Adequate ambulatory care is the cornerstone of prevention of HIV disease progression and its complications

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ABSTRACT

Lack of access to outpatient services and medications results in preventable hospitalizations and contributes to rising healthcare costs. We report four recent cases of HIV-positive patients, hospitalized after a minimum of four months without ambulatory care (including *Pneumocystis jiroveci* pneumonia after 2 years out of care, CNS Toxoplasmosis after >1 year, Influenza A w/o vaccination after 4 months, and Cryptococcal meningitis after 1 year). Stated perceptions of barriers to access are presented in this poster. In summary, patients on admission had a mean absolute CD4+ count of 84 cells/mm^3 and mean HIV viral load of 175,000 copies/mL. The average cost of these 4 patients was $6600 per day. 3 of the 4 cases had multiple admissions. The PJP case was admitted once, for 16 days. In contrast, estimated costs for ambulatory care in 2012 were approximately $24,000/patient: outpatient visits every three months comprised $380, labs $3800, and anti-retrovirals/prophylaxis medicines $20,000. Patient-reported barriers to ambulatory care included lack of insurance, ineligibility for private insurance or outpatient assistance programs, missed outpatient follow-up due to embarrassment of HIV diagnosis. Additional factors included disinterest in care and reports of feeling healthy.

METHODS

Vignettes

As part of standard care, patients lacking primary care are interviewed about barriers to care, especially those with multiple admissions. HIV+ patients admitted to the UCSD Medical Center in Hillcrest during Dec 2012 - Jan 2013 with AIDS-defining illnesses and lacking a primary care provider were interviewed. The attending selected cases that represented severe results of lack of outpatient care. Patients were interviewed during their hospitalizations with the following exceptions; one patient was contacted by telephone for additional information after discharge and one patient provided supplemental information at his first ambulatory care visit that was later extracted from the progress note. To determine barriers to care, an open-ended interview style without a pre-designated question set was employed. To determine total admitted days, pertinent lab results, and hospitalization costs, patient medical records were data-mined according to an approved IRB (UCSD IRB Approval 071931; Owen Clinic Master protocol; Retrospective Use of Existing Clinic Data; Renewed 7/26/12; Expires 7/26/14).

Costs

Annual outpatient care cost was estimated by summation of reported cash prices for services, medications, and labs. Cash prices were provided by UCSD and LabCorp. Inpatient costs were calculated from actual hospital bills for the selected patients. Bills from at least one hospitalization per patient were used. When bills were not available, costs were extrapolated for all hospitalizations taking into account bed location (ICU vs IMU vs Med/Surg) and one-time major procedures. The cost of an ICU bed is $6672, an IMU bed is $5582, and a semi-private Med/Surg room is $2017 per day.

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VIGNETTES & RESULTS

Case 1: The Self-Employed Interior Designer

Off ARVs: 4 months
Complications: Oral candidiasis
Influenza A
Peri-rectal abscess
Hospitalizations: Twice (9 days; extrapolated cost $48,090)
Barriers to care:

1. **Insurance Denials**
2. **Not enough time/energy to fill out paperwork**

JG is a 41 yo Mexican HIV+ male off of ARVs for 4 months due to lack of insurance, also with chronic Hepatitis B, and anal dysplasia (HSIL) who presented with peri-anal tenderness, fever, night sweats and productive cough for 5 days. He was admitted with peri-rectal abscess, Influenza A, and oral candidiasis. He had been laid off in Sept 2010 & retained insurance for a month but uninsured since. He did not qualify for ADAP or Ryan White funding and for several months worked on an LIHP application, finally learning that he was denied because he "had too much income" from a single project he completed at his design firm. Much of that income went directly to overhead business costs, but this did not affect the decision. Thus, he remained without any medical care. His last labs before stopping ARVs showed a CD4+ count of 153 cells/mm^3 (averaging 318 cells/mm^3 during care), with a VL of 696 copies/mL. He noted, "When I decided to go to the ED, I didn't have any other options." He is uncertain how he will afford his hospital bills and states, "I may lose my house, and I don't know where I'm going to go. I may be homeless and that may make me worry about my survival, not my health." At admission, his CD4+ count was slightly elevated to 270 cells/mm^3 with VL increased to 76,253 copies/mL. With quicker attention to his perianal infection, we believe that abscess would not have progressed to needing admission. We manage many mild peri-rectal abscesses as outpatients.

Case 2: The Embarrassed Mother

Off ARVs: ARV naïve
Complications: *Toxoplasma* encephalitis
Right-sided paralysis
Steroid-induced hyperglycemia
Hospitalizations: Four admits
(30 days; extrapolated cost $248,854)
Barriers to care:

1. **Does not want people to know she has HIV**
2. **Felt healthy and did not apply for other insurance**
3. **Now feeling unwell and cannot work nor provide money for care**
4. **Could not concentrate to complete needed insurance paperwork. (Social work tried to help her and she did not follow-up.)**

JLG is a 36 yo HIV+ AA female with 4 recent hospitalizations from Oct 2012 to Jan 2013. She stopped working several years ago and lost her insurance but did not apply for private insurance because she felt healthy. In early 2012, she developed abdominal pain and was diagnosed with HIV at a community hospital. She was reluctant to seek outpatient services as she feared others finding out about her diagnosis. Several months later she was admitted to UCSD from jail, to which she had turned herself in to "sober up," for CNS toxoplasmosis and its complications. She has required 3 subsequent hospitalizations to date. Her boyfriend is still unaware of her HIV diagnosis and she is still without insurance and has not established care at a clinic. She remains ARV naïve with last CD4+ count 12 cells/mm^3 and VL 507,911 copies/mL as of Oct 2012. Each readmission was for recurrent cerebral edema after not being able to fill Decadron prescribed at prior discharge: 30 days of 4 mg/day=$11.10.

Case 3: The Stubborn Professor

Off Anti-Retrovirals (ARVs): 24 months
Complication: *Pneumocystis jiroveci (PJP)* pneumonia
Hospitalizations: One admit
(16 days; actual cost $92,973)
Barriers to care:

1. **Felt healthy**
2. **Let insurance lapse**
3. **Pre-existing condition made him ineligible for work insurance**
4. **Cost of private insurance**

GR is a 59 yo HIV+ white male who presented with 3 weeks of progressive dyspnea, found to have diffuse ground-glass opacities on CXR and hypoxia, and was admitted for treatment of PJP pneumonia. He lacked insurance for 2 years after allowing his private plan lapse. He felt "10-feet tall" and believed a healthy lifestyle would keep him well. He complained of overtreatment at another facility, as they were "making the treatment a focal part of my life. I felt I wasn't fitting into the system, and I was so stable (healthy)." He wished the other system had compromised more to fit his needs. He denied any side effects from his ARVs that would have contributed to his decision to discontinue their use. At the time of his insurance lapse 2 years ago, patient stated he had been on anti-retroviral treatment for 8 years with a CD4+ count of 500 cells/mm^3. After 2 years off ARVs, his CD4+ count dropped to 38 cells/mm^3. This case was preventable. Risk of PJP is near nil with trim/sulfa prophylaxis.

Case 4: The Homeless Christian

Off ARVs: 12 months
Complications: Oral candidiasis
Cryptococcal meningitis
Probable cryptococcal pneumonia
Hospitalizations: Three admits
(21 days, extrapolated cost $145,215)
Barriers to care:

1. **Medication inconvenience**
2. **Medication side effects**

KE is a 60 yo AA HIV+ male who discontinued his ARVs for 12 months because the pill was "too big," and upon requesting a change, the new regimen contained "5-6 pills, which were too many." He reported side effects from ARVs, notably nausea and stomach pain. No lab data is available prior to stopping ARVs. KE relocated to San Diego and remained without care for 12 months, finally establishing care at the UCSD Owen clinic for treatment of oral candidiasis. (CD4+ count 17 cells/mm^3). Further studies revealed a diagnosis of cryptococcal meningitis & probable pneumonia. Dissatisfied with numerous blood draws & medications, he left the hospital against medical advice but developed pain & swelling of his leg within two nights of sleeping on the street. He returned for treatment of a new deep vein thrombosis, and in spite of this remained upset regarding the treatment for his meningitis & required ongoing encouragement from his friend, pastor & staff to remain hospitalized to undergo the two weeks of initial therapy. We believe the multiple hours a day spent with the medical student and his pastor led to increased trust in the healthcare system and his not leaving AMA again. At time of discharge, he restarted ARVs and was working with Social Work to arrange ADAP, Medi-Cal and housing.

Estimated annual cost of outpatient HIV services is $24,000

	Price per test ($)	Cost per year ($)
Limited Physical	95	**380**
Prophylactic Medications/ARVs		**20,000**
Labs		
RPR	137	548
Hep C antibody	25.45	25.45
Serum creatinine	15	60
CBC	60	240
Urinalysis	77	77
CMP	273	1092
Lipid	239	478
Annual Pap	37.5	37.5
CD4/CD8 Panel	102	408
HIV Ultra PCR (Viral Load)	208	832
Lab subtotal		**3,798**
Total		**24,178**

CONCLUSIONS

These case vignettes demonstrate HIV disease progression and related complications after as few as four months off ARVs and no access to outpatient care. Inpatient costs for these disease complications are considerable; approaching $250,000 for one patient. With adequate outpatient healthcare for patients with HIV, annual costs can be can substantially reduced by minimizing or eliminating inpatient admissions. Avoiding hospitalizations in these patients would result in cost savings of 50-90%, with mean annual savings of 74%. However, we feel it is worth mentioning that chargemaster rates are almost never the real rates, and medical bills are complicated.[1] Managed care and contracted rates were not available, and differ from the chargemaster. Larger studies are still needed to address these cost differentials, although these numbers do provide estimates for stimulating further discussion. Obtaining adequate healthcare is not only a problem of cost, but, as we demonstrate, is also related to various psychosocial issues. Further exploration into ways we can adapt our healthcare system to address those barriers is warranted.

In California, HIV patients face additional challenges in accessing high-quality outpatient services. Medi-Cal (Calfornia Medicaid) patients have reported to us that they are reassigned to non-HIV specialists, and complained of difficulty accessing HIV specialists, which leads to inadequate HIV care and hospital re-admissions. It is well accepted that HIV-infected patients have longer life spans with better outcomes when cared for by specialists, and many states recommend this.[2] Implementation of the new Affordable Care Act (ACA) may improve access to outpatient services. However, the new ACA does not recognize, in practice, the survival benefit related to seeing an HIV expert. The new ACA should recognize this and allow for easier access to HIV experts, which would in turn lead to better patient care and decreased costs.

As a single day of hospitalization in our cases averages $6600 and has generally been related to progression of disease, focusing on the importance of outpatient care may provide solutions for preventing progression of disease and reducing costs.

1. Steven Brill. "Bitter Pill: How outrageous pricing and egregious profits are destroying our health care." *Time (Special Report),* 4 March 2013.
2. "HIV Specialist Credentialing." *Advancing Excellence in HIV care, American Academy of HIV medicine*, 18 Oct 2006, www.aahivm.org.