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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

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Washington DC 20201

JAN 14 1994

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Peter S. Arno, Ph.D.
Associate Professor
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Bronx, New York 10467-2490

Dear Peter:

Thank you very much for the information sent with your letter of December 3. I appreciate you taking the time to put the information together. I will forward the materials to Ms. Kristine Gebbie, National AIDS Policy Coordinator and Dr. David Satcher, Director, Centers for Disease Control and Prevention.

I will look forward to seeing the final report on the role of pharmaceuticals in health care reform. I appreciate your offer of assistance and will certainly keep you in mind for any activities that would make use of your considerable expertise and experience.

Again, thanks for the materials.

Sincerely yours,

Phil

Philip R. Lee, M.D.
Assistant Secretary for Health

cc: Kristine M. Gebbie, RN, MN
David Satcher, M.D., Ph.D.

IN PRESS: The Journal of Laws, Medicine & Ethic.

THE ECONOMIC IMPACT OF TUBERCULOSIS IN HOSPITALS IN NEW YORK CITY: A PRELIMINARY ANALYSIS

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October 14, 1993

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December 3, 1993

Philip R. Lee, M.D.
Assistant Secretary for Health, HHS
Room 710-H
200 Washington Avenue
Washington D.C. 20201

Dear Phil:

From all accounts you appear to be flourishing in what must be a frenetic and exciting time in Washington. I thought you may be interested in some recent work on AIDS (housing and unmet needs) and TB (economic impact in NY) which I am enclosing, or perhaps distribute it to other interested parties.

I am currently preparing our final report on the role of pharmaceuticals in health care reform which I will also forward when it is complete.

I recently heard about the panel on expediting AIDS drugs which you will be heading. If I can be of any help please feel free to give me a ring.

I hope all is well.

Best regards,

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THE ECONOMIC IMPACT OF TUBERCULOSIS IN HOSPITALS IN NEW YORK CITY: A PRELIMINARY ANALYSIS

INTRODUCTION

There is a nationwide resurgence of tuberculosis (TB) in the country's urban centers; New York City stands at the forefront of this resurgence. The root causes are increased homelessness, drug addiction and poverty, all symbols of deteriorating social and economic conditions in the City. The inadequate level of public health resources devoted to TB has also contributed to its spread. Still, even with these factors, it is questionable whether the escalating number of TB cases in this country would have occurred without the reservoir of immunosuppressed persons, who are less resistant to the disease, created by the AIDS epidemic. The fear and urgency of this public health crisis, which has been emerging since the beginning of the last decade, is fueled by the rise of TB strains resistant to the first-line drugs and by the disease's contagiousness.

The economic implications of TB are far-reaching, including expenditures on inpatient and outpatient medical treatment; infrastructural changes needed to minimize the transmission of TB in large institutions such as hospitals, nursing homes and correctional facilities and; education, prevention, and surveillance efforts.

There has been no comprehensive study of the national economic costs of the TB epidemic. In New York City, home to nearly 15% of the nation's TB cases and with more than triple the caseload of any other major city in the country, these costs are undoubtedly substantial.[1] Due to the paucity of reliable data sources for all forms of health care delivery in the city we have chosen to focus on the most costly component of TB-related care — acute care hospitalizations. However, this is not to minimize the amount of outpatient services devoted to

persons with TB. For example, nearly 140,000 TB-related visits were made to the City's 10 chest clinics and to outpatient facilities operated by the City's Health and Hospitals Corporation during a recent one year period between 1991 and 1992.[2] Given the number of other hospital clinics and private physicians treating TB patients, the total number of outpatient visits in the City may well be in the range of several hundred thousand per year. However, even at this level, the magnitude of costs would be dwarfed by the costs of inpatient care.

To assess the inpatient impact of TB in New York City, we undertook a study of all TB-related hospitalizations from 1983 to 1990. This paper reviews our data, which include: the number of TB-related hospitalizations; the demographics of persons hospitalized; estimated costs and payment sources. In addition, we examine the relationship between HIV and TB by analyzing the hospitalizations associated with their co-infection. Given the dearth of accurate surveillance data on the relationship between TB and HIV, this study provides some preliminary epidemiological data as well.

BACKGROUND

The active TB case rate began rising in New York City in 1979, and nationally in 1985, after decades of steady decline. Between 1979 and 1990, the incidence of reported TB increased 140%.[3] New York City's overall TB case rate — 50 per 100,000 — is more than five times the national average and represents 14 percent of all cases in the United States.[4]

The disease's resurgence took many in the medical and public health establishments by surprise. Increasingly, resources of the City's hospitals and clinics are strained by new cases and by recurrences among individuals who were inadequately treated or received no treatment at all.

Tuberculosis is an especially critical concern to persons infected with HIV. The incidence of active TB among persons with AIDS is estimated to be almost 500 times the rate in the general population,[5] and that figure is growing.[6] The Centers for Disease Control reports that between 13% and 46% of patients with TB are also infected with HIV.[7] The risk of developing active TB among HIV-infected persons known to have been previously infected with *Mycobacterium tuberculosis* is extraordinarily high, estimated to be 8% per year.[8]

Perhaps the most dramatic development is the emergence of multiple drug resistant TB (MDR-TB), after 30 years of stable or declining incidence (1950-1986).[9] TB that is resistant to specific medications typically develops in patients with active tuberculosis who do not complete treatment[10] but once developed, it can be transmitted to anyone. MDR-TB is often incurable, with an estimated case fatality rate of 40% to 60%, and treatment is always difficult and time-consuming.[11] A 1991 New York City survey found that one third of all TB isolates were resistant to one or more anti-TB drugs and 19% were resistant to the two first line drugs, isoniazid and rifampin.[12]

Despite the historical legacy of TB, there is a paucity of reliable data on its economic impact. Most of the published economic studies have focused on the cost-effectiveness of different forms of chemotherapy.[13] A few international studies have examined the economic impact of TB control programs in developing countries.[14] In their recent analysis of the resurgence of TB in the United States, Bloom and Murray estimated that the average hospital cost per TB patient was approximately $25,000.[15] A Greater New York Hospital Association survey in February, 1993 found that 948 hospital beds in the City were occupied by patients with confirmed or suspected TB,[16] which implies an annual cost of several hundred million dollars. Incremental costs associated with drug-resistant strains are even higher because treatment requires more frequent and resource-

intensive hospitalizations, and the use of more expensive drugs. Inpatient care for MDR-TB is estimated to approach $100,000 per patient.[17]

This study represents the first known attempt to quantify the direct economic costs of resurgent TB in a major urban area. The data presented provide an initial guide to the epidemic's current and future economic impact. It is our hope that the availability of this preliminary data will help health planners and policymakers avoid the mistakes made with AIDS, where inadequate resources were allocated long after hospitals, clinics and public health authorities began to buckle under the strain of providing patient care. If a single lesson should have been learned from AIDS, it is that epidemics do not vanish by ignoring them and that proper planning and the allocation of sufficient resources are the only effective ways to grapple with a burgeoning problem.

METHODS

Hospitalization data come from New York State's Statewide Planning and Research Cooperative System (SPARCS) universal discharge data set, for the years 1983-90. SPARCS is a comprehensive database of all hospitalizations in New York State that provides information about facility, patient demographics, clinical diagnoses, length of stay, admission route, discharge disposition and payer associated with hospitalizations. Data were analyzed at the discharge (hospitalization) level.

The sample consisted of TB and HIV-related hospitalizations that occurred in New York City facilities during the study period. The sample was chosen based upon *International Classification of Diseases*, 9th version (ICD-9) discharge diagnosis codes in which HIV or TB was one of the first five discharge diagnoses. Although hospitals can record as many as 24 ICD-9 codes, no more than six to eight are normally recorded. Since diagnoses are listed in order of the most

important reason for a hospitalization, the first five diagnoses are sufficient to capture hospitalizations that are directly related to TB, rather than cases in which TB infection is merely a co-morbid condition.

The index ICD-9 diagnostic codes on which TB cases were selected were 01x, and 011 through 018. For HIV we included codes specific to: HIV-related illness (042, 043, 044); *Pneumocystis carinii* pneumonia, the most common cause of HIV-related hospitalizations (136.3x) and; the code found to be most related to AIDS prior to 1986 (279.19). The codes used to identify HIV-related hospitalizations are highly sensitive and specific for HIV-related illness according to researchers who analyzed matched files of hospital discharges with case surveillance records.[18]

We stratified the samples' hospitalizations into three major groups for analysis:

TB+/HIV+	TB and HIV diagnoses
TB+/HIV-	TB diagnosis, no HIV diagnosis
TB-/HIV+	HIV diagnosis, no TB diagnosis

In order to estimate the cost of a day of inpatient TB care, we used a simple formula that roughly accounts for disease severity and hospital-specific costs and the length of stay for the DRG which a patient is assigned:

$$\text{Cost per day} = \frac{\text{DRG weight} * \text{Case Payment Rate} + \text{Capital Cost per Discharge}}{\text{Downstate DRG-specific Average Length of Stay}}$$

A DRG is a diagnostic related group code, which is assigned to each hospitalization at discharge and corresponds to a weight for reimbursement purposes. Medicaid DRG weights and case payment rates are used because our preliminary analyses indicate that Medicaid is the primary payer for the majority of the index hospitalizations. Downstate DRG-specific average length of stay is used because the index hospitalizations occur in the downstate (New York City)

region. The total cost for inpatient TB care is determined by multiplying the cost per day by the actual number of hospital days. However, if the cost per day is multiplied by the number of hospital days covered by the assigned DRG, that product represents the approximate amount of reimbursement that hospitals receive. Thus, the total amount of unreimbursed care is determined by subtracting the reimbursement that hospitals receive from the cost of inpatient TB care.

RESULTS

FREQUENCY AND DEMOGRAPHICS OF TB-RELATED HOSPITALIZATIONS

The total number of TB and HIV-related hospitalizations in New York City rose substantially between 1983 and 1990 (Figure 1). During this period, TB hospitalizations jumped from 3,233 to 8,016, an increase of 148%. There was also a dramatic increase in the number of hospitalizations associated with co-infection compared to those associated with TB alone. TB+/HIV+ hospitalizations increased by 4,216%, in contrast to an increase of 76% for TB+/HIV- hospitalizations during the study period. These numbers support our contention that the pool of immunosuppressed persons with AIDS greatly contributed to the substantial rise in TB during the past decade.

This rise in HIV co-infection among persons with TB is dramatic. The proportion of TB hospitalizations associated with HIV co-infection rose from 3% in 1983 to 46% in 1990 (Figure 2). Likewise, the prevalence of TB diagnoses among HIV-related hospitalizations was higher than expected — rising from 6.1% in 1983 to 11.5% in 1990 .

A comparison, by age, of TB+/HIV- and TB+/HIV+ hospitalizations in 1990 is shown in Figure 3. Not surprisingly, those in the middle age groups who have the highest AIDS prevalence rate also have the highest rate of co-infection.

The higher incidence of TB alone in the age group over 55 years is characteristic of reactivation of latent TB infection. TB in the youngest age group (14 or younger) deserves special attention because it generally represents new TB transmission, rather than reactivation of latent infection. Although most children with TB remain uninfected with HIV, co-infection with HIV in the youngest age group grew to nearly 20% in 1990.

The race and ethnicity of persons incurring TB-related hospitalizations is shown in Figure 4. Compared to the demographics of persons living in New York City, blacks are over-represented and whites are under-represented. Since blacks in the City are in general poorer and more likely to be homeless, this demographic picture fits with the social factors that are believed to be among the root causes of TB's resurgence. This observation leads to the question of whether blacks with TB are hospitalized more often than whites with TB, indicating differences between the two groups in the success of ambulatory treatment.

PAYMENT SOURCE

Figure 5 illustrates the distribution and changes in payer source for inpatient TB care in New York City from 1984 to 1990. Medicaid is by far the largest payer, covering 65% of all discharges in 1990. The share of Medicaid financed, TB-related hospitalizations increased during that period from 40% to 65%, while hospitalizations paid for by Medicare and the privately insured, decreased from a combined total of 33% to 20%. The decrease in percentage of Medicare financed hospitalizations is a function of individuals in the oldest age groups— nearly all of whom are Medicare beneficiaries— comprising a decreasing percentage of all TB-related hospitalizations over the years.

UTILIZATION AND COST OF INPATIENT TB CARE

Table 1 compares the utilization and costs associated with hospitalized TB patients and those indicating HIV co-infection. These figures are based on the actual lengths of stay and thus represent hospitals' approximate costs of providing inpatient TB care. The total number of hospital days associated with TB was nearly 200,000 in 1990 and cost an estimated $179 million. Fifty-five percent of those days were associated with TB/HIV co-infection, although this group comprises only 46% of hospitalizations; percentages for total costs are similar. As expected, the average length of stay for persons co-infected with TB and HIV is longer (30 days) than for those diagnosed with only TB (20 days). The longer stays for co-infected individuals help explain why they account for more total hospital days and higher costs, than individuals with TB alone.

UNREIMBURSED INPATIENT TB CARE

Table 2 represents the amount of unreimbursed inpatient TB care. As shown, TB hospitalizations were actually 6 days longer than the DRG-derived length of stay (LOS) and TB/HIV hospitalizations were actually 9 days longer than the DRG-derived LOS. In total, this led to more than 60,000 unreimbursed TB-related hospital days, and an estimated $56 million of unreimbursed care provided by the city's hospitals. The $56 million figure is only a rough estimate. It does not take into account the impact of long stay outlier payments or enhanced rates that some hospitals may receive for HIV-related care. Nor does it account for additional costs to hospitals associated with infection control. However, these figures illustrate the magnitude of unreimbursed care which results in part from a cost structure based on DRGs that predated the resurgent TB epidemic.

DATA LIMITATIONS

This study presented preliminary data on the economic impact of inpatient TB care in New York City. There are a number of limitations to the data. First, hospitalizations, although the costliest component of inpatient care, are not the only cost associated with TB treatment. The data presented do not quantify costs associated with outpatient treatment, or the expense of structural modifications such as negative pressure hospital rooms designed to control TB's transmission. The costs for such modifications varies from $1,000 to install a new ultraviolet light, to $4,000 for a new room exhaust system, to as much as $75,000 to construct a code compliant isolation room.[19]

Second, study data are limited in the accuracy with which they can identify epidemiological trends in either TB or HIV because they capture only persons ill enough to be hospitalized. Hospitalization patterns among persons with TB and or/HIV depend on the course of illness, and vary with the availability of alternatives to hospitalization, social supports, personal preferences, etc. Likewise, the incidence of TB/HIV co-infection may be overstated because of the study's reliance on inpatient data.

Third, TB cases were based upon selected ICD-9 codes. Medical record coders are instructed to code TB only when it is confirmed or strongly suspected based upon chart notes or a physician. However, it is unclear to what extent our case selection method over- or under-estimated "real" TB. We are in the process of validating SPARCS data with medical chart reviews to estimate the sensitivity and specificity of our case selection method. A pilot study to confirm that TB-coded hospitalizations represent active, confirmed or highly suspected TB is underway. Preliminary data suggests that TB codes are in fact applied correctly to such hospitalizations.[20]

DISCUSSION

The number of TB-related hospitalizations in New York City rose 148% over a seven year period, reaching approximately 8000 in 1990. Much of this increase tracks the rise in HIV and AIDS in New York City during the same period. By 1990, almost half of all TB hospitalizations were also a result of HIV infection. Hospitalizations associated with TB/HIV co-infection are 50% longer than those associated with TB alone. Given the $179 million spent for TB-related hospitalizations in New York City in 1990, it is apparent that inpatient TB care could have severe economic consequences for New York City if these trends continue.

Medicaid is by far the largest payer for inpatient TB care. This has a direct effect on the local budget because City, State, and federal cost-sharing guidelines require that New York City pay one-quarter of the Medicaid bill. This trend towards "Medicaidization," as a similar trend in inpatient AIDS care has been called, [21] suggests that the public sector, which is already financially stressed from the burden of AIDS, will be further strapped by the onslaught of TB .

Hospitals are especially strapped by TB because they are not reimbursed for a large share of their TB-related expenses. More than 30% of all TB-related hospital days are potentially unreimbursable because they exceed the length of stay set by the DRG reimbursement system. This resulted in an estimated $56 million of unreimbursed care to hospitals — institutions that are already coping with expensive infrastructural changes to minimize TB transmission and low reimbursement rates from Medicaid.

The TB-related hospitalizations identified in this study are of concern not only because of their growing number, but also because of their demographics and their impact on the health care system. TB hospitalizations occur overwhelmingly among persons who are black or Hispanic, and those more

likely to be poor. Poverty has long been associated with the most costly admission route to a hospital — through the emergency room. Our data confirm that TB patients are disproportionately admitted to the hospital through the emergency room — this was the route for 79% of all TB-related admissions, in contrast to approximately 50% of all New York City hospital admissions.[22] This is particularly disturbing given the recent finding that the mean emergency room waiting time for TB patients entering City hospitals was 20 hours (median = 13 hours)[23] and the fact that emergency rooms, due to their crowding and often poor ventilation, may be suitable environments for the transmission of airborne disease.

Similarly, our data showed that 14% of all TB hospitalizations culminated in the patient leaving against medical advice (AMA), compared with just 3% of all discharges citywide.[24] Follow-up and continuity of care are jeopardized when patients leave AMA. A recent single-hospital study of TB patients in New York City, which analyzed follow-up data on 178 hospital discharges, concluded that 89% of those studied were lost to follow-up and presumably failed to complete therapy.[25] Such patients are at extreme risk of developing and transmitting TB, particularly drug resistant TB.

The data presented, though specific to New York City, clearly have national implications. Perhaps the most important lesson that can be learned is that without additional public health resources devoted to the early control of this epidemic, other cities are likely to face increased caseloads of active TB along with its associated economic burdens.

FUTURE RESEARCH

Because this study was based on discharge level data, it can not answer questions that depend on additional information about individuals who have

been hospitalized. Further research is underway to refine the data and develop a clearer picture of the resurgent epidemic. Among the questions that we hope to answer:

- To what extent do the number of TB hospitalizations represent multiple hospitalizations for individual, uncured patients, as opposed to an expansion of the number of patients requiring hospitalization?
- How many TB and HIV patients were repeatedly hospitalized as a result of their HIV co-infection and how many were specifically hospitalized for TB?
- Why are TB patients hospitalized for such a long period of time, particularly those without HIV co-infection?
- Given the finding that 65% of TB hospitalizations were financed by Medicaid, can we conclude that 65% of TB patients were Medicaid enrollees? Also, to what extent are payment shifts occurring among different patient groups?
- What is the most cost-effective strategy for supervising chemotherapy for TB patients?

Conclusion

TB can often be managed on an ambulatory basis both before and after individuals become acutely symptomatic and require costly inpatient care. In order to reduce the further spread of TB, particularly strains of TB resistant to first-line drugs, long-term intensive post-hospitalization follow-up of active cases must be emphasized. Directly observed therapy (DOT), combined with comprehensive medical care and social service support, has been shown to be effective in ensuring that patients — even historically non-compliant patients — complete TB therapy[26] and is recommended for all active TB patients in New

York City.[27] DOT requires health care workers to observe patients actually ingesting all their prescribed anti-TB medications for a period of six months or more, depending on their clinical condition.

This paper has shown that inpatient TB care is costly, especially to the public sector. However, much of this expensive, clinical care would be unnecessary given a more appropriate public health response to TB, including early identification of cases and early treatment, screening and prophylaxis. A better funded, more efficient public health response would significantly reduce the inpatient burden and help bring the epidemic under control.

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Figure 1

THE TB & AIDS EPIDEMICS
NYC, 1983–1990

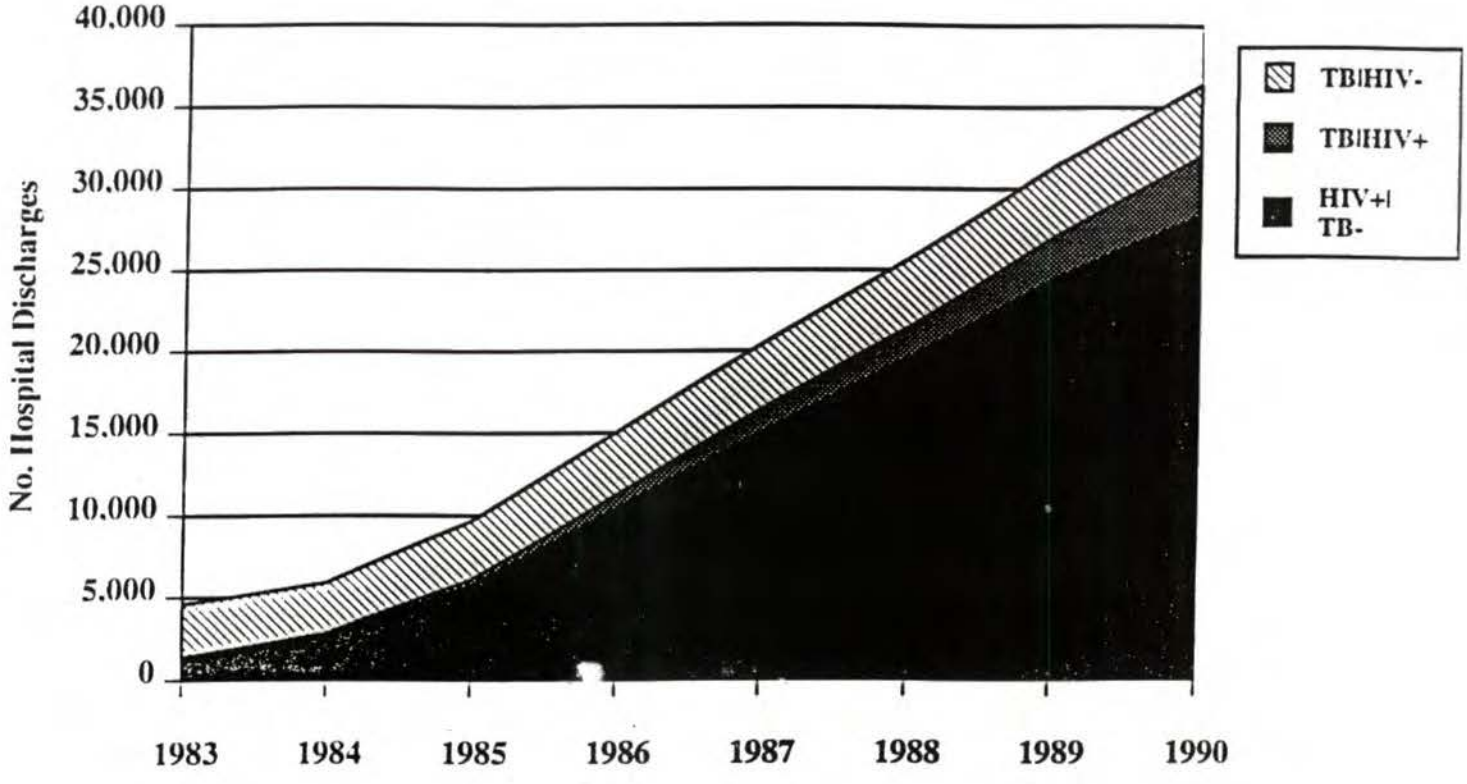


Figure 2

TB and HIV CO-INFECTION, NYC 1986-1990

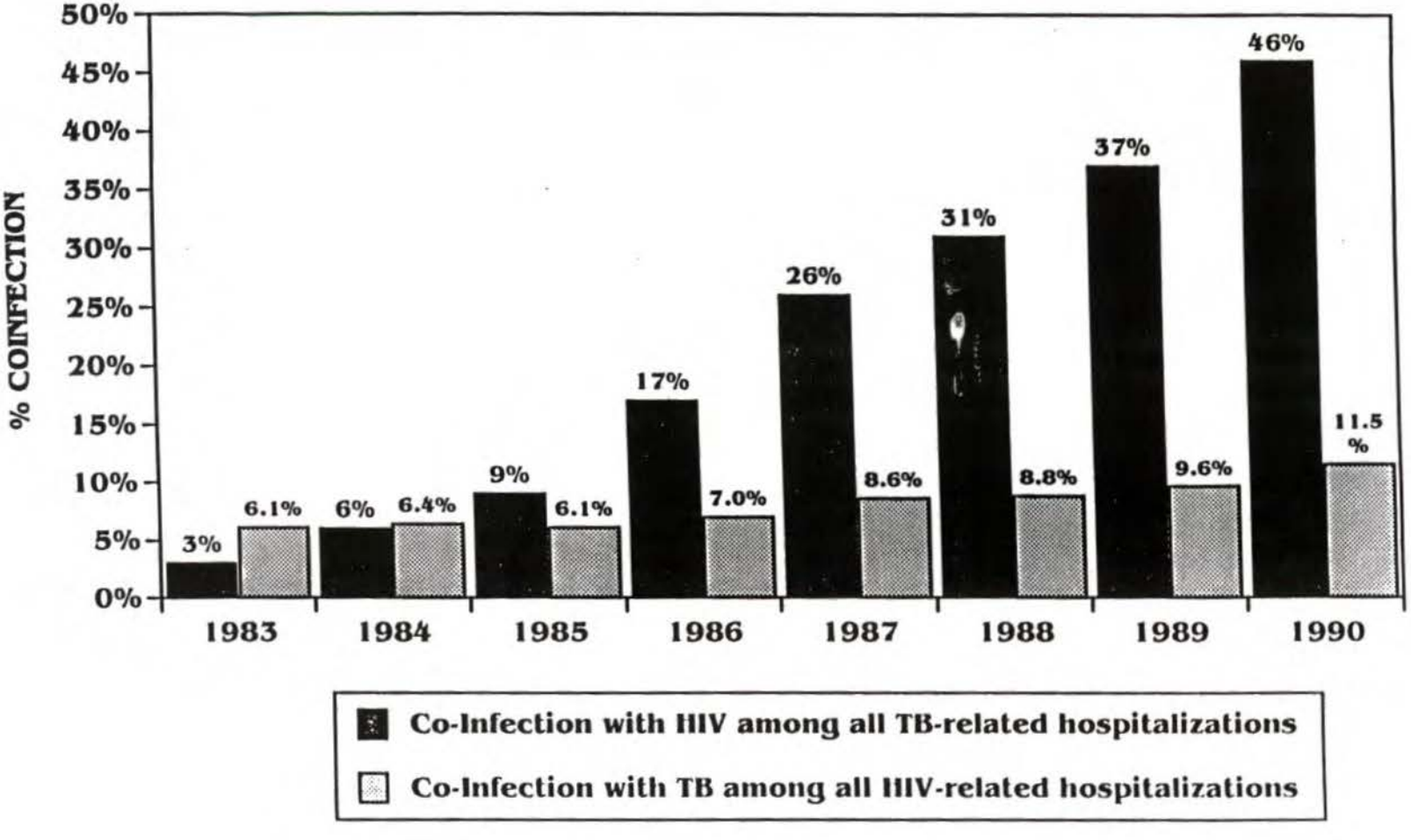
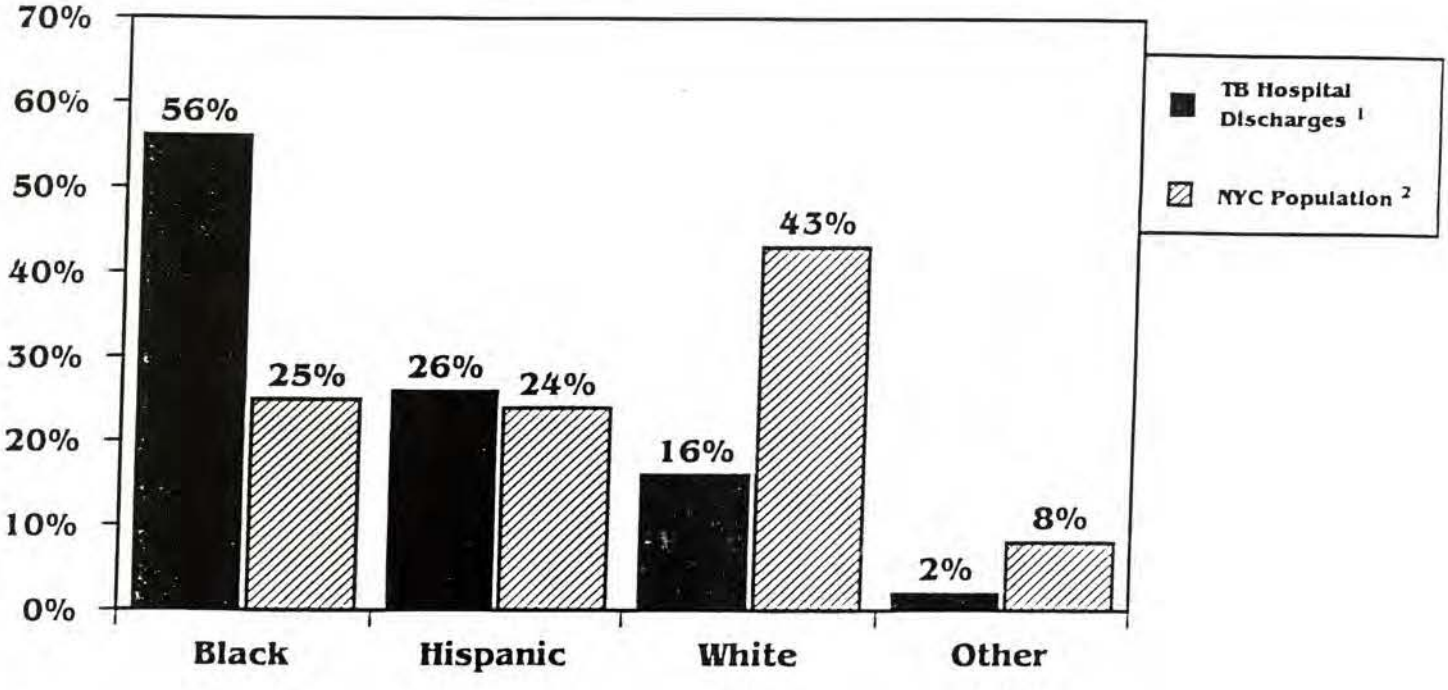


Figure 4

TB Hospitalizations vs. NYC Population by Race/Ethnic Groups, NYC 1990



1 SPARCS database
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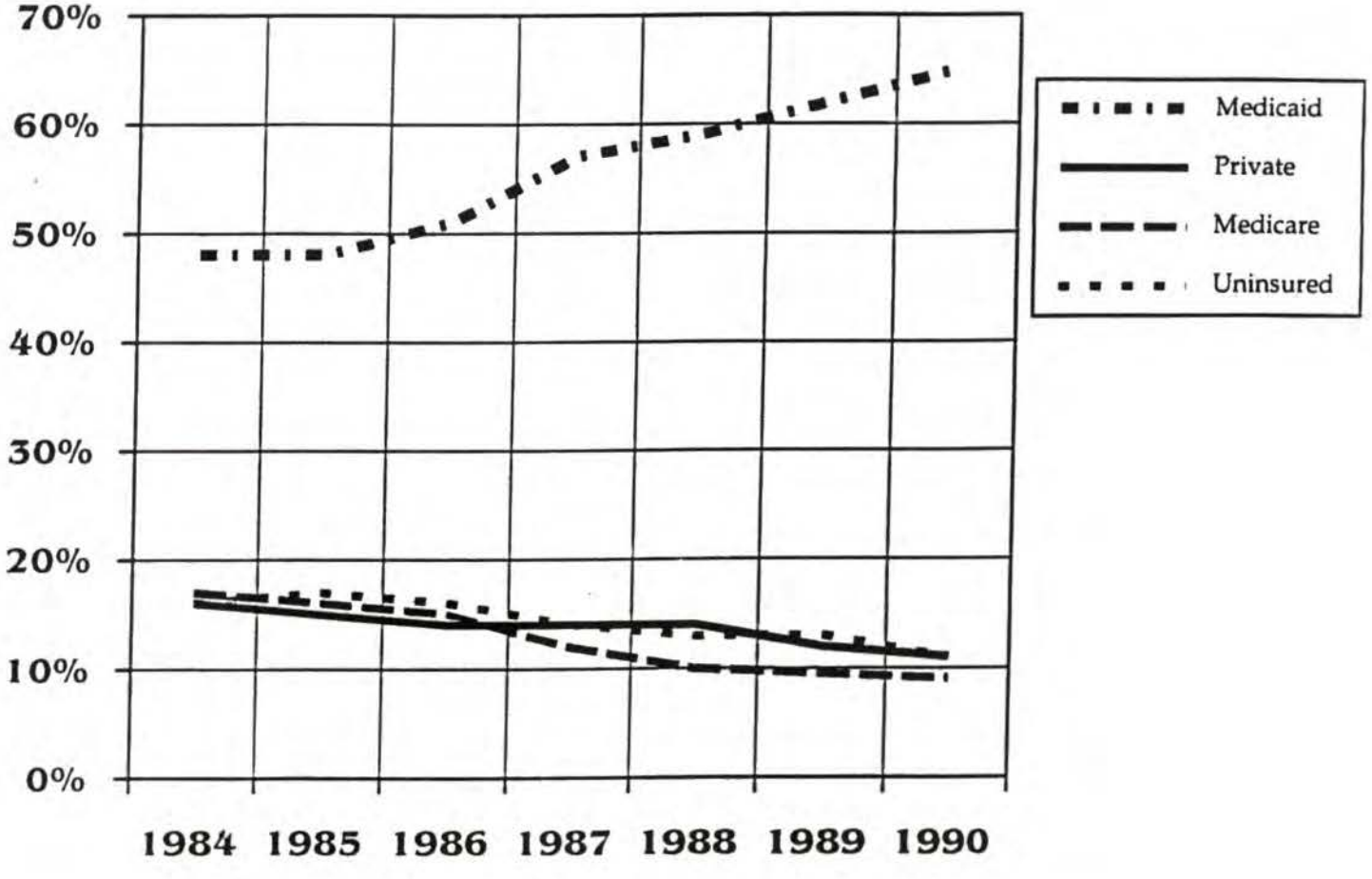
Figure 5

Changes in Payer Source for TB NYC, 1984 – 1990



THE IMPACT OF HOUSING STATUS ON HEALTH CARE UTILIZATION AMONG PERSONS WITH HIV DISEASE

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ABSTRACT

The Impact of Housing Status on Health Care Utilization Among Persons with HIV Disease

This study characterizes the housing status of persons with HIV disease and examines its impact on health care utilization. Using data from a large national sample of approximately 1,800 HIV-infected persons, we compared inpatient and outpatient health care utilization for those stably and unstably housed. Nine percent of the sample were in unstable housing situations, most of which were characterized as marginal or precarious rather than homeless. Unstable housing was most prominent among women, blacks, injection drug users, the publicly insured, and persons with lower functional status compared with those in stable housing. The unstably housed had fewer ambulatory visits ($p<.03$); they also had more ER visits, more hospital days, and longer average lengths of stay, although not significantly so. Findings indicate that access to ambulatory care is particularly difficult among unstably housed persons with HIV disease, leading to an increased reliance upon emergency rooms and hospitals. Helping the unstably housed, many of whom are not yet homeless, to maintain adequate housing could reverse this pattern.

INTRODUCTION

The interconnected relationship between HIV disease, unstable housing, and health care utilization is an unexamined area with direct relevance for public health policy. Because HIV disease, perhaps more than most illnesses, reflects complex social problems, effective strategies to deter transmission and provide appropriate treatment demand a sophisticated knowledge of conditions beyond the usual scope of medicine *per se,* including factors such as poverty, drug use, and homelessness.

Yet, existing research about the health care of the HIV/AIDS population who are unstably housed is generally limited to a restricted sample from a single site or hospital. And, although housing problems are believed to be pervasive among HIV-infected persons, they have not been documented on a national scale. Nor has the impact of inadequate housing on health status or health care utilization, such as patterns of emergency room visits, outpatient use, and hospitalization, been adequately explored.

To address these gaps, we conducted a study based on data collected by the AIDS Cost and Services Utilization Survey (ACSUS) in ten cities throughout the United States. Our first objective was descriptive: to identify the prevalence of unstable housing situations in the sample and who experienced them. Our second objective was to examine differences in health care utilization patterns by housing status.

BACKGROUND

A broad definition of unstable housing permits the most meaningful analysis of the impact of housing status on health care utilization. Persons who routinely live in shelters or on the street comprise only a small portion of those with precarious or marginal (hereafter called unstable) housing. Unstable situations may also include: living "doubled up," or rotating among family and friends; living in single room occupancies

(SROs) or welfare hotels; living in an AIDS residence; and shifting between stable and unstable housing situations over time.

There are many reasons that persons with HIV experience housing problems. The loss of a job or the health insurance it provides[1,2,3] may deplete resources and make it impossible to cover rent or mortgage obligations. Despite federal fair housing law and many state laws, persons are sometimes evicted because of their HIV illness.[4] Chronic substance abuse can also be a cause of homelessness, or it may develop in response to it.[5] Drucker found that 40 percent of 174 drug users in New York City were homeless or precariously housed prior to their first hospitalization leading to an AIDS diagnosis.[6]

While HIV disease can precipitate housing loss, unstable housing can also lead to, or exacerbate, HIV-related illness. A 1990 study of programs targeted at the homeless reported that substance abuse, chronic infections, and inadequate nutrition indirectly compromise host defenses and may play a role in the vulnerability to HIV infection.[7] Participating agencies also reported that poor health status prior to HIV infection appeared to accelerate the course of the disease. It has also been established that the risk of tuberculosis, particularly drug-resistant tuberculosis, increases in the presence of HIV infection, homelessness and substance abuse.[8,9,10]

Because unstable housing makes it difficult to negotiate bureaucracies, file entitlement applications and keep appointments, access to social and medical services is frequently undermined. Moreover, self-care regimens and home care are difficult to maintain.[11] For example, it is difficult for individuals living on the streets, in shelters, or in other inadequate environments to keep medications and supplies sterile and maintain adequate personal hygiene. Homecare agencies are often unwilling to deliver services under these conditions. Tuberculosis infection adds to the complications facing HIV-infected people who are often required to adhere to complex therapeutic regimens in the absence of stable housing.[12]

Unstable housing situations may have particularly negative consequences for injecting drug users. For example, homeless drug users are more likely to use needles more frequently, to inject themselves in locations where needles are shared, and to maintain poor needle hygiene.[13] Homelessness has also been associated with a lower rate of HIV testing among drug users.[14]

Housing status also affects when and where care is delivered. Homeless persons often delay treatment until their condition becomes acute,[15] although one study found that the homeless presented for primary care at a similar stage of HIV infection as the non-homeless.[16] Other research has supported the finding that unnecessary hospitalizations and excessive lengths of stays among persons with HIV is linked to the lack of community-based care.[17,18] Inadequate housing undoubtedly contributes to this problem. For example, while *Pneumocystis Carinii* pneumonia can often be treated on an outpatient basis, patients known to live in unhygienic or unsafe conditions are sometimes hospitalized for an extended time period to be certain that appropriate treatment is delivered.

The increased hospitalization costs associated with unstable housing were documented in a study that found the average length of stay among stably housed persons with HIV disease hospitalized at four New York City medical centers to be 19.5 days, compared with 24.5 days among the unstably housed.[19] The same study found that people with housing-related barriers to discharge averaged 30.2 hospital days, compared with 19.6 days for the entire sample. Similarly, in a small study of drug users with AIDS, Bennett found that people in unstable living situations accrued more than twice the inpatient medical charges of people in stable housing.[20]

METHODS

STUDY DESIGN

This study is based on data collected from a sample of individuals who participated in ACSUS. ACSUS was an 18-month, prospective study of health care services and costs for HIV-infected people conducted by Westat, Inc., a private research firm, under contract to the federal Agency for Health Care Policy and Research (AHCPR). Westat interviewed 2,090 participants six times between March 1991 and November 1992 at intervals of 12 to 14 weeks. Findings presented here draw on the self-administered screener questionnaire, housing status data secured at the second interview, and health care utilization data aggregated from the first and second interviews.

ACSUS used a three stage, purposive, sample design. First, geographic areas were selected; second, health care provider sites were identified within the selected regions, and third, HIV-infected persons seeking treatment at identified provider sites were enrolled over a four-month period. Women were oversampled at all sites. A small number of pediatric patients were sampled. Findings from this study are based only on the adult sample.

Ten cities, selected from the 25 with the greatest number of AIDS cases in the Unites States, were ACSUS enrollment sites. The sample was selected to provide diversity in terms of payer source, service delivery systems, HIV exposure route, and the race/ethnicity of the HIV-infected population.

The provider sites within the ten geographic areas comprised the second stage of the ACSUS sampling design. Primary providers included hospital inpatient units, hospital outpatient clinics, private clinics, and physician offices. The providers selected as enrollment sites all served large numbers of people with HIV disease in the area and an attempt was made to include both private and public providers.

In the final sampling stage, all patients receiving treatment at selected provider sites during the enrollment period completed a screener questionnaire that asked for information about HIV status, age, gender, race/ethnicity, insurance status, transmission

category, and health status. The screener questionnaire was usually self-administered, but the site coordinator provided assistance in a few cases..

Eligible subjects were required to be HIV positive and visiting the provider site for the first time since March 20, 1991. Coordinators stratified HIV-infected persons by illness stage, defined as HIV asymptomatic, HIV symptomatic or CDC-defined AIDS; by HIV exposure route; and by insurance status and selected a systematic sample within each stratum. Illness stage was the primary sampling criterion used for enrollment. The sample from each site was also intended to be proportional in terms of the exposure route and payment source of the HIV-infected population within each geographic area.

Individuals selected for the study signed consent forms and designated a proxy to complete future interviews if they became too ill to do so. Subjects were also given a toll-free number to call with their questions and paid $50 for each interview completed (one site paid $25). Further details about the study's design are described elsewhere.[21]

DESCRIPTION OF SAMPLE

Table 1 presents simple descriptive statistics of the second interview sample which included approximately 1,800 adults. The sample was diverse in terms of age, ethnicity, gender, transmission route, and payment sources.

DEFINITION OF VARIABLES

In this study, housing status was the main variable of interest. Study participants were considered unstably housed if they reported in their second interview having lived in any of the following places since their first interview: a) temporarily "doubled up" with a friend or relative; b) a single room occupancy or welfare hotel; c) specialized AIDS housing; d) shelters; e) street or other public place. Unstable housing was defined broadly to include this range of situations often considered marginal or precarious in nature. However, it is conceivable that some persons who are housed e.g., in SROs,

welfare hotels or in specialized AIDS housing may in fact be stably housed. Future analyses will explore this issue.

We controlled for the effect of health status on health care utilization. To do so, we developed a functional status measure from two subscales of physical impairment. At their second interview, participants were asked: a) six questions to determine whether they were limited in a range of physical and daily living activities (e.g., walking 1 block, dressing, etc.), and; b) eight questions to determine the nature and severity of their pain. Scores on each scale were converted to standardized scores (mean= 0 and variance= 1) and added to form a composite scale of functional impairment. This composite scale showed significant effects on medical utilization and had scores ranging from -1.63 to 4.29.[22]

We also controlled for the effect of health insurance on health care utilization. Anyone holding any commercial or non-profit coverage (such as Blue Cross) at the second interview was considered privately insured. Persons receiving Medicaid or Medicare were classified as publicly insured. Persons were deemed uninsured if they had no private insurance and were not receiving either Medicaid or Medicare. Included among the uninsured were individuals with some other type of public assistance that paid for medical care, e.g., a drug assistance program. Other public insurance was classified as uninsured because it is not as comprehensive or reliable as Medicaid or Medicare.

Measures of health care utilization served as the primary dependent variables. Health care utilization data were based on respondent self-report, aggregated over the first and second interview periods and generally covering a period of six months. The dependent variables were:

• Emergency Room (ER) Visit: A dichotomous variable indicating whether the respondent had made at least one emergency room visit, including any visit that resulted in a hospital admission.

• Hospitalization: A dichotomous variable indicating whether the respondent had been hospitalized at least once.

• Number of ER Visits: Number of emergency room visits, among persons with at least one emergency room visit.

• Number of Ambulatory Visits: Number of visits to private doctor's offices, freestanding clinics, or hospital-based outpatient facilities.

• Number of Hospital Days: Number of inpatient hospital days, among persons with at least one hospitalization.

• Average Length of Stay: Average length of hospital stay among persons with at least one hospitalization.

The number of hospitalizations was not included as an dependent variable given the clustering of cases at 0 or 1. The dichotomous hospitalization variable was instead taken as a proxy for hospitalization rate. To account for slight differences in the time period covered, continuous dependent variables were standardized to reflect a common six-month period.

Statistical Methods

Descriptive statistics on the sample were calculated for independent and dependent variables. To predict unstable housing, we used logistic regression to compute odds ratios, controlling for insurance, race, and a variable denoting both sex and HIV transmission route. For continuous dependent variables (frequency and duration of health care utilization), we first compared cohort differences using Student's t-test for independent samples and then repeated the analyses using the SAS ANOVA and GLM procedures to control for functional status and insurance as covariates.

Results

Overall, 171 persons, or 9% of the sample had ever been unstably housed in the past three months. Figure 1 illustrates the distribution of housing situations among these 171 persons. Only a minority had ever lived on the street (7%) or in a shelter (13%). By contrast, 31% had lived doubled up, 31% had lived in an SRO or welfare hotel, and 18% lived in special AIDS housing.

The prevalence and nature of unstable housing, examined by five descriptive features — sex, race, HIV transmission mode by sex, insurance source, and functional status — is shown in Table 2. Each feature had distinctive associations with housing status. For example, 14% of women respondents were unstably housed, compared to fewer than 9% of the men. Only 6% of whites were unstably housed, while 14% of Blacks and almost 10% of Hispanics reported precarious housing situations. Gay/bisexual men were the least likely to be unstably housed (5%), while female injection drug users followed by male injection drug users were the most likely to be unstably housed (24% and 20%, respectively). Individuals with public insurance were also more likely to be unstably housed than others. Mean functional status scores were significantly lower among unstably housed persons compared with stably housed persons ($P<.005$).

We also examined the effects of race, sex/HIV transmission mode, and insurance on housing status. The results of each effect, controlling for the presence of the other two, are shown in Table 3. Race was not a significant predictor of housing status controlling for sex/HIV transmission route and insurance, although blacks are still the most likely to be in unstable housing. The findings for sex/HIV transmission route and insurance are similar to the unadjusted analyses shown in Table 2.

Differences in health care utilization were examined as a function of housing status. Table 4 indicates the proportion of the sample with at least one emergency room visit or hospitalization. A significantly higher percentage of unstably housed individuals had an

ER visit, compared with the stably housed (51% vs. 35%). While the unstably housed were more likely to be hospitalized at least once, the difference was not statistically significant.

Additional cohort differences in the frequency and duration of health care utilization are compared in Table 5. Among individuals who had at least one emergency room visit during the six-month reference period, the unstably housed visited the ER more frequently than the stably housed, although this difference was not significant, and became less so after controlling for functional status and insurance. However, the unstably housed made approximately two fewer ambulatory visits, a difference that was amplified when controlling for functional status and insurance.

Differences in the number of hospital days and average length of stay among individuals who had at least one hospitalization during the study period are also shown in Table 5. Those who were unstably housed incurred nearly five more hospital days than the stably housed, although the difference was not significant in controlled analyses. The difference in number of hospital days approached significance when controlling for functional status. Similarly, although the average hospital stay lasted about 1-1/2 days longer for the unstably housed, this difference was not statistically significant.

In all of the analyses presented in Table 5 the effects of functional status and insurance were consistent. Functional status had the strongest, and always a significant effect upon utilization. Having Medicaid or Medicare always had a significant effect on utilization, and was related to greater utilization than private insurance.

DISCUSSION

The 9% prevalence of homelessness and precarious housing found among persons with HIV disease is smaller than has previously been reported.[4] Because the survey involved only those individuals receiving medical care, it may not be fully representative of the HIV-infected population and may underestimate the true

prevalence of housing difficulties. On the other hand, some proportion of those persons housed in AIDS residences, single room occupancies or welfare hotels, and termed unstably housed for the purposes of this study, may actually be living in suitable environments. Although further research may refine the estimates of the unstably housed, the baseline prevalence of homelessness and precarious housing found in this sample allows a reasonable assessment of the impact of housing status on health care utilization.

The finding that unstable housing is more common among HIV-infected women, Blacks, Hispanics, drug users and publicly insured persons highlights the fact that housing difficulties are concentrated among the most vulnerable populations. Unstably housed individuals are also in poorer health. Although the direction of causality can not be gleaned from this cross-sectional analysis, it may be a two-way street — it is plausible that housing instability, especially where it results in an unhygienic environment or situations that preclude stable outpatient or home care, hastens the progression of illness and equally plausible that HIV-infected individuals will experience more housing problems. Further research may provide insights about the interrelationship between illness progression and the deterioration of housing status.

The less frequent use of ambulatory care and the higher utilization of emergency room services among the unstably housed suggest they have difficulty accessing ambulatory care. Since unstable housing and public insurance appear to be highly correlated, public insurance could explain greater use of the ER among the unstably housed. Difficulties accessing ambulatory care, especially among the publicly insured may, in turn, lead to greater reliance on hospitalization.

Despite a lesser use of ambulatory services, however, analyses not presented here found the two cohorts equally likely to have a routine source of care. This suggests that many unstably housed individuals have difficulty scheduling or keeping clinic appointments despite having a care provider. It may therefore be of value to replicate

programs that enhance access to ambulatory services and emphasize continuity of care. Examples include: hospital-operated satellite AIDS care programs; mobile vans to reach the homeless; and on-site primary care at methadone maintenance treatment programs.[23] Calling patients prior to clinic appointments and providing transportation assistance may also bolster the use of ambulatory services.

The higher total number of hospital days among persons with unstable housing was not statistically significant but began to approach significance when controlling for functional status and insurance. This is counter-intuitive: Given the poorer health and lower levels of private insurance of the unstably housed, it might be expected that the difference would diminish when controlling for health and insurance. Most likely, the greater number of hospital days, as well as the longer average lengths of stay among the unstably housed, are due to social rather than medical factors.

We did not examine differences in lengths of hospital stay between the stably housed and subgroups of the unstably housed because of the small numbers within each subgroup. In a larger sample, it may be possible to determine whether individuals living on the street or in a shelter had longer lengths of stay than other precariously housed people and to determine whether the absence of appropriate discharge options played a role in these longer stays.

Because precariously housed individuals are more likely to be treated in an emergency room than an ambulatory care facility, and more likely to spend time in the hospital, they incur greater health care costs. Policies designed to ensure housing stability, such as income supports and rent subsidy programs, may therefore be cost-effective and should be promoted more aggressively.

Because housing status may be jeopardized by the disclosure of HIV disease and the fears associated with it, or by the burden of caregiving, programs to educate the public and to provide respite care to lessen the stress on household members may also help maintain stable housing situations. Where marginal or precarious housing predates

HIV illness, supported housing that provides adequately for the unique health and social service needs of immunocompromised individuals may be the best available option.

In conclusion, this study clearly supports the need to provide the social and financial supports that allow HIV-infected persons to maintain stable housing or to secure it. Further research will help refine our understanding of the relationship between HIV disease and housing status.

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Table 1.

Demographics of the Sample

Age/Median	**35.5 years**	
Sex		
Male	**81%**	**(1504)**
Female	**19%**	**(344)**
Race/Ethnicity		
White	**42%**	**(776)**
Black	**29%**	**(545)**
Hispanic	**27%**	**(495)**
Other	**2%**	**(35)**
HIV Transmission Route/Sex		
Gay/Bisexual Male	**55%**	**(1009)**
Male Injection Drug User	**15%**	**(281)**
Female Injection Drug User	**7%**	**(128)**
Other Male	**11%**	**(208)**
Other Female	**12%**	**(213)**
Insurance		
Private	**33%**	**(603)**
Medicaid/Medicare	**44%**	**(799)**
None/Other Public	**24%**	**(432)**
Income		
Median monthly	**$525**	
Functional status		
Range =	**-1.63 -4.29**	
Mean =	**0.00**	

Table 2.

Sample Demographics, by Housing Status

	Unstable Housing		P value *
Sex			p < .005
Male	8.5%	(124)	
Female	14.1%	(47)	
Race			p < .005
White	6.1%	(46)	
Black	14.0%	(73)	
Hispanic	9.7%	(47)	
HIV Transmission Route/Sex			p < .005
Gay/Bisexual Male	4.6%	(45)	
Male Injection Drug User	19.9%	(54)	
Female Injection Drug User	24.0%	(29)	
Other Male	11.6%	(23)	
Other Female	8.6%	(18)	
Insurance			p < .005
Private	1.4%	(8)	
Medicaid/Medicare	14.2%	(109)	
None/Other Public	12.2%	(51)	
Functional Status			p < .005
Mean	-0.05 (vs. stably housed=0.55		

* All tests by x^2 except for functional status which compared means of those with stable and unstable housing with Students t distribution.

Table 3.

Effects of Race, HIV Transmission Route/Sex, and Insurance on Housing Status

	Odds of Unstable Housing	
	Odds Ratio	95% Confidence Interval
Interval		
Race		
White	1.00	----
Black	1.25	.82 - 1.92
Hispanic/Other	0.86	.55 - 1.35
HIV Transmission Route/Sex		
Gay/Bisexual Male	1.00*	----
Male Injection Drug User	3.05*	1.93 - 4.83
Female Injection Drug User	3.67*	2.12 - 6.36
Other Male	1.87*	1.07 - 3.26
Other Female	1.19*	.65 - 2.17
Insurance		
Uninsured/Other Public	1.00	----
Medicaid/Medicare	.91	.62 - 1.33
Private	.13*	.06 - .27

* ANOVA, t probability, $p < .05$

Table 4.

Proportion of Sample with at Least One Emergency Room Visit or Hospitalization, by Housing Status

	At least one ER visit [a]	At least one hospitalization
Unstably Housed	51% (86)	33% (55)
Stable Housing	35% (560)	27% (436)

[a] Cohort differences significant at $p<.05$

Table 5. **Frequency/Duration of Emergency Room, Ambulatory and Hospital Use, by Housing Status***

	Unstably Housed mean (sd)	Stably Housed mean (sd)	P value, unadjusted [a]	P value controlling for functional status & insurance [b]
Number ER visits	2.45 (2.23)	2.04 (1.78)	.11	.18
Number ambulatory visits	9.68 (12.60)	11.62 (13.70)	.08	.03
Number of hospital days	23.47 (29.44)	18.73 (20.11)	.28	.17
Average length of stay	12.03 (17.06)	10.61 (10.76)	.57	.55

* Data are based on persons utilizing these services.

[a] t test for differences in group means, unstable housing vs. stable housing.

[b] ANOVA, t probability.

UNMET HEALTH SERVICE NEEDS OF PERSONS WITH HIV DISEASE

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ABSTRACT

Unmet Health Service Needs of Persons with HIV Disease.

The complex needs of persons with HIV disease create a demand for myriad services, yet scant empirical research at the national level exists on individuals' access to them. We examined the prevalence of, and factors associated with unmet health service needs among persons with HIV disease. Using data collected from a large national sample of approximately 1,800 HIV-infected persons in ten cities throughout the United States, we examined the relationship between unmet needs and: stage of illness, type of insurance, source of care, living arrangement, and AIDS prevalence of respondents' geographic region. One-fifth of the sample reported at least one unmet need. Non-institutional services, such as dental care, mental health, and medications were more likely to be reported as an unmet need than resource-intensive services such as emergency room and hospital care. The odds of having an unmet need were significantly affected by most factors listed above. The greatest effects were found for private insurance and HIV asymptomatic status, both of which decreased the odds of unmet needs by approximately 50%. These findings suggest that insurance coverage for the varied services required during the chronic phase of HIV illness is inadequate and should be augmented.

INTRODUCTION

The complex social, medical, and financial needs of persons with human immunodeficiency virus (HIV) disease create a demand for myriad services. In order to plan rationally and allocate resources appropriately, policy makers and planners must know what services needs are unmet, and for whom among the estimated one million persons infected with HIV.[1] This is especially true as health care reformers contend with the public's twin demands for expanded access to health care and control of its skyrocketing costs.

To address these information needs, we examined the prevalence of and factors associated with unmet health service needs among persons with HIV and AIDS. Factors examined for their relationship to unmet need were: stage of illness, type of insurance, source of care, social support, and AIDS prevalence.

BACKGROUND

Existing empirical work has not identified the full range of perceived unmet needs among the HIV-infected population. Instead, much of it has focused on area-based estimates of the need for specific institutional services, such as acute or long-term care beds, or relied on single-site studies that did not fully represent the HIV and AIDS population. Many prior studies also focused exclusively on AIDS, rather than the full spectrum of HIV illness.

Despite these limitations, the earlier studies are revealing. One survey found that more than 80% of respondents had at least one unmet need, with the mean being 2.4.[2] Needs differed according to a number of demographic features. For example, women were most often lacking drug treatment, mental health and transportation services while the typical unmet needs of injection drug users (IDUs) were housing, entitlements and drug treatment. In another survey, nearly 60% of HIV-infected individuals listed financial assistance as a priority, while one third had been unable to obtain needed medicines, health insurance, legal assistance, or

mental health services.[3] A 1989 study also identified income as the greatest need and found access to inpatient and outpatient services to be less of a problem.[4]

Access to specific services among persons with HIV has also been examined. One study found that men were more likely than women to have received AZT as were non-Hispanic whites in comparison with minorities. Similarly, men who had sex with men (MSWM) were more likely to have been given AZT than individuals who had become HIV-infected via other transmission routes.[5] However, other researchers found less difference in AZT use when clinical criteria were considered.[6] In another study, more than one-third of the individuals who were discharged from the hospital were unable to obtain the home care services they needed. [7] Studies in New York and California reached similar conclusions, finding that nearly 15% of persons with AIDS did not have the subacute care they needed at home.[8] [9] Another service-specific study found that waiting lists deterred drug users with AIDS in San Francisco from seeking treatment.[10]

To strengthen the database on which policy is developed, we conducted a study of perceived unmet needs and barriers to care. Data were analyzed to determine the likelihood that stage of illness, insurance, routine source of health care, social support, and AIDS prevalence were associated with unmet need. We predicted the following associations between unmet need and these independent variables:

- An advanced level of illness was hypothesized to be associated with higher levels of unmet need.[11] [12]
- Higher levels of unmet need were thought likely to be associated with lower income; public or no insurance.[13]
- It was also hypothesized that lack of a usual source of care, indicating no consistent point of access to the health care system, would be associated with more unmet need. Further, it was believed that a private physician's office as a usual

source of care would be associated with less unmet need than a hospital or clinic as a routine source of care. [14]

- Persons living alone were likely to have a higher level of unmet needs than persons living with others. This hypothesis was based on research suggesting that living with another person sometimes provided a source of care or assistance in finding care.[15] [16]
- There may be greater levels of unmet need in geographic areas designated as low AIDS prevalence, where AIDS is less readily recognized or understood.[17] [18]

METHODS

This study is based on data collected from a sample of individuals participating in ACSUS. ACSUS was an 18-month, prospective study of health care services and costs for HIV-infected people conducted by Westat, Inc., a private research firm, under contract to the federal Agency for Health Care Policy and Research (AHCPR). Westat interviewed approximately 2,000 participants six times from March 1991 through November 1992 at intervals of 12 to 14 weeks.

ACSUS used a three-stage sample design for data collection. First, geographic areas were selected; second, health care provider sites were identified within the selected regions, and third, HIV-infected persons seeking treatment at identified provider sites were enrolled over a four-month period. Women were oversampled at all the sites. A small number of pediatric patients were sampled. Findings from this study are based only on the adult sample (aged 18 and older).

Ten cities, selected from the 25 with the greatest number of AIDS cases in the Unites States, were ACSUS enrollment sites. The sample was selected to provide diversity in terms of payer source, service delivery systems, HIV exposure route, and the race/ethnicity of the HIV-infected population.

Selection of provider sites within the ten geographic areas comprised the second stage of the ACSUS sampling design. Subjects were sampled at 26 provider sites in these ten geographic areas. The majority of ACSUS subjects were sampled from hospital outpatient clinics. Just a few patients were sampled on hospital inpatient wards and only three private physician's offices were used for study enrollment. The providers selected as enrollment sites all served large numbers of people with HIV disease in the area and an attempt was made to include both private and public providers.

In the final sampling stage, patients receiving treatment at selected provider sites during the enrollment period were asked to complete a screener questionnaire that asked for information about HIV status, age, gender, race/ethnicity, insurance status, transmission category, and health status. The screener questionnaire was usually self-administered, although site coordinators provided assistance in a few cases.

Eligibility for the study, determined from the screener questionnaire, required that potential subjects be HIV positive and visiting the provider site for the first time since March 20, 1991. Coordinators stratified HIV-infected persons by illness stage, defined as HIV asymptomatic, HIV symptomatic or CDC-defined AIDS; by HIV exposure route; and by insurance status and selected a systematic random sample within each stratum. Illness stage was the primary sampling criterion used for enrollment, although pediatric patients and women were oversampled regardless of illness stage. The sample from each site was also intended to be proportional in terms of the exposure route and payment source of the HIV-infected population within each geographic area.

Individuals selected for the study signed consent forms and designated a proxy to complete future interviews if they became too ill to do so. Subjects were

paid $50 for each interview completed (one site paid $25). The study's research design is described in further detail elsewhere.[19]

Findings presented here are based on the second of the six interviews, the first time questions about barriers and access to care were asked. At this time, 1,851 participants were asked whether they had a routine source of health care, what it was, and how long it took to travel to it. To determine unmet needs, interviewers referred to a list of eight services— emergency room, overnight hospital care, home care, mental health, residential, medication, dental, and substance abuse treatment— and said to participants: "There are many health care services that people need which they sometimes do not receive. Look at this card and please tell me if you felt you needed any of these services since (reference date) but for some reason you did not receive them." [Reference date refers to the last time subjects were interviewed.] Thus, need for each of the services was termed "unmet" on the basis of respondent perception.

DEFINITION AND CONSTRUCTION OF MEASURES

The key dependent variable was "unmet need indicated," a dichotomous variable indicating whether at least one unmet service need was reported. It should be emphasized that the study identifies only unmet needs, and not the proportion of all "needs" that were unmet. Of course "unmet needs" and "any needs" are probably correlated. That is, as needs increase, the potential for one or more of them to be unmet increases. Accordingly, the findings should be interpreted as the probability that individuals will experience difficulties receiving care they believe they need, and not a measure of whether all their needs were met or not.

Five independent variable domains were identified:

ILLNESS STAGE

HIV status was determined during the initial eligibility screening. Persons were classified with AIDS (as it was defined by the Centers for Disease Control in 1987) if a doctor told them within the past five years that they had an AIDS defining disease. HIV symptomatic status was assigned to persons who had experienced at least one HIV-related symptom in the past five years or had only herpes or candidiasis, but had not yet been told they had an AIDS defining disease.[20] HIV-infected individuals who had not experienced an HIV-related symptom or been diagnosed with an AIDS-defining disease within the past five years were classified as asymptomatic.

FINANCIAL RESOURCES

Insurance: Anyone holding any commercial or non-profit coverage (such as Blue Cross) at the second interview was considered privately insured. Persons receiving Medicaid or Medicare were classified as publicly insured. Persons were deemed uninsured if they had no private insurance and were not receiving either Medicaid or Medicare. Included among the uninsured were individuals with some other type of public assistance that paid for medical care, e.g., a drug assistance program. Other public insurance was classified as uninsured because it is not as comprehensive or reliable as Medicaid or Medicare.

SOURCE OF CARE

The usual source of care available to each respondent was classified as clinic or hospital; doctor's office; or none. Among the 1,725 persons who reported having a routine source of care, a continuous variable was developed to indicate how long, in minutes, it took to travel to the identified provider from home.

SOCIAL SUPPORT

Whether one lived alone or with others since the reference date served as a proxy for social support. A dichotomous variable indicating whether or not each respondent lived alone was created.

AIDS PREVALENCE

Of the ten cities in the sample, the same three cities had both the fewest reported AIDS cases between March 30, 1991 and March 21, 1992[21] and the lowest AIDS incidence rate between August, 1988 and September, 1989.[22] AIDS incidence rates may not accurately reflect HIV infection incidence rates but they are used here as a proxy for them. Accordingly, these three cities were denoted low AIDS prevalence and a dichotomous variable was used to indicate whether or not respondents lived in a low-prevalence city.

STATISTICAL ANALYSES

Relationships between categorical independent variables and unmet need were analyzed by the chi-square test for association. The Mantel-Haenszel trend test analyzed associations when the independent variable was ordinal level. Logit analysis examined multivariate relationships between selected independent variables, and unmet need indicated. Logit is similar to multiple regression or ANOVA with a dichotomous dependent variable, but is preferred with dependent variable splits more extreme than 25%/75% because it has no parametric assumptions that are likely to be violated.[23] Logit analysis tests for significant associations between each of the independent variables' dummy categories, and the (dependent variable) outcome. For each independent variable, the odds ratio was calculated. Stratified analyses for race/ethnicity, and a composite HIV transmission route and sex variable (HIV transmission route/sex) were run as independent logistic regressions. Race/ethnicity and HIV transmission route/sex interactions were evaluated by examining the differences between stratum-specific odds ratios. Hypothesis tests employed assume a simple random sample although non-probabilistic methods were used in sampling. There is no correct method for adjusting hypothesis tests to yield more accurate results.

DESCRIPTION OF THE SAMPLE

Table 1 presents simple descriptive statistics of the sample at the second interview and draws on data from the screener questionnaire. The median age was 35.5. Men comprised slightly more than four-fifths of the sample. The sample was ethnically diverse— whites represented 42% of the sampled population with Blacks and Hispanics almost equally divided among the rest; only 2% belonged to other racial/ethnic groups. The primary transmission route for HIV was male to male sex (gay/bisexual male, 55%), followed by injection drug use among men (15%). Public insurance, in the form of Medicaid or Medicare, was the most common type of insurance (44%). In terms of illness stage, 22% were HIV asymptomatic, 44% were HIV symptomatic, and 34% had AIDS.

Nearly all the sample (94%) reported having a particular clinic, office, or other facility where they could obtain health care or advice. Among persons who had a usual source of care, almost 80% went to a hospital or clinic. Three-quarters of the individuals with a usual source of care reported seeing the same physician. Median travel time to the routine source of care was 30 minutes (mean = 35 minutes).

RESULTS: UNMET HEALTH SERVICE NEED

Nineteen percent (n=359) of the sample indicated at least one unmet need, of whom 77% had just one unmet need (not shown). The prevalence of specific unmet needs varied considerably, but in general, institutionally-based services and those requiring intensive physical care were more adequately provided than less intensive services (Table 2). Dental services were the most commonly reported unmet need (9%), followed by mental health services (5%), and medications (4%). In contrast, less than 1% of the sample reported an unmet need for residential care

while 2% said they had not been able to obtain overnight hospital or emergency room services and slightly more than 3% said their need for home care was not met.

BIVARIATE ANALYSES

Hypotheses concerning the relationship between each of the five independent variables and the presence of an unmet need were tested separately. These findings are presented in Table 3 and summarized below.

ILLNESS STAGE - HIV status was significantly associated with an unmet need. More than 20% of persons with CDC-defined AIDS or symptomatic HIV reported an unmet need, compared with 13% of asymptomatic persons.

FINANCIAL RESOURCES - Insurance status was related to unmet needs. Twenty-one percent of persons classified as uninsured, and 23% of those with Medicaid or Medicare had an unmet need compared to 14% of the privately insured. The five income categories were moderately correlated with insurance (ranked ordinally as private, Medicaid or other public, none), Spearman-Rho= .54. To reduce multicollinearity in the multivariate analyses, only insurance was included in those analyses.

SOURCE OF CARE - The availability and type of routine care provider was not significantly related to an unmet need. Still, persons without a usual source of care were the most likely to report an unmet need. Twenty-five percent of those without a usual source of care reported an unmet need, compared with 20% of individuals using a hospital or clinic, and 16% using a private doctor's office. Travel time to routine providers was apparently not a factor in creating unmet needs (not shown).

SOCIAL SUPPORT- Twenty-two percent of persons living alone had an unmet need, compared to 18% of those living with others, an association that was nearly statistically significant. Other analyses investigated, not shown, sought to identify sociodemographic differences among persons living alone. Although the likelihood of living alone did not vary by race and varied only slightly by HIV transmission route, women were significantly more likely to live alone than men.

AIDS PREVALENCE- Reports of unmet need varied significantly among the ten study cities, ranging from a low of 7% to a high of 29%. Twenty-four percent of those in low AIDS prevalence cities reported an unmet need, compared with 18% in high AIDS prevalence cites.

There were no statistically significant differences in the report of unmet need by race/ethnicity or HIV transmission route/sex.

MULTIVARIATE ANALYSES

Multivariate logistic regressions were used to determine the effect of each of the following independent variables, in the presence of the others, on unmet needs: insurance, source of care, illness stage, social support, and AIDS prevalence. Interpreting odds ratios in terms of the characteristics that are *least*, rather than most, associated with unmet need is appropriate to predict low occurrence outcomes. Thus, most of the odds ratios are less than one, and may be interpreted as the extent to which a given characteristic decreased the probability of having an unmet need. All of the odds ratios should be considered in light of the relatively wide 95% confidence intervals surrounding them.

The unstratified sample results are shown in Table 4. Having private insurance decreased the odds of having an unmet need by about half, compared to

being uninsured. The impact of having Medicaid or Medicare was nearly identical to being uninsured or having other public insurance. Being asymptomatic lowered the odds by approximately 45% compared with having AIDS. These are striking findings considering that insurance status and illness stage are often related, (i.e. private insurance is often lost with advancing illness stage) and that each variable's effect upon the other was controlled for. Low prevalence was the only positive predictor variable. Having a routine source of care decreased the odds of unmet need, but there was only a slight difference between those who went to a hospital or clinic, and those who went to a private physician.

Differences between stratum-specific odds ratios were also examined using race/ethnicity, and HIV transmission route/sex variables. Non-significant effects are discussed because they are meaningful, even in the absence of statistical power to detect differences between the variable level and the reference category.

Stratum-specific findings of interest were apparent in analyses stratified by race/ethnicity, (Table 5). For Blacks, the odds of an unmet need barely differed between Medicaid/Medicare and Uninsured/Other Public. The benefits of private insurance were negligible for Hispanics, while the odds of unmet need for Hispanics actually increased with Medicaid/Medicare compared to Uninsured/Other Public. Private insurance had the greatest impact on whites. As with the unstratified results, being asymptomatic decreased the odds by about half. Being HIV symptomatic compared with having AIDS had no effect for whites, while it decreased the odds for Blacks and increased them for Hispanics. Source of care had only a minimal effect for white respondents. In contrast, at least having a routine source of care, especially a hospital or clinic, appreciably lowered the odds of unmet need for Blacks. The odds ratios for low prevalence, the only positive predictor in the model, was highest for Blacks and lowest for Hispanics.

We found an interaction between HIV transmission route/sex and certain independent variables (Table 6). Private insurance decreased the odds of unmet need substantially for three of the groups: gay/bisexual men, female injection drug users, and other women. Similarly, women seemed to gain more from having Medicaid/Medicare compared with no insurance or other public insurance. Being asymptomatic substantially decreased the odds of unmet need for most groups by about half, but slightly less so for male IDUs. Availability and type of routine source of care had little effect for gay/bisexual males and other females. On the other hand, the odds of unmet need were decreased by about three-quarters for female IDUs by having a routine source of care, and by about half for other males. Living alone decreased the odds of unmet need in most groups to a similar degree, except it did not make a difference for other females. Living in a low prevalence AIDS area increased the odds for all groups, especially the gay/bisexual male and other female groups.

Both the unstratified and stratum-specific models of multivariate logistic regressions were repeated excluding dental need. These analyses revealed no significant variations from those including dental need.

DISCUSSION

A number of striking findings emerged from this study. First, the level of unmet needs across a broad-based sample of HIV-infected individuals was not as great as other research has suggested. However, it should be noted that we did not ask respondents to identify all their needs during the study period. Therefore, comparisons with other work, which are often needs assessments rather than measures of unmet need, must be made with caution. The bias of the study toward persons already receiving health care might also contribute to the relatively low level of unmet need.

The finding that non-institutional services, such as dental care, mental health, and medication, are more likely to be unmet needs than more resource-intensive services, such as emergency room and hospital care, suggests the need to focus attention and resources on making community-based care more accessible. They are less accessible than institution-based services because they are not as well reimbursed, and there is often lack of coordination between them. The acute-care orientation of the health care system, which pre-dates the AIDS epidemic, continues to have negative effects on HIV-infected individuals.

Illness stage was associated with unmet need; asymptomatic persons had less unmet need than symptomatic persons or those with AIDS. This suggests that as physical (and sometimes mental) capacities diminish, access to services that could mitigate their effects become more difficult. Diminished capacity is often accompanied by a decreased sense of control over oneself and one's environment. Difficulties accessing services can exacerbate feelings of being out of control. The physical and psychological impact of unmet need is probably greatest for persons experiencing the highest prevalence of them— those at advanced stages of illness.

The value of private insurance as a tool for providing access to care was obvious. Insurance status had a particularly significant impact when stratum-specific multivariate analyses were performed. The finding that any form of insurance had more of an effect on reducing unmet needs for women, including IDUs, than it did for men controlling for other factors, suggests that women are more likely to access available care or are more adept at negotiating systems. By contrast, insurance had a weaker effect on reducing unmet needs for Blacks and Hispanics than for whites. This may be due to factors other than those examined which operate to limit access to care among minorities, such as prejudice. For example, research indicates that Blacks wait longer than whites at clinics and private

physician offices, controlling for income, insurance status and source of care, suggesting the importance of discrimination in limiting access to care.[24]

AIDS prevalence had a significant impact on unmet need, however, sampling differences limit our ability to interpret these findings. We believe the effect of AIDS prevalence is confounded by demographic and recruitment site differences among the ten cities.

The highest level of unmet need (29%) was reported from a city that mandates managed care for the majority of its Medicaid population. While this study did not attempt to identify an association, the finding raises concerns about access to care for persons enrolled in managed care plans, whether or not they are HIV-infected. In theory, a managed care system should foster continuity of care. However, financial incentives may operate to limit access to needed services, particularly for those with serious, chronic illnesses such as AIDS. Given the central role of managed care in the Administration's health care reform plan, further scrutiny of its potential impact on access to care is warranted.

There are a number of limitations to this study. Conceptualization of need is mired in use of the terms "need", "want", and "demand" interchangeably. The data do not record the duration or severity of unmet needs and do not reflect the social, cultural, or psychological factors that affect health care behaviors. For example, there may be significant differences in the rate at which: needs are perceived, attempts are made to seek assistance, and reports of unmet needs occur. The study was not equipped to analyze the effect of these subjective differences.

Despite these limitations, the need for integrated community-based services and insurance coverage that allows access to care emerge as urgent priorities. While this has long been the assertion of service providers in the field, analysis of the ACSUS data provides, for the first time, a broad patient perspective with firm

empirical grounding for aggressive action. If those with HIV disease are to receive the spectrum of care that is required over the course of their disease, rational long-term planning is long overdue.

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Table 1.

Description of the Sample

Demographics		
Age/Median	**35.5 years**	
Sex		
Male	**81%**	**(1,504)**
Female	**19%**	**(344)**
Race/Ethnicity		
White	**42%**	**(776)**
Black	**29%**	**(545)**
Hispanic	**27%**	**(495)**
Other	**2%**	**(35)**
HIV Transmission Route/Sex		
Gay/Bisexual Male	**55%**	**(1,009)**
Male Injection Drug User	**15%**	**(281)**
Female Injection Drug User	**7%**	**(128)**
Other Male	**11%**	**(208)**
Other Female	**12%**	**(213)**
Insurance		
Private	**33%**	**(603)**
Medicaid/Medicare	**44%**	**(799)**
None/Other Public	**24%**	**(432)**
Income		
Median monthly	**$525**	
Illness Stage		
Asymptomatic	**22%**	**(404)**
Symptomatic	**44%**	**(808)**
AIDS	**34%**	**(633)**
Routine Provider Availability and Type		
None	**6%**	**(n=111)**
Clinic/Hospital	**76%**	**(n=1,393)**
Doctor's Office	**18%**	**(n=325)**
Particular Doctor at Routine Source of Care	**74%**	**(n=1,277) (Among persons with a routine provider)**
Travel Time to Routine Provider		
Median	**30 Minutes (Among persons with a routine provider)**	

Table 2.

Prevalence of Unmet Service Needs

	Percentage (n) reporting Unmet Need for Service*	
Service:		
Emergency Room	2.4%	(45)
Overnight Hospital	1.6%	(29)
Home Services	3.1%	(58)
Residential	0.7%	(13)
Medication	3.9%	(73)
Dental	8.8%	(162)
Mental Health	4.9%	(91)
Drug Treatment	1.2%	(23)

Overall, 19% (n=359) reported at least one unmet need.

* Persons may report more than one unmet need.

Table 3.

Percent of Persons in Sample Reporting at least One Unmet Need

	Percentage (n) reporting at least one unmet need	P value*
Insurance		p<.001
Private	14% (83)	
Medicaid/Medicare	23% (183)	
None/other Public	21% (91)	
Source of Care		p<.16
Clinic/Hospital	20% (275)	
Doctor's Office	16% (53)	
None	25% (28)	
Illness Stage		p<.001
HIV Asymptomatic	13% (51)	
HIV Symptomatic	21% (167)	
AIDS	22% (140)	
Social Support		p<.06
Lived Alone	22% (135)	
Lived with Others	18% (224)	
AIDS Prevalence		p<.03
Low Prevalence	24% (83)	
High Prevalence	18% (276)	

* p value for chi-square

Table 4

Effects of Insurance Status, Illness Stage, Source of Care, Social Support, and AIDS Prevalence on Unmet Needs

	TOTAL SAMPLE	
	Odds Ratio	(95% CI)
Private Insurance	.52*	(.36 - .76)
Medicaid/Medicare	1.03	(.76 - 1.39)
Uninsured/other Public	1.00	
Asymptomatic	.55*	(.38 - .78)
Symptomatic	.97	(.74 - 1.26)
AIDS	1.00	
Hospital/Clinic	.64*	(.41 - 1.01)
MD Office	.75	(.43 - 1.31)
No Routine Source of Care	1.00	
Lives with Others	.79	(.62 - 1.00)
Lives Alone	1.00	
Low Prevalence	1.40*	(1.05 -1.87)
High Prevalence	1.00	

Based on 1,851 in sample

* Significant by chi-square, p<.05

Table 5

Effects of Insurance Status, Illness Stage, Source of Care, Social Support, and AIDS Prevalence on Unmet Needs, by Race/Ethnicity

	White/Non-Hisp. Odds Ratio (95% CI)	*Black/Non-Hisp.* Odds Ratio (95% CI)	*Hispanic* Odds Ratio (95% CI)
Private Insurance	.32* (.19 - .55)	.68 (.32 -1.42)	.85 (.33 -2.33)
Medicaid/Medicare	.72 (.44 -1.18)	.94 (.54 -1.65)	1.90* (1.01 -3.58)
Uninsured/other Public	1.00	1.00	1.00
Asymptomatic	.57 (.30 -1.06)	.52* (.27 - .97)	.56 (.27 -1.15)
Symptomatic	1.00 (.66 -1.52)	.75 (.47 -1.20)	1.29 (.74 -2.22)
AIDS	1.00	1.00	1.00
Hospital/Clinic	.82 (.35 -1.92)	.40* (.20 - .77)	.91 (.33 -2.52)
MD Office	1.05 (.42 -2.64)	.67 (.25 -1.77)	.50 (.10 -2.56)
No Routine Source of Care	1.00	1.00	1.00
Lives with Others	.90 (.62 -1.32)	.64* (.41 - .99)	.86 (.52 -1.44)
Lives Alone	1.00	1.00	1.00
Low Prevalence	1.25 (.82 -1.91)	1.50 (.92 -2.40)	1.17 (.41 -3.32)
High Prevalence	1.00	1.00	1.00
	n= 776	n= 545	n= 495

* Significant by chi-square, p<.05

Table 6.

Effects of Insurance Status, Illness Stage, Source of Care, Social Support, and AIDS Prevalence on Unmet Need by HIV Transmission Route/Sex

	Gay/Bisexual Male	*Male Injection Drug User*	*Female Injection Drug User*	*Other Male*	*Other Female*
	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Private Insurance	.51* (.32 - .82)	1.01 (.24 - 4.24)	.57 (.06 - 1.64)	.89 (.35 - 2.84)	.20* (.04 - .92)
Medicaid/Medicare	1.01 (.64 - 1.58)	1.54 (.70 - 3.38)	.84 (.27 - 2.64)	1.29 (.55 - 3.05)	.46 (.20 - 1.08)
Uninsured/other Public	1.00	1.00	1.00	1.00	1.00
Asymptomatic	.49* (.28 - .83)	.72 (.26 - 1.95)	.59 (.14 - 2.46)	.39 (.15 - 1.05)	.50 (.19 - 1.31)
Symptomatic	.99 (.68 - 1.43)	1.19 (.62 - 2.29)	1.27 (.47 - 3.43)	.55 (.24 - 1.24)	1.01 (.44 - 2.31)
AIDS	1.00	1.00	1.00	1.00	1.00
Hospital/Clinic	.79 (.39 - 1.61)	.75 (.25 - 2.26)	.18* (.04 - .76)	.48 (.14 - 1.65)	.92 (.23 - 3.65)
MD Office	.89 (.40 - 1.97)	0.00 -------	.25 (.03 - 1.96)	.47 (.08 - 2.61)	3.86 (.65 -22.85)
No Routine Source of Care	1.00	1.00	1.00	1.00	1.00
Lives with Others	.70* (.50 - .98)	.89 (.49 - 1.63)	.72 (.28 - 1.81)	.86 (.42 -1.76)	1.08 (.40 - 2.91)
Lives Alone	1.00	1.00	1.00	1.00	1.00
Low Prevalence	1.51* (1.02 - 2.23)	1.11 (.48 - 2.54)	1.00 (.38 - 2.60)	1.18 (.49 -2.83)	1.83 (.76 - 4.41)
High Prevalence	1.00	1.00	1.00	1.00	1.00

* Significant by chi-square p<.05