SPNS 101: SYSTEMS LINKAGES AND ACCESS TO CARE: A SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE INITIATIVE

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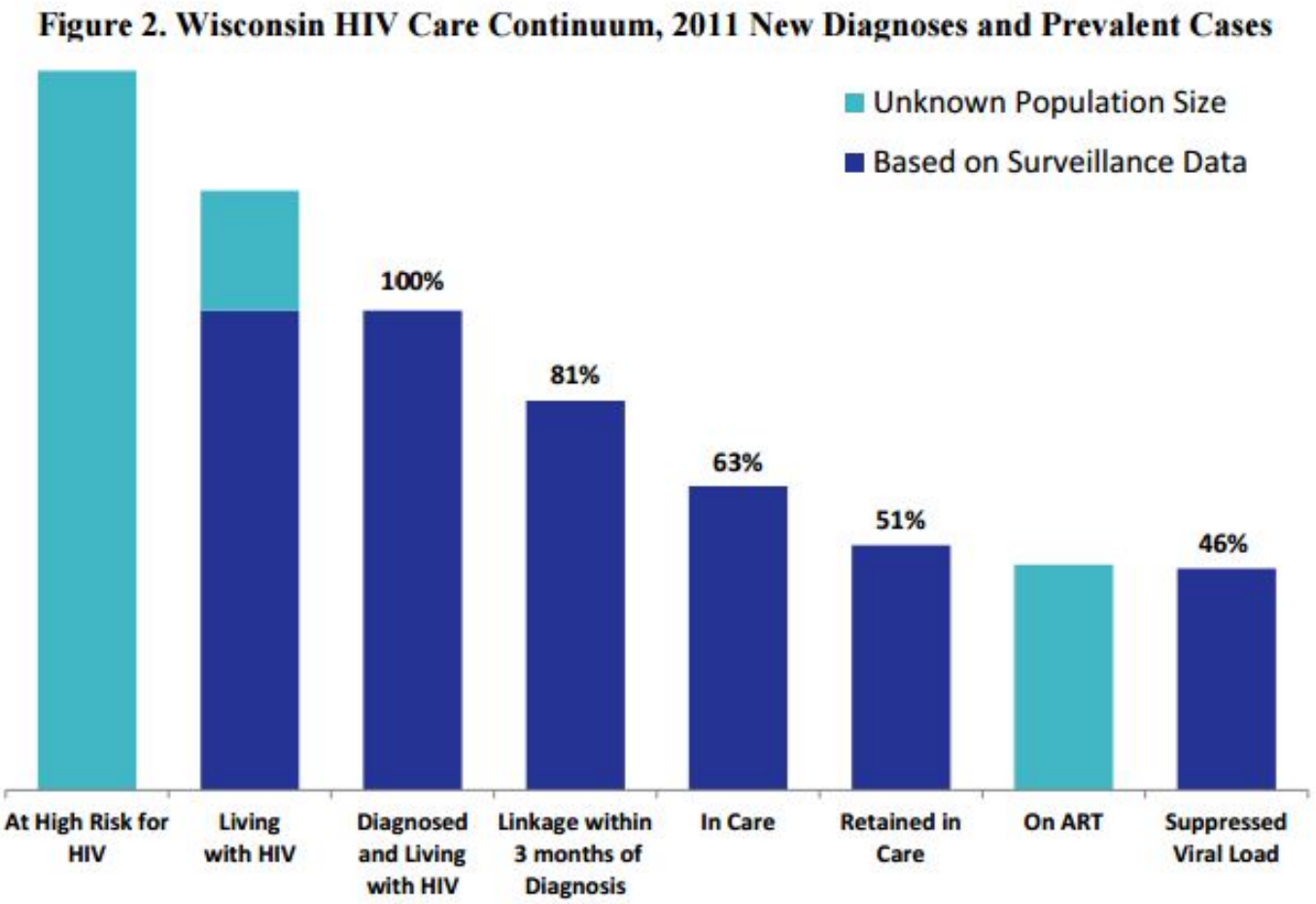
Learning Objectives

- At the conclusion of this activity, the participant will be able:
  - To describe the different interventions implemented under the Systems Linkage Initiative
    - Wisconsin's Linkage to Care intervention, implemented through a new position, "Linkage to Care Specialists"
  - To identify the barriers and facilitators to implementing the interventions.
    - Focus groups conducted with the Specialists
  - To evaluate the benefits provided by interventions used to facilitate engagement/re-engagement in HIV care.
    - Interviews conducted with clients of the pilot phase of the program

Continuum of Care in Wisconsin



Schumann, C. (2014). Wisconsin HIV Care Continuum: Statewide and select population groups. In Wisconsin Department of Health Services AIDS/HIV Program (Ed.), *Wisconsin AIDS/HIV Program Notes* (Vol. February). Madison, WI.

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

Outreach Community Health Centers

- 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.

Development over time

- Collaborative Model
  - Plan-Do-Study Act (PDSAs)
  - Learning Sessions
- Pilot phase qualitative evaluation

- Protocol development
  - Clarify distinction from case managers
  - Exact time to discharge
  - Transportation
  - Documentation

Overview

- Participants
  - All Specialists (n = 10)
  - 16 Clients, representing all Specialists
    - 5 Newly Diagnosed, 8 Recently Out of Care, 3 Post-Incarcerated
    - 11 male, 3 female, 2 transgender
    - 18-68 years old, 56% under 30 years old
    - 13 African American, 2 Hispanic, 1 White
- Methods
  - One-on-one, audio taped interviews at either CAIR or agency
  - Semi-structured interview guides
    - LTCSs: Barriers/challenges to implementation, suggested improvements, approach to building caseload, perceptions of clients' response to program and outcomes
    - Clients: Previous experiences with agency/case managers, expectations/initial understanding of LTC, likes/dislikes of program, barriers to care, outcomes
  - Clients received small incentive

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Linkage to Care Specialists

New program without 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?
  - If there is a new post-incarcerated client but LTCSs with experience with incarcerated populations are at different agencies or are full
  - Once or twice realized that the same client had 2 LTCSs
- Changes in the focus on specific services to be offered "mid-stream" (e.g., transportation)
  - Perspective that some clients will simply not attend appointments without the level of support of someone coming to pick them up, regardless of the length of the program

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
    - For example, case managers providing different services/roles depending on agency
  - Different individuals within one agency communicating slightly different versions/interpretations to outside agencies/referral agencies

Within agency communication

- Challenges of integrating into the LTCSs' "space" within agencies
  - Understanding the job description
  - Understanding what other people's roles were
  - Not "Stepping on toes" or doing other people's jobs
  - Communication from both the State and the within agency team to define roles that both agreed on

Collaboration with case managers

- Duplication of services
  - Some services may still require a case manager (HUD/housing)
- More collaboration with case managers at the initial training stages
  - Learn from experiences
  - Clarify everyone's roles so no one "feels threatened"
- How to integrate case managers into transition, especially if clients want/need to go to different agencies for case management

LTCS as systems navigators

- LTCS as the “one person” who can coordinate and navigate among many different appointments, agencies, and people
  - Can “absorb some frustration” with dealing with multiple agencies
  - Can keep different services organized
  - Can help clients navigate the system

Anxiety about discharging

- LTCSs have developed trusting relationships with clients who may have never had an advocate or ally before
  - Clients may not feel “done”
  - Intense issues with housing security remain
  - Clients have had difficult life situations, are living a “crisis life”
  - Clients may be “one incident away” from losing stability in medical care
  - Suggestion of a more “client centered” approach as opposed to one standard length of time
- Clients believe LTCS will be there for them “forever”

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Clients

Levels of Closeness in Relationships

- Service oriented
  - Transportation
  - Insurance
  - Clothing
  - Food
- Comfortable
  - “I just felt comfortable with her… I don’t know, I guess it just feel genuine.”
- Close Relationships
  - “Mom,” “auntie,” “sister”
  - Quote: 23 years old, Newly Diagnosed, Hispanic, Male
    - “She makes me feel that I’m not alone”

Relationship with LTCSs as Motivation

- Recognizing the effort LTCSs put in to help their clients
- Especially impactful for clients without existing strong support systems, distant families

- Quote: 27 years old, Out of Care, African American, Male
  - "If this complete stranger wants to see me do okay, then it's worth it coming up here."

- Quote: 52 year old, Post-Incarcerated, African American, Male
  - "She never missed a time, never missed a time."

Reluctance to Transition out of LTC

- Relationships with LTCSs were seen as investments
- Many participants were reluctant to end that relationship
- Uneasy with transitioning to a case manager

- "I'm always going to call her because, you know, I'm always going to yell at her to tell her that I'm alright."

- Quote: 41 years old, Out of Care, African American, Transgender
  - "I don't want to go through all of that."

Lessons Learned

- Facilitate communication among community agencies about goals
- Create job descriptions with clear guidelines and responsibilities, distinguished from similar staff positions
- Clarify program's expectations for meeting transportation needs
- Capture the provision of direct social support by LTCSs in documentation
- Need for protocol and final decisions to avoid "selling" the program differently to initial clients

Lessons Learned

- Invest in an initial meeting that addresses the client as a “whole person,” however, be aware that many clients may have initial feelings of wariness or mistrust and a relationship needs to grow with time
- Schedule time to discuss psychosocial issues outside of medical/HIV care
- Ensure client understanding of time frame, help smooth transitions to new case managers/workers by facilitating an introduction

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