High-cost, high-need users of acute unscheduled HIV care: a cross-sectional study of patient characteristics and costs

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Abstract

High-cost, high-need users are defined 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. This phenomenon has not been previously described in HIV-infected individuals.

We analysed 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.

22/2063 HIV-infected individuals had a cumulative length of stay greater than 30 days in the study period. These individuals accrued 99 ED attendances and 1581 inpatient bed days with a direct cost to the hospital of over 1 million euros during the study period.

18/22 had potentially preventable requirements for unscheduled care. 2/18 had a late diagnosis of HIV. 16/18 had not been successfully engaged in outpatient HIV care and presented with consequences of advanced HIV. 14/16 of those who were not successfully engaged in care had one or more barrier to care (addiction, psychiatric disease and/or homelessness).

In conclusion, 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.

Key words: HIV, engagement in care, super utilisers, high cost high need users, barriers to care
Introduction

Healthcare providers and funders are increasingly focussing on “super-utilisers” or “high-cost, high-need users” or simply “high need patients”. These individuals are defined by the Center 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-utilisers account for a staggering percentage of healthcare costs. For example, in the US, 4% of individuals covered by public health insurance Medicaid account for over 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 characterised based on total accrued health care costs, intensity of care utilized for a given period of time, and/or functional limitations\(^4\); or sub-divided 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 socio-economically deprived circumstances\(^6\)^7.

Prior to the advent of highly active anti-retroviral therapy (ART), the majority of individuals with human immunodeficiency virus 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 \(^8\text{-}^{10}\). However, adherence to ART is required to ensure immune restitution and prevent hospital admissions \(^{11}\text{-}^{13}\). Delayed diagnosis of HIV can also result in the development of profound immunosuppression with consequent opportunistic infections and hospital admissions \(^{14}\).

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

We characterised HIV-infected super-utilisers in Dublin, Ireland and their usage of unscheduled healthcare and attendant costs.

**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 healthcare in Ireland is provided by General Practitioners (GPs), who are independent contractors. Individuals with low income (approximately 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 centres (DTCs) or through certified general practitioners. At the end of December 2009,
8,551 patients were engaged in OST, of whom 5,352 were attending DTCs.

St James’s Hospital is a university teaching hospital and tertiary referral centre for HIV care. It
provides outpatient care to approximately 2,500 HIV-infected individuals per year. Inpatient medical
care to HIV-infected individuals is provided by physicians trained in HIV medicine.

**Super-utilisers:**

We used an operational definition of a super-utiliser as any patient who accrued more than 30 days
of inpatient care during the one-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 or more days of
unscheduled inpatient care in a one-year period from October 1st 2014 to September 30th 2015.
Individuals attending the outpatient clinic were used as controls.

**Unscheduled Care:**

Unscheduled care was defined as unplanned hospital admissions i.e. 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. A HIV specialist physician manually searched the patient electronic and paper record of super-utilisers 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 centre. 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-squared test was used to compare proportions, a Mann-Whitney u-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-utilisers during the study period. The cost estimates include an individual patient-level attributable component (for example, 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, ED visits and outpatient ART were not included. In addition, radiological investigations, blood products, medical consultations, inpatient bed days, 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**

208/2043 HIV-infected individuals attending HIV outpatient services had one or more unscheduled inpatient admission during the study period. Admissions for all HIV-infected patients accounted for inpatient bed days. We categorised 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.

22 HIV-infected individuals had a cumulative length of stay greater than 30 days during the one-year study period and were identified as super-utilisers. These individuals accounted for 1581/3380 (47%) of bed days during the study period (Figure 2).
Resources:

The mean number of visits to the Emergency Department during the study period per individual was 4.5 (range 0-17). The mean number of inpatient admissions per individual was 3.4 (range 1-10) with a mean of 72 inpatient bed days per super-utiliser over the study period (range 32-275).

Cumulatively, the 22 super-utilisers 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 totalled 3380 inpatient bed days.

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

|                      | Super-utilisers (n=22) | Controls (n=2043) | P Value |
|----------------------|------------------------|-------------------|---------|
| **Age**              | Median 42, Range/27-57 | Median 43, Range/20-82 | Ns      |
| **Female Gender**    | 9/22 (41%)             | 637/2043 (31%)    | p=0.32  |
| **Irish Origin**     | 19/22 (86%)            | 1063/2043 (52%)   | p=0.0015|
| **Current or prior** | 18/22 (82%)            | 381/2043 (19%)    | p < 0.0001|
| **injecting drug use** |                      |                   |         |

Super-utilisers 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-utilisers (Table 2).
Table 2: HIV characteristics

|                                | Super-utilisers (n=22) | Controls (n=2043) | P Value |
|--------------------------------|------------------------|-------------------|---------|
|                                | Median | Range or % | Median | Range or % |       |
| Nadir CD4 during study period  | 182    | 4-969      | 503    | 4-1993     | p<0.0001 |
| Nadir CD4 count less than 250 during study period | 12/22 | 55%       | 220/2043 | 11%       | p<0.0001 |
| Virally suppressed throughout study period | 8/22 | 36%       | 1737/2043 | 85%       | p<0.0001 |
| Hepatitis C co-infection       | 18/22 | 82%       | 360/2043 | 18%       | p<0.0001 |
| Mortality at 30 months from start | 11/22 | 50%       | 28/2043  | 1%        | p<0.0001 |
Medical records of super-utilisers were studied in more detail to determine the prevalence of factors associated with poor adherence to ART. Only two had no identified barrier to accessing care (Table 3).
### 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 centre | 14/22 | 64%|

The indications for inpatient admissions of super-utilisers were reviewed. Bacterial infections (sepsis, septic arthritis, infective endocarditis and pneumonia) were the most common reasons for admission (Table 4).
Table 4: Acute Illnesses Requiring Hospital Admission

| Condition                                           | Number 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%                                  |

Preventability:

Admissions were deemed potentially preventable if they were felt to be due to immunosuppression due to a late diagnosis of HIV or non-adherence to ART (Figure 3). Of 22 patients, 2 were diagnosed with HIV within one 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 prior to the study period, all had been diagnosed as having HIV at least 9 years prior to the study period. 7/20 had undetectable HIV viral loads for duration of the study period. Of these, three 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 three had CD4 counts of >250 and had presentations not related to uncontrolled HIV – one of these was with large bowel perforation and one with somatisation 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 four patients presented with disease associated with advanced HIV (advanced perianal cancer secondary to HIV, sepsis, pneumonia).

13/20 patients were not engaged in scheduled outpatient care and were not on ART for the duration of the study period. Of these, three had a CD4 count of >250 at presentation during the study period. Two of these had cirrhosis (and had prolonged period of more advanced immunosuppression and HCV infection in the past) and one presented with complications of injecting drug use (infective endocarditis). The remaining ten 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-utiliser outcomes:

18 months after completion of the study period, 10 of the 22 super-utilisers (45%) were known to have died. The relative risk of dying (within 30 months of start of study) of a super-utiliser compared with the general HIV cohort was 33.1656 (95% CI 18.4352 to 59.6660, p < 0.0001). In addition, one patient required long-term residential care due to 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 one-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 totalled €1,085,449. On average, an expense of €49,339 was incurred by the hospital for each super-utiliser in the 1 year for inpatient costs only. 77% of this total cost estimate attributable at the individual patient and expense level.

These estimates do not include any outpatient expenses, costs of any Emergency Department visits or the cost to state care facilities, prison facilities or existing outreach teams. Excluding the two 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 which might have been prevented by relatively inexpensive early interventions and primary care. 22 super-utilisers accounted for 99 ED, 77 inpatient admissions, 1581 inpatient bed days and 74 ITU bed days, with a direct cost to the hospital of almost one million euros.
We identified 18 of these 22 individuals as having presentations that were potentially preventable. 2/18 individuals had a late diagnosis of HIV. 16/18 had not been successfully engaged in HIV care following diagnosis, and presented with consequences of prolonged periods of HIV viraemia and immunosuppression: chronic organ failure (HIVAN, HAND, cirrhosis due to HCV/HIV co-infection), cancer or infection. 14/16 of those who were not successfully engaged in care had one or more 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 patient 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 to comparators.

Given the high hospital costs incurred by high need patients in our centre, 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 phonecall. Integrating HIV care with opiate substitution has also been shown to be feasible in our setting. Evidence-based interventions which can improve adherence to ART include housing for homeless patients.
counselling, cognitive behavioural therapy, treatment of depression and substance abuse treatment. Recently, integrated care programmes to address medical, psychiatric, addiction and social needs for multimorbid super-utilisers have been reported to yield benefits in health outcomes and use of unscheduled health care. When assessing the cost-effectiveness of potential interventions (e.g. adherence support workers, cash incentives, housing), particularly in settings with public healthcare, 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.

Conclusion:

A small number of HIV-infected individuals use large amounts of unscheduled healthcare 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 co-morbidities (psychiatric illness, addiction) and social circumstances (homelessness) which 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, programmes to identify and provide integrated health and social care with an assertive engagement approach to these individuals are worth developing and evaluating.
1. Zulman DM, Pal Chee C, Wagner TH, et al. Multimorbidity and healthcare utilisation among high-cost patients in the US Veterans Affairs Health Care System. *BMJ Open* 2015;5(4):e007771. doi: 10.1136/bmjopen-2015-007771

2. Zulman DM, Pal Chee C, Ezeji-Okoye SC, et al. Effect of an Intensive Outpatient Program to Augment Primary Care for High-Need Veterans Affairs Patients: A Randomized Clinical Trial. *JAMA Internal Medicine* 2017;177(2):166-75. doi: 10.1001/jama.2016.8021

3. Bannon BL, Lucier M, Fagerlin A, et al. Evaluation of the intensive outpatient clinic: study protocol for a prospective study of high-cost, high-need patients in the University of Utah Health system. *BMJ Open* 2019;9(1):e024724. doi: 10.1136/bmjopen-2018-024724

4. Long P, Abrams M, Milstein A, et al. Effective Care for High-Need Patients. *Washington, DC* 2017

5. Figueroa JF, Jha AK. Approach for Achieving Effective Care for High-Need Patients. *JAMA Internal Medicine* 2018;178(6):845-46. doi: 10.1001/jamainternmed.2018.0823

6. Joynt KE, Gawande AA, Orav E, et al. Contribution of preventable acute care spending to total spending for high-cost medicare patients. *JAMA* 2013;309(24):2572-78. doi: 10.1001/jama.2013.7103

7. Guilcher SJT, Bronskill SE, Guan J, et al. Who Are the High-Cost Users? A Method for Person-Centred Attribution of Health Care Spending. *PLoS ONE* 2016;11(3):e0149179. doi: 10.1371/journal.pone.0149179

8. Cohen CJ, Meyers JL, Davis KL. Association between daily antiretroviral pill burden and treatment adherence, hospitalisation risk, and other healthcare utilisation and costs in a US medicaid population with HIV. *BMJ Open* 2013;3(8) doi: 10.1136/bmjopen-2013-003028

9. Pulvirenti J. Changes in HIV-related hospitalizations during the HAART era in an inner-city hospital. *The AIDS reader* 2007;17(8):390-90.

10. Venkat A, Shippert B, Hanneman D, et al. Emergency department utilization by HIV-positive adults in the HAART era. *International Journal of Emergency Medicine* 2008;1(4):287-96. doi: 10.1007/s12245-008-0066-7

11. Fielden SJ, Rusch ML, Yip B, et al. Nonadherence increases the risk of hospitalization among HIV-infected antiretroviral naive patients started on HAART. *Journal of the International Association of Physicians in AIDS Care (JIAPAC)* 2008;7(5):238-44.

12. Cohen CJ, Meyers JI, Davis KL. Association between daily antiretroviral pill burden and treatment adherence, hospitalisation risk, and other healthcare utilisation and costs in a US medicaid population with HIV. *BMJ Open* 2013;3(8) doi: 10.1136/bmjopen-2013-003028

13. Krentz H, Auld M, Gill M. The high cost of medical care for patients who present late (CD4< 200 cells/μL) with HIV infection. *HIV medicine* 2004;5(2):93-98.
15. Huntley AL, Thomas R, Mann M, et al. Is case management effective in reducing the risk of unplanned hospital admissions for older people? A systematic review and meta-analysis. *Family Practice* 2013;30(3):266-75. doi: 10.1093/fampra/cms081

16. McGutrick P, Ghavami-Kia B, Tinago W, et al. The HIV Care Cascade and sub-analysis of those linked to but not retained in care: the experience from a tertiary HIV referral service in Dublin Ireland. *HIV Clinical Trials* 2017;18(3):93-99.

17. Kinahan J, Surah S, Keating S, et al. Effect of integrating HIV and addiction care for non-engaging HIV-infected opiate-dependent patients. *Irish Journal of Medical Science* (1971-) 2016;185(3):623-28.

18. Wolitski RJ, Kidder DP, Pals SL, et al. Randomized Trial of the Effects of Housing Assistance on the Health and Risk Behaviors of Homeless and Unstably Housed People Living with HIV. *AIDS and Behavior* 2010;14(3):493-503. doi: 10.1007/s10461-009-9643-x

19. Sadowski LS, Kee RA, VanderWeele TJ, et al. *JAMA* 2009;301(17):1771.

20. Buchanan D, Kee R, Sadowski LS, et al. The health impact of supportive housing for HIV-positive homeless patients: a randomized controlled trial. *American Journal of Public Health* 2009;99(S3):S675-S80.

21. Simoni JM, Pearson CR, Pantalone DW, et al. Efficacy of Interventions in Improving Highly Active Antiretroviral Therapy Adherence and HIV-1 RNA Viral Load: A Meta-Analytic Review of Randomized Controlled Trials. *Journal of acquired immune deficiency syndromes (1999)* 2006;43(1):S23-S35. doi: 10.1097/01.qai.0000248342.05438.52

22. Parsons JT, Golub SA, Rosof E, et al. Motivational Interviewing and Cognitive-Behavioral Intervention to Improve HIV Medication Adherence Among Hazardous Drinkers: A Randomized Controlled Trial. *Journal of acquired immune deficiency syndromes (1999)* 2007;46(4):443-50.

23. Horberg MA, Silverberg MJ, Hurley LB, et al. Effects of Depression and Selective Serotonin Reuptake Inhibitor Use on Adherence to Highly Active Antiretroviral Therapy and on Clinical Outcomes in HIV-Infected Patients. *JAIDS Journal of Acquired Immune Deficiency Syndromes* 2008;47(3):384-90. doi: 10.1097/QAI.0b013e318160d53e

24. Palepu A, Horton NJ, Tibbetts N, et al. Uptake and adherence to highly active antiretroviral therapy among HIV-infected people with alcohol and other substance use problems: the impact of substance abuse treatment. *Addiction* 2004;99(3):361-68. doi: 10.1111/j.1360-0443.2003.00670.x

25. Charania MR, Marshall KJ, Lyles CM, et al. Identification of evidence-based interventions for promoting HIV medication adherence: findings from a systematic review of US-based studies, 1996–2011. *AIDS and Behavior* 2014;18(4):646-60.

26. Miller A, Cunningham M, Ali N. Bending the cost curve and improving quality of care in America's poorest city. *Population health management* 2013;16(S1):S-17-S-19.

27. Schamess A, Foraker R, Kretovics M, et al. Reduced emergency room and hospital utilization in persons with multiple chronic conditions and disability receiving home-based primary care. *Disability and Health Journal* 2017;10(2):326-33. doi: https://doi.org/10.1016/j.dhjo.2016.10.004

28. Cohen E, Lacombe-Duncan A, Spalding K, et al. Integrated complex care coordination for children with medical complexity: A mixed-methods evaluation of tertiary care-
community collaboration. *BMC Health Services Research* 2012;12(1):366. doi: 10.1186/1472-6963-12-366

29. Durfee J, Johnson T, Batal H, et al. The impact of tailored intervention services on charges and mortality for adult super-utilizers. *Healthcare* 2018;6(4):253-58. doi: https://doi.org/10.1016/j.hjdsi.2017.08.004

30. George M, Manuel JJ, Gandy-Guedes ME, et al. “Sometimes What They Think is Helpful is Not Really Helpful”: Understanding Engagement in the Program of Assertive Community Treatment (PACT). *Community Mental Health Journal* 2016;52(8):882-90. doi: 10.1007/s10597-015-9934-9

The authors of the study report no conflicts of interest. This study was unfunded. This information has been presented in part at the Irish Society for Infectious Diseases annual meeting, May 2016.
Figure 1: Number of individuals categorised by number of bed days used by each individual in study period.
Figure 2: Total number of bed days accrued by individuals in each bed-day category.
Figure 3: Potentially preventable admissions analysed by points of potential intervention