“SHE MAKES ME FEEL THAT I’M NOT ALONE”: LINKAGE TO CARE SPECIALISTS PROVIDE SOCIAL SUPPORT TO PEOPLE LIVING WITH HIV

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BACKGROUND

- 46% of people living with HIV (PLH) in Wisconsin have suppressed viral load (1), well below the 80% benchmark delineated in the National HIV/AIDS Strategy (2).
- Viral suppression depends upon engagement in care, and PLH may face several barriers
- Unstable housing, competing subsistence needs
- Stigma, lack of social support systems
- Mental health/illness comorbidities, substance abuse problems (3-6)
- Negative experiences/distrust of health care and medical establishment
- Stigma, lack of social support systems
- Unstable housing, competing subsistence needs

The Wisconsin Health Department AIDS/HIV Program instituted an intervention aimed at increasing linkage and retention in medical care among PLH through the hiring of full-time “Linkage to Care Specialists” within clinical agencies and community based organizations in Milwaukee and Madison.

Specialists provide intensive patient navigation plus case management services for approximately nine months for small caseloads (10-15 clients) of PLH who are newly diagnosed, previously out of care or new to care, and recently incarcerated.

OBJECTIVE

To describe preliminary qualitative evaluation of Wisconsin’s Linkage to Care intervention during its pilot phase, focusing on the provision of social support by Specialists to their clients.

METHOD

PARTICIPANTS

- 16 Clients, representing all Specialists
- 5 Newly Diagnosed, 8 Recently Out of Care, 3 Post-Incarcerated
- 11 male, 3 female, 2 transgender
- 13 African American, 2 Hispanic, 1 White
- Received $15 incentive

PROCEDURES

- Referred by Specialists, participants determined by randomized list of clients
- One-on-one, semi-structured interviews:
  - Previous experiences with agency/case managers, expectations/initial understanding of LTC, likes/dislikes of program, barriers to care, outcomes

DATA ANALYSIS

- Using MAXQDA software to query data using grounded theory approach

RESULTS

CLOSE RELATIONSHIPS

“I actually talked about something that was kind of confidential… I’ve never felt like this before and she actually makes me feel comfortable. She makes me feel that I’m not alone, you know. And I like that ‘cause there is not a lot of people out there like that.” (NDMH23)

“Specialists as motivators for achieving or maintaining positive outcomes

“She never missed a time, never missed a time, so you know what that means. That made me feel more positive to go and do what I had to do… that is why I’m undetectable right now because I helped to push me forward instead of feeling all sorry for myself, and rebellious.” (PIMAAS2)

“If this complete stranger wants to see me do okay, then it’s worth it coming up here.” (OCMAA47)

COMFORT WITH MEDICAL CARE AND STIGMA

“Regretfully comfortable with my diagnosis… I’m still keeping it to myself like I been doing, but she has helped me to deal with this more.” (OCFAA41)

“I had problems working with other people because people discriminate [against] you when they find out that you are HIV positive… and that includes family members. And then when I met [my Specialist] she kind of motivated me and made me realize that it’s nothing bad. She made me feel like I was a human again.” (OCFAA59)

RELUCTANCE TO TRANSITION OUT OF LTC

“Yeah, that’s what I asked her about, ‘Can I just keep going?’ And she’s like, ‘No…” She said, “I’m not going term for one.” I said, “So what if I don’t feel right with my new case manager?” So she said, “Well, you can always switch off case managers.” And I was like, I don’t want to go through all of that… I don’t know her… I don’t know what she’s like or nothing.” (OCFAA41)

“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.” (PIMAAS2)

DISCUSSION

- The Specialists of Wisconsin’s Linkage to Care Program increased comfort with medical care, assuaged concerns regarding HIV stigma or discrimination, and motivated clients to maintain their health by providing direct social support and developing relationships with their clients.
- Continued offering of intensive programs like these may be necessary for some clients who are higher need. However, cost-effectiveness and sustainability remain concerns, especially given the reluctance of clients to transition out of the program, and stated intentions to continue contacting their Specialists as problems arise.
- Future interventions to increase medical care engagement among PLH should include strategies to “personalize” the patient experiences within health care and psychosocial services delivery systems, as well as screening tools to triage clients into different levels of personal service provision intensity based on need and desire.
- Analysis is currently underway with data from clients from the implementation phase of the intervention.

REFERENCES


