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“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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Abstract

Wisconsin’s Linkage to Care intervention incorporates elements of individually tailored patient navigation and case management designed to increase linkage and retention in HIV-related medical care. It is delivered by Linkage to Care Specialists in HIV medical clinics and community-based agencies. Researchers interviewed a diverse sample of clients to conduct preliminary evaluation of the pilot phase of this intervention. The participants’ relationships with their Specialists emerged as a major unifying theme of the data. Comfortable and close relationships with Specialists served as motivation to adhere to medical care, mitigated negative feelings associated with HIV-related stigma, and resulted in increased comfort with medical care and positive health outcomes including engagement in care and undetectable viral load. As a result of the Specialists’ support, many participants were reluctant to transition out of the Linkage to Care program. The positive effects demonstrated by Specialists are balanced against the costs of small caseloads that are potentially not feasible within traditional case management models. Future interventions to increase medical care engagement, among HIV+ individuals at risk of lack of engagement, should develop 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.

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Keywords

HIV Medical Care; ART Adherence; Patient Navigation

As a result of sub-optimal engagement in HIV medical care only 46% of people living with HIV (PLH) in Wisconsin have suppressed viral load (Schumann, 2014). Wisconsin's Linkage to Care intervention is specifically designed to increase linkage and retention in HIV-related medical care, especially for Black men who have sex with men (MSM), as an estimated one in three Black MSM in Wisconsin is living with HIV, compared to 8% of Hispanic MSM and 3% of White MSM (AIDS/HIV Program, 2014). Full-time Linkage to Care Specialists provide and coordinate services, referrals and appointments, attend appointments with clients, and help navigate health care systems. They work within HIV medical clinics and community-based agencies providing services for clients who are newly diagnosed with HIV, recently released from incarceration, or recently not engaged in medical care. Specialists are non-medical professionals who receive specific training on basics of HIV disease transmission, progression and treatment, principles of case management, motivational interviewing, and professional ethics. Specialists' scope is narrow and specialized, focusing on barriers that have prevented ongoing engagement in medical care, such as mental health or other comorbidities, substance use, transportation difficulties, and housing instability. They work intensively with clients for up to nine months and carry a maximum caseload of only 15 clients. During the pilot phase of the program, we aimed to qualitatively describe clients' barriers to medical care, how well the Specialists were able to decrease barriers, and perspectives on program improvements for incorporation into the implementation phase.

Method

Participants and Procedures

The research team interviewed 16 clients from the pilot phase of the program in February through August of 2013. Lists of three eligible participants were generated for each of the 9 Specialists, specifically to maximize sample diversity. Specialists directly referred clients to the research team, who described the study, and coordinated with the Specialists to schedule informed consent and interview procedures. Approval was provided by the Medical College of Wisconsin's Institutional Review Board. Semi-structured interviews were conducted in private rooms at agency locations, focusing on participants' experiences in the program, benefits of the program, communication with and impressions of the Specialists, and remaining barriers to care. Interviews were audio recorded and transcribed verbatim. Participants were compensated $15.

Data Analysis

After reading all interview transcripts, members of the research team developed an initial coding scheme, corresponding with interview guide questions, and capturing emerging themes. After individually coding two transcripts, they refined, expanded or deleted codes to more accurately capture themes and ensure consistent coding. The revised coding scheme was used to code the remaining transcripts. The research team members conducted a targeted reading of each theme using MaxQDA software, and wrote summaries of each theme, choosing quotes that particularly captured the theme as well as quotes that contradicted common opinions. Patterns that emerged from each major theme were then explicitly analyzed with dual coded text segments. Analysis focused on providing suggestions for program improvement and a preliminary understanding of the potential benefits and limitations of the program.

Results

Recruitment resulted in a sample that represented the diversity of the pilot clients, described in Table 1 (see Note for description of the participant codes used below). The clients' relationships with Specialists emerged as a major unifying theme of the data.

Service Oriented, Comfortable, and Close Relationships

While a minority of participants described a strictly service oriented relationship with their Specialists, many participants described a close relationship with their Specialist, sometimes using terms like “sister,” “auntie,” and “mom.” During analysis a third group emerged in which participants described personal relationships with their Specialists, but at a less intense degree, often described as “comfortable.” The theme of “comfort” was often difficult for participants to specifically define: “I don't know, I guess it just feel genuine” (OCFAA25). A personal connection may be especially important for PLH who do not have other strong, stable sources of social support.

> 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)

Comfort with Medical Care and Stigma

Participants discussed how Specialists also helped increase comfort with diagnosis, and accessing medical care: “Really I'm more comfortable with my diagnosis because… she has helped me to deal with this more.” (OCTAA41). The relationship with the Specialist was also a buffer against some participants' perceptions and experiences of HIV stigma, which may have kept them from engaging in medical care.

> 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)

LTCSs as Motivators for Achieving or Maintaining Positive Outcomes

Many participants cited their relationship with their Specialist as motivation to prioritize engagement in care: “It really sunk me in and I'm like, okay, if this complete stranger wants to see me do okay, then it's worth it coming up here…. I haven't missed any appointments”

(OCMAA27). For a few participants, the Specialist's dependability motivated the participant to be more accountable for their own health:

> 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 non-detectable right now because I had help to push me forward instead of feeling all sorry for myself, and rebellious. (PIMAA52)

Reluctance to Transition out of LTC

Participants' relationships with their Specialists were seen as investments. Therefore, many participants were reluctant to end that relationship and transition out of Linkage to Care services, sometimes expressing unease with having to get to know a new case manager:

> Yeah, and that's what I asked her about, "Can I just keep her?" And she's like, "No…." She said, "I'm not long-term for no one." I said, "So what if I don't feel right with her or him [the 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. (OCTAA41)

Many clients indicated that they intended to remain in touch with their Specialists even after discharge if they encountered further difficulties or barriers to care, or simply to "check in."

Discussion

Medical care engagement is affected by acceptance of one's HIV status, coping with stigma, relationships with health care providers, and external support systems that provide motivation to remain in care (Rajabiun et al., 2007). 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. The ability of the Specialists to mitigate barriers is consistent with previous research demonstrating positive effects of social support on health, depression, and quality of life (Ashton et al., 2005; Jia et al., 2004; Uchino, 2006), disclosure of HIV status (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003), stigma (Colbert, Kim, Sereika, & Erlen, 2010), and medication adherence (Gonzalez et al., 2004).

The sample included a variety of genders, races/ethnicities, ages, and client types, thematic saturation was reached, and the interviews provided an in-depth exploration of the Linkage to Care program, however sample size was small. Additionally, the intervention changed during the pilot phase, in order to incorporate lessons learned through a Collaborative Learning Model approach (Nembhard, 2009). Future work will describe qualitative evaluation and clinical quantitative outcomes from the implementation phase of the project, including retention in care and viral load suppression. In future efforts, interviews with former clients may provide additional information about the program's successes, as participants in this study were interviewed while still actively enrolled in the program, which may have affected answers and does not provide evidence of sustained success.

Traditional case managers may not have the ability to build such close bonds with clients, given large caseloads and administrative burden. Therefore continued offering of intensive programs like these may be necessary for some clients. 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.

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References

AIDS/HIV Program. Summary of the HIV/AIDS Surveillance Annual Review: New Diagnoses, Prevalent Cases and Deaths Reported through December 31, 2013. Madison, WI: 2014.

Ashton E, Vosvick M, Chesney M, Gore-Felton C, Koopman C, O'Shea K, Flamm J. Social support and maladaptive coping as predictors of the change in physical health symptoms among persons living with HIV/AIDS. AIDS Patient Care & STDs. 2005; 19(9):587–598. [PubMed: 16164385]

Colbert AM, Kim KH, Sereika SM, Erlen JA. An examination of the relationships among gender, health status, social support, and HIV-related stigma. Journal of the Association of Nurses in AIDS Care. 2010; 21(4):302–313. [PubMed: 20116295]

Emlet CA, Brennan DJ, Brennenstuhl S, Rueda S, Hart TA, Rourke SB. Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada. AIDS Care. 2013; 25(10):1330–1339. [PubMed: 23452022]

Fortenberry JD, McFarlane M, Bleakley A, Bull S, Fishbein M, Grimley DM, Stoner BP. Relationships of stigma and shame to gonorrhea and HIV screening. American Journal of Public Health. 2002; 92(3):378–381. [PubMed: 11867314]

Gardner LI, Metsch LR, Anderson-Mahoney P, Loughlin AM, Del Rio C, Strathdee S. the Antiretroviral Treatment and Access Study (ARTAS) Study Group. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. AIDS. 2005; 19(4):423–431. [PubMed: 15750396]

Gonzalez JS, Penedo FJ, Antoni MH, Duran RE, Fernandez MI, McPherson-Baker S, Schneiderman N. Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. Health Psychology. 2004; 23(4):413–418. [PubMed: 15264978]

Jia H, Uphold CR, Wu S, Reid K, Findley K, Duncan PW. Health-related quality of life among men with HIV infection: Effects of social support, coping, and depression. AIDS Patient Care & STDs. 2004; 18(10):594–603. [PubMed: 15630787]

Kalichman SC, DiMarco M, Austin J, Luke W, DiFonzo K. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. Journal of Behavioral Medicine. 2003; 26:315–332. [PubMed: 12921006]

Lee RS, Kochman A, Sikkema KJ. Internalized stigma among people living with HIV/AIDS. AIDS and Behavior. 2002; 6(4):309–319.

Miller CT, Kaiser CR. A theoretical perspective on coping with stigma. Journal of Social Issues. 2001; 57(1):73–92.

Nembhard IM. Learning and improving in quality improvement collaboratives: Which collaborative features do participants value most? Health Services Research. 2009; 44(2p1):359–378. [PubMed: 19040423]

Rajabiun S, Mallinson RK, McCoy K, Coleman S, Drainoni M-L, Rebholz C, Holbert T. 'Getting me back on track': The role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. AIDS Patient Care & STDs. 2007; 21(S1):S-20–S-29. [PubMed: 17563286]

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

Slater LZ, Moneyham L, Vance DE, Raper JL, Mugavero MJ, Childs G. Support, stigma, health, coping, and quality of life in older gay men with HIV. Journal of the Association of Nurses in AIDS Care. 2013; 24(1):38–49. [PubMed: 22687445]

Uchino BN. Social support and health: A review of physiological processes potentially underlying links to disease outcomes. Journal of Behavioral Medicine. 2006; 29(4):377–387. [PubMed: 16758315]

Valdiserri RO. HIV/AIDS stigma: An impediment to public health. American Journal of Public Health. 2002; 92(3):341. [PubMed: 11867303]

Wisconsin Department of Health Services AIDS/HIV Program. Wisconsin Department of Health Services HIV/AIDS Surveillance Annual Review: New diagnoses, prevalent cases, and deaths through December 31, 2013. In: Wisconsin Department of Health Services AIDS/HIV Program. , editor. Wisconsin HIV Surveillance Reports. Madison, WI: 2014.

Table 1

Participant Characteristics

Participant Code	LTCS code	Clinic Type	Gender	Race/Ethnicity	Age
Newly Diagnosed					
NDMAA18	2	Clinical	Male	African-American	18
NDMAA19	2	Clinical	Male	African-American	19
NDMAA21	3	Non-clinical	Male	African-American	21
NDMAA23	7	Clinical	Male	African-American	23
NDMH23	5	Clinical	Male	Hispanic	23
Out of Care					
OCFAA23	3	Non-clinical	Female	African-American	23
OCFAA25	4	Non-clinical	Female	African American	25
OCFAA59	3	Non-clinical	Female	African-American	59
OCMAA24	9	Non-clinical	Male	African-American	24
OCMAA27	1	Clinical	Male	African-American	27
OCMW44	4	Non-clinical	Male	White	44
OCTAA41	1	Clinical	Transgender (MTF)	African-American	41
OCTH31	5	Clinical	Transgender (MTF)	Hispanic	31
Post-Incarcerated					
PIMAA42	6	Clinical	Male	African-American	42
PIMAA52	8	Clinical	Male	African-American	52
PIMAA68	2	Clinical	Male	African-American	68

Note: Participant codes were created through a combination of client type (ND = newly diagnosed, OC = recently out of care, PI = post-incarcerated), gender (F = female, M = male, T = transgender), race/ethnicity (AA = African American, H = Hispanic, W = White), and age.