AETC AIDS Education & Training Center Program Southeast

Improving Engagement in HIV Care

Who are the People Who Are Not My Patients Anymore?

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Disclosures

- The activity planners and speaker do not have any financial relationships with commercial entities to disclose.
- The speaker will not discuss any off-label use or investigational product during the program.

This slide set has been peer-reviewed to ensure that there are no conflicts of interest represented in the presentation.

Learning Objectives

After attending this educational session, participants will be able to:

1. Identify the period of time that patients most often "drop out" of HIV treatment and care.
2. Explain how engagement in HIV care supports antiretroviral (ARV) adherence and viral load suppression.
3. Outline the steps that assist healthcare teams review "no show" data.
4. Discuss two low cost, but high impact strategies that improve clinic "no show rates" and patient health outcomes.

Retention in Care

- **Least studied component** of the HIV care continuum
- **Critically important** for the individual and the community
- **Extremely cost-effective target** for engagement-in-care interventions and programs
- Enhanced retention activities **have potential** to be **cost-effective** and potentially **worth the investment**

Gardner, EM (2016). Improving Retention in Care: A cost-effective strategy to turn the tide on HIV and AIDS in the United States, *IDSA, 62(15 January), 230-232.* Shah, M et al. (2016). The epidemiologic and economic impact of improving HIV testing, linkage, and retention in care in the United States, *Clin Infect Dis, 62, 220-9*

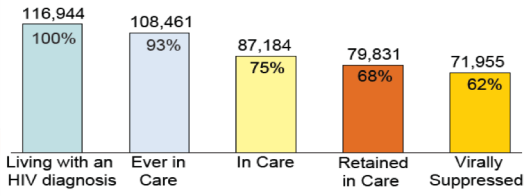
HIV AIDS Bureau (HAB)

Retention In Care is measured by:

Documented care ≥2 times,
≥3 months apart

Florida's 2017 HIV Care Continuum

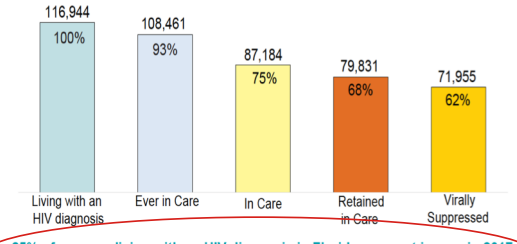
The HIV Care Continuum reflects the series of steps a person living with an HIV diagnosis (PLWH) takes from initial diagnosis to being retained in care and achieving a very low level of HIV in the body (viral suppression). A PLWH with a suppressed viral load is highly unlikely to transmit the virus to others.



In Care: Documented care ≥1 time in 2017. **Retained in Care:** Documented care ≥2 times, ≥3 months apart in 2017. **Virally Suppressed:** Viral load <200 copies/mL

Resource Accessed on 3.19.2019 www.floridaaids.org

Florida's 2017 HIV Care Continuum The HIV Care Continuum reflects the series of steps a person living with an HIV diagnosis (PLWH) takes from initial diagnosis to being retained in care and achieving a very low level of HIV in the body (viral suppression). A PLWH with a suppressed viral load is highly unlikely[1] to transmit the virus to others.



25% of persons living with an HIV diagnosis in Florida were not in care in 2017.

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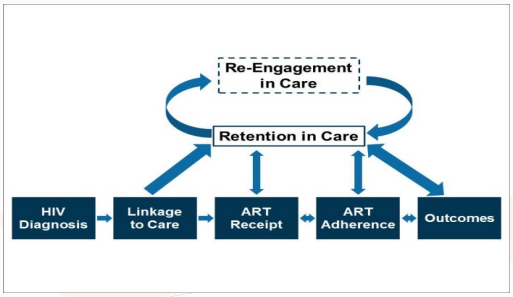
Resource Accessed on 3.19.2019 at www.floridaaids.org

The HIV Care Continuum is Not Linear



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Reference: https://s.yimg.com/fz/api/res/1.2/9fD3yhtf7x0Ky3vanG70xw--/YXBwaWQ9c3ljaGRkO2ZpbiT1TO3E9OTU7dcd3MDA-/http://img.medscape.com/article/767/261/767261-fig2.jpg

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Poor Retention = Poor Patient Outcomes

Patients who are not retained in HIV care have:

- decreased likelihood of receiving antiretroviral therapy
- higher rates of antiretroviral therapy failure
- immune system damage
- increased risk behaviors promoting HIV transmission
- more emergency department visits
- increased rates of hospitalization
- decreased survival

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Turn to Your Neighbor on your Right

Take 1 minute to list together as many unique reasons as you can think of that might prevent a patient living with HIV from showing up at their medical appointment.
Keep track of the number.

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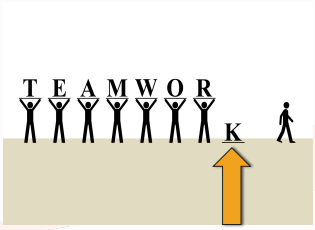
PATIENT ENGAGEMENT



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Barriers to Engagement

Barriers to Care among Participants in a Public Health HIV Care Relinkage Program

Barriers to HIV Care (N=247)	N (%)
No insurance	124 (50)
Forget appointments	83 (34)
Trouble getting appointments	79 (32)
Costs not covered by insurance are too high	75 (30)
No transportation	70 (28)
At least one healthcare organization and delivery barrier	**184 (74)**
Homelessness	59 (24)
Using drugs	56 (23)
Don't need a doctor	48 (19)

*69% screened positive for depression, 54% reported substance use

Healthcare organization & delivery barriers are the most common "important" barriers

Dombrowski JC, *AIDS Patient Care STDS.* 2015;29(5): 279-287.

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Barriers to Engagement

Patient-Level

- Forgets appointment
- Competing priorities
- Substance use
- Mental health diagnosis
- Homeless
- Caregiver
- Work
- Incarcerated

Systems-Level

- Clinic hours
- Lack of childcare
- No transportation
- Challenging call system for making appointments
- Lack of cultural humility
- Poor customer service
- Confidentiality concerns

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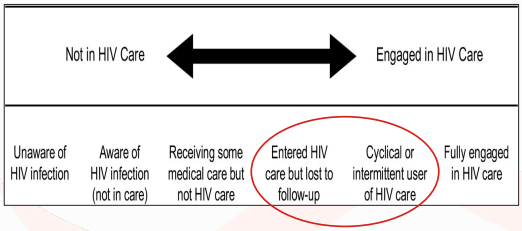
Health Resources and Services Administration (HRSA) continuum of HIV care, describing the spectrum of engagement in HIV care.



Edward M. Gardner et al. Clin Infect Dis. 2011;52:793-800

Clinical Infectious Diseases

Engagement in Care

- Engagement in HIV care involves a spectrum of activities, **not a singular event or visit**
- A patient's location on the continuum of HIV care **is not static**
- Movement away from engagement in care often occurs as a **result of unmet needs**

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Let's Do the Math…

- **PLWH are most vulnerable to being lost to care in the first 12 months of being diagnosed with HIV**
- A feeling of connection at the first appointment is key to some patients returning for their *next appointment*.

Few Empirical Data Exists on How to Improve Retention in Care

Challenges

1. **Complicated Issues**
2. **One size does not fit all**
3. **Complex social and behavioral issues**
4. **Labor intensive**
5. **Too expensive**

$1000/Patient Per Year Retention Intervention

Using this **theoretical intervention** for **20 years** would **cost $256 billion** and prevent

✓ 494,000 new HIV infections
✓ 195,000 deaths from AIDS

Gardner, EM (2016). Improving Retention in Care: A Cost-effective strategy to turn the tide on HIV and AIDS in the United States, *IDSA, 62(15 January), 230-232.*

HIV Transmission Prevention Outcomes

- One single prevented HIV infection in the United States **saves** the healthcare system lifetime **$300,000-$500,000.**
- 100,000 prevented HIV infections would **save $30-$50 billion**!

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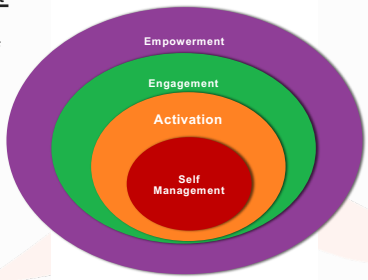
Gardner, EM (2016). Improving Retention in Care: A Cost-effective strategy to turn the tide on HIV and AIDS in the United States, *IDSA, 62(15 January), 230-232.*

1. Model for Patient Engagement

Four Levels of Patient Beliefs

1. Passive recipients of care
2. Learning: How does behavior connect to health?
3. Building: Has knowledge, but lacking in confidence/skills
4. Taking active role to maintain health, but **unsustainable during times of extreme stress and/or crisis**



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Hibbard, J. et al. (2007). Self-Management and Healthcare Utilization, *HSR,* 42(4), 1443-1463 accessed at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1955271/pdf/hesr0042-1443.pdf

PAM® Tool can be accessed at http://www.insigniahealth.com/products/pam-survey

CASE STUDY
Clinical Presentation

- 44-year-old female born in Haiti
- Has a 5-year-old son
- Lives in Port St. Lucie
- Acute dental visit
- Chief Complaint: Severe burn to roof of mouth after drinking very hot tea

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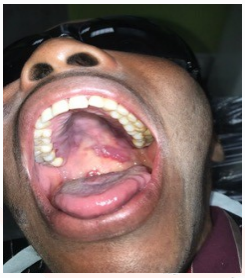
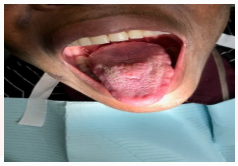
Case Discussion

- What is going on for this patient?
- What did the dentist see after doing a oral examination?

Oral Examination Findings



- Lesions?
- What should the dentist do?



Case Discussion

Epilogue

- ✓ HIV test in the dental chair
- ✓ Result: HIV-positive
- ✓ Originally diagnosed with HIV in 2012
- ✓ Stopped taking antiretrovirals after the birth of her baby in 2013
- ✓ What is this patient's diagnosis?

Late Stage Identification of HIV Infection

AIDS: Defining Signs & Symptoms

- CD4 cell count less than 200 cells/mm3
- High Viral Load
- Opportunistic infections (weak immune system)

No Show Visits: Strong Predictor of Mortality

Dr. Michael Mugavero
University of Alabama
1917 Clinic

Clinical Infectious Diseases, Volume 48, Issue 2, 15 January 2009, Pages 248–256, https://doi.org/10.1086/595705

"Patients who missed visits within the first year after initiating outpatient treatment for HIV infection had more than twice the rate of long-term mortality, compared with those patients who attended all scheduled appointments."

3. Evidence-Based Care
AIDS CARE Study 2014

Key Finding

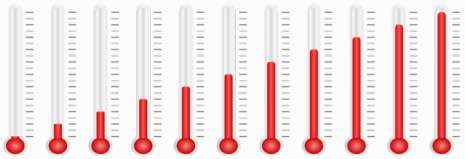
Contact with providers improved engagement in care

Munene, E. & Ekman, B. (2015). *AIDS Care*, 27(3):378-86. E pub 2014, Oct 8.
Crawford et al (2014). *J. Int Assoc Provid AIDS Care*, May/June: 13(3): 242-9.

2. Set the Goal: Patient Engagement

"PLWH are more than their circumstances."

Goal: We want to retain and engage 85% of our patients in HIV care by January 1, 2020.



YOU CAN'T IMPROVE THAT WHAT YOU CANNOT MEASURE

Creating a Culture of Ongoing Learning and Quality Improvement

- Create a culture of safety and trust in learning
- Create a culturally conscious and responsive service environment that focuses on partnering with patients

Creating A Retention in Care *QI Playbook*

Playlist	Due Date	Action
First Steps	4/1/2019	
Clinic "No Show" Data	5/1/2019	
Data Analysis	6/20/2019	
Identify QI Challenge #1	7/20/2019	

Drilling Down the Data

What data sets can we use to analyze those factors that enhance retention in care rates for our patients and those factors that are barriers to patient retention?

Example:
- No show rates

- ✓ Process
- ✓ Definition
- ✓ Framing is important

Steps to Data "Drill Down"

1. **Develop list of patients who do/do not not meet the defined criteria** of your measure (no show rates).
2. **Identify reasons** each patient does not meet the criteria.
3. **Tally** the reasons.
4. **Develop targeted plans** to address the most common or relevant issues.

Image accessed on 6.19.2018 at https://pixabay.com

Drill Down the Data to Better Understand Gaps in Care

Prioritizing data "drill down" by

- number of appointment "no shows"
- number of appointments attended over a 12-month period
- patients new to care
- patients re-engaging in care
- highest viral load

Retention/Engagement Activity

Instructions (15 minutes)

1. Review Patient Data using a lens of retention/engagement in HIV care.
2. **Drill down the data in a visual format** on your poster sheet that supports **identification of persons who are out of care**.
3. **Two questions to answer:**

- What is the top unmet need of your clinic patients who are **not engaged** in HIV Care?
- What group of individuals at your clinic are **most engaged** in HIV Care?

Mentimeter Question- White Sands

What is the **top unmet need** of your clinic patients who are **not engaged** in HIV Care?

a) Gender identify
b) Ethnicity
c) Food Security
d) Transportation
e) Depression
f) Drug misuse
g) Interpersonal violence
h) Age
i) Relationship status
j) Sexual partner preferences

Mentimeter Question- White Sands

What group of individuals at your clinic are most engaged in HIV Care?

a) Men
b) Women
c) Transgender persons
d) Youth
e) Married persons
f) Single persons
g) Persons with secure housing
h) Persons with transportation

Mentimeter Question- Community Care Clinic

What is the **top unmet need** of your clinic patients who are **not engaged** in HIV Care?

a) Gender identify
b) Ethnicity
c) Food Security
d) Transportation
e) Depression
f) Drug misuse
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h) Age
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People Go in and Out of Care

Strategies to Improve HIV Retention in Care

1. Patient reminders
2. Peer Advocacy partners
3. Whole clinic messaging
4. EMR retention reminders to providers
5. Data share agreements between agencies

Building Engagement

- Longer a person is out of care the harder it is to find them
- People show up when they are ready
- How early do we intervene to prevent clinic no shows?
- High cost/high effort versus low cost/low effort strategies?

Image accessed on 3.19.2019 at https://pixabay.com/images/download/medical-563427_1920.jpg?attachment&modal

Stay Connected Intervention

- *CDC HRSA funded*
- *N= 10,018*
- (2009-2010)
- *Stay Connected* staff training and signage
- Same message from all staff

Results

- 3% improvement
- Low cost, low effort

Gardner, L. I., Marks, G., Craw, J. A., Wilson, T. E., Drainoni, M. L., Moore, R. D., . . . Retention in Care Study Group. (2012). A low-effort, clinic-wide intervention improves attendance for HIV primary care. *Clinical Infectious Diseases, 55*, 1124-1134.

LaPHIE Linkage and Engagement

- Louisiana Public Health Intervention Exchange
- Special Project of National Significance (SPNS)
- Automated information exchange that generated alerts for HIV+ lab results and out-of-care information (no VL or CD4 on file)

- Hospital and community healthcare information exchange
- DIS workers responsible for generating active referrals to link and re-engage patients in care

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Accessed on 3.19.2019 at https://doi.org/10.1016/j.ijmedinf.2012.06.005

Additional Retention in Care Strategies

- Re-engage client to a different clinic system rather than return patients to the same system that failed to engage them the first time.

Hardest to Reach Patients

1. Walk in clinics
2. "High Needs" Outreach Workers to provide "Recapture Blitzes" and re-linkage/engagement outreach
3. Develop daily slots that are open to walk-in patients: for patients who do not like scheduled appointments (homeless, PrEP follow-up)
4. "Max Clinic" (Maximum Assistance) for patients with impoverished resources: Focus on harm reduction and whole person care.

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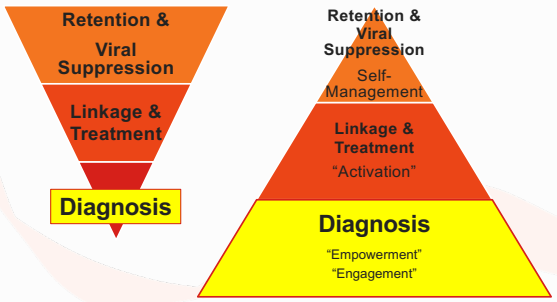
Reference: Dombrowski ( ) University of Washington & DOH Seattle & King County, ADH8_Sat1_Dombrowski.pdf Accessed on 3/20/2019

A Model for *Whole-Person* HIV Care



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Reference: D.Cestaro-Seifer (2019), MS, RN, NC-BC, Tallahassee NFAETC Symposium, 2/22/2019.

HIV Retention QI Project Activity

Instructions (15 minutes)

Create an intervention on a poster sheet that your team wants to use to improve retention for patients currently out of HIV care. The intervention should :

- Support meaningful use of clinic data
- Have a name
- Have a short description of the intervention: who, what, where, and when
- Have an evaluation method: What will you measure to determine success of the intervention?

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HIV Retention/Engagement Art Walk

Purpose

Walk to each group poster and write a sticky note about an aspect of the intervention that you you believe makes the QI Engagement Intervention powerful, interesting, engaging, cultural relevant, unique, creative etc.

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Turn to Your Neighbor on your Left

Take 1 minute to tell each other the **1 most important take-away that you learned in this presentation** that you will use in your clinic or practice.

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Question, Comments and "Aha Moments"

Speaker Contact Information

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