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

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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 located in SUNY Health Science Center of Brooklyn

- Level 3 Patient-Centered Medical Home (PCMH)
- Provides interdisciplinary/medical HIV care for 1200 PLWHA
Located in Flatbush, Brooklyn
11203 zip code
51% (38,646) of residents from West Indies or Guyana

Largest sub-group (6,835 or 20%) born in Haiti
Nostrand Ave. and Lenox Rd.
one week before Labor Day
Flowerboxes on Nostrand Avenue
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 2\textsuperscript{nd} 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.”
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

Overall:
Of the 1.1 million Americans living with HIV, only 25% are virally suppressed.
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

Primary Medical Care

- Benefits and Services Coordination
- Navigation
- Health Promotion
- Treatment Adherence

Information sharing
Outreach
Assessment & Planning
- Care Coordination Team

**MEDICAL PROVIDER**
- Refers patients
- Takes part in case conferences
- Relays clinical concerns to CC staff
- Puts medical plan into Pt chart

**PATIENT**
- Identifies Goals
- Agrees to Home Visits, Accompaniment, And to stay in contact

**NAVIGATOR**
- Field-based education
- Accompanies to appointments
- Tracks education progress
- Reassess need for Benefits/social services

**CARE COORDINATOR**
- Verifies eligibility
- Enrolls patients
- Conducts Intake Assessment Develops Care Plan
- Assists with Benefits/Social Services
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
Clients may change tracks within the model based on their needs.
Health Promotion Curriculum

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

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and Paul Volberding, MD,#### For the OAR Working Group on HIV and Aging
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 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.

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


- 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 (2 boys/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.
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.

- 10% Directly Observed Therapy
- 45% Weekly Home Visits
- 45% Monthly Home Visits
3 Key Aims of CDC’s HIV Continuum of Care achieved for STAR 2013 Care Coordination

- 98% of PTs prescribed ART
- 75% of PTs retained in care (kept medical appts each month)
- 68% PTs enrolled continuously reach viral suppression (< 200 ml.)
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)