Novel public health approaches to enhance engagement in care

Wisconsin's Linkage to Care Specialists: Successes in Navigating Complex Systems to Address Barriers to Care

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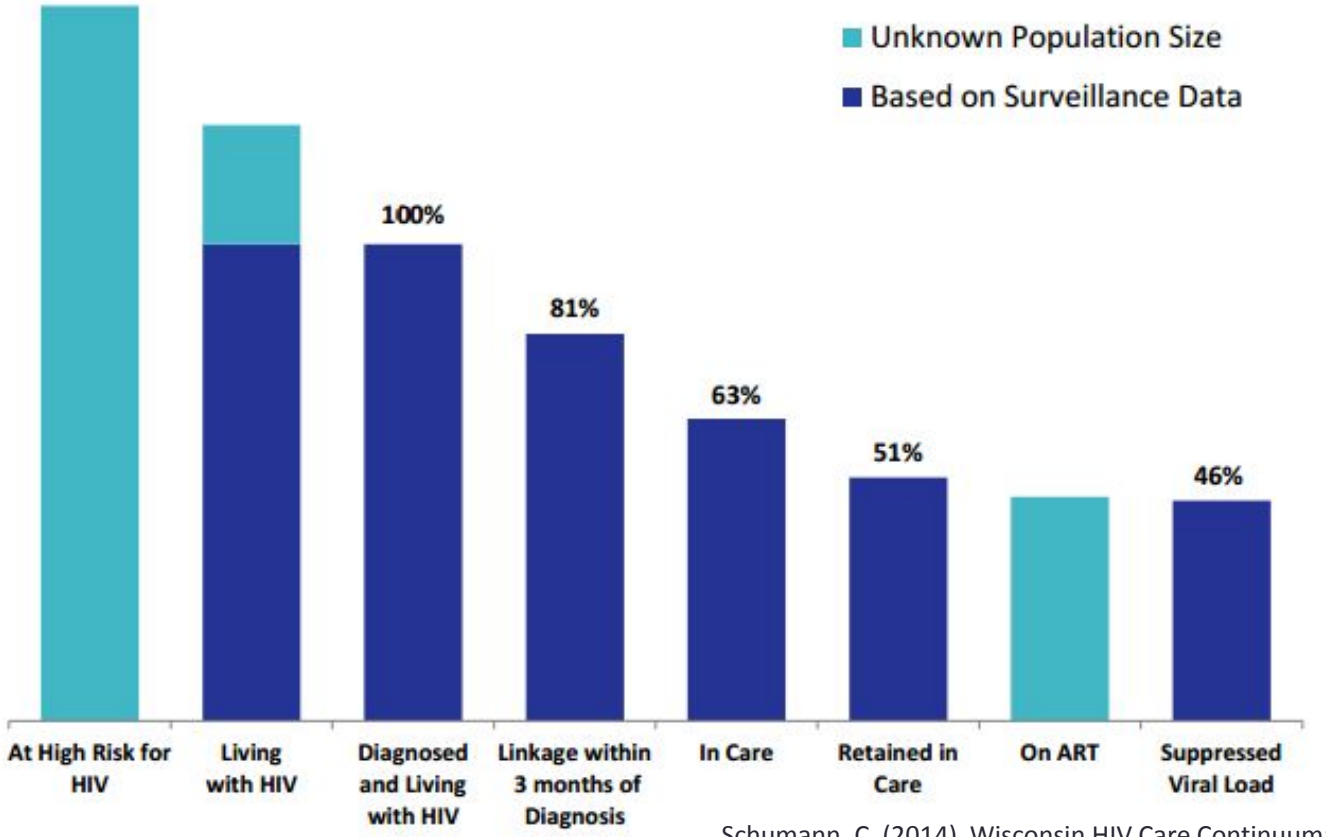
Learning Objectives

- At the conclusion of this activity, the participant will be able:
  - **To describe benefits and barriers of a unique Linkage to Care Specialist position for clients**
  - **To compare and contrast Linkage to Care Specialists with other case managers or systems representatives.**
  - To identify ways to optimize surveillance data for use in identifying out of care patients.

Continuum of Care in Wisconsin

Figure 2. Wisconsin HIV Care Continuum, 2011 New Diagnoses and Prevalent Cases



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Barriers to Engagement in Medical Care

- Unstable housing
- Competing subsistence needs
- Denial of HIV status
- Stigma
- Negative experiences/distrust of health care and medical establishment
- Lack of social support systems
- Mental health/illness comorbidities
- Substance abuse problems [1-5]

Linkage to Care

"The short-term objectives are for the client to attend at least three HIV medical visits over the course of nine months while enrolled in the LTCS program, and to increase independence and transition to self-management or case management after completion of the LTCS program."

- Case Management
  - Individualized service plan development and implementation
  - Referrals, service coordination
- Patient Navigation
  - Attending appointments with clients, acting as "advocate"
  - Navigating complex systems (medical care, insurance, etc.)

Linkage to Care Specialists

- Small caseloads (approx. 15)
- Frequent communication, ability to do home visits
- Provide transportation, social support, education, navigation
- Discharge to self-management or case management after 9 mo.s

Eligible Clients

1. **Newly Diagnosed**: clients first diagnosed with HIV infection during the previous 90 days.
2. **New to Care**: clients previously diagnosed (more than 90 days ago) with HIV infection but not previously linked to HIV medical care.
3. **Out of Care:** clients who have not attended an HIV medical visit during the previous six months.
4. **Post-Incarcerated:** clients previously diagnosed with HIV infection who are referred by and recently released from a Wisconsin Department of Corrections (DOC) institution.
5. **At-Risk:** clients who meet one or both of the following criteria:
   a. Have missed two or more consecutive HIV medical appointments, and/or
   b. Have a detectable viral load while on HIV treatment.

Lessons Learned from Pilot Phase

- Lack of protocol/definition of role and changes over time was a challenge
- Need to capture provision of direct social support to clients among “services”
- Ensure clients understand short-term nature of program
- Challenges of discharge for both clients and Specialists
- Need to differentiate Specialists versus case managers

Description from Manual

- “The LTCS serves as a patient navigator, providing short-term, intensive case management and care coordination services aimed at assisting clients in identifying and overcoming barriers to accessing and maintaining engagement in HIV medical care.”
- “Because each client has a unique set of barriers, the individual tasks performed by the LTCS cannot be defined as a specific set of services. Through this client-centered approach, the LTCS provided the client with the knowledge and skills necessary to actively participate in their healthcare, and to maintain engagement in care and adherence to treatment after discharge from the LTCS program.”

Linkage to Care Specialists versus Case Managers

- From the manual in “Differentiation from case management”:
  - “Focuses primarily on addressing client barriers that prevent linkage to or engagement in HIV medical care. The LTCS refers their clients to existing case managers for assistance with needs that do not affect medical adherence. This is in contrast to case management, in which the case manager assists their clients with all needs.”

Methods

- Participants
  - Specialists during the summative phase (n = 9)
  - 30 Clients, interviewed in collaboration with SPNS ETAC
    - 16 African American, 9 White, 3 Latino/Hispanic, 1 Indian, 1 African
    - 8 Female, 12 Male
    - 22-68 years old, 11 under 30
    - 6 Newly Diagnosed, 7 Out of Care, 8 At Risk, 8 Post Incarcerated, 1 Newly Diagnosed/Post Incarcerated
- Methods
  - 2 Focus Groups with Specialists, recorded, semi-structured:
    - Remaining barriers, LTCSs within larger context of HIV care
  - One-on-one Interviews with clients, recorded, semi-structured:
    - Barriers to initial linkage, continued retention
    - Clients given small incentive

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Linkage to Care Specialists

Referrals

- Referrals mostly from health department/Partner Services, prison social worker, CTR sites, hospitals, when clients are re-engaging in care at clinic, or self-referral (word getting out in community)
  - Some referral mismatch: referrals that technically meet eligibility criteria, but are adherent on meds, or people that have a lot of social needs, but don't meet criteria
- Specialists also take all types of clients, as opposed to what was originally envisioned.
  - As clients were first beginning to be enrolled, caseloads became unbalanced: newly diagnosed clients came in more rapidly, while DOC and out-of-care took longer to be referred.
  - Perhaps DOC clients should be assigned to someone with more experience

Service Provision

- Very client-centered: adjustment of approach based on type of client
  - Newly diagnosed need orientation to HIV/HIV care in general, need more emotional support
    - First appointments can be too overwhelming with too many different people coming in the room
  - Discharging still depends on “where your client is”
    - Clients that don’t need help anymore versus “trickier” clients
    - Discharged clients still call
      - Sometimes it’s just easier to take care of a quick client need that “pawn off” on overburdened case managers

Service Provision

- Clinic staff may not be well equipped to give the level of empathy and emotional support that LTCSs can
  - Relationship building in creative ways: liking cats, meeting at Starbucks, gardening
  - Advocating for what's best for the client, sometimes in opposition to doctor/providers
  - But need to be careful of boundaries, maintaining professional relationship
  - Support/rapport as most important aspect of job

Barriers

- Originally role confusion and tension over "turf"
  - Over time the distinct role of the LTCS was defined (not just case management)
  - Skepticism about Specialists' abilities due to their demographic characteristics
    - More important that they know who to contact for services
    - While not as much a concern from providers, still seem to be concerns from community members
  - Newer hires didn't notice same level of resistance

Barriers

- What “counts” as direct client time?
  - Pre-enrollment and post-discharge
  - Transportation
  - Collateral contacts
- Lack of consistency across agencies
  - Documentation/EMR
  - Expectations of one-on-one time with clients
- Transitioning out of LTC a struggle
- Service referral outside the “HIV world” is a time consuming, difficult process for LTCSs

Facilitators

- Protocol now in place, more guidance and supervision
  - Existence of protocol biggest suggestion for future work, lack of protocol was biggest challenge at the beginning
  - Might work better in some clinics, especially ones with Enterprise/documentation program/bigger agencies
  - Strength: “just knowing how to deliver the message of Linkage to Care… [before the protocol] didn’t have a uniform definition,” “having something to back it up.”
  - But at the same time, “I can’t remember the last time that we looked at the protocol, “You don’t have to look at it you just know what to do.”

Benefits

- LTC definitely fills a need/gap.
- “We’ve gotten these supports in different places and we’re just kind of filling this gap with being able to help people navigate… there wasn’t this type of really intense service and the availability to have this intense and flexible relationship within some of the existing structures….I’ve been that one person that is flexible, that can be there, that they can call on.”

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Clients

Role description

- Specialists as described by Manual:
  - Conceptualized as a very functional role
  - Focused on engagement in medical care
  - Highlights importance of developing skills
- Specialists as described by clients:
  - Appreciation for direct service provision
  - But characterized more as a relationship built on trust and developed over time
  - Might help explain why patients don't want to be discharged and why Specialists also resist discharging them

Social Support

- Direct social support, especially for those without existing support systems
  - Quote: 61 years old, Out of Care, African American, Male
    - “Somebody other than myself cares about what happens to me.”
  - Quote: 40 years old, Post Incarcerated, White, Male
    - “I guess those are what they’re for, somebody to talk to and stuff”
  - Quote: 61 years old, Out of Care, African American, Male
    - “That made me feel important.”

Motivation to maintain health

- “I really got serious about me and my health and when [my Specialists] came along, I seen how serious she was about tryin’ to help me.”

- Quote: 61 years old, Out of Care, African American, Male
  - “I’m feeling better about myself and the situation. And she’s part of the reason I did that. Because she called and talked to me.”

Post Incarcerated clients

- Often intertwining issues with housing, substance use, leading to interactions with various systems
- "I've been in and out of the system quite a bit. I don't like to link the two together, but a lot of my addiction problems I think stem from my HIV status… 'Cause I just didn't care… I had no regard for the law or society or anything like that."

- Quote: 48 years old, Post-Incarcerated, White, Male
  - "All my incarcerations, my family's helped me out, they're just not gonna do it anymore."

Efficient Post-Incarceration Linkage

- LTCSs do linkage work before (potential) clients are released
- Have maintained contact with clients who become incarcerated and then re-link
- Good coordination with prison social worker

- Quote: 53 years old, Post Incarcerated, African American, Male
  - “Man, I was overwhelmed!”

Specialists as part of complicated system for post-incarcerated clients

- High degree of “surveillance” for some clients who are asked to divulge personal information
  - Especially DOC, housing difficulties

- Quote: 26 years old, Newly Diagnosed/Post Incarcerated, African American, Male
  - “I was wondering, what, are they gonna be checkin’ on me on every little thing I do…”

Specialists have more freedom in some areas than case managers

- Quote: 53 years old, Post Incarcerated, African American, Male
  - "The case managers there were bound by only certain things that they could do for you."
- Quote: 44 years old, Post Incarcerated, White, Male
  - "I think just having a case manager, you get lost in the system."

Navigating systems

- LTCSs referred to as “representatives” or “advocates”
- LTCSs are seen as caring, “not just there for a job,” often in contrast to other individuals in these systems who may be responding to pressures of bureaucracy, high documentation demands, large caseloads

- Quote: 53 years old, Post Incarcerated, African American, Male
  - “I don’t like to overuse the word, ‘heaven-sent.’”

Reluctance to transition out of LTC

- Relationships as investments
- Quote: 44 years old, Post Incarcerated, White, Male
  - "I get attached to people, and I hate to start over with different people."

- Lack of continuity, humanization
- Quote: 36 years old, Post Incarcerated, White, Male
  - "When you switch workers, then you have to start all over again, 'cause they don't personally know you. They only go by what's in your file."

Reluctance to transition out of LTC (not just for post-incarcerated clients)

- Quote: 22 years old, Newly Diagnosed, African American Male
  - "You just can't leave – come in my life and then drop out of my life that fast. That's too short a time for me."

- Quote: 33 years old, Newly Diagnosed, White, Male
  - "I will forget about things."

Need versus (in)dependence

- How much do clients become dependent upon LTC?

- "Constantly pick up a baby from birth, I always want to be picked up [laughs]…I just know how I am. I'll eventually fade back."
- "It's been kinda strivin' to motivate you to start, doin' things for yourself, too, which I appreciated... That's why she said she push so hard to try and get people what they need and get 'em on they feet so they can, successfully re-enter into society, 'cause it's a nine-month program."

Role description, revisited

- From Manual:
  - "The LTCS serves as a patient navigator, providing short-term, intensive case management and care coordination services aimed at assisting clients in identifying and overcoming barriers to accessing and maintaining engagement in HIV medical care."
- From Clients:
  - Quote: 23 years old, Newly Diagnosed, African American, Female
  - "She was very uplifting at the point in time when I came in."

Conclusions

- Small caseloads and flexibility on the part of Specialists may have resulted in:
  - Development of relationships that provided social support, resulting in reluctance to discharge.
  - Many clients successfully navigating complex service systems, in contrast with previous experiences with bureaucratic systems.

Conclusions

- Clients perceive LTC program quite positively, and often attribute some degree of their successes to their Specialists.
- The Linkage to Care Specialist is a unique position, and Wisconsin intends to maintain the program despite end of SPNS funding.

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