Beyond Viral Suppression

Whole-Person Health among Women Aging with HIV since birth

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Women lifetime survivors have a distinct life-course experience

COMMUNITY LANGUAGE

Lifetime survivors and Dandelions

People who have lived with HIV since birth or early childhood

RESEARCH LANGUAGE

Perinatally acquired HIV

HIV acquired during pregnancy, birth, or breastfeeding

What makes this population distinct?

- HIV and treatment have been present across every developmental stage
- Disclosure decisions recur as relationships, workplaces, and care settings change
- The first large cohorts are now entering adulthood and approaching midlife
- Women’s experiences often disappear inside mixed-gender samples

HIV across the life course



Stigma, disclosure, resilience, and care engagement evolve across every stage

The literature snapshot examines psychosocial survivorship

Purpose

Identify recurring evidence on internalized stigma and care barriers among adults with perinatally acquired HIV

Topics included

- Internalized stigma
- Disclosure and identity
- Mental health
- Treatment fatigue
- Care engagement
- Coping and resilience

Scope

Narrative synthesis of peer-reviewed studies and reviews. The original review included adults of all genders. This presentation adds a women-centered interpretation.

Stigma changes across development and relationships



Disclosure recurs with each new relationship, workplace, and healthcare setting

Clinical success does not fully describe behavioral health

WHAT CARE COMMONLY MEASURES	WHAT THOSE MEASURES MAY NOT REVEAL
Medication adherence	Anxiety, depression, and grief
Viral load	Isolation and fear of rejection
Appointment attendance	Treatment exhaustion
Retention in care	Identity and relationship stress

Care engagement reflects emotional safety, trust, social support, and whether care fits a woman's life

Women’s sexuality is often studied through risk rather than wellbeing

THE LITERATURE OFTEN ASKS

- **Will she disclose?**
- **Will she transmit HIV?**
- **Will she use contraception?**
- **Will she adhere during pregnancy?**

A WOMEN-CENTERED AGENDA ALSO ASKS

- **Does she experience pleasure and agency?**
- **How does sexual identity shape care?**
- **Can she pursue intimacy without shame?**
- **Does she define relationships on her terms?**

Intimacy, orientation, body image, desire, and relationship satisfaction belong in the research agenda

Reproductive autonomy extends beyond pregnancy outcomes

CHOICE

Whether and when to parent

PLANNING

Contraception and fertility goals

RELATIONSHIPS

Partner communication and disclosure

CARE

Provider attitudes and counseling

PREGNANCY

Clinical and emotional support

AFTER BIRTH

Postpartum mental health and HIV care

The evidence should also respect a woman’s decision not to parent

Midlife evidence for women lifetime survivors remains limited

WHAT BROADER HIV RESEARCH SUGGESTS

- Menopausal symptoms can overlap with anxiety, depression, and other health concerns
- HIV care and menopause care may remain fragmented
- Sexual and reproductive needs change across midlife

WHAT WE STILL NEED TO KNOW

- Whether broader findings apply to lifelong infection
- How lifelong ART exposure interacts with hormonal and bone health
- How women want midlife care, sexuality, and identity addressed

This is an evidence frontier, not a set of established findings about women with perinatally acquired HIV

Resilience grows through relationships and supportive systems

What women draw upon

- Peer connection
- Trusted relationships
- Positive identity
- Adaptive coping
- **Purpose and community leadership**

Resilience does not remove institutional responsibility

Women may thrive despite fragmented services. Research and practice should strengthen the conditions that support health rather than treating resilience as an individual obligation.

Protective factors belong in study designs, care plans, and outcome measures

The dissertation addresses one part of the evidence gap

The Impact of Internalized Stigma on Medication Adherence and Retention in Care Among Adults Living with Perinatally Acquired HIV

DESIGN

Qualitative descriptive

SAMPLE

Approximately 25 adults

METHOD

In-depth Zoom interviews

POPULATION

Adults of all genders

Primary domains

- Internalized stigma
- Medication adherence
- Retention in care
- Coping and protective factors

Conceptual foundation

Health Stigma and Discrimination Framework
Social Cognitive Theory
Resilience Theory

Proposed study. No interview findings are. presented

The next research agenda should measure thriving

RESEARCH

- Include women lifetime survivors in aging and menopause research
- Study intimacy, sexual identity, and reproductive autonomy
- Report findings by gender and mode of HIV acquisition
- Measure quality of life alongside viral suppression

PRACTICE

- Integrate HIV, behavioral health, and reproductive care
- Provide ongoing disclosure support
- Build peer-led and trauma-aware services
- Prepare for midlife needs before menopause

What are we missing when viral suppression becomes our primary measure of successful survivorship?

THANK YOU!

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