

High-Cost, High-Need Users of Acute Unscheduled HIV Care: A Cross-Sectional Study

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Background. High-cost, high-need users are defined as patients who accumulate large numbers of emergency department visits and hospital admissions that might have been prevented by relatively inexpensive early interventions and primary care. This phenomenon has not been previously described in HIV-infected individuals.

Methods. We analyzed the health records of HIV-infected individuals using scheduled or unscheduled inpatient or outpatient health care in St James's Hospital, Dublin, Ireland, from October 2014 to October 2015.

Results. Twenty-two of 2063 HIV-infected individuals had a cumulative length of stay >30 days in the study period. These individuals accrued 99 emergency department attendances and 1581 inpatient bed days, with a direct cost to the hospital of >€1 million during the study period. Eighteen of 22 had potentially preventable requirements for unscheduled care. Two of 18 had a late diagnosis of HIV. Sixteen of 18 had not been successfully engaged in outpatient HIV care and presented with consequences of advanced HIV. Fourteen of 16 of those who were not successfully engaged in care had ≥1 barrier to care (addiction, psychiatric disease, and/or homelessness).

Conclusions. A small number of HIV-infected individuals account for a high volume of acute unscheduled care. Intensive engagement in outpatient care may prevent some of this usage and ensuing costs.

Keywords. barriers to care; engagement in care; high-cost, high-need users; HIV; super utilizers.

Health care providers and funders are increasingly focussing on “super-utilizers” or “high-cost, high-need users,” or simply “high-need patients.” These individuals are defined by the Centers for Medicare and Medicaid Services as “patients who accumulate large numbers of emergency department visits and hospital admissions which might have been prevented by relatively inexpensive early interventions and primary care.” Despite representing a small percentage of the population, super-utilizers account for a staggering percentage of health care costs. For example, in the United States, 4% of individuals covered by public health insurance Medicaid account for >50% of costs [1].

Definitions of high-need patients vary; some studies use a definition of the top 1%–5% of the population in terms of health care costs per annum [2], whereas others use a definition of those with high number of emergency department attendances or unscheduled hospital admissions per annum [3]. High-need patients can be characterized based on total accrued health care

costs, intensity of care utilized for a given period of time, and/or functional limitations [4], or they can be subdivided into categories based on age and disability [5]. What all high-need patient studies share, however, is that (1) a relatively small percentage of the population accounts for a huge percentage of health care costs, (2) the vast majority of these individuals have multiple physical and psychiatric comorbidities, and (3) these individuals are frequently from severely socioeconomically deprived circumstances [6, 7].

Before the advent of highly active antiretroviral therapy (ART), the majority of individuals with HIV developed profound immunosuppression and had frequent hospital admissions with opportunistic infections. ART restores immune function to a large degree and reduces the incidence of opportunistic infections and need for hospital admission [8–10]. However, adherence to ART is required to ensure immune restitution and prevent hospital admissions [11–13]. Delayed diagnosis of HIV can also result in the development of profound immunosuppression with consequent opportunistic infections and hospital admissions [14].

HIV-infected super-utilizers typify patients whose requirement for unscheduled hospital visits is potentially preventable. To date, however, this subgroup among the HIV-positive population has not been described or investigated.

We characterized HIV-infected super-utilizers in Dublin, Ireland, and their usage of unscheduled health care and attendant costs.

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METHODS

Study Setting

HIV care in Ireland is provided in specialist units in university teaching hospitals. HIV care and antiretroviral medications are free of charge. Primary health care in Ireland is provided by general practitioners (GPs), who are independent contractors. Individuals with low income (~30% of the population) have access to free GP care under the General Medical Scheme (GMS). Opiate substitution therapy (OST) in Ireland is delivered free of charge either through drug treatment centers (DTCs) or through certified general practitioners. At the end of December 2009, 8551 patients were engaged in OST, of whom 5352 were attending DTCs.

St James's Hospital is a university teaching hospital and tertiary referral center for HIV care. It provides outpatient care to ~2500 HIV-infected individuals per year. Inpatient medical care of HIV-infected individuals is provided by physicians trained in HIV medicine.

Super-Utilizers

We used an operational definition of a super-utilizer as any patient who accrued >30 days of inpatient care during the 1-year study period. We searched an extant database of hospital admissions to retrospectively identify all HIV-infected patients with an inpatient admission. A unique identifier (medical record number) was used to identify individuals who accrued ≥ 30 days of unscheduled inpatient care in a 1-year period from October 1, 2014, to September 30, 2015. Individuals attending the outpatient clinic were used as controls.

Unscheduled Care

Unscheduled care was defined as unplanned hospital admissions, that is, admission to an inpatient ward with an overnight stay that was not previously planned or scheduled or "elective" [15].

Patient Characteristics

All patients attending the HIV service have age, gender, country of origin, current or prior injecting drug use, hepatitis C antibody status, and date of first contact with HIV service extracted from the patient record by a data manager. HIV viral loads and CD4+ T-cell count during the duration of the study period were extracted from a database maintained by the hospital laboratory. An HIV specialist physician manually searched the patient electronic and paper record of super-utilizers for evidence of the following diagnoses: alcohol dependence, psychiatric diagnoses (depression, anxiety, schizophrenia, schizoaffective disorder, bipolar affective disorder), documented intellectual disability/cognitive impairment. The physician also searched for evidence of homelessness, undocumented migrant status, and evidence of attendance at an opiate substitution treatment center. The physician also extracted the year of HIV diagnoses

from the patient's clinical notes. Patient deaths are reported on an ad hoc basis to the department. A chi-square test was used to compare proportions, and a Mann-Whitney test was used to compare continuous variables between groups.

Costing

We used the hospital Finance Department's patient-level costing software to generate cost estimates for all inpatient expenses accrued by super-utilizers during the study period. The cost estimates include an individual patient-level attributable component (eg, the cost of each lab test used by the patient), and an apportioned overhead component for those costs not linkable to individual patients. Expenses related to outpatient clinic attendances, emergency department (ED) visits, and outpatient ART were not included. In addition, radiological investigations, blood products, medical consultations, inpatient bed days, intensive therapy unit (ITU) bed days, and ED attendances were manually extracted from the patient record.

Ethics Approval and Consent to Participate

Ethical approval was granted by the Joint Hospital Research Ethics Committee. Informed consent was not sought for the extraction of data from existing patient records.

RESULTS

Two hundred eight of 2043 HIV-infected individuals attending HIV outpatient services had ≥ 1 unscheduled inpatient admission during the study period. Admissions for all HIV-infected patients accounted for inpatient bed days. We categorized patients according to the number of bed days each individual accrued over the study period; the number in each category is shown in Figure 1. We then calculated total bed days for each category.

Twenty-two HIV-infected individuals had a cumulative length of stay >30 days during the 1-year study period and were

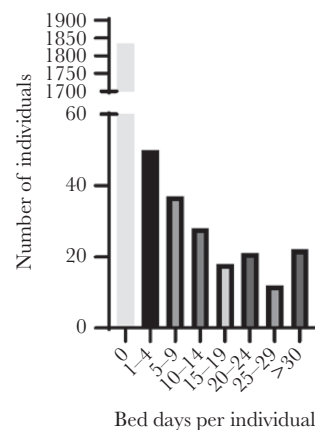


Figure 1. Number of individuals categorized by number of bed days used by each individual in the study period.

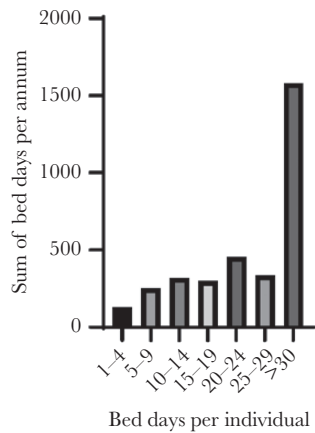


Figure 2. Total number of bed days accrued by individuals in each bed-day category.

identified as super-utilizers. These individuals accounted for 1581/3380 (47%) bed days during the study period (Figure 2).

Resources

The mean number of visits to the ED during the study period per individual (range) was 4.5 (0–17). The mean number of inpatient admissions per individual (range) was 3.4 (1–10), with a mean (range) of 72 (32–275) inpatient bed days per super-utilizer over the study period. Cumulatively, the 22 super-utilizers accounted for 99 ED attendances and 77 inpatient admissions, 1581 inpatient bed days, and 74 ITU bed days. All HIV-related admissions in the hospital within the study period totaled 3380 inpatient bed days.

Super-utilizers were more likely to be of Irish origin and to have a history of current or prior injecting drug use than controls (Table 1).

Super-utilizers had lower CD4 counts and were less likely to be virally suppressed throughout the year-long study period than controls. Mortality was higher in super-utilizers (Table 2).

Medical records of super-utilizers were studied in more detail to determine the prevalence of factors associated with poor adherence to ART. Only 2 had no identified barrier to accessing care (Table 3).

The indications for inpatient admissions of super-utilizers were reviewed. Bacterial infections (sepsis, septic arthritis, infective endocarditis, and pneumonia) were the most common reasons for admission (Table 4).

Preventability

Admissions were deemed potentially preventable if they were felt to be due to immunosuppression due to a late diagnosis of HIV or nonadherence to ART (Figure 3). Of 22 patients, 2 were diagnosed with HIV within 1 year of the study period. One of these individuals presented with opportunistic infections and advanced HIV. Extending HIV screening to ensure earlier diagnosis of HIV would potentially have prevented this admission. The other new diagnosis was diagnosed during seroconversion.

Of the 20 patients with a diagnosis of HIV before the study period, all had been diagnosed as having HIV at least 9 years before the study period. Seven of 20 had undetectable HIV viral loads for the duration of the study period. Of these, 3 had never disengaged from HIV care. One of these had been a late diagnosis and had never attained a CD4 count of >100, despite ART. Two of these 3 had CD4 counts of >250 and had presentations not related to uncontrolled HIV; 1 of these had a large bowel perforation and 1 had somatization disorder. Four of those with undetectable HIV viral loads for the study period had previous episodes of prolonged disengagement from care and had failed to reconstitute CD4 T-cell counts to >250. These 4 patients presented with disease associated with advanced HIV (advanced perianal cancer secondary to HIV, sepsis, pneumonia).

Thirteen of 20 patients were not engaged in scheduled outpatient care and were not on ART for the duration of the study period. Of these, 3 had a CD4 count of >250 at presentation during the study period. Two of these had cirrhosis (and had a prolonged period of more advanced immunosuppression and hepatitis C virus [HCV] infection in the past), and 1 presented with complications of injecting drug use (infective endocarditis). The remaining 10 had CD4 counts of <250 and presented with infections (*Pneumocystis*, *Streptococcus pneumoniae*, gram-negative sepsis, septic arthritis) or chronic organ failure (HIV-associated nephropathy, HIV-associated neurocognitive disorder) related to advanced immunosuppression.

Super-Utilizer Outcomes

Eighteen months after completion of the study period, 10 of the 22 super-utilizers (45%) were known to have died. The relative risk of dying (within 30 months of start of study) of a super-utilizer compared with the general HIV cohort was 33.1656 (95% confidence interval, 18.4352–59.6660; $P < .0001$). In addition, 1 patient required long-term residential care due to

Table 1. Demographics

	Super-Utilizers (n = 22)		Controls (n = 2043)		P Value
	Median	Range or %	Median	Range or %	
Age	42	27–57	43	20–82	Ns
Female gender	9/22	41	637/2043	31	.32
Irish origin	19/22	86	1063/2043	52	.0015
Current or prior injecting drug use	18/22	82	381/2043	19	<.0001

Table 2. HIV Characteristics

	Super-Utilizers (n = 22)		Controls (n = 2043)		PValue
	Median	Range or %	Median	Range or %	
Nadir CD4 during study period	182	4–969	503	4–1993	<.0001
Nadir CD4 count <250 during study period	12/22	55	220/2043	11	<.0001
Virally suppressed throughout study period	8/22	36	1737/2043	85	<.0001
Hepatitis C co-infection	18/22	82	360/2043	18	<.0001
Mortality at 30 mo from start	11/22	50	28/2043	1	<.0001

HIV-associated dementia, and 6 of the remaining patients were lost to follow-up.

Costing

The following were ordered for the 22 patients during the 1-year study: 66 computed tomography (CT) scans, 40 magnetic resonance imaging (MRI) scans, 303 x-ray studies, 28 echocardiograms, 25 interventional radiography procedures, 180 blood cultures, 27 endoscopic investigations, 35 packed red cell units, 29 units of platelets, and 113 medical consultations.

The inpatient cost to the hospital of these 22 patients in 1 year totaled €1 085 449. On average, an expense of €49 339 was incurred by the hospital for each super-utilizer in the 1 year for inpatient costs only. Seventy-seven percent of this total cost estimate was attributable at the individual patient and expense level. These estimates do not include any outpatient expenses, costs of any ED visits, or the cost to state care facilities, prison facilities, or existing outreach teams. Excluding the 2 patients whose admissions were not directly related to HIV, the inpatient cost to the hospital for the remaining 20 patients was €973 460.

DISCUSSION

We describe a small number of HIV-infected individuals who accumulated large numbers of emergency department visits and hospital admissions that might have been prevented by relatively inexpensive early interventions and primary care. Twenty-two super-utilizers accounted for 99 ED visits, 77 inpatient admissions, 1581 inpatient bed days, and 74 ITU bed days, with a direct cost to the hospital of almost €1 million.

We identified 18 of these 22 individuals as having presentations that were potentially preventable. Two of 18 individuals

had a late diagnosis of HIV. Sixteen of 18 had not been successfully engaged in HIV care after diagnosis and presented with consequences of prolonged periods of HIV viremia and immunosuppression: chronic organ failure (HIV-associated nephropathy [HIVAN], HIV-associated neurocognitive disorder [HAND], cirrhosis due to HCV/HIV co-infection), cancer, or infection. Fourteen of 16 of those who were not successfully engaged in care had ≥ 1 barrier to engaging in scheduled care identified, including addiction, psychiatric disease, and homelessness.

Limitations to the study include its retrospective nature and the use of a single definition of high-need patients based on inpatient bed days. Prospective studies testing a number of different methods of identifying potential high-need patients in HIV are needed. An additional limitation to the study is the method of ascertaining mortality. This was based on ad hoc reports of patients' deaths to the HIV clinic, and a comprehensive mortality register was not accessed; therefore, there is the possibility of a difference in the likelihood of identifying the death of a high-need patient compared with comparators.

Given the high hospital costs incurred by high-need patients in our center, it is worth considering interventions to improve engagement in outpatient care and adherence to ART. A study of the HIV care cascade in another Irish hospital reported that of 15 patients who had stopped attending HIV clinic but were contactable, 6 were re-linked to care successfully after a phone call

Table 3. Barriers to Accessing Care

	Count	%
Alcohol dependence	9/22	41
Psychiatric diagnosis	10/22	45
Intellectual disability/cognitive impairment	2/22	9
Current homelessness	9/22	41
Undocumented migrant	0/22	0
Attending opiate substitution treatment center	14/22	64

Table 4. Acute Illnesses Requiring Hospital Admission

Condition	No. of Individuals With This Condition	% of Individuals With This Condition
Decompensated chronic liver disease (including hepatic encephalopathy)	5	23
Sepsis	6	27
Septic arthritis	3	14
Infective endocarditis	3	14
Pneumonia	6	27
HAND	1	5
HIV nephropathy	1	5
PCP	1	5

Abbreviations: HAND, HIV-associated neurocognitive disorder; PCP, primary care provider.

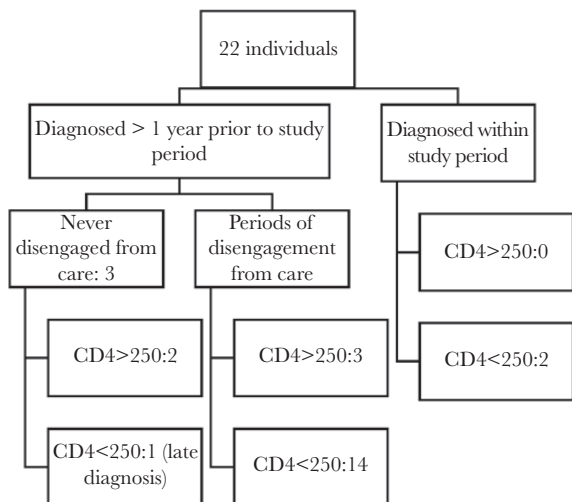


Figure 3. Potentially preventable admissions analyzed by points of potential intervention.

[16]. Integrating HIV care with opiate substitution has also been shown to be feasible in our setting [17]. Evidence-based interventions that can improve adherence to ART include housing for homeless patients [18–20], counseling [21], cognitive behavioral therapy [22], treatment of depression [23], and substance abuse treatment [24, 25]. Recently, integrated care programs to address medical, psychiatric, addiction, and social needs for multimorbid super-utilizers have been reported to yield benefits in health outcomes and use of unscheduled health care [26, 27–29]. When assessing the cost-effectiveness of potential interventions (eg, adherence support workers, cash incentives, housing), particularly in settings with public health care, it is important to consider the magnitude of costs associated with a small number of high-need patients. An assertive engagement model, such as that used with patients with severe mental illness, may be required in order to ensure engagement in HIV care [30].

CONCLUSIONS

A small number of HIV-infected individuals use large amounts of unscheduled health care, resulting in significant cost, which, in a European setting, is borne primarily by the state. These individuals are also at significantly increased risk of mortality. The majority of the usage of unscheduled health care is potentially preventable by earlier diagnosis of HIV and better adherence to ART. These individuals frequently have other comorbidities (psychiatric illness, addiction) and social circumstances (homelessness) that act as barriers to engagement in scheduled outpatient care and adherence to ART. Given the significant cost associated with providing unscheduled care to these individuals, programs to identify and provide integrated health and social care with an assertive engagement approach to these individuals are worth developing and evaluating.

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Potential conflicts of interest. The authors of the study report no conflicts of interest. All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Conflicts that the editors consider relevant to the content of the manuscript have been disclosed.

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