Barriers to Care for Persons Living with HIV Post Affordable Care Act Implementation

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People Living with HIV

- About 1.2 million persons living with HIV (PLWH) in the US at the end of 2012
- In 2013, Indiana ranked 21st of the 50 states for new diagnoses
- 818 PLWH in North Central Indiana in 2014 (7.06% increase from 2013)

Changes in HIV Medical Care

- Antiretroviral therapy (ART) as been shown to increase the survivability of PLWH and reduce the risk of transmission
- In 2015, the World Health Organization changed their guidelines, which state ART should commence upon HIV diagnosis regardless of CD4 count

Acute, Fatal Condition → Manageable, chronic disease

CDC State HIV Prevention Progress Report – Indiana

- 78.1% of PLWH in were successfully linked to treatment three months after their diagnosis
- 52.8% of PLWH are retained in HIV care.
- Of those retained in care, 69.6% of PLWH had viral suppression.

“Traditional”Barriers to Care

- Access, social stigma, transportation, convenience, fear of abandonment, feelings of shame, and child care issues
- Cost- one of the most consistent barriers to accessing medical services for HIV
- Average cost of HIV care in 2006 was $19,912 per person annually ranging from $16,614 to $40,678 depending on the severity of the disease.
- “Insurance status was found to be one of the strongest factors associated with utilization patterns” among PLWH.

Affordable Care Act

- Considered the most important legislation in the fight against HIV and AIDS
- Expansion of Medicaid coverage to include a number of individuals living below the poverty line and childless adults (Indiana- HIP 2.0)
- Administratively more complex than other state plans
  - Four different Medicaid benefit packages
  - Additional administration and tracking of various financial and health outcome information
  - Individuals receive different benefits under the various Medicaid packages
  - Additional punitive enrollment and disenrollment rules as it relates to income levels and payment of premiums

Research Purpose

- Community Partner- AIDS Ministries AIDS Assist (AMAA)
- Qualitatively examine the issue of continuity of care for PLWH after the implementation of the Affordable Care Act (ACA) and HIP 2.0.
- ‘Gap in care’ - Not seeing a health care professional within the past six months.

Methodology

- Phenomenological study
  - Understand the meaning and essence of the lived experiences and behaviors of people who have experienced a particular phenomenon in a given context while maintaining scientific rigor
  - Seeks a deeper level of understanding of the collective lived experiences
  - Unstructured, in depth interviews with open-ended exploratory questions
- Inductive data analysis
  - ‘Bringing salient pieces of data together to create a meaningful whole’ - Hatch

Study Sample

- Phenomenological studies generally conducted with small sample sizes (3-10 people)
- Study criteria:
  - PLWH
  - 18 years or older
  - Had or were eligible for health insurance (public or employer)
  - Not utilized medical care for at least 6 months after ACA was implemented

Study Participant Demographics/Health Status

Table 1: Participant Demographics

Patient*	Age	Gender	Race	Marital Status	Education Level	Employed	Year of HIV Diagnosis
C	45	M	White	Single	High School Grad	Yes	2006
D	34	F	Black	Single	College Grad	Yes	2002
E	51	M	White	Single	High School Grad	No	2011
F	38	F	Black	Single	Did not graduate High School	No	2001
G	25	M	White	Single	High School Grad	Yes	2011
H	42	M	Black	Single	High School Grad	No	1993

* Client A served as a pilot and Client B did not satisfy all the inclusion criteria.

Table 2: Health Status of Participants

Patient	CD4/Year	Viral Load/Year
C	710 mm^3* in 2015	20 ml** in 2013
D	810 mm^3* in 2015	2050 ml in 2015
E	669 mm^3* in 2016	102 ml in 2016
F	673 mm^3* in 2015	5170 ml in 2015
G	788 mm^3* in 2015	199 ml in 2015
H	331 mm^3 in 2015	46,900 ml in 2015

* CD4 count considered healthy: 500 – 1200 mm^3

** Viral load considered undetectable: 40 – 75 ml copies

Theme 1: Minimization of Traditional Barriers

- Study participants did not discuss “traditional barriers” in the context as a barrier
- AMAA alleviated “traditional barriers”
  - “Since … I’ve had a relationship with them (AMAA) they’ve been a world of help. No question about it” (Client E, p. 2).
  - “Yeah, yeah. She gets the appointments, makes sure the appointments are there… Least I have a worker, someone, a counselor, that’s there because I have no way of getting around, other than by foot“

Theme 2: Complexity of Health Insurance

- Complexities of obtaining, maintaining, and navigating health insurance was discussed in every interview
- Participants did not discuss complexities as a barrier, however, the analysis identified it as such. Each comment about insurance was accompanied with a comment about the lack of access to a physician, medications, etc.
  - Client D reported “I’ll say within the last year, healthcare has been more accessible” (p. 8), but then said, “Like right now I don’t have a primary care doctor” (p. 8)
  - “I pay nothing for my insurance” but then something changed without his knowledge and “Just the last time I was there I went for blood work and I just got a bill … and it’s like why am I getting a bill. This is supposed to be 100% covered” (p. 3 and 4 – Client C)

Theme 2: Complexity of Health Insurance (cont.)

- Study participants didn't understand the insurance coverage
  - "It was overwhelming cuz it was a lot and I didn't, I didn't clearly understand every single thing" (p. 6 – Client H).
- Discussed frustration with the income ceilings of their insurance plans
  - "so, I'll stick to bus driving. You know, I can pay my bills, and you know how to live on it… It's a shame we have to do that. It really, it's sad to me (p. 5 – Client C).

Theme 3: Gap in Care Definition

- Disconnect between the health care seeking behavior of the participants and the expectations of AMAA
- ***None*** of the study participants recognized their inconsistency in HIV care utilization as a gap.
- Reported feeling fine and did not see the necessity in returning to the doctor as soon as recommended.

Theme 3: Gap in Care Definition (cont.)

- “Um, because my viral load and CD4 count were the same as when I was tested [at initial diagnosis]. So I said ok… I didn’t continuously go to the doctor” (Client G).
- “I was doing so well and at that time when I moved I just didn’t take the initiative to get a doctor… since I was doing so well I thought I’m ok… I wasn’t sick. I wasn’t having any complications. I wasn’t losing weight or anything of that nature. So to me I thought I’m doing everything they said to do” (Client H).

Theme 2 (Complexity of Health Insurance) Discussion

- Limited experience navigating health insurance environment
- Low health literacy
  - "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions"
- An assumption that once a person obtains health insurance the person will understand what insurance is and how to use, however, with low health literacy, PLWH will have difficulty navigating the healthcare system
- In order to correctly utilize their health insurance, PLWH need an improvement in their health literacy and development of a greater degree of self-management

Theme 3 (Gap in Care Definition) - Discussion

- Assumptions that continuum of care for PLWH is understood.
- Participants did not view their inconsistent HIV treatment and care as problematic as long as they were ‘feeling fine.’
- Participants were not ‘fine’
  - one of the six (16.7%) had a viral load in the undetectable range. significantly lower than the rates found in Indiana (36.7% - 3,943 PLWH) had viral suppression
  - Five participants are still at risk of transmitting HIV and/or developing opportunistic infections.

Discussion

- Addressing the structure of the health insurance system may be out of the control of care coordination organizations, but there are still steps AMAA can consider to overcome these barriers.
- Incorporate intentional education regarding:
  - navigation of the health insurance system
  - viral load suppression
  - importance of continuity of care
- Strategies may increase healthy literacy and empower and engage study participants to access HIV care more consistently and effectively, thus minimizing barriers, improving self-management and health status, and preventing HIV transmission.

Conclusions

- As the system of treatment for PLWH has shifted toward a chronic disease model system of care, HIV care coordination should follow suit.
- The study revealed participants are ready for a higher level of engagement with regard to their care and their overall quality of life.
- Once PLWH are linked to care, AMAA should consider structures and processes to shift the conversation, services, education and care coordination to a more holistic system in order to remove new barriers
  - Chronic disease management, viral suppression education, reinforce continuity of care, improve health literacy

Limitations

- PLWH in the community who were not affiliated with AMAA and experienced a gap in care were not interviewed
- Difficulty in scheduling interviews (disruptions in cell phone services, last minute cancellations, or no-shows)

Acknowledgements

- AIDS Ministries AIDS Assist
  - Leeah Hopper, Executive Program Director
  - Bethany Anglin, Past Client Services Manager
- Eck Institute for Global Health