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) has 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
• 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

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

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

## Table 2: Health Status of Participants

<table>
<thead>
<tr>
<th>Patient</th>
<th>CD4/Year</th>
<th>Viral Load/Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>C</td>
<td>710 mm³* in 2015</td>
<td>20 ml** in 2013</td>
</tr>
<tr>
<td>D</td>
<td>810 mm³* in 2015</td>
<td>2050 ml in 2015</td>
</tr>
<tr>
<td>E</td>
<td>669 mm³* in 2016</td>
<td>102 ml in 2016</td>
</tr>
<tr>
<td>F</td>
<td>673 mm³* in 2015</td>
<td>5170 ml in 2015</td>
</tr>
<tr>
<td>G</td>
<td>788 mm³* in 2015</td>
<td>199 ml in 2015</td>
</tr>
<tr>
<td>H</td>
<td>331 mm³ in 2015</td>
<td>46,900 ml in 2015</td>
</tr>
</tbody>
</table>

* CD4 count considered healthy: 500 – 1200 mm³
** 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

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