Barriers and Implications of Sub Optimal Retention to HIV Medical Care in One of Miami Dade's Largest HIV Out-patient Clinics

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Unique Challenges in Miami

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Pre-intervention year (2008-2009)</th>
<th>Intervention year (2009-2010)</th>
<th>% relative improvement*</th>
<th>GEE-based p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boston</td>
<td>.764 (N=873)</td>
<td>.779 (N=938)</td>
<td>2.0</td>
<td>0.109</td>
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<tr>
<td>SUNY</td>
<td>.640 (N=823)</td>
<td>.648 (N=895)</td>
<td>1.1</td>
<td>0.435</td>
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<tr>
<td>Hopkins</td>
<td>.614 (N=1558)</td>
<td>.621 (N=1735)</td>
<td>1.2</td>
<td>0.359</td>
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<tr>
<td>Miami</td>
<td><strong>.656 (N=1411)</strong></td>
<td><strong>.645 (N=1588)</strong></td>
<td><strong>-1.7</strong></td>
<td><strong>0.233</strong></td>
</tr>
<tr>
<td>UAB</td>
<td>.750 (N=1066)</td>
<td>.756 (N=1220)</td>
<td>0.8</td>
<td>0.546</td>
</tr>
<tr>
<td>Houston</td>
<td>.635 (N=2379)</td>
<td>.678 (N=2621)</td>
<td>6.8</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Unweighted average</td>
<td>.677</td>
<td>.689</td>
<td>1.7</td>
<td></td>
</tr>
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Results showed that whereas the mean proportion of kept visits (the number of completed visits/number of total scheduled visits) was 0.689 in all five clinics, in Miami the mean proportion was 0.645 during the same time period. In addition the intervention did not impact the Miami population.
Aim

- Investigate the individual, provider & system level barriers reported by PLWHA who drop out of HIV medical care from the UM/JMMC Adult HIV Clinic in Miami-Dade County

Design/Analytic Plan

- Compare Regular, Irregular, and Non-Attenders
  - Aim is 200 in each group for a total n=600
- Qualitative and quantitative
Patient Characteristics

n = 237

Non-Attenders and Irregular Attenders were combined for quantitative analysis.
Patient Demographics

- Not Hispanic or Latino: 203 (86%)
- Hispanic or Latino: 34 (14%)
  - American Indian or Alaskan Native: 1 (0%)
  - Native Hawaiian or other Pacific Islander: 2 (1%)
- White: 35 (15%)
- Black or African-American: 196 (84%)
Qualitative Component

Qualitative

• Open-ended questions
  • Why patient did or did not keep appointments
  • What they like/dislike about the clinic
  • What they could change about the clinic

• Audio-taped responses and transcribed
• Responses Coded by Co-PI
• Preliminary analyses, n= 112
  • 50 irregular and non-attenders
  • 62 regular attenders
Why Missed Appointments?
(n=50, irregular/non-attenders)

30% (15/50) - Transportation Issues
28% (14/50) Dealing with another health issue
16% (8/50) Overslept/Too Tired
12% (6/50) Could not get off work
12% (6/50) Forgot or just didn’t want to go
10% (5/50) Didn’t know about appointment
10% (5/50) Had other caregiver responsibilities

Other (high on drugs, 1/50, 2%, incarcerated, 1/50, 2%).
Transportation is largest barrier

“Can‘t afford to catch a bus right now – I’m not receiving my benefits. And they take away my bus pass. I’m not working. So sometimes that, kinda like, stop me, you know from getting here. But I will always call and tell her to reschedule it. And make sure the next time the appointment I have enough here and back.” (1177).

“Sometimes the weather, sometimes transportation. Sometimes I take the bus down here, sometimes I take the MetroRail. So it it’s raining really, really badly, for me to walk to catch the bus, it’s going to be quite difficult because I don’t want to get wet. If I get wet, I get sick. If I get sick, I end up in the hospital. I don’t wan to do that.” (1702).
Barrier – Dealing with Other Health Issues

“Well I missed the one appointment because I was lifting weights, and my chest was hurting. And that’s the only reason I didn’t come. The day before, I couldn’t get around the way I wanted to.” (2597).

“Yeah I’ve been getting sick a lot. Shingles. So I didn’t make it. So I called and they rescheduled me for today.” (710).

“Just tired. Fatigue. The disease itself, you know. Not being up to it. Depressed, in one word.” (719).
What do they **NOT** like about Clinic at Jackson?  
(n=112, irregular, non-attenders, and attenders)

**42%** (47/112) said there was **nothing** that they did not like about the Jackson clinic.

**50%** (56/112) said it was the wait time.

(Irregular attender): “Well, how long it takes. It seems that there is no regard to the patient’s time and schedule. And how difficult it is to get..you have to go one place for medication, you go to another place..it just makes it more challenging.” (383).

(Regular attender): “The fact that it takes so long to register, so long to see the doctor, the whole day. It’s too time consuming. All day here. It’s an all-day ordeal.” (787).
What do they like about Clinic at Jackson? (n=112, irregular, non-attenders, and attenders)

58% (63/112) said what they liked was their HIV providers (doctors, physician assistants and nurses):

(Regular attender): “What I like about the clinic is that they’re very on top of the latest evidence-based practice and they know what they’re doing and they have experience. For example, Dr. Rodriguez, whose taking care of me, he’s been in the field for some many years that I feel this someone that is experienced in the field and experimenting with new drugs and new treatments.” (119).

(Irregular attender): “Because of my doctor, Dr. Jay. He’s like my big brother. He’s been my doctor for 20 years now. Everybody’s friendly. I’ve been coming here so long. I know everybody. “ (2437).
What do they like about Clinic at Jackson? 
(n=112, irregular, non-attenders, and attenders)

53% (59/112) said what they liked was that the staff at the clinic are open, honest, courteous, patient, respectful, accepting and supportive.

(Irregular attender): “I like that they come out with a smile and respect our feelings and when we talk to them they answer to the best of their ability. And they’re never late, always on time.” (224).

(Irregular attender): “They take care of me, I feel comfortable. I feel like I’m home. My needs are taken care of.” (674)
What do they like about Clinic at Jackson? (n=112, irregular, non-attenders, and attenders)

(Regular attender): “I like everything because they’re nice. Most places you go, people are like, stand off. But since I’ve been coming and since I’ve been a patient at Jackson, they seem the same to me. They don’t try to put you down, like my family.” (166).

(Regular attender): “Some of the people are really nice. They treat you like a person. They’re glad to see you. There a contact there. “Hey (patient’s name)!“ I know I built that over time. I’ve been coming here for over 10 years…They know me and I feel comfortable around them. I think that’s the best thing about Jackson. And the care is excellent too.” (638).
What could Jackson Clinic do to help people living with HIV to make all their appointments? (n=112, irregular, non-attenders, and attenders)

30% (34/112) said to reduce the waiting time and speed up process of checking in.

20% (22/112) said to change nothing.

16% (18/112) said to continue to remind patients about their appointments.

12% (13/112) said it is not the clinic, it is individuals who do not want anyone to know they have HIV, not ready to take care of themselves.

11% (12/112) said to provide transportation, pick up vans.
Secrets of Success

Why NO Missed Appointments?
(n=62, regular attenders)

77% (48/62) said they regularly attend because they recognize they need to come to clinic to continue living.

“Well number one – I don’t have a job to go to – this is my job, to stay alive. And I want to live the rest of my life out. I don’t want to die because of this disease I have. And it motivates me to come and keep up and then it keeps me healthy and up. You see I’m not laying down. I’m not sick, I’m okay. As long as I do what I’m told. It’s very important for me.” (035).
Secrets of Success
Why NO Missed Appointments?
(n=62, regular attenders)

11% (7/62) said that the clinic sends them reminders in the mail and they receive phone calls.

10% (6/62) keep a schedule in their calendar, on their phone, writes it down

8% (5/62) said it because the way their doctors treats them and that confidentiality is maintained

5% (3/62) say they want to live for their grandkids, supportive family

5% (3/62) schedule appointments on their day off of work.

3% (2/62) lost relative to HIV/AIDS and now vows to take care of themselves

3% (2/62) staying drug free
Quantitative Measures

Quantitative

- Health knowledge
- Self-reported health
- Social perception of HIV
- Medication adherence
- Social support

- Alcohol & drug use
- Barriers to attendance
- Physician trust
- Depressive symptoms
- Socioeconomic status
Have you ever received a diagnosis of AIDS from an HIV care provider?

- Yes: 89 (37%)
- No: 139 (59%)
- Don't know: 9 (4%)
AIDS Diagnosis

Regular Attenders were 1.95 times more likely to have been diagnosed with AIDS compared to Irregular/Non-Attenders ($\chi^2(1) = 5.79$, $p = .016$).
Undetectable Viral Load?

Have you ever been told that your viral load was undetectable?

- Yes: 175 (76%)
- No: 32 (14%)
- Does not recall: 23 (10%)
Undetectable Viral Load

Regular Attenders were 3.03 times more likely to be told they were undetectable compared to Irregular/Non-Attenders ($\chi^2(1) = 11.87, p = .003$).

% of all patients

% in each group
Lowest self-reported T-cell count were higher for Irregular/Non-Attenders compared to Regular Attenders (F(1,102.73)=4.68, p=.039).
Missed Medication

This did not differ between patient categories.
Drug Use Ever

This did not differ between patient categories for any drug.
Regular attenders were more likely to never had alcohol in the past 90 days ($\chi^2(5) = 12.43$, $p = 0.029$).
Time Incarcerated

This did not differ between patient categories.
Money for Food

In the past year, were you ever hungry but didn’t eat because you couldn’t afford enough food?

This did not differ between patient categories.
This did not differ between patient categories.
More regular attenders reported having language difficulty with their provider ($\chi^2(1) = 7.86, p = .005$).
Problem with Transportation

This did not differ between patient categories.
Summary

• Interim findings & currently in progress; 40% of the sample has been recruited
  • Non-attenders underrepresented; outreach workers currently targeting this group

• Barriers being identified in all patient groups
  • 1 out of 5 did not have enough money for food.
  • Approximately 60% have used some type of drug
  • Two-thirds have been incarcerated at some point
  • Approximately 30% reported transportation problems as a barrier to keeping appointment

• Individual health concerns motivate patients to overcome these barriers