

Delayers and Dropouts

C.H.A.I.N Study Contributions to
Understanding Unmet Need for
HIV Care

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The Problem

- Half of New York City PLWHAs either delay HIV testing, delay entry into medical care, or BOTH
- 25%-30% of NYC HIV diagnoses are persons with an advanced stage of infection, indicating delayed testing
- Among those who TEST promptly, 1 in 5 delay medical care more than 3 months after their HIV diagnosis

The Problem

Delayed presentation for treatment evaluation:

- Limits treatment options
- Affects clinical outcomes and quality of life
- Contributes to expanding epidemic

Research Questions

1. Who delays entry into medical care for HIV, and who remains outside of care?
2. What are the psychosocial and contextual barriers that contribute to delays in HIV care and “dropping out” of care?
3. What are the points of entry into medical care for those who delay seeking care for HIV?

Research Questions

4. What brings drop-outs back into care?
5. What policy or program interventions can be designed to reduce delays in HIV care?
6. What interventions can support continuity of care?

CHAIN Data Sources

- **Delayers Study**

HIV positives who delay 4+ months to med care

- Orig CHAIN Cohort (n=247 delayers)
- New CHAIN Cohort (n=174 delayers)

Quantitative and qualitative interview data

- demographics, health status, service need/use
- narrative descriptions: Why delay? Why enter?

Key informant interviews

- providers serving groups at risk for delay

Focus groups with clients

CHAIN Data Sources

- **Original Unconnected Study**

Aware, no medical care, no case mgmt
6+months

- 1995 (n=48 unconnected)
- 1999 (n=24 unconnected; 26 marginal)

- **Current Unconnected Study**

Aware, no medical care, no case mgmt
6+months

- 2003 (n=23 unconnected; 36 high risk)

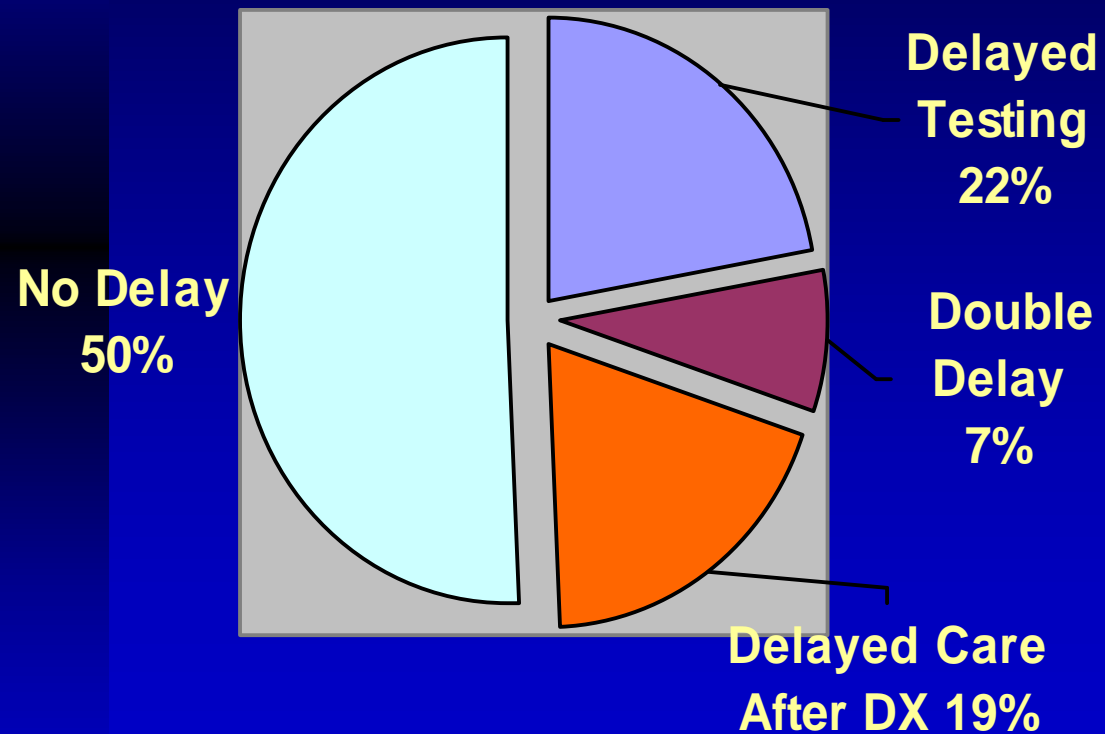
Who is a "delayer"

- **DELAYED TREATMENT:** More than 3 months between HIV result and first *evaluation* for treatment

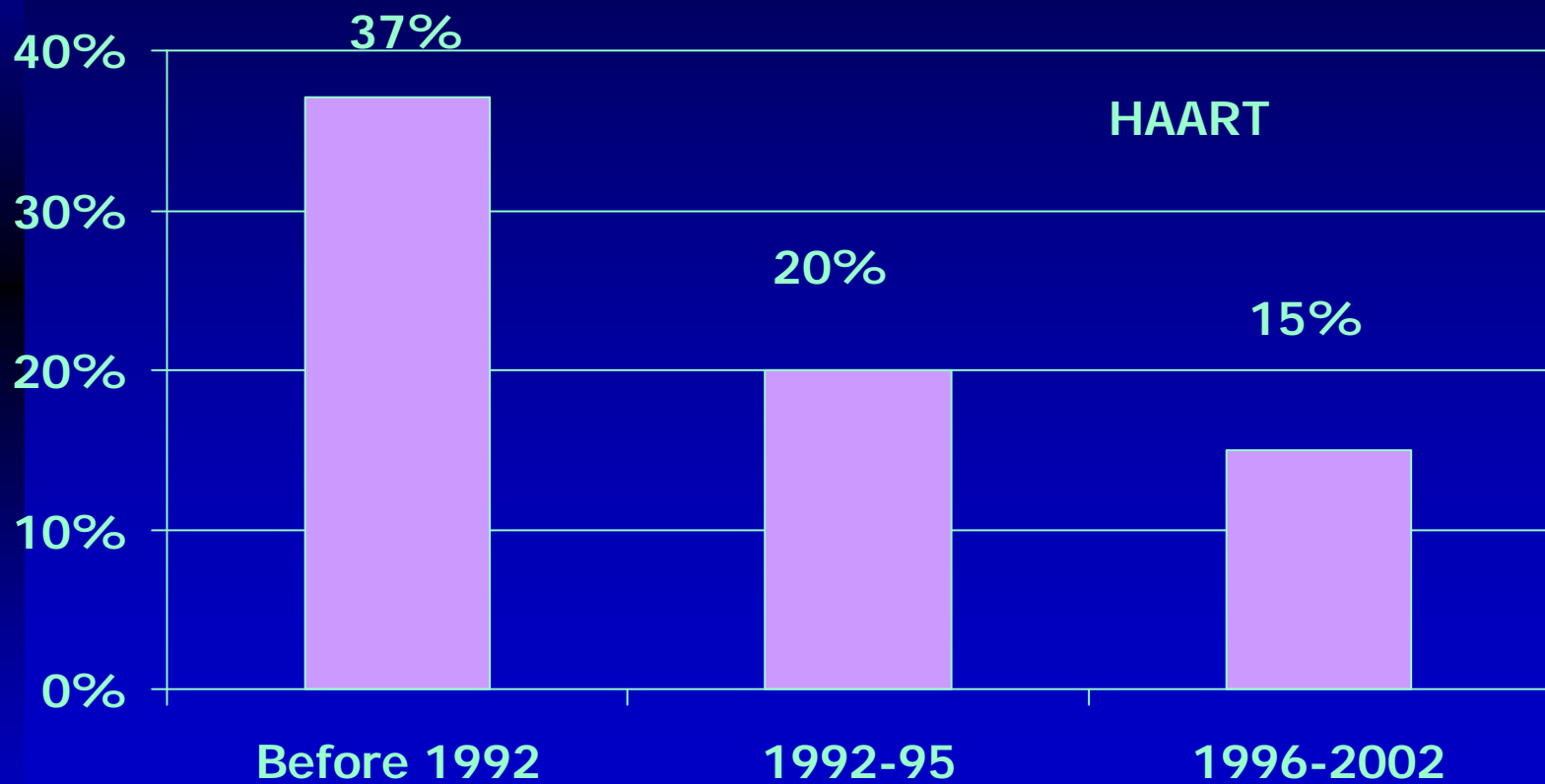
-- OR --

- **DELAYED TESTING:** HIV diagnosis at same time as presentation with
 - Opportunistic or AIDS-defining Infection -- OR -- <200 CD4

Estimated HALF of all NYC PLWH are Delayers

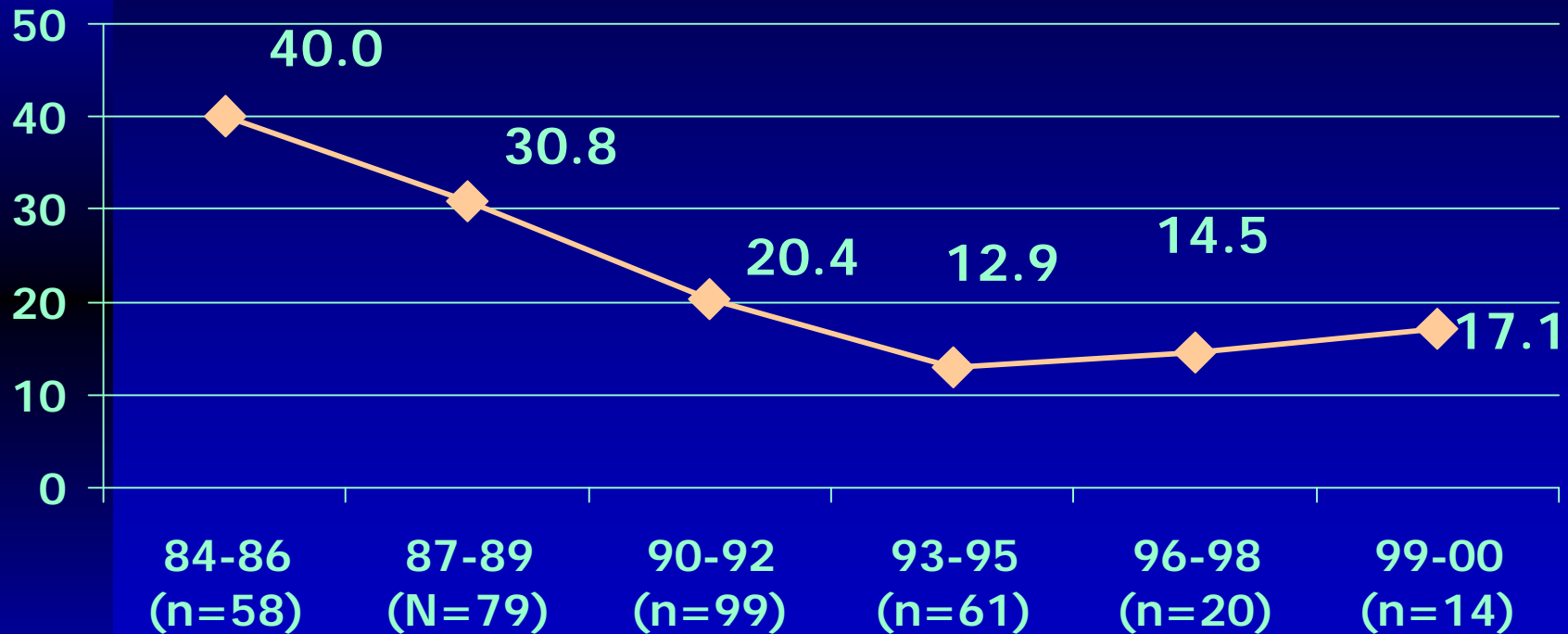


How many delay?



Delayed Entry to Care by Date of HIV Diagnosis

How long do they delay?



Average Months to Treatment for Delayers by Date of Diagnosis

Who is more likely to delay?

Delayers *do not* differ significantly in background characteristics

- Gender
- Race/ethnicity
- Place of birth
- Education

Delayers continue to differ by situation at time of diagnosis

- Not experiencing symptoms
- Active drug use
- Mental health difficulties
- Homeless/unstable housing
- Little social support
- Testing in corrections system

Emerging factors for delay among recent cohort (2002-03 CHAIN)

- Younger age at diagnosis (< 35 yrs)
- Newer immigrants
- No insurance at time of diagnosis
- Residential neighborhood (borough)
- Lack of active referral to services

Why do PLWHs delay?

Data sources:

- Delayers give reasons
- Focus groups with PLWHs
- Informant interviews with providers

Delayers describe their reasons for delay

<i>Delayers Interviewed n=</i>	<i>(157)</i>
In denial about HIV	33%
Was doing drugs	18%
I felt fine, wasn't sick	14%
I was in jail	13%
I was going to die anyway	9%

SOURCE: NEW CHAIN COHORT

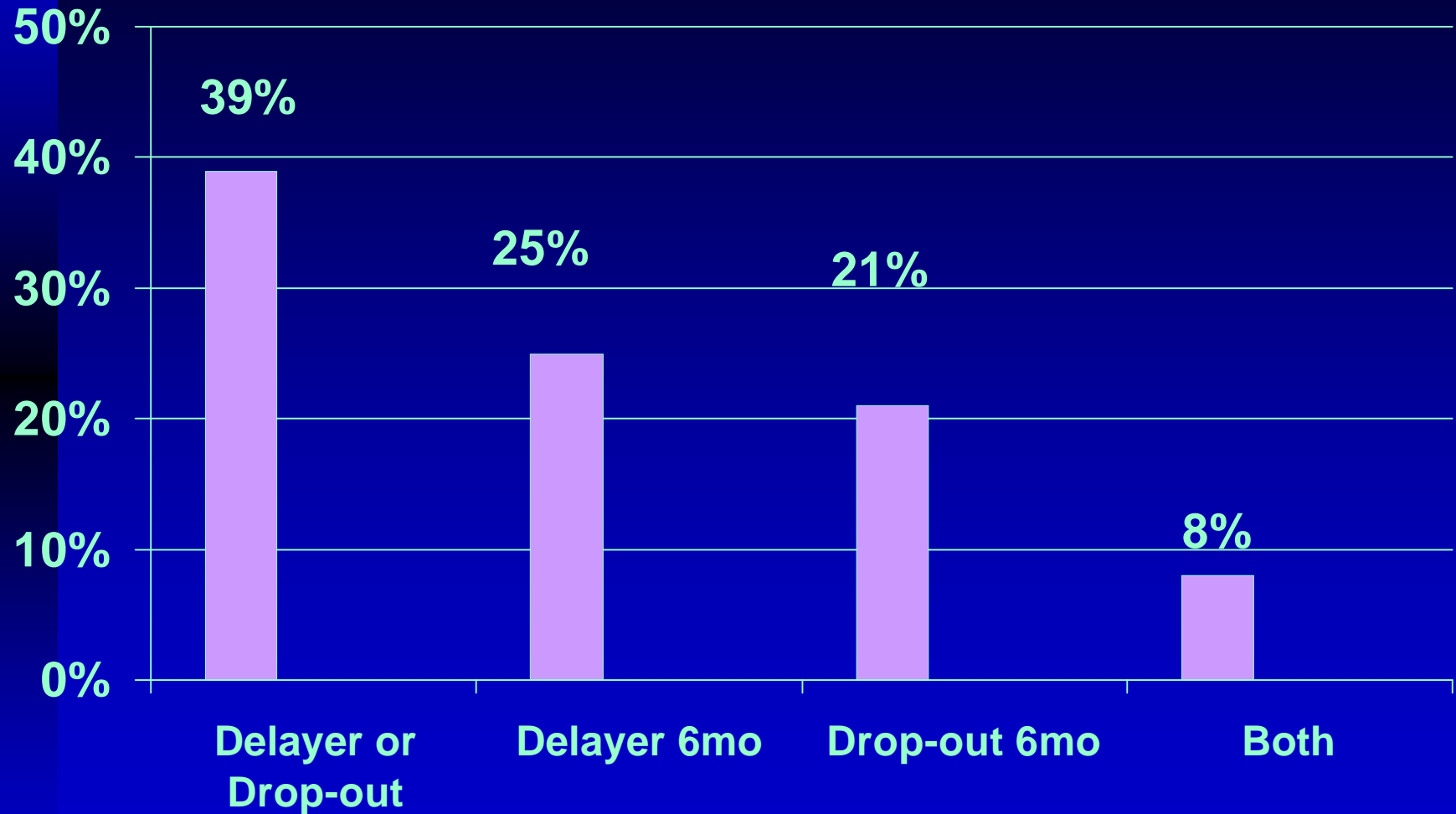
Answers to open-ended questions - multiple responses possible

Recurrent Themes

Client interviews, focus groups and provider interviews

- Similar reasons for both delay to testing for HIV and
- Delay from testing and diagnosis to treatment for HIV
- Similar reasons for dropping out of care

Delayers and Drop-outs



CHAIN New Cohort, n=625

Drop outs describe their reasons

<i>Drop-outs Interviewed n=</i>	<i>(124)</i>
Was doing drugs	27%
I didn't care, just stopped	19%
Doc left, program closed, I moved	13%
Didn't want medication	10%
Was fed up, treatment exhaustion	9%

SOURCE: NEW CHAIN COHORT

Answers to open-ended questions - multiple responses possible

Before the clinic waiting room

- Accessing care as a multi-stage process
- Stages build on each other
- Delay/ drop-out can occur at any stage
- Different subpopulations at different stages of 'readiness' prior to HIV infection

Prerequisites for timely treatment

Health
knowledge

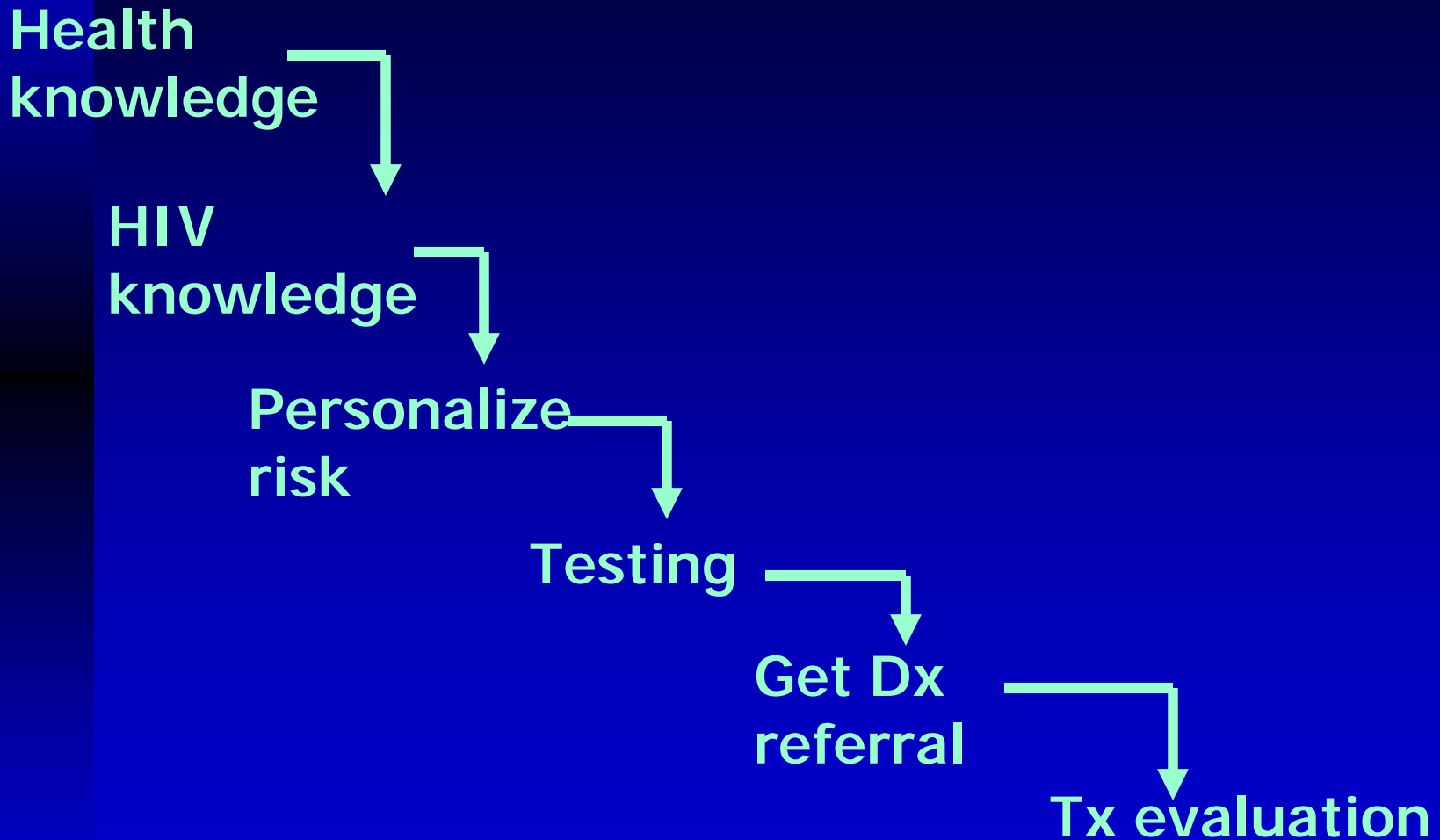
HIV
knowledge

Personalize
risk

Testing

Get Dx
referral

Tx evaluation



Weighing disclosure

- Rejection, anger, violence
- Loss of social support
- Reveal past behavior

- Certainty
- Practical benefits

Barriers to Testing

Costs

- Paper trail
- Disclosure
- Risk of rejection
- "Once you know..."
- Fearful of Treatment
- Labeling by self and others as HIV+

Benefits

- May lead to M11Q to DASIS
- Social support
- Certainty
- Get treatment
- Self-acceptance

Barriers to Testing

- Need to balance perceived costs and benefits: What's in it for me now?
- Testing often secondary to something else
 - Other health conditions
 - Institutional 'capture'
 - Lifestyle change

Barriers to Results and Referral

- Institutional referrals are difficult to follow up
- Finding a welcoming provider
- Costs of labeling and disclosure
 - Emotional
 - Social
 - Practical
- Unknown disease course
- Little knowledge of treatment options

Barriers to Accessing Treatment

- Lack of understanding of basic disease process
- Folk knowledge about medications
- Little knowledge in advance of diagnosis
- Competition from other medical conditions or medications, e.g. Hep C

Barriers to Treatment

- Anticipate and fear side effects
- Competing concerns
 - Life Issues (housing, child care)
 - Drug Use
 - Medications / other disorders
- Fear of unknown
- Be your own doctor / social worker

Barriers to Treatment

Costs

- Involvement in medical system
- Loss of control
- Time, inconvenience, paperwork
- Disclosure
- Fear of unknown

Benefits

- Entry to medical system
- Limit spread of infection, re-infection
- Financial benefits

Prior Medical Care

General medical care facilitates HIV care
BUT

- Delayers/ drop outs lack routine care
- Distrust, bad experiences, conspiracy, incompetence
- Paperwork, insurance problems
- Don't distinguish HIV care from general care
- Lifestyle constraints (homeless, drugs)

Stigma and Disclosure

Stigma and HIV

- Testing/ treatment suggests behavior
- Distrust of institutions
- Consequences of disclosure for persons with few resources

"Overlapping stigmas" suggests greater need for specialized treatment settings

Little realistic information

What is treatment *really* like?

Benefits available to HIV+s

Consequences for other systems

- Corrections
- Immigrant eligibility
- Income maintenance
- Child custody

Question: *What can be done?*

- Distribute more realistic information about treatment, in advance of testing or diagnosis
- Improve ease, speed, and convenience of HIV testing
- Culturally sensitive pre- and post-counseling
- Testing sites must actively facilitate entry into medical care
- Develop population-friendly providers
- Maintain and expand outreach efforts to marginalized populations
- Intercept HIV+ where they go for non-HIV services