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[AHCPR's [Agency for Health Care Policy and Research] "Highlights of HIV-Related Research" and News Clips] [loose]

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February 17, 1994

MEMORANDUM

TO: Kristine M. Gebbie

FROM: Alice M. Litwinowicz

SUBJECT: AHCPR's "Highlights of HIV-Related Research" and News Clips "Early HIV Infection Guideline" -- INFORMATION

AHCPR provided copies of the latest version of "Highlights of HIV-Related Research" for our office. I have distributed copies to staff at HHH and 750.

Also, AHCPR printed a special publication of news clips on the "Early HIV Infection Guideline." This is your copy; a copy is also being circulated at HHH and 750.

I understand AHCPR plans to send you directly a copy of the most recent report regarding the distribution of the "Early HIV Infection Guideline."

cc:
Barrer
Lee

AGENCY FOR HEALTH CARE POLICY AND RESEARCH HIGHLIGHTS OF HIV-RELATED RESEARCH

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AGENCY FOR HEALTH CARE POLICY AND RESEARCH
HIGHLIGHTS OF HIV-RELATED RESEARCH

February 1994 Working Document

Please Note: Unpublished information provided here is to be regarded as strictly confidential and not for reference, publication, citation, or public discussion without the explicit permission of the researcher, or of the Administrator, Agency for Health Care Policy and Research.

"AIDS Cost and Service Utilization Survey" (ACSUS)
Westat, Inc., Rockville, MD
Contract No. 282-89-0020 (Project Officer: Fred Hellinger)
Expected completion: 6/31/94

ACSUS is a national survey that collects data on the utilization and costs of health and social services for persons with AIDS and other HIV-related illnesses. The sample includes approximately 1900 adults and adolescents, plus 100 children. Respondents were recruited from 26 providers of medical care, located in 10 communities across the country. Respondents have been interviewed every 3 months over an 18-month period. In addition to receipt of inpatient and ambulatory medical care, respondents were asked about their use of social, mental health, and oral health services; informal social supports; barriers to care; employment history; and quality of life. Interview data will be supplemented by clinical data abstracted from patient medical records and by information on charges for services, which are supplied by providers and insurers. These sources will provide a comprehensive picture of the direct and indirect costs of medical and support services, during various stages of HIV-related illness. Data will include third-party and out-of-pocket payments, for both inpatient and outpatient care, including care received in physicians' offices, ambulatory clinics, and the patient's home. Utilization and charges for the services of physicians, nurses, and other health care workers will be obtained, as will charges for drugs, medical supplies, and devices. Documented data tapes will be available for use by the research community. The data from ACSUS will support examination of utilization, cost, and access across HIV exposure categories (e.g., homosexual, heterosexual, or intravenous drug use), stage of illness, demographic characteristics, geographic area, and payment source. By addressing the full spectrum of HIV-related illness and the range of health care pro-

viders and payers, ACSUS will provide a rich source of data for research and the basis for policy-relevant analyses concerning the utilization and costs of health care services associated with HIV illness.

The AHCPR is publishing a series of reports on ACSUS. The first report, by Berk, Mafeo and Schur, describes the research design and analysis objectives of the study (*ACSUS Report* No 1, AHCPR Pub. No. 93-0019). The second report entitled, "Health Insurance Coverage of Persons with HIV-related Illness" by Claudia L. Shier, Ph.D. and Marc L. Berk, Ph.D., Project HOPE, covers insurance data from the ACSUS. The third, and last in the series, entitled, "Patterns of Health Care Use Among HIV-infected Adults: Preliminary Results" by Penny Mohr, M.A., Project HOPE looks at factors affecting utilization of several different types of health and social services.

Data from ACSUS have been used by Hellinger (*J. Amer. Med. Assoc.*, 270:474-8, July, 1993) to estimate the cost of medical care for persons with HIV infection from the time of infection until death. Data from patient interviews conducted during the spring and early summer of 1992, and billing data from a survey of providers were used. The monthly cost of care at each of four HIV-disease stages was multiplied by the estimated mean occupancy time at each stage (using data from the San Francisco Men's Health Study) to derive a synthetic estimate of the cost of treating a person with HIV. Under the assumption that persons receive treatment continuously from the moment of infection until death, the upper bounds of the lifetime cost of HIV-related medical care was approximately $119,000. The cost of care from the time of HIV infection until the development of AIDS was estimated to be $50,000. It was found that the cost of treating a person with AIDS, which has risen rapidly in the past, has fallen as a result of a reduction in the use of inpatient hospital services.

In an article in *Health Services Research* 28:543-61, Dec. 1993, Hellinger used ACSUS data to find that women and adolescent girls infected with HIV receive fewer medical services, such as medications, hospital admissions and outpatient visits, than similarly diagnosed men. An asymptomatic HIV-infected female is 20 percent less likely to receive AZT than an asymptomatic male, and females with AIDS are 20 percent less likely than a male drug user to be hospitalized. This suggests that females with AIDS incur less hospital costs than male injection drug users with AIDS. It is unclear why females receive fewer health services than males after adjusting for income, race, insurance and geographic differences. This finding may reflect the fact that women have more family-related responsibilities, but discrimination could be a factor.

Three ACSUS Public Use Data Tapes are now available through NTIS. They are:

- ACSUS Tape 1, "AIDS Cost and Services Utilization Survey 1 (ACSUS 1) (for microcomputer)
- ACSUS Tape 2, "Adult Time 1 and 2 Questionnaire Data"
- ACSUS Tape 3, "Adult Time 3 and 4 Questionnaire Data"

Other early, but unpublished findings from ACSUS include:

- Controlling for disease stage, African-Americans were more likely to report a hospitalization than either whites or Hispanics.

- Level of physical impairment was associated with higher numbers of inpatient admissions and with more total nights spent as an inpatient. (based on waves 1-4)

- In general, people without health insurance were less likely to be hospitalized than those with either public or private insurance. The effects of insurance appear to be more pronounced at earlier stages of HIV infection than for people with AIDS.

- Among people with AIDS, women were less likely to be hospitalized than men. Gender differences are less strong for earlier stages of HIV infection.

- People in unstable housing circumstances, compared to those with stable housing, were more likely to be hospitalized, were more likely to use the emergency room, and reported higher mean number of inpatient nights.

- The proportion of HIV-infected persons reporting a stay in a nursing home was low (e.g., less than 2 percent of people with AIDS).

- The median number of ambulatory medical visits reported for a three-month period was 3.5 for asymptomatic respondents, 4.2 for HIV-symptomatic persons, and 5.3 for persons with AIDS.

- Among people with AIDS, white respondents reported more ambulatory visits than either African-Americans or Hispanics.

- Among people with AIDS, people with private insurance had more ambulatory visits than those with public insurance or no insurance. (Effects of insurance were less pronounced for people at earlier stages of HIV infection.)

- Among people with AIDS or with symptomatic HIV infection, women had more ambulatory visits than men. Gender differences were less pronounced for asymptomatic respondents.

- People in unstable housing circumstances reported fewer ambulatory medical care visits than people in stable housing situations

- Regardless of disease stage, a high proportion of respondents (>60%) reported using AZT.

- ACSUS data show little variation in use of AZT as a function of exposure group or race/ethnicity.

- Among asymptomatic respondents, women were less likely to receive AZT than men. Gender differences were less strong for respondents with more advanced HIV infection.

- People without any health insurance were less likely to receive AZT than those with public or private coverage.

- Among respondents with AIDS, whites were more likely than African-Americans or Hispanics to report receiving psychiatric or other mental health services.

- Among people with AIDS, those with private insurance were more likely to have received psychiatric support than those without insurance.

- In all disease stages, women had higher rates of use of psychosocial support services than men.

- Use of a dental care provider was strongly related to socioeconomic status: whites (compared to African-Americans or Hispanics), those with higher incomes (compared to those with lower incomes), and those with insurance

(compared to those without) were more likely to report use of dental services.

- Ten percent of respondents could be characterized as being in unstable or precarious housing circumstances at the time of the second interview.

- About one-third of the precariously housed were living "doubled up" in temporary arrangements with friends or family. Another one-third were living in SRO or welfare hotels.

- Women and African-American respondents were overrepresented among the precariously housed.

- 19% of respondents at the second interview reported at least one unmet need for medical or social services.

- Dental care was the most prevalent unmet need (9% of respondents).

- Respondents with private health insurance were less likely to report an unmet need than those with either public or no insurance.

- 30% of the pediatric sample experienced a hospitalization during the first six months of the observation period.

- For pediatric cases older than seven, 32% had used mental health services.

- 42% of the pediatric sample used formal home care services in the first six months of the observation period.

"Psychosocial Predictors of Pregnancy, Women at HIV Risk"
Ahluwalia, Indu B., University of North Carolina
R03 HS 07958 (Dissertation) (Project Officer: Julius Pellegrino)
Expected completion: 8/31/94

The study examines empirically the relationship between specific social psychological and demographic factors on pregnancy intentions and subsequent pregnancy status of women at risk for HIV. The specific aims of this research include: 1) to determine the role of psychosocial and demographic factors, and knowledge of HIV serostatus in predicting pregnancy intentions and subsequent pregnancy status; 2) to assess the psychometric properties of the study variables; and 3) to determine whether the psychosocial, demographic, HIV serostatus and barrier contraceptive use variables can discriminate between women with planned and unplanned pregnancies.

A longitudinal data set obtained from the National Institutes on Drug Abuse will be used to examine the role that social psychological and demographic factors play in explaining women's pregnancy intentions at baseline and pregnancy status at follow-up. Seventy-five percent of this nationwide sample are minority women reached by extensive outreach methods. Analyses will encompass descriptive statistics, principal component and factor analyses to construct scales and indexes, and tests of multivariate models using logistic regression. Findings from this research can help in preventing the incidence of unintended pregnancy among women at high risk for HIV and thus reducing HIV in children.

"Outcomes of Hospital Dedicated AIDS Units"
Aiken, Linda; University of Pennsylvania
R01 HS 06858 (Project Officer: Anne Bavier)
Expected completion: 8/31/94

The AIDS epidemic has served as a catalyst for experimentation in the organization of inpatient care which, if carefully evaluated, could yield promising solutions to many of the persistent problems of hospitals, including a dissatisfied and unstable nurse work force and uneven quality of care. Two models for organizing inpatient care have emerged as hospitals in high HIV incidence cities have responded to the AIDS epidemic: dedicated AIDS units with contiguous beds and a separate nursing staff specializing in the care of people with HIV-related illnesses, and scattered-beds located usually on multi-diagnosis medical units. Debate on the pros and cons of these two models has been heated, but empirical evidence has been largely lacking. This study is a 23 hospital study comparing clinical and economic outcomes of care provided in these two models. The study is a comparative, multi-site observational study, in which matching is employed at the hospital level to introduce the control elements of quasi-experimental design. Approximately 1500 patients are being studied, half having received their care in dedicated AIDS units and half in scattered-beds on medical units. Using state-of-the-science instruments to stage severity of illness, the study will examine inhospital mortality, patient satisfaction, length of stay, destination at discharge, and costs.

"Pediatric AIDS: Local Responses, Service Use, and Cost"
Allison-Cooke, Sherry; National Perinatal Information Center
R01 HS 06271 (Project Officer: Frantz Wilson)
Completed: 6/30/92

This project provided both longitudinal and cross-sectional data about the utilization and costs of inpatient and outpatient care for infants, children, and women with AIDS. The data was obtained through interviews with providers at 83 sites. One aspect of the study focused on discharge, billing, and cost data for HIV positive women in childbearing years and their offspring from 10 hospitals in 7 urban areas with high incidence of pediatric AIDS (Atlanta, Baltimore, Boston, Bronx, Miami, Los Angeles, and Newark) and analyzed trends from 1987 to 1990. In addition, detailed case studies were developed to address questions about alternate community responses to meeting the health care needs of women and children with AIDS and to obtain data on outpatient services.

Selected findings of the study include:

- While coordinated, comprehensive family centered care is a general goal of most programs, few fully achieve this goal in part because the programs rely on hospital-based specialty and primary-child care which does not lend itself to being dovetailed with services for other family members, and in part because the extensive range of services required by children complicated attempts to create "one-stop shopping."

- Services tailored to women with HIV are scarce and are not well utilized in part due to conflicting demands of other family members. Women neglect their own needs while making significant efforts to care for their HIV-infected children.

- Only rarely do private physicians treat women or children with AIDS, while many Community Health Centers have developed systems for diagnosis, referral, follow-up and primary care, forging links with community providers.

- A common response to fragmented care had been case management, yet case management is often fraught with duplication and inefficiency. The investigators reported frequent accounts of multiple managers per client, but with none of them having sufficient time to achieve optimal results.

"1988 U.S. Hospitals AIDS Survey"
Andrulis, Dennis; National Public Health & Hospital Institute
R03 HS 06445 (Project Officer: Melford Henderson)
Completed: 4/30/91

The 1988 U.S. Hospital Survey assessed the financial and programmatic impact of AIDS on hospitals. The study surveyed over 1200 hospital members of five associations: The National Association of Public Hospitals, COTH, The National Association of Children's Hospitals and Related Institutions, The National Council of Community Hospitals, and the Catholic Health Association. Research focused on examining hospital variation in utilization, the hospital's organizational structure, AIDS/HIV outpatient services of hospitals, financial characteristics of hospitals, and specific treatments. Additional analyses focused on use of AZT and aerosolized pentamidine, the financial and programmatic impact of HIV-related illnesses, hospitals participation in clinical trials, and community linkages and support.

Comparisons across hospital type indicate that patients in Catholic hospitals and community hospitals were more likely to be privately insured than those in public and/or teaching hospitals where Medicaid was the predominant payer. Lengths of stay were observed to be decreasing across all types of hospitals and large caseload growth was observed in public and teaching hospitals where longitudinal data were available. Forty-four percent of all patients in public hospitals with HIV did not have AIDS, but they had fewer admissions and lower lengths of stay. Across hospital type, patients with "other" HIV-related illness were more likely to be IVDUs (IVDUs represent 75% moreHIV than AIDS clients). Medicaid was the primary payer for those with other HIV. Children with HIV were most likely to be cared for in public hospitals.

In a report by Andrulis, et al. (*J. Amer. Med. Assoc.*; 1992;267;2482-6) on 325 responding hospitals, it was observed that these hospitals treated 30 percent of all AIDS patients alive during 1988, but that service utilization by other HIV patients was found to comprise a substantial portion of the total HIV burden and related costs. The average hospital was found to lose $204,000 a year treating uninsured persons hospitalized for AIDS, plus another $109,360 for treating HIV illness in uninsured patients. For every 100 AIDS cases admitted to hospitals, an additional 53 persons are admitted with other HIV-related

illnesses. Other HIV patients were more likely than AIDS patients to be intravenous drug users, female, non-white, and to have no source of health care coverage. The authors conclude that accounting only for the utilization of services by persons with AIDS, as defined by the CDC, will understate significantly the total burden of the HIV epidemic on hospitals, and the losses sustained from treating HIV cases other than AIDS, added to the treatment expenses for AIDS may someday force hospital to limit the number of these patients they admit. The results suggest that the expanded definition (then) proposed by the CDC would incorporate a large hospitalized population.

"Variations in Care of AIDS Patients with 1st Episode PCP"
Bennett, Charles Lee; The RAND Corp.
R01 HS 06494 (Project Officer: Elinor Walker)
Completed: 8/31/93

This study analyzed retrospectively five years of hospitalization data on patients presenting with a first episode of PCP in order to assess variations in quality of care, outcome (mortality), and resource use. AIDS care was examined in 5 high-AIDS-familiarity and 10 low-AIDS-familiarity hospitals located in Los Angeles, Chicago, Miami, and New York (a total of 45 hospitals). Patient discharge records were reviewed for patients admitted from October 1, 1986 through October 1, 1991. Factors associated with familiarity in treating PCP patients, hospital resource scarcity, process of care (period of time in diagnosing, initiating therapy, and recognizing failure to respond), and patient severity will be examined in relation to outcome.

Preliminary findings were presented at the VII International Conference on AIDS in Florence, entitled "1987 Volume-Caseload Relationships of HIV-Related PCP in New York City." Replicating a study previously performed in California, the investigators found, across 75 hospitals in NYC, that patients in high-caseload hospitals (those treating at least 150 cases of PCP) were significantly less likely to die than patients in low-caseload hospitals, after controlling for insurance status, illness severity, race, and prior hospitalizations.

Further results were presented in a 1992 article in the *J. Acquired Immune Deficiency Syndrome*. The chances of death from PCP decreased when care was given at hospitals with higher numbers of PCP cases (i.e., patients with HIV-related PCP were twice as likely to die when they recieved care at hospitals that treated more than 160 cases of first-episode PCP in 1987). It is suggested that hospital experience may decrease mortality with this subset of patients with HIV disease. A 1993 article in the *J. Acquired Immune Deficiency Syndrome* discusses policy implications of this finding, including regionalization of AIDS care.

In another 1993 article, differences were found between care received by men and women with PCP. The differences seemed to revolve around access to care--not having health insurance and being admitted thru the emergency room, and these differences seemed to be associated with a greater likelihood of women than men to die in hospital.

"Hospital Resource Use for HIV-infected Patients"
Bialy, David J.; University of Michigan
R03 HS 07493 (Dissertation) (Project Officer: Melford Henderson)
Completed: 9/29/93

Using data from 114 hospitals, this retrospective study measured the actual hospital inpatient resources required for the care of people with AIDS/HIV infection. The study was to: develop a profile of inpatient services (DRGs 488, 489 and 490); develop a profile based on major severity stages based on the International Classification of Clinical Services, and determine variations in the use of inpatient resources according to payor.

"Discriminatory Attitudes and Knowledge about AIDS"
Blendon, Robert Jay; Harvard School of Public Health
R03 HS 06379 (Project Officer: Jean Carmody)
Completed: 12/31/91

This is a secondary analysis of public opinion survey data to examine the relationship between hostile attitudes held by individuals toward persons who are infected with HIV and misinformation held by those individuals about how the virus is transmitted. Data come from surveys conducted by the Roper Center for Public Opinion Research, the Gallup Organization, and the *Los Angeles Times*, among randomly selected, national household samples, since 1985. Variables include knowledge and beliefs about how HIV is transmitted, demographic characteristics, attitudes and moral judgments about persons who are infected. Findings will inform the policy debate regarding the need for anti-discrimination legislation to protect individuals infected with HIV, and should be useful in addressing educational efforts.

"State Medicaid Policies for AIDS-related Health Care"
Buchanan, Robert J., Ph.D, University of Illinois
R03 HS 07210 (Project Officer: Melford Henderson)
Expected completion: 8/31/94

The objective of the project is to describe and catalog current Medicaid payment, coverage, and eligibility policies for a range of health services provided to Medicaid recipients with AIDS. The study includes assessment of prescription drugs and services provided by hospitals, nursing facilities, physicians, home health care agencies and hospices. Payment, coverage, and eligibility data will be collected by surveys mailed to the Medicaid programs and to the associations representing the health providers in each state and the District of Columbia. Survey questions will elicit information on services and access, comparing AIDS care with Medicaid reimbursement for other patients. The study will: (1) describe how State Medicaid programs are addressing the health needs of Medicaid recipients with AIDS, (2) identify innovative

policies which increase their access to care, and (3) identify Medicaid policies that create obstacles to providing care to Medicaid recipients with AIDS.

Preliminary findings include: With respect to hospice care, at least 13 Medicaid programs do not cover hospice services, but at least 13 programs do cover services which would allow AIDS hospice patients to stay at home. Complications of Medicaid hospice care relate to coverage of drug therapies (e.g., should hospice patients receive aggressive drug therapies?). With regard to home health care, almost all Medicaid programs pay home health providers for SNC and HHAS on a per visit basis, without adjustment for intensity of care, providing a disincentive to care for patients with AIDS. Similarly, AIDS patients can have care needs in excess of many program's utilization limits. Medicaid payments for home health care is low relative to other payment sources, but innovative and expansive programs have used the Home and Community-Based Waiver option.

"HIV Prevention in Primary Care: An Objective Assessment"
Carney, Patricia A.; University of Washington
R03 HS 07988 (Dissertation) (Project Officer: Julius Pellegrino)
Expected completion: 7/31/94

Providers in primary care have had a significant impact on patients' preventive health behaviors, and are appropriate health professionals to address the challenge of primary prevention of AIDS. Physician self-report, patient report and chart review of HIV preventive performance in primary care indicate these activities are not occurring at an acceptable rate. These methods of evaluation have inherent inaccuracies, and variability in patient presentation can influence provider's performance. Unannounced standardized patients (lay individuals trained to replicate a clinical encounter consistently for the purposes of evaluation) offer an objective prospective method of provider assessment, while controlling for patient variability. Using unannounced standardized patients and audiotaping via a hidden microphone and recorder for validation, this exploratory study aims to assess the frequency, and content of HIV risk factor determination, education, and counseling provided to heterosexual men and women by 20 primary care providers (family nurse practitioners and family physicians). The study also will assess the process of preventive health delivery in sequence and content of risk assessment and services delivered, and cost and time spent during the periodic health exam provided to individuals at risk of HIV exposure. This research would identify gaps in HIV risk factor determination, counseling and education being provided to heterosexual patients. Understanding how primary care providers organize the delivery of preventive health services will assist in the design of interventions to increase providers skill at identifying and assessing patient needs and delivering appropriate services.

"Outcomes of Pharmaceutical Therapy of HIV Disease"
Chaisson, Richard E.; Johns Hopkins University School of Medicine
R01 HS 07809 (Project Officer: Lynn Bosco)
Expected completion: 1/31/98

This project will assess the impact of antiretroviral and prophylactic and treatment antimicrobials on the natural history of human immunodeficiency virus (HIV) infection using a comprehensive longitudinal data base. The population studied is representative of the HIV-infected population in Maryland. The aim of the research plan is to develop a data base of individuals receiving care for infection with the HIV in order to assess utilization, appropriateness, and effectiveness of pharmaceutical therapies used in treating HIV disease. The specific aims are as follows: 1) to complete and maintain a comprehensive automated clinical data base--3,000 patients will be enrolled (30 percent female and 70 percent male comprised of 75 percent African-American and 25 percent non-Hispanic whites); 2) to delineate the frequency, consistency, and appropriateness of prescription drug use; 3) to determine factors that are associated with differences in prescription drug use, including insurance status, sociodemographic variables, psychiatric co-morbidity clinical status, and functional status; 4) to delineate differences in rates of drug-related adverse reactions to therapies for HIV disease by patient characteristics and determine how these rates affect subsequent outcomes; 5) to evaluate the effectiveness of antiviral and other antimicrobial therapy in preventing progression of HIV disease; 6) to determine the association of surrogate laboratory and clinical markers such as the CD4 lymphocyte count, CD4 cell percentage, and functional status with subsequent clinical outcomes; and 7) to determine the natural history of specific opportunistic infections and malignancies that complicate HIV infection treated with current prophylactic and maintenance pharmaceutical therapy.

In a report now in press, Moore, Stanton, Gopalan and Chaisson write that, although there were no racial differences in stage of HIV disease of subjects at presentation, there were racial disparities in receipt of therapy, with antiretrovirals received by 48 percent of eligible African-Americans and 63 percent of eligible non-hispanic whites. PCP prophylaxis was received by 58 percent of eligible African-Americans and 82 percent of eligible whites. There were no significant differences in receipt by age, gender, HIV transmission, insurance, income, education or residence. The observation that African-Americans are significantly less likely than whites to receive antiretroviral or PCP prophylaxis at first presentation suggests a need for culturally-relevant interventions to ensure that uniform standards are applied.

"Variations in AIDS Care in North Carolina"
Cohn, Susan, E., University of North Carolina
R03 HS 07526 (Project Officer: Jean Carmody)
Expected completion: 9/29/94

The study examines factors associated with morbidity and mortality that occur in the context of inpatient care for HIV-associated *Pneumocystis carinii* pneumonia (PCP). Data will be collected through a review of medical records from at least 300 adult patients admitted to 16 area hospitals for HIV-associated pneumocystis carinii pneumonia. Hospital medical records staff will identify cases based upon nine codes. Additional data will be obtained from interviews of hospital administrators to determine such characteristics as bed number, percentage Medicaid as payor, etc. The major outcome variable is in-hospital mortality.

Predictor variables include location of residence, rural vs. urban residence, gender, HIV risk factor, type of hospital, and characteristics of the hospital. In addition to comparisons within the proposed study population, comparisons will be made between the study population (North Carolina only) and four other urban populations (Miami, Chicago, Los Angeles, and New York) with much higher HIV caseloads. Finally, study data will be compared to those derived from a study at a Veterans' Administration (VA) hospital, to identify any differences that might exist in the outcome of care at the regional VA hospital.

"Physicians, Nurses, and AIDS: A National Study"
Colombotos, John; Columbia University
R01 HS 06359 (Project Officer: Jean Carmody)
Completed: 3/30/93

The researchers conducted a national survey of physicians and nurses to obtain data on how their knowledge, attitudes, risk perceptions, practices, and career plans relate to AIDS. Descriptive findings were extended through analyses of the interrelationships among these variables, e.g., the relationship between knowledge about AIDS and willingness to treat AIDS patients. Variations associated with respondents' professional characteristics and personal background were studied. Other analyses focused on the influence of geographic location, comparing health care workers from San Francisco with those from New York/New Jersey, and examining the possible influence on health care workers of the cumulative AIDS caseload in their State.

Upon completion of data collection (as reported in an *AHCPR Program Note*, June 12, 1991), weighted respective response rate for physicians and nurses of 80% and 73% were achieved. Preliminary univariate analyses indicate a willingness by over one-half of health professionals to have health care workers tested, and even larger percentages were in favor of mandatory testing for patients. Overall, however, a substantial proportion of providers incorrectly equate transmission probabilities of HIV and hepatitis B and believed that the risk to the health professional of contacting

HIV was greater than that estimated by public health authorities. Furthermore, whereas a majority of professionals had provided care to HIV patients, very small proportions spend more than 10 percent of their time with HIV patients. Despite their experience and sense of ethical responsibility to care for HIV patients, many providers, especially physicians, did not believe that the provision of care to HIV persons was binding legally or desirable personally.

In another not yet published report (7/17/92), the investigator notes that HCW's in rural areas, compared with those in urban areas, are less willing to provide care to AIDS patients and they are less likely to feel that they have a "duty to treat"--although rural HCW's are neither less knowledgeable than urban HCW's nor do they perceive more risk in contracting HIV from infected HIV/AIDS patients. They hold attitudes commonly associated with unwillingness to treat--negative attitude toward gay men and IVDU's and conservative political views, and they are more likely to be affiliated with conservative religious groups and to be religious. These views, more deeply entrenched and more resistant to change than, say, knowledge about AIDS transmission and precautionary guidelines, pose a significant challenge for professional training programs about HIV/AIDS.

"Evaluation of Community-based Clinical Studies for AIDS"
Cozen, Myrna L.; University of Michigan, Ann Arbor
R03 HS 07998 (Dissertation), (Project Officer: J. Pellegrino)
Expected completion: 8/31/94

The purpose of this project is to explore the quality of information that results from conducting trials of experimental therapies for AIDS in community settings. Traditionally, drug trials are conducted in tightly controlled medical care settings. Because of the nature of HIV disease--its long latency period and the fact that there are no effective cures--there has been increased pressure on the biomedical community to broaden the availability of experimental treatments, including the testing of new therapies in community medical care settings. This study will test the quality of data emanating from those studies to determine whether factors existing in the community that are not found in the medical research center environment seriously affect the results of the studies. If such biases or sources of error are found to exist, then study designs can be modified to improve the reliability of these results in the future.

The characteristics of two groups of HIV infected patients will be compared: those enrolled in simple follow-up studies of disease progression who receive standard therapies for HIV related disorders, and those who are selected to participate in clinical experiments. This study will examine the characteristics of both groups. The appearance of significant differences in characteristics between the two groups could indicate biases that jeopardize the validity of the results of these studies. The effects of any such biases also will be measured.

"Health Care Costs and Utilization in AIDS Home Care"
Crystal, Stephen; Rutgers University
R01 HS 06339 (Project Officer: Frantz Wilson)
Completed: 9/29/93

This is an in-depth study of the utilization and costs of health and social services for participants in New Jersey's Home and Community-based Services Waiver for Persons with AIDS/ARC--i.e., the AIDS Community Care Alternatives Program (ACCAP). Data sources include complete Medicaid payment records for all program enrollees, case management records, and (for 400 new enrollees), personal interviews conducted monthly, from enrollment in the program for up to 18 months. A combination of cross-sectional and longitudinal analyses will focus on service utilization across subgroups of persons with AIDS-related illnesses, including ethnic minorities, women, and children; the interrelationships between home care, institutional care, and social supports; and differences in utilization and costs for persons who are and those who are not enrolled in ACCAP.

Two papers from this research were presented at the VII International Conference on AIDS in Florence, Italy. One, by Dr. Crystal, "Outpatient Medical Care and the Course of AIDS," focused on in-depth interviews with 107 persons with AIDS from a statewide representative sample drawn from the state registry of patients reported to the CDC with AIDS. Results indicated a dramatic shift to reliance on hospital clinics for outpatient care as illness progressed. These changes were concurrent with dramatic impoverishment and shift in payor status as the illness progressed.

The second paper, by Cheryl Merzel, "Predictors of Inpatient Utilization in an HIV Medicaid Waiver Population," examined number of hospitalizations and inpatient utilization for 733 adults enrolled in the New Jersey ACCAP. Results indicate use of AZT had a significant impact on decreased hospitalization. In contrast to this, being black, an IVDU, and having a history of PCP increased hospitalization. No gender effect was noted, but a significant interaction between gender and race was present--with black women experiencing higher utilization. Effects for blacks and IVDUs were on longer hospital stays, not more admissions. The effect of AZT was on both admissions and lengths of stay.

In a paper in *Health Care Financing Review*, 1992;13:27-44, Merzel et al., provide information about the study's population, types of health services used, costs, service delivery problems, and unmet needs of participants. Comparisons are made to general Medicaid AIDS patients in New Jersey. It also examines the role of case management, client satisfaction, and related policy issues.

"Effective Strategies of AIDS Programs in San Francisco"
Dearing, James W., Michigan State University, East Lansing, MI
R01 HS 07610 (Project Officer: Terry Shannon)
Expected completion: 7/31/95

With diffusion theory and social marketing theory as a starting point, this project will explore the organizational strategies used by various community-based HIV education programs targeted to unique population groups in San Francisco to learn lessons from effective and ineffective dissemination strategies employed by these programs. This project will use the experiences of a broad range of programs in San Francisco which are responding to HIV/AIDS as the basis for identifying important elements of effective dissemination strategies, as well as assessing the degree to which these programs are consistent with principles of the theoretical models chosen. The principles gleaned could have broad application across a wide range of programs currently seeking to provide services to other than mainstream populations.

"Health Care Workers Overcoming Fear of HIV Contagion"
Duffy, Pam; University of Arizona
R01 HS 06448 (Project Officer: Bill Maas)
Completed: 12/31/92

The purpose of this study was to generate a process model explaining how providers successfully manage the threat of occupational HIV exposure. The grounded theory method of analytic induction (Glaser and Strauss, 1967) was utilized. Data were gleaned from 51 audiotaped interviews of physicians and nurses practicing in Arizona and New York.

The discovered process of Finding a Comfort Zone is evidenced by a litany of strategies used routinely and bolstered by mastery techniques such as 'self-talk,' personal algorithms or acronyms. An expectation of periodic recycling, reactive to "close calls", through four behavioral substages of the process was found.

The four substages inherent to Finding a Comfort Zone are [1] Checking It Out, an active search for information about occupational exposure through scientific literature, clinical immersion in HIV care, and/or consultation with credible experts; [2] Bringing It In, an experiencing of the threat as personal rather than theoretical, evidenced by recalling past incidents of possible exposure and imagining 'what if' scenarios; [3] Fitting It In, or affirming a just cause for the threat through one or more of five rationales; and [4] Taking It On, an ongoing series of technical changes, innovations, and skill adaptations accompanied by a commitment to mastering the threat.

Discovery of the process of Finding a Comfort Zone may have implications for provider education, research, and theory. The theory may be used as a teaching model, preparing providers for cognitive, emotive, and behavioral strategies that "work." Further research may provide a means of "staging" various providers and factoring specific interventions to facilitate management of the threat of occupational exposure.

"Direct Medical Costs of Pre-Class IV/HIV Care in an HMO Setting"
Ehreth, Jenifer; University of Washington
R03 HS 06880 (Project Officer: Melford Henderson)
Expected completion: 8/31/94

The primary purpose of this study is to quantify the direct medical care costs and utilization of pre-Class-IV HIV patients who are actively receiving care at the Group Health Cooperative of Puget Sound (GHC) in 1990. While there have been numerous empirical studies of the use and costs of medical care for persons with AIDS, there are practically no similar data for other HIV-infected persons. With early medical treatment of HIV-infected persons before the development of AIDS becoming the generally accepted practice, data for this group of patients are urgently needed by health care providers and planners at all levels. This study will explore: the costs and utilization occurring prior to showing symptoms; treatment costs using the latest treatment modalities; and treatment costs occurring within an HMO setting. The HMO setting is a particularly desirable one in which to study asymptomatic HIV-positive patients in that their condition may be non-reportable to health officials until AIDS symptoms appear and, hence, they are difficult to study in other settings.

The study will compare costs and utilization of the following three groups: (1) GHC enrollees (n=250-275) who have had a T4/T8 cell count performed at the GHC laboratory in 1990, but have not been designated class IV HIV-positive (AIDS); (2) all class IV HIV-positive enrollees (about 200); and (3) a group of other GHC enrollees matched on age and sex. Comparisons will be made separately for males and females, although the number of HIV-infected female enrollees is expected to be small. In addition, the study will quantify the use and costs of care by specific type of service (e.g., inpatient care, outpatient primary care, pharmacy). Cost and utilization data will be collected from GHC's Utilization Management/Cost Management Information System (UM/CMIS) for one year, 1990. Because GHC provides comprehensive medical coverage and also documents out-of-plan services which are reimbursable by the plan, it is believed that practically all services used by the study populations will be captured. For comparison of the use and cost data of the three groups, a linear regression analysis will be performed. A time series regression model will be used to predict the increase in use and cost of HIV infection from diagnosis to AIDS to death.

"Strategies for Improving Primary Care for HIV Patients"
Epstein, Ronald M.; University of Rochester
R03 HS 06444 (Project Officer: Frantz Wilson)
Completed: 1/1/92

This grant was a hypotheses-generating, qualitative first-phase of a planned three-phase study to explore physicians' fears, concerns, attitudes, and beliefs toward HIV disease. This study intended to identify a variety of barriers to care, and design, implement, and evaluate proposed educational interventions, alterations in reimbursement schemes, and changes in practice management

in order to overcome these barriers. The study employed open-ended interviewing of 30 primary care physicians (general internists, family practitioners, and obstetricians) who provided care to at least two HIV positive patients in the preceding two years in small metropolitan areas in New York State and New England. The study: explored what motivates physicians to provide care for HIV patients; identified specific difficulties faced by these physicians, such as financial considerations, time constraints, fear of contagion, difficulty with terminal illness, burnout, prejudicial attitudes, and lack of knowledge and/or experience with HIV patients; learned what factors were influential in overcoming these difficulties, such as educational or clinical experiences; and use these findings to develop recommendations for primary outpatient care.

Findings based on 30 qualitative narrative interviews with primary care physicians in five small Northeastern towns who provided care to HIV patients indicated that most believed HIV care to be no different than managing complications associated with any chronic illness. Primary care physicians were thought to be able to provide continuing care for HIV patients, but needed more education in counseling skills, accessible biomedical information, reliable subspecialty backup, and opportunities through focus groups to deal with personal reactions to HIV patients. The same physicians found relationships with HIV-infected injection drug users more difficult and less rewarding because physicians perceived that these patients were more destructive and less apt to follow their physician's advice. Results were published in *Archives of Family Medicine*, 2:159-67, 1993.

Epstein and others, in a paper in *Family Medicine*, 25:264-68, 1993, noted that although primary care physicians believe they are of low risk of contracting HIV from their patients, for some physicians the fear of contagion takes a high emotional toll. Conflicts between fears and ethical responsibilities create intense personal dilemmas. Some physicians reported taking excessive precautions to prevent exposure to body fluids, while others took inconsistent or no precautions. The study confirms the existence of significant contagion in the clinical workplace.

"Costs, Correlates and Outcomes for Persons with AIDS"
Epstein, Arnold M.; Harvard Univ. School of Public Health
R01 HS 06239 (Project Officer: Frantz Wilson)
Completed: 9/29/93

Investigators collected and analyzed information on the use and costs of medical services and outcomes for a cohort of approximately 500 AIDS patients who receive primary care at one of three Boston-area providers. Data included the costs of a wide range of inpatient and outpatient services, as well as indirect costs associated with disability and premature mortality. Data on patient clinical characteristics, stage of illness, functional status, and socioeconomic status were used to explain costs and to predict costs, utilization, functioning, satisfaction, and survival. The purpose of the survey was to identify how formal and informal

services to AIDS patients affect their survival, quality of life, and costs of care.

The investigators, in *Medical Care*, 1992;30:1059-66 (Fowler et al.), describe unique factors involved in surveying people with AIDS. Key issues include the need to have specific techniques to avoid disclosing a persons's HIV status; the difficulty in recruiting patients, many of who may be too sick to participate, and the difficulty and variability in identifying a site where interviews could occur. Face-to-face interviews took twice as long as they ordinarily would have for persons without HIV. Procedures for consent and protection were lengthy and exhausting for respondents. The authors offer suggestions to improve survey procedures and recommend ways to overcome data collection difficulties.

At the 1993 annual meeting of APHA, the investigators reported (Abstract page 232) that average reporting error on patient self-reports, as compared to medical billing records, was very small. They concluded that self-reports of utilization by AIDS patients during a period of 4 months or less will provide valid data for analytic purposes.

"Alternative Assessments of Functional Status of AIDS Patients"
Felton, Barbara (formerly Bruce, D. Rapkin); New York University
R01 HS 06415 (Project Officer: Elinor Walker)
Completed: 6/30/93

The purpose of the study was to develop and test two complementary approaches to the measurement of functional status (defined as overt performance of behaviors important to successful adjustment and quality of life) in persons with a diagnosis of HIV-related illness. The first instrument involves adaptation of a nomothetic measure of activities of daily living and instrumental activities of daily living to include HIV-specific areas of instrumental functioning such as "finding rest," "immunity-promoting behaviors," "coping with inhospitable living conditions," "meeting demands of social service red tape," "making it on the street," "reciprocating support," and "passing in non-AIDS environments." The second approach is an extension of idiographic techniques that emphasizes current goals and concerns of patients related to performance of activities. Both basic and higher order aspects of functioning will be addressed and measurement of construct validity will be undertaken by demonstrating relationships with treatment and service usage, history of illness, concurrent measures of health and well-being, and predictions of health outcomes (survival) and subsequent use of services.

The proposed project was carried out in two phases. Measurement development involved focus group sessions and interviews with people with HIV care partners, and health care providers to ensure measures are relevant. The field test involved empirical research on 224 subjects (15% female) in three facilities (day care setting, residential setting, and outpatient setting) who were followed twice after an initial interview over the course of one year. Early analyses of field test data are focusing on differences between patients' and providers' ratings of functional status, and upon patients' strategies for maintaining independent function. Adherence to regimens were also examined.

"Delivery of Home Care for People with AIDS"
Fleishman, John A.; Brown University
R03 HS 06378 (Project Officer: Katy Benjamin)
Completed: 11/30/90

This grant focused on the availability and organization of home health services for people with AIDS. Data were collected from a sample of home health care agencies, providing different levels of service to persons with AIDS, in nine cities with varying incidence of AIDS. Issues addressed were: 1) organizational characteristics of agencies that provide various amounts of care to AIDS patients; (2) organization of AIDS services within these agencies; 3) coordination with other service providers; and 4) problems in delivering home care to AIDS patients. Analysis include descriptive statistics explaining home care agencies' involvement with the AIDS population.

The investigator found that, although three-quarters of the sample served at least one AIDS patient, within each geographic area only a few agencies served a large number of AIDS patients. Proprietary status and services offered were associated with whether or not an agency served HIV patients. Freestanding agencies, proprietary agencies, and agencies offering specialized services (e.g., high-tech nursing, hospice care, home attendant care) were more likely to treat AIDS patients. Reimbursement issues were a major impediment in providing AIDS care, particularly the willingness to accept patients on Medicaid. Psychological stress and safety concerns were considered a significant problem for staff. Staff reluctance, was a significant, but not overwhelming problem in influencing involvement with AIDS care. The reluctance to serve seemed to be concentrated among the lesser skilled staff. The lack of willingness to accept drug users almost was entirely concentrated in areas where substance abuse was not prevalent. Another frequently cited problem was in inter-agency communication, with half of agencies noting problems in communicating with other agencies, service duplication, difficulty in communicating with physicians, and lack of consensus on primary care responsibility across agencies.

"ATHOS -- AIDS Time-Oriented Health Outcome Study"
Fries, James J.; Stanford University Medical School
R01 HS 06211 (Project Officer: Robert Ullom)
Expected completion: 5/31/94

This study is developing a prospective, longitudinal information system on 5,000 to 8,000 AIDS, HIV-positive, and at-risk subjects. Medical record and patient interview data on clinical, laboratory, economic, and quality of life indicators will be obtained from private practices and clinics in the San Francisco Area, Los Angeles (Keith Clinic) and San Diego (Owen Clinic). As of January 1993, 5,650 patients have been enrolled in ATHOS and detailed clinical/laboratory data are available on over 3,700 patients. Analyses will include: factors influencing transition between clinical states, quality of life, patient outcome, and costs; as

well as assessment of both direct and indirect costs and efficacy of both approved and unapproved therapies. The conceptual framework for ATHOS was described by Fries in *Computers and Biomedical Research*, 1992;25:586-601.

Two papers from this study were presented at the Annual Meeting of the American Public Health Association, 1990. One paper, by Lubeck, et al., focused on a description of the system. Preliminary data indicate that patients' insurance status is related to the locus of care, with 41% of patients at the Owen Clinic being on Medicaid and 17% uninsured. In comparison, less than one percent of patients in private practice were on Medicaid and 78% had private insurance. The second paper by Hubert, et al., indicated that key factors in predicting disability include number of symptoms, self-assessed health status, reliance on home care, gender and ethnicity. Women and nonwhites were more likely to report being disabled.

A paper by Lubeck and Fries, in *Quality of Life Research*, 1992; 1:359-66, compared patient-reported quality of life obtained from questionnaires which cover functional ability, social functioning, cognition, mental health, disability days, disease symptoms, and overall health in the previous 3 months. These scales have been validated on HIV populations. Declines in health status and psychosocial status were found over the year for all persons. Individuals with symptomatic disease or AIDS had significant declines of 10-20 percent in all aspects of role functioning (social, daily activities, energy, and global health) and increased disease symptoms, but no significant declines in cognition or mental health. Persons with AIDS had greater declines that those with symptomatic disease. AIDS and symptomatic patients also reported significantly fewer hours at work and more disability days than asymptomatic patients. The impact that HIV disease has on the health status of non-AIDS symptomatic patients is especially striking. These results, though preliminary, offer encouragement regarding the potential of self-administered health status scales in surveys of HIV-infected patients, and they indicate that a major focus of the care and treatment of HIV-infected persons should be on the psychosocial aspects of the disease. In a report in *Medical Care*, 1993; 31:269-76, Lubeck and Fries noted that the lower sensitivity of the mental health scales may be a function of patient treatment and the existence of extensive patient social support networks.

Lubeck, et al. (*J. Acquired Immune Deficiency Syndrome*, 1993;6:478-84) reported that HIV-infected patients with diarrhea miss twice as much work, socialize less, and decline more rapidly in health and functioning than those with HIV who do not have diarrhea. Care for patients with chronic diarrhea is costly--about 50 percent higher than for similar patients without diarrhea ($24,567 vs. $14,471), and these patients need nearly 60 percent more health resources, including diagnostic tests and outpatient visits.

Kupperman, et al. (*Amer. J. Ophthalmology*, 1993;115:575-82) reported confirmation of the clinical impression that cytomegalovirus (CMV) retinitis and HIV-related noninfectious retinal vasculopathy are late manifestations of AIDS, and that those with CD4 lymphocyte counts of 50 or less are far more likely to suffer from this condition. Patients with CMV retinitis often are not referred to an ophthalmologist

until the condition threatens their sight. A primary care physician can only see the posterior one-third of the retina with direct ophthalmoscopy, but the specialist can use indirect ophthalmoscopy to diagnose the condition. The authors recommend periodic screening of AIDS patients for CMV retinitis once their CD4 cell counts fall to 200, with screening repeated every 3 to 4 months.

Tamayo et al., in *J. Gen. Inter. Med*, 1993;8:69-75, evaluated the efficacy of specific diagnostic methods compared with ultrasonography to detect enlarged spleens in 27 individuals with HIV infection. They concluded that physical diagnostic techniques for detection of splenomegaly are relatively insensitive but specific. Using either percussion or palpation in conjunction with ultrasound increased diagnostic accuracy.

At the 1993 Annual Meeting of APHA, the investigators presented additional findings (Abstracts, pages 31, 298, 309, 316 and 395):

- In the course of a year, ARC patients suffer declines in the quality of life similar to AIDS patients; HIV negative (at-risk) individuals are more similar to asymptomatic, positive individuals than the general population. Work disability is associated with disease progression in a manner similar to other chronic illnesses. However, there was no difference between controls and HIV+ (but not AIDS) individuals for days not able to work. Employed patients with AIDS reported about 6.8 more days unable to work than either controls or HIV+ non-AIDS individuals. These data call into doubt the popular view that HIV infected individuals are far more likely to be absent from work than persons without AIDS.

- AIDS and ARC patients reported significantly more fatigue than HIV+ patients, but HIV- (at-risk) individuals report levels of fatigue more similar to HIV+ persons than to the general population.

"Concentration of AIDS-Related Inpatient Care"
Green, Jesse, New York University Medical Center
R03 HS 07205 (Project Officer: Melford Henderson)
Completed: 8/31/93

The study was to measure the concentration of AIDS-related hospitalizations within 27 US metropolitan service areas (MSAs) accounting for 60 percent of US AIDS cases. Earlier studies suggested that AIDS inpatient admissions were not only highly geographically concentrated, but occur in a small number of hospitals within those areas, and that such concentration may result in improved clinical outcome. Other reports indicated that concentration of AIDS inpatient services may be harmful, if it reflects limited access to hospital care in a wide array of facilities. Concentration of AIDS care may also result in serious financial losses for those hospitals with a disproportionately large share of AIDS inpatient treatment.

Concentration of AIDS-inpatient hospitalizations will be assessed by using measures of inequality of a distribution, including the Gini

index. Inpatient discharge data for the period between 1983 through 1990 were studied. The relationship between the measure of concentration of AIDS admissions and patient and hospital characteristics were assessed.

"Monitoring Trends in the Financing of HIV-Related Care"
Green, Jesse, New York University Medical Center
R03 HS 07847 (Project Officer: Melford Henderson)
Expected completion: 4/30/94

This retrospective study will examine trends in the financing of HIV-related inpatient care over a ten year period. The purpose of the study is to determine how the distribution of payers for HIV-related hospitalizations has changed over time, to consider how these changes can be accounted for, to compare the mix of payers that finance HIV-related care with the financing of care for other diseases, and to consider some implications for access to care.

This investigation builds upon and extends an earlier study which used hospital discharge data from New York City, San Francisco, and Los Angeles to analyze trends in the financing of AIDS. The prior study covered three cities and five years (1983-1987); the proposed study covers 33 cities and the non-urban areas of six states and extends the time period to ten years (1983-1992). In addition to expanding the investigation, this study also considers new hypotheses, including a comparison of the financing of AIDS with several other medical conditions, and the relationship of payer to stage of illness.

"Impact of Computer Support on HIV Infected"
Gustafson, David; University of Wisconsin
R18 HS 06177 (Demonstration) (Project Officer: J. Pellegrino)
Completed: 9/30/93

This study conducted a longitudinal experiment to determine whether use of the Comprehensive Health Enhancement Support System (CHESS) by HIV-positive patients resulted in more efficient utilization of health services, improved functional status, and reduced risk behavior. CHESS is a PC-based system, with individual units connected by modems to a central "host" computer to allow anonymous communications with other CHESS users. The project assessed the cost of operating CHESS, characteristics of individuals who use it, and variations in utilization across time depending on patient characteristics and the location of the system. Among the types of information available on CHESS are: listings of available services, summaries of key research findings on AIDS, and answers to questions raised by subjects through the computer. In FY '92, a minority supplement was awarded to the project' investigators in order to analyze aspects of CHESS

specifically geared to minority males.

Preliminary results of the first phase of the study indicate that CHESS was used 5520 times in 982 person weeks of access to CHESS. Usage was very high during the first two weeks after receiving CHESS, averaging over 19 uses per user per week, then settled into a pattern of between 100 and 300 uses per week. The data generally support the expectation that CHESS had a positive effect on emotional health of persons with HIV infection. Heavy users of CHESS benefit most from CHESS. Visits to primary care physicians increased 252% in the control group visits and stayed essentially unchanged or decreased slightly in the experimental and heavy user groups. Use of HIV specialists increased in control, experimental and heavy user groups but decreased 57% in the female group. Feelings of control over their health care increased for experimental, heavy user and female groups. CHESS use was significantly related to improved feelings of control. The amount of reported anal sex increased for the control group and decreased for the experimental group.

"HIV Home Health Care Services: Survey and Policy Analysis"
Hanley, Barbara E.; University of Maryland at Baltimore
R01 HS 06404 (Project Officer: Julius Pellegrino)
Completed: 8/31/93

This descriptive study assessed resource allocation of home health care services for persons with HIV/AIDS across 14 states moderately affected by the epidemic. Factors related to the availability of services for adult and pediatric persons were analyzed. The first phase of the study performed an analysis of state long-term plans for HIV-related direct service provision and public policies related to access, availability, and reimbursement for HIV home health care. The second phase of the study involved analysis of a mail survey sent to 2000 home health agencies. The survey captured information on access to home health care services, the array of services offered, types of services refused, problems with staff refusal to provide services, and problems experienced by the agencies in servicing the HIV population.

"Cost of Treatment of IV Drug Users with AIDS"
Hidalgo, Julia; Department of Health and Mental Hygiene, Maryland
R03 HS 06185 (Project Officer: Claire Maklan)
Completed: 3/31/90

Using a Statewide (Maryland) AIDS information system, this study identified characteristics of intravenous drug abusers with AIDS, studied the use and costs of health care services they receive, the fiscal impact of their care on Medicaid and other public programs, and the level of uncompensated hospital costs.

The study detected racial and gender differences. For example, whites were 1.8 times more likely to receive AZT than non-whites; males were 1.8 times more likely

to receive AZT than females; homosexual males were 2.0 times more likely to receive the drug than IVDUs; and patients who received care in outpatient departments or from office-based physicians were nearly 4 times more likely to use the drug than those with no primary source of care. These patterns persisted even within primary care settings. Improved survival was evidenced between 1983 and 1989 with whites experiencing a median survival of 584 days compared to 407 for non-whites in 1989. Whites receiving AZT were also more likely to live significantly longer (761 days) compared to non-whites taking the drug (620 days). Female survival was also 610 days. The investigators postulated that delayed diagnosis was responsible for the variation.

"Costs of Health Services for HIV Infected Individuals"
Hogan, Andrew J.; Michigan State University
R03 HS 06260 (Project Officer: Melford Henderson)
Completed: 12/30/90

Using Medicaid records and some private health insurance data, this project studied use and cost of services for HIV-related illnesses between 1985 and March 1989 in Michigan. Hypotheses focused on differences in use and cost by risk group and sex, on the impact of AZT on average monthly Medicaid payments, and on apparent underutilization of services by some AIDS patients.

Findings, presented at the American Public Health Association Annual Meeting in October 1990 in New York City, indicated that female use of and payments for medical services were far less than that observed for men. In particular, only 19 percent of women had a paid prescription for AZT, compared to nearly 61 percent of men. Differences between the genders among IVDUs were not significant. In multivariate analysis, gender and its interaction with race are related to whether an individual used AZT. White women were the least likely to use it, and white men the most likely. Reasons for the gender differences are unexplainable and may be related to variations in provider prescribing patterns. Black women were shown to use significantly more services than white females. Survival among persons using AZT was twice that of others, regardless of gender and race. A critical factor explaining survival differences is "living in Wayne County." This may point to the significance of its Coordinated Community AIDS Program or to informal care provision by families among people returning home to die.

In *Public Health Reports*, 1992; 107:461-8, Solomon and Hogan report that the average monthly Michigan Medicaid payment in 1989 dollars for HIV services was $1,302.57. Services unrelated to HIV infection accounted for 12.5 percent of the total amount for health care received, and 2.5 percent was undetermined. The average monthly expenditure for men was roughly twice that for women. Payments for HIV-related treatments rose with age to about 40 years and declined slightly among older adults, with the highest payments for those 19-35 years of age.

"Interactive Video for AIDS Prevention Education to Persons with Mental Retardation"
InfoUse; Berkeley, California
Contract No. 213-90-0032 (Project Officer: Gerald Cohen)
Completed: 9/28/93

The goal of this contract was the development of a production-ready system for AIDS prevention education to be used by agencies serving persons with mental retardation. The project had the following objectives:

- Refine information on AIDS education needs of persons with mental retardation, identify curricula or tools used by field trainers and the identify the needs of providers and potential of their settings.
- Create an interactive video system product by identifying topics for inclusion, generating an instructional design, creating a script and a storyboard, and do the Hypercard programming.
- Determine the effectiveness of the product in terms of knowledge gains in users of the system, and test facilitators for subjective responses to system usefulness
- Make any changes necessary from the evaluation, and create a production ready product.

"Prospects for Caring for Persons with AIDS in Nursing Homes: Perspectives of Current Residents, Policy Implications"
Kane, Rosalie; University of Minnesota
Contract No. 282-87-0049, Task 35, (Project Officer: J.Pellegrino)
Completed: October 1989

This project explored the issues surrounding admission of persons with AIDS to nursing homes in Minnesota. The researchers interviewed key informants and conducted a series of focus groups with nursing home residents, staff, and family members from both nursing homes that were receptive toward HIV patients and those which were not. Results indicated that residents of receptive homes were more comfortable about receiving HIV patients than were residents of the comparison homes; staff members had more active feelings of discomfort in admitting HIV patients than did residents, although feelings of discomfor t were stronger in the comparison homes; 27 percent of staff across nursing homes would prefer not to care for an HIV patient; and positive attitudes towards HIV patients was directly related to the rank of the nurse. Qualitative findings indicated that among those who cared for PWAs comfort increased with time, although the care was judged to be more difficult physically and emotionally; considerable emphasis among all was placed on the necessity of having separate facilities for PWAs.

"The Quality of Care in AIDS: *Pneumocystis Carinii* Pneumonia"
Kanouse, David E.; The Rand Corporation
R01 HS 06016 (Project Officer: Bertha D. Atelsek)
Completed: 12/30/92

This project examined the quality of medical care provided to patients with AIDS by conducting a retrospective review of hospital records of about 600 newly diagnosed AIDS patients (from 1983-87) in Southern California with an initial episode of *pneumocystis carinii* pneumonia (PCP). The researchers developed prognostic staging models based on clinical and laboratory markers and measures of early resource use. Indices of severity were used to control for severity and comorbidity. Preliminary results indicate that the process of care does affect patient outcomes for the first episode of PCP. Although most patients in the study were appropriately diagnosed, and started on antimicrobial therapy, failure to deliver therapy in adequate dosages increases the odds that a patient either will die or experience severe respiratory failure. The study also found substantial beneficial effect of receiving active anti-PCP agents before hospital admission, which has important implications for assessing institutional quality of care, inasmuch as quality differences may reflect patient's previous treatment history, as well as average severity of illness at admission. Results suggest that the decreased survival of patients who had "do not resuscitate" (DNR) orders written early could be seen as humanitarian because of the extremely poor prognosis, during the period covered by the study, for PCP patients requiring mechanical ventilation.

"AIDS and Insurance: The Experience of a High-Risk Cohort"
Kass, Nancy E.; Johns Hopkins University
R03 HS 06108 (Project Officer: Fred Hellinger)
Completed: 11/31/90

This study surveyed homosexual and bisexual men who voluntarily participated in the Baltimore and Los Angeles chapters of the NIH-funded Multi-center AIDS Cohort Study, homosexual AIDS patients at Johns Hopkins University, and a control group of male leukemia patients at Johns Hopkins University. The research addressed issues of access to insurance by examining the relationships among HIV testing, antibody status, and symptom status with the experiences of respondents in applying for health, life, or disability insurance over the past five years, and their current insurance coverage. Results from this nonrepresentative sample suggest that although persons with AIDS are not significantly more likely to be uninsured than persons who do not have AIDS, they are thirty-six times more likely to have Medicaid coverage (roughly 28 percent of the AIDS patients were covered by Medicaid, compared with less than 1 percent of the gay and bisexual men without AIDS, and 7 percent of leukemia patients). Although health insurance loss in the total sample was small, this too, varied by antibody status, with more AIDS patients losing coverage than the other groups (Kass, N.E., et al. *Inquiry*, 1991;28:249-54). Persons

with AIDS were also five times more likely to report AIDS-related discrimination from employers than persons who do not have AIDS. Eighteen percent of persons with AIDS were denied treatment from a doctor or dentist due to known or suspected HIV-related condition, compared to five percent of seropositive and one percent of seronegative. Significantly more respondents reported refusal of dental care than of medical care (Kass N.E., et al. *Am. J. Public Health*, 1992;82:1277-9).

"Research Agenda on Community-Based Care of Persons with AIDS"
Keenan, Joseph M.; University of Minnesota
R13 HS 06224 (Conference) (Project Officer: Jerry Weston)
Completed: 12/31/89

This grant supported a conference on research problems and issues related to home and community-based care for AIDS patients. The purpose of the conference was to identify and prioritize research issues related to appropriate care settings, quality of care, cost, health care policy, and both lay and professional caregivers. The conference met in Minneapolis, August 14-16, 1989. Papers presented covered: caregiver issues, settings of care, policy issues, ethical issues, and research design. The proceedings have been published in *Community-Based Care of Persons with AIDS: Developing a Research Agenda*, April 1990, USDHHS, PHS, AHCPR.

"AIDS and Medical Residency Selection in NY, SF, and LA"
Kelly, Joyce V.; Association of American Medical Colleges
R03 HS 06428 (Project Officer: Jean Carmody)
Completed: 12/31/90

This project examined the effects of the AIDS epidemic on the selection of post-graduate training by senior medical students in three cities with very high AIDS caseloads. Available data on medical students, residency programs, and residency matches were linked with measures of the prevalence of AIDS in residency hospitals. Specialty choice and preferred hospital location were analyzed in terms of student background, exposure to AIDS in medical school, student test scores, and characteristics of the residency programs. Trends between 1983 and 1988 were examined in residency recruitment to New York City (NYC), the city that reports the greatest number of AIDS cases nationally, to a comparison group of hospitals in the four largest US cities with the fewest AIDS cases.

Recruitment to high-AIDS and low-AIDS programs in voluntary hospitals in the four largest cities with the fewest AIDS cases and nationally increased as much as 10% above baseline. The exception was the high-AIDS voluntary hospital programs in NYC City, which dropped precipitously to 30% in the year 1988 to 1989. In 1990, high-AIDS voluntary internal medicine programs' U.S. graduate matches plummeted by over 50% in one year. Fill rates in 1990 decreased in high-AIDS municipal programs by 29.4% from a baseline rate of 68.7% and in low-AIDS

voluntary hospitals by 16.1% from a baseline rate of 58.9%. A similar rate of decline was not found among categories of surgery or in other specialties including family practice, etc.

Data indicated an eroding ability of high-AIDS municipal residency programs in NYC to attract U.S. medical graduates. Most or all of the programs studied demonstrated these same trends. Although some of these service positions were filled by foreign medical graduates, a quarter went unfilled by 1990. These observations make it difficult to attribute the observed trends predominantly to a systemic avoidance of large numbers of AIDS patients. Multiple economic and social factors, including AIDS, may have contributed. Results of the study appeared in *J. Amer. Med. Assoc.*, 1991;266:2843-6.

"The New York State Response to AIDS"
Lambright, W. Henry; Syracuse Research Corp.
R01 HS 06184 (Project Officer: Julius Pellegrino)
Completed: 3/31/91

New York State's emergency response to AIDS, especially the work of the AIDS Institute, was studied. The focus was on the coordinating role of the Institute and its regional outreach organizations. By identifying factors that have led to success and to problems in coping with AIDS in New York, the investigators define a model administrative organization that other States may replicate. The AIDS Institute developed from a research and community outreach organization, largely arising from the advocacy of the gay population, to a centralized system of resource allocation with decentralized service delivery attempting to represent the divergent needs of various exposure categories.

"In Whose Care and Custody? Orphans of the HIV Epidemic in Historic and Global Perspectives"
Levine, Carol; The Orphan Project, Fund for the City of New York
R13 HS 07872 (Conference) (Project Officer: Tom Lally)
Expected completion: 1994

One of the most alarming--yet unstudied--socialramificationsof the worldwide HIV pandemic is the large number of children who have become, or will become, orphans. This conference will explore the critical policy and service delivery questions raised by this aspect of the AIDS crisis. The conference will examine analytically other historical instances--wars, famines, and other epidemics--which left large numbers of orphans. The conference will assess those social, cultural, and biological forces that shaped the experiences of children in the context of massive familial and community disruption. By examining these historical cases, and the wide variety of social and institutional responses to children without parents, the investigators intend to identify a range of policy options for serving the important health and social service needs of orphans in the contemporary context. The conference

will bring together scholars and policy experts as a working group to identify policy options and propose possible solutions. The role of governments, religious institutions, extended families, and philanthropies will be evaluated. The conference will produce recommendations and a book of critical historical essays and policy analyses that will shape the response to orphans of the HIV epidemic in the future.

"Caregiving for Minority Women with AIDS"
Litwak, Eugene, Columbia University
R03 HS 07265 (Project Officer: Linda Siegenthaler)
Expected completion: 09/29/94

The main objective of this study is to explore the caregiving needs of minority women who are HIV seropositive and to identify the actual caregivers and the caregivers who are best suited to provide the needed services. Thirty open-ended interviews of HIV-infected women were conducted at the Columbia-PresbyterianMedical Center outpatient HIV clinic. The sample was evenly divided between African-American and Latina women (the latter equally between first and second generation immigrants). Most of the respondents were relatively asymptomatic and ambulatory. Analysis of the data indicates that acute needs, problems, and significant gaps between actual and desirable caregiving in the following areas: 1. Disclosure of HIV condition. 2. Practicing safe sex. 3. Compliance with medical regimen. 4. Keeping periodic clinic appointments at required time intervals. 5. Maintaining welfare and medicaid entitlements.

"Caregiver Burden with AIDS"
Lynn, Lorna (previously Eisenberg, John); Univ. of Pennsylvania
R03 HS 06640 (Project Officer: Linda Siegenthaler)
Completed: 7/31/92

The unusual nature of contagion in HIV infection, the special vulnerability of the population and the stigma of the disease provide special sources of caregiver strain, especially as more and more care is being provided in the home. This study describes persons with HIV who are in need of informal care and the types of persons providing such care. The intent is to measure caregiver burden and determine the factors associated with it. Chart review was used to assess clinical characteristics of patients. Caregiver perception of burden was measured through a battery of instruments measuring health, social health, psychological well-being, financial cost of care, and knowledge and attitudes about AIDS.

It was found that caregivers were most often female relatives or male homosexual lovers of patients. Drug or alcohol abuse in the patient, personal risk for HIV, and being employed increased caregiver burden. For those with personal risk for HIV, factors increasing burden were lower mental health, financial strain, and

the patient's level of disability. For those without risk, lower mental health of social support and patient's need for assistance with activities of daily living increased burden. Many caregivers wanted more contact with health care providers and needed more information about caring for patients.

"Ambulatory Care for HIV/AIDS: Models and Outcomes"
Markson, Leona E. (previously Turner, Barbara J.); Jefferson Medical College
R01 HS 06465 (Project Officer: Melford Henderson)
Expected completion: 5/31/95

The original study "Consequences of Patterns of Provider Care for AIDS" (Barbara Turner, Principal Investigator) utilized secondary data from 1983 through 1990 in order to examine the differential outcomes associated with illness severity and varying patterns of provider care, involving such factors as primary care status of practitioners, AIDS experience of providers, Medicaid experience of providers, and continuity of care. One arm of the study focused on adult homosexual men and IVDUs. A second arm will focus on children and will involve the development of a pediatric indicator of illness severity, which would be useful in secondary data analysis. Such indicators have been developed previously by the investigator for the adult population. Focus will be placed primarily on the Medicaid populations in the states of New York and California. An attempt is being made to control for left-censoring by supplementing data with SPARCS discharge data and Empire Blue Cross/Blue Shield data for the state of New York. Right-censoring will be controlled by obtaining and integrating data from the National Death Index.

Early findings indicated that Medicaid women in NY State from 1983-87, regardless of IVDU status, used fewer health resources than men (with IVDU's using more than non-IVDUs), but this had little impact on survival. Instead survival was determined primarily by AIDS-defining diagnosis and age.

A second analysis found that the SIAP (Severity Index for AIDS Patients, based on a model derived from expert opinions by grouping patients into four categories based on survival estimates), is a predictive tool for health resource utilization. More severely ill patients had expenditures respectively at 3, 6, and 12 month intervals. Data were analyzed for New York State Medicaid patients diagnosed between 1983 and 1986. Other findings include:

- 83 percent of patients surviving more than 6 months after AIDS diagnosis have clinic visits within the first 6 months of diagnosis.

- the role of clinics as the dominant site, or primary provider, of ambulatory care increases dramatically from 54% before AIDS diagnosis to 79% after diagnosis, while the role of private physicians diminishes, from 46% to 21%.

- the odds are greater that AIDS patients with a primary provider will present in emergency rooms (ERs) for care than will those without primary providers.

- women are less likely than men to have a consistent ambulatory care provider and to receive AZT, but are more likely to use ERs.

Keyes, Fanning and Turner reported at the 1993 APHA meeting (Abstract page 30) that, overall and within provider type, the proportion of primary caregivers declined over time and the proportion of specialists increased, suggesting that there have been substantial change in the composition of providers of AIDS Medicaid beneficiaries in New York. Also, it was found that, state-wide, the number of low volume clinics declined over time while the remaining high-volume clinics absorbed ever-increasing numbers of AIDS cases.

In an abstract presented at the 1993 APHA meeting (page 66) by Turner it was reported that many specialists proceeded before official approval to offer children with AIDS a drug shown to be beneficial to HIV infected adults. It was suggested that managed care programs need to develop links between primary care providers and specialists who can advise about the use of potentially life-prolonging therapeutic advances.

Keyes, Markson and Turner, writing in *AIDS and Public Policy J.*, 1993;8:142-50, noted that a large and increasing number of primary care physicians and clinics provided ambulatory care for New York State Medicaid patients between 1983 and 1990. However, the percent of primary care providers--as a proportion of all physicians--declined over time, while the percentage of specialists and subspecialists increased. Most primary care physicians treated a small number of AIDS patients, and the level of "experience" did not increase over the eight years of the study. The authors found a large increase not only in the numbers of AIDS patients treated by infectious disease and other specialty clinics, but also by primary care clinics within and outside of State-designated AIDS centers. Although larger primary care clinics treated a larger number of AIDS patients, the turnover in staff may overstate the experience level in these clinics. These clinics may be reaching a threshold where staff will become overburdened, and it was suggested that offering consultative services to primary care physicians may increase the likelihood that AIDS patients will remain with their current providers. Large increases in the proportion of persons using mental health, psychiatric and ambulatory surgery centers also was observed, but the rate of use of the emergency room as a source of ambulatory care did not increase, although half of all study subjects visited the ER at least once each year.

Markson's continuation of Turner's project carries forward research on ambulatory care for HIV/AIDS patients by gathering additional data on organizational features of such care and analyzing the implication of these for patients. An elaborate data base that originated from New York State Medicaid files will be extended for two years, and additional provider data will be generated from a survey of up to 250 clinics caring for HIV/AIDS patients in New York State. The clinic survey data will provide information on organizational features of ambulatory care that can be linked with the core data on patients. The analytical goals of the proposed project are to: 1) classify emerging models of clinic care for persons with advanced HIV disease in order to compare the differences in services and staffing of HIV/AIDS specialty clinics with primary care clinics, and 2) determine whether specific organizational features of ambulatory care

influence hospital and emergency room use, use of drug therapies and patient survival times.

The data span the years 1986-92 and cover more than 25,000 individuals during 1983-90, of which nearly 19,000 have a specific AIDS defining diagnosis. Data are available on nearly 1,000 clinics and 4,000 physicians. The provider data relates to Medicaid only, and does not include non-Medicaid HIV/AIDS related data. Using these data, the project will measure continuity of care (COC), identify dominant providers, and measure severity of illness. The dominant provider is the one that provides half or more of the care. Dominant provider type will be categorized as: no primary provider; AIDS designated center; other clinic; and other physician. Providers are classified as those that "mainstream" care, and those that provide a designated or specific program for HIV/AIDS care; the latter are further subdivided by those directed by infectious disease or other subspecialties, those directed by internists or family practitioner, and those that are shared by various subspecialists.

The survey of clinics will be a telephone-based effort directed to the medical director. The sample will be drawn from dominant providers of identified PWAs.

The 100 most frequently used providers and up to 150 of the rest (i.e., smaller caseload clinics) will be sampled. Clinics having a specific program for HIV/AIDS care will be distinguished from clinics with a program that "mainstream" HIV/AIDS care into services provided to other types of patients. Within the former, clinics will be subdivided by type of providers. Five hypotheses are proposed: Days hospitalized will be lower for clinics that offer case management and support services; ER use will be lower if the dominant clinic provides walk-in or other unscheduled services; PCP prophylaxis and zidovudine use will be greater if the primary providers are AIDS centers or centers staffed by AIDS specialists; AIDS specialty clinics will have better survival rates than "mainstreaming clinics"; and Female patients of clinics with gynecological services will experience fewer hospitalizations for gynecological complications. The project hypothesizes that clinics providing the greatest continuity in one site and having the greatest expertise in the disease are going to do the best job in managing the disease. This project has potential to address issues of how alternative delivery modes (including case-management and support services) affect the costs of HIV/AIDS care, as well as longevity of PWAs.

"Longitudinal Study of AIDS Health Services Use and Costs"
Mor, Vincent; Brown University
R01 HS 06214 (Project Officer: Fred Hellinger)
Completed: 12/31/92

This project builds upon an evaluation of the Robert Wood Johnson Foundation's AIDS Health Services Demonstration by re-interviewing 1031 patients from 9 to 12 months after their initial evaluation interview. Hospital, clinic, physician, and home care service use records were abstracted. The overall goal is to describe patterns of medical and social service use by persons with AIDS, to determine the degree to which their needs are met, and the de-

gree to which their preferences for palliative versus aggressive treatment alter as their disease progresses.

Preliminary findings suggested that preferences for palliative vs. aggressive treatment were stable over a one-year period, with a slight trend toward increasing preference for palliative care. Analyses of costs indicated that costs increased dramatically in the six months prior to death. Mor et al., in *Medical Care*, 1992; 30:17-29, reported that white males who do not use intravenous drugs have higher rates of outpatient clinic use, while nonwhite, female, intravenous drug users have higher rates of emergency room use.

Wachtel et al., in *Annals of Internal Medicine*, 1992;116:129-37, reported on the validity of the Medical Outcomes Study (MOS) Short Form Health Survey as an indicator for quality of life in persons infected by HIV. The authors found the MOS to be a reliable measure; they also found it to be extremely sensitive to the effects of symptoms, suggesting that it might be useful as a quality-of-life indicator for AIDS clinical drug trials.

Fleishman and Mor, in *Inquiry*, 30:180-8, 1993, reported that insurance coverage varied widely by geographic location, although gay and bisexual men were most likely to have private insurance coverage. People in the South had a greater chance of losing private insurance and less chance of gaining public Medicaid insurance than people in the Northeast. The proportion of those who were covered by public insurance since losing private insurance after AIDS diagnosis was 81.8 percent in the Northeast, 90 percent in Seattle, but only 52.2 percent in Florida and 30.8 percent in the rest of the South. In all regions studied, uninsured PWA's seemed to have less access to medical care.

"Computer Support for Protocol-Directed Therapy"
Musen, Mark A.; (formerly Edward H. Shortliffe); Stanford Univ. Medical Center
R18 HS 06330 (Project Officer: Jim McAllister)
Expected completion: 2/28/95

This project will develop computer-based techniques for management of knowledge and of clinical data in AIDS therapy, to implement them in two THERAPY-Helper (T-HELPER) systems for patient care, and to evaluate them in clinical settings. T-HELPER I is a data-management environment which allows the physician to enter and review data and examine information on treatment protocols. It includes an electronic flowsheet of time-oriented patient data, medical record, online library of protocol documents, patient database, and additional support functions. T-HELPER II adds active decision-support capabilities to T-HELPER I, such as situation-specific therapy advice, critique of physician's plans for therapy, explanation of therapy recommendations, and automated determination of protocol eligibility. Clinicians will use the two T-HELPER systems to help identify patients suited to experimental protocols and to maintain records of patients receiving protocol-directed therapy for HIV-related disease. The investiga-

tors will take advantage of their past experience in developing the ONCOCIN system, a data-management and advice system for use by clinical oncologists. ONCOCIN technology will be adapted to AIDS management, and current hardware-dependent software will be rewritten to be adaptable to general purpose computers (i.e. personal computers and work stations). The investigators plan to evaluate the tool's effects on patient care and on clinical research, and to determine the value of active decision-support capabilities as an adjunct to computer-based data management.

In *Proceedings of the Annual Symposium on Computer Applications in Medical Care*, 1992, pp 128-32, Das et al. notes that, as data base models have incorporated more semantics to interact with clinical decision-supportcapabilities, the temporal dimension of clinical data has become increasingly important. The authors describe the new temporal data model of the T-HELPER system. They discuss the types of temporal predicates needed for HIV clinical trial protocols and present their approach to providing temporal operations on these data. They also provide a basis for understanding and executing a temporal version of the relational query language, SQL.

Henry et al., in the same publication (*Proceedings*, 1992, pp. 59-63) describes the complexity of telephone-triage in a community-based clinic for patients with AIDS. The authors performed a needs analysis to identify deficiencies in documenting and maintaining data on telephone-triage encounters, including inaccessibility of the medical record and failure to document required data elements. The needs analysis suggests five design criteria for a computer-based system to assist nurses with telephone-triage: (1) on-line accessibility of the medical record; (2) ability to move among medical record and triage-encounter modules; (3) ease of data entry; (4) compliance with standards for documentation, and (5) notification of the primary-care physician in an appropriate and timely manner.

Additionally, Musen et al., also in *Proceedings*, 1992, pp 719-23, observes that T-HELPER, as described in this article, offers enhanced possibilities for community-based physicians to enroll patients in clinical trials of experimental drugs by providing patient-specific and situation specific advice concerning new protocols for which patients may be eligible, as well as the treatment required by those protocols in which patients are already enrolled.

"AIDS Workplace Policies: Local Government Responses"
O'Neill, Nancy G., Florida International University
R03 HS 07467 (dissertation) (Project Officer: Melford Henderson)
Expected completion: 9/29/94

This project is an in-depth study focusing on one large government agency located in an urban area of high AIDS prevalence. The purpose of the study is two-fold: (1) to provide a comprehensive view of the types of AIDS policies, programs, and practices in the workplace and, (2) to determine the motivations and/or barriers to organizational response to AIDS in the workplace.

Phase I should assist AIDS educators and employers to understand the range of choices and combina-

tions of activities that can be used in responding to AIDS in the workplace. Phase II results could yield practical information about the processes of decision making in organizations which facilitate or impede responses to AIDS; this information would supplement the relatively sparse survey data on employers' responses to AIDS.

"Guidelines for HIV Screening"
Owens, Douglas K., Stanford University
R03 HS 07273 (Project Officer: Frantz Wilson)
Expected completion: 2/28/94

The applicant is developing a decision analytic model to determine the impact of HIV screening in different groups of patients and to make quantitative estimates of the potential gain in health benefits that accrue when screening guidelines are adapted to specific clinical settings. Rather than looking at overall cost-effectiveness, the study emphasizes cost-effectiveness in specific clinical settings. The aims of the grant are: 1) to extend a pilot model on the cost-effectiveness of HIV screening; 2) to make estimates of the importance of variations in characteristics of different populations and practice settings on the cost-effectiveness of screening; 3) to make estimates of the potential benefits of determining these differences; and 4) to estimate the cost associated with determining these differences. The investigators plan to do multi-way sensitivity analyses on study parameters and explore different probability distributions of model parameters. The methods proposed include formal decision analyses utilizing data from published literature. In addition, data will be collected from practice sites in Palo Alto, Hanover, and Northern California.

"Modeling Methodology for Projecting the AIDS Epidemic"
Pagano, Marcello; Harvard U. School of Public Health
R03 HS 06183 (Project Officer: Fred Hellinger)
Completed: 9/29/91

The issue addressed by the researchers is how population dynamics affect the spread of HIV among different, interacting population groups. Due to random variation, many different epidemics can be produced from the same initial conditions. This complicates the understanding of the epidemic, and adds to the uncertainty attached to any predictions one can make about its future course. This is especially important if one wished to evaluate the consequences of intervention strategies.

One method for quantifying possible future outcomes is to use a simulation model. A discrete time stochastic model for the AIDS epidemic was described. It allows contacts between and within groups, using different parameters for the different modes of transmission. This flexibility allows a more realistic evaluation of the uncertainties inherent in models dealing with human behavior. To this end, the model yields variance estimates of predicted inference. The code for the model is written in C, and is available from the researchers.

"Determinants of Individual Demand for HIV Testing"
Paringer, Lynn; Western Consortium for Public Health
R01 HS 06352 (Project Officer: Miriam Kelly)
Completed: 8/31/90

This study identifies the factors influencing demand for voluntary HIV testing and develops a model to predict future demand. Data are from the "AIDS Knowledge and Attitudes" supplement to the National Center for Health Statistics' National Interview Survey for 1987 and 1988. In addition, available data on the policies of individual States regarding testing and confidentiality are incorporated. Separate regression models are estimated for the two data years, and some comparisons are drawn. The analysis provides: (1) historical view of demand for HIV testing (i.e., prior to effective treatment); (2) estimates of demand among different subpopulations; (3) impact of AIDS knowledge on demand; and (4) impact of State policies on demand.

Multivariate analysis revealed that, in 1988, the level of AIDS information, knowledge of risk status (not asked in 1987) and state policies regarding protection of an individual's privacy were significant predictors of likelihood of being tested. Also, persons living in urban areas, males, blacks, and younger persons were significantly more likely to be tested, even upon controlling for perceived risk status. Of all persons tested for HIV (nearly 21 percent of adults), two-thirds were tested in blood donations (these were excluded from multivariate analysis). Most of these are ignorant that their blood was being tested (e.g, as of 1987, of 2,000 persons who had blood tested since 1985, only 410 indicated they had their blood tested for HIV as a result of a blood donation; respective figures for 1988 are 3,672 and 1,022) and this population was somewhat more likely than the general population to report being in a risk group (3.1 percent vs. 2.9 percent). 1988 results further point to a significant portion of individuals who never heard of the AIDS test (c. 25%). While this groups was excluded from the above analysis, the researchers found this group to have higher incidence of risk group membership and lower AIDS knowledge than the study sample.

"Financing Treatment Costs for IVDA AIDS Patients"
Pascal, Anthony H.; Rand Corp.
R03 HS 06130 (Project Officer: Melford Henderson)
Completed: 11/30/89

Based on a random sample of AIDS patients affiliated with one New York City hospital, data were collected in 1989 to assess the cost of treatment for a panel of 38 intravenous drug abusers. Data on costs, payments, patient economic variables, and service utilization were used to construct longitudinal profiles of these patients.

The study estimates that the average annual charge for medical care was approximately $33,000. This figure includes $24,171 for hospital inpatient care and $8,831 for outpatient services. Over 80% of the latter charge was for pharma-

ceutical. Those who were homeless or who changed residences frequently had nearly double the amount of charges than the group as a whole.

Findings indicate differential financing and resource utilization between this sample of New York City IDUs and a sample of men from Los Angeles. Only five percent of the New York City men were never on Medicaid, compared to 53 percent of the Los Angeles men (who were predominantly white). The Los Angeles sample was significantly more likely to be hospitalized and incur higher costs per day. However, the New York City sample had greater lengths of hospital stay, but had lower charges for lab tests and pharmaceuticals. Total median costs for the Los Angeles sample were nearly double that for the IVDUs in New York City and the largest differential was attributed to outpatient costs.

Estimating the use of medical care by IVDUs with AIDS patients and the costs of their care is important because they now constitute the largest AIDS risk group. Most AIDS studies have focused on white, middle-class homosexual or bisexual men. In contrast, IVDU patients with AIDS are disproportionately low-income, inner-city black or Hispanic residents.

Bennett, Pascal and Cvitanic estimated in the *Journal of Acquired Immune Deficiency Syndrome*, 1992; 5:1-6, that the total average annual medical charge (in 1989) for a group of male intravenous drug users was roughly $33,000, including $24,171 for hospital inpatient care, and $8,831 for outpatient services. Over 80 percent of the latter charge was for pharmaceuticals. Charges for homeless addicts and those who changed residencies frequently were nearly double the average for the group as a whole. Each man spent an average of nearly 39 days in the hospital during the 1 year study.

"Validating Hospital Discharge and AIDS Surveillance Data"
Payne, Susan McNair Cobb; Boston University
R03 HS 06426 (Project Officer: James Ullom)
Completed: 9/29/91

This research examined the completeness of routinely collected data on utilization and costs of persons with AIDS and HIV infection using data from two sources: the Massachusetts AIDS Reporting System and hospital discharge data from the Massachusetts Rate Setting Commission. The performance of individual codes (both AIDS/HIV specific and manifestation codes) and combination of codes in identifying AIDS/HIV were assessed. Thirty seven previously unreported cases were found. The completeness of reporting in Massachusetts was 96 percent. However, certain patients were more likely to be under-reported: intravenous drug users, women, residents outside metropolitan Boston, those presumptively diagnosed, and patients with cryptococcoses, HIV encephalopathy, and wasting syndrome. The study also concluded that: (1) the HIV specific ICD-9 codes are reliable indicators of HIV/-AIDS patients (although code 795.8 is less reliable than the 042-044 codes); (2) manifestation codes alone are inefficient predictors and should only be used with follow-up with the medical record to ascertain patients' AIDS/HIV sta-

tus; (3) hospital coders may need additional training in using the 042 and 044 codes accurately to distinguish between HIV+ patients who do and do not meet the AIDS case definition and in using the 795.8 code; (4) combinations of codes using a more narrow or strict definition of AIDS offer higher specificity and predictive value positive, while codes using broader definitions identify more AIDS cases but also have a higher false positive rate; (5) hospital discharge data can be used to identify patients based on residence, sex, race/ethnic group hospital, or diagnosis for focussed follow-up by AIDS epidemiologists.

"Management Systems for Home Health Care Clients with AIDS"
Payne, Susan McNair Cobb; Boston University
R01 HS 06843 (Project Officer: Melford Henderson)
Expected completion: 3/31/94

This project will refine an existing classification system (Patient Classification System for Home Nursing) for nursing home care visits so that it will accurately predict the length of home health visits for clients with AIDS.

"Public Policy and Screening: The Influence of State Policies and Funding in HIV Screening Utilization"
Phillips, Kathryn; Case Western Consortium of Public Health
R03 HS 06629 (dissertation) (Project Officer: Mim Kelly)
Completed: 8/31/91

This study examined the manner in which HIV testing is influenced by local government policies regarding the testing and care of HIV patients. The study used data obtained from the AIDS Knowledge and Attitude Survey Supplement of the National Health Interview Survey. The major research questions to be addressed were: 1) the influence of government intervention on screening use; 2) the relationship between government AIDS intervention in each state with specific characteristics of each state; 3) the comparability of HIV screening to other screening tools such as mammography and syphilis; and 4) the policy implications of these analyses.

Results show that in 1988 states with "Leading" policies designed to protect the individuals being tested were associated with increased voluntary testing only among whites and low-risk group members. "Reporter" states are not associated with significantly increased testing. Public policies had only marginal impact on decisions, but difficulties in interpretation due to sample size, group-specific effects, and data interpretation may obscure potential policy effects.

"Staging AIDS Prognoses: An Extension of the Turner System"
Piette, John; Brown University
R03 HS 06914 (dissertation) (Project Officer: Melford Henderson)
Completed: 6/30/92

The purpose of this research was to determine whether levels of severity, defined by the Turner classification system (SCAH), predict mortality, morbidity, and medical resource consumption. The study attempted to validate and refine the SCAH classification system as a predictor of mortality, in combination with T4 counts. Validation and refinement of measures was made on 1,780 hospital admissions in 9 U.S. cities between 1987 and 1991. Subjects were clients interviewed as part of the RWJ AIDS Health Services Program Evaluation.

Findings showed that information on CD4 counts, anemia, and hemoglobin improved prediction of mortality, over and above SCAH stage. In a report in *Amer. J. Public Health* (1993;83:510-514), medical records for 571 HIV-infected individuals were analyzed. Incidence rates and relative rates across CD4 strata (defined by cell counts) were calculated for inpatient and outpatient events. Rate ratios comparing people of color with whites were estimated within strata, adjusting for confounding factors using a Mantel-Haenszel pooling procedure. It was found that both inpatient and outpatient service use increased over progressively lower levels of CD4 counts. Within each CD4 stratum and controlling for other factors, white participants had more HIV clinic visits and fewer admissions than people of color. Among participants with fewer than 51 CD4 cells per cubic millimeter, people of color were admitted 20% more often, had 35% more inpatient days per person-year, and had only 74% as many HIV clinic visits as their white counterparts. It was concluded that CD4 lymphocyte count is strongly associated with increased usage of health services. People of color with HIV disease are more likely than similar whites to be admitted to the hospital and less likely to use outpatient care.

"Evaluating AIDS Education in Black Churches--RACE"
Quinn, Sandra C.; University of Maryland
R03 HS 07457 (dissertation) (Project Officer: Isabel Garcia)
Completed: 8/31/93

In 1988, the Southern Christian Leadership Conference was funded by the Centers for Disease Control to implement RACE: Reducing AIDS through Community Education. The primary objective of RACE was to provide AIDS education to Black communities in five cities. The RACE project represents the most comprehensive effort to date to target Black church congregations with culturally sensitive AIDS education. The primary goal of this dissertation study is to conduct a secondary analysis of RACE data to determine the efficacy of this community-based initiative. Ten research questions will be addressed by secondary data analyses. Results of this study will contribute to the replication of culturally sensitive, AIDS education program components and provide guidance for broader health promotion and disease prevention efforts through Black churches.

"Primary Care of Patients With or At-Risk for HIV"
Ramsey, Paul; University of Washington
R01 HS 06454 (Project Officer: Isabel Garcia)
Completed: 12/31/93

The objective of this project was to assess the quality of care provided to patients with, or at-risk for, HIV infection by primary care physicians with varying levels of expertise in treating HIV patients. Methods were established to judge the behavioral competency of physicians in identifying, managing, and counseling patients. A standardized patient examination was developed to evaluate the knowledge, interviewing, physical examination, and counseling skills of physician-subjects. Modified existing health status measures were used to evaluate outcomes associated with patient functioning, satisfaction with care, and compliance. One component of the study also assessed the degree to which receipt of a continuing education course on identification, management and counseling of HIV patients enhances the performance of physicians with no experience in treating HIV patients on the standardized patient examinations.

Preliminary findings on patients reported to the State of Washington Registry and from a survey of general internists and family practitioners in the State of Washington indicated that 45 percent of patients were seen by physicians who saw fewer than five patients with AIDS and that 68% of physicians saw only one case. Approximately three-quarters of family practice specialists and 57% of internists, regardless of specialty, had some experience in handling HIV patients, but 68% of family practice specialists and 61% of internists saw fewer than six patients in the preceding two years. Thus, the care of HIV patients is not consistently concentrated in the hands of a few. Further work is needed to determine the extent and quality of care.

"Changes in Health Status/Utility in HIV Infected Patients"
Revicki, Dennis A.; Battelle Human Affairs Research Center, Seattle, WA
R01 HS 06727 (Project Officer: Isabel Garcia)
Expected completion: 7/30/94

This pilot study, encompassing a sample of 150 HIV infected patients from three clinics in the Baltimore-Washington area who will be followed for 12 months, will develop and test various health status measures for HIV infected patients. Specifically, the study will: 1) develop or test instruments for health status, neurocognitive function, health utility, and HIV-related symptom assessment; 2) develop and test a medical record abstraction forms; 3) evaluate alternative patient recruitment and retention; 4) examine potential sample biases; 5) estimate sample attrition; and 6) examine interviewer and subject burdens. The study methodology is a longitudinal, observational design with multiple measurements for asymptomatic HIV disease, symptomatic HIV disease and AIDS. Interviews will provide data on general health status, depression, neurocognitive functions, health utility and HIV related symptoms.

The patients' clinical status, symptoms and severity of illness will be abstracted from the medical record.

Fulfilling the study's aims will serve to: explore methodological issues regarding psychometric health status and health utility measures; provide information on the progression of HIV disease in its relationship to functional status and psychological well being; develop health utility assessment instruments for evaluation of new medical treatments for HIV disease; and examine the clinical responsiveness of health status measures to changes in clinical status. The pilot study findings will be used to plan specifics for a larger study.

The investigation would link clinical findings with quality of life secondary to health status. The net rational question is: At what point is life not worth living because of its quality? This type of research may lead to a new policy of advance directives, with its opening question: What is the validity of an advance directive by an AIDS patient with a possible unrecognized neurocognitive deficit that affects competency? This project will have useful methodologic contribution, particularly in clinical trials of new AIDS therapies. The challenge of this effort will be to develop instruments which can address issues of HIV infected young men, pregnant women, and drug abusers. A further challenge will be to identify actual impairment of health utility due to HIV infection in a large group of patients with considerable co-morbidities.

"Effects of Case Management on AIDS Informal Caregivers"
Reynolds, Nancy R.; Ohio State University College of Nursing
R03 HS 06971 (dissertation) (Project Officer: Julius Pellegrino)
Completed: 8/31/92

The objective of this study was to examine the effectiveness of case management as a strategy to enhance the well-being among informal caregivers of persons with HIV. Monthly data on physical and emotional health, satisfaction with formal services, and a descriptive account of the caregiver role were collected among subjects participating in this study, which is a part of a larger randomized controlled trial (funded by NIMH) analyzing the effects of case management on client outcomes.

"Is Family Medicine Meeting the HIV/AIDS Challenge?"
Ryan, John G.; University of Texas Health Science Center
R03 HS 06615 (dissertation) (Project Officer: Greg Alexander)
Completed: 7/31/91

This study involved a mail survey of a nationally representative random sample of 2,500 board certified or eligible family practitioners to ascertain their knowledge, attitudes, and experiences concerning HIV/AIDS patients. The survey was used to analyze the relationship between these factors and physician characteristics such as residency training, urban/rural location, and academic/private

practice. A response rate of 63.7 percent was achieved.

About 77 percent of respondents were unable to identify the universal precautions for blood and body fluids to prevent occupational transmission of HIV/hepatitis B virus. Residency trained and board certified physicians expressed fewer "external constraints" (i.e., fear of losing patients) and fewer "internal constraints" (fear of becoming infected) to providing treatment to HIV patients. Residency trained physicians expressed a greater comfort with discussing sexually-related topics with their patients than did non-residency trained physicians. Sixty seven percent of the physicians reported never providing treatment to an individual with HIV disease. Residency trained and board certified physicians expressed a greater likelihood to provide treatment to HIV patients than non-residency trained and non-board certified physicians.

Finding were published in *Archives of Family Medicine*, 1993;2:637-44; *Journal of AIDS*, 1992;5:835-40, and *Journal of Family Practice*, 1991;32:559.

"Knowledge-Based Records for Patients with HIV Infections"
Safran, Charles; Beth Israel Hospital
R01 HS 06288 (Project Officer: James McAllister)
Expected completion: 6/30/94

This project is developing a knowledge-based medical record system (KBMR-HIV) for the care of patients with HIV illnesses. It will provide the physician reminders, directed access to the biomedical literature, and information on research protocols, community resources, and cost-effective strategies for the management of common problems. Teams of physicians will be randomly assigned to experimental (those with access to KBMR-HIV) and control groups. It is hypothesized that physicians who use the system are more satisfied with the care they deliver to their patients. The study also will analyze the degree to which physicians adhere to agreed upon standards of care to help assess their effectiveness.

In an article *J. Amer. Med. Assoc.*, 1992;268, Locke, et al. reported on the rate of detection of HIV-related factors elicited by computer interview in comparison to a standard American Red Cross procedure for donor suitability. Among 272 donors who provided completed data, the computer identified 12 who reported either behaviors associated with a risk of HIV acquisition or symptoms compatible with AIDS; none of these donors has been so identified either by routine written questionnaires or by face-to-face interviews used to screen potential blood donors. The rate of elicitation of HIV-related factors by the computer interview was 12/272 or 4.4%, compared with 2/1,536 using the standard Red Cross procedure. Tests for antibodies to the HIV were negative in blood samples from all of the 272 subjects studied. The subjects enjoyed the computer interview and judged it to be more private than the standard donor interview and predicted that donors would be more honest with the computer interview than with a human interviewer. It was concluded that computer-based screening elicits more HIV-related factors in the health histories of blood donors than do the standard questionnaire

and interviewing methods currently in use.

Preliminary results of the KBMR-HIV controlled clinical trial show that workstation users provide more primary care than physicians without this support, and that reminders are very effective in documentation of guideline implementation.

Findings are discussed in *MD Comput*, 1991;8:291-9, and *AIDS Clinical Care*, 1992;4:25-29.

"Costs of Medical Care for HIV & Non-AIDS Patients"
Scitovsky, Anne A.; Palo Alto Medical Foundation/Research Institute
R03 HS 06646 (Project Officer: Melford Henderson)
Completed: 7/31/91

This study examined the use and costs of medical care of HIV-infected persons without AIDS and with a CD4 cell count of less than 200/mm^3 From a registry of 386 persons who qualified for the study, data analysis ultimately was conducted on only 47 persons who agreed to participate and who did not take part in other clinical trials. It was found that the mean annual costs of the patients who developed AIDS were almost twice the costs of those who did not develop AIDS, ($18,579 compared with $9,578) during the 1 year study period. Their costs of physician and outpatient ancillary services were more than twice those of the latter, averaging $8,538 compared with $3,564, and their inpatient hospital costs were more than five times those of the latter, $4,735 compared with $887. The cost of drugs, however, was much the same for the two groups, $4,422 for those who developed AIDS and $4,704 for those who did not progress to AIDS. Because of these differences, the distribution of costs by type of service was found to vary greatly between the two groups (e.g., the cost of drugs accounted for just under one quarter of total costs of patients who developed AIDS compared with just under one half of the costs of those who did not develop AIDS). By contrast, hospital inpatient costs accounted for 26% of the total costs of the former compared with only 9% of the total costs of the latter. The data on number of services per person per year showed much the same differences between the two groups as do the cost data, the patients who progressed to AIDS being higher (and usually significantly higher) users than those who did not develop AIDS. Finally, comparing the mean monthly pre-AIDS costs and use of those who developed AIDS with their costs and use in the months they had AIDS, only the differences in total costs were found to be statistically significant. It was concluded that the proposed expansion of the CDC AIDS case definition should have no effect on the costs of the epidemic, unless persons with CD4 cell counts of 200/mm^3 or less who previously had not had any medical care would now seek and obtain care.

"Variation in Cost of AIDS Related to Gender and Risk Status"
Seage, George R.; Boston Dept. of Health and Hospital Corporation
R03 HS 06150 (Project Officer: Melford Henderson)
Completed: 8/31/90

This study was a population-based cost of illness study which used records from the Massachusetts AIDS Surveillance Program to compare patterns of utilization of inpatient services by women and intravenous drug users to a group of non-IVDU men with AIDS in 1987. Estimates were made of costs per patient, controlling for stage of disease, site of hospitalization, socioeconomic status, and levels of social support. Comparisons were also made of utilization in hospitals with high and with low experience treating AIDS patients.

Mean ALOS was 15.5 days and cost of stay was $11,852. IVDUs had 42% longer hospital stays, 38% higher costs, and 50% higher incidence of hospitalization than did the control group of homosexual men. Women had similar cost, length of stay, and incidence of hospitalization as did the control group of men. Disease severity, as measured by the Turner SCAH system, was a significant predictor of cost, mortality, and ALOS, but could not explain the elevated resource use of IVDUs. The Yale-Justice system of severity also could not explain the higher resource use of IVDUs, but was associated with survival and incidence of hospitalization.

Overall, patients within low-experience hospitals were more likely to be placed in an ICU and have longer stays. The relative risk of dying within 30 days of discharge and during an inpatient admission at a low-experience hospital relative to a high experience hospital respectively were 1.68 and 1.86 after adjusting for a host of factors. In a report of the study in *J. Amer. Med. Assoc.*, 1992;268:2655-61, it was noted, even after controlling for multiple patient-level and hospital-level variables, that the relative risk of death was more than twice as high at hospitals with lower AIDS familiarity than at hospitals more experienced in AIDS care. Moreover, the better outcomes in high-experience hospitals did not appear to be the result of more intensive use of resources as measured by admission to the ICU, length of stay or cost. The researchers noted that most high-experience hospitals offer AIDS patients access to clinical trials, which also may have an effect on outcome. The authors state that their results offer preliminary support for policies calling for the development of regional networks of HIV care, referral and provider education. Shapiro notes, in an editorial in that issue of *J. Amer. Med. Assoc.*, that additional work is needed in this area to assure that such findings are contemporary and relevant.

"Outcomes of Symptomatic Episodes in HIV Infection"
Shapiro, Martin; University of California, Los Angeles
R03 HS 06775 (Project Officer: Elinor Walker)
Completed: 12/31/93

This prospective, longitudinal study will test the diagnostic yield of a standard medical workup for diarrhea and constitutional symptoms in AIDS patients, in terms of the likelihood that diagnosis is made and a specific treatment instituted, and to determine the effect upon health-related quality of life. The intent of the study is to contribute to the diagnostic evaluation of such patients by: 1) describing the spectrum, frequency, and outcome of such episodes; 2) estimating the effects of medical procedures and fever on quality of life, and ability to diagnose; 3) describing the totality of commonly used diagnostic tests; 4) characterizing clinical syndromes that allow for a more focused investigation; 5) identifying patient characteristics which support differing investigational and therapeutic strategies; and 6) developing predictive models for different diagnostic strategies. The study will include 355 patients who receive inpatient or outpatient services at a county hospital or a Veterans Affairs Medical Center. Using medical record information and patient interviews, this study will examine the utility of diagnostic investigation at different stages of HIV illness.

"HIV Treatment Decision-Making"
Siegel, Karolynn, Sloan Kettering Inst. for Cancer Research, NY
R01 HS 07656 (Project Officer: Jean Carmody)
Expected completion: 7/31/95

This exploratory study will involve open-ended interviews with 25 Black, 25 Latino, and 25 non-Hispanic Caucasian women with HIV infection, not diagnosed with or presenting evidence of AIDS. Unstructured interviews together with data from a short questionnaire will be used to generate grounded theory regarding the treatment behavior among these groups of women. Theory development will be based on explorations, via data gathered in the interviews, of how these women's experiences and perceptions influenced their decisions concerning three aspects of treatment: deciding to be HIV tested, deciding to initiate treatment, and deciding to comply with the treatment regimen. It is anticipated that increased understanding of treatment decision-making within the three racial/ethnic groups will emerge from the analytical process.

"Utilization and Insurance Among HIV Positive Drug Users"
Solomon, Liza; Johns Hopkins University
R03 HS 06441 (Project Officer: Melford Henderson)
Completed: 1/31/92

This project described and compared patterns and changes in patterns of health services utilization between a cohort of 600 HIV seropositive IVDAs and 600 HIV seronegative IVDAs. It built upon the NIDA-funded Project-Alive, which is a natural history study of a cohort of HIV seropositive IVDAs in Baltimore. Prospective data were obtained by interviewing participants twice a year for a period of two years, and included information on illness severity (results from a physical examination including T cell count), serostatus, illness, insurance status, drug use, and social status.

In a report in *Amer. J. Public Health*, 1991:81:1285-90, it was noted that, of 1881 individuals studied, the proportion of the population that was HIV seropositive was 32 percent. In multivariate analysis, the single most important predictor of both inpatient and outpatient utilization was the presence of two or more HIV-related clinical symptoms. HIV positive serostatus alone or known low CD4 counts were not significantly associated with use of health care services. These data are consistent with other research documenting the important role of symptoms and complaints in predicting services use, and suggest that HIV-seropositive IVDUs are not receiving recommended preventive care. Additional efforts will be needed to ensure that HIV-seropositive drug users participate in currently recommended protocols for early treatment of asymptomatic HIV infection.

"Quality and Cost of Care for HIV Infected Medicaid Patients"
Soumerai, Stephen B.; Harvard University
R01 HS 06893 (Project Officer: James R. Ullom)
Expected completion: 3/31/95

Although the prevalence of HIV disease is on the rise, with an increasing burden being shouldered by Medicaid, relatively little is known about the patterns, costs, and quality of care provided to Medicaid patients infected with HIV. The objective of this project is to study issues of cost and quality of care for the HIV-infected Medicaid population in New Jersey, with a specific focus on women and children. The investigation will encompass three phases: (1) description of patterns of care among patient subgroups; (2) trends and variation in adherence to scientifically-based clinical guidelines; (3) predictors of variation in treatment of HIV-infected women by patient, physician and practice setting characteristics. This research will take advantage of and enhance an existing data base containing information on all Medicaid claims, patient demographic characteristics, and provider characteristics in caring for 1.8 million individuals served by the New Jersey Medicaid Program from 1980 to 1991. These Medicaid data will be supplemented with information from the AIDS Registry for validating HIV diagnosis. In addition, risk and social factors

from the AIDS Registry will be retrieved and linked in a confidential manner with patient-level Medicaid data, resulting in a resource for monitoring variations in quality of AIDS care among women, children, intravenous drug-using males. Physician, setting, and patient characteristics associated with these variations will be identified and measured. Identification of physician groups at risk of providing inappropriate care is essential in designing quality improvement programs to correct gaps in care.

"The Effect of Case Management on Cost of Care for PWAs"
Sowell, Richard L.; Medical College of Georgia
R03 HS 06315 (Project Officer: Gary Young)
Completed: 12/31/90

This study compared the cost of two alternative approaches to delivery of health care to persons with AIDS. The subjects were men, ages 20 through 49, who died of AIDS, in Georgia, between 1986 and 1989. A case management approach was compared with a less organized, ad hoc approach to care, in terms of lifetime costs. Retrospective inpatient medical and financial data on 150 deceased AIDS patients drawn from five hospitals throughout Georgia were analyzed. Half of the patients participated in a case management system at one public teaching hospital and the other half from four other hospitals did not. Charge figures across hospitals were standardized and adjusted for annual inflation rates. The two groups were equivalent in terms of race, IV use history, alcohol use, and use of other drugs. PWAs who had hospitalizations at sites other than those participating in the study were excluded from analysis.

Results show that for the 121 patients in the study the total adjusted hospital charges for the case managed group were significantly lower ($11,143 compared to $20,523). The mean diagnosis to death charge for hospital care in the entire total sample (including patients who received care at hospitals other than those included in the study) was $21,394 (N=150). Multivariate analyses indicated that approximately 24% of variation in hospital costs was related to number of opportunistic infections and participation in case management. Race, IVD use, type of infection, and AZT use did not contribute significantly to the model. Also, case managed patients lived significantly longer and longer between first hospitalization and death. Thirty-one percent of the case managed group received their diagnosis during their first hospitalization, compared to 56 percent of the total sample (mean=47%).

"Living Wills: For Primary Care, AIDS, and Cancer Patients"
Stoeckle, John D.; Massachusetts General Hospital
R01 HS 06120 (Project Officer: Julius Pellegrino)
Completed: 2/28/91

The specific Medical Directive intervention preferences of cohorts of oncology and HIV patients seen in primary care physician practices were compared to those of the general public. Patient

intervention preferences for advanced care planning across four scenarios were measured: persistent vegetative state, coma with small chance of recovery, dementia without life-threatening illness, and dementia with life-threatening illness. Descriptive and analytic information were used to tailor predrafted living will forms to better meet the needs of patients whose situation and treatment preferences might change.

Findings suggest that discussions about treatment options in physicians' offices enable patients to make specific choices and may later improve adherence to those choices. Patients' desire for advance directives planning did not vary from that found among the general population. However, while the majority of patients and the general populations wanted advance directives, only 15 to 20 percent of each had planned for such. Two reasons were cited for failure: patients' expectation that physician would initiate contact or a sense that the issue was relevant only for those in worse health or older. Increased motivation for advance care planning was noted upon completion of interviews. The majority of patients and general population also declined life sustaining treatment, with the smallest proportion (64%) declining simple tests and the largest (76%) major surgery. The decline rate was lowest in the coma scenario and highest for dementia with terminal illness. "Common sense" prediction based on age, health or demographic features was not related to patients' wishes. However, in contrast to these decisions, the majority of patients wanted to be cared for in a hospital vs. a hospice or home. Non-sensible response combinations were extremely low (e.g, decline of antibiotics while requesting major surgery). Treatment declines were durable across time, but treatment acceptance was highly variable. Durability was highest for dementia with terminal illness and did not vary by age or health status. Initial choices for treatment declined over time, uncertainty tended toward declines, and declines remained fairly constant.

"Cost-Effective Management of HIV-Related Illnesses"
Tosteson, Anna; Beth Israel Hospital
R01 HS 06694 (Project Officer: Howard Fishbein)
Completion: 5/30/94

This project will develop a decision-analytic model to aid in the determination of optimal clinical management strategies and in the assessment of the potential impact that policy initiatives could have on the cost and outcomes of care for HIV-infected persons presenting with CNS disorders. The CNS model will assess the life-expectancy, quality adjusted life expectancy, short-term morbidity, cost, and cost-effectiveness of all clinically reasonable strategies in patients presenting with focal neurologic deficits, or with headache and/or confusion in the absence of the former. Analyses will allow for an assessment of the impact of improvements in the treatment of CNS disorders, such as screening for toxoplasma gondii on the health and economic outcomes of those presenting with neurologic symptoms.

Freedberg et al., reported in the *Journal of Internal Medicine*, 1992;7:261-72, that different methods of diagnosing and treating

Pneumocystis carinii pneumonia (PCP) make some strategies more cost effective than others in managing HIV infected patients. Although estimated levels of effectiveness among various strategies were similar, there was a marked variation in costs. Three approaches were consistently most cost-effective, with incremental cost-effectiveness ratios below $50,000 per quality-adjusted life year saved. The authors suggest testing patients at highest risk for infection first with induced sputum analysis, followed by tri methoprim-sulfamethoxazol if the test proves positive, or bronchoscopy with lavage, if negative. Intermediate-risk patients should be tested with arterial blood gas analysis followed by induced sputum analysis if the alveolar-arterial (A/a) oxygen gradient is abnormal, or erythromycin, if normal. Low risk patients should be given erythromycin for 1 week followed by induced sputum analysis if symptoms persist. Changing management strategies (compared with no treatment) extended life expectancy from 0.2 percent in low risk patients to 3.8 percent in those with highest risk of PCP.

"Quality of Life in HIV+ and Primary Care Patients"
Tsevat, Joel.; Harvard Medical School, Beth Israel Hospital
R03 HS 06673 (Project Officer: Melford Henderson)
Completed: 9/30/92

This study prospectively collected three types of quality of life data over a period of twelve months from two cohorts of patients at Healthcare Associates. One cohort was 190 patients with HIV, and another was a control group of primary care patients who were matched on demographic variables. The three types of quality of life variables included measures of: (1) clinical epidemiologic status, operationalized by health functional capacity (the dyspnea-fatigue index); (2) health services research operationalized by health status (medical outcome study short form, mental health inventory, quality of well-being scale); and (3) decision analytic patient utilities operationalized by preferences (time trade-off and verbal categorical scales).

This methodological project was designed to: (1) assess the relationship among quality of life measures that have historically been poorly correlated; (2) explore reasons for poor correlation, including interaction effects (e.g., correlation exists among specific segments of the population, such as sicker AIDS patients) or correlation is time-dependent, such that clinical epidemiologic and health services measures correlate with utilities at a certain point in time, but diverge as patients adapt.

Preliminary findings, presented at the 1992 International AIDS Conference in Amsterdam, examined the relationships among 5 quality-of-life measures. Compared to other HIV+ patients (both asymptomatic and symptomatic), patients with AIDS had worse scores on indices of dyspnea-fatigue, of physical function, and of general health perception, and they had better scores on the Mental Health Inventory. Time trade-off utility scores did not differ according to disease stage, and utilities correlated only moderately with health status measures.

"Developing Tools to Study Resource Consumption in AIDS"
Williams, Sankey V.; University of Pennsylvania
R03 HS 06230 (Project Officer: Jennifer Mayfield)
Completed: 6/30/90

This pilot project developed methods that use computerized hospital data-reporting systems to identify AIDS patients and improve understanding of the costs of care and patterns of inpatient resource use for AIDS patients. Discharge data from Philadelphia's five medical school teaching hospitals were studied for a 30-month period. Resource consumption patterns within and between hospitals were compared.

The final report, "Improved Identification of Patients with HIV-Related Conditions," by David B. Nash, et al., includes results on the implementation and evaluation of an algorithm designed to account for AIDS/HIV under-reporting. Utilizing the Philadelphia Hospital Research Consortium (PHRC) database, which cares for 40 percent of cases in Philadelphia, 250,000 discharges in five teaching hospitals from July 1, 1985 to December 1987 were identified. Based on an initial screen for diagnostic and demographic indicators taken from automated data base codes, investigators found 274 known HIV cases, 84 definite cases, 111 highly probable patients, and 31 low probable patients.

Further validation of some records by chart review led to a 91% success rate for coding for "definite" cases, and a 56% success rate for "high probable" cases; but only a 6% success rate for "low" probable cases. Further validation compared PHRC data using Turner's classification scheme with New York data and found high comparability, but with a higher proportion of severe cases (23.5% compared to 15%). Only 14% of cases were PCP, ALOS was 13.2 days, and charges were on the high side ($1,612 per day), probably reflective of the teaching status of the hospitals and the severity of the patients. Mortality was low also compared to New York (11% vs. 27.5%). Collapsing Turner's 21 substages into 3, showed consistent charges and mortality across most categories.

"A Health Status Measure to Evaluate Drug Therapy for PCP"
Wu, Albert W.; John Hopkins University
R01 HS 07824 (Project Officer: Lynn Bosco)
Expected completion: 8/31/94

This questionnaire validation study is an ad-on to an ongoing randomized clinical trial of several antibiotic regimens in the treatment of PCP among patients with HIV infection. The aims of the study are to: 1) determine the reliability and construct validity of the health status measure; 2) determine if the health status measure accurately reflects changes in a physiologic measure of oxygenation (the A-a gradient) measured at the same time point and to determine responsiveness of the health status measure to changes over time in the A-a gradient; 3) determine if changes in drug regimen are related to patient perceived health status; 4) determine if the health status measure provides additional clini-

cally useful information beyond that conveyed by conventional study endpoints; and 5) compare the reliability and validity of Spanish and English versions of the health status measure. While traditional measures of improvement in survival and physiologic improvement in AIDS are important for evaluating efficacy of pharmacologic therapy, these measures do not necessarily relate to how the affects the feelings and percep tions of the patients. Measuring patient perceived health is particularly important in evaluating new forms of therapy for PCP in patients with HIV infection because all of the existing treatments involve toxicities. Use of a health status measure provides a patient based assessment that takes into account both patient perceived improvement in health status and patient perceived discomfort from toxicity.

"Determinants of House Officers' Responses to AIDS"
Yedidia, Michael, J.; New York University
R01 HS 06539 (Project Officer: Jean Carmody)
Completed: 6/30/93

This study was directed at discerning factors lying behind differences in attitudes toward caring for AIDS patients that are held by fourth year medical students and second year medical residents. From prior work, it has been found that the residents were significantly more negative in their attitudes. The investigators attempted to discern if the reason for the difference was due to socialization or a cohort effect. Included in the study were all 4th year students from six medical schools in New York State who participated in a former study and are being resurveyed in their second year of residency. A companion cohort of second year residents who did not participate in the first study also were surveyed. In particular, an examination of factors responsible for students' attitudes toward AIDS patients and aspects of their training experience was investigated. The study was designed to assist in developing intervention strategies to promote positive attitudes towards AIDS care among physicians in training.

Preliminary findings from the study included the observation that AIDS-related attitudes did not differ by geographic location or over time. AIDS was not a deterrent to choosing residency programs in areas with high AIDS prevalence. In fact, medical students' attitudes toward treating patients with AIDS were not important in determining residency choices, while attitudes of residents regarding AIDS care were strongly predictive of career plans. Yet, fourth year medical students with greatest willingness to treat AIDS patients entered specialties which had a greater likelihood of treating these patients, and students least interested in involvement with PWAs selected themselves out of specialty training where such involvement is sustained. Although residents' assessment of the educational value of treating PWA's increased, willingness to treat declined during training. Residency faculty outlook was determined to be the most important predictive variable of willingness to treat. Homo- and drug-phobia were also strongly predictive. Several potentially alterable aspects of residency training were identified which might improve attitudes of students. A number of papers are being prepared for publication.

"Determinants of MDs' AIDS-Related Practice Behavior"
Yedidia, Michael J. New York University
R01 HS 08095 (Project Officer: Jean Carmody)
Expected completion: 01/01/95

This project expands the researcher's prior work by performing the third in a series of surveys of medical students who graduated from six New York State medical schools in 1989. These physicians were first surveyed upon medical school graduation, again in the third year of residency, and now in their sixth post-graduate year when most have entered practice. The hypotheses of this prospective longitudinal project are directed by the investigators' prior findings concerning the AIDS-related characteristics, attitudes, and experiences of these physicians. The project will focus on identifying factors that shape physicians' willingness to care for HIV infected persons, especially for the large proportion of physicians who, at the end of their residency, remain uncommitted regarding their willingness to care for HIV infected persons. The goals of this project relate to studying formation of attitudes, individual characteristics, and actual behavior of physicians over time in order to define possible interventions to increase the supply of physicians committed to treating patients with AIDS and HIV infection. Another goal is to document institutional factors that impact the attitudes, knowledge and behavior of future physicians related to the caring of persons with HIV/AIDS.

AHCPR news Clips

Early HIV Infection Guideline

February 3, 1994

SPECIAL EDITION

The New York Times

Friday, January 21, 1994

U.S. Offers Guide for Doctors On Care of Those With H.I.V.

By WARREN E. LEARY
Special to The New York Times

WASHINGTON, Jan. 20 — Federal health officials released new guidelines today to help family doctors, pediatricians, nurse practitioners and other non-AIDS specialists diagnose the virus that causes AIDS and treat people infected with it.

Experts said that many of these non-specialists had had limited contact with people infected with the virus but that the guidelines should help them offer better care to increasing numbers of infected patients, especially at early stages, before symptoms of AIDS develop.

Dr. Philip R. Lee, Assistant Secretary for Health of the Health and Human Services Department, said more than half of the estimated one million people infected with H.I.V. might not know they are infected and therefore were being denied early care, counseling and treatment.

Part of the problem, he said at a news briefing, is that family doctors and others providing primary care are far more likely to ask a patient about cigarette smoking than to take a sexual history or drug-use history or ask other questions that might lead to testing for H.I.V.

And too often when a patient is found to be infected, he said, the family doctor quickly refers the patient to a specialist or center, often far away, when special treatment is not yet needed.

"There are simply not enough infectious-disease specialists to care adequately for the growing numbers of people living with H.I.V.," Dr. Lee said.

Kristine M. Gebbie, the White House AIDS Policy Coordinator, recommended the new guidelines, saying, "Many people can get the care they need closer to home with health providers they know."

The detailed guidelines, in a 196-page book that will be distributed free to doctors, nurses, hospitals and clinics, were assembled by a 19-member committee of doctors, nurses, researchers, social workers, H.I.V. patients and others. The panel was convened by the Agency for Health Care Policy and Research, which is part of the Federal Public Health Service.

Among the specifics are treating H.I.V. patients early with preventive doses of a sulfa drug known to prevent a form of pneumonia that is a principal killer of those with the virus, screening for tuberculosis, which is particularly deadly for those with weakened immune systems, and providing regular oral and eye exams to catch associated problems early.

The agency also announced two new consumer guides aimed at people with H.I.V. and parents of children with the virus.

Copies of the practitioners' guidelines, called "Early Evaluation and Management of H.I.V. Infection," an accompanying quick reference guide, and the consumer booklets are available free by calling (800) 342-2437. An overview of the guidelines and the consumer booklets also are available by fax by calling 1-301-594-2800.

The Washington Post

Friday, January 21, 1994

Public Health Service Publishes Guide for AIDS Treatment

By David Brown
Washington Post Staff Writer

Ignorance of medical particulars will no longer be a good excuse for doctors and nurses to avoid taking care of people infected with the AIDS virus, the United States Public Health Service said yesterday.

The agency published a 196-page "clinical practice guideline" on how to diagnose and manage patients in the early stages of infection with the human immunodeficiency virus (HIV).

"Some providers are reluctant [to treat HIV patients] for a variety of reasons," Philip R. Lee, director of the Public Health Service, said at a news conference. Some of that reluctance comes from fear and prejudice, though most, he said, comes from the belief by many doctors that HIV infection is too complicated for anyone but experts to manage.

"By having the knowledge base in one place, at their fingertips, I think we'll overcome the major obstacle," Lee said.

The guideline is the seventh in a series of PHS pamphlets aimed at improving treatment of common medical problems. As with the others, the one for HIV infection stresses the importance of primary care practitioners, not specialists, in making the diagnosis and providing routine treatment of the illness.

The document functions not only as a "how-to" manual for strictly medical questions; it also details issues such as the risks and benefits of revealing one's HIV status to others; the importance of including women and minority groups in AIDS drug experiments; and some of the particular problems of access to care encountered by poor people infected with the virus.

The guideline addresses the needs not only of adult men—the original and largest infected population—but also pregnant and nonpregnant women, adolescents, children and infants.

About 1 million Americans are now infected with HIV. This year, between 40,000 and 60,000 new infections will occur, and between 47,000 and 66,000 people are expected to die of AIDS, according to federal estimates. About half of all AIDS patients are blacks or Hispanics.

During the early years of the 10-year-old epidemic—and to a large extent still—HIV patients were treated by infectious disease specialists or other physicians who had developed a particular interest and expertise in the infection.

"In too many communities, people have been undiagnosed, misdiagnosed or ignored after diagnosis . . . by providers who are ignorant of how to treat or unwilling to treat," said Cornelius A. Baker, a representative of the National Association of People with AIDS. The guideline "is an extremely useful tool in demystifying treatment . . . especially in those providers who are seeing their first case of confirmed HIV infection."

Though the guidelines acknowledge that people with advanced AIDS may need specialty care, they stress that treatment of relatively stable HIV infection falls well within a generalist's realm.

"We are here today to say there is no magic to taking care of HIV-infected patients. It is no different from taking care of a person with any other chronic condition," said Wafaa El-Sadr, chief of infectious diseases at Harlem Hospital Center and a co-chairman of the 19-member panel that wrote the guideline.

El-Sadr and James M. Oleske, a pediatric AIDS specialist at New Jersey Medical School and the other co-chairman, examined 30,000 articles on HIV infection, ultimately reading and evaluating 700 of them, with the help of other panel members.

The guideline offers advice on such subjects as: how frequently HIV patients should undergo blood tests to measure the condition of their immune systems; when antiviral drugs are most useful; what is the best drug regimen for preventing *Pneumocystis carinii* pneumonia, a common infection in AIDS patients; and what routine screening tests (such as those for TB and cervical cancer) doctors should be sure to order for HIV patients.

The document is very specific, in some places naming drugs and dosages. In addition, it cites the medical literature when discussing various issues, and labels its recommendations as "supported by evidence," "suggested by evidence" or simply the product of "expert opinion."

A 36-page "Quick Reference Guide for Clinicians," which includes recommendations and treatment "decision trees," and a 17-page "Consumer Guide" to early HIV infection were also released yesterday.

Copies of the documents will be sent to hospitals, clinics, medical societies and any person who requests one. Persons wanting an English-language copy can call 1-800-342-AIDS, and those wanting a Spanish-language version can call 1-800-344-SIDA. Deaf access is 1-800-AIDS-TTY.

The ASSOCIATED PRESS Article shown below appeared in the following newspapers on January 21, 1994

American-Statesman

Denver Rocky Mountian News

Houston Post

New York Daily News

St Petersburg Times

Panel advises primary care givers on treating early stages of HIV

ASSOCIATED PRESS

WASHINGTON — Seeking to overcome the reluctance of doctors to treat people with the virus that causes AIDS, a government panel offered primary care providers new advice Thursday on how to treat patients with early HIV infection.

Those with HIV can lead longer, more productive lives if they get early counseling and treatment, and that care does not have to come from an AIDS specialist, the experts said.

"Today we bring a message of hope to those living with HIV," said Dr. Wafaa El-Sadr of Harlem Hospital Center in New York.

The 196-page paperback book of guidelines distills the latest scientific wisdom on drug treatment of HIV patients, how to ward off opportunistic infections, detecting and dealing with tuberculosis, syphilis and other problems.

The guidelines urge that all HIV patients be put on a sulfa drug to avert a deadly pneumonia when their CD4 cell counts fall below 200. They also urge that patients be offered the AIDS drug zidovudine, or AZT, when their CD4 count drops below 500. A low cell count indicates a compromised immune system.

The Agency for Health Care Policy and Research also published two consumer guides aimed at people with the virus and parents of children with HIV.

El-Sadr, who co-chaired the panel with Dr. James M. Oleske of the New Jersey Medical School in Newark, N.J., said the guidelines will make primary care providers "more confident and more comfortable" in caring for patients with HIV.

The American Medical Association applauded the new guidelines and has sent a 25-page booklet offering similar advice on early treatment of HIV to all 192,000 primary care doctors across the country.

Cornelius A. Baker of the National Association of People with AIDS said in one survey, 24 percent of people with HIV said health-care workers were afraid to care for them.

"This guidance will be an extremely useful tool in demystifying treatment and hopefully removing the fear," said Baker.

Seattle Times

Thursday, January 20, 1994

Early care urged for HIV-positive patients

BY CHRISTOPHER CONNELL
Associated Press

WASHINGTON — People infected with the AIDS virus can live better and longer if primary care doctors follow new government guidelines stressing early counseling and treatment, a federal agency said today.

"There are simply not enough infectious disease specialists to care adequately for the growing numbers of people living with HIV," the virus that leads to AIDS, said Philip R. Lee, the assistant U.S. secretary for health.

The guidelines recommend that even symptom-free HIV patients be given daily doses of a sulfa drug to ward off a deadly pneumonia when their CD4 cell count falls below 200. A low count indicates a compromised immune system.

An outside panel of experts convened by the Public Health Service also urged that patients be offered the AIDS drug zidovudine, or AZT, when their CD4 count drops below 500.

Lee, director of the Public Health Service, said half the estimated 1 million Americans who carry the deadly virus do not know they are infected.

Some family doctors fail to ask patients about their sexual history or drug use that might lead to testing and early detection of HIV, he said.

To get a copy

Free copies of the guideline "Early Evaluation and Management of HIV Infection" and consumer booklets are available by calling 1-800-342-2437.
Copies in Spanish are available by calling 1-800-344-7432. Information is also available by fax by calling 1-301-594-2800.

ASSOCIATED PRESS

And too often, primary care doctors refer patients who test positive to "costly and distant" specialists, Lee said in prepared remarks. Primary care physicians can often manage HIV patients "at less cost and with greater convenience."

In addition to the guidelines for physicians, the federal Agency for Health Care Policy and Research also released two booklets for people living with HIV and for parents of children infected by the virus.

The 19-member panel of physicians, nurses, social workers and other experts that prepared the guidelines included two people living with the infection.

The American Medical Association applauded the federal guidance but is also sending its own 25-page booklet of advice on early HIV intervention to all the country's 192,000 primary care doctors.

The federal guidelines say:

- A detailed medical history, including sexual and substance abuse history, is crucial.
- Doctors should closely monitor patients' count of CD4 cells.
- HIV patients should be screened for tuberculosis and checked regularly for syphilis and other sexually transmitted diseases.
- Women should be given regular pelvic exams, including Pap smears.
- The doctor should conduct both an oral exam and an eye exam and urge patients to see a dentist every six months.
- Patients should be offered zidovudine, or AZT, when their CD4 count falls below 500.
- To prevent pneumocystis carinii pneumonia, oral doses of Bactrim, Septra or generic sulfa drugs should be given daily when CD4 counts fall below 200.

That last recommendation alone "if universally applied can result in immense benefit to thousands, perhaps tens of thousands of people with HIV," Lee said.

Baltimore Sun

Friday, January 21, 1994

Panel gives advice to doctors on how to care for HIV patients

Associated Press

WASHINGTON — Seeking to overcome the reluctance of doctors to treat people with the virus that causes AIDS, a government panel offered primary care providers new advice yesterday on how to treat patients with early HIV infection.

Those with the human immunodeficiency virus can lead longer, more productive lives if they get early counseling and treatment, and that care does not have to come from an AIDS specialist, the experts said.

"Today we bring a message of hope to those living with HIV," said Dr. Wafaa El-Sadr, co-chairman of the panel.

The 196-page paperback book of guidelines distills the latest scientific wisdom on drug treatment of HIV patients, how to ward off opportunistic infections, detecting and dealing with tuberculosis, syphilis and other problems.

The guidelines urge that all HIV patients be put on a sulfa drug to avert a deadly pneumonia when their CD4 cell counts fall below 200. CD4 cells are the components of the immune system that are targeted by HIV, and a low cell count indicates a compromised immune system. The guidelines also urge that patients be offered the AIDS drug zidovudine, or AZT, when their CD4 count drops below 500.

The Agency for Health Care Policy and Research has also published two consumer guides.

The American Medical Association applauded the new guidelines.

Free copies of the book of guidelines, "Early Evaluation and Management of HIV Infection," and the consumer booklets may be obtained by calling (800) 342-2437.

Boston Globe

Saturday, January 22, 1994

US panel offers patients, physicians advice on HIV

Associated Press

WASHINGTON - Seeking to overcome the reluctance of doctors to treat people with the virus that causes AIDS, a government panel yesterday offered primary care providers new advice on how to treat patients with early HIV infection.

The Agency for Health Care Policy and Research also published two consumer guides aimed at people with the virus and parents of children with HIV.

Those with HIV can lead longer, more productive lives if they get early counseling and treatment, and that care does not have to come from an AIDS specialist, the experts said.

"Today we bring a message of hope to those living with HIV," said Dr. Wafaa El-Sadr of Harlem Hospital Center in New York.

"Early Evaluation and Management of HIV Infection" distills the latest scientific wisdom on drug treatment of HIV patients, how to ward off opportunistic infections, detecting and dealing with tuberculosis, syphilis and other problems.

The guidelines urge that all HIV patients be put on a sulfa drug to avert a deadly pneumonia when their CD4 cell counts fall below 200. They also urge that patients be offered the AIDS drug zidovudine, or AZT, when their CD4 count drops below 500.

'Today we bring a message of hope to those living with HIV.'

WAFAA EL-SADR
New York doctor

El-Sadr, who co-chaired the panel with Dr. James M. Oleske of the New Jersey Medical School, said the guidelines will make primary care providers "more confident and more comfortable" in caring for patients with HIV. Two of the panel live with the infection themselves.

Kristine Gebbie, national AIDS policy coordinator, said HIV positive patients are too often referred to to distant, advanced medical centers for treatment.

Kansas City Star January 21, 1994

Government has new guidelines on detection, treatment of HIV

Knight-Ridder Newspapers

WASHINGTON — Hoping to stave off the onset of AIDS and hold down health care costs, the federal government offered new guidelines Thursday for early detection and treatment of HIV infection to doctors and other health care workers.

The U.S. Public Health Service and the Centers for Disease Control and Prevention also announced that they had published new pamphlets with health care tips for people with HIV and for families of children with the infection.

"HIV now is not a disease just in Newark (N.J.), New York, San Francisco and Miami," said James M. Oleske, director of infectious diseases at the New Jersey Medical School and co-chairman of the panel of experts that drew up the guidelines. "It's showing up in vast areas of this country, even the most rural."

Two of the 19 members of the panel are HIV-infected.

"Front-line physicians who may not know what they're dealing with don't do the simple things that can improve the quality of life and extend the lives of these patients."

James M. Oleske, New Jersey Medical School

"Front-line physicians who may not know what they're dealing with don't do the simple things that can improve the quality of life and extend the lives of these patients," Oleske said in an interview.

For example, the guidelines suggest when to begin giving daily doses of sulfa drugs to help prevent the onset of the type of pneumonia that weakens and kills AIDS victims.

They also suggest what tests should be given, and when, to track the stages of the disease, then how to react. And they give tips about counseling HIV-infected patients and their families.

Two of the most sought-after targets for the guidelines are obstetricians and pediatricians because pregnant women and infants are among the fastest-growing segments of the population with HIV, officials said.

"We feel that well-trained primary care physicians can provide the basic care these patients require so that they don't need to be seen by a specialist or travel to a special center," Oleske said.

Kristine M. Gebbie, the nurse who serves as President Clinton's AIDS policy coordinator, said: "Evaluating and managing HIV at an early stage will help reduce the number of persons who are underdiagnosed and undertreated" and, it is hoped, extend their life spans. She said too many physicians and other health care workers "are not as current as they should be about HIV."

Oleske said the guidelines also would help inexperienced doctors overcome their fears about handling HIV-infected patients.

January 21, 1994

USA Today

TREATING HIV: Family doctors who may feel ill-equipped to treat people with HIV, the AIDS virus, got help from the government Thursday. The Public Health Service released guidelines telling physicians how best to treat such patients — explaining, for example, the importance of giving early drug treatment to prevent pneumonia. Guidelines and new brochures for patients, are available from the national AIDS hot line, 800-342-2437.

New York Newsday

AIDS Guide Teaches MDs

By Jessie Mangaliman
STAFF WRITER

A new set of guidelines that federal health officials hope will educate and encourage primary care physicians to overcome their reluctance to treat people with AIDS or HIV was issued yesterday.

"We've got to demystify this disease," said Dr. Wafaa El-Sadr, chief of infectious diseases at Harlem Hospital Center and chair of the 19-member expert panel that drafted the guidelines for the U.S. Department of Health and Human Services.

Thousands of people infected with the human immunodeficiency virus are not receiving proper or any medical care that could help prolong their lives, in part because physicians are unaware of medical knowledge on HIV treatment, said Dr. Philip R. Lee, head of the federal Public Health Service.

"This is a call to arms to primary care providers to step up care for individuals with HIV," said El-Sadr.

Earlier this week, the American Medical Association sent its own guidelines on early HIV treatment to 192,000 primary care physicians nationwide who said in a survey they lacked the appropriate knowledge and were reluctant to treat patients infected with HIV.

The federal guidelines advocate the use of a sulfa drug that prevents pneumocystis carinii, a form of pneumonia that remains the principal killer of people with AIDS. They also recommend emphasis on getting early HIV treatment, including anti-retroviral drugs such as AZT, to women, teenagers and children, and screening for infections such as tuberculosis.

"Anything that increases treatment resources for people with AIDS and HIV is sorely needed and overdue," said John Hatchett, executive director of the People With AIDS Coalition of New York.

"I think especially now that when . . . a whole new world of treatment issues are being re-examined, the basics of primary care are even more important," said Hatchett, who has AIDS.

Copies of the guide may be obtained by calling 1-800-342-2437, and for Spanish guides, 1-800-344-7432.

San Jose Mercury News

Doctors, nurses get guidelines for treating HIV

Ignorance of medical particulars will no longer be a good excuse for doctors and nurses to avoid taking care of people infected with the AIDS virus, the United States Public Health Service announced Thursday.

The agency published a 196-page "clinical practice guideline" on how to diagnose and manage patients in the early stages of infection with the human immunodeficiency virus (HIV).

"Some providers are reluctant (to treat HIV patients) for a variety of reasons," Philip R. Lee, director of the Public Health Service, said at a news conference. Some of that reluctance comes from fear and prejudice, though most, he said, comes from the belief by many doctors that HIV infection is too complicated for anyone but experts to manage. [N&O]

San Francisco Chronicle January 21, 1994

New Guide Tells Doctors, Nurses How to Care for AIDS Patients

Washington Post

Washington

Ignorance of medical particulars will no longer be a good excuse for doctors and nurses to avoid taking care of people infected with the AIDS virus, the United States Public Health Service said yesterday.

The agency published a 196-page "clinical practice guideline" on how to diagnose and manage patients in the early stages of infection with the human immunodeficiency virus (HIV).

"Some providers are reluctant (to treat HIV patients) for a variety of reasons," Philip Lee, director of the Public Health Service, said at a news conference. Some of that reluctance comes from fear and prejudice, though most, he said, comes from the belief by many doctors that HIV infection is too complicated for anyone but experts to manage.

"By having the knowledge base in one place, at their fingertips, I think we'll overcome the major obstacle," Lee said.

The guideline stresses the importance of primary care practitioners, not specialists, in making the diagnosis of HIV infection and providing routine treatment.

The document functions not only as a how-to manual for strictly medical questions but also discusses issues such as the risks and benefits of revealing one's HIV status to others, the importance of including women and minority groups in AIDS drug experiments, and some of the problems of access to care encountered by poor people infected with the virus.

About 1 million Americans are now infected with HIV. This year, between 40,000 and 60,000 new infections will occur, and between 47,000 and 66,000 people are expected to die of AIDS, according to federal estimates. About half of all AIDS patients are blacks or Hispanics.

Though the guideline acknowledges that people with advanced AIDS may need specialty care, it stresses that treatment of relatively stable HIV infection falls well within a generalist's realm.

"We are here today to say there is no magic to taking care of HIV-infected patients. It is no different from taking care of a person with any other chronic condition," said Wafaa El-Sadr, chief of infectious diseases at Harlem Hospital Center and a co-chairman of the 19-member panel that wrote the guideline.

Copies of the documents will be sent to hospitals, clinics, medical societies and any person who requests one. People wanting an English-language copy can call 1-800-342-AIDS, and those wanting a Spanish-language version can call 1-800-344-SIDA. Deaf access is 1-800-AIDS-TTY.

WASHINGTON
Afro-American
AND THE WASHINGTON TRIBUNE

JANUARY 29, 1994

New guidelines will help HIV patients

The Public Health Service's Agency for Health Care Policy and Research (AHCPR) has released guidelines aimed at rectifying the issue of under-detection and under-treatment of HIV (the virus that causes AIDS) by family physicians and other primary care practitioners.

Developed by a 19-member panel of experts and people living with HIV, the new clinical practice guideline addresses preventive therapy, special precautions for pregnant women and children, disclosure of HIV status and other key selected aspects of the evaluation and management of early HIV infection.

Titled, "Evaluation and Management of Early HIV Infection: Clinical Practice Guideline" it recognizes the crucial roles of clinicians, scientists, administrators, advocates, politicians, activists, those infected and affected families and educates individuals on many aspects of HIV and AIDS.

Here are some facts stressed by AHCPR that make the guideline an important tool:

From 1981 to the end of 1992, more than 250,000 Americans had developed AIDS and more than 170,000 had died. In 1994, an estimated 40,000 to 60,000 will become infected with HIV and from 47,000 to 66,000 Americans are likely to die of AIDS.

Studies have shown the economic impact of the disease. In 1992, the cost of medical care and time lost from work for the United States was more than $10 billion.

Although African Americans account for only 12 percent of the U.S. population, they represent 31 percent of all reported AIDS cases in the United States and the numbers continue to rise.

HIV infection was the leading cause of death for African American men aged 25 - 44 years in 1991 and 1992. The death rate for Black men in this age range is three times higher than that for White men in the same age group.

To obtain a free copy of the guideline call the National AIDS hotline at 1-800-342-AIDS or write: HIV Guideline, CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003.

Reuter January 20, 1994

WAS04:USA-HEALTH-AIDS:WASHINGTON,20JAN94-White House Aids Policy czar Kristine Gebbie talks to reporters about a new set of government guidelines (L) to help family doctors diagnose and treat people with the AIDS virus., January 20 during a Washington news conference. The guidelines also are aimed at helping people living with and giving care to an infected person. sv/Donald R. Winslow REUTER

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GOVERNMENT RELEASES GUIDELINES FOR AIDS TREATMENT (Eds: adds details throughout)

WASHINGTON (Reuter) - The government Thursday relea.ed new guidelines to help family doctors diagnose and treat people infected with HIV, the virus that causes AIDS.

The guidelines are aimed at helping laymen as well as family doctors who may have had limited contact with people infected with the Human Immunodeficiency Virus (HIV) which causes AIDS.

''More than half of the million people infected with HIV probably do not know they are infected,'' Health and Human Services Assistant-Secretary Dr Philip Lee said at a news conference.

He and others involved in developing the guidelines said the goal was to help doctors become more comfortable diagnosing and treating AIDS.

The guidelines, produced by the Public Health Service Agency for Health Care Policy and Research, urge doctors to take detailed medical histories of all patients including sexual and drug use history, to identify people who should be tested for AIDS.

They also stress that early diagnosis and care are essential, and draw on a wealth of experience to guide family doctors in the treatment of people with AIDS or HIV, the agency said.

They also provide specific guidelines in treating women, children and adolescents, who are making up a greater share of people with AIDS.

National AIDS Policy Coordinator Kristine Gebbie said early diagnosis of the disease will help patients live longer and lead more productive lives.

''Evaluating and managing HIV at an early stage will help reduce the number of persons who are under-diagnosed and under-treated,'' Gebbie said.

A key recommendation is to treat patients who have yet to develop symptoms with daily doses of a sulfa drug to prevent Pneumocystis carinii pneumonia, a principal killer of HIV-infected people, Lee said.

That alone will all but eliminate that ailment among AIDS patients, he said.

The guidelines were developed by a private sector panel of physicians, dentists, nurses, social workers, physician assistants and a man and woman living with the virus, and have been endorsed by some 19 organizations, the agency said.

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National Public Radio

TRANSCRIPT

DATE January 20, 1994
TIME 5:00-6:30 PM (ET)
NETWORK National Public Radio
PROGRAM All Things Considered

Corey Flintoff, anchor:

A federal health panel offered new guidelines today to help doctors treat patients who have the virus that causes AIDS. The guidelines are an effort to get early counseling and treatment for people with HIV, even if they don't have access to an AIDS specialist. The book is also designed to relieve the fears of doctors who may not want to deal with HIV patients.

# # #

Corey Flintoff, anchor:

The federal government is sending some two hundred thousand family doctors a set of guidelines for treating people infected with the AIDS virus. The idea is to help local doctors obtain the latest information about the disease. NPR's Joe Palca has more.

Joe Palca reporting:

According to government figures, there may be more than a half million people in this country who are infected with the AIDS virus but don't know it. The point of the new guidelines is to give family doctors a leg up in diagnosing the infection, and since there aren't nearly enough infectious disease specialists in the country, the guidelines also provide primary care physicians with the latest information about treating patients in the early stage of the disease.

For example, a family doctor should know that some patients may benefit from the drug AZT long before the patients develop symptoms, and that they can prescribe sulfa drugs to healthy patients to prevent bouts of a deadly pneumonia that strikes people with AIDS. The government is hoping that adopting these recommendations will help more AIDS patients receive appropriate treatment.

This is Joe Palca, in Washington.

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TELEVISION AND RADIO COVERAGE

Television

ABC - Channel 7 TV News - Washington, DC
American Medical Television (AMTV)
Cable News Network (CNN)
Comus TV
NBC - Today Show - Promo before Press Conference

Radio

ABC Radio
Associated Press Radio
CBS Radio
NBC/Mutual Radio
Paul Harvey News

Local Radio

KCBS - AM	San Francisco
KMOX - AM	St. Louis
KNX - AM	Los Angeles
KRLD - AM	Dallas
WBBM - AM	Chicago
WBZ - AM	Boston
WIOD - AM	Miami
WJR - AM	Detroit
WTOP - AM	Washington
WWNZ - AM	Orlando