Retention in HIV Care
Interpretation, interventions, & identifying those in need of support.

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Some things to consider...
it’s not just about remembering appointments.

**Discrimination.**
In a study of HIV+ Latino MSM, those who reported being treated differently based on their sexual orientation were less likely to be retained in care.

Whol et al 2011

**HIV Status Disclosure & Support.**
Individuals who report never telling anybody about their HIV status have been shown to be twice as likely to be poorly retained.

Elopre et al 2015

**No shows have clinical significance.**
Poor retention in care and no shows are associated with increased mortality risk.

Mugavero et al 2014
Why does retention matter?
Why

Patients who are poorly-retained in care are:

• More likely to have detectable viremia.

• More likely to have prolonged viral burden.

• Less likely to maintain access to ART.

• At higher risk of death.

Crawford, Sanderson, Thornton 2013.
Rebolledo et al. 2011;
Horberg et al. 2013
Why

https://www.whitehouse.gov/administration/eop/onap/nhas

https://aidsinfo.nih.gov/guidelines

Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents
Individuals who are retained in care are less likely to transmit HIV to someone else, even when they are not on ART.

Improving retention among those most affected could help lessen health disparities because retention behaviors contribute to health disparities.

Racial disparities in viral suppression lessen when you account for no shows.

Zinski 2015
Skarbinksi et al 2015
Rosenberg et al. 2014
Marks et al. 2010
Challenges
Challenges

- Retention is complex, difficult to define, hard to measure.
  - Fluid vs Static
  - “Churn”

- Multiple definitions:
  - **Missed visits**
  - **Visit Constancy**: Time intervals with at least 1 visit.
  - **Gaps in care**: 6-month intervals that contain no appointments.
  - **Visit adherence**: Proportion of kept visits/scheduled visits
  - **HRSA/HAB measure**: “At least 1 medical visit in each 6 month period within a 24 month period (2 months apart).”

Gill & Krentz 2009
Rebeiro et al. 2013
Mugavero et al. 2012

Challenges

Limitations and considerations

– Churn, geographic mobility, transfer.
– Measures and endpoints.
– Data origin.
– Population captured: Difficult to measure people you can’t find.
– Comparison between studies/measures.
– Evolving treatment recommendations.

Mugavero et al. 2012
Crawford et al. 2013
Horberg et al. 2015
Medland et al. 2015
Who is affected?

Scope, impact, risk factors
Who

Scope & impact

• Meta-analysis of multiple different studies on retention found that only 69% of individuals included had 2 or more visits during 6-month intervals.

• NA-ACCORD: 25% of individuals who accessed care from 2000-2008 had one or more “out of care” episodes.

• Good news: improved trends over time across the nation.

Marks et al. 2010
Rebeiro et al. 2013, 2015
Poor engagement among new patients:

- A study of 581 newly diagnosed patients from 2004-2011 found that 63% had at least 1 gap in care.

- A study using the 1917 Clinic Cohort found that 60% of new patients missed a visit during the first year of care. These patients also had higher mortality risk.

Mugavero et al. 2009
Rana et al. 2015
Who

Geographic & regional differences

Just as distribution of disease differs geographically, rates of retention vary by region.

Chances of being poorly retained are higher for people living in the South and the West.

http://aidsvu.org/map/
Rebeiro et al. 2016
Who

Geographic & regional differences

Culture, risk factors, socioeconomics, political structures, and healthcare vary by region.
Who

Geographic & regional differences

http://aidsvu.org/map/
Considering geographic differences in retention is a critical component of evaluating and implementing interventions. A “one size fits all” approach will not be effective. When considering interventions, we need to ask whether efficacy has been shown in the South.

Good news: Many of the nations leading retention experts live and practice in the South!
Risk for poor retention is not equally distributed.

- Race (Black)
- Age (young)
- HIV Risk Factor & substance abuse (IVD and hetero)
- Neighborhoods
- Quality of life (pain)
Who

Stigma & Social Support

• From Birmingham, Alabama: 1917 Clinic found that patients who reported never disclosing their status to another person were twice as likely to be poorly retained in care.

• Poor retention in care was also independently associated with living alone.

• Smaller study linked increased internalized stigma to gaps in care.

• From Atlanta, Georgia: Patients who always attended appointments reported knowing someone else who was HIV+.

Elopre et al. 2015
Earnshaw et al. 2013
Rebolledo et al. 2011
Wohl et al. 2011
<table>
<thead>
<tr>
<th>Population Level</th>
<th>Collaborations between public health and academic research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Level</td>
<td>Clinic-based interventions</td>
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</table>
Tennessee Center for AIDS Research (TN CFAR)

Tennessee State Department of Health
Meharry Medical College
Vanderbilt University Medical Center

Continuum of Care Working Group
– Joined forces for analysis and interpretation of surveillance data
– Community engagement with ASOs
– Writing groups and joint submissions of abstracts to conferences
Rates of Retention in Care in Tennessee

Clinical Retention (based on CD4, VL)

Counties of TN
- <27%
- 27-43%
- 44-60%
- 61-72%
- >72%

Presentation: Rebeiro P. Vanderbilt HIV/AIDS Symposium 2015, Nov
Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention

NEW Linkage to, Retention in, and Re-engagement in HIV Care (LRC) Chapter

Background

LRC Best Practices Review Methods

LRC Best Practices Criteria

Complete List of LRC Best Practices

Stratified List of All LRC Best Practices, by Characteristic
Solutions

Enhanced Personal Contact

- Compared “enhanced contact” with the routine appointment reminders (standard of care).
- Population: Patients with a history of missed visits and new patients.
- Intervention lasted 12 months.

Gardner et al. 2014
Solutions

Enhanced Personal Contact

The Intervention:

– Face-to-face meeting to establish relationship
– Brief meetings at each HIV appointment
– Phone call halfway between scheduled appointments
– Reminder call 7 days before scheduled appointment
– Reminder call 2 days before scheduled appointment
– No show call within 24 hours of missed appointment

Gardner et al. 2014
Solutions

Enhanced Personal Contact

• **1st study:**
  – Increased visit constancy.
  – Increased visit adherence.

• **2nd study on higher risk patients:**
  – Highlighted challenges reaching high risk patients
  – Those who received adequate “dose” of intervention benefited.

• **Cost analysis:** Can be implemented at low cost and could result in financial benefits based on improved attendance.

Gardner et al. 2014; 2016
Shrestha et al. 2015
Solutions

Stay Connected

• Clinic-wide messaging campaign.
• Focused on health benefits of keeping appointments and staying in care.
  – Printed: posters, brochures
  – Verbal: consistent messages

Gardner et al. 2012
Solutions

- Improved attendance to future appointments.
- Especially effective among patients with detectable VL.
- Found to lower financial risk and improve revenue for the clinic.
- All materials available online.

Gardner et al. 2015
We adapted the Stay Connected posters and placed them in clinic exam rooms and other patient areas.
Patient-provider relationships

– Greater trust in physicians associated with better retention among newly-diagnosed patients.

Provider Constancy

– Provider constancy has been associated with improved retention among HIV+ IVD users.

Graham et al. 2015
Westergaard et al. 2013
Treatment guidelines and expert panels recommend monitoring retention in care and identifying patients at-risk.

How do we choose who to target in our world of limited clinical resources?
Solutions at the Comprehensive Care Clinic

CCC + Care and Prevention in the U.S. Project (CAPUS) Partnership

- Regular meetings between RN Case Manager and CAPUS DIS Worker.
- Direct referrals to CAPUS Program with ongoing follow-up.
- Face-to-face and designated contact person on both sides.
- Clear plan, including referral to CCC social worker when needed.
- So far, we have identified 76 patients as being lost to care.
- We have referred 60 of these to CAPUS in 18 months.

http://www.cdc.gov/hiv/prevention/demonstration/capus/
Solutions

Of all the patients we identified as “lost”:

- 35 (46%) are re-engaging at the CCC
- 21 (28%) are still lost
- 8 (11%) are in care somewhere else
- 6 (8%) are in jail and receiving care
- 4 (5%) have died
- 1 is declining care
- 1 is on the wait list for referral
Of the patients we identified as “lost”:

- Referred: 79%
- Not Referred

We got them back in:
- We got them back in 13%
- Came back in on their own 4%
- Died 2%
- Transferred care 1%
- Wait list 1%
- Not Referred
Solutions

Of the patients referred to CAPUS (n = 60)

- 22 are re-engaging at the CCC
- 21 are still lost
- 7 are in care somewhere else
- 6 are incarcerated
- 3 are deceased
- 1 is declining care

Returning to CCC: 36%
In care somewhere else: 12%
Incarcerated: 10%
Declining care: 5%
Deceased: 35%
Solutions at the Comprehensive Care Clinic

Screening for at-risk patients

Scoring based on 7 risk factors → Scores associated with virologic failure risk and no show risk.

- Missed clinic visits
- Poor adherence to medications
- Heavy ART exposure
- Prior history of virologic failure
- Substance abuse
- CD4 <100
- Unsuppressed VL during previous 12 months

Robbins et al. 2009
Woodward et al. 2015
### Screening for at-risk patients.

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Points</th>
</tr>
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<tbody>
<tr>
<td><strong>Poor medication adherence:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>Documented during prior 12 month.</td>
<td></td>
</tr>
<tr>
<td><strong>Poor clinic attendance:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>Two or more “no-shows” during prior 12 months.</td>
<td></td>
</tr>
<tr>
<td><strong>Substance abuse:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>Documented within prior 12 months.</td>
<td></td>
</tr>
<tr>
<td><strong>Low CD4 count:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>CD4 count &lt;100 copies/mm³.</td>
<td></td>
</tr>
<tr>
<td><strong>Heavy ART exposure:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>Prior exposure to NNRTI, NRTI, and PI classes.</td>
<td></td>
</tr>
<tr>
<td><strong>Prior treatment failure:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>With genotypic confirmation showing resistance to previous regimen.</td>
<td></td>
</tr>
<tr>
<td><strong>Unsuppressed viremia:</strong></td>
<td>1 point for yes, 0 for no</td>
</tr>
<tr>
<td>VL &gt;200 copies/mL.</td>
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**Total score:**
- 0-1 = Low Risk
- 2-3 = Medium Risk
- ≥4 = High Risk
Solutions

Routine screening for high risk patients

Pros:

– “Population triage”: Reduced a large panel to a more manageable group.
– Focused resources.
– Helped develop our CAPUS Partnership
– Correlated with appointment patterns: High Risk patients were almost 10 times more likely to no show or cancel.

Limitations:

– Results of Program Evaluation showed no improvement in retention for the high risk group compared to the “medium risk” group.
– Likely highlight challenges intervening with high risk populations (similar to other studies).
– No control group, needed more data, “extreme” target group
Resources on the web

CDC Compendium of effective interventions:
http://www.cdc.gov/hiv/prevention/research/compendium/

Stay Connected:
Thank you.

Questions?