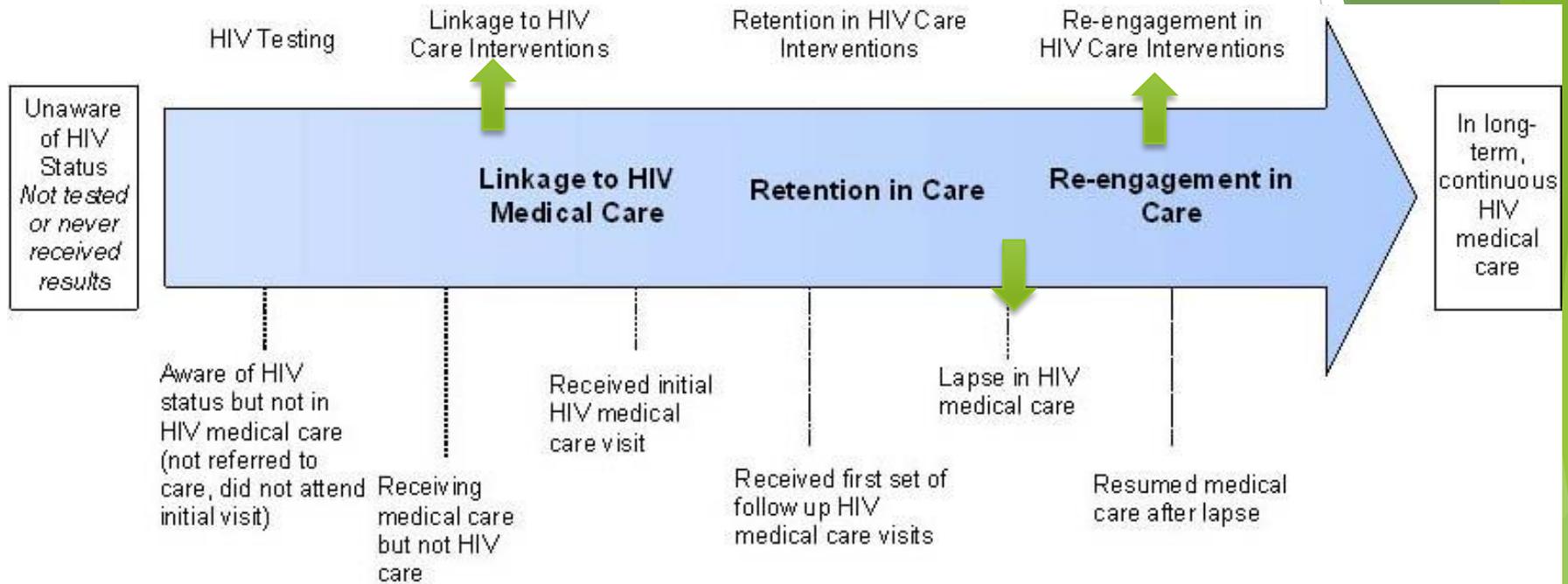


A Qualitative Investigation of Patients' Transitional States of Engagement in HIV- Related Medical Care

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HIV Care Cascade



Source: Adapted from Health Resources and Services Administration, HIV/AIDS Bureau. Continuum of engagement in HIV care. Cheever LW. Engaging HIV-infected patients in care: their lives depend on it. Clin Infect Dis 2007; 44(11):1500-02.

Objectives

To investigate the transitions in and out of care for HIV-positive patients who had history of one or more of the following:

- ▶ Delayed linking to care following diagnosis
- ▶ Returning to care after non-engagement
- ▶ Engaged in care but have had previous periods of non-engagement

Project design

- ▶ Recruitment through flyer distribution and medical chart review by TMC ID staff
- ▶ Collection of data via qualitative interviews
 - ▶ Interviews were semi-structured and person-level
 - ▶ Interviews were professionally transcribed and thematically coded
- ▶ Coding
 - ▶ Naturalistic Inquiry
 - ▶ Theory generated from the information provided by the subjects
 - ▶ Data was independently coded by members of the research staff
 - ▶ NVIVO software used to unitize and thematically code data
 - ▶ Research staff collaborated to reconcile the findings and design the thematic structure that is reflective of peoples' experiences in receiving HIV medical care

Sample

- ▶ Final set of participants:
 - ▶ n = 22
 - ▶ 10 women
 - ▶ 11 men
 - ▶ 1 transgendered individual
 - ▶ 45% White
 - ▶ 50% Black
 - ▶ 14% Hispanic
 - ▶ Time since diagnosis: 2-26 years
 - ▶ 22% (n = 5) living with HIV for over 20 years

Results

The background of the slide is white with abstract green geometric shapes on the right side. These shapes include overlapping triangles and polygons in various shades of green, ranging from light lime to dark forest green. The shapes are layered, creating a sense of depth and movement.

Thematic categories of engagement

- ▶ **Health factors**
- ▶ **Resources**
- ▶ **Support factors**
- ▶ **Personal factors**
- ▶ **Treatment factors**
- ▶ **Clinic factors**

Health Factors

Reengagement

- ▶ 45% participants reported that health problems led them to reengage after being out of care for at least six months
- ▶ Due to both acute illnesses and chronic conditions

Resources

Disengagement

- ▶ 41% of participants referenced insurance and/or financial stress as the primary reason for disengaging or being out of care
- ▶ Transportation was mentioned by 72% of participants and was the primary cause of transitioning out of care at some point in time

Clinic factors

In care after periods of nonengagement

- ▶ 81% of participants reported that a good relationship with their provider was the utmost important clinic factor

Disengagement

- ▶ Scheduling was defined as a barrier to engagement by 60% of participants, 15% of whom disengaged due to the inability to schedule an appointment at a time that would allow them to keep their work schedule

Treatment Factors

Disengagement

- ▶ 77% mentioned that burden of treatment had been discouraging at some point in time
- ▶ 14% of participants disengaged due to the negative side effects of ARVs
- ▶ Management of HIV with additional comorbidities

Personal Factors

Disengagement

- ▶ 18% delayed engagement or disengaged to put their children's needs before their own

Reengagement

- ▶ 18% of participants ultimately reengaged to fulfill their parenting responsibilities

Support

Disengagement

- ▶ Impact of stigma

Reengagement

- ▶ 23% reengaged with the help of family or friend support

Discussion

- ▶ Engagement is specific to each individual
- ▶ Clinicians: Management of people versus disease
- ▶ Role of health literacy
- ▶ Self-management support
 - ▶ Use of patient navigators; maximize peer support positions
- ▶ Limitations

Implications

- ▶ Improved synergies between funding and service agencies
- ▶ Improved education and resources
- ▶ Maximizing current roles
 - ▶ Peer Educators
 - ▶ Nursing staff
 - ▶ Case managers
- ▶ Reevaluation of policy surrounding eligibility for services

Future Work

- ▶ Further validation of the data with additional patients via focus groups
- ▶ Further exploration of transitions
 - ▶ What kind of support, systems, and resources would make a difference?
- ▶ Research on management of co-morbidities and chronic conditions

Acknowledgements

Dr. Mary Gerkovich, PhD
Dr. Karen Williams, PhD
Dr. Julie Banderas, PharmD

A special thanks to Truman Medical Center
for their support and participation

Funded by the University of Missouri
Research Board

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