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

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HIV Care Cascade

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
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
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