Lessons from Community demonstration sites engaging transgender women of color living with HIV into care

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TransLife Center Project

The Intervention: Individual Level

- Outreach
- Connection to Services – Legal, Housing, Health Care, Employment, Safe Space
- Focus on Social Determinants of Health

The Intervention: Systems Level

- Transgender Cultural Competency Training
- Medical and Social Service providers

Lessons Learned

Relationship, Relationship, Relationship

- Integration with Community Partners
- Patience, Persistent, & Consistent Presence
- Partnering Agencies without expectation of return
- Outreach Venues in underserved communities

Meaningful Services

- Legal, Housing, Health Care, Employment, Safe Space
- Bundled services in a drop-in environment
- Not focusing on HIV in order to address HIV

Engagement

As of 07/31/16, 114 Enrolled in Services and Evaluation

Preliminary Baseline Data for N=105 participants

	Chicago House N=105; n (%)
Age in years	
Mean (SD); Range	30.9 (9.5); 18-64
Hispanic/Latina	5 (4.8)
Race	
Black/African-American/Afro-Caribbean	105 (100)
Education	
Less than HS	26 (24.8)
HS/GED	60 (57.1)
Greater than HS	19 (18.1)
Annual Income	
Less than $600 -$11,490	97 (95.1)
$11,491 - $59,999	5 (4.9)
Ever Hormones	82 (83.7)
Currently Hormones (n=136)	46 (57.5)

	Chicago House N=105; n (%)
Unemployed	95 (92.2)
Homeless, ever (since age 16)	79 (76.0)
Homeless, p6M [Sometimes, often]	54 (57.4)
Arrest, ever	52 (57.8)
Incarcerated, p6M	10 (10.8)
Exchange sex, past 6M	59 (64.1)

	Chicago House N=104; n (%)
Ever primary care for HIV	74 (71.2)
Sporadic care (>= 1 visit P12M)	51 (49.1)
Retained in HIV care (>=2 visits P12m)	45 (43.3)
Currently on ART	52 (50.0)
Suppressed viral load	47 (45.2)

Lessons Learned

Challenges

Intervention is short-term, based on linkage to services related to social determinants of health

- Lack of focus on Retention in Care
- Difficulties motivating participants to follow up in evaluation
- Participants feel “done” once successfully linked (e.g. housing)
- Safe Space and Community are a draw for some while others feel connected and safe once housed and legal issues such as name and gender marker are addressed

Educational Sessions (Preliminary Analysis through March 2015)

- Six Sessions Held
- Pretest and Posttest
- Completed Cases for Analysis = 234
- Average Duration 2.5 Hours
- Average Dosage = 92%
- Analysis: Comparing knowledge, attitudes, behavioral skills suggests significant gains
- To Date: 345/400, 12 sessions

Bienestar Human Services, Inc.

141 participants enrolled (as of 8/12/16)

Program Components

* Outreach: to identify Latina transgender women non-diagnosed, dropped out of care, never engaged in care, subpar engagement
* Linkage to medical care
* Social network testing/social network engagement
* Peer navigation to promote engagement & retention in care

Peer Navigation: Promoting Engagement/Retention in Care and Viral Suppression

* **Modeling behavior:**
  * **Talking with medical staff**
  * **Overcoming fear of confronting challenges with care**
  * **Being pro-active**
  * **Encouraging self-advocacy**

* **Increasing knowledge related to behavior change:**
  * **Encouraging communication with medical staff**
  * **Connecting behaviors with specific outcomes**
  * **Exploring positive/negative consequences of factors affecting health**
  * **Correcting misunderstandings**

Lessons Learned from Peer Navigation

Peer navigation works!

- **Medical staff take more time explaining information to patients and in more detail.**
- **Patients broaden their understanding of medical care and their health.**
- **Participants feel cared about; develop more self-confidence and ability to advocate for themselves.**

Lessons Learned from Peer Navigation (continued)

Important to be creative in finding ways to overcome barriers to engagement/retention in care: examples:

* **Homelessness: demonstrate benefits of shelter versus living on the streets**
* **Requirements of clinics leading to frustration and missed appointments: assist with filing out complicated forms**
* **Clinics' inability to connect with clients due to cell phones' not being charged: invite to Bienestar to recharge cell phones**

Local Evaluation Domains

* Religiosity: examples: self-rated religiosity, importance of religion in life, attendance at services
* Partner violence: (1) sexual partners, (2) primary partner, (3) strangers
* Their roles as facilitators of or impediments to
  * Engagement in care; retention in care
  * Viral suppression

THE PRINCESS PROJECT

Public Health Institute
Oakland, CA

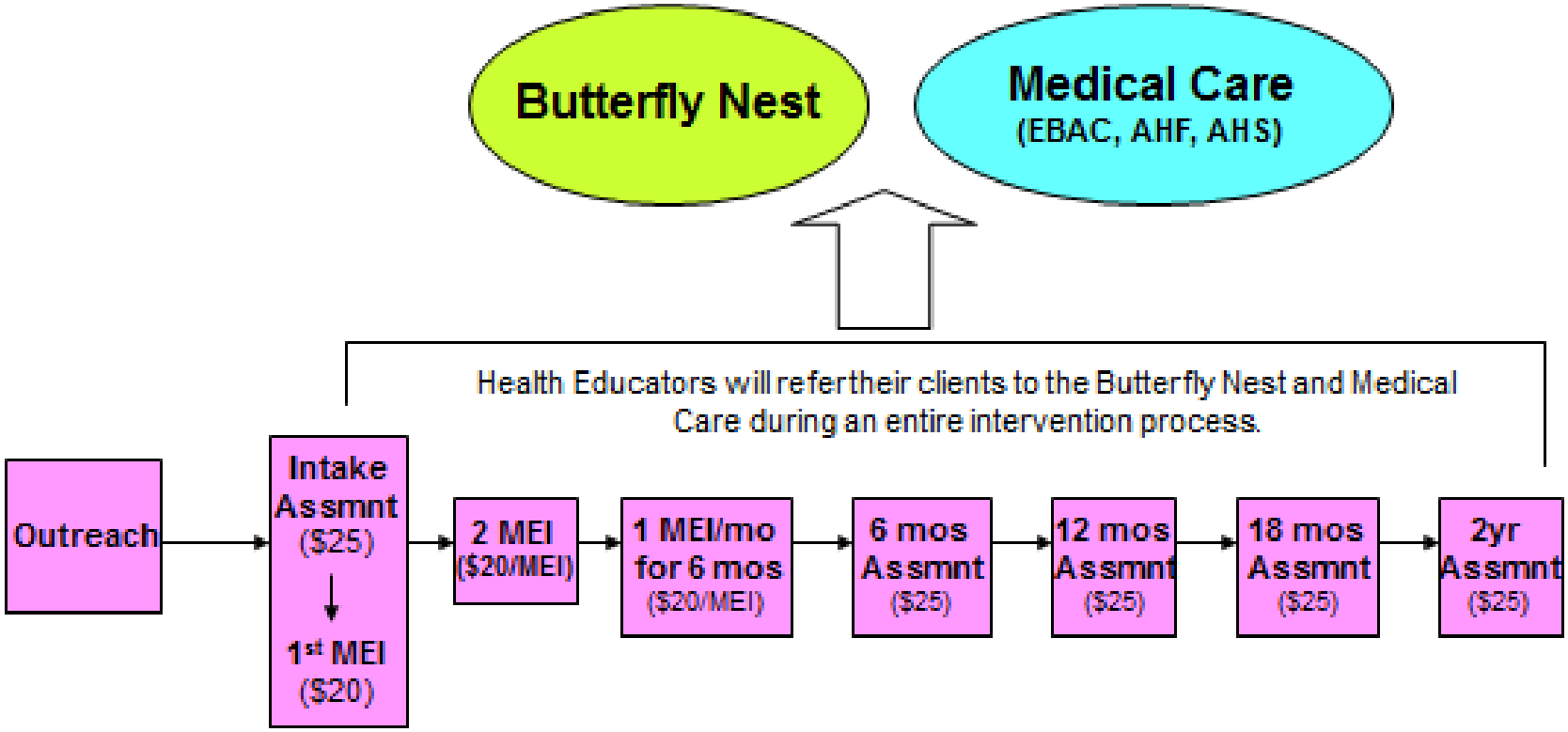
Tooru Nemoto, Ph.D.

The PRINCESS Project

August 2016

PUBLIC HEALTH INSTITUTE®

Intervention Design



Highlight

- 59 transgender women living with HIV enrolled in Princess Project

- Clients received continuous support from the Health Educators during and outside of intervention.

Total Minutes Health Educators Spent with clients
13,948 minutes (As of Dec 2015)

- Access to Care (As of Jun, 2016)

Out of Care (Baseline)	Access/ Re-engagement of Care (During Intervention)
33 clients	11 clients

- Weekly Support Group (as of April 2016)

Number of Meetings	Total attendees
80 meetings	642 transgender women

Lessons and Learned

Challenges	Strategies
Retention to Project	• Emphasize convenience to meet *"Anytime, Anywhere!"* • Numerous reminder calls and text messages *Week before, a few days before, a several hours before* • Detail contact information sheet *Cell phone, friends/family's contact info, hang out location* • Incentive! • Weekly support group • Maintain project visibility Community events, collaboration with • Well-trained and qualified Health Educators

Lessons and Learned

Challenges	Strategies
Access to Care	• Close working relationships with front-line clinic staff (social workers, etc) • Escorting clients to medical appointments • Having a discussion with clients to reduce obstacles of staying in care (Motivational Interviewing)

Enhancing Linkage to and Retention in HIV Care for Transgender Women of Color: *The Alexis Project*

the Alexis PROJECT

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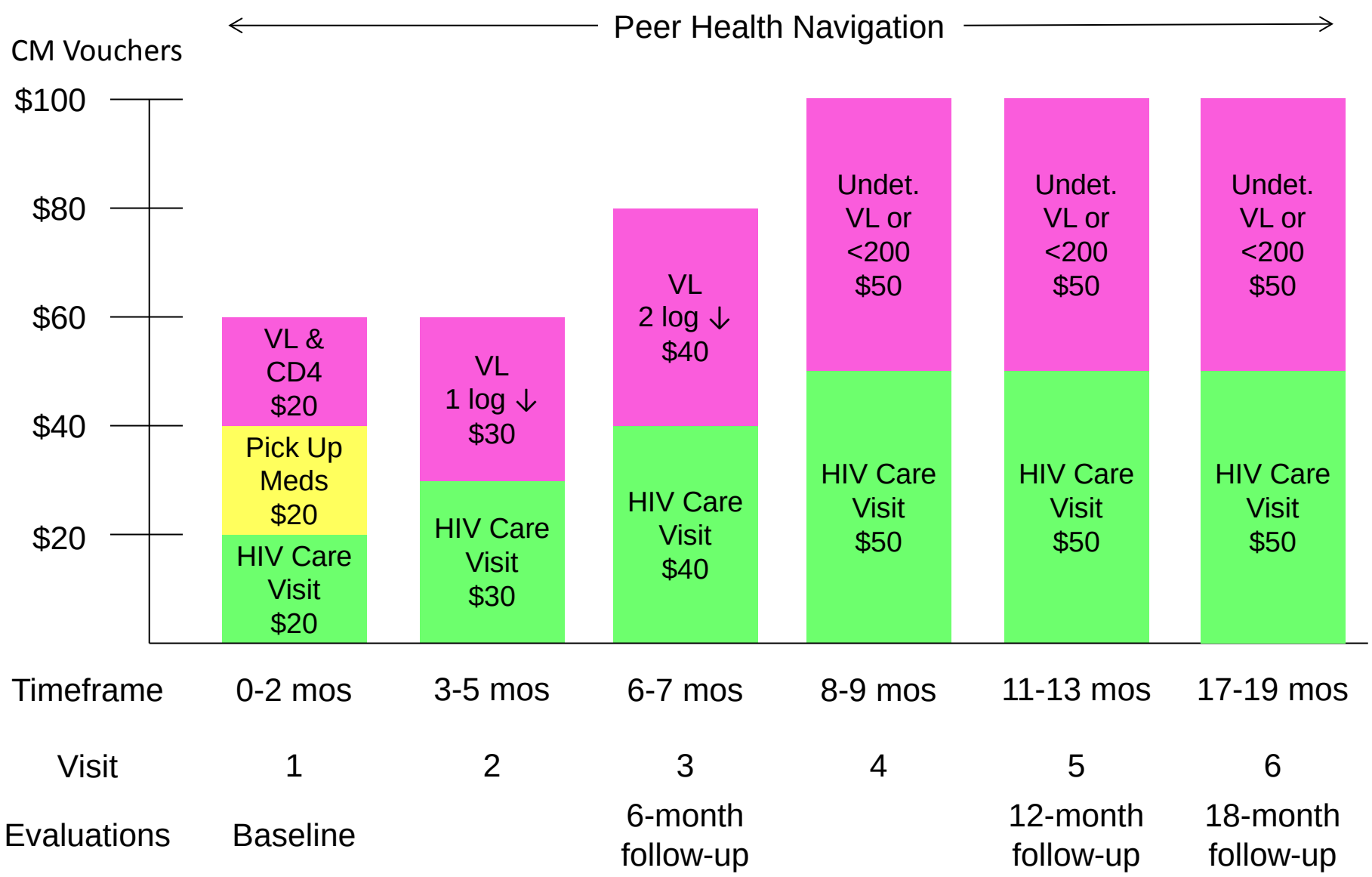
Presented at the National Ryan White Conference on HIV Care and Treatment, Washington DC, August 2016.

This presentation was made possible by grant number H97HA24968 from the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's Special Projects of National Significance Program (SPNS). Contents of the presentation are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. government.

Combined PHN + CM Intervention



Peer Health Navigation

The PHN sessions include (1) identify the barriers to HIV care, (2) identify and link participants into other auxiliary needed services, and (3) increase participants' self-efficacy in working with HIV care providers. Peer Health Navigators do not provide counseling or psychotherapy; rather, they work with participants to successfully navigate complicated health care and social service systems.

Contingency Management

Behavioral economics is the application of contingencies to motivate individuals toward health-promoting behavior change. The escalating reinforcement schedule (a primary tenet of CM) serves to motivate behavior change. The CM intervention provides vouchers redeemable for goods or services (or purchasing the goods or services online for the participant) that promote a healthy/health-promoting lifestyle.

Baseline Demographics (N = 140)*

Variable	n (%)
Race/Ethnicity	
African American/Black	58 (41.5%)
Hispanic/Latina	45 (32.1%)
Multi/Other	28 (20.0%)
Native American/American Indian	9 (6.4%)
Age	
Range	21 – 61 years
Mean	37.3 yrs (9.8)

***Reached total sample size (N=140) on August 5, 2016!**

Stage of HIV Care Continuum

- 11 were unaware of their HIV positive status; 8.1% new positivity rate
- 32 (22.9%) had never been in care

Engagement in Care Continuum at Enrollment (not mutually exclusive)					
Unaware of HIV Status	Know HIV Status	Never in HIV Care	Dropped out of HIV Care	Need ART	On ART but non-adherent
11	129	32	34	52	80

- 97/134 (72.4%) linked to care
- Range of time from baseline assessment to linkage to care:
  - Range 0 – 488 days
  - Mean 51.1 (SD=91.6) days to link to care

Intervention Process Outcomes

Peer Health Navigation Sessions to Date

- Range of PHN sessions: 1-31 sessions (everyone gets a baseline PHN session); Mean 5.6 (SD = 6.7)
- 37 (26.4%) participants have not had one PHN session after their initial baseline PHN session

Contingency Management Payout to Date

Range of CM Payout $0 - $500; Mean $76.36 (SD = $105.20)

To date, 39/101 (38.7% of those enrolled at least 9 months) participants have achieved an undetectable viral load

Challenges & Lessons Learned

Challenges

- Incarceration
- Homelessness
- Substance abuse
- Participants lack phone, computer access, or other means of direct contact

Lessons Learned

- Patience: a participant may require multiple visits before she is ready to make a significant lifestyle change
- Hormone Replacement Therapy (HRT): educate the participant about HRT and HIV medication, i.e. “protect your beautiful body”
- Staff may disclose their own HIV-positive status to participants, which helps participants relate to and build trust with the PHN
- Use a client-centered approach: Meet the participant where she is at emphasizing *The Alexis Project* is not a drug/alcohol treatment program, increases trust to link participant to care
- Educate doctors and staff at clinics about trans issues via in-services, which has led to better treatment and more respect for our participants

Conclusions

- To date, 72.4% have been linked into HIV care
- Three-quarters (73.6%) have utilized ongoing PHN
- Two-thirds (68.6%) have earned a CM reward
- The combined Peer Health Navigation + Contingency Management appears to be promising for linking and retaining trans women into HIV care
- Participants have been responding to the PHN+CM intervention
  - Achieving undetectable viral load; currently 39 participants have achieved an undetectable viral load
  - Obtaining housing, jobs, substance abuse treatment and other needed services for our participants
- Longitudinal data will provide distal outcomes on viral load suppression