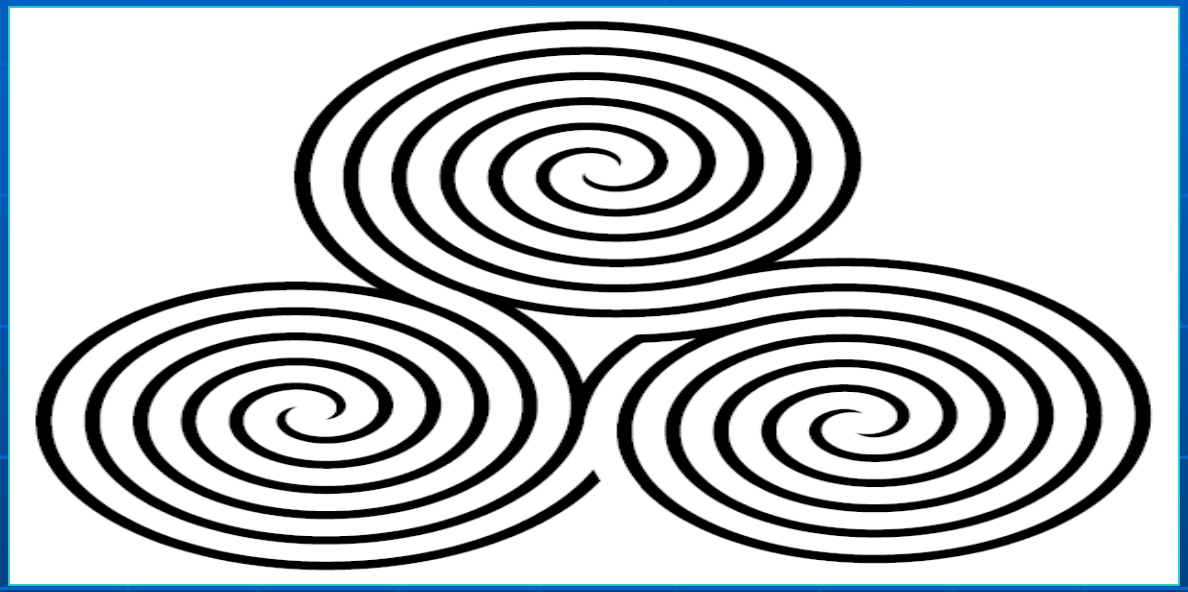
Unraveling the Mystery:



How Culture, Stigma & Aging Influence Adherence and Viral Load in STAR patients over 50

Providing HIV care to women over 50 in Flatbush, Brooklyn

Lori Hurley, LMSW, MPH
Sanna A. Moore, LMSW
Laurie Sadofsky, BA

STAR HEALTH CENTER
www.downstate.edu/star

Factors affecting engagement

- Co-morbidities/Co-occurring disorders
- Cultural influences on engagement in care

Factors affecting engagement

- Strengths and Resilience
- How NYCDOH Care Coordination program makes a difference
- Best Practices

STAR Health Center

- STAR Health Center located in SUNY Health Science Center of Brooklyn

- Level 3 Patient-Centered Medical Home (PCMH)
- Provides interdisciplinary/medical HIV care for 1200 PLWHA

STAR HEALTH CENTER

Located in Flatbush, Brooklyn

11203 zip code

11203 Demographics

2010 Census

- 51% (38,646) of residents from West Indies or Guyana
- Largest sub-group (6,835 or 20%) born in Haiti


Caribbean Sea
HAITI
DOMINICAN REPUBLIC
Port-au-Prince
Les Cayes
Santo Domingo
Montego Bay
Kingston
JAMAICA
Navassa Island (U.S.)
Mona Passage
Isla Mona
San Juan
Puerto Rico (U.S.)
British Virgin Is. (U.K.)
Anegada Passage
Virgin Is. (U.S.)
Neth. Antilles (NETH.)
St. Croix
Anguilla (U.K.)
St. Martin (Guad. and Neth. Antilles)
St. Barthelemy (Guad.)
ANTIGUA AND BARBUDA
St. John's
Basseterre
ST. KITTS AND NEVIS
Plymouth
Montserrat (U.K.)
Guadeloupe (FRANCE)
Basse-Terre
Marie-Galante
Isla Aves (VENEZUELA)
DOMINICA
Roseau
Martinique (FRANCE)
Fort-de-France
Castries
ST. LUCIA
BARBADOS
Bridgetown
Kingstown
ST. VINCENT AND THE GRENADINES
GRENADA
St. George's
Aruba (NETH.)
Oranjestad
Netherlands Antilles (NETH.)
Curaçao
Bonaire
Willemstad
Santa Marta
Barranquilla
Cartagena
Maracaibo
Puerto Cabello
Caracas
Isla la Tortuga
Isla de Margarita
Tobago
Port-of-Spain
TRINIDAD AND TOBAGO
Trinidad
Cumaná
Barcelona
Maturin
Barquisimeto
Valencia
Maracay
Panama
Monteria
Mérida
Ciudad Bolivar
Ciudad Guayana

Nostrand Ave. and Lenox Rd. one week before Labor Day

Flowerboxes on Nostrand Avenue

RESEARCH AND PRACTICE

HIV/AIDS Surveillance Data for New York City West Indian—Born Blacks: Comparisons With Other Immigrant and US-Born Groups

Susie Hoffman, DrPH, Yusuf Ransome, MPH, Jessica Adams-Skinner, MPH, EdD, Cheng-Shiun Leu, PhD, and Arpi Terzian, PhD

American Journal of Public Health, November 2012, vol 102, No. 11

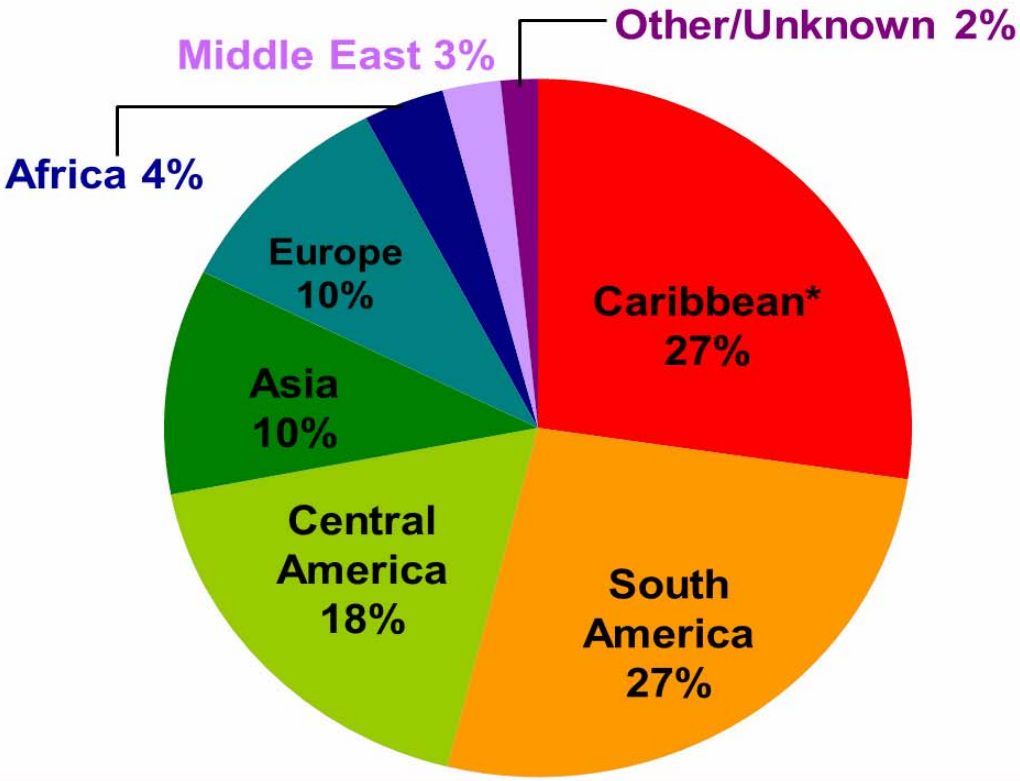
- Of all NYC foreign-born persons newly reported in 2010 with HIV, 881 (39%) were born in the Caribbean. Overall prevalence in this community is high, at 0.66%

- Caribbean has 2nd highest level of adult HIV prevalence (1.0 %) after sub-Saharan Africa (Montealegre, AIDS Behav, 2013)

- HIV-positive individuals from the Caribbean region have been motivated to migrate to obtain treatment in the U.S.

- Hoffman et al advocate interventions that focus on this “hidden immigrant group.”

Percentage of New HIV Diagnoses among Foreign-born MSM by Region of Birth, NYC 2011



The foreign-born account for 30% of new HIV diagnoses overall, and 27% among MSM. The Caribbean* and Central and South America accounted for 72% of new HIV diagnoses among foreign-born MSM in 2011.

*Excludes Puerto Rico and the US Virgin Islands.

As reported to New York City Department of Health and Mental Hygiene as of September 30, 2012.

Challenges Addressed by Care Coordination

Pt medication adherence are sub-optimal

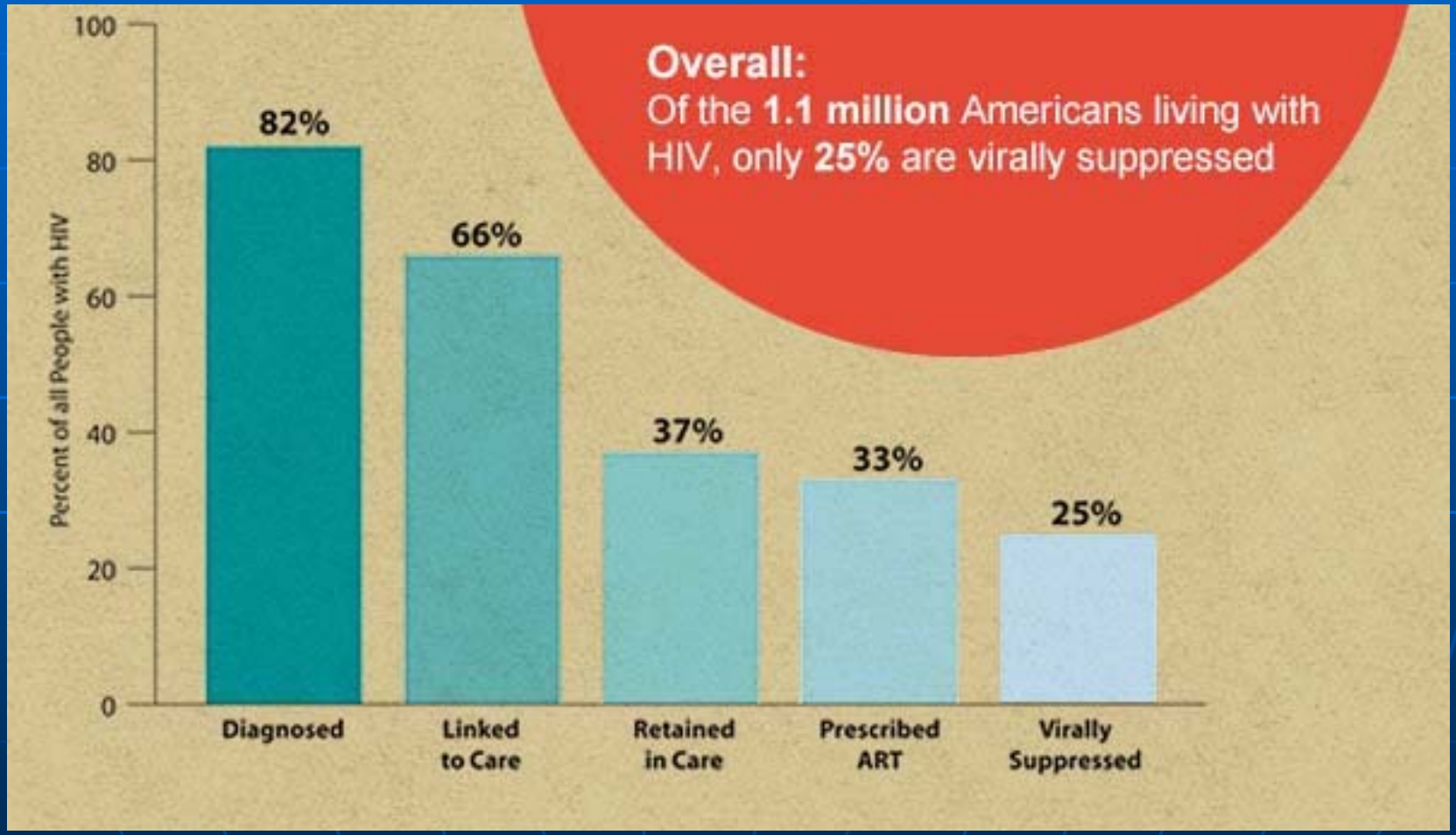
Current treatments offer great potential for improving lives of persons living with HIV

Assistance navigating the healthcare system

Patient Navigators work with Patients to break down barriers to care and build trust

HIV Continuum of Care

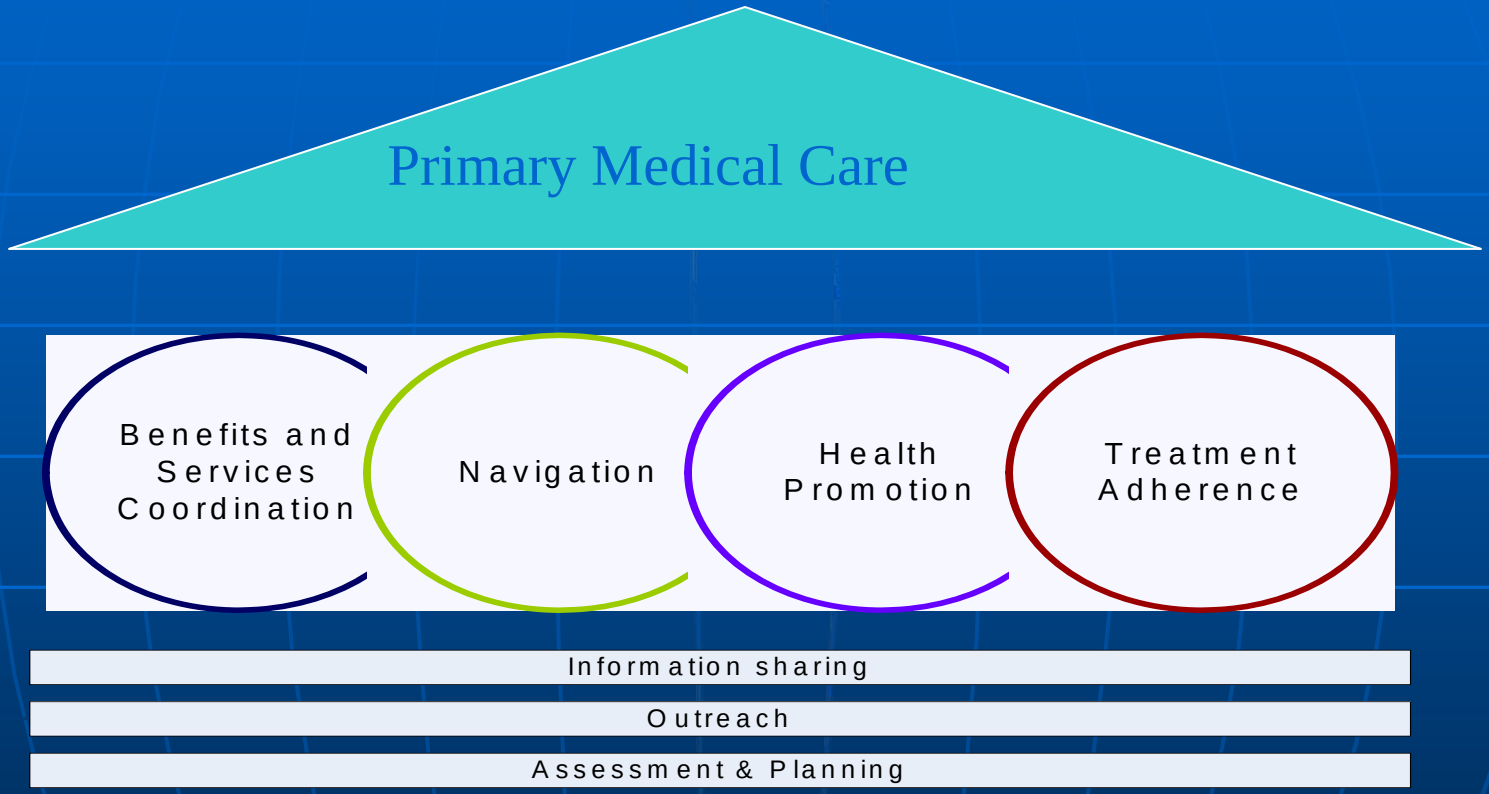
aids.gov 2013



PATIENT ELIGIBILITY

- Newly diagnosed with HIV
- Lost to care: Last PCP visit at facility was over 9 months ago
- Sporadic/irregular care or difficulty keeping appointments
- History of non-adherence to antiretrovirals

PATIENT NAVIGATION: KEY ASPECT

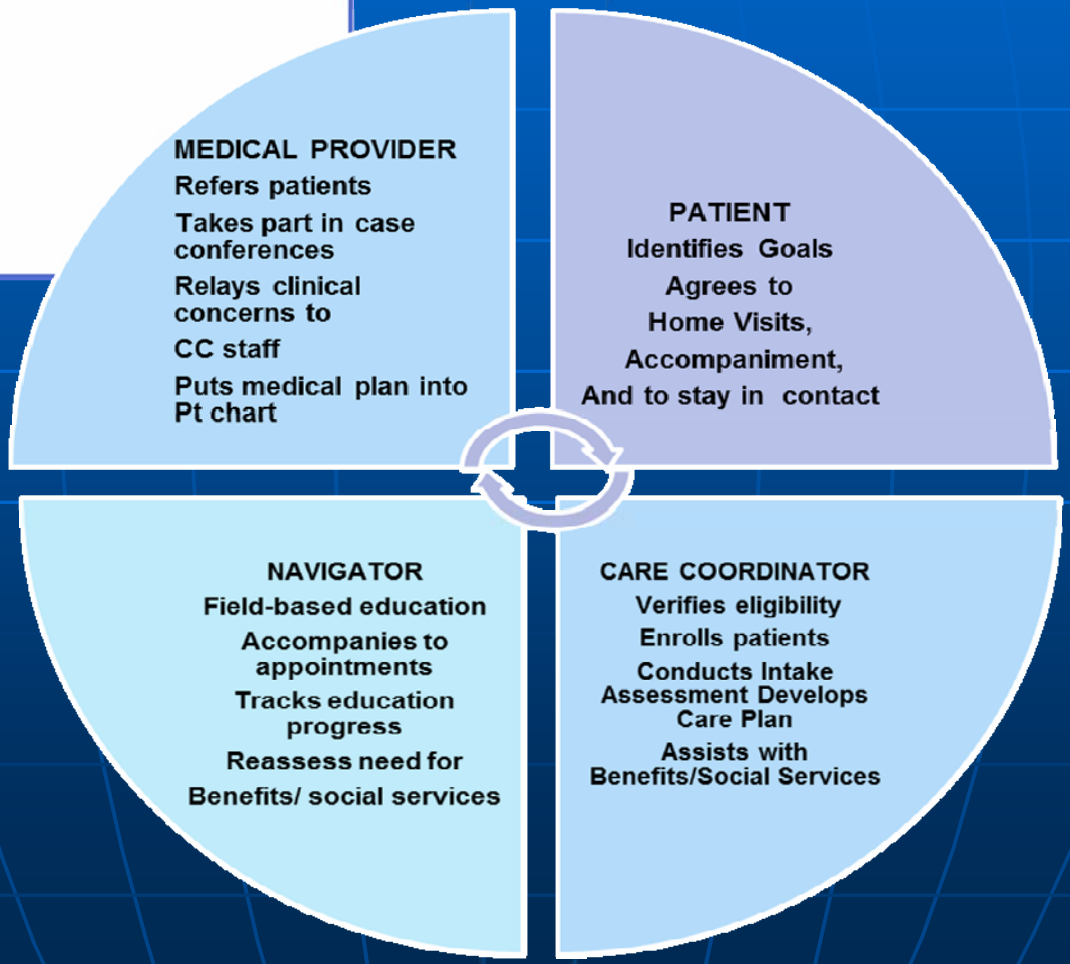


SUNY Downstate Medical Center

University Hospital of Brooklyn
College of Medicine
School of Graduate Studies
College of Nursing
College of Health Related Professions

Special Treatment and Research Program

- *Care Coordination Team*



PATIENT NAVIGATOR

- Navigation
  - Logistical support
  - Reminder calls
  - Coordinate transportation
- Accompany clients to appointments
- Outreach clients for engagement by phone and at home
- Conduct social service and benefit reassessment

PATIENT NAVIGATOR

- Home-based program
- Build rapport and foster relationship
- Provide field-based education
  - Monthly or weekly
  - Facilitate topics in Care Coordination Curriculum
- Treatment Adherence
  - Monthly Pill Box Log

GOALS FOR CLIENTS IN CARE COORDINATION

- Retention in Care
- Improved Clinical Outcomes
- Treatment Adherence
- Independence/Self Sufficiency
- Intermediate Needs: Housing, Entitlements

THE NEW YORK CITY DEPARTMENT OF
HEALTH AND MENTAL HYGIENE

NYC Health

A

TRACK A

- No Antiretroviral Therapy (ART)
- Quarterly Health Promotion

B

TRACK B

- ART with quarterly adherence assessments
- Quarterly Health Promotion

C1

TRACK C1

- ART with monthly adherence assessments
- Monthly Health Promotion

C2

TRACK C2

- ART with weekly adherence assessments
- Weekly Health Promotion

D

TRACK D

- ART with daily adherence assessments (directly observed therapy)
- Weekly Health Promotion

Clients may change tracks within the model based on their needs

THE NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE

Health Promotion Curriculum

- Handling your ART medications
- What is adherence?
- What is HIV?
- Using a pillbox
- Side effects

THE NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE

HEALTH PROMOTION CURRICULUM

- Me and HIV
- Safety in relationships
- Harm reduction around substance use and sexual behavior
- Medical appointments and providers
- Identifying and building social support networks

HIV and Aging: State of Knowledge and Areas of Critical Need for Research. A Report to the NIH Office of AIDS Research by the HIV and Aging Working Group

Kevin P. High, MD, MS, Mark Brennan-Ing, PhD,† David B. Clifford, MD,‡ Mardge H. Cohen, MD,§ Judith Currier, MD, MSc,‖ Steven G. Deeks, MD,¶ Sherry Deren, PhD,# Rita B. Effros, PhD,‖ Kelly Gebo, MD, MPH,** Jörg J. Goronzy, MD, PhD,†† Amy C. Justice, MD, PhD,‡‡ Alan Landay, PhD,§§ Jules Levin,‖‖ Paolo G. Miotti, MD,¶¶ Robert J. Munk, PhD,## Heidi Nass, JD,*** Charles R. Rinaldo Jr, PhD,††† Michael G. Shlipak, MD, MPH,‡‡‡ Russell Tracy, PhD,§§§ Victor Valcour, MD,‖‖‖ David E. Vance, PhD,¶¶¶ Jeremy D. Walston, MD,**** and Paul Volberding, MD,### For the OAR Working Group on HIV and Aging*

J Acquir Immune Defic Syndr • Volume 60, Supplement 1, July 1, 2012

HIV and Aging: State of Knowledge

- By 2015 half of people in the U.S. with HIV will be > 50 years
- Median life expectancy > 70 yrs
- HIV associated Non-AIDS conditions are increasing

HIV and Aging: State of Knowledge

HIV associated non-AIDS (HANA)

- Cardiovascular disease
- Osteopenia/osteoporosis
- Liver disease
- Renal disease
- Neurocognitive decline

HRSA study of HIV+ Caribbean immigrants

- Social networks tend to be close-knit, and when service sites are located in the neighborhood,

- Potential clients feared that even persons they did not know personally could know someone related to them and their positive status might be divulged in this way

- Journal of Immigrant & Refugee Studies, Vol. 6(4), 2008 *526* doi: 10.1080/15362940802480407

Case Studies: Common Themes

- Disclosure issues
- Perceiving PN as a threat to privacy- lack of trust in System
- Neuro-cognitive issues such as dementia & co- morbidities such as ESRD (Dialysis), Diabetes, Hypertension, CHF, etc

Case Studies: Common Themes
(cont'd)

- Elder Abuse – financial, emotional
- Anxiety and Depression – untreated mental illness
- Homelessness – lack of support system

Patient #1 Background

- 61 year old pt. Haitian women who emigrated to US in 1978 in search of a better life.
- Pt. Dx in 2009. She stopped working as a HHA in 2011 after starting dialysis and became very depressed. Pt. refused MH services saying she is not “crazy”.
- She was referred to MCM program in March 2011 for poor adherence to HIV and other medications.
- She has 4 children (2boys/2 girls); husband deceased in 1993.

Patient #1 ART Experience

- Pt. was undetectable at intake but confused about medication regimen.
- Pt. memory progressively became worse; she was confused and distrustful of Home Health Aides, Visiting Nurse and PN.
- Pt. refused assistance with medication adherence such as pillbox, specialty pharmacy, DOT, etc.
- VL increased however CD4 remained stable or increased.

Patient #1 Outcome

- Pt. was facing eviction due to unpaid back rent; suspected her children of stealing her money, etc. Pt. referred to Legal Services with PN escort - which enabled her to keep her apartment.
- Referred for neuro-cognitive evaluation with PN escort – found to have dementia. Recently put on Psych meds for hallucination and is now sleeping at night.
- Advocacy with Home care agency to put 24 hour services in place.
- CD4 was 204 at intake; current CD4 = 521 with varying VL over past 3 yrs.

Patient #2 Background

- 78 year old woman born in Barbados
- Diagnosed 11/2013 while inpatient at DMC
  - Admitted for fatigue, dizziness and general weakness
- Viral load >10 million
- Likely heterosexual risk
- Current hypertension
- Breast cancer 15 years ago.

Patient #2 ART Experience

- Started on ART while inpatient
- Medication Adherence work included Patient Navigator, Patient and Patient's daughter
- Viral load has dropped to 114 copies from 10 million

Patient #2 Assistance from PN

- The Patient Navigator and Care Coordinator spoke with the Patient several times about her diagnosis, how the virus is spread and how to treat it.

Patient #2 Assistance from PN

- Patient claims her previous primary care doctor disclosed her status to her children w/o permission.
- Patient's family needed information about the ways the virus can and cannot be spread.

Patient #3 Background

- Pt is a Spanish-speaking 58 year old female from Honduras. Patient first came to STAR in September 2013 and was unsure of her exact diagnosis date as she has memory loss. Patient enrolled in Care Coordination in October 2013. Patient's co-morbidities are Asthma and depression.

Patient #3 Background

- Living in a homeless shelter after being thrown out of a friend's apartment after discovery of her diagnosis.
- Patient was admitted to hospital for several weeks due to severe dementia and paranoia. Patient was discharged to another friend's home.

Patient #3 ART History

- Patient was started on ARVs while inpatient and viral soon dropped from over 4 million to 3k.
- Patient's memory improved dramatically and she became physically stronger.
- 6 months later, the Patient's viral load is almost undetectable

Patient #3 Outcome

- PN and CC accompanied Patient from her home to several medical and social service appointments.
- Patient was connected with an agency and immigration lawyer and now has PRUCOL and is eligible for HASA, Medicaid and cash assistance.
- She is living in an SRO with case management on site and looking for congregate housing.

Patient #4

- Pt. is 50 year old Haitian woman
- Dx with HIV in 2002 – by needle stick working as HHA
- Dx. with ESRD in August 2012 and had to start Dialysis; Pt. became anxious and depressed
- Referred to Care Coordination in October 2012 for poor medication adherence.
- Pt. was homeless after losing apartment and being discriminated against by family member
- Pt. referred to Emergency housing – escort by CC

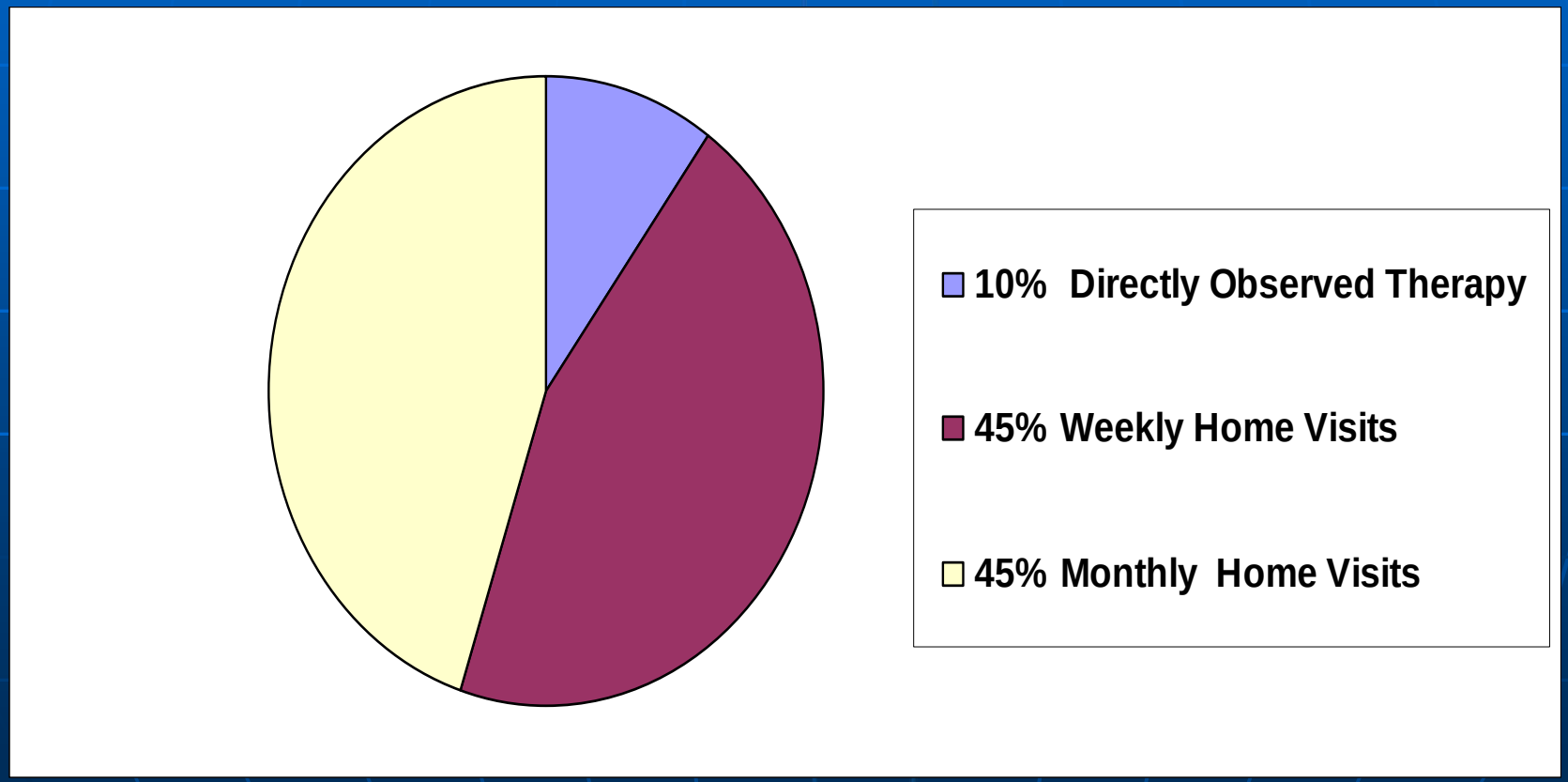
Patient #4 ART Experience

- Pt. resumed medication adherence after receiving supportive housing;
- Advocacy to change Dialysis center;
- Grieving loss of mother and brother within 2 months of each other;
- CD4 at intake was 128
- VL was 1,040,582
- Pt. graduated in February 2014
- CD4 was 404 VL was undetectable

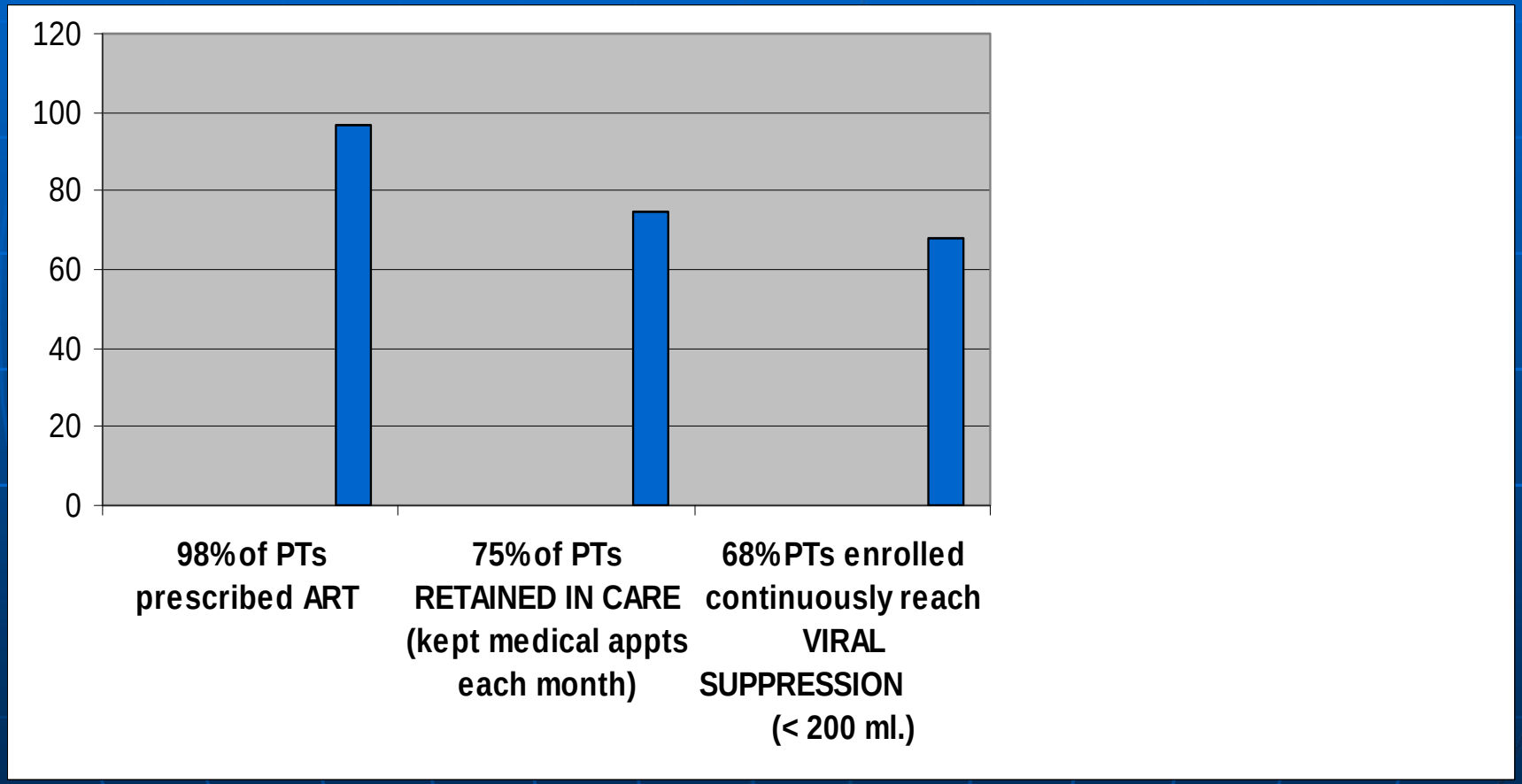
2013 STAR Care Coordination

- 166 unique patients enrolled
- 62 people over age 50
  - women 48% of this group
- PTs assigned Navigator/Coordinator Team

Navigators visit home to assess barriers to adherence & conduct Health Education



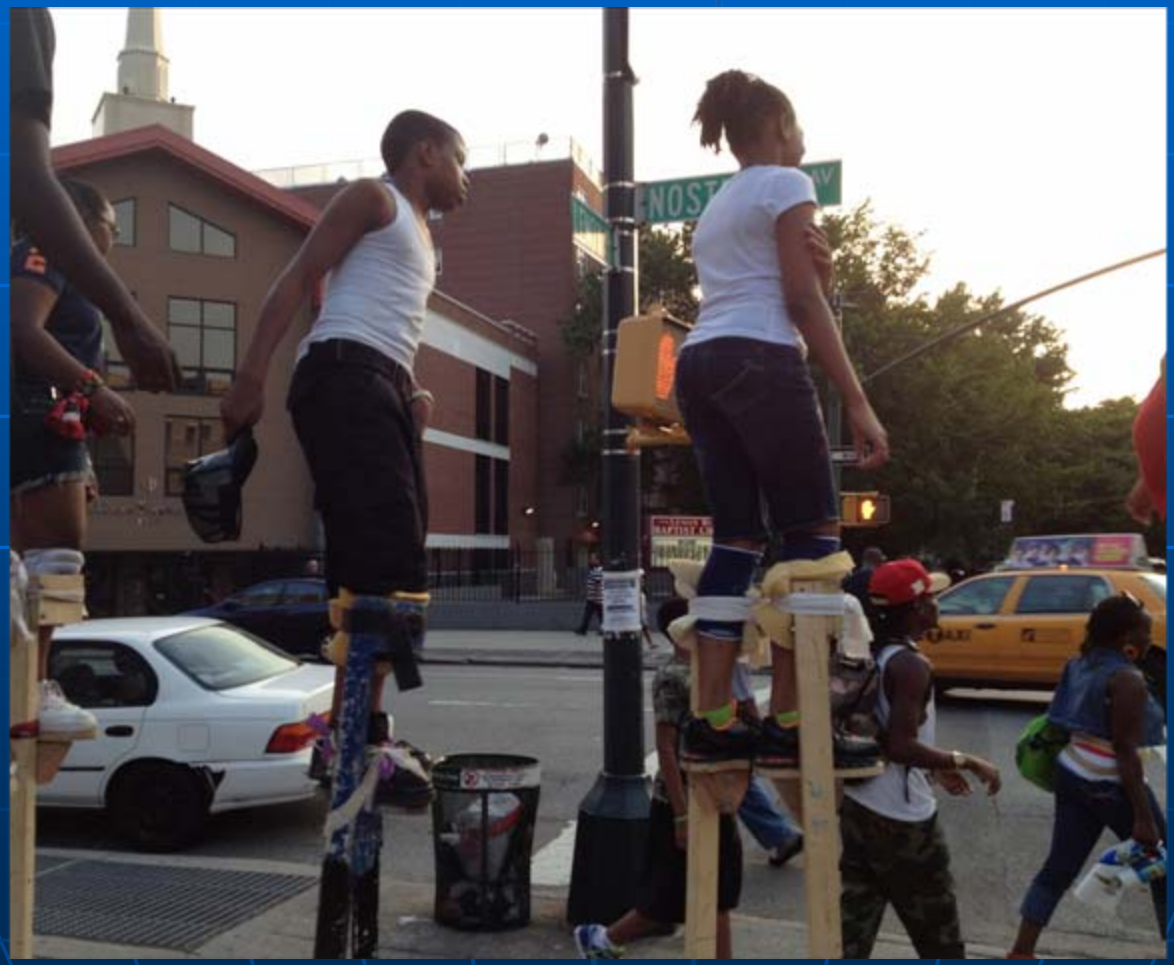
3 Key Aims of CDC's HIV Continuum of Care achieved for STAR 2013 Care Coordination



Best Practices

- Establish good communication with other providers and family
- Immediately report to PCP possible signs of neurocognitive problems
- Promote completion of HCP
- Be alert to signs of financial abuse

Best Practices: Be prepared



Mokojumbie

walk the streets in a celebration of freedom-
protecting the city from danger

(Stefan Falkes)