



Behavioral Health and Retention in HIV Care Mother and Child

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Behavioral Health and Retention in HIV Care Mother and Child

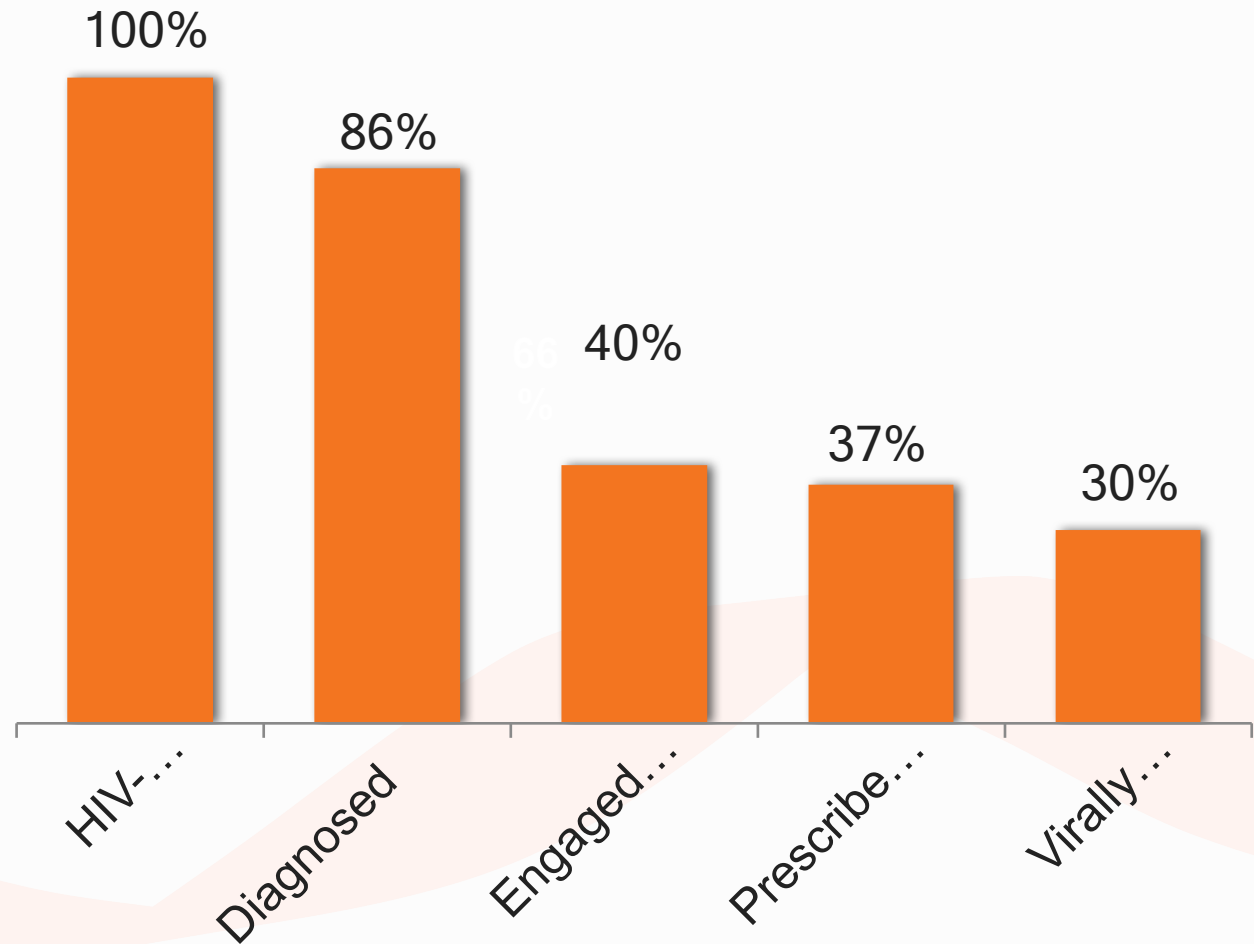
By participating in today's webinar participants will be able to:

1. *Discuss* how providing cross cultural responsive care can positively impact the lives of individuals living with HIV.
2. *Discuss* some of the psychosocial factors that influence antiretroviral (ARV) adherence and engagement in care during and following childbirth.
3. *Identify* some of the potential psychosocial outcomes of HIV stigma for women across the lifespan.
4. *Discuss* the risks and benefits of HIV disclosure for women during the childbearing years.
5. *List* two screening instruments that assist in the identification of women living with HIV who may have experienced interpersonal violence (IPV) and other traumatizing events.

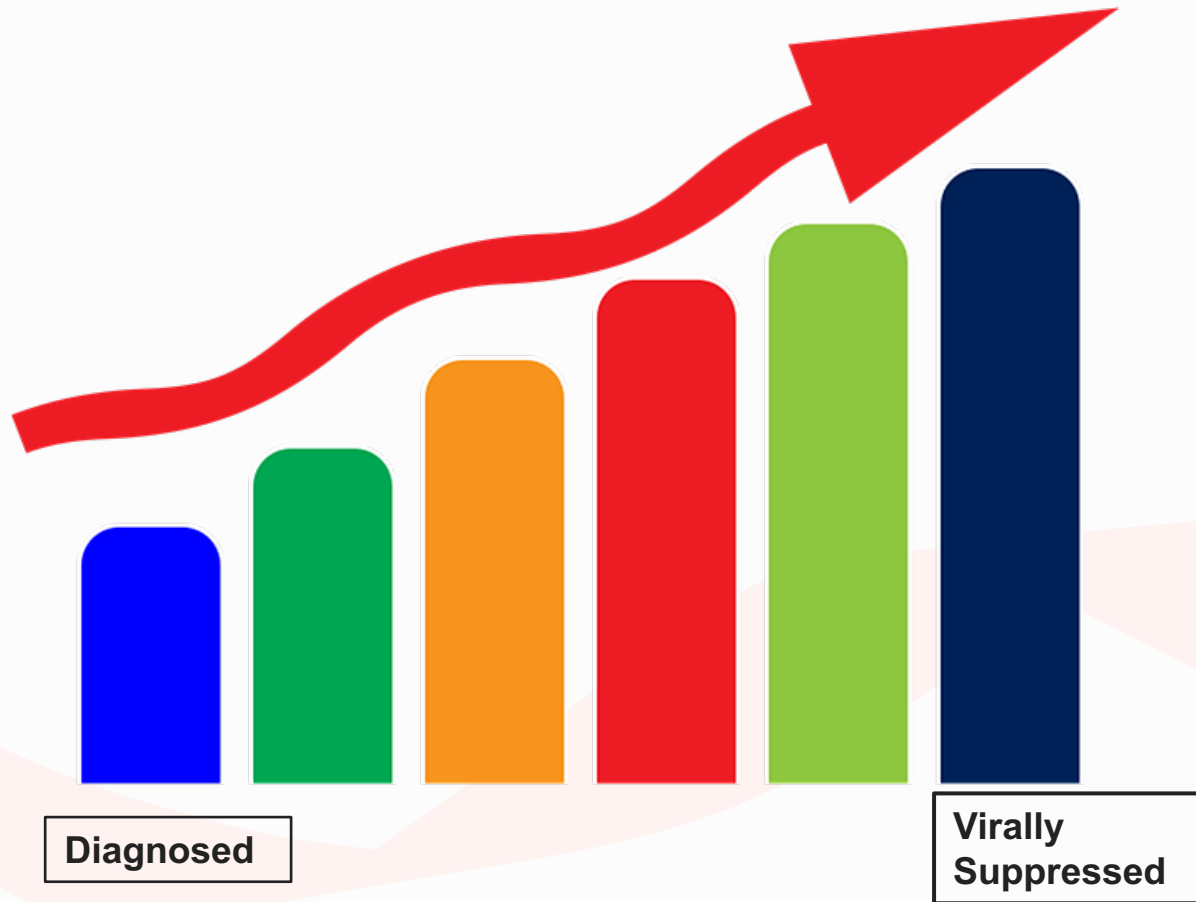
The HIV Care Cascade in the US (2014)

Biggest drop-offs in the care continuum result from inadequate supports to link, retain, re-engage, and support people to remain engaged in care — functions the health system historically has not been good at performing.

ART = antiretroviral therapy.



HIV Care Cascade 2020- United States



Evidence *AIDS CARE* Study 2014

What Drives Antiretroviral Therapy Adherence and Viral Suppression?

Key Finding

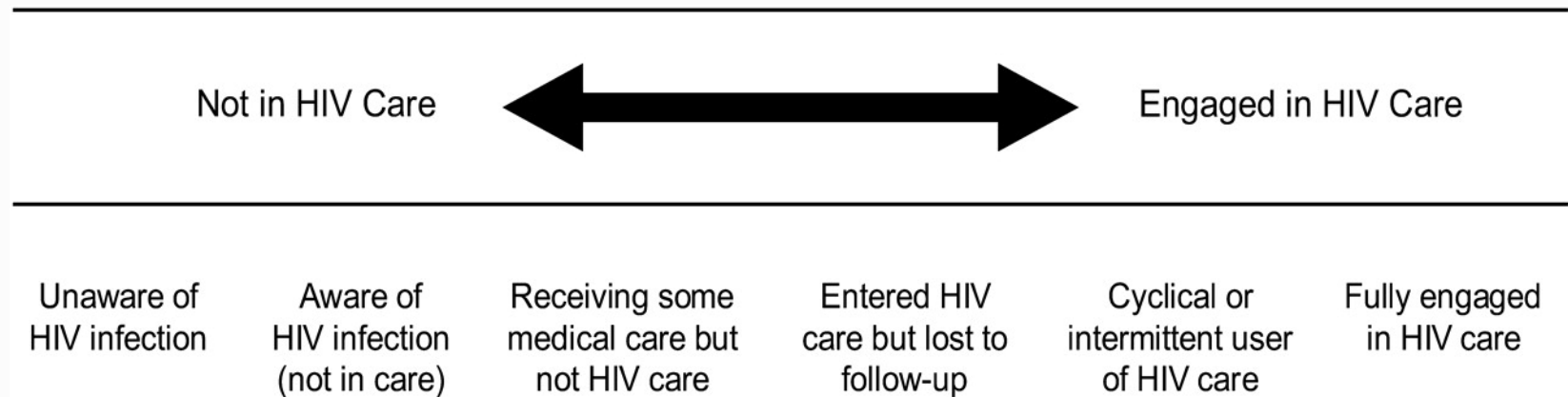
**Contact with Providers
Improved engagement in care**

Engagement in Care

ALL Persons in HIV Care:

- are more likely to have a prescription for antiretroviral treatment (ART)
- are more likely to be taking ART
- ↑ **Quality of Life** with reduced co-morbidities

Health Resources and Services Administration (HRSA) continuum of HIV care, describing the spectrum of engagement in HIV care.



Edward M. Gardner et al. Clin Infect Dis. 2011;52:793-800

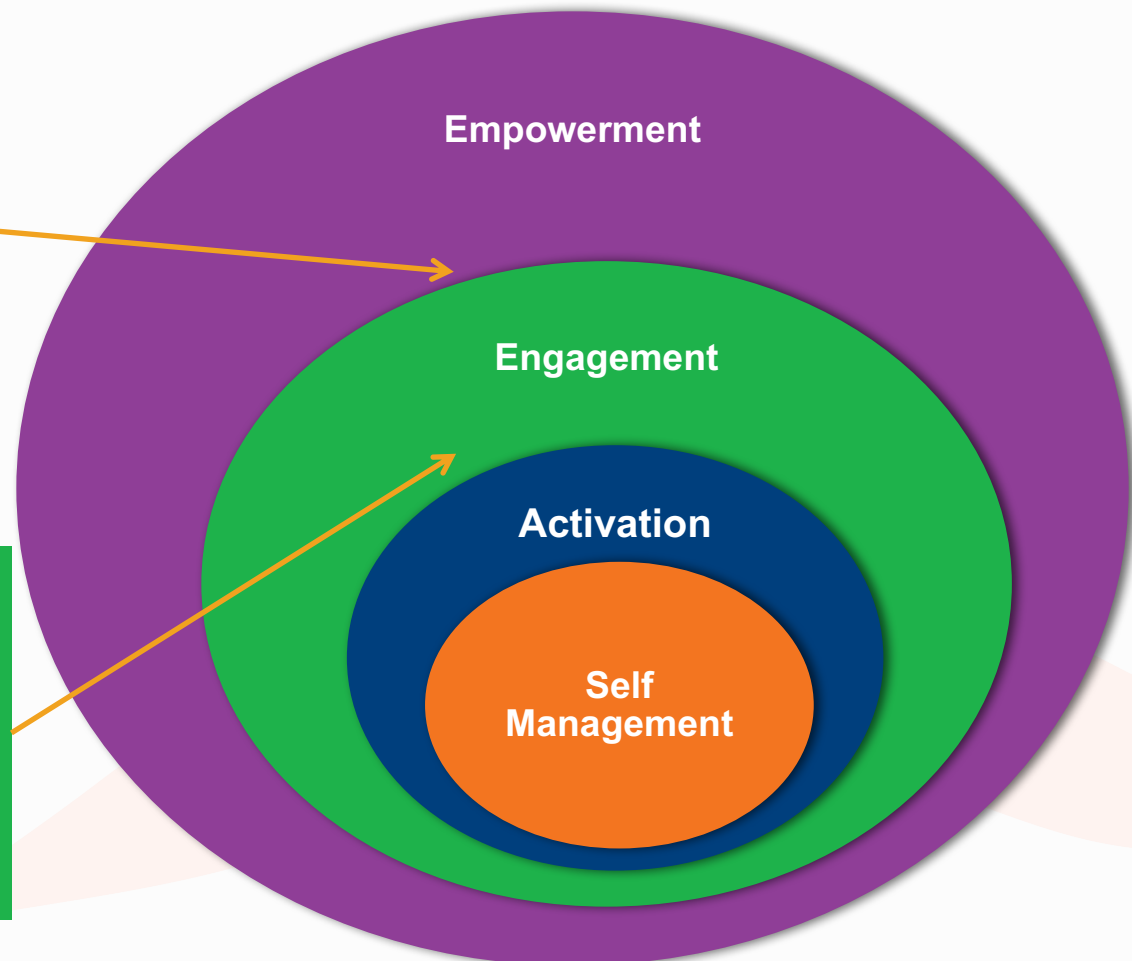
Patient Empowerment & Engagement in Care

“A process through which people gain control over decisions and actions affecting their health.”

(WHO, 1998)

“Actions individuals must take to obtain the greatest benefit from the healthcare services available to them.”

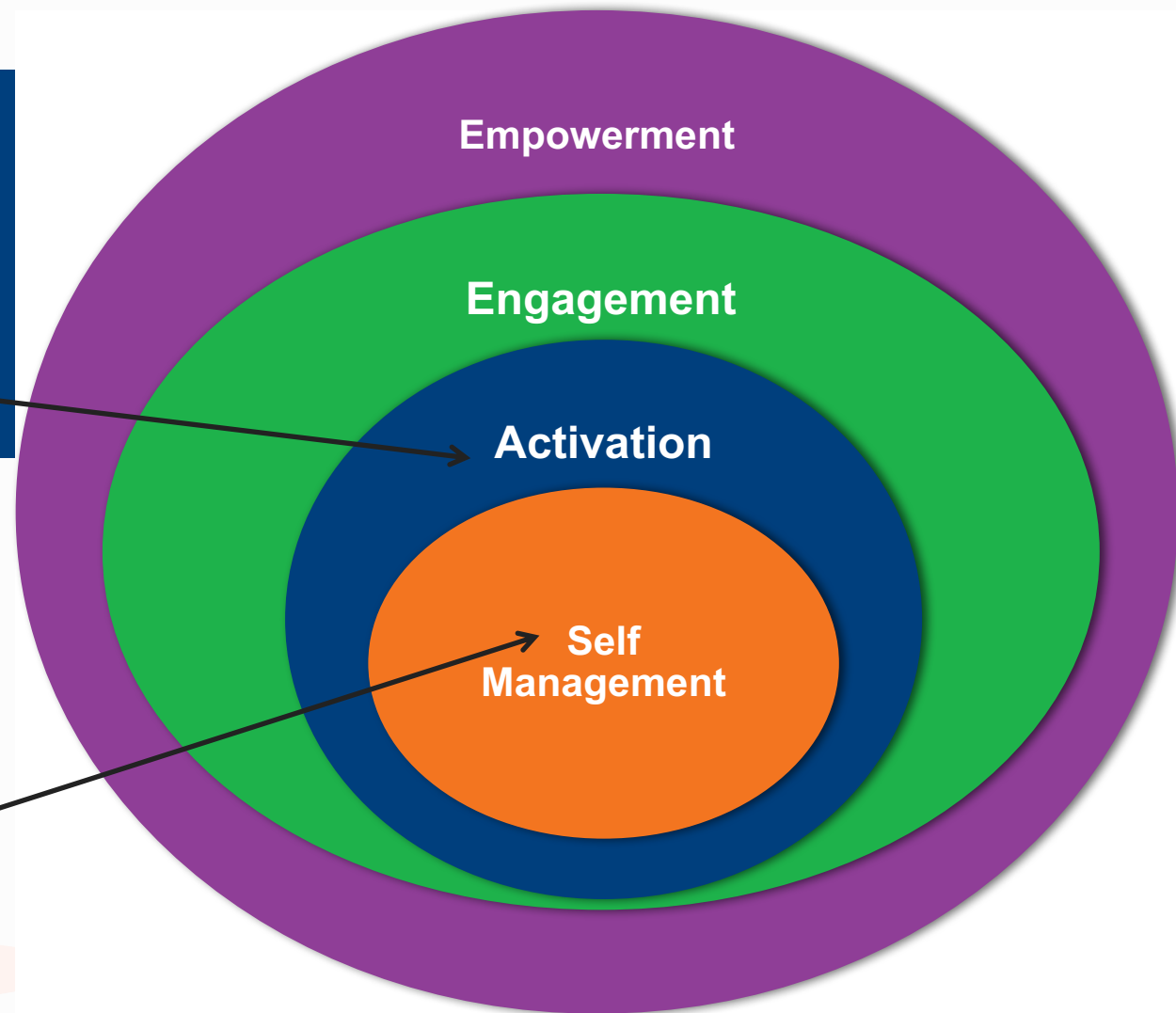
(AHRQ, 2010)



Activation and Self-management

“An individual’s knowledge, skill and confidence for managing their health/healthcare.”
(Hibbard, 2004)

“Tasks individuals must undertake to live well with illness & includes having the confidence to deal with medical, role and emotional management of illness.”
(IOM, 2003)



Who is NOT Engaged in HIV Care?

Four Key HIV Subpopulations

- MSM of Color
- African American and Latina Women
- Youth (under age 24)
- Transgender People

Who Else?

Post-partum women
Living with HIV

I found out about my HIV status when I was 16 weeks pregnant.



I am a pregnant woman living with HIV.

I face many issues.



HIV-positive & pregnant?

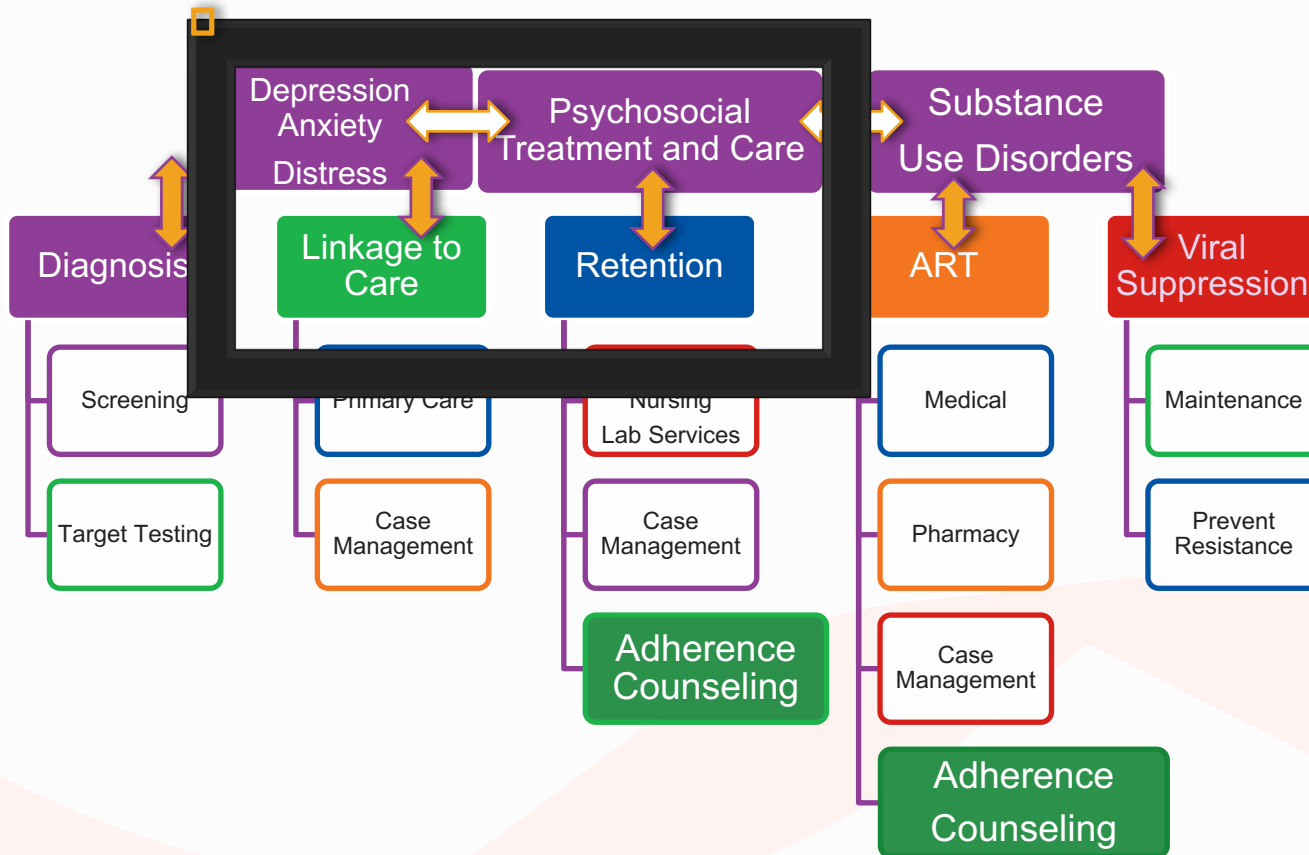


Protect your own health and **lower your risk** of passing HIV to your baby **by taking HIV meds**

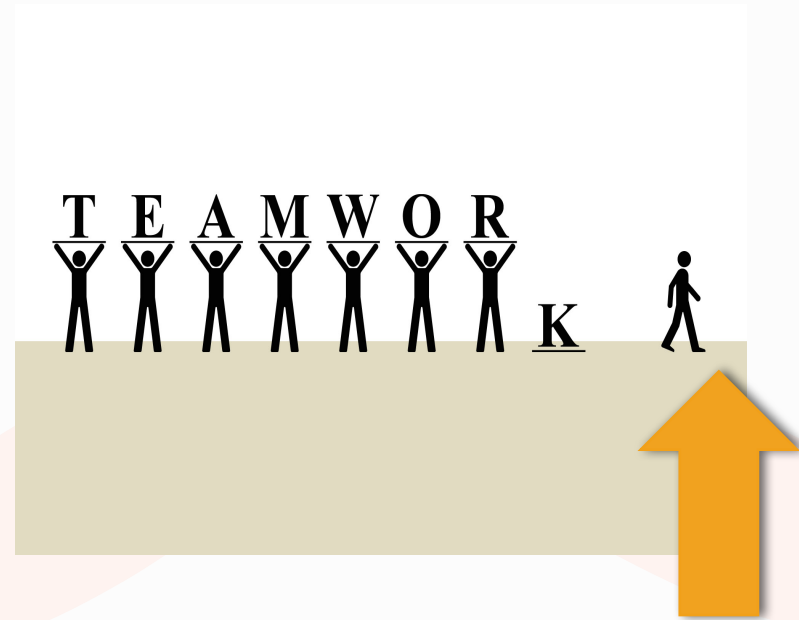


Andrew McCaul

Pregnancy and the HIV Care Continuum



PATIENT ENGAGEMENT AND TEAM-BASED HEALTHCARE



Real people with
different health
journeys make up
the HIV Care
Cascade



Health Journey: J's Story

Diagnosis

- 21 year old Black African American
- Perinatally infected

Linkage Retention

- Raised by maternal grandmother because mother died from HIV complications when J was two years old
- Many childhood losses including house burning down resulting in temporary homelessness
- Biological father died when she was 13
- Grandmother died when she was 14

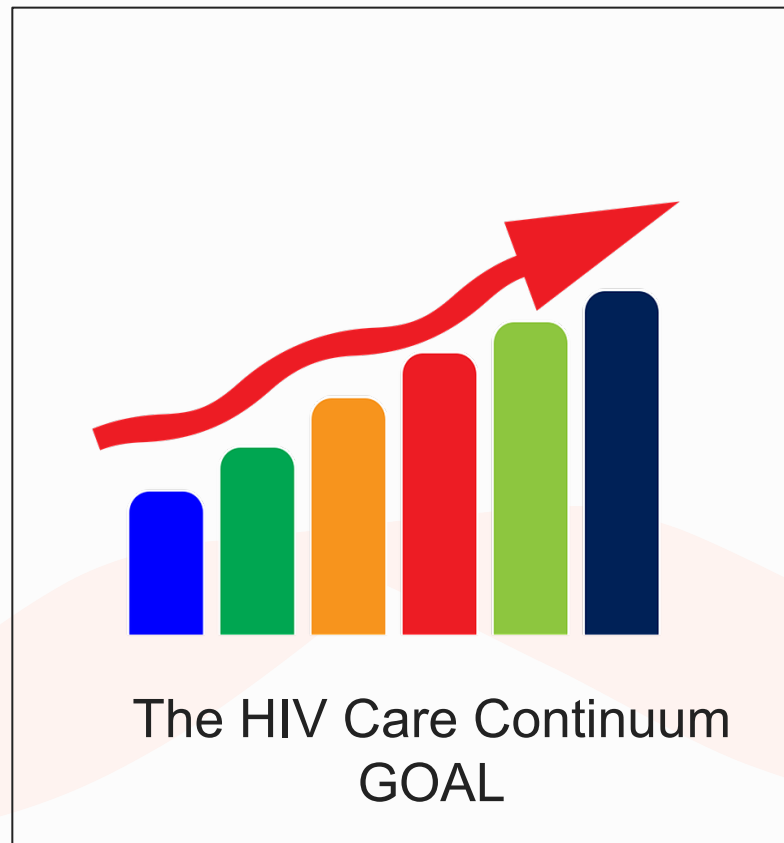
Antiretroviral Treatment

- Started ART at birth; some adherence challenges at age 14
- First pregnancy at age 16 (Child HIV-negative)
- Second pregnancy at age 19 (Child HIV-negative)
- Viral load hovers between 200 and 9000
- Lost to care for 1-2 years after each pregnancy
- Heavy alcohol use; works at fast food restaurant; positive screen for depression
- Healthcare team describes her as being “slightly obese, sweet-natured, but stubborn, and moderately adherent”

“MOTIVATION TO ENGAGE IN CARE IS NOT PUSHING.”



What is the Healthcare Professional's Role in Guiding Patients to Change their Health Behaviors?



Close Loops on Gaps in Care



Think Tank: Short Response Group Question



What happens after childbirth that interferes with a woman's ability to stay engaged in HIV Care?



I don't have
child care

I'm too tired

I feel fine

Taking care of my
baby takes all my time

My baby's
health is
more important

Postpartum Disengagement

I don't have
anyone to help
me

I don't have any time to go anywhere

I couldn't reschedule

I had to go back to work

Research on Postpartum Engagement in Women Living with HIV (WLWH)

Collaborative effort between Drexel University College of Medicine and the Philadelphia Department of Public Health

- **Retrospective study:** HIV-infected women delivering babies in Philadelphia between 2005 and 2013
- **Engagement in HIV care** was defined as a recorded CD4/Viral Load within 90 days of delivery and at 12 and 24 months post delivery
- **At 90 days postpartum 38% of the women were engaged in care**

Philadelphia Study (2015) Findings

- Women who engaged in HIV care within 90 days of delivery were more likely to be retained at 1 year postpartum.
- This pattern persisted in the second year postpartum for both retention and viral load (VL) suppression.

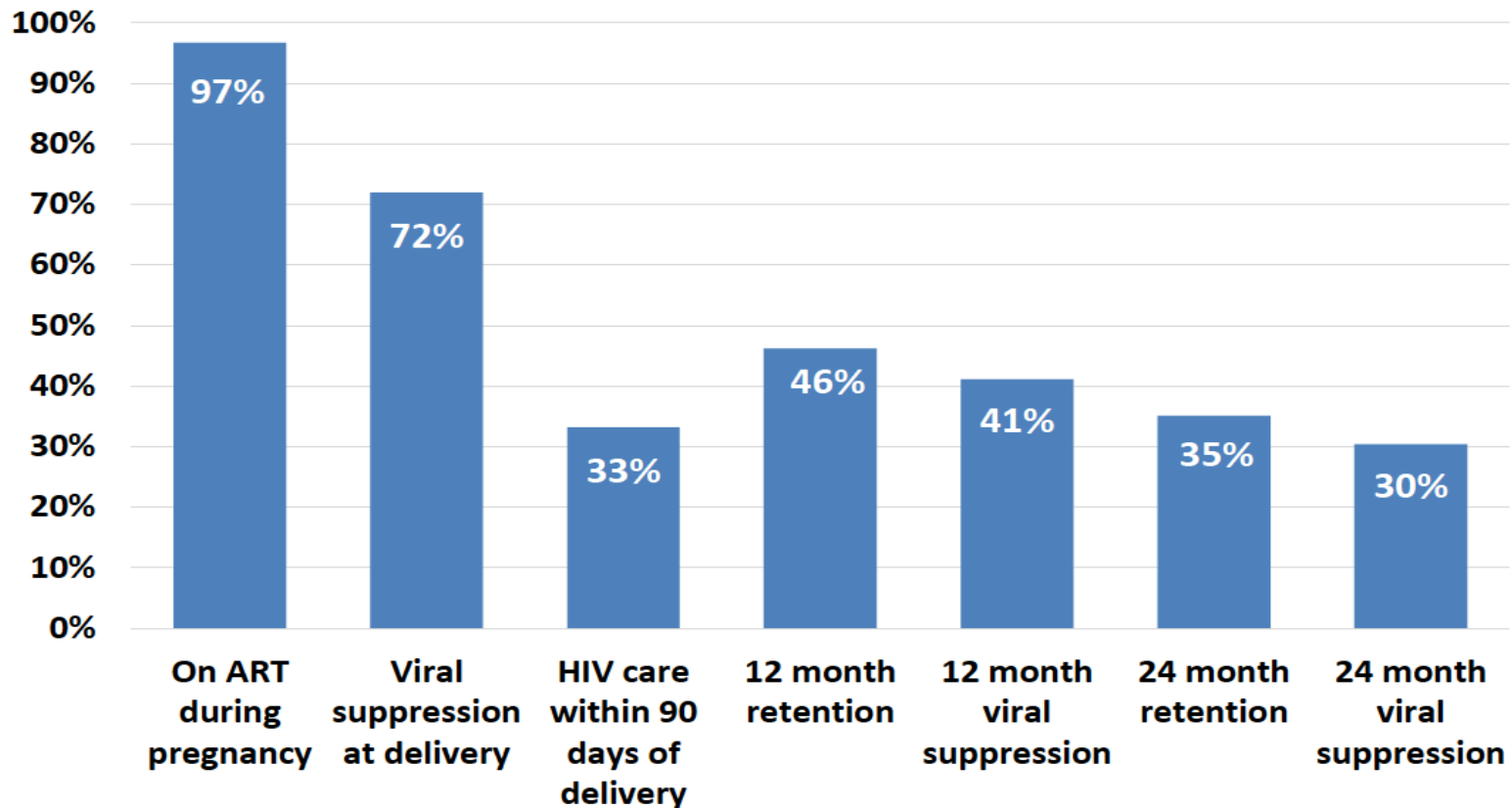
Research on Postpartum Engagement in Women Living with HIV (WLWH)

Repeat Pregnancies and HIV Care Engagement among Postpartum HIV-infected Women in Atlanta, Georgia, 2011-2015

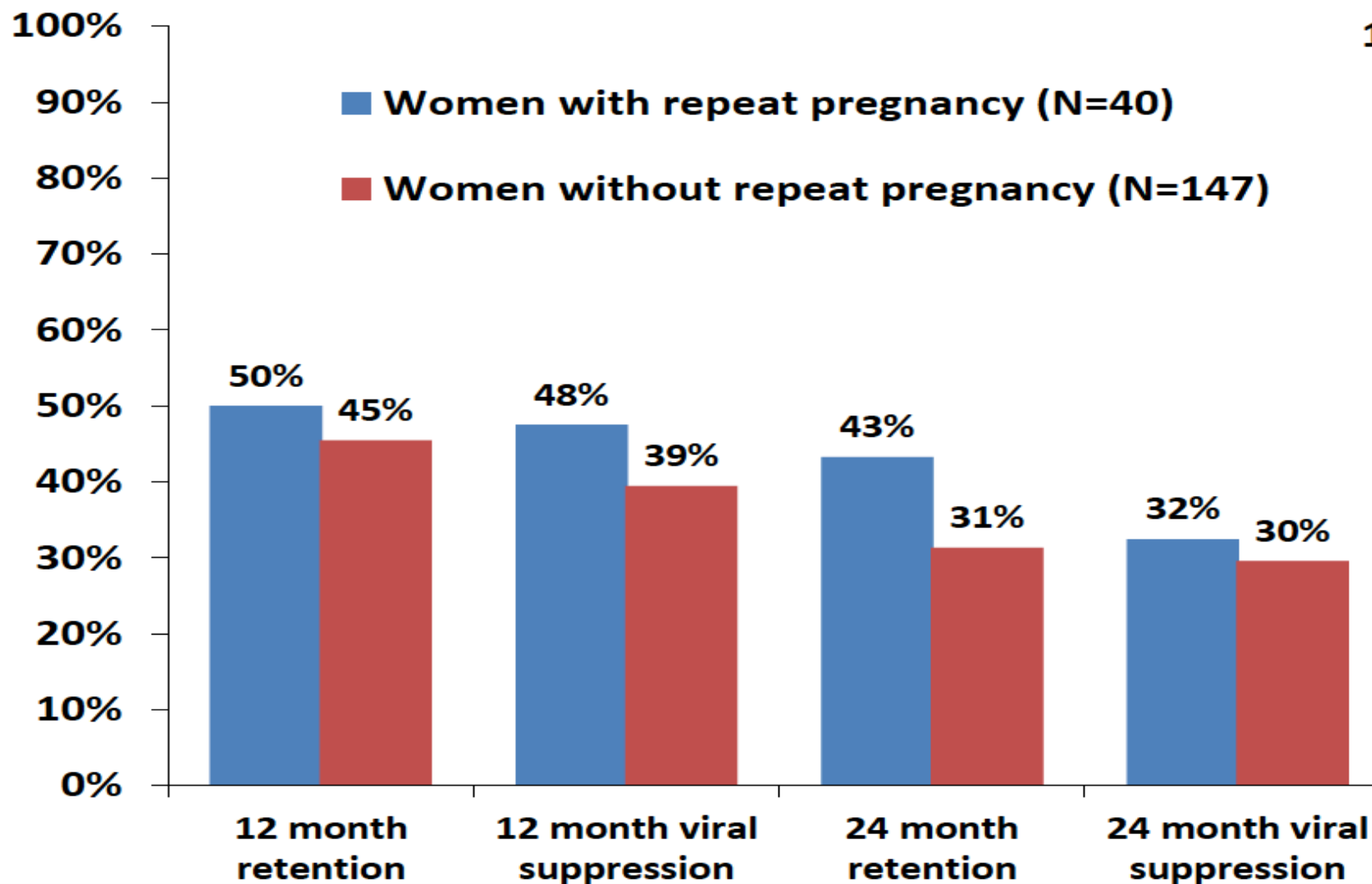
- **Retrospective Study**
- **Findings: 33% attended HIV care visit within 90 days of pregnancy; 64% experienced ART treatment interruption;**
Women without repeat pregnancy=147; Women with repeat pregnancy=40
- **Definitions:**
 - Postpartum HIV care engagement = first HIV care visit after delivery
 - Retention in HIV care= 2 HIV care visits or Viral Load (VL) measures > 90 days apart at 12 and 24 months postpartum
 - VL Suppression= last HIV-1 RNA level within the time interval <200 copies/mL
 - Repeat Pregnancy= Any pregnancy after the “index” delivery over a 2-year period

Atlanta Study 2015 Findings

Postpartum HIV Care Continuum (N=214 deliveries)



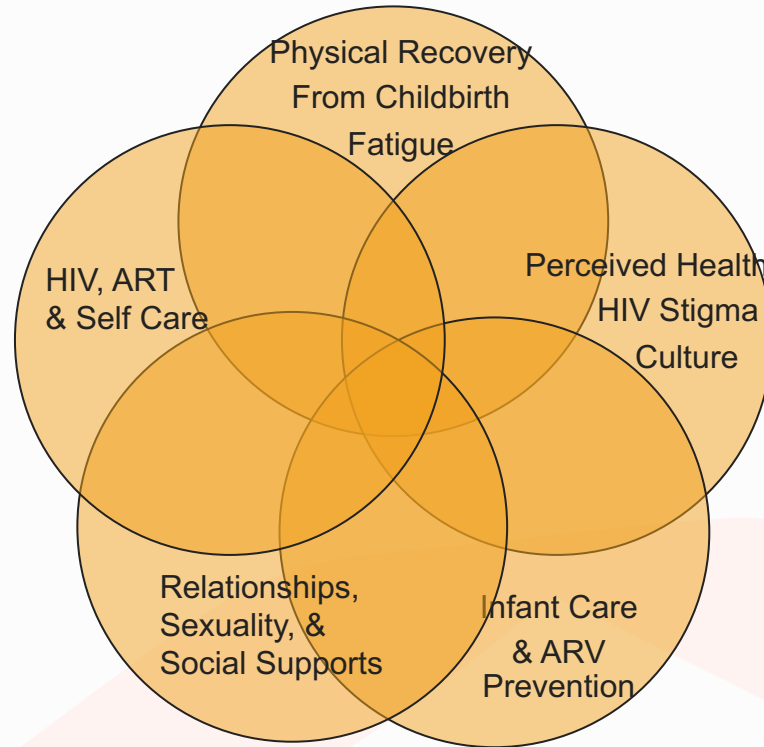
Atlanta Study 2015 Findings



Conclusions from Retrospective Studies on Postpartum Care for WLWH

- Long-term postpartum HIV care retention and viral suppression was low in both studies
- Second study (Atlanta population) discovered that repeat pregnancy *was not* associated with worse long-term health outcomes AND repeat pregnancy *may have had a beneficial impact* on health outcomes related to the intensity of the HIV treatment and care received during the subsequent pregnancy
- Prompt transition to postpartum HIV care can optimize HIV health outcomes and should be continuously integrated with reproductive health care throughout the reproductive years

What are the Key Issues that Need to be Addressed During and After Pregnancy for WLWH?



providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions

Person-Centered Care

- Institute of Medicine Crossing the Quality Chasm: A New Health system for the 21st Century (2001)

Person-Centered Team Care

- **Patient care clinic visits are organized to address both acute and planned care needs, such as postpartum**
- **Protocols/alerts exist** for when a patient comes to clinic and is overdue for screenings and/or assessments, including behavioral health screenings
- **Individualized Healthcare Plan** updated at each visit



Healthcare Teams are in the Business of Empowering Patients

**EMPOWERED
PATIENTS**

**PLAY AN
ACTIVE ROLE**

**IN THEIR OWN
TREATMENT**



Models of Care that Address

- Patient Activation
- Patient Engagement

Process

Tools

Interventions

Practice
Transformation

Engagement in Care: Critical 90-Day Window for Postpartum WLWH

ASSESS

Engagement, Unmet Needs,
Fatigue, Health Literacy,
Behavioral Health, IPV

BUILD Partnership
FACILITATE Self Care &
HIV Self Management

REASSESS

Level of Engagement/Unmet
Needs/Health Outcomes

EVALUATE

30
Days



60
Days



90
Days

Working Together to Identify Optimal Practices to Improve Health Outcomes

The 4th Trimester Project

Goal:

- To bring together patients, clinicians, researchers, and other stakeholders to define patient-centered research priorities in the first three months after birth, laying the groundwork for comparative effectiveness studies that will determine optimal practices to improve outcomes for mothers and infants.

Follow on Social Media:

Website: 4thtrimester.web.unc.edu

Facebook: <http://j.mp/4thTriFB>

Twitter: [@4thTriProject](https://twitter.com/4thTriProject)



Patient Activation

Judith Hibbard, Health Policy Professor,
University of Oregon

Patient Activation Measure (PAM)

- Instrument designed to identify how actively patients will participate in their care
- **Premise: patients will not follow treatment goals that they do not believe they can follow or that compromise other priorities**
- Tool has been used to tailor information and intervention to patients' needs
- Patients with little to no understanding of their disease and little to no confidence receive more support/education
- Short Form 22 items(2005)

Engagement in Care Components

1. Clinic structure
2. Provider approaches
3. Ancillary services
4. Personal/cultural
5. Financial
6. Medical
7. Co-existing conditions
8. Engagement Measurement

Retention Readiness Indicator Tool

Why Retention Matters

The Retention Readiness Indicator Tool (RRIT) uses the latest research on why the most vulnerable populations fall out of care, and is intended to support HIV treatment teams in assessing their ability to screen for and counter these factors. By identifying the treatment team's goals for a patient and assessing both individual and structural barriers to care, RRIT provides the opportunity for evidence-based decisions with patients.

Practical Retention Strategies

The 4 components of the RRIT can be used independently or comprehensively, depending on the needs of your patients and your resources and infrastructure. The tool can be used as a framework for case conferencing, as a checklist for clinicians at screening or intake, as a treatment planning worksheet, or infused into quality assurance protocols.

Measure Retention Efforts

HIV treatment and care providers are working to implement high-impact prevention to better serve the 80% of HIV infected individuals who are not fully engaged in care. The RRIT identifies opportunities to evaluate the process measures that have been shown to lead to increased retention in care.

O'Neill Center: Interactive Care Model (ICM)

Five Key Encounters

1. Assessing patient's capacity for engagement
2. Exchanging information and communicating choices
3. Planning between the person and the care team
4. Determining mutually agreed upon interventions
5. Evaluating effectiveness of the interventions in

O'Neill Center: Interactive Care Model (ICM)

Person Engagement Index (PEI)

- Currently being used in a multisite study to determine the instrument's ability to measure a person's capacity to engage in their care
- Next step will be to incorporate the tool into practice (Practice Transformation Project)

CULTURE

CULTURAL
CONSIDERATIONS

CULTURAL
LEVERAGING



Transcultural Healthcare

- Healthcare that incorporates individual and family cultural values and practices

- Patient adherence to treatment is better when patients' cultural values and beliefs are incorporated into their care
- Conflict often results when treatment and regimens clash with patients' belief systems

Culture Can Influence...

Understanding
of and
priorities
about health
and illness

The way
people
interact with a
health care
system

Decisions
about seeking
medical help
and
adherence to
treatment

Individual
participation in
prevention
and health
promotion
programs

Culture, Families & Healthcare

Family Constellations Are Different in Different Cultures

- Nuclear family
- Extended family
- Extended family plus friends

Culture May Determine Who Makes Important Health Decisions in a Family

- Individual
- Head of household
- Medically trained family member
- Healer

Cultural Terms



Cultural Relevancy

- improve patient engagement in care by **modifying care to accommodate the patient's needs**

1. Does the care fulfill the person's needs?
2. Does the care bring the person closer to their goals?
3. Does the care resonate with them?
4. Does the care help to simplify peoples' lives?
5. Does the care give people hope?



Questions: What Happens When you are Sick? Giving birth?



Cultural Leverage

Definition: A system of shared values and attitudes that creates a commitment within an organization to boost performance by shaping and coordinating the actions and behaviors of health care professionals

- Improving individual access to care using culturally relevant initiatives
- Improving the delivery of culturally tailored health information to individuals



Mental Health Behavioral Health



Up to 20%

of women develop a
mental health problem
during pregnancy or
within a year of
giving birth

from The Costs of Perinatal Mental Health Problems, available at:
<http://www.centreformentalhealth.org.uk/perinatal>

© 2014 London School of Economics and Centre for Mental Health

Depression is not "Fine"

I'm fine.

F : falling

I : insecure

N : not good enough

E : empty

Is this Person Depressed?



“Depression is such a cruel punishment. There are no fevers, no rashes, no blood tests to send people scurrying in concern, just the slow erosion of self, as insidious as cancer. And like cancer, it is essentially a solitary experience; a room in hell with only your name on the door.”

This Doesn't Work



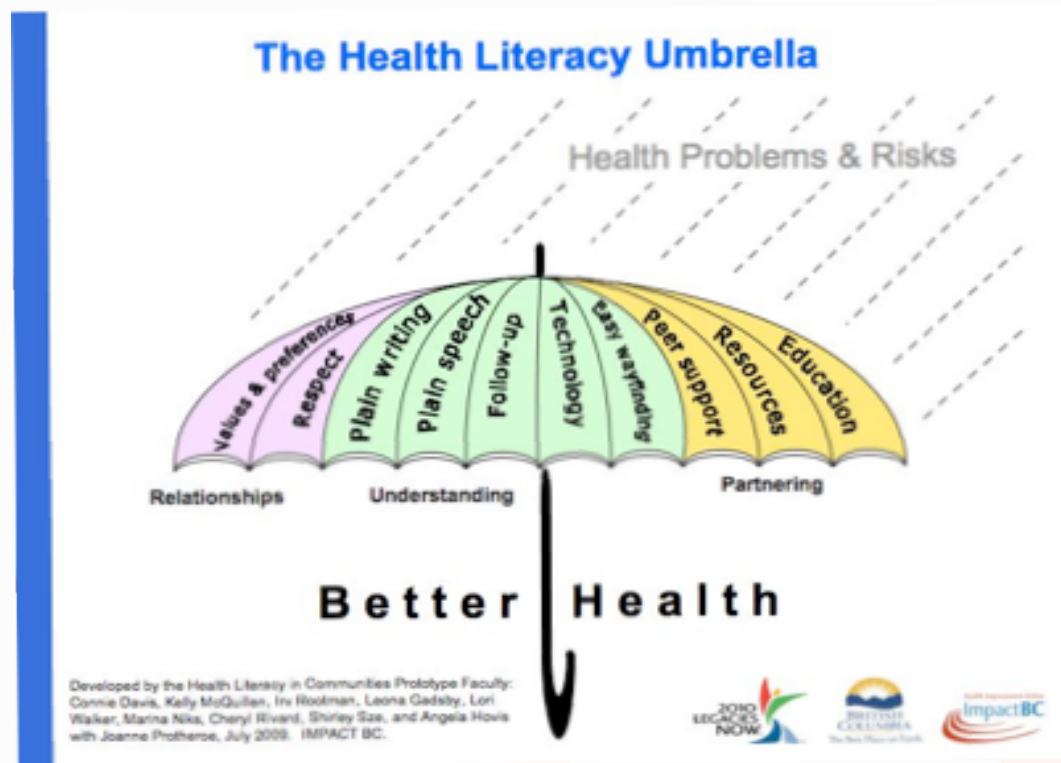
THERE'S NOTHING
WORSE THAN
SOMEONE SAYING,
"JUST SNAP
OUT OF IT."

Screening for Behavioral Health During Pregnancy

- Depression
- Anxiety
- Alcohol Use
- Drug Use

- PHQ 4
- PHQ 9
- Edinburgh Postnatal Depression Scale (EPDS)
- Quick Inventory of Depressive Symptomatology QIDS-SR-16
- Hamilton Depression Rating Scale (HAM-D)
- CAGE

Health Literacy



Health Literacy

Expanding the definition

A **patient's ability** to obtain, understand and act on health information

A **provider's capacity** to communicate clearly, educate about health and empower their patients



Communication

Building Partnerships with Patients



Communication is Key

Use understandable language being aware of the patient's cultural needs and try to share **analogies that will help the patient better understand what is happening to their body.**

What do you think the HIV virus does to your body?

What matters to you most moving forward?

Swapping for Simpler Words and Phrases

INSTEAD OF

Accompany

Comply with

Designate

Facilitate

Indication

Methodology

Pertaining to

Subsequently

Warrant

Prioritize

USE

Go with

Follow

Appoint, choose, name

Ease, help

Sign

Method

About, of, on

After, later, then

Call for, permit

Rank

Source: Simple Words and Phrases. Plainlanguage.gov website.
plainlanguage.gov/howto/wordsuggestions/simplewords.cfm.
Accessed September 16, 2015.

“Patient’s as Partners”



“Instead of treating patients as passive recipients of care, they must be viewed as partners in the business of healing, players in the promotion of health, managers of healthcare resources, and experts on their own circumstances, needs, preferences and capabilities.”

Coulter (2011)

Use “People First” Language

- “People first” language puts the person before the disability or condition and describes what a person has, not who a person is
- A person is not their illness or their lifestyle
- Using a diagnosis or a lifestyle choice as a defining characteristic reflects prejudice and also deprives the person of the opportunity to define him/herself

Recommendations to Increase Engagement in Care



- **Incorporate engagement in care into the clinic culture using brief messages from all staff**
- **Contact patients who miss appointments**
- **Improve patients' healthcare experience**

Pearls of Motivational Interviewing: Active Listening

Describe active listening

Mentimeter



How to Address Individuals' Unmet Healthcare Needs

- Create opportunities for meaningful personal encounters to increase patient engagement
- Focus on two essential questions to guide all encounters
 1. What do you need know?
 2. How do you live with HIV and maintain your wellness?

Create Conversations and Experiences

Helping Individuals Tackle Limiting Thoughts

■ **Examples of Limited Thinking**

- “My mother is an alcoholic.”
- “My family has always been poor.”
- “My friends are all getting pregnant or going to jail.”
- “All my friends use drugs.”
- “My mother had me when she was 15.”
- “What’s the point; HIV is going to kill me no matter what I do or don’t do. Same end.”

Innovative Interventions to Support Self-motivation and Self-efficacy



Individual Interventions

- Values work
- Personal importance
- Meditation
- Trauma-informed care
- Goddess hour (self-care)
- Clinic *learning studio*
- Mobile phone *clinic reach-out*
- **Dysfunction is not normal**

The Goddess Hour
is ON ...
Our **New Time**
is
Thursdays, **8 pm ET**

Hosted By:

REENAH OSHUN GOLDEN
& NIEMA NETERI



@TheGoddessHour

Listen online www.wayfm.org

*This is an alternating week show. Visit wayfm.org for the schedule.

WAYC 104.3 FM



Innovative Interventions to Support Self-motivation and Self-efficacy in PLWH

Group Interventions

- Lock-in's & lock downs
- Mom's cafe
- Life skills
- Meditation
- Obstacle course/treasure hunt
- Sista's curriculum (empowerment)
- DNA-V Walk of Life Curriculum
- Beach walking group
- Spa day
- Camps (adolescent, new moms, post-partum moms)

Reflection & Expression



Postpartum Fatigue



Nursing Diagnosis: Fatigue

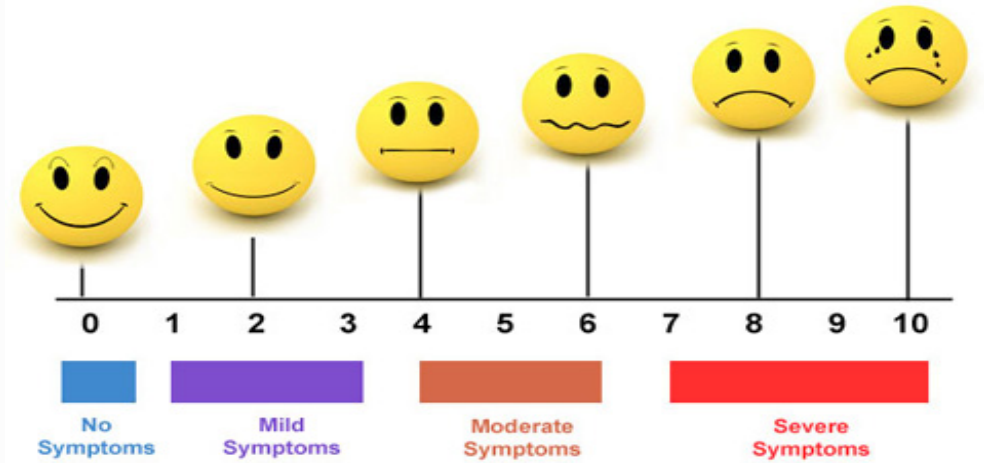
Fatigue related to:

- Difficulty resting and sleeping associated with fear anxiety and/or discomfort
- Overwhelming emotional demands associated with infant/child care and HIV prevention and HIV self-care
- Nutritional deficiencies
- Increased energy expenditure caused by infection(s)
- Effects of ART
- High Viral Load
- Potential metabolic conditions

Fatigue Assessment

Screening Tools

- Multidimensional Assessment of Fatigue (MAF)
- Global Fatigue Index (GFI)
- HIV-Related Fatigue Scale (HRFS)



MAF Item #1

- On a scale of 1-10 to what degree to you experience fatigue?
 - Not at all (1)
 - A great deal (10)

Fatigue: Desired Outcomes

The patient will experience a reduction in fatigue as evidenced by:

1. Verbalization of feelings of increased energy
2. Ability to perform usual activities of daily living, including infant care and HIV preventative care
3. Increased interest in surroundings and ability to concentrate
4. Ability to engage in HIV self-management and care activities

Stress, Trauma & Distress



Words of Encouragement

"We will get through this"

"I am here for you"

"You will get better"

"This is not your fault"

"You did not cause your illness"

"You are doing a good job"



Trauma

- Trauma is one of the most avoided, ignored, belittled, denied, misunderstood and untreated causes of suffering
- Efforts to address trauma and PTSD should be a priority in HIV prevention and care
- Screening and referrals for recent and past trauma and PTSD should be a core component of HIV treatment

The focus of recovery is not “What’s wrong with you?” but rather, “What happened to you?”

The Potential Effects of HIV Stigma and Feelings of Shame on Engagement in HIV Care



Stress/Isolation



Inadequacy/Self-Rejection



**Depression/Anxiety/
Self-medicating**

Stress Trauma Distress

Screening Tools

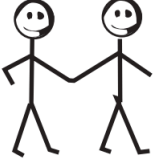
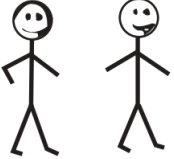
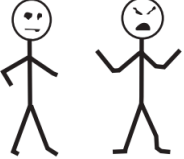
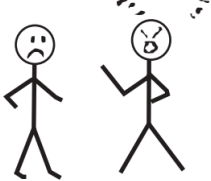

- Life Events Checklist (LEC-5)
- Primary Care PTSD Screen (PC-PTSD)
- RADAR for women
- The Relationship Chart (IPV Screen)
- The Distress Thermometer

IPV Screening: The Relationship Chart

The Relationship Chart

DURING THE PAST 4 WEEKS, HOW OFTEN HAVE PROBLEMS IN YOUR HOUSHOLD LED TO:

- INSULTING OR SWEARING?
- YELLING?
- THREATENING?
- HITTING OR PUSHING?

None of the Time	
A Little of the Time	
Some of the Time	
Most of the Time	
All of the Time	

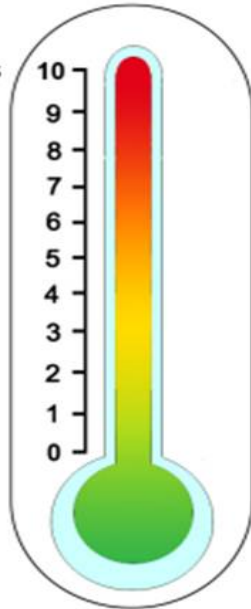
Distress Assessment

The Distress Thermometer

First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

Extreme Distress



No Distress

YES	NO		YES	NO	
<input type="checkbox"/>	<input type="checkbox"/>	Practical Problems	<input type="checkbox"/>	<input type="checkbox"/>	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child Care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
		Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhoea
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with close friend/relative	<input type="checkbox"/>	<input type="checkbox"/>	Feeling Swollen
		Emotional Problems	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/religious concerns	<input type="checkbox"/>	<input type="checkbox"/>	Pain
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual
			<input type="checkbox"/>	<input type="checkbox"/>	Skin dry itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
			<u>Other problems</u>		

Providing Trauma-Informed Care

- Create a safe and sensitive environment
- Communicate sensitivity to individuals who have experienced traumatizing events
- Provide brief empathic responses to individuals who do report experiencing trauma
- Provide services in a trauma-informed manner

Summary

- Engagement in HIV care is increasingly recognized as a critical step in maximizing health outcomes for postpartum WLWH
- There is a 90-day window for engagement in care that predicts short and long term health outcomes for postpartum WLWH
- WLWH have the capacity to live long healthy lives and when they partner with their reproductive and HIV healthcare team they are more likely to develop the motivation and skills to have undetectable viral loads

Postpartum WLWH: What Will You Do?



Group Question (Short Answer)

What will you do by next Wednesday to address engagement in HIV care challenges presented by postpartum WLWH?

Postpartum WLWH: What Will You Do?

Reminders:

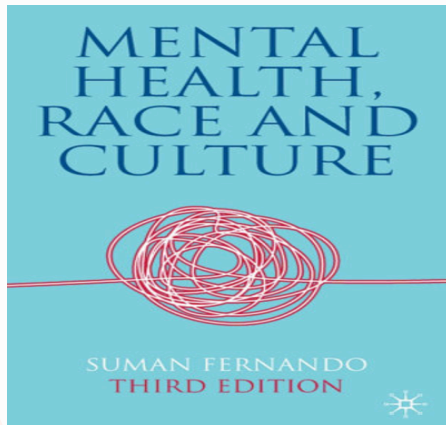
1. Nothing changes until you do.
2. Know who your patients are.
3. What can you do by next Wednesday?
4. What is the most you can do?
5. Recognize that we get stuck in practice patterns and that it takes energy to change.
6. Practice makes permanence.

Question, Comments and “Aha Moments”



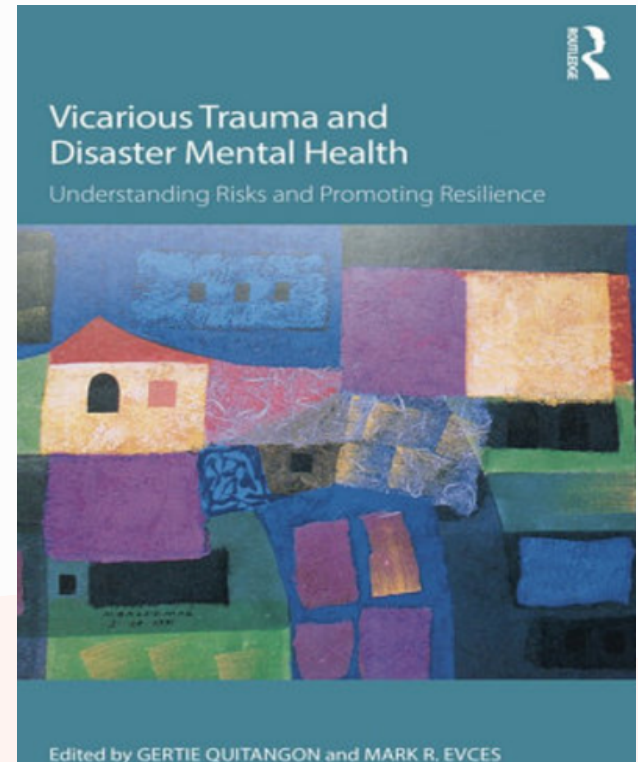
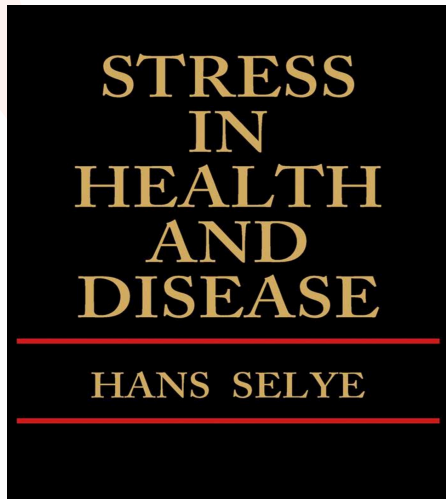
**QUESTIONS?
COMMENTS?**

Additional Resources on Trauma-Informed Care



Handbook on Sensitive Practice for Health Care Practitioners:

Lessons from Adult Survivors of Childhood Sexual Abuse



Schachter, C.L., Stalker, C.A., Teram, E., Lasiuk, G.C., Danilkewich, A. (2008). *Handbook on sensitive practice for health care practitioner: Lessons from adult survivors of childhood sexual abuse*. Ottawa: Public Health Agency of Canada.

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