Notes From the Field: Engaging and Retaining Women of Color In HIV/AIDS Care

Special Projects of National Significance Program: Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative

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National Evaluation and Technical Assistance Center for the Special Projects of National Significance Program, Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative

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Acknowledgements:

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Learning Objectives

- To identify barriers and facilitators that impede or enhance engagement and retention in HIV/AIDS primary care for women of color
- To learn about multi-level interventions that can sustain patient-provider partnerships
- To learn how to include empowerment/strengths-based approaches while working with women of color during HIV/AIDS treatment

Disclosures

Arthur E. Blank, PhD, Dr. Phil Farmer, LMSW, Elizabeth Eastwood, PhD, Rachael Morgan Peters, MPH have no financial interests or relationships to disclose.

HRSA Education Committee Disclosures
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Estimated Numbers of AIDS Cases and Rates for Female Adults and Adolescents, by Race/Ethnicity 2007—50 States and DC

Race/Ethnicity	Cases	Rate (Cases per 100,000 population)
American Indian/Alaska Native	46	5.0
Asian*	93	1.6
Black/African American	6,243	39.8
Hispanic/Latino†	1,452	8.9
Native Hawaiian/Other Pacific Islander	12	7.1
White	1,600	1.8
Total‡	9,579	7.5

Note. Data have been adjusted for reporting delays.
*Includes Asian and Pacific Islander legacy cases.
†Hispanics/Latinos can be of any race.
‡Includes 132 female adults and adolescents of unknown race or multiple races.

AIDS Rates for Female Adults and Adolescents Reported in 2007—United States and Dependent Areas

2.2
2.2
4.2
6.2
*
1.5
1.2
*
4.0
2.1
1.9
*
*
1.9
1.8
3.6
7.2
1.8
1.0
4.2
3.8
14.7
1.9
5.8
8.2
3.5
2.9
7.9
5.8
3.6
3.2
2.1
4.9
10.0
17.7
7.8
13.0
12.3
17.0
*
1.0
3.4
1.7

NH	2.5
MA	6.0
RI	3.4
CT	11.3
NJ	10.3
DE	14.4
MD	22.2
DC	90.2

Rate (per 100,000 population)

<5.0
5.0–10.0
>10.0

American Samoa	*
Guam	*
Northern Mariana Islands	*
Puerto Rico	14.2
U.S. Virgin Islands	27.2

*Rates were not calculated for areas reporting fewer than 5 AIDS cases in females in 2007.

Female Adults and Adolescents 15 to 44 Years of Age Reported to be Living with HIV Infection (not AIDS), 2007—47 States the District of Columbia and 5 U.S. Dependent Areas

N=56,235*

State	Number
WA	435
OR	150
CA	1,970
ID	47
NV	374
MT	17
WY	24
UT	123
AZ	568
CO	389
NM	104
ND	16
SD	51
NE	136
KS	186
OK	290
TX	4,675
MN	582
IA	112
MO	647
AR	489
LA	1,927
WI	338
IL	1,501
MI	1,008
IN	590
OH	1,274
KY	252
TN	1,462
MS	1,142
AL	1,254
GA	2,213
FL	8,427
SC	1,404
NC	2,835
VA	1,823
WV	138
PA	2,477
NY	8,333
ME	38
AK	52
NH	82
MA	188
RI	32
CT	712
NJ	2,982
DE	258
DC	329

Area	Number
American Samoa	1
Guam	6
Northern Mariana Islands	0
Puerto Rico	1,388
U.S. Virgin Islands	79

Legend: Confidential HIV reporting; Confidential HIV reporting <4 years

Note. Data from 47 states, the District of Columbia, and 5 U.S. dependent areas with confidential name-based HIV infection reporting as of 2007. Data based on person's age as of December 31, 2007.
*Includes 130 persons reported from areas with confidential name-based HIV infection reporting, but who were residents of areas without confidential name-based HIV infection reporting. Includes 175 persons whose state of residence is unknown or missing.

POWER: Peer Outreach Worker Entry and Retention Program

FACES Network
Brooklyn, New York

Elizabeth Eastwood, PhD, Project Evaluator, Brooklyn College Department of Health & Nutrition Sciences

Rachael Morgan Peters, MPH, LMSW, POWER Program Coordinator, SUNY Downstate Medical Center

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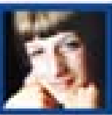
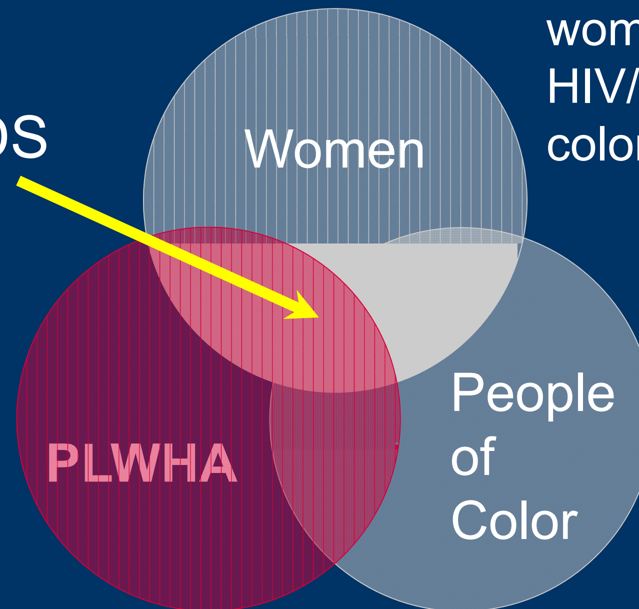
The Setting: Who we are and who we care for

Brooklyn



What barriers impede women of color from accessing or remaining in care?

Women of color who are living with HIV/AIDS



The barriers our target population experience converge at the intersection of the barriers experienced by women, People Living With HIV/AIDS, and People of color.

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How does our intervention address the barriers women of color encounter in accessing or remaining in care?

- Peer
  - “She [a client] popped open when I told her.”
  - “I saw a look of relief spread over her face.”
  - “I wish I had had someone like this.”
- Outreach
  - “I feel so special.”
  - Shift priorities
- Worker
  - “This could be me.”

How does the theory behind our intervention build on, or build up the strengths of Women of Color?

Motivational Interviewing (MI)

- "*Motivational interviewing is a directive, client-centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence*."
  Stephen Rollnick, Ph.D., & William R. Miller, Ph.D.

- Peer Outreach Workers trained in MI. Focused on helping the client to make changes that the client has identified. The Peer Outreach Workers respect the client's decisions and choices regarding their behavior.

What challenges have we encountered in developing or implementing our intervention?

- Hiring
  - Salary/Benefits
- Training
- Supervision
  - Documentation
  - Boundaries
  - Over identifying with clients
- Morale
- HIV all day

Evaluation – the challenges of creating an efficient and effective system across five Network partners

- Developed simple, easily measurable outcomes
- Sought buy-in from medical providers at the outset
- Had case management supervisor across all sites
- Had buy-in from partners that ‘barriers to care’ is an important clinical issue so willing to use research methods to find solutions
- Used Andersen’s (1995) behavioral and contextual model of health-seeking factors

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Lessons Learned

- It's possible to hire, train, and deploy peers. They are smart, resourceful, and really motivated.

- Can we collect data and do a good evaluation demonstrating the peers had an impact on client outcomes?... stay tuned!

Project WE CARE:

Women Empowered to Connect and Remain Engaged in Care

Ruth M. Rothstein CORE Center

CORE Foundation

Marisol Gonzalez and Allison Precht

L'Oreal Bailey, Seliciano Douthard, Debbie Mata, Nichelle Pierson, (Not pictured: Susan Ryerson Espino, Lynne Mock, Jennifer Camacho Catrambone)

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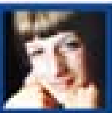

The Setting: Who we are and who we care for

- Cook County Health and Hospitals System – Public “Safety-Net” Facility
- 5,000 active patients, 35,000 primary care visits annually
- 64% African American and 20% Hispanic/Latino
- Frequent history of drug use, incarceration
- Approximately 1200 women with HIV annually.
- An estimated 70-75% of all HIV infected women and 25-30% of HIV infected children known to be in care in the Chicago area.

The Setting: Who we are and who we care for (cont.)

- Women of color
- Below federal poverty level
- Newly diagnosed – (Diagnosis in the last 6 months)
- Lost to Care: No HIV primary care visit in 12 month period
- Sporadic Care: One HIV primary care visit in 12 month period
- Lost to Follow-Up: 2 or more missed and re-scheduled visits

What barriers impede women of color from accessing or remaining in care?

Individual-Level

- Poverty
- Homelessness
- Mental Health/ Substance Abuse
- Personal Beliefs / Stigma
- Domestic Violence
- Depression

How does our intervention address the barriers women of color encounter in accessing or remaining in care?

- Co-located Medical and Social Services
  - case management
  - chemical dependency
  - dental labs
  - legal services
  - peer education
  - pharmacy
  - mental health
  - nutrition
  - research
  - children's play room
- Culturally Competent and Experienced Providers

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How does our intervention address… (cont.)

- **Use of Patient Navigators**
  - Replicate model shown to be successful with breast cancer patients.
  - Consumers at CORE Center
  - Culturally matched to establish trust/patient identification
- **Healthy Relationships Intervention**
  - Skills building/educational intervention
  - Centers for Disease Control and Prevention DEBI (Diffusion of Effective Behavioral Interventions) model

How does our intervention address… (cont.)

Building on Consumer Strengths

- Indigenous Peer Patient Navigators will improve linkages to care from:
  - John H. Stroger Hospital Emergency Department
  - Cook County Department of Corrections
  - Community based HIV testing settings
- Peer Patient Navigators will work individually with clients to:
  - Dispel myths
  - Build trust and reduce stigma associated with HIV, help with accessing various services
  - Provide follow-up on patients who miss appointments through phone calls, home visits and outreach in the community

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How does the theory behind our intervention build on, or build up the strengths of women of color?

- Theoretical Basis of Project WE CARE:
  - Social Learning Theory/Social Cognitive Theory (SCT)
    - Consumers at CORE Center
    - Culturally matched to establish trust/patient identification
    - Patient Navigators are positive role models of PLWHA who exhibit healthy life-style behaviors
  - Health Belief Model (HBM)
    - Patient Navigators will:
      - Dispel myths
      - Provide HIV education and Medication Adherence

What challenges have we encountered in developing or implementing our interventions?

- Patient Navigators (PN) may be viewed as case managers by patients and case managers
- Interviewing Process
  - Interview Panel
  - Candidate Interviewing Skills
- Patient Navigator Job Descriptions

Lessons Learned

- Emphasize that Patient Navigators are an adjunct service to case management through informational sessions to all disciplines
- Need of Interview skill trainings
- Importance of multi-disciplinary interview panel
- Importance of working with HRSA officer, HR and legal department on developing patient navigator job descriptions

Special Health Resources for Texas, Inc. (SHRT)

Dr. Phil Farmer, LMSW

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The Setting: Who we are and who we care for

- Special Health Resources for Texas, Inc. (SHRT) serves the 23 counties of Northeast Texas.
- SHRT is the primary testing, prevention, education, and treatment provider for HIV/AIDS in the region.
- This region has 1 million residents, spread out across 23 rural counties.
- SHRT serves over 1,000 of the 1,400 identified persons living with HIV/AIDS in care.

What barriers impede women of color from accessing or remaining in care?

- Primary barriers include:
  - lack of services in rural areas
  - attitudes of the faith community about HIV
  - need for ongoing supportive contact with clients

How does our intervention address the barriers women of color encounter in accessing or remaining in care?

- SHRT has a “one stop shop” model of care to engage and retain HIV infected women of color in care, providing medical services at 4 locations: Longview, Tyler, Texarkana, and Paris.
- SHRT will provide primary medical care through its Federally Qualified Health Center (FQHC) look-alike clinic in Longview.
- After engagement in care, an intensive case management model will be used that includes a strengths perspective theoretical foundation.

How does our intervention address the barriers… (cont.)

Engagement in care will occur in a variety of ways:

- Women of Color (WOC) already in care will be strongly encouraged to enroll in the program
- WOC who have dropped out or are sporadic in their care will be assigned to the program
- Newly diagnosed HIV positive WOC will receive same day initial appointment
- Clients, families/significant others and the community at large will receive education
- Clients and families/significant others will be included in support groups

How does the theory behind our intervention build on, or build up the strengths of women of color?

- The strengths perspective is taken from social work theory
- This approach views the client as a partner in treatment, not the object of treatment
- Work is focused on what a client likes and is willing to do to meet their needs, rather than from a problem-based perspective

What challenges have we encountered in developing or implementing our intervention?

- A primary challenge involves finding ways into the African American faith community, which has been identified as an important subgroup to involve in education and support.
- The agency has begun this process by applying for a grant focused on just this issue and has engaged in a partnership with an African American minister in Atlanta, Georgia in order to develop new approaches to the faith based community.

Lessons Learned

- Since SHRT has been providing these kinds of services for many years; previously learned lessons have been applied to this program.
- At this time, the only lesson has been to include staff in the evaluation process from the very beginning and, as clients become involved, they will be included in the evaluation process as well.

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Guide to Healing
University of North Carolina – Chapel Hill

E. Byrd Quinlivan

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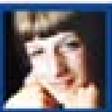

The Setting: Who we are and who we care for

HIV + Women seen in 2009

Demographics:

- WOC = 81% (380)
- AA = 84% (320)
- IVDU = 11% AA, 1% Hispanic
- HTS = 81% AA, 87% Hispanic

Geography, Transportation

- Intercity w/ urban buses
- Rural w/ Medicaid vans, informal

Qualitative Study:

- 2 focus groups
- 19 interviews*
- Recorded, Transcribed, Reviewed

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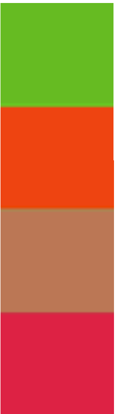

What barriers impede women of color from accessing or remaining in care?

	Accessing	Remaining
B	Not getting immediate results Waiting for appointment Feeling like you are going to die	Felt good Tired of seeing sick people Depression Medications make you sick Travel time, weather Did not get reminder Appointment availability
F	Family support Getting educated Anonymous testing Friend dies in prison (IVDU partner) Money for testing Found life partner Afraid would infect baby	MD being advocate (w/ referrals) MD / staff caring Seeing positive progress Education Medications work Social workers Appointment reminders

How does the theory behind our intervention build on, or build up the strengths of women of color?

Self-Determination Theory

Competency

“Feel confident”
“Capable”
“Able to do my care”
“Able to meet challenge “
“able to learn new skills”

Autonomy

“free to decide”
”free to express”
“takes my feelings into account”
“can be myself”

Relatedness

“provided choices & options”
“feel understood”
“able to be open”
“has confidence in my ability”
“Accepts me”
“makes sure I really understand”
“encourages me to ask questions”
“answers my questions”
“listens to how I would like to do things”

Theoretical framework … (cont.)

Competency

"… don't send us to do the test like just that. Have the person who knows everything about the test, and make feel us like we're prepared to this. Because we're not prepared, but we're gonna get prepared if they do all the stuff. 'Look this, look that, you can do this, you can do that. And change this, and change that. And take care of yourself'…."

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Theoretical framework … (cont.)

Autonomy

"…I feel good that I've been following this regimen, and doing what she asks of me. You know. And see the progress."

****

"… I like seeing her because I can tell her that I've got a lot going on. …"

****

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Theoretical framework … (cont.)

Relatedness

… Some people don't understand how it makes you feel to know that you're not in this thing by yourself.."

****

"At first I was scared, 'cause I said, 'Why are all these people so nice?' …. I started to just leave the clinic, but they made me feel comfortable. That's why I kept coming..."

****

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How does our intervention address the barriers women of color encounter in accessing or remaining in care?

Structural

- Appointment access
- Cells phones, child care

Provider

- Nurse case manager
- Support / educational group

Patient

- Motivational interviewing
- Strengths perspective

Relatedness

- Support group
- Nurse case manager

Competency

- Education, orientation
- Resources: phones, childcare

Autonomy

- Motivational interviewing
- Strengths perspective
- Participant input

What challenges have we encountered in developing or implementing our intervention?

Phone support:

- No texts
- Yes use for information, like drug interactions
- No, not someone who asks 50 questions
- "Talk to a person, not machine"
- "Have prerecorded messages like the IRS to choose from"

Child care:

- Recognized as needed by some but not all
- Important to be away from child to get care needed
- Irritated with children who are not well-controlled
- H1N1 lead to efforts to minimize visitors, esp. children
- One child found out mother's diagnosis by coming to clinic

Lessons Learned, Next Steps

- Complex individual networks of barriers & facilitators.
- Core needs are expressed.
- Relatedness was expressed more often than competency or autonomy. *More important or are we more successful in meeting this need?*
- Analysis of the impact that core needs have in successful medical encounters needs to be completed.
- Interventions that address the core needs as well as the overt barriers, facilitators need to be developed.

Some Lessons Still to be Learned: Stay Tuned

- Will peers effectively engage, and help retain women of color in care?
- Will one stop shopping effectively engage and retain women of color in care?
- Which intervention(s) will be easier to adopt, implement and maintain?
- How will the various intervention(s) improve the quality of clinical care?