

Original Article

Patient Reports of Symptoms and Their Treatment at Three Palliative Care Projects Servicing Individuals with HIV/AIDS

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Abstract

*Self-reports of 32 symptoms and their treatments were obtained from patients of three palliative care programs that provide services to seriously ill HIV patients ($\geq 95\%$ AIDS) in Alabama ($n = 47$), Baltimore ($n = 91$), and New York City ($n = 117$). On average, patients reported 10.9 ($SD = 7.6$) to 12.7 ($SD = 6.2$) symptoms. Pain, lack of energy, and worrying were reported by a majority of patients at all sites, often with a high level of associated distress. For only four symptoms (pain, nausea, difficulty swallowing, and mouth sores) did half or more of patients at all sites experiencing the symptom also report treatment. Less than a third of patients experiencing 12 symptoms (five of six comprising a psychological subscale) reported treatment. Results show that despite the availability of more efficacious treatments, many HIV/AIDS patients continue to experience significant physical and psychological symptomatology. Many of those experiencing symptoms, however, do not perceive their symptoms as being treated. *J Pain Symptom Manage* 2005;30:408–417. © 2005 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

HIV/AIDS, palliative care, symptom evaluation, underserved populations

Introduction

The development of more efficacious treatment regimens has resulted in increased

survival and reduced incidence of various comorbid conditions for many living with HIV/AIDS.^{1–2} However, there remain thousands of individuals for whom these regimens have been less successful due to a variety of factors, including initiation of treatment after the patient's immune system had already been severely compromised, nonadherence to treatment regimens, an inability to tolerate treatment(s), and/or nonresponse to treatment.

Although a large number of studies have included symptomatology of HIV patients as

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either a dependent or an independent variable in analyses, most have either used only summary measures (e.g., a count of symptoms reported) or restricted analysis and discussion to one or two specific symptoms. Several reports have described the prevalence of a wider range of individual symptoms experienced by HIV/AIDS patients; however, the symptoms described remain those specifically associated with disease progression or a poor prognosis for survival and are based on information from patients living with the disease prior to the advent of highly active antiretroviral therapy (HAART) and other treatment advances.³⁻⁴ Specifically, these studies have documented a high prevalence of fatigue, weight loss, cough, memory loss, insomnia/sleep disturbance, depression/sadness, and paresthesias in this population.

Not much is known about the prevalence, severity, and level of distress associated with symptoms that can adversely impact the quality of life of individuals living with HIV/AIDS, even though they may not be life threatening or associated with a poor prognosis. One study that described the prevalence and experience of 32 symptoms in a sample of 504 ambulatory AIDS patients⁵ found that patients reported an average of 16.7 symptoms, with 19 or more symptoms reported by at least half of the subjects. About two-thirds or more of patients reported each of the six symptoms comprising a psychological subscale. However, the patients in that study were accrued prior to the widespread availability of HAART.

There is reason to believe that the symptomatology experienced by HIV/AIDS patients may have changed as a result of improvements in the treatment of the disease and its associated conditions. Potential toxicities and other side effects have been associated with individual treatments and there is also the potential for unanticipated drug interactions as a result of polypharmacy either for treatment of HIV/AIDS or, as is often the case, for treatment of HIV/AIDS in conjunction with other medical conditions or diagnoses.⁶⁻⁷ The shift in the demographics of the disease toward patients diagnosed with comorbidities (e.g., substance abuse or mental illness) and patients from resource-poor and minority communities is also likely to have affected the prevalence and impact of symptoms associated with these

factors among persons living with HIV/AIDS as a whole. The impact of this shift may be particularly evident among patients with advanced disease, given that persons with a history of drug abuse and a high level of homelessness have been found in previous studies to receive an HIV/AIDS diagnosis and to enter treatment at a later stage of the disease compared to other groups.⁸⁻¹³

This report compares patient reports of symptomatology from three palliative care programs providing services to seriously ill HIV/AIDS patients. Specifically, it describes the prevalence of symptoms at each site; the prevalence of highly problematic symptomatology among patients experiencing a symptom; and patient reports of whether they have received treatment for each symptom experienced.

Methods

Program Sites

The patients described are clients of three demonstration programs funded as Special Projects of National Significance through an initiative of the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) in the Department of Health and Human Services (HHS) to provide appropriate palliative care and services to individuals with advanced HIV/AIDS. Although all projects participated in a multisite study designed to permit comparisons of programmatic experiences and patient outcomes, individual programs were developed and delivered at each site. Table 1 presents a brief description of each project site and its programmatic goals. Similarities and differences among the sites with regard to their programmatic elements and client populations have been described in earlier reports.¹⁴⁻¹⁵

Measures

All three projects collected a common set of items and measures—the Palliative Care Assessment Forms for HIV (PCAF-HIV). Both the patient and a staff member completed appropriate forms of the PCAF-HIV at accrual and at regular intervals thereafter (monthly for standardized measures, every 3 months

Table 1
Project Sites

| | Alabama | Baltimore | New York City |
|--------------------------------|--|---|---|
| Geographic locale/service area | The agency serves a 14-county, primarily rural area in Northeastern Alabama through its main clinic in Hobson City and regularly scheduled satellite clinics in other towns. | Downtown, close to areas where the homeless congregate and neighborhoods with high rates of substance abuse and HIV infection. | A densely populated urban neighborhood of the Bronx in an area with high rates of HIV infection. |
| Institutional setting | Service is offered through a freestanding, nonprofit clinic for persons with HIV/AIDS. | Large university-affiliated medical center. | Large medical center with services and clinics for HIV/AIDS care. |
| Target client population | Terminally ill HIV/AIDS patients who are poor and usually uninsured. In many instances, patients are also homeless and/or substance abusers. | Terminally ill HIV/AIDS patients who include substance abusers, the homeless, multiply diagnosed, and the uninsured urban poor. | Seriously ill HIV-infected patients who are often poor, uninsured, substance abusers, and homeless. |
| Service model | Hospice care. | Augmented hospice model. | Augmented palliative care, consultative service. |
| Programmatic goals | Development of a palliative care team to provide clients in need of such care with medical and support services, either at the clinic or in the patient's home. Development of a community hospice residence for a limited number of clients who are either homeless or inadequately housed. | Development of a palliative care service to maintain—through active community outreach and other efforts—an ongoing relationship with clients that supports the utilization of available medical and support services (i.e., facilitating the making and keeping of appointments encouraging adherence to treatment regimens), as well as the articulation and achievement of realistic life goals. | Development of a palliative care team to provide both palliative care consultative services (i.e., a resource at the disposal of hospital staff to provide assessments of patients' palliative service needs and to identify appropriate referrals) and ongoing palliative support services to clients identified through outreach at outpatient clinics. |
| Palliative care team | Physician, nurse, social worker, addictions specialist. | Physician, nurse, social worker, chaplain/pastor, addictions specialist, outreach worker. | Physician, psychiatrist, nurse practitioner, social worker, outreach worker, chaplain/pastor, bioethicist. |

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for sociodemographics and service needs/utilization assessments). Analyses presented are based on data from patient interviews conducted from June, 2000 to March, 2003. Appropriate Institutional Review Board approval was obtained for projects at all sites. Included in the PCAF-HIV are questions eliciting basic sociodemographic information (age, gender, race/Hispanic origin); HIV medical status (HIV/AIDS status, CD4+ count, viral load); brief histories of mental illness/treatment (ever, past 3 months) and alcohol/substance abuse/treatment (ever, past 3 months); and a battery of standardized measures.

Symptomatology. Patients completed the Memorial Symptom Assessment Scale (MSAS), a comprehensive symptom assessment measure developed by Portenoy et al.¹⁶ for use with cancer patients, which has also been used with ambulatory HIV/AIDS patients,⁵ as well as

with AIDS inpatients receiving long-term care at a skilled nursing facility.¹⁷ The MSAS elicits information regarding the presence, frequency (if relevant), severity, and distress associated with each of 32 symptoms during the past week and yields a separate score for each symptom as well as four summary measures: a total score (total MSAS) (Cronbach's $\alpha = 0.86\text{--}0.93$ in present samples); a psychological symptoms subscale (PSYCH) ($\alpha = 0.69\text{--}0.81$); a physical symptoms subscale (PHYS) ($\alpha = 0.79\text{--}0.82$); and a global distress index (GDI) ($\alpha = 0.72\text{--}0.83$). Scores for all summary measures can range from 0 to 4, with higher scores indicative of greater problems.

Based on discussions among the investigators and with approval of an author of the original scale (A. Kornblith, personal communication), two modifications were made to the original MSAS form for the purposes of this evaluation. First, a symptom in the original

MSAS specifically associated with cancer treatment but not HIV/AIDS (“hair loss”) was replaced with a symptom more relevant to patients with advanced HIV/AIDS (“fever lasting more than 2 weeks”). This substitution does not impact individual symptom scores for three of the summary measures (PSYCH, PHYS, or the GDI), since the symptom replaced does not factor into the computation of these measures. Impact on the total MSAS is minimal given that only 1 of the 32 symptoms being assessed was changed.

Another modification implemented for the purposes of the multisite evaluation, was the addition of an item to assess whether the patient was being treated for each symptom reported. This item was added because it was felt that information regarding the patient’s perceptions of whether his or her symptoms were being addressed was important, not only for understanding the patient’s condition but for identifying potential gaps in care or patient-staff communication. Whereas at Alabama and Baltimore the MSAS was administered to patients by a nurse practitioner, in New York City (NYC) the measure was administered by a nurse practitioner, a social worker, or a community outreach worker.

Statistical Methods

One-way analysis of variance was used to determine whether means of continuous ordinal variables, including scale scores, significantly varied among the three projects. When differences among projects were noted, Scheffe’s tests were conducted to identify significant differences between each pair of projects. Comparisons of the distribution of categorical variables among sites were made using χ^2 tests. The criteria for significance used for all statistical tests were $P \leq 0.05$.

Results

The findings presented reflect patients’ symptomatology at the time of their first assessment. Of 376 patients accrued at the three sites (52 at Alabama, 94 at Baltimore, and 230 at NYC), 255 completed an MSAS. Completed forms were obtained from 90% ($n = 47$) of patients at Alabama, 97% ($n = 91$) of patients at Baltimore, and 51% ($n = 117$) of patients at NYC. The proportion of patients completing

an MSAS was particularly low at NYC due, at least in part, to the consultative nature of the program and the accrual of many patients hospitalized within days or weeks of death. For these patients, completion of forms was unfeasible or even unethical given the severity of their medical condition. All patients with a completed MSAS were HIV positive, with 95% or more at all three sites meeting the criteria for an AIDS diagnosis. Among patients for whom lab results were also available, 81% at NYC, 85% at Alabama, and 98% at Baltimore not only met the Centers for Disease Control and Prevention (CDC) criteria for an AIDS diagnosis but also reported a CD4+ count of <200 cells/mm³ at last assessment. At least half of the patients at all sites had viral loads higher than 50,000.

Patient Characteristics

Characteristics of patients at the three sites are presented in Table 2. A majority of patients at all three sites were in their 30s or 40s. Although a majority at all sites identified themselves as male, this proportion varied significantly among sites ($\chi^2 = 9.684$, $df = 2$, $P = 0.008$) and was particularly high at Alabama (83%). The racial/ethnic distribution of patients was also significantly associated with site ($\chi^2 = 117.710$, $df = 6$, $P < 0.001$). Whereas at Alabama most patients were either Black non-Hispanic (46%) or White non-Hispanic (44%), at Baltimore the vast majority was Black non-Hispanic (92%), and at NYC patients were primarily Hispanic (50%) or Black non-Hispanic (34%).

About half or more of patients at all three sites reported a history of substance abuse. However, this proportion varied significantly among sites ($\chi^2 = 10.487$, $df = 2$, $P = 0.005$), as did the proportion of patients reporting such a problem in the past 3 months ($\chi^2 = 6.579$, $df = 2$, $P = 0.037$). In both instances, the proportion reporting a problem was highest at Baltimore and lowest at Alabama. It should also be noted that while staff at Alabama indicated that substance abuse among their patients was primarily associated with alcohol use, staff at Baltimore and NYC reported that although many of their patients abused alcohol, a high proportion also had histories of abusing other illicit substances, often intravenously. The proportion of patients with a history of substance abuse who had ever received

Table 2
Patient Characteristics by Project Site

| | Alabama (<i>n</i> ≤ 47) | Baltimore (<i>n</i> ≤ 91) | New York City (<i>n</i> ≤ 117) | <i>P</i> -value |
|---|-----------------------------|-------------------------------|------------------------------------|------------------|
| | Mean (SD) % | Mean (SD) % | Mean (SD) % | |
| Age | 40.5 _y (8.8) | 40.9 _z (7.2) | 44.4 _{y,z} (8.9) | <i>P</i> ≤ 0.01 |
| <30 | 8 | 7 | 5 | ns |
| 30–39 | 45 | 41 | 28 | |
| 40–49 | 34 | 42 | 38 | |
| 50–59 | 11 | 10 | 22 | |
| 60+ | 2 | 1 | 6 | |
| Gender: male | 83 | 59 | 61 | <i>P</i> ≤ 0.05 |
| Race | | | | <i>P</i> ≤ 0.001 |
| Black, non-Hispanic | 46 | 92 | 34 | |
| White, non-Hispanic | 44 | 8 | 10 | |
| Hispanic | 9 | — | 50 | |
| Other/multiple races | 2 | — | 6 | |
| Ever dependent upon/addicted to alcohol/another drug | 49 | 79 | 65 | <i>P</i> ≤ 0.01 |
| Dependent upon/addicted to alcohol/another drug in past 3 months | 17 | 38 | 24 | <i>P</i> ≤ 0.05 |
| Ever treated for drug/alcohol dependency ^a | 59 | 72 | 86 | <i>P</i> ≤ 0.05 |
| Ever diagnosed as having a mental health condition/illness | 34 | 22 | 31 | ns |
| Mental health condition/illness in past 3 months | 31 | 12 | 24 | <i>P</i> ≤ 0.05 |
| Ever treated for a mental health condition/illness ^b | 92 | 88 | 91 | ns |

ns = not significant.

^aRestricted to those ever dependent upon/addicted.

^bRestricted to those ever diagnosed with condition.

Note: Means sharing a subscript differ significantly from each other (*P* ≤ 0.05).

treatment for it also varied among sites ranging from only 59% at Alabama to 72% at Baltimore and 86% at NYC ($\chi^2 = 7.154$, *df* = 2, *P* = 0.028).

Although the proportion of patients who reported having ever been diagnosed with a mental health condition or illness did not vary significantly among sites, the proportion experiencing such a condition in the past 3 months did, ranging from only 12% at Baltimore to 24% at NYC and 31% at Alabama ($\chi^2 = 6.691$, *df* = 2, *P* = 0.035). The vast majority of patients with such a diagnosis reported receiving professional care or counseling for their condition.

Symptom Prevalence

Given the important differences noted between sites with regard to the palliative care programs established and the client populations served, as well as the imbalance among sites with regard to the number of clients interviewed and the proportion of clients who completed an MSAS, it was deemed both important and methodologically necessary to

present results separately for each site. Mean scores of patients did not differ significantly among sites for any of the four summary measures (Table 3).

The proportion of patients at each site reporting individual symptoms in the past week is presented in Table 4. For presentation purposes, the symptoms are ordered by the proportion of patients in all three total samples combined who reported the symptom during the past week. Symptoms comprising the

Table 3
Mean Scores for Summary MSAS Measures
by Project Site

| | Alabama (<i>n</i> = 47) | Baltimore (<i>n</i> = 91) | New York City (<i>n</i> ≤ 102) | <i>P</i> -value |
|---------------------|-----------------------------|-------------------------------|------------------------------------|-----------------|
| | Mean (SD) | Mean (SD) | Mean (SD) | |
| Total MSAS score | 1.1 (0.6) | 1.0 (0.6) | 0.9 (0.7) | ns |
| Psychological Index | 1.2 (1.0) | 1.1 (0.9) | 1.2 (1.0) | ns |
| Physical Index | 1.1 (0.7) | 1.1 (0.7) | 1.0 (0.8) | ns |
| GDI | 1.3 (0.8) | 1.2 (0.8) | 1.2 (0.9) | ns |

ns = not significant.

Table 4
Symptom Prevalence, Proportion for Whom Symptom Is Frequent, Severe, and Distressing,
and Proportion Receiving Treatment

| Symptom | Among Patients Reporting Symptom: | | | | | | | | | | | |
|---|--|-----------|-----|----------------|--|-----------|-----|---------------|---------|-----------|-----|---------------|
| | Symptom Prevalence Among All Patients | | | | Symptom Frequent, Severe and Distressing ^a | | | | | | | |
| | | | | | Receiving Treatment ^a | | | | | | | |
| | Alabama | Baltimore | NYC | | Alabama | Baltimore | NYC | | Alabama | Baltimore | NYC | |
| | % | % | % | P-value | % | % | % | P-value | % | % | % | P-value |
| Lack of energy ^b | 77 | 71 | 70 | ns | 47 | 66 | 53 | ns | 44 | 16 | 32 | $P \leq 0.01$ |
| Pain ^b | 64 | 74 | 69 | ns | 53 | 72 | 61 | ns | 73 | 83 | 67 | ns |
| Worrying ^c | 51 | 55 | 53 | ns | 38 | 72 | 46 | $P \leq 0.01$ | 27 | 6 | 23 | $P \leq 0.05$ |
| Shortness of breath | 57 | 58 | 43 | ns | 26 | 57 | 34 | $P \leq 0.05$ | 44 | 69 | 52 | ns |
| Dry mouth ^b | 62 | 55 | 45 | ns | 17 | 54 | 31 | $P \leq 0.01$ | 29 | 19 | 33 | ns |
| Feeling sad ^c | 43 | 50 | 50 | ns | 20 | 36 | 44 | ns | 26 | 26 | 26 | ns |
| Weight change ^b | 43 | 56 | 39 | ns | 25 | 61 | 39 | $P \leq 0.05$ | 30 | 31 | 44 | ns |
| Cough | 64 | 50 | 32 | $P \leq 0.001$ | 27 | 42 | 26 | ns | 40 | 52 | 48 | ns |
| Nausea ^b | 57 | 46 | 42 | ns | 26 | 40 | 40 | ns | 67 | 66 | 49 | ns |
| Difficulty sleeping ^c | 57 | 47 | 40 | ns | 52 | 49 | 64 | ns | 33 | 32 | 44 | ns |
| Feeling drowsy ^b | 51 | 40 | 35 | ns | 25 | 44 | 32 | ns | 8 | 9 | 21 | ns |
| "I don't look like myself" | 45 | 37 | 41 | ns | 43 | 65 | 55 | ns | 19 | 3 | 24 | $P \leq 0.05$ |
| Lack of appetite ^b | 47 | 32 | 41 | ns | 32 | 52 | 56 | ns | 23 | 22 | 33 | ns |
| Numbness/tingling in hands/feet | 45 | 41 | 30 | ns | 43 | 60 | 44 | ns | 35 | 40 | 37 | ns |
| Itching | 38 | 46 | 29 | $P \leq 0.05$ | 50 | 69 | 53 | ns | 33 | 43 | 52 | ns |
| Feeling nervous ^c | 43 | 31 | 40 | ns | 25 | 39 | 32 | ns | 32 | 22 | 26 | ns |
| Changes in skin | 21 | 50 | 38 | $P \leq 0.01$ | 60 | 61 | 46 | ns | 44 | 43 | 70 | $P \leq 0.05$ |
| Difficulty concentrating ^c | 40 | 34 | 40 | ns | — | 19 | 23 | ns | 21 | 4 | 21 | ns |
| Diarrhea | 53 | 37 | 29 | $P \leq 0.05$ | 28 | 54 | 58 | ns | 33 | 66 | 58 | $P \leq 0.05$ |
| Sweats | 38 | 31 | 26 | ns | 22 | 36 | 30 | ns | 28 | 41 | 20 | ns |
| Irritable ^c | 43 | 29 | 28 | ns | 25 | 38 | 39 | ns | 22 | 4 | 33 | $P \leq 0.05$ |
| Vomiting ^b | 28 | 30 | 23 | ns | 8 | 33 | 40 | ns | 62 | 70 | 41 | ns |
| Dizziness ^b | 36 | 22 | 26 | ns | 23 | 20 | 48 | ns | 18 | 5 | 12 | ns |
| Swelling of arms/legs | 19 | 25 | 27 | ns | 56 | 35 | 54 | ns | 22 | 64 | 62 | ns |
| Change in taste ^b | 34 | 28 | 20 | ns | 50 | 28 | 33 | ns | 27 | 8 | 25 | ns |
| Feeling bloated ^b | 28 | 19 | 26 | ns | 15 | 29 | 46 | ns | 23 | — | 40 | $P \leq 0.05$ |
| Difficulty swallowing | 19 | 23 | 20 | ns | 56 | 48 | 43 | ns | 56 | 48 | 53 | ns |
| Constipation ^b | 23 | 19 | 22 | ns | 64 | 47 | 50 | ns | 46 | 65 | 54 | ns |
| Problems with urination | 21 | 22 | 16 | ns | 50 | 80 | 41 | $P \leq 0.05$ | 30 | 37 | 60 | ns |
| Fever | 4 | 12 | 28 | $P \leq 0.001$ | — | 54 | 66 | ns | — | 73 | 86 | ns |
| Problems with sexual interest/activity | 15 | 11 | 19 | ns | 57 | 20 | 33 | ns | 14 | 10 | 6 | ns |
| Mouth sores | 2 | 11 | 12 | ns | 100 | 50 | 58 | ns | 100 | 80 | 75 | ns |

ns = not significant.

^aRestricted to patients who reported symptom.

^bSymptom included in the physical (PHYS) subscale.

^cSymptom included in the psychological (PSYCH) subscale.

PSYCH and PHYS subscales are noted. As with other summary measures, the mean total number of symptoms reported by patients did not vary significantly by site. On average, patients at NYC reported 10.9 (SD = 7.6) symptoms compared to 11.9 (SD = 6.6) at Baltimore and 12.7 (SD = 6.2) at Alabama.

Whereas 20 of the 32 symptoms assessed were reported by at least 25% of patients at all three sites, 8 were reported by at least 40% (lack of energy, pain, worrying, shortness of breath, dry mouth, feeling sad, nausea, and difficulty sleeping), and 3 (lack of energy, pain, and worrying) were reported by 50–

74%. The prevalence of five symptoms varied significantly by site, with two (coughing, itching) reported by a disproportionately low number of patients at NYC, one (diarrhea) reported by a disproportionately high proportion of patients at Alabama, and two (changes in skin, fever) reported by a disproportionately low number of patients at Alabama.

In addition to prevalence of symptoms, Table 4 also presents the proportion of patients who described each symptom as *frequent*, *severe*, and *distressing* as well as the proportion who reported receiving treatment for it. A symptom

was defined as *frequent* if it occurred “frequently,” “almost constantly,” or if it was one of the eight symptom conditions/states for which frequency was not assessed because it was assumed to be constant. A symptom was defined as *severe* if it was described by the patient as either “severe” or “very severe.” A symptom was defined as *distressing* if the patient reported that it caused “quite a bit” or “very much” distress. Preliminary analyses showed that patients experiencing a high level of problems with regard to one dimension were likely to report high levels of problems regarding other dimensions as well. Therefore, to minimize the presentation of redundant results, we have limited discussion to those patients who described their symptoms as frequent, severe, and distressing.

A total of 23 symptoms were described by at least 25% of patients at all three sites who experienced the symptom as frequent, severe, and distressing. For 11 symptoms (lack of energy, pain, difficulty sleeping, changes in appearance, numbness/tingling in hands/feet, itching, changes in skin, difficulty swallowing, constipation, problems with urination, and mouth sores), this proportion was at least 40%, and for 3 symptoms (pain, itching, and mouth sores), it was at least 50%. The proportion of patients describing five symptoms (worrying, shortness of breath, dry mouth, weight change, and problems with urination) as frequent, severe, and distressing varied significantly among sites. In all five such instances, the proportion reporting highly distressing symptomatology was particularly high at Baltimore, even though the overall prevalence of these symptoms did vary among sites.

With regard to treatment, for only four symptoms (pain, nausea, difficulty swallowing, and mouth sores) did at least half of the patients who reported the symptom also report receiving treatment. Conversely, for 12 other symptoms (worrying, dry mouth, feeling sad, feeling drowsy, changes in appearance, lack of appetite, feeling nervous, difficulty concentrating, feeling irritable, dizziness, and sexual problems), a third or less of patients at all three sites who reported the symptom reported receiving treatment. Among these 12 symptoms were 5 of the 6 that comprise the PSYCH subscale and 5 of the 12 that comprise the PHYS subscale.

A comparison of prevalence data with patients’ reports of treatment for their symptoms suggests that many of the most common symptoms at each site, including the three symptoms reported by a majority of patients at all three sites (lack of energy, pain, and worrying), were perceived by the patient as not having been treated. At Alabama, for 5 of the 10 symptoms experienced by half or more of the patients, treatment was reported by a third or less of those who reported experiencing the symptom. Similarly, low levels of treatment were reported for five of the nine symptoms reported by at least half of the patients at Baltimore and for three of the four such symptoms at NYC.

Discussion

The data presented in this report from patients at three diverse programs targeting underserved populations living with HIV/AIDS demonstrate the feasibility of obtaining a detailed assessment of patients’ symptomatology from this vulnerable population. The findings also document that, despite improved treatments for HIV/AIDS, many living with the disease continue to experience high levels of physical and psychological symptomatology.

Although the mean number of symptoms (10.9–12.7) reported by patients at each of the three programs described was approximately 25% less than the mean number of symptoms (16.7) reported in a study of ambulatory AIDS patients accrued 1992–1995,⁵ and less than half the mean number of symptoms (27.67) reported for a sample of 50 inpatients of an AIDS inpatient unit in a skilled nursing facility at NYC accrued in 1997–1998 prior to or shortly after initiating protease inhibitor use,¹⁷ the total number of symptoms experienced by seriously ill HIV/AIDS patients continues to remain very high. From a clinical perspective, managing treatment for a patient with 10–12 symptoms is highly complex, often involving detailed clinical assessment and review, polypharmacy, assessment of drug and symptom interactions, and the potential for compound side effects. High levels of symptomatology may also impact patients’ ability or willingness to adhere to various treatment regimens.

Eight symptoms—physical (pain, lack of energy, shortness of breath, dry mouth, and nausea) as well as psychological (worrying, feeling sad, and difficulty sleeping)—were reported by 40–74% of patients at all three sites, with about half or more of patients at all sites describing three of these (pain, lack of energy, and difficulty sleeping) as highly frequent, severe, and distressing. Thus, there remains a need for detailed symptom management among seriously ill HIV/AIDS patients. The prevalence of many of these symptoms was similar to (and in some instances worse than) that of terminally ill cancer patients.^{18–21} It should also be noted that although less prevalent than nausea, several additional symptoms associated with gastrointestinal problems (weight change, diarrhea, difficulty swallowing, urination, and vomiting) were also common and found at levels similar to those reported for cancer patients.²² Previous research has identified nausea, vomiting, and diarrhea as potential side effects of various nucleoside reverse transcriptase inhibitors.²³

The present analyses also suggest that a substantial proportion of patients at all three sites perceive that many of their symptoms, including some of the most prevalent, go untreated. This could occur for several reasons. First, it may be that many symptoms commonly experienced by patients in this population are not routinely screened for by medical staff. As a result, some of the symptoms reported by patients in this report were not previously reported to medical staff and, therefore, remained undiagnosed and untreated. A second possibility is that some symptoms reported as untreated by the patient are associated with a condition that is being treated, but the patient is unaware of the connection (e.g., patients may perceive that their fatigue is not being treated although the physician is treating them for anemia). Third, it could also be that medical staff are aware of some symptoms but cannot treat them for medical reasons (e.g., they are side effects of other treatments or the condition causing the symptom is untreatable) or financial constraints (e.g., funds are unavailable for the treatment). All three of these possibilities may be indicative of insufficient or poor physician–patient communication.

It is encouraging to note that two-thirds or more of patients at each site experiencing pain

reported receiving treatment for it, although one would hope that all patients experiencing pain felt they were being treated for it. Even though treatment of pain is more complex in patients with drug and/or alcohol dependence, effective regimens can still be devised.²⁴ Less encouraging are the low proportions of patients who reported treatment for symptoms with known effective treatments,²² such as constipation, vomiting, nausea, and diarrhea. These findings call for improvements in education among general medical staff and indicate a need for more skilled palliative assessment and management.

The findings presented also provide empirical evidence of variation among sites with regard to the symptoms reported and the proportion of patients who describe various symptoms as frequent, severe, and distressing. Significant differences were noted among sites with regard to the prevalence of five symptoms. Coughing and diarrhea were most likely to be reported by patients at Alabama and least likely to be reported by patients at NYC. On the other hand, fever was most prevalent at NYC, where patients were more likely to have been accrued while in the hospital and within 1 month of death. Finally, two skin-related symptoms likely associated with substance abuse (itching and changes in skin) were most prevalent at Baltimore, where homelessness and substance abuse were especially high. Patients at Baltimore were also disproportionately likely to describe four common symptoms (worrying, shortness of breath, dry mouth, and weight change) as particularly distressing, even though the prevalence of these symptoms did not differ among sites.

Such differences underscore the importance of carrying out a population-based needs assessment prior to the establishment of palliative care programs for HIV/AIDS patients to ensure that as many of the patients' medical needs as possible are identified and addressed. To the extent that they are receiving regular ongoing treatment at all, patients entering programs in different settings are likely to arrive with different comorbidities, treatment histories, and are on different treatment regimens. These differences are, in turn, likely to impact the overall prevalence and experience of individual symptoms. For example, a program with a majority of patients who enroll

while on HAART might be expected to report a higher prevalence of treatment-related symptoms among its patients, while a program serving patients with histories of erratic treatment or poor adherence might be expected to report a higher prevalence of symptoms related to opportunistic infections. Similar differences would be expected based on the prevalence of substance abuse and the types of substances for which abuse is reported.

Three methodological issues merit discussion. First, missing data may have biased the findings. Second, findings may also have been biased as a result of the MSAS being administered by a registered nurse at Alabama and Baltimore and by a nurse practitioner, a social worker, or a community outreach worker at NYC. However, the likelihood of such a bias is minimal since the form elicits patient reports regardless of who administers it and, although nonclinical staff administered some of the forms at NYC, most were administered by the nurse practitioner. Third, the generalizability of results is unknown. Although all three programs described target underserved individuals living with HIV/AIDS, important structural differences between the program sites were noted. Sites differed with regard to their geographic location, patient populations served, services provided by staff, service delivery model, and the level of contact and intimacy that staff can develop with patients during the course of service provision. Evidence that there are also differences among sites with regard to the prevalence of specific symptoms and whether they are treated, as well as patients' perceptions of symptom intensity and treatment, is consistent with the hypothesis that patient symptomatology is associated with structural factors. Unfortunately, because there were only three sites, each with a unique combination of structural attributes, it was impossible to control for important differences between the sites in these analyses.

Overall, despite the trend toward increased survival for patients with HIV/AIDS, many living with the disease experience a wide range of frequent, severe, and distressing symptoms, not all of which are directly associated with HIV/AIDS disease progression or survival. They are also likely to perceive that many of their symptoms are not being treated. In combination with earlier investigations that have

documented a lack of agreement between physician and HIV/AIDS patients' reports of symptoms,³⁻⁴ these findings underscore the importance of improving patient-physician communication around the patient's experience of symptomatology and symptom management. It is incumbent upon physicians to more systematically query HIV/AIDS patients with regard to symptoms they are experiencing; provide patients with a more complete understanding of the treatments they are receiving; and, foster realistic expectations with regard to symptom treatability, palliation, and potential side effects.

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