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evidence review

Effectiveness of Outreach and Care Coordination Interventions in Engaging and Retaining Hard-to-Reach People Living with HIV/AIDS in Medical Care

Why is it Important to Engage and Retain Hard-to-Reach People Undergoing HIV Treatment?

Engaging hard-to-reach populations in care is often described as cyclical. Many people may enter the care system at some point but are sporadic users of care, often missing appointments or dropping out of care for periods of time. The challenge that outreach programs face is not only to engage hard-to-reach populations in medical care but to retain them once they have accessed care. Retaining hard-to-reach populations in care is essential for adherence to antiretroviral therapy, which is necessary for the delay of clinical progression to AIDS (1, 2).

Antiretroviral therapy (ART) is effective at improving the health and reducing the mortality rate among people living with HIV/AIDS (PHAs). Non-adherence to medical

This evidence review is part of a series on HIV prevention and control produced by the National Collaborating Centre for Infectious Diseases. It is intended to inform public health practitioners and community-based workers and guide their practice.

appointments is associated with increased viral load and decreased CD4 cell counts (1). Use of health care services that promote safer sexual practices and enable a “positive” approach to prevention has an indirect effect on preventing HIV transmission by reducing viral load and infectiousness of HIV positive individuals (3, 4). Structural changes for improving access to care that have been positively associated with use of HIV-related health services include ensuring shorter appointment wait times, making convenient appointment times, and engaging health care providers who speak the same language as their clients (5).

This paper will examine the effectiveness of outreach and coordinated care programs in engaging and retaining PHAs in medical care. Barriers to care will be examined to understand the mechanisms that delay treatment for PHAs.

Highlights

- Engagement in care for hard-to-reach populations is often described as cyclical. Many people may enter the care system at some point but are sporadic users of care, often missing appointments or dropping out of care for periods of time. The challenge that outreach programs face is not only to engage hard-to-reach populations in health care but also to retain them once they have accessed service.
- Repeat contact with health providers, case managers, patient navigators, and outreach workers for appointment reminders or rescheduling, service coordination, relationship building, and for provision of specific services such as food, transportation, and counseling increased PHAs’ access and retention in medical care.
- Health care providers who focused on engaging newly diagnosed PHAs in medical care by offering HIV education and support, addressing stigma, and helping with access to resources to address financial and structural barriers, increased their retention in care.

How Many People Living with HIV/AIDS Are Not Accessing Care?

In 2008, an estimated 2,300 to 4,300 new HIV infections occurred in Canada, bringing the estimated total number of PHAs to approximately 65,000—a 14% increase from 2005 estimates (6). In 2008, an estimated 33.4 million people were living with HIV/AIDS worldwide (7). By December 2008, it was estimated that 3.7 to 4.4 million PHAs were receiving treatment in low and middle income countries, representing 39% to 46% of the estimated 8.1 to 9.5 million people who meet eligibility criteria (8). Even though the initial UNAIDS and World Health Organization “3 by 5” Initiative, which aimed to have three million HIV-positive people in developing countries on ART by the end of 2005, did not reach its goal, these organizations have renewed their commitment to achieving universal access to HIV/AIDS treatment and care by 2010.

Studies estimate that approximately 17%–40% of all people who know their HIV status in the USA do not receive routine HIV care (9–11). Individuals from marginalized populations are difficult to retain after diagnosis and often re-enter care once their HIV infection has progressed with serious illnesses requiring hospitalization. At this point, treatment is expensive and often ineffective (12). Some studies indicate as many as 25% of PHAs who enter care with serious opportunistic infections or CD4 cell counts below 200/mm³ die within 12 months of initial HIV diagnosis (13–17). According to a statistical

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model, the life expectancy of PHAs would only be eight years shorter than that of individuals in the general population if they received HIV care concordant with guidelines and adhered to their medication regimens. Delayed initiation of ART resulted in 3 additional years of life lost, whereas premature ART discontinuation led to 0.7 more years of life lost (18).

Are Certain Populations Harder-to-Reach and Retain in Medical Care?

Of 61 low and middle income countries, 30 (49%) had retention rates in antiretroviral care of over 80%, 10 (16%) of which exceeded 90% retention at 12 months. Fifty-one (84%) countries reported retention rates at 12 months greater than 70% (8). Aggregate retention rates across reporting countries did not differ by sex or by age. However, there is concern that women may experience more barriers in accessing

treatment programs than men. Studies found that women are often inaccurately diagnosed and seek care later in the course of their illness (19–21). Contrary to these findings, there appear to be more women accessing antiretroviral care in low income countries than men (22, 23). In a review of studies conducted in Southern African countries, proportionally more females were receiving antiretroviral treatment than men, even when the higher HIV infection prevalence in females was taken into account (female:male ratio in treatment exceeded 1.6) (23).

In high income countries, the trend in antiretroviral uptake seems to be equalizing between the sexes. One Ontario study which evaluated longitudinal patterns of antiretroviral use, based on information from medical records (N=104), found no gender differences in access to and uptake of ART over time among PHAs who initiated therapy within 2.2±2.3 years of HIV diagnosis at an average CD4 count of 300±150 cells per microliter (24). In another study where data from medical records were reviewed for 414 severely marginalized PHAs in New York, the investigators found that women were significantly less likely to use HIV health care services optimally, including lower use of HIV primary care and greater use of the emergency department. In addition to female gender, suboptimal use of HIV health care was associated with low education, insurance status, mistrust of the health care system and health care providers. The researchers were unable to identify factors that explained the observed gender disparities (25). A US study of 474 PHAs in four states observed no racial/ethnic or gender disparities in ART receipt; however, minority racial/ethnic groups discontinued ART and experienced virologic failure sooner (26). Other studies have suggested gender differences in premature discontinuation of ART care, in which female subjects cited poor adherence, dermatological symptoms, neurological reasons, constitutional symptoms, and concurrent medical conditions as reasons for stopping treatment (27, 28). Marginalized populations such as racial/ethnic minorities, the unstably housed, and the mentally-ill have poor access to, and utilization of, health care services (19). In an evaluation of 17 outreach interventions serving poor minority populations, 7% to 49% of participants were sporadic users (missed 3 or more appointments within a 12 month period), and 4% to 22% were lost to follow-up (29). In particular, cocaine users were significantly more likely than non-opioid/non-cocaine users to miss a scheduled medical appointment and use the emergency room, and were less likely to receive antiretroviral medications. Opioid users were even more likely to miss medical appointments than cocaine users (30).

What Are Some of the Barriers to Accessing Care?

Barriers associated with poor utilization of HIV medical care and treatment include competing needs, substance use, mental illness, lack of trust in the health care system, fear of losing one’s child, poor understanding of the health system and HIV disease, negative provider attitudes, managing co-morbidities, fear of confidentiality violations, and culture and language (9, 11, 19, 20, 31–38).

As well, some Canadian PHAs living in rural and remote areas still struggle to access the care and treatment they need due to geographic isolation and distance of travel (2, 35, 39–41). In one study, rural PHAs reported more frequently that the shortage of adequately trained health professionals, lack of public transportation, and stigmatization by community residents are the primary barriers to health care (20).

Why is the Coordinated Approach to Outreach and Health Care Interventions Important?

Community outreach and health care coordination interventions for PHAs enable health workers to locate clients and help them access services. Many PHAs prioritize food and shelter over health care needs, and it is only by attending to these more immediate needs that other health care needs can be addressed (39, 42). Qualitative studies reveal that outreach programs are often the first point of contact with the health care system for hard-to-reach PHAs (3, 43). Research has shown that the most effective outreach programs gain the trust of clients through emotional support and an understanding of their lifestyle. The B.C. Centre for Disease Control has an ongoing street outreach training program that provides distance-learning modules along with community-based outreach training (44).

How do Interventions Increase Medical Appointment Adherence?

In one study, reminder calls and periodic check-ins from outreach workers helped clients focus on improving their adherence to medications and appointments (2). In two other studies, outreach program staff accompanied clients to their appointments and provided financial help for transportation (2, 19). Program staff also facilitated communication between clients and their doctors. In yet another study by Cunningham and colleagues (2007), 610 hard-to-reach PHAs, who were clients in seven different outreach programs around the United States, were enrolled to determine factors contributing to adherence to medical appointments (defined as primary care, emergency room, and hospital visits). "Staying in care" was associated with having insurance, receiving case management, and using mental health services (19). A qualitative study of 76 underserved PHAs suggested that outreach programs can foster sustained and regular HIV medical care by conducting client-centered risk assessments to identify and reduce sources of instability (2). The study also recommended that sustained care can be achieved by implementing strategies that promote healthy practices, creating a network of support services in the community, and supporting adherence through frequent follow-ups for medication and appointment keeping (2). Mobile van outreach has also been effective in finding clients who were lost to follow-up (45, 46). Effective treatments for opioid use, such as buprenorphine and methadone, have facilitated access to medical care for HIV-positive opioid users (47, 48).

In an outreach study of 773 PHAs, participants who received nine or more outreach contacts during the first three months were about half as likely to have a substantial gap (defined as four months or more) in primary care during the first 12 months of follow-up (49). The purposes for outreach were building relationships with clients, reminding clients of their appointments, rescheduling appointments for clients, coordinating care services, and providing clients with other specific services such as food, transportation, and counselling. Street-based outreach is effective at connecting with homeless PHAs (50–52). Tommasello and colleagues (2006) studied 110 homeless PHAs (75% male, 85% black) who were contacted using outreach methods (51). As a result of outreach interventions, a significant reduction in unmet needs in housing, financial, and mental health services was observed among the study participants. The majority (84.5%) of participants interviewed at 12 months had attended at least one medical appointment during the study period, with a median number

of visits being 4.1 per person. Depression in participants decreased significantly from 41.5% at baseline to 27.5% after 12 months. In a multi-site US study of 224 young PHAs (73% African American; 66% between 19–22 years, 81% gay), only 11% of visits were missed without explanation or patient contact over the first 27 months during the study period. Retention in health care was associated with being under 21 years old, a history of depression, receipt of program services, and feeling respected at clinic; participants who were lost to health care had a CD4 count under 200 at baseline and were of the Latino heritage (53).

Outreach services have also been successful at reducing sexual risk behaviour among newly diagnosed PHAs (4, 9). In a sample of 116 newly-diagnosed PHAs (80% male; 64% gay; 59% Black; 24% substance users), 31% reported that they had not seen a health care provider for HIV since testing positive (4). However, in the six months following study enrolment, 81% of study participants had at least two HIV medical visits, and were more likely to have an undetectable viral load at 6-month (34%) and 12-month follow-up (45%) compared to baseline (12%). Incidence of unprotected sex was significantly reduced at 6 months (76%) and 12 months (79%) compared to baseline. In addition, individuals with 1-3 program contacts per month were 80 times less likely to report risky sexual behavior compared to those with 2 or less contacts (4).

Can Interventions Reduce HIV/AIDS Discrimination?

Bird and colleagues (2004) found that a large percentage of PHAs perceived stigma and discrimination from their health providers (54). Differential ART prescribing practices were found in one study, depending on the race of the patient and whether they had a racially concordant provider or not (55). Poor quality care and medical access

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were associated with providers' negative attitudes (56, 57). Feelings of HIV-related stigma following diagnosis may also affect coping, adjustment, and care-seeking behaviour (9). Persons who perceive a higher level of HIV-related stigma are more likely to experience depression and a lower quality of life than those who perceive a lower level of stigma (58).

Perceptions of the client-provider relationship emerged as a central element of the process by which PHAs engaged or remained in care (20, 59). Outreach workers have been effective in minimizing

stigma, increasing PHA's trust, and retaining them in care (9, 38, 60). Outreach staff counsel participants on how to cope with stress, address competing needs, disclose to partners and families, and manage perceived stigma. For example, in one observational longitudinal outreach study, the providers focused on engaging newly diagnosed PHAs (N=104) in medical care by offering HIV education and support, addressing stigma, and helping with access to resources to address financial and structural barriers (9). At the 12-month follow-up, HIV-related provider stigma significantly decreased from 46.2% at baseline to 22.4%, and 45% of participants had undetectable viral load (9). In another study, PHAs that reported provider stigma as a barrier at baseline and continued to report stigma at 6 months had less than adequate retention (2).

In a recent longitudinal intervention using "patient navigators" in four U.S. sites, the proportion of participants (N=437) that reported "no care" significantly decreased from 12% to 8% at 12 months (61). In this study, patient navigators were lay educators who worked with clients to develop their communication skills when interacting with health providers by modelling behaviours or rehearsing conversations in preparation for appointments. This study demonstrated that participants with a better perceived relationship with their health provider had 41% greater odds of an undetectable viral load during the study period and 32% greater odds of attending HIV medical visits at 12-month follow-up.

Are Case Management Interventions Effective?

A case manager is defined as a social worker, nurse, AIDS service organization staff member, or anyone else who is formally trained to coordinate care (62). Case management involves an assessment of a client's needs; case managers are often involved in obtaining social security for clients, providing mental health and substance abuse treatment/counseling, partaking in advocacy, offering respite and buddy/companion services, and in addressing basic sustenance, housing, and transportation needs of the clients (63, 64). In addition, the case manager also monitors each client's medical progress and provides psychosocial support.

A recent Cochrane review of care coordination programs for PHAs (2006) examined 28 studies involving 39,776 study subjects (63). The studies indicated that case management strategies were associated with decreased mortality. Case management was also associated with increased receipt of ART. The three randomized case management trials included were Katz et al (62), Messeri et al (65), and Laraque (66). The Katz study (2001) involved 2437 PHAs and found that 56.5% had contact with a case manager at 6 months (62). Case management contact was significantly associated with increased utilization of ART (odd ratio [OR] 1.68, 95% confidence interval [CI] 1.24 to 2.27) and with sustained contact antibiotic prophylaxis against *Pneumocystis carinii* pneumonia or toxoplasmosis (OR 1.77, 95% CI

1.28 to 2.46). Significant increases in both entry and continuity in medical care (65) and a decrease in mortality (66) were found in two social services models.

The U.S. Antiretroviral Treatment Access Study demonstrated that when newly diagnosed PHAs (N=136) meet up to five times in a 3-month period with a case manager, they had a greater chance of being linked to care (13, 67). It was shown that 78% of PHAs who met with a case manager had stayed in care for 6 months (versus 60% of those who received a passive referral), and 65% stayed in care for 12 months (versus 49%). The estimated cost for this case management program was USD \$600–1200 per client. Data for the period of 3 months prior to intervention to 6 months after enrolment for 218 participants newly enrolled in the U.S. Health Services Program, showed one or more case management visits significantly increased the odds of quarterly medical visits (2 or more visits versus 0-1 visit; 35% versus 22%) (68). Another randomized controlled trial (RCT) of case management of 936 PHAs (80% male; 72% gay; 45% African American), conducted in four U.S. cities over 25 months, demonstrated significant and sustained reduction in substance abuse in the 15-session intervention compared to the control arm (69). Finally, a Toronto-based intervention study examined whether 79 PHAs (89% were male; 79% participants were depressed at baseline) randomized to receive either case management or usual care for a six-month period would benefit from the intervention (70). Participants, who were case-managed and were depressed at baseline, had a 31% improvement in their mental health index score and 45% improvement in social function, compared to participants receiving usual care who exhibited a 1% and 27% deterioration in mental health index score and social function, respectively.

In contrast, a randomized study by Sorenson and colleagues (2003) of substance-using PHAs (N=190) showed improvement in a variety of patient outcomes (substance use, HIV transmission risk, physical health, psychological status, and quality of living situation) in both the case management group and brief contact group, with no statistically significant differences between the two groups (71). The authors hypothesize that although participants were contacted for the purpose of information-gathering rather than encouraging behavioural change, the brief contact on the several occasions might have been sufficient to bring about improvement in patient outcomes. Sixteen percent of the sample died by the 18-month interview; however, deaths were distributed equally across both study conditions.

Gaps

Sensitivity training programs are needed for care providers to reduce discrimination against PHA drug users, women, the homeless, and minorities. Canadian studies on retention of hard-to-reach PHAs in health care are largely lacking in the current body of literature.



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