Linkage to and Retention in HIV Medical Care

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Outline of Presentation

- Why are linkage and retention in care important?
- Definitions
- Desired outcomes
- Documenting outcomes/CDC grantee requirements
- Example of a successful intervention
- Barriers and facilitators of care entry
- Tools and training
- Packaged interventions
- Research

Why are linkage and retention in care important?

- Early initiation of HIV treatment and long-term adherence leads to better health outcomes and reduces transmission of infection.
- Linkage to care shortly after HIV diagnosis provides opportunities for intervention to prevent transmission.
- Many persons living with HIV are not linked to care shortly after HIV diagnosis or do not stay in care.

Continuum of Engagement in Care

Continuum Engagement in Care

Not in care					Fully engaged
Unaware of HIV status (not tested or never received results)	Aware of HIV status (not referred to care; didn't keep referral)	May be receiving other medical care but not HIV care	Entered HIV primary medical care but dropped out (lost to follow-up)	In and out of HIV care or infrequent user	Fully engaged in HIV primary medical care

- The concept of "in care" encompasses relationships with the care system that may vary in their level of consistency and durability and that may change over time.
- The terms linkage to care, engagement/retention, and re-engagement in care and re-entry to care reflect the degrees of relationship with the care system.
- Each step requires different intervention activities.

Figure adapted from Cheever LW. Engaging HIV-infected patients in care: Their lives depend on it. Clin Infect Dis 2007; 44: 1500-1502.

Definitions

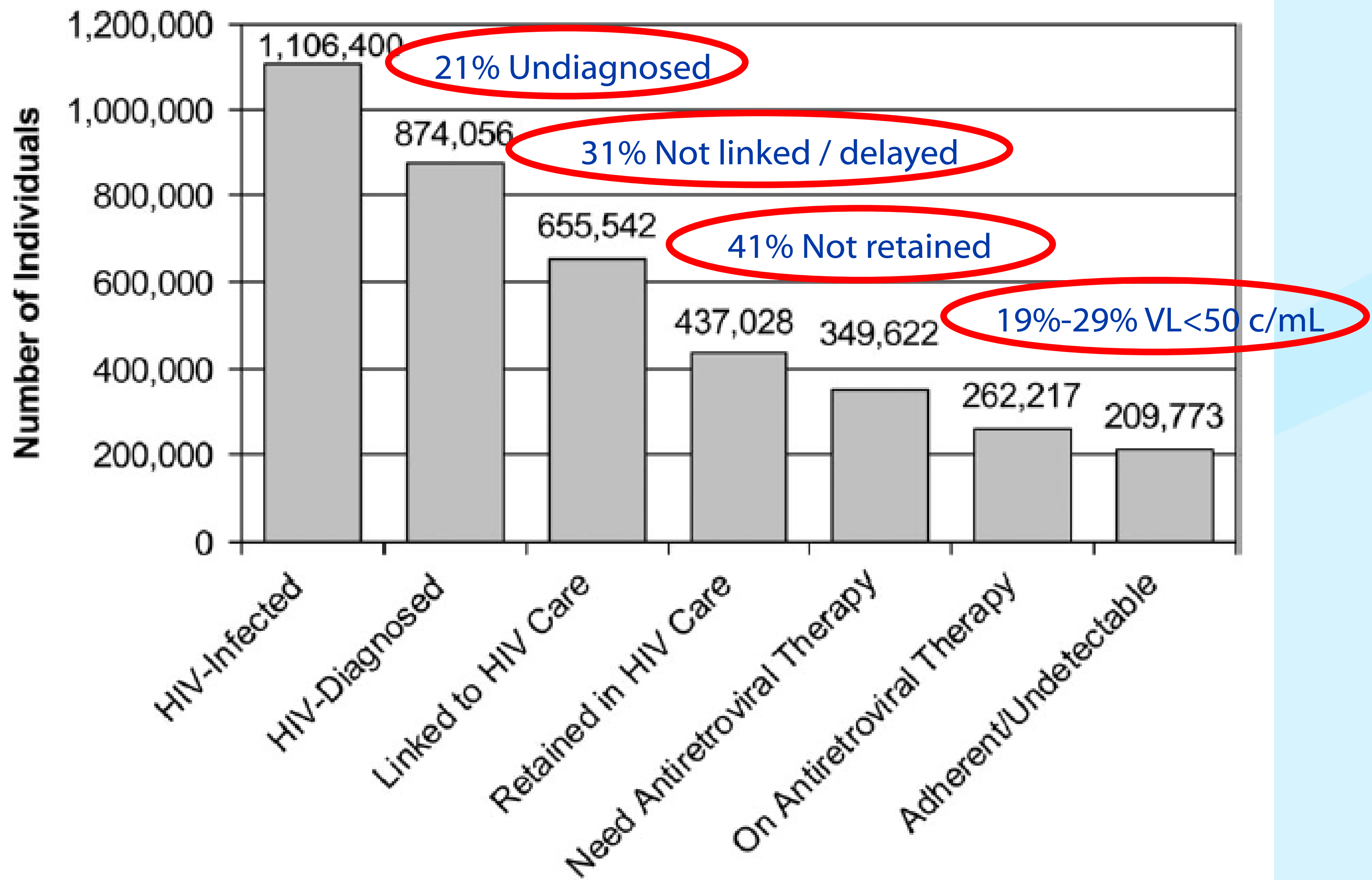
- **Linkage to care**
  - the process of assisting HIV-diagnosed persons to enter medical care (levels of assistance vary according to need).
- **Engagement or re-engagement and retention in care**
  - the process of helping HIV patients keep their scheduled clinic appointments.
- **Re-entry**
  - the process of re-connecting HIV patients to primary care after they have dropped out of care.

Definition of “Care”

- Patient has attended an initial HIV medical care visit with an HIV primary care provider (authorized to prescribe medication) following receipt of HIV diagnosis

Desired Outcomes of Processes to Promote Linkage, Engagement and Retention in Care

- **Improve health outcomes and prevent onward transmission by:**
  - Diagnosing infection
  - Linking HIV-positive persons to care
  - Retaining HIV-positive persons in care
  - Providing prevention counseling / intervention
  - Initiating antiretroviral treatment at the appropriate time
  - Promoting adherence to treatment
  - Reducing viral load



Gardner et al. Clin Infect Dis 2011;52; Marks et al. AIDS 2010;24

Documenting Linkage, Engagement, Retention, Re-Entry, Re-Engagement

- **Indicators in use may vary depending on**
  - the purpose of documentation (process or outcome monitoring?)
  - who is doing the monitoring (health department, CBO, clinic?)
  - available data
    - some data measure what matters more directly, or with less error
- **Need for standardization for national monitoring**

Documenting "Linked to Care"

- **Outcome of Interest:**
  - Patient has attended an initial HIV medical care visit with an HIV primary care provider following receipt of HIV diagnosis
- **Indicators may address whether persons testing HIV-positive**
  - Attended an initial care visit with an HIV primary care provider (authorized to prescribe medication), confirmed through check of medical records or self report
  - Received a CD4 or HIV viral load test(s) (confirmed through CD4/VL reports to surveillance

CDC Grantee Data Requirements* – Referral and Linkage to care

Was client referred to HIV medical care?

- ◯ Yes ⟶ If yes, did client attend the first appointment?
  - ◯ Yes ⟶ If yes, was the first appointment within 90 days of the HIV test?
    - ◯ Yes
    - ◯ No
    - ◯ Don't know
  - ◯ No
  - ◯ Don't know
- ◯ No ⟶ If no, why?
  - ◯ Client already in HIV medical care
  - ◯ Client declined HIV medical care

*These requirements will be in effect in January 2012.

Documenting "Engaged in Care"

- **Outcome of Interest:**
  - Patient has attended two or more HIV medical care visits with an HIV primary care provider in the 12 months following the initial care visit
- **Indicators may address whether persons testing HIV-positive**
  - attend a specific number of appointments with an HIV care provider (authorized to prescribe medication), e.g., at least two visits at least 3 months apart during the 12 months after diagnosis, confirmed through check of medical records or self-report
  - received at least 2 CD4 or HIV viral load tests at least 3 months apart during the 12 months after diagnosis, confirmed through CD4/VL reports to surveillance

Documenting "Retained in Care"

- **Outcome of interest:**
  - Patient has attended two or more HIV medical care visits with an HIV primary care provider in each 12-month period following the initial 12-month period
- **Indicators may address whether persons testing HIV-positive**
  - attend a specific number of appointments with an HIV care provider (authorized to prescribe medication), e.g., at least two visits at least 3 months apart during any 12-month period starting ≥12 months after diagnosis, confirmed through check of medical records or self report
  - receive at least 2 CD4 or HIV viral load tests at least 3 months apart during any 12-month period starting ≥12 months after diagnosis, confirmed through CD4/VL reports to surveillance

Documenting "Re-Entered Care"

- **Outcome of interest:**
  - Patient has attended an HIV medical care visit with an HIV primary care provider following a lapse of 12 or more months
- **Indicators may address whether persons testing HIV-positive**
  - attend an appointment with an HIV care provider (authorized to prescribe medication) after a period of at least 12 months without any HIV care visits, confirmed through check of medical records or self report
  - receive a CD4 or viral load test after a period of at least 12 months without a CD4 or viral load test, confirmed through CD4/VL reports to surveillance

Documenting "Re-Engaged in Care"

- **Outcome of interest:**
  - Patient has attended two or more HIV medical care visits with an HIV primary care provider in the 12 months following the re-entry visit
- **Indicators may address whether persons testing HIV-positive**
  - attend a specific number of appointments with an HIV care provider (authorized to prescribe medication), e.g., at least two visits at least 3 months apart in the 12 months following re-entry, confirmed through check of medical records or self report
  - receive two or more CD4 or viral load test at least three months apart after a period of at least 12 months in the 12 months following re-entry, confirmed through CD4/VL reports to surveillance

Example of a Successful Linkage To Care Intervention

- ARTAS
  Anti Retroviral Treatment Access Study
- ARTAS-1: Randomized Controlled Trial
- ARTAS-2: Real-world demonstration

ARTAS Brief Strength-Based Intervention

- **Recently HIV diagnosed**
- **Up to 5 sessions with linkage facilitator within 90 days of enrollment**
  - Identify client strengths/skills, assets/abilities
  - Foster empowerment and self-efficacy to overcome barriers
  - Individual goal setting
  - Motivate person to enter care (motivational interviewing)

ARTAS-1 Trial Results (N=273)

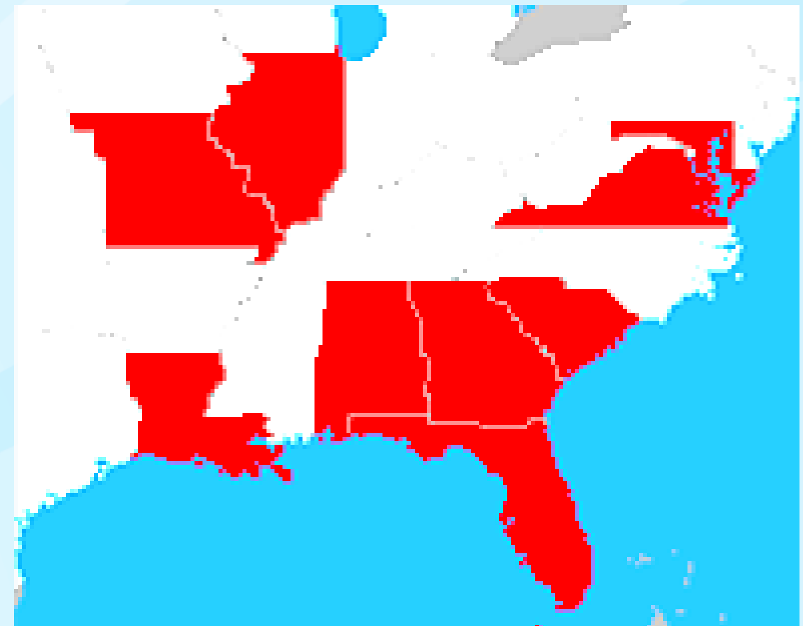
Percent Linked to Care

	Primary care visit within 6 months of enrollment	**Primary care visit in 2 consecutive 6-month periods (6+12)**	**Med record confirmed 6+12 months (N=224)**
SB* Intervention (n=137)	**78%**	**64%**	63%
Passive referral (n=136)	**60%**	**49%**	48%
p-value	0.0006	0.007	0.03

* SB = Strengths Based

ARTAS-2 Sites

- **10 project sites funded**
  - 5 state, local health departments
  - 5 CBO's
    - **Anniston, AL**
    - **Atlanta, GA**
    - **Baltimore, MD**
    - **Baton Rouge, LA**
    - **Chicago, IL**
    - **Columbia/Greenville, SC**
    - **Jacksonville, FL**
    - **Kansas City, MO**
    - **Miami, FL**
    - **Richmond, VA**



Summary of Findings: ARTAS-2

- **79%** (497/626) entered HIV medical care within the first 6 months.
  - **Comparable to the 78% linked in ARTAS-I trial arm**
- On average, the amount of time needed to link clients to care was relatively moderate:
  - Median # SB* sessions per client = 2 (mean, 2.3)
  - Total average time spent per client = 7.2 hours

*Strengths Based

Factors Associated with Entering HIV Care

- Findings from:
  - ARTAS-1 & -2; qualitative findings from site interviews
  - CDC-sponsored "Never in Care Study"
    - HIV-diagnosed persons never in care (ranging from 4 months to 24 post-diagnosis)
  - Project CONNECT (University of Alabama, Birmingham)
  - Other studies and best practices (e.g., Craw et al., Kendrick et al., Lubelchek et al., Molitar et al.)

Systems, Structural, and Organizational Factors Associated with Care Entry

- Rapid HIV testing (vs. traditional)
- HIV testing site is co-located with primary care site
- HIV counselor cross-trained as linkage facilitator
- Partnerships/processes established between testing sites and HIV care facilities
- Active assistance (e.g., identifying provider, making appt)
- Getting newly diagnosed "in the door" ASAP
- Follow-up contacts

Some Individual-Level Factors Associated with Care Entry

- Being employed
- Having health insurance
- Older age (26+ vs. 18-25 years)
- Sexual orientation (MSM more likely; or no difference)
- Not being a drug user (no crack, coke, meth, IDU)
- Stable housing
- Transportation

Individual's Stage of Readiness to Enter HIV Care

Pre-contemplation	"I am not thinking about HIV medical care at this time"
Contemplation	"I have thought about starting HIV medical care but I have not yet tried to find a doctor or clinic.
Preparation	"I have an appointment for HIV care with a doctor or clinic but have not been there yet"
Action	"I have already gone to a doctor or clinic for HIV care once"

Stage of Readiness to Enter HIV Care is Associated with Care Entry (ARTAS-1)

Stages of readiness to enter HIV care	% with care visits in 2 consecutive 6-month periods	
Action	67%	47/70
Preparation	62%	45/73
Contemplation	52%	39/75
Pre-contemplation	52%	23/55
	$P < .01$	

Assessing client readiness informs the client-centered approach

Self-Reported Barriers to Entering Care (ARTAS-2)

Frequently reported barriers*	Not entered HIV care (n = 60)	Entered care, missed ≥ 1 appt (n = 117)
Felt well or had no symptoms	70%	58%
Lacked transportation to the clinic	37%	39%
Not ready to start taking HIV meds	37%	33%
Takes too long to get appointment	20%	38%
No insurance/could not afford cost	33%	31%
Could not take time off of work	25%	33%

*Respondents could choose more than 1 barrier

Feeling Well is a Risk Factor for Not Entering Care (ARTAS-1)

	% with care visits in 2 consecutive 6-month periods	
Felt well		
– Yes	39% (29/74)	
– No	63% (125/199)	$P < .005$

Top 5 Most Frequently Reported Reasons* for Not Entering Care (Never in Care Study)

1. Lack of money/insurance	57%
2. Not wanting to think about HIV+ status	55%
3. Feeling good/healthy	54%
4. Feeling depressed	44%
5. Not wanting to disclose HIV+ status	43%

*Respondents could choose more than 1 reason

Top 2 Reasons* That Would Promote Entry into Care (Never in Care Study)

1. Having sufficient money/insurance	39%
2. Feeling sick	31%

*Responses not mutually exclusive

Never in Care Study also Found That….

- 77% of respondents said they were fairly-to-very likely to enter HIV care within the next 3 months.

    - But only 17% entered care within 3 months (determined by a CD4 or viral load lab result in surveillance database).

Good intentions don't always translate into action.

Findings point to importance of active assistance in helping people enter care (vs. passive referral).

CDC Training and Tools

- **ARTAS training and implementation manual**
  - Train-the-trainer at 9 agencies (Prevention Training Centers, Capacity Building Partners) http://www.cdc.gov/hiv/topics/cba/pdf/artas_implementation_manual.pdf
- **Training of HD directors of HIV Counseling, Testing, and Referral Programs and directors of Comprehensive Risk Counseling and Services**
  - Addresses making appropriate referrals (e.g., housing, mental health, substance abuse) and linkage to care

CDC Packaged Interventions

- **The CLEAR intervention for HIV+ persons**
  - Multi-component intervention that addresses importance of entering HIV medical care and skills needed to communicate with care providers
- **The START intervention for incarcerated persons**
  - Intervention sessions before and after release. For HIV-positive persons, emphasizes importance of connecting to medical care in the community upon release

CDC Research in Collaboration with HRSA and NIMH

- **With HRSA, a randomized controlled trial at 6 HIV clinics**
  - To identify HIV clinic-based strategies to help patients stay in care (e.g., enhanced contact, improvement of patients' skills (organizational, problem solving, and communication)
- **With NIMH, a clinic-wide implementation of a comprehensive PwP program at 6 HIV clinics**
  - Gives attention to retention in care, ART adherence, and sexual risk

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