteristics of persons with HIV infection (with special attention to gender) and the utilization of medical services.

This study used data obtained at sites that treat the highest number of HIV-infected patients in their geographic region. Undoubtedly, the use of services by patients at sites that have extensive experience treating persons with HIV infection differs from the use of services by patients at sites that provide care to few persons with HIV infection. Existing studies have found that sites with more experience in treating HIV-positive people often produce better outcomes and use fewer resources (Bennett, Garfinkle, Greenfield, et al. 1989; Stone et al. 1992).

Multivariate analyses of naturally occurring phenomena in the social sciences often are confounded by serious problems with multicollinearity (i.e., strong interrelationships among the independent variables) (Maddala 1977, 183–200). Serious multicollinearity problems result in few statistically significant coefficients for the independent variables. In this study, it is difficult to separate the effects of income,

race, and insurance status from the effects of gender because of the close relationship among these variables. Women with HIV infection are more likely to be poor, nonwhite, and uninsured than men with HIV infection. In addition, the income variable may be picking up some health effects. Higher-income PWAs may constitute a subset of PWAs who are in better health, are more likely to be employed, and are better able to tolerate AZT. The close relationship between health status and income makes it difficult to disentangle their effects.

Our findings are biased to the extent that the women in our sample are sicker than the men. This might not be a notable problem if the disease stages in our study had been narrowly defined and had included only persons who manifested the same clinical conditions. However, our disease categories are broad, and it is certainly possible that the women with AIDS in our sample are more seriously ill than the men with AIDS.

It is unclear why women with AIDS use fewer health services than men with AIDS after adjusting for income, race, insurance, and geographic differences. To some extent, this finding may simply reflect the fact that women have more child care and other family-related responsibilities. Or to some extent, this may result from a situation where women are healthier than men in the reference category or where discrimination occurs against women with HIV infection.

One unanticipated finding of this study is that geographic variations in the use of AZT, outpatient care, and inpatient hospital care were rarely statistically significant in the multivariate analyses. Only the variable representing Miami in the symptomatic outpatient equation and the variable representing Tampa in the symptomatic hospital admission equation were statistically significant.

CONCLUSIONS

This study shows that, even after they have been diagnosed and have gained access to the medical care system, women receive fewer medical care services than men. In particular, women with AIDS receive fewer services than male IDUs with AIDS, and asymptomatic women with HIV infection are less likely to receive AZT.

This study focuses only on persons who have access to the health care system. Yet there are increasing indications that many HIV-infected women are not being diagnosed accurately and are at elevated risk of having a primary health care provider who knows little about HIV (American Public Health Association 1991; Harvard AIDS Institute

:991). Issues about access to care are not addressed in this study, and research is needed to examine patterns of utilization of services by women with HIV infection before the time they are diagnosed.

NOTE

1. My derived estimate for the annualized cost of hospital care for a PWA in 1991 is $45,900. I estimated that the calendar year cost of inpatient care for a PWA was $28,700, and that the average PWA who is alive during any part of a calendar year lives 7.5 months during that calendar year—so that the annualized cost (i.e., the cost for 12 months of life) of inpatient care is ($28,700/7.5) × 12 = $45,900 (Hellinger 1992).

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No. 2 • April 1994

ACSUS Report
AIDS Cost and Services Utilization Survey

Health Insurance Coverage of Persons With HIV-Related Illness: Data From the ACSUS Screener

by Claudia L. Schur, Ph.D., and
Marc L. Berk, Ph.D., Project HOPE

Introduction

Although health care services for persons infected with HIV (human immunodeficiency virus) are financed by the same public and private sources of payment as is care for the rest of the population, the relative importance of each type of health insurance coverage is markedly different. The role of Medicaid, for example, is more central to financing care for persons with HIV-related illness than it is for other care, and that of private insurance and Medicare is less significant. The outcome is a larger residual pool of persons with no outside source of payment for care and less adequate benefits for those who are covered (discussed in Baily et al., 1989, among other sources).

Despite the significant interest in understanding patterns of health insurance coverage among the HIV population, important gaps in knowledge remain. The Agency for Health Care Policy and Research designed the AIDS (acquired immunodeficiency syndrome) Cost and Services Utilization Survey, or ACSUS, to meet the needs of health services researchers and health policymakers concerned with HIV. ACSUS is a longitudinal survey of persons with HIV-related illness in 10 major cities. Although ACSUS is not a national probability sample and thus should not be used for deriving national estimates of the HIV population, its broad representation of persons with HIV-related illness allows examination of a wide range of issues related to the financing of care for this population. (A more detailed description of the study design and objectives is provided in Berk, Maffeo, and Schur, 1993.) Because survey respondents were identified through major providers of care to the HIV population, all information collected pertains to persons already receiving care for the illness. The data in this report are based on a screener questionnaire completed by almost 6,000 persons; these persons formed the sampling frame from which the ACSUS sample was selected.

Data presented in this report suggest that type of health insurance coverage, if any, is related to self-reported stage of illness among persons who are infected with HIV. There are two primary reasons why source of payment may change over the course of the disease. First, as the illness progresses, persons infected with HIV may become unable to work and are at risk of losing their employment-related insurance. Second, as individuals' resources diminish or as they become disabled, both the previously insured and the uninsured may become eligible for Medicaid. In controlling for stage of illness, however, wide variation is observed in type of

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No. 1 • August 1993

ACSUS Report

Research Design and Analysis Objectives

by Marc L. Berk, Ph.D., Project HOPE;
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and Claudia L. Schur, Ph.D., Project HOPE

Objectives

The increase in the number of reported cases of AIDS (acquired immunodeficiency syndrome) and the expanded demands on the health care system for treating persons with illness related to HIV (human immunodeficiency virus) have been widely reported. Despite the growing problem, data on use of and expenditures for health care services for this population are surprisingly scarce. Thus, public policy related to the HIV epidemic has often been formulated on the basis of limited case studies and cross-sectional research.

ACSUS is the largest data collection effort targeting the population of persons infected with HIV. In addition, its design addresses three major limitations of current data. First, data from other sources do not permit examination of early stages of HIV illness, such as periods of asymptomatic infection, or HIV illness that does not satisfy diagnostic criteria for AIDS. The ACSUS sample includes more than 400 adults who reported being HIV positive but having no HIV-related symptoms or conditions. Second, despite the fact that the disease is increasingly treated in outpatient settings, current information on AIDS does not permit analysis of the use of a wide variety of outpatient services. ACSUS data, on the other hand, include the use of and charges for the full range of ambulatory physician settings, use of both formal and informal home care services, use of a number of mental health and support services, and use of and charges associated with various drug therapies. Finally, perhaps of greatest importance is the longitudinal nature of ACSUS. Length of survival after infection has been increasing and may continue to do so as prophylactic treatment for HIV infection becomes the norm. Yet there is little information on how levels and mix of service use, sources of payment for care, or quality of life change over the course of the illness. With six interviews over the course of an 18-month period, ACSUS will provide a wealth of information on factors affecting the use of services over different stages of the illness.

Data collected through ACSUS will be key to the formulation of Federal strategies for the allocation of resources to the care of persons with HIV-related illness and to a broader understanding of the effect of HIV on segments of the U.S. health care system. Moreover, the information needs of State and local governments parallel those of the Federal Government as they deliver care to persons with HIV-related illness.

This report, the first in a proposed series presenting findings from ACSUS, introduces the study by providing a broad overview of data collection procedures and by describing general

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