

ORIGINAL ARTICLES

Propensity of HIV Patients to Seek Urgent and Emergent Care

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OBJECTIVE: To assess the propensity of HIV-infected adults to seek care for common symptoms, and to determine whether they would seek care in the emergency department (ED) or with their primary care provider.

DESIGN: Cross-sectional interview study.

SETTING: Patients in care in the 48 contiguous United States.

PARTICIPANTS: A nationally representative group of HIV-infected adults selected using multistage probability sampling.

MEASUREMENTS: Subjects were interviewed between January 1996 and April 1997. Patients with advanced disease (past AIDS diagnosis and/or CD4 cell count <200/ μ L) and early disease were asked how they would seek care for key HIV-associated symptom complexes. Three advanced disease and 3 early disease symptom scenarios were used.

MAIN RESULTS: Most advanced disease patients (78% to 87%) would seek care right away from the ED or primary care provider for the symptoms asked. Most early disease patients (82%) would seek care right away for new respiratory symptoms; fewer would do so for headache (46%) or oral white patches (62%). In a multivariate model, independent predictors of propensity to use the ED for advanced disease symptoms included African-American ethnicity (adjusted odds ratio [OR], 2.5; 95% confidence interval [95% CI], 1.8 to 3.4); less education (adjusted OR, 1.4; 95% CI, 1.1 to 1.7); drug dependence (adjusted OR, 1.4; 95% CI, 1.1 to 1.7); annual income less than \$5,000 (adjusted OR, 1.5; 95% CI, 1.0 to 2.3); and lower psychological well-being (adjusted OR, 0.9; 95% CI, 0.9 to 1.0). In early disease, the following independently pre-

dicted ED use: African American (adjusted OR, 4.7; 95% CI, 3.1 to 7.1) or Hispanic ethnicity (adjusted OR 2.4; 95% CI, 1.4 to 4.3), female gender (adjusted OR, 1.6; 95% CI, 1.2 to 2.2), annual income less than \$5,000 (adjusted OR, 1.8; 95% CI, 1.1 to 3.0), and lower psychological well-being (adjusted OR, 0.9; 95% CI, 0.8 to 1.0).

CONCLUSIONS: Many patients would use the ED instead of same-day primary care for several common symptoms of HIV disease. African Americans, the poor, and patients with psychological symptoms had a higher propensity to use the ED.

KEY WORDS: patient HIV infection; emergency department utilization; acceptance of health care; health services accessibility.

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Patients' decisions about how and where to seek care for new symptoms are an important and underrecognized determinant of the quality and efficiency of health care. Patients who fail to quickly seek care for potentially dangerous symptoms may have poor outcomes, even when care is excellent. Conversely, patients who use emergency department (ED) care for nonurgent symptoms contribute to the rising costs of care and to crowding in the ED, reducing access to care for patients with more serious problems. Furthermore, ED care and primary provider care are often poorly coordinated, leading to suboptimal treatment outcomes.

Understanding the decisions made by chronic disease patients seeking care is important in helping clinicians and health care systems develop strategies to encourage prompt ED care for dangerous symptoms while discouraging unnecessary use of the ED for nonurgent symptoms.¹⁻⁷ Research on care seeking has rarely focused on high-intensity users of care for whom optimal care seeking has the greatest implications for costs and health outcomes. These issues are particularly relevant for patients with HIV, who experience symptoms with different levels of severity affecting multiple organ systems.⁸⁻¹¹

The propensity to seek health care is influenced by many factors. The behavioral model of health services use described by Andersen et al. suggests that predisposing patient characteristics (race, education, psychological state),

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enabling factors (access to care, health insurance), and need (symptom severity) all play a role.^{5,12-14} But differences in propensity to seek care are difficult to study by measuring actual care seeking, because of confounding factors. Severity adjustment methods are too coarse to fully account for differences in severity and frequency of symptoms between patients. And individuals and cultures differ in how they notice or recognize symptoms,¹⁵⁻¹⁷ and thus variations in noticing rather than in responding to symptoms may lead to differences in care seeking.

We used survey data from a nationally representative sample of patients in care for HIV infection to describe the propensity of patients to seek care for HIV-related symptoms, as assessed by responses to a set of clinical scenarios. To provide a benchmark for evaluating patients' responses, we surveyed HIV clinicians regarding how they believe patients should respond to the symptom scenarios. Finally, we examined the predictors of propensity to use ED care for each scenario.

METHODS

Study Design

Baseline interviews were conducted between January 1996 and April 1997 as part of the HIV Cost and Services Utilization Study (HCSUS). Emergency department use data from the first follow-up HCSUS interview were also used. The HCSUS is an observational cohort study of a nationally representative probability sample of HIV-infected adults receiving care in the contiguous United States. The HCSUS reference population was comprised of patients 18 years or older with known HIV infection receiving care at other than a military facility, prison, or ED. A multi-stage sampling design was used to assemble the HCSUS cohort, and analytic weights were constructed to adjust the survey sample to represent the entire reference population of patients in care.¹⁸⁻²¹

Subjects were interviewed by trained research personnel using computer-assisted personal interviewing devices.

Topics addressed included sociodemographic characteristics, clinical and health factors, psychological characteristics, knowledge and attitudes about care, and access to care. Sampling and survey methods are described in detail elsewhere,¹⁸⁻²¹ and the specific survey questions have been published.²² The RAND institutional review board and, when available, a local board reviewed all forms, materials, and procedures.

Propensity to Seek Care

Propensity of patients to seek care was assessed using questions about clinical symptom scenarios included in the HCSUS survey. Standardized clinical scenarios were used to control for variations between subjects in symptom awareness and to focus the analysis on nonclinical factors that influence care seeking. Each subject was presented with 3 symptom scenarios. Different scenarios were presented to patients with early and advanced disease (Table 1). Those with early HIV disease (no past AIDS-defining diagnoses and CD4 cell count $\geq 200/\mu\text{L}$) were presented with a set of clinical scenarios typical of mild immunosuppression (respiratory symptoms with fever, sinus/retro-orbital headache, and oral white plaques). Those with advanced HIV disease (history of an AIDS-defining illness and/or CD4 cell count $< 200/\mu\text{L}$), were presented with a set of clinical scenarios of particular importance in severe immunosuppression (respiratory symptoms with fever, headache with stiff neck, and loss of vision). The scenarios were constructed to query patients about symptoms that could indicate diseases that are common and important at their stage of disease. Respondents were asked what they would do for each scenario: go to the emergency room, go to the doctor's office or speak to the doctor the same day, schedule a special appointment, wait until the next scheduled appointment, or give it a chance to get better before seeing a doctor.

Propensity to use the ED was determined by summing the number of "go to the emergency room" responses

Table 1. Symptom Scenario Questions

Symptom Descriptions*	Symptoms Consistent with . . .
Early HIV disease	
Suppose you began to have difficulty breathing and had a cough with fever. (What would you do?)	Pneumonia
Suppose you had a headache with pressure behind your eyes and nose . . .	Sinusitis
Suppose you developed a whitish, painless coating on the tongue, throat, or inside of your cheeks . . .	Oral candidiasis
Advanced HIV disease	
Suppose you began to have difficulty breathing and had a cough with fever. (What would you do?)	Pneumonia
Suppose you developed a severe headache that gets worse over two weeks and stiffness in your neck . . .	Meningitis
Suppose you had a change in your ability to see clearly and developed loss of visual field or blind spots . . .	Cytomegalovirus retinitis

*Response options were go to the emergency room, go to the doctor's office or speak to the doctor the same day, schedule a special appointment, wait until the next scheduled appointment, or give it a chance to get better before seeing a doctor; the last two categories were combined in analyses. Identical symptom descriptions and response options were used in the physician survey, and physicians were asked to indicate which patient responses would be appropriate for each symptom description.

across the 3 symptom scenarios. Propensity to use the ED was categorized as: low (go to the emergency room for none of the clinical scenarios), medium (go to the emergency room for 1 scenario), and high (go to the emergency room for 2 or 3 scenarios). These groupings were chosen to meet the proportional odds assumptions of ordered logit modeling, which suppose that for all independent variable combinations, the odds ratios for groups above and below each of the 2 dividing cut points are equivalent.²³

Predictors of Propensity to Use the Emergency Department

We hypothesized that propensity to use the ED for care is determined by predisposing, enabling, and need factors.^{12,13} Sociodemographic variables included race/ethnic group, gender, age, education, income, drug use, and geographic region. Questions about general health were asked of all participants, and reports of lowest-ever CD4 lymphocyte counts were collected.

Self-perceived knowledge about HIV, desire for involvement in medical decisions, trust in the primary HIV provider, and length of time in continuity care with the primary HIV provider were all assessed. Perceived social support was measured using 3 items ($\alpha = 0.71$) drawn from the Medical Outcomes Study Social Support Survey; the questions asked how often support to meet financial, practical, and emotional needs was available in the past 4 weeks.²⁴

Psychological well-being was measured with a 5-item scale asking how often the respondent felt downhearted and blue, very nervous, sad, anxious, or depressed.^{25,26} Use of denial as a way of coping with AIDS and its associated problems was assessed using a brief 3-item scale.²⁵ Summed and transformed psychological status and denial scale scores ranged from 1 to 10.

Health insurance status was categorized as Medicare, privately insured, Medicaid, and no insurance, with those dually eligible for Medicaid and Medicare assigned to the Medicare category. Perceived access to care was measured by asking about overall ability to get medical care, going without care because of cost, and perceived access to hospital admission, emergency care, specialist care, and conveniently located care.²⁷ Barriers to accessing primary care were assessed by asking about the time needed to travel to the usual HIV caregiver, the number of days wait to get an appointment with the usual HIV caregiver when needed, the usual waiting time at the care site before seeing the provider, whether the patient generally saw the same provider at the care site, and the length of time in care with the patient's usual HIV provider.

Physician Survey

To obtain physician opinions about acceptable responses to each scenario, we surveyed a convenience sample of academic physicians at 1998 meetings of the AIDS

Clinical Trials Group (physician researchers) and the AIDS Task Force of the Society of General Internal Medicine (physician researchers, educators, and policy advocates). All respondents reported providing continuity care for HIV patients, and were board- or subspecialty-certified. Not all respondents were subspecialty trained in infectious diseases. Of 64 physicians, 42 (66%) completed the survey. Clinicians rated each of the symptom scenarios using symptom descriptions and response options identical to those used in the patient survey. For each symptom scenario, physician respondents indicated whether each of the care-seeking response options was appropriate. Physician opinions were totaled and summarized, allowing classification of each of the scenario response options according to the physician opinions about appropriate care seeking.

Data Analysis

Distributions of responses to the symptom scenarios were generated from patient and physician data. "Wait until the next scheduled appointment" and "give it a chance to get better before seeing a doctor" responses were combined in all analyses. Patient analyses were conducted using HCSUS analytic weights to correctly represent the target population.

Scores describing propensity to use the ED for early and advanced disease were evaluated for internal consistency reliability using Cronbach α (early disease, $\alpha = 0.70$; advanced disease, $\alpha = 0.71$). Validity of the propensity to use the ED scores was assessed using data from the first follow-up HCSUS survey, which was completed by 2,466 subjects an average of 6 months after baseline. Frequency of actual ED use between the baseline and the first follow-up survey was calculated for patients with high, medium, and low propensity to use the ED, respectively.

We used a hypothesis-driven approach to build multivariate models of the social and psychological factors predicting propensity to use the ED. Health status variables (general health and CD4 cell count) were used as covariates in the multivariate models. Ordered logit models were constructed separately for the early disease and advanced disease groups, using the sociodemographic, knowledge/attitude, psychological status, and access variables described above.²³ Each group of social and psychological variables was added according to hypothesized relationships; the adjusted Wald test was used to assess the joint significance of adding each variable group. Models were explored to look for important colinearities and first-order interactions.

It is of particular importance to determine the non-health-related factors associated with patient decisions to seek care from the ED instead of their primary HIV provider. Therefore, we controlled for clinical disease severity in our analyses in two ways. Statistical adjustment was used in all multivariate models for variations in general health and immune status (CD4 cell counts). Use of

scripted scenarios controlled for the variations that occur with actual clinical symptoms.

In all multivariate models, Taylor linearization methods were used to estimate the variance of regression coefficients, accounting for clustering, stratification, and incorporation of sampling weights in the study design.

RESULTS

A total of 2,864 adults were interviewed. Of these, 1,616 subjects had advanced HIV disease (1 or more AIDS-defining conditions or most recent CD4 cell count $<200/\mu\text{L}$). The remaining 1,248 subjects had early HIV disease (no AIDS-defining conditions and CD4 cell count $\geq 200/\mu\text{L}$). Patients in the early and advanced disease groups differed somewhat in their characteristics. Compared with advanced disease patients, early disease patients were more often African American (38% vs 29%), women (28% vs 18%), less than 35 years old (40% vs 30%), and uninsured (24% vs 13%) (all $P < .0001$). Income, education, and geographic region did not differ between the two groups.

Responses to Symptom Scenarios

Patient Responses. Weighted distributions of patient responses to the 6 symptom scenarios are shown in Table 2. For 5 of the 6 scenarios, most patients said they would seek care urgently either in the ED or from their primary care provider the same day. For example, even for a symptom that was not life-threatening, such as oral white patches, 48% said they would see or talk to their doctor the same day, and 14% said they would go to the ED. For the respiratory symptoms with fever scenario, over 40% of

both early and advanced disease patients chose the ED for care and 40% to 42% chose to see their doctor the same day. Headache behind the nose and eyes was the only symptom for which most subjects said they would delay care, with 54% indicating that they would schedule a special appointment or wait.

Clinician Responses. For comparative purposes, physician responses from our convenience sample are shown in Table 2. Like patients, more physicians indicated that urgent ED or primary provider care the same day was appropriate for respiratory symptoms (early or late disease), and for headache with stiff neck or loss of vision (late disease). Unlike patients, the physicians surveyed almost never considered the ED appropriate for evaluating headache behind the nose and eyes, or oral white patches. Physicians were also unlikely to consider it appropriate to wait for any symptom to get better, while patients more often chose this option.

Propensity to Seek Care in the Emergency Department

Patients varied widely in their overall propensity to seek ED care. Propensity scores from patients with advanced HIV disease indicated that propensity to seek ED care was high in 29%, medium in 27%, and low in 44% of patients. Early disease patients had slightly lower propensity to use the ED: 20% had high propensity, 27% had medium propensity, and 53% had low propensity to use the ED.

Propensity to use the ED at the start of the study was a significant predictor of actual ED use assessed at the first follow-up interview. For advanced disease patients, 41% with high propensity to use ED care went on to visit

Table 2. Patient and Physician Care Seeking Responses for Early and Advanced Disease Symptom Scenarios

	Care Seeking Responses to Symptom Scenarios							
	Patient Responses, %*				Physician Responses, %†			
	Emergency Department	Doctor's Office the Same Day	Schedule Special Appointment	Give It a Chance to Get Better	Emergency Department	Doctor's Office the Same Day	Schedule Special Appointment	Give It a Chance to Get Better
Early disease								
Respiratory symptoms with fever	42	40	9	9	36	43	21	0
Headache behind the nose and eyes	18	28	6	48	1	36	43	20
Oral white patches	14	48	21	17	0	30	50	20
Advanced disease								
Respiratory symptoms with fever	45	42	6	7	42	47	11	0
Headache with stiff neck	25	53	11	11	42	44	14	0
Loss of vision	29	53	12	6	37	44	19	0

*Patients selected the one clinical venue they would use for each scenario. Percentages shown are weighted to represent the full population of patients in care in the United States.

†Physicians surveyed indicated whether each venue would be appropriate for treatment of the symptom scenario described. Distribution of appropriate responses shown for each symptom scenario.

the ED, compared with 32% of medium propensity patients, and 22% of low propensity patients ($P < .0001$; Pearson χ^2). For early disease patients, 34% with high propensity to use ED care visited the ED in the interval between baseline and follow-up interview, compared with 33% of medium propensity patients, and 17% of low propensity patients ($P < .0001$; Pearson χ^2).

The results of multivariate ordered logit models using fully weighted HCSUS datasets are shown in Table 3. African-American race was the strongest overall predictor of propensity to use the ED in both early and advanced disease models, associated with a more than four-fold increase in odds in early disease patients and a more than two-fold increase in advanced disease patients. Low income was associated with small but significant increases in propensity in both models, and higher psychological well-being predicted lower propensity to use the ED. Other

socioeconomically vulnerable patient groups, such as Hispanics and women among patients with early disease, and patients with drug dependence and less education among patients with late disease, were more likely to have a propensity to use the ED. Patients in the northeastern United States had a twofold increase in odds of saying they would use the ED for symptom care, compared with patients elsewhere in the United States. Patient age, trust in the primary HIV care provider, knowledge about HIV disease, perceived access to health care, and social and tangible support were not associated with propensity to use the ED in either early or advanced disease.

DISCUSSION

Responses to the symptom scenarios suggest that although most patients would seek care promptly for the

Table 3. Multivariable Predictors of Propensity to Seek Care in the Emergency Department for HIV-Associated Symptoms

	Early HIV Disease*		Advanced HIV Disease†	
	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value
Race or ethnic group				
White	Ref		Ref	
African-American	4.7 (3.1 to 7.1)	<.0001	2.5 (1.8 to 3.4)	<.0001
Hispanic	2.4 (1.4 to 4.3)	<.01	1.3 (1.0 to 1.8)	—
Other	2.1 (1.0 to 4.4)	<.05	1.5 (0.5 to 4.2)	—
Gender				
Female	1.6 (1.2 to 2.2)	<.01	1.1 (0.8 to 1.4)	—
Less education				
High school or less	1.0 (0.7 to 1.6)	—	1.4 (1.1 to 1.7)	<.01
Habits				
Drug-dependent	1.0 (0.7 to 1.3)	—	1.4 (1.1 to 1.7)	<.01
Income				
>\$25,000 per year	Ref		Ref	
\$10,000 to \$25,000	1.4 (0.9 to 2.1)	—	1.1 (0.8 to 1.5)	—
\$5,000 to \$10,000	1.2 (0.7 to 2.0)	—	1.4 (0.9 to 2.1)	—
<\$5,000 per year	1.8 (1.1 to 3.0)	<.05	1.5 (1.0 to 2.3)	<.05
Access to care				
Long wait to get an appointment	1.5 (1.0 to 2.1)	<.05	1.2 (0.8 to 1.8)	—
Long travel time to appointments	1.1 (0.9 to 1.3)	—	1.1 (1.0 to 1.2)	<.05
Usually see the same provider	0.7 (0.4 to 1.3)	—	0.7 (0.5 to 1.0)	<.05
Long time in care with usual provider	1.0 (0.8 to 1.1)	—	0.9 (0.8 to 1.0)	<.06
Psychological status				
Psychological well-being	0.9 (0.8 to 1.0)	<.01	0.9 (0.9 to 1.0)	<.05
Greater cognitive denial	1.0 (0.9 to 1.0)	—	0.9 (0.9 to 1.0)	<.01
Geographic region				
Midwest	Ref		Ref	
Northeast	2.5 (1.6 to 4.0)	<.0001	1.9 (1.3 to 2.8)	<.001
South	1.4 (0.9 to 2.2)	—	1.1 (0.7 to 1.6)	—
West	1.5 (0.9 to 2.4)	—	1.1 (0.9 to 1.4)	—

*No past AIDS-defining opportunistic complications, most recent CD4 cell count $\geq 200/\mu\text{L}$. Pseudo $R^2 = .21$.

†One or more AIDS-defining opportunistic complications, or most recent CD4 cell count $< 200/\mu\text{L}$. Pseudo $R^2 = .10$.

Ordered logit models from weighted data predicting high, medium, or low propensity to seek care in the emergency department. Models include covariate adjustment for CD4 cell count, general health, and health insurance status; odds ratios for these covariates were not significant. Other variables included in the models but not significant were trust in provider, social and tangible support, knowledge about HIV, and desire for involvement with medical decisions. For full variable descriptions, see Methods.

CI indicates confidence interval; Ref, the reference group.

most urgent symptoms (those suggestive of AIDS opportunistic complications), a substantial minority of patients would delay their care. Furthermore, many patients said they would use the ED for care rather than seeking care from their own HIV provider the same day. This was particularly common among African Americans, those with low income, those with symptoms of anxiety or depression, and those in the northeastern United States. Because the HCSUS population consists entirely of people sampled from nonemergent outpatient HIV care settings, almost all subjects reported having a usual primary health care provider. Furthermore, in our analyses, we controlled for perceived access to this usual health care provider and for insurance status and other access barriers to care. This suggests that many patients would have chosen the ED for their care even when same-day access to their own provider was available.

Care in the ED for nonurgent symptoms is inefficient and interrupts continuity of primary care. Efforts should be made to improve the quality and efficiency of care by encouraging doctor's office use.

Delays in care seeking can be dangerous for patients with advanced HIV disease and urgent symptoms. Among those with advanced HIV, the proportions who reported they would delay care ranged from 13% for patients with respiratory symptoms and fever to 22% for patients with headache and stiff neck (Table 2). Given the serious illnesses these symptoms could indicate and the importance of starting treatment quickly, primary care practices should work to facilitate rapid access to care for such patients. Ways to do this include making access to urgent appointments easy by holding a number of appointment slots open for same-day use, offering evening office hours, and providing off-hour on-call physician consultation which could help triage patients to the ED when necessary. Patient education programs to teach effective "self-triaging" should be considered for patients with advanced HIV disease. Printed flowcharts have been published that can help patients assess the seriousness of their own symptoms.²⁸

Patient responses to the scenario describing headache behind the nose and eyes differed substantially from responses to other scenarios. Nearly half of all patients indicated they would wait until the next scheduled appointment, giving the symptoms a chance to get better. Physicians most often felt that these headaches should be evaluated the same day or at a special appointment. The physicians may have interpreted the scenario as indicating bacterial sinusitis, a condition that requires antibiotic treatment, and which is more serious in patients with HIV infection than in HIV-negative patients. Patients may have tended to attribute the headaches to more chronic or benign causes, such as tension or drug side effects, and in fact, patients with these more chronic or benign headaches would be correct to wait and use self-care strategies.

Results of multivariate analyses confirmed many of the relationships hypothesized in the behavioral model of

health service use. Income and access to care (enabling factors) and psychological status (predisposing factor) were all associated with propensity to use the ED. African-American race, in particular, had the strongest influence, even after multivariate adjustment for other predisposing factors as well as enabling and need variables. This finding is disturbing, but perhaps not surprising given the remarkable consistency of racial and ethnic disparities in health care in the United States.²⁹ Other analyses of HCSUS data have revealed racial disparities in care received by patients with HIV.²⁰ Many of these disparities undoubtedly reflect racial differences in access to care. However, differences among patients in knowledge, cultural beliefs, and preferences for care may also lead African Americans to pursue care differently. Racial discrimination on the part of providers or care systems could also play a role if experiences of racial discrimination alter patients' care-seeking strategies.³⁰

Low income was associated with small but significant increases in propensity for ED use, in spite of adjustment for differences in health insurance. Poor patients may lack telephones, child care, or other resources not measured in this analysis that are needed to make outpatient primary care a preferred option for symptom evaluation. Even if equal access to health care for all patients were achieved, there might still be inequities in the social resources necessary to allow patients to participate fully in the management of their chronic diseases.

The poor, African Americans, and those without a regular source of primary care are particularly likely to use the ED for nonurgent problems.^{3,5} Those with lower socioeconomic status may have less access to continuity care, and therefore may receive care in the ED for lack of other options.³¹ However, while differences in access certainly explain some of the variation in ED use, even those with equal access may vary in their ED use due to differences in knowledge, habits, and cultural norms.^{1-7,11,32-34} Many HIV patients who have primary care providers still go to the ED for treatment.¹¹ Propensity to use the ED may emerge as a pattern of behavior in social groups that have a long history of difficulty gaining access to care, and may persist even after access barriers have been removed. If this is the case, analyses to determine the predictors of ED use might continue to show differences in use by traditionally disenfranchised sociodemographic groups, even when degree of illness, accessibility of primary care, economic factors, and education are all accounted for.

Many of our findings about propensity for ED use are consistent with results from other investigators who have studied actual ED use. Although they lacked race/ethnicity data, Markson et al. found that HIV patients who were women, who were intravenous drug users, and who had psychiatric disease were more likely to use the ED repeatedly.⁹ Mor et al. found that nonwhite, female, and intravenous drug-using HIV patients were most likely to seek care in the ED.¹¹ Cohen et al. found that African Americans also

had higher rates of ED use.³⁵ Kass et al. found that while race was not a predictor of ED use, whites used outpatient clinic care more frequently than did African Americans.³⁶

The use of clinical scenario questions to assess propensity to use the ED has important advantages. Acute symptoms that lead individual patients to go to the ED are highly variable; using uniform scenarios across patients helps control for these variations in clinical presentations. Scenario questions also allow assessment of patient care seeking for specific clinical conditions that are most common or of particular concern as causes of HIV-related morbidity/mortality.

This study has several limitations. First, CD4 cell counts and ED use were based on patient self-reports; access to medical and billing records might produce a more accurate picture of these variables. However previous work has suggested that patient interviews can provide valid data for assessing CD4 cell count strata in patients with HIV.³⁷

Second, no recognized quality standards exist for how HIV patients should seek care in response to symptoms. In addition, the HIV physician survey data presented here are useful for making general comparisons with patient data, but they come from a convenience sample and may not properly represent all HIV clinicians. Evidence from studies, and formal group consensus methods and sampling would be needed to develop better quality criteria for patient care seeking.³⁸

Third, it is widely recognized that highly active anti-retroviral combinations, including protease inhibitors, have transformed HIV care. Our data were collected after FDA approval and nationwide marketing of protease inhibitors; however, because these drugs were still relatively new, it is possible that symptom complexes and patient responses to symptoms have now changed.

Finally, although the relationships found here are consistent with theory-driven hypotheses, our multivariate models explained a relatively small part of all variation observed in propensity to use the ED for care. Some potentially important variables were not collected. For example, Markson et al. found that certain clinic features led to fewer ED visits, including availability of on-call physicians, and evening or weekend clinic hours.⁹ Automobile ownership, presence of dependent children or adults in the home, or workplace sick-leave policies and ability to contact providers on the telephone could all play a role. These and other clinic and access-related factors were not assessed in our survey and might influence ED use among HIV patients nationally.

There were strong regional differences in propensity to use the ED, with patients in the Northeast showing greater propensity compared with patients in other regions. Although this finding remained strong in multivariate models that controlled for numerous patient-level variables, our study lacked the detailed clinic and provider characteristics that could be important in interpreting these findings. Thus, we cannot determine whether

regional differences in propensity to use the ED reflect regional differences in patient attitudes or culture, or differences in health care delivery systems. Regional variations in care seeking by patients could reflect patient cultural factors, just as small-area variations in practice patterns partly reflect differences in provider culture.³⁹

In conclusion, patients receiving HIV care in the United States generally express a propensity to seek care urgently for new symptoms, and they often seek care in the ED rather than in the outpatient offices of their own primary care physicians. Systems caring for HIV patients should make prompt access to primary care providers a priority.⁹ When access is adequate, education and outreach programs could help patients use care sites appropriately and efficiently, thus helping more patients to be seen by their primary providers, and improving coordination of care. Efforts may be particularly important in care sites that serve African-American and low-income patients, because these groups have the greatest propensity to use the ED.

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