Treatment Adherence across the Spectrum of Care

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Cases

Mr. W: 28 year-old man

- Diagnosed with HIV in late 1998
- CNS toxoplasmosis, wasting, dementia, CMV esophagitis
- CD4 cell count = 6
- Mr. T: 26 year-old man
 - Diagnosed with HIV in 1999
 - Pulmonary tuberculosis
 - CD4 cell count = 265



Which patient is alive today?



Rembrandt, The Raising of Lazarus, c. 1630

HRSA Engagement in Care Continuum



Adherence to the Spectrum of Care

- Link to care after HIV diagnosis
- Be retained (persist) in care, or stay in care chronically
- Adhere to medications

Outline

- Magnitude of the problem
- Why at an adherence conference?
- Predictors
- Impact on outcomes
- Interventions
- Challenges
- Recommendations

Magnitude of the Problem

- HCSUS: 1/3 to 2/3 of persons with HIV in US are not in regular care, half of whom know they have HIV
- CDC: 17-40% of PLWHA who know status are not in regular care
- Deaths with HIV in B.C., Canada, 1997-2001
 - Of 554 non-accidental deaths, 69% were HIV/AIDS-related
 - Median proportion of time on HAART = 20%
 - >50% not on HAART at death
- ARTAS: 40% of patients newly diagnosed did not see provider within 6 months
- "No-show" rates are high
 - 30% of patients missed ≥25% of their appointments in Birmingham
 - 50% of new patients were poorly engaged in care at 1 year in Houston
 - 70% no-show rate in a clinic for marginalized HIV patients in NYC

Bozzette, NEJM 1998, 339:1897; Fleming, 2002, *9th CROI*: abstract 11; Recksy, *JID* 2004, 190:285; Gardner, *AIDS* 2005, 19:423; Mugavero, *IDSA* 2007, Abstract 1134; Giordano, *AIDS Care*, 2005: 773; Cunningham CO *AJPH* 2007, 97:1758

Retention in Sub-Saharan Africa



Rosen, *PLoS Medicine* 2007, 4:1691

Why at an Adherence Conference?

- Similar predictors
- Intertwined behaviors
- Theoretical overlap
 - Complex behavior around health decision making, communication and interaction with healthcare team
- Process/system factors
- Some similar measurement issues



Predictors of Poor Linkage and Appointment Adherence or Retention in Care

- Demographic characteristics
 - Younger age
 - Racial/ethnic minority status
 - No or public insurance
 - Lower socioeconomic status
 - Rural residence
 - No usual source of care
- Disease severity
 - Less advanced HIV disease
 - Fewer non-HIV comorbidities
- Psycho-social characteristics
 - Substance use / Hepatitis C infection
 - Low readiness to enter care
 - Less social support / lower perceived social support
- System and patient factors
 - Less use of ancillary services / greater unmet need

Samet, AJM 1994, 97:347; Samet, Arch Internal Med 1998, 158:734; Turner, *Arch Internal Med* 2000, 160:2614; Giordano, *AIDS Care* 2005:773; Mugavero, *CID* 2007, 45:127; Gardner *AIDS Pt Care STD* 2007, 6:418

Kissinger JNMA 1995:19; Catz, AIDS Care 1999:361; McClure AIDS & Behav 1999:157; Israelski, Preventive Medicine 2001:470; Arici, HIV Clin Trials 2002:52; Samet J Health Care Poor Underserved 2003:244; Giordano Adherence Conference 2006; Mugavero, IDSA 2007, Abstract 1134; Krentz, CID 2007, 45:1527

Impact on Outcomes

- Delayed linkage
 - Delay in getting HAART
 - Irreversible immune damage
 - More HIV transmission
- Poor retention in care
 - Less likely to get HAART
 - Higher rates of HAART failure
 - More hospitalizations
 - Worse survival

Giordano, *JAIDS* 2003, 32:399; Lucas, *Annals Intern Med* 1999:81; Berg, *AIDS Care* 2005:902; Macharia, *JAMA* 1992, 267:1813; Fleishman, *HSR* 2008, 43:76

US VA Patients Starting ART Quarters in First Year with Visits

N=2619

Quarters with Visit	Ν	%
Visit in 4 quarters	1685	64%
Visit in 3 quarters	479	18%
Visit in 2 quarters	286	11%
Visit in 1 quarter	169	6%



Giordano et al., CID 2007, 44:1493



Adjusted Analyses (Cox) (n=2619)

Characteristic	AHR	95% CI	P value
Visit in 4 quarters	referent		
Visit in 3 quarters	1.41	1.10-1.82	< 0.01
Visit in 2 quarters	1.68	1.24-2.26	< 0.001
Visit in 1 quarter	1.94	1.36-2.76	< 0.001

Adjusted for age, race/ethnicity, baseline CD4 cell count, HAART use, hepatitis C coinfection, non-HIV related comorbidity score, alcohol abuse, hard drug use, and social instability.



Giordano et al., CID 2007, 44:1493

Interventions

ARTAS study

- Randomized controlled trial
- HRSA Ancillary Services Use set of studies
 - Retrospective observational data
- SPNS Outreach Initiative
 - Non-randomized intervention
- CDC / HRSA Retention in Care
 - Randomized controlled trial underway



Gardner, *AIDS* 2005, 19:423; *AIDS Care Supp 1,* 2002; *AIDS Pt Care STD Supp* 2007

Intervention to Improve Linkage: ARTAS

- 273 participants from 4 U.S. cities
- 78% diagnosed <6 months
- 90 days of strengthbased case management
- Replicated in ARTAS II



Gardner, AIDS 2005, 19:423; Gardner AIDS Pt Care STD 2007, 6:418

Outreach Intervention

TABLE 3.Associations Between Degree of Engagement in HIV Primary Care at
Baseline and Engagement in HIV Primary Care at Twelve-Month Follow-Up

	n	% Engaged in care	Unadjusted odds Ratio (95% CI)	Adjusted odds Ratio (95% CI) ^a	p value
Engaged at baseline Somewhat engaged ^b	290 260	75.9 59.6	Reference	Reference	0.002
Not engaged ^b	68	52.9	0.35 (0.20, 0.63)	0.41 (0.23, 0.72)	0.001

 Factors associated with retention at 12 month follow-up (adjusted for race and last CD4):

 Discontinued drug use, decreased structural barriers, decreased unmet needs, and stable beliefs about HIV

Rumptz, AIDS Pt Care STD 2007, 21:S-30

SPNS Model for Opportunities to Improve Adherence to Care



Challenges

- Measurement issues
- Patient and provider / system level
- Staffing and resources
- Finding patients who are out of care



Operationalizing "Retention in Care"

- Appointment Adherence:
 - Proportion of scheduled visits that were kept
 - Strengths:
 - Conceptually simple and familiar
 - Smoothes out erratic behavior over time
 - Limitations:
 - Automatic rescheduling
 - Clinics may stop rescheduling patients after certain number of missed visits
 - Handling canceled visits, including canceled by patient and canceled by provider or clinic
 - Distinguishing and handling triage, urgent care, sick visits
 - Smoothes out erratic behavior over time

Operationalizing "Retention in Care"

- Retention in Care (Persistence)
 - Minimum standard of visits per time period
 - Typically one visit per 6 month period
 - Strengths
 - Conceptually simple and familiar
 - Simple to compute and describe
 - Do not need data on missed visits
 - Self-report may be valid
 - Limitations:
 - Insensitive to disease severity
 - Low standard
 - Distinguishing and handling triage, urgent care, sick visits

Operationalizing "Retention in Care"

• Gaps in care

- Lack of 3, 4, 6, or 12 month gap in care
- Longest gap in care
- Strengths:
 - Conceptually simple
 - Simple to compute
 - Do not need data on missed visits
- Limitations:
 - Insensitive to disease severity
 - Low standard
 - Difficult to describe
 - Distinguishing and handling triage, urgent care, sick visits
 - "Undefined" value if using longest gap and patient is LTFU

Challenges: Measurement Issues



Slide courtesy of M. Mugavero, UAB

Challenges: Patient & Provider Level

Patient level changes

- Changing behavior, similar to medication adherence
- Improving trust, communication, stigma
- Removing structural barriers and unmet need (transportation, housing, child care, financial)
- Reducing substance use
- Provider and system level changes
 - Provider communication and decision-making style
 - Appointment scheduling systems (open access?)
 - Extended clinic hours
 - Accurate contact information
 - De-fragmenting health insurance

Challenges: Staffing and Resources

Inadequate staffing and resources

- ARTAS: 120 clients per year, so about 10 new CM for Houston
- SPNS Outreach Initiative had average of 4.9 contact hours per new client per month, for 12 months
 - 21 work days per month, 8 hours per day, = 168 work hours per month; 168 / 4.9 = 34.3 clients per outreach worker. At TSHC (300 newly diagnosed patients per year) = 9 dedicated outreach workers
- SPNS outreach initiative had effect if ≥9 contacts over 90 days
 - If 15 minutes each contact, at TSHC (1000 patients with poor retention) = 5 dedicated outreach workers
- Sustainability, translation and dissemination

Gardner, *AIDS* 2005, 19:423; Naar-King, *AIDS Pt Care and STD* 2007, 21:S-40; Cabral *AIDS Pt Care STD* 2007, 21:S-59

Recommendations for Now

- Examine your processes: bringing patients back is much more difficult once out of care completely
- Work with the resources you have: make the clinic visit pleasant, spread the word about the importance of retention, have staff advocate with patients for retention, communication skills training for providers
- Strengthen substance use, case management, and outreach or peer navigator programs
- Minimize time between appointment making and appointment date
- Nutritional support (developing and developed settings)

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Leonardo da Vinci, Genevra de' Benci, 1474