LINKAGE TO CARE SPECIALISTS: LESSONS LEARNED DURING IMPLEMENTATION OF AN INTENSIVE PATIENT NAVIGATION PROGRAM IN WISCONSIN

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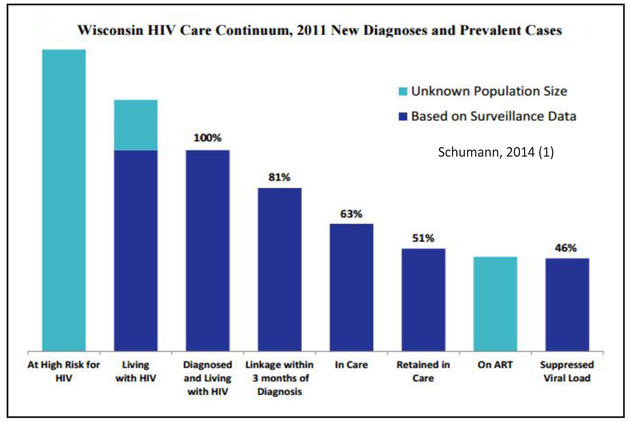
ISSUES



- Viral suppression depends upon engagement in care, and PLH may face several barriers
  - Unstable housing, competing subsistence needs
  - Stigma, lack of social support systems
  - Negative experiences/distrust of health care and medical establishment
  - Mental health/illness comorbidities, substance abuse problems (2-5)

DESCRIPTION

LINKAGE TO CARE SPECIALISTS

- Address barriers to linkage/engagement in HIV medical care, ART adherence
  - Case Management: Individualized service plans, referrals, service coordination
  - Patient Navigation: Attending appointments with clients, acting as "advocate," navigating complex systems (medical care, insurance, etc.)
- Small caseloads (approximately 15)
- Discharge to self-management or case management after 9 months
- Types of clients: Newly Diagnosed, Recently Out of Care, Post-Incarcerated, "At Risk"

PROCESS

- Protocol and definition of Specialists' role was developed over time
  - Collaborative Model
  - Plan-Do-Study Act (PDSAs)
    - Learning Sessions
    - Interviews with Specialists and clients for suggested changes

LESSONS LEARNED

LACK OF EXISTING PROTOCOL

- "Down time" at the beginning
- How to implement clearer organization of client uptake
  - When caseloads are full where do we send the next client?
  - Once or twice realized that the same client had 2 Specialists
- Changes in the focus on specific services to be offered "mid-stream" (e.g., transportation)

ACROSS AGENCY COLLABORATION

- Challenges of the collaborative model of the protocol development and inherent changes over time
  - Each agency developed protocols to meet their specific needs and context
  - Different roles at different agencies
  - Different individuals within one agency communicating slightly different versions/interpretations to outside agencies/referral sources

WITHIN AGENCY COMMUNICATION

- Communication from both the State and the agency team to define roles that all agree on
- Initial reluctance of medical care providers to allow Specialists in appointments
- Collaboration with case managers
  - Some services may still require a case manager (HUD/housing)
  - Train with them/Learn from their experiences
  - Clarify roles, how Specialists are distinct, avoid "stepping stones"
  - Integrate into discharge transition, especially if clients want/need to go to different agencies for case management

DIFFICULTY WITH DISCHARGING

- Specialists have developed trusting relationships with clients who may have never had an advocate or ally before
  - Specialists provide direct social support to clients who may lack other sources of support
  - Clients may be one crisis away from losing stability in medical care
  - Specialist as the "one person" who can coordinate and navigate among many different appointments, agencies, people, and complicated systems/bureacracies
  - Clients indicate will still contact Specialists after discharge
- Clients believe Specialists will be there for them "forever"

> "So communication from both the state and my supervisor with our team just as far as defining roles… I would have liked to have seen existing case management [cases] from the get-go and having an active role because we could have learned so much from them … they have had this down pat for a long time … would have been great to have had case managers on board and engaged in helping to shape what this would look like as partners… everybody was really threatened because they weren't engaged."

> "Explaining what Linkage to Care was, was difficult … once he started to do better and made appointments you know got to his appointments and he was on medications and doing well then it was … you are doing ok on your own you can be discharged from the program… and he was really, really nervous about that because he was just like, no, I want you permanently… [It] is still difficult to know when people are really ready for discharge."

> "The other [challenge] was, you know, in the very beginning we were told to market the program with transportation because that was huge, huge, huge barrier for a ton of people and so we marketed with transportation and so we were all over, we were driving people to this, that and everywhere and anything, because as long as it was a barrier to getting into care we were doing it. And then they kind of told us to cut back on that so we could get more clients through the program… I remember having to tell, tell my client that we will have to start looking at other options and I think that was an issue too knowing that he wasn't going to have that source of transportation forever and to need to start figuring it out on his own."

COLLABORATING AGENCIES

Froedtert & Medical College of Wisconsin
ARCW AIDS Resource Center of Wisconsin — Excellence in HIV Health Care
AIDS Network
Sixteenth Street Community Health Center
Milwaukee Health Services, Inc.
UW Health

RECOMMENDATIONS

- Incorporating short-term, intensive intervention for some high-need clients within the existing case management system may be beneficial
- Facilitate communication among community agencies about goals
- Create job descriptions with clear guidelines and responsibilities, distinguished from similar staff positions
- Develop basic protocol before initiation of program to avoid "selling" the program differently to initial clients
- Create a streamlined referral system that maintains and equalizes caseloads across personnel.
- Acknowledge and help to minimize complicated and invasive applications, help manage/navigate/coordinate multiple bureaucracies.
- Ensure client understanding of time frame at initiation of program
- Have specific protocol in place to address how to prepare clients for transitioning out of intensive linkage programs, including competencies to address, and what issues would still be appropriate for clients to initiate contact even if they are no longer in the program

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