Reasons for Lack of ART Usage Among Well-Engaged, ART-Eligible Clinic Patients

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HIV Engagement in Care Cascade

Gardner et. al, CID 2011
Background

• HIV appointment attendance does not equal antiretroviral therapy (ART) initiation for all patients
• In an era of tolerable and efficacious ART and new ART guidelines, we need to re-examine barriers to ART initiation
• Exploring the perspective of the patient and his/her provider is necessary
Study Objectives

To explore barriers to ART initiation from the perspectives of patients engaged in clinic care and eligible for ART and their primary care providers.

To identify factors promoting regular primary care attendance for these patients in the absence of ART.
Study Design

In-depth interviews by graduate-level medical anthropologists and sociologists

At least 3 months
Study Setting and Population

Two academic HIV clinics with different patient demographics
   - San Francisco General Hospital Ward 86
   - Columbia University Comprehensive HIV Program

Recruitment goal = 20 patient/provider pairs (10 pairs at each site)
Eligibility Criteria

Patients

- Met the Health Resources Services Administration definition of retention (2 visits at least 90 days apart in the past year)
- In clinic care for at least 6 months
- CD4 cell count under 500 in the past year

Providers

- Primary care provider for an eligible patient, meaning the provider who bears responsibility for prescribing ART
Interview Guide Line of Inquiry

**Patient**
- Experience with HIV, HIV care, and HIV provider
- HIV and ART knowledge
- Medication usage (ART and non-ART)
- Relationship with provider
- Motivations for clinic attendance

**Provider**
- ART Philosophy/Practice
- Discussion of Specific Patient and ART
Analysis Framework

Â Elements of dyadic analysis

- Phenomenological
- Assesses contrasts and overlaps between the pair of individual narratives
- Examines levels of awareness about what the other person thinks and feels

Eisikovits and Koren, Qualitative Health Research, 2012
# Characteristics of Study Sample

<table>
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<th></th>
<th>Patients (n=17)</th>
<th>Providers (n=13)</th>
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<tr>
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<tr>
<td><strong>Gender</strong></td>
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<td></td>
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<tr>
<td>M</td>
<td>15</td>
<td>5</td>
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<td>F</td>
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<td><strong>ART naïve</strong></td>
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<tr>
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<tr>
<td>&gt;15 years</td>
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Preliminary Findings

Concordance between provider & patient views

Reasons for lack of ART usage include

- Known barriers (e.g. homelessness, substance use) leading to desire for “stability”
- Complex narratives of suffering, lack of self-worth, and hopelessness
- Patient and provider belief systems
Preliminary Findings: Belief Systems

Patient belief systems
- Side effects/toxicities of ART
- Suspicion of institutions (e.g. medical establishment, government)
- Assessments of one’s health (physical, mental, emotional)

Provider belief systems
- When is ART medically indicated?
- What signifies readiness?
Preliminary Findings

What keeps patients coming to appointments?

- Desire to be in medical care and manage one’s HIV (e.g. lab monitoring)
- Positive relationships with provider
- Receipt of other medications, particularly opiate analgesics
- Availability of social services
HIV Care is More Than Just ART

They (antiretrovirals) just didn’t fit. I was homeless for a long time. And I had probably no self-worth or anything.

I trust her with my life. If I was at the point where I was out and couldn’t make a decision, then if L. said what to do, that’s what I’d do. That’s how I feel.

-47-year-old white MSM, CD4 417

In my mind, he’s a case where yes, by the numbers he should be on medicine. But he’s not for reasons that to me make a lot of sense. He’s engaged in care because he really desperately needs emotional support and I think that’s contributed to his life despite the fact he hasn’t been on ART. ART is not the end all be all of caring about a human being who has HIV. In his case, I care about him and hope he will go on ART but even if he didn’t I still care about him. I still affirm him when he comes to the clinic. It just hasn’t been his priority or my priority in his care.

-Female white nurse-practitioner with >15 years in HIV care
Shared Perception That Patient’s Health is Good

When I see that my numbers are – like my T-cells are like under 200 or 500, then I’ll consider it. Or my viral load is over 100,000 or something like that, then I’ll consider it. But if it’s only 900 and 6,000, I don’t think those are numbers to consider starting it.

She tells me that I don’t need it because my body’s handlin’ it.

-27-year-old black woman, CD4 903

So while she wants to be a mom, she’s having a hard time having this child for 16 hours a week. So that really is her biggest concern at this point, I think, in her life, and I think she already has as much as she can handle. And so that, coupled with her past non-adherence, and what I think are weak medical indications for treatment – I’m actually discouraging her from taking antiretrovirals. I think she’s got enough on her plate.

-Female white MD with >15 years in HIV care
This interview has made me think about how I talk about things with patients. I am more forceful with patients. No, that is not the right word. My way of interacting with patients when approaching treatment initiation is to bring a lot of empathy and to listen, to make the decision together. I am now making myself more clear – going through the same process, but then sitting back and saying clearly this is how I feel and what I recommend.

-White male NP with >15 years in HIV care
Preliminary Conclusions

• Patient and provider belief systems are at play in the clinical interaction
• Practical barriers may be present but they may not be the most important barriers
• Patients are actively managing their HIV but this management does not include ART
• Spectrum of willingness to take ART
Preliminary Implications

Â Assessing how patients perceive their health status and the meaning of ART initiation should be formalized as part of ongoing ART counseling

Â Providers need strategies to address particular patient beliefs, e.g. conspiracy theories

Â The clarity of provider messaging should be evaluated and sharpened if necessary
Acknowledgments

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