Client Perspectives on the HRSA/SPNS Systems Linkage and Access to Care Initiative Interventions

Kimberly Koester, Shannon Fuller, Andre Maiorana, Sophia Zamudio-Haas, Wayne Steward, Janet J. Myers

University of California San Francisco



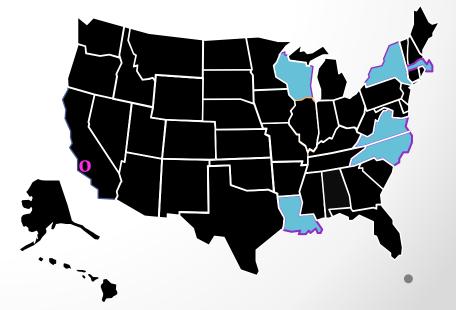
AIDS Research Institute Center for AIDS Prevention Studies



Background

- In 2011, HRSA/SPNS launched the Systems Linkage and Access to Care Initiative.
- Six State Departments of Public Health were funded to develop and implement testing, linkage & retention interventions.





Interventions

- States developed and implemented 17 discreet interventions.
- Majority focused on linkage, re-engagement and retention activities.
- Majority combined systems-level changes with individual-level interventions.
 - E.g., surveillance data used to identify persons out-of-care/newly diagnosed shared with clinicbased navigators

Navigation Interventions

- "Navigation" interventions resemble case management, but have unique elements:
 - Intensive services offered to a select group of clients.
 - Services are offered on a short-term basis.
 - Caseloads are intentionally small.
 - Interventionists are encouraged to leave the office to meet with clients in non-clinical environments.

Research Question

 To assess whether and how the 'navigation' interventions worked from the clients' perspectives.

Methods

- Sampled clients from a navigation intervention in each state.
- Local site personnel purposefully recruited "typical" clients.
- UCSF researchers conducted in-depth interviews with clients.
- Examples of interview domains included:
 - Health assessment
 - Current/previous HIV care experiences
 - Diagnosis narrative/gap in care narrative
 - Intervention experiences/impact

Data Analysis

- We utilized the Framework Analysis.¹
- We drafted fieldnotes after each interview.
- Digital recordings transcribed verbatim.
- Primary analyst reviewed fieldnote, then coded interview and drafted a memo; secondary analyst reviewed.
- Interviews, fieldnotes, memos entered into Dedoose.
- Themes generated during data reduction of key codes

1. Ritchie J, Spencer L (1994) Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. Analyzing Quantitative Data. London: Routledge. 173–194.

Preliminary Findings

- We conducted 89 interviews between Jan 2014 -May 2015.
- We noted differences between newly diagnosed and those who were out of care.
- Variations within the groups included:
 - 'High touch' clients required and received frequent contact by interventionists.
 - 'Low touch' clients had minimal needs and infrequent contact with the interventionists.
 - 'Indifferent' clients were not well served by the interventionists.



Linkage to care is relatively straightforward. The needs of newly diagnosed clients are typically well outlined.

Newly Diagnosed Receive a Roadmap

I: So tell me about working with Annie.

P: I didn't know what to expect. I was just blind to the whole thing, what was gonna happen next. She really helped me. When you don't know and you're confused and you're dazed, <u>they really lay out a program for you</u>, like, this is what you need to follow. . . . And they even tell you – there's times when people get tired of taking a pill every day. So they prepare you for this phase in your life. They take you step by step and they're there for you when you fall down, and help pick you up."

*Greg, 42 years old, African-American, diagnosed 3 months prior

*All names in findings section are pseudonyms



"There was never anyone to call him..."



On the other hand, clients who are "outof-care" are more of a mystery.

Mind the Gap [in Care]

- High touch clients were out of care due to a combination of life situations:
- HIV care not a priority and
 - Expired insurance
 - Struggling with depression, anxiety, bad mood
 - Involved in drug and/or alcohol use
 - In transition e.g., recent move, starting school, work
 - Feeling well enough to miss appointments
 - Managing grief or other stressful issues
 - Tired of dealing with healthcare system
 - Competing health issues

"It's one of the best programs I've ever encountered within my whole life of program hopping. It's just, like you ever met someone that's just so honest with you, that won't sugar-coat stuff, that won't tell you stuff to make you feel better? They're upfront with you about everything; you know? There's no secrets. There's no no confusion. If there's confusion, you get clarity....." -Bethany, 22 year old, previously out of care

Interventionist gives extra push/pull



"What does she look like again?"

-the Indifferent Client

Why are clients indifferent?

- Clients may be self-managing/self-sufficient.
- Clients do not feel they need assistance.
- May be a poor match for the intervention service.

Summary

- Overall, clients are responding well to the interventions.
- Newly diagnosed clients are well-served thanks in part to an explicit set of goals.
- Follow-thru and reliability on the part of the interventionist engenders trust and meaningful connection between navigator and client
- Light touch clients have circumscribed, but variable needs and appreciated the extra push.

Recommendations

- With regard to engaging, re-engaging and retaining people in care, we need tools to:
 - Facilitate identification of clients who need a little push vs. intensive support vs. those who want to be left alone.
 - Generate practical advice to pre-emptively discuss situations that derail care/treatment - "what to do if e.g.,:"
 - Your insurance runs out
 - You have not come to terms with living with HIV
 - You don't get along with your provider
 - You can't find a ride to the clinic, you don't have money for the bus
 - You don't feel like attending your appointments

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