



LIT REVIEW:

LINKAGE TO CARE TO VIRAL
SUPPRESSION

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Introduction

The Canadian Treatment Action Council was funded by the Public Health Agency of Canada in 2017 to explore issues affecting the engagement of people living with HIV in healthcare. Our study seeks to identify policy issues that impact upon treatment access for people living with HIV, and to explore opportunities to make the healthcare system more accessible for people living with HIV.

The first part of this project consisted of two comprehensive literature reviews of the research relating to the HIV Treatment Cascade in Canada with particular focus on two portions of the HIV Care Cascade: 1) HIV testing/linkage to care and 2) retention in care leading to viral suppression of HIV. These reviews identified issues facing people living with HIV generally and specific issues for various communities disproportionately impacted by HIV. Where our literature reviews have uncovered possible policy barriers for people living with HIV, CTAC has completed supplementary research on relevant federal and provincial policies that may be implicated.

The second part of this project consisted of a series of qualitative interviews with service providers and people living with HIV in the Province of Ontario. Interviews with 20 service providers focused on the scope of their work with people living with HIV, their role supporting people living with HIV to access healthcare and stay on treatment, and barriers they see impacting access to health care. People living with HIV were engaged in focus groups of 10 participants on average; with questions exploring their experiences with health care in their city/region, how living with HIV has changed their experience with health care, challenges with engaging in health care across the cascade, and specific challenges that have negatively impacted their accessing health services.

In order to have a sample that is representative of the epidemic in Ontario, CTAC recruited people living with HIV from each of Ontario's priority populations (gay, bi and other MSM; African, Caribbean and Black people; Indigenous People; People who use injection drugs). We also worked with community partners to gather a geographically diverse sample including hosting 11 focus groups in total (5 in Toronto, 4 in suburban and rural communities in the GTA, 1 in northern Ontario, and 1 in Ottawa).

Partnerships with the community in terms of recruitment and review of project outputs were key to making this project a success, as well as relevant. From this project, we have gained valuable insight into the challenges in the treatment cascade for frontline service providers and policy makers, as well as revealing opportunities for community-based agencies to organize and promote policy change that will broaden access to treatment. The next steps for this project will include dissemination of the valuable insights and knowledge gathered throughout the course of this project in order to help service providers more effectively advocate for the needs of their clients and the identification of further areas of work for policy with communities most affected by HIV and HIV/Hep C co-infection. Although this project was focused on access to services within Ontario, the literature reviews drew on literature and evidence from around the world. Also, many of the treatment access issues that were brought to light during this project can be found across Canada.

History – improved mortality rates:

“based on data from 14 HIV cohort studies in Canada, Europe and the USA, someone with HIV could expect to live two-thirds as long – or 21 years less – than someone not infected with HIV. However, life expectancy increased the earlier the person was diagnosed: someone diagnosed as age 35 who had early access to care could expect to live to 72 or about 90% of the U.S. average at the time, which was 77. Early diagnosis and timely access to care is also good prevention. People diagnosed with HIV are much more likely to act to prevent HIV transmission than people who do not know they are infected. By lowering viral load, timely access to HIV treatment also reduces the risk of HIV transmission.”^{vi}

“People infected in their 20s who are diagnosed early, engaged in care and receive treatment to suppress the virus (as well as high-quality care for other health issues) can expect to live into their early 70s; a life expectancy approaching that of the general population. The prognosis is not the same for people who have other serious issues that affect longevity, such as an addiction, homelessness or comorbidities like hepatitis C.”ⁱⁱ

“There are also considerable differences in life expectancy by HIV transmission group, with lower life expectancies reported in all periods for individuals with a history of IDU...We hypothesize a number of possible reasons for these differences, including increased comorbidity with greater non-AIDS related mortality, as well as challenges with ART adherence, active drug use, hepatitis C co-infection, housing instability, and lower socioeconomic status. Our findings here clearly illustrate that individuals with IDU history have not seen the increases in life expectancy that are evident in other groups. Differences in life expectancy by race were also evident, with white individuals having higher life expectancies in all periods. As with persons with a history of IDU, these differences in life expectancy may be reflective of underlying differences in socioeconomic conditions, access to care, and health insurance coverage, suggesting an urgent need for strategies and programs to combat these inequities. However, we note that the gap in life expectancy between white and non-white individuals has decreased substantially, from 23.0 years in 2000-2, to 8.5 years in 2006-7.”ⁱⁱⁱ

Comorbidities as a Barrier to Treatment Adherence:

“...among those on cART, HIV infection is part of a complex cascade of interacting and summative conditions that together drive morbidity and mortality. Individuals on suppressive anti-retroviral treatment experience HIV infection as a complex chronic disease. For these individuals, all contributing causes of morbidity and mortality are important and worthy of intervention...As in these complex, chronic diseases, morbidity and mortality among those with HIV infection reflect the overall impact of diverse conditions and multiple pathophysiologic processes – some tied to HIV and its treatment, and some associated with health behaviours and conditions more common among those with HIV infection, but not causally associated (e.g., hepatitis C infection) and, increasingly, age-associated comorbid conditions.”^{iv}

“Many PLHIV live with a number of complex health conditions, which may or may not be related to their HIV status. Living with comorbidities poses an additional challenge to treatment adherence...because of drug interactions and multidrug fatigue.”^v

“While new drug therapies have had a dramatic impact on the treatment of HIV/AIDS and reduced AIDS associated morbidity and mortality...these therapies are not a cure and many persons living with HIV/AIDS (PHAs) must contend with complex medication regimens, medication side effects, and comorbidities with conditions such as hepatitis C...”^{vi}

“...we know that for many complex chronic conditions specialty care may improve disease-specific indicators while strong primary care is required for improved who-person care for those with multiple conditions.”^{vii}

Cascade of Care:

“The HIV care cascade, also called the care continuum, has been increasingly used to document engagement in care among people living with HIV (PLWH). The care cascade documents losses from each “step” between HIV status awareness, linkage to care, engagement and retention in care, initiation of antiretroviral therapy (ART), and viral suppression. While the care cascade has become of increasing importance in understanding the HIV response, this tool has been less rigorously applied to document the health disparities of key populations.”^{viii}

“Successful treatment can sustain viral suppression and lead to immunological improvement among those that are HIV-infected but requires that individuals engage and remain in the HIV care cascade. This cascade involves a series of actions, starting with HIV screening/testing, and followed by linkage to HIV care after HIV diagnosis, retention in pre-ART care prior to ART initiation, initiation of ART once eligible for treatment, retention on treatment once ART is started, and then maintenance of good ART adherence in order to achieve viral suppression and immunological improvement. However, evidence indicates that many individuals are lost at each stage of the cascade, and many individuals are diagnosed late, only initiating ART at the onset of symptoms.”^{ix}

“The HIV continuum of care has become a standard framework for understanding the HIV epidemic and developing interventions. It underlies the UNAIDS 90-90-90 targets, which call for 90% of persons with HIV to be aware of their HIV infection, 90% of all diagnosed will be on ART, and 90% of people on ART will have an undetectable HIV viral load. The continuum of care facilitates consideration of the challenges and potential solutions surrounding HIV in nonurban areas. Barriers that contribute to this continued epidemic are many, and include lack of access to primary care, lack of prevention and harm reduction services, limited affordable transportation, and lack of culturally congruent services.”^x

“Effective and safe delivery of medical care for HIV requires a sequence of diagnostic tests, assessments, treatment delivery, support and monitoring. This care continuum has been termed the ‘HIV treatment cascade’. The cascade can be used to illustrate and measure the effectiveness of a country’s ART programme. Cascades report various stages, including total; HIV positive people diagnosed, linked to care, retained in care, treatment eligibility, on ART, adherence to treatment, retention post ART initiation and viral suppression...several key factors affect coverage of the various steps of HIV cascades; individual, societal and structural. Initially, community education and uptake of testing is required at a population level, widespread among generalized epidemics and targeted testing within focused epidemics. Second, linkage to care, retention in care and support following diagnosis is required for all HIV positive individuals prior to starting treatment. Sustainable procurement and provision of ART is imperative. Finally, individual understanding and motivation is required to maintain treatment adherence and post-ART retention combined with HIV viral load testing for monitoring. Until recently, there has been an absence of standardized reporting methodologies, stage definitions and agreed structures to unify cascade data making comparison of HIV treatment cascades difficult.”^{xi}

“Efficient diagnosis, linkage-to-care, and retention in the first year of ART is essential for PLHIV to reach viral suppression...In Canada, there is no national estimate of the treatment cascade, but in British Columbia, 71% of all PLHIV are diagnosed, 51% are on ART, and 35% are virally Suppressed [2015].”^{xii}

“... The COC is usually predicated on a model of a local population documenting progression of new patients from diagnosis to viral suppression. Although powerful in assessing the success of the local programs in service delivery. The use of a COC to reflect the dynamics of care of the whole local HIV community may be misleading, as it may fail to account for the impact of patient migration. If a sizeable number of HIV-experienced patients (i.e.: previously retained in care and on ART) (transfer into a community at different stages of their HIV infection, they can introduce uncertainty, bias, or inaccuracy into the COC in that community. The widespread use of ART., which has resulted in a dramatic improvement in the quality and quantity of life, has enabled migration both for personal choice or economic necessity leading to an associated transfer of HIV care. Migration or geographic mobility may be “internal” (i.e.: within a country) or “external” (immigration between countries sometimes due to forced displacement). Movement between communities and HIV care centers has been reported to have negative consequences on the individuals’ HIV health. The status of transfer patients within the local COC remains problematic. Individuals who acquire their HIV infection elsewhere but are first diagnosed locally would be considered a “locally diagnosed” patient in public health metrics. Those diagnosed who accessed care elsewhere before moving are included in the regional COC model although at a different entry point from locally diagnosed individuals. The time spent in the local community before accessing HIV care also is often not taken into consideration. HIV-experienced transfer patients thus are neither “newly diagnosed” HIV cases, nor are they nonlinked, nonretained, lost to follow-up (LTFU), nor necessarily treatment naive.... Transfer patients constitute a significant and unique demographic within an HIV community, population, and/or cohort. They are not newly diagnosed with HIV, but are new “HIV cases” to the region. Many have been living with HIV for long periods of time, were previously linked and retained in care elsewhere with the majority being ART, experienced, and achieving viral suppression...Once linked to HIV care, the progression or engagement in the COC of transfer patients was superior to locally diagnosed patients with higher rates retained in care, started and continuing on ART, and achieving viral suppression. Transfer patients had been living with HIV much longer... {This research} may also reflect a higher level of HIV knowledge and commitment to care instilled at previous care centers reflecting the more “experienced” nature of the patients.”^{xiii}

Treatment adherence:

“High treatment adherence confers significant public health benefits, including less transmission (treatment as prevention) and reduced economic costs (otherwise related to hospitalization) ...In spite of ART’s demonstrated benefits and considerable availability, a large group of PLHIV in high-income countries significantly delay treatment, or take “drug holidays”, often not clinically monitored.”^{xiv}

Barrier to Linkage to Care-Homelessness/Lack of Affordable Housing:

“Research has revealed strong associations between unstable housing and deleterious adherence patterns. Compared to housed individuals, the unstably housed or homeless have increased rates of drug and alcohol abuse, as well as higher rates of HIV infection and HIV/AIDS-related morbidity and stigma, poor physical and mental health, or a lack of routine, privacy, and storage for medications. Our analyses show that homeless individuals are at risk of becoming non-adherent, emphasizing an already established need for housing interventions.”^{xv}

“People who are living with HIV/AIDS and are homeless face additional burdens not faced by homeless people without HIV/AIDS. For instance, individuals with HIV/AIDS need greater access to comprehensive health care, and barriers to care – including lack of financial resources, lack of transportation, and insufficient (or nonexistent) health insurance coverage – may be compounded among homeless people living with the disease. People

with HIV/AIDS also may have difficulty adhering to prescribed HIV antiretroviral medication regimens. These regimens can be complex and often involve restrictions on when and how the medications should be taken and stored. In addition, these medications can have side effects, such as recurring diarrhea, that are especially problematic for homeless individuals. Medical providers may believe that homeless individuals will not be adherent, and thus they may be reluctant to prescribe antiretroviral medications for these individuals given that inadequate adherence can lead to drug resistance.”^{xvi}

“In terms of housing status, respondents were categorized as homeless if they reported living in a shelter or on the streets at the time they were interviewed...our results showed that homeless respondents were more likely than those in stable housing situations to report a wide range of negative health outcomes. For example, homeless respondents had more medical and social service needs, suggesting that they have maybe been sicker than housed respondents. Although nearly all of the respondents in both groups reported receiving the services they needed, homeless respondents reported poorer health on a variety of mental and physical health measures, including markers of HIV disease progression. In addition, more homeless respondents received care from emergency departments, they were hospitalized more often, and they had more frequent visits to medical care relative to housed respondents...they were less likely to have ever taken or to currently be taking HIV antiretroviral medications and more likely to have stopped taking these medications...rates of self-reported adherence were lower among those who were homeless...having a place to stay can improve people’s mental and physical health by decreasing their stress and fatigue and allowing them to focus on other health care needs, such as medical appointments and adherence to medications.”^{xvii}

“Several factors related to substandard living conditions are likely related to HIV-positive IDU’s ability to follow through with HIV treatment. These include crowded living environments, lack of security and privacy, food insecurity, absence of cooking and food storage facilities, as well as inadequate sanitary facilities.”^{xviii}

“Considerable research has shown a lack of access to primary care and/or inappropriate use of health care services among general samples of homeless or unstably housed persons...limited or inadequate health care utilization has also been reported among unstably housed persons living with HIV...research has shown that substantial proportions of adults experience a single or limited number of episodes of housing instability; relatively few are homeless for protracted periods of time. Even among the ‘chronic’ homeless, most have had intermittent periods of stable housing...most persons living with HIV/AIDS face considerable challenges to maintaining regular employment that would provide income sufficient to cover housing costs...PLWH relying upon disability income (SSI or SSDI) face even greater challenges maintaining adequate housing...it is misleading at best to consider housing as important for the relatively small proportion of PLWHs who are literally homeless at any point in time, seen as a ‘special population.’ While it is important to understand and respond to what might be special needs of the currently homeless, it is important to understand that literal homelessness is only the most extreme form of housing need that can affect medical care and medical care outcomes. Housing needs are fluid and prevalent among persons living with HIV and the tendency to view homelessness as a trait of individuals and ‘the homeless’ as a special service population can deflect attention from the broadly shared, fundamental need for stable and adequate housing among a wide range of persons living with HIV/AIDS...these findings provide strong evidence that housing needs are a significant barrier to consistent, appropriate HIV medical care, and that receipt of housing assistance has an independent, direct impact on improved medical care outcomes...Findings indicate that it is the social service element of case management (often addressing housing and related needs) and not medical referrals per se that is associated with access, entry and maintenance in care, especially medical care that meets clinical practice standards.”^{xix}

Barrier to Linkage to Care: Food Security:

“The urban poor are disproportionately affected by HIV. Well-described barriers to antiretroviral treatment access and adherence among HIV-infected urban poor include substance use, mental illness, social stigma, provider trust, medication side effects, lack of social support, low patient self-efficacy, forgetting, and homelessness...Food insecurity is defined as having uncertain or limited availability of nutritionally adequate or safe food or the inability to procure food in socially acceptable ways, and is highly prevalent both among the urban poor, and among people living with HIV/AIDS...food insecurity adversely affects health behaviour, functional health status, and health outcomes for several diseases other than HIV. Food insecurity is associated with poor physical and mental health among both children and adults, including worse self-reported health status, and higher rates of obesity, depression, diabetes and heart disease. Food insecurity has also been found to be associated with postponing needed medications and care, and increased emergency department use and hospitalizations in the U.S...we found that half of urban poor HIV-infected individuals in a particularly well-resourced North American setting were food insecure, and that food insecurity independently increases the risk of incomplete viral suppression...we also found that severe food insecurity was associated with nearly 80% lower odds of viral suppression when controlling for other covariates. This suggests that ensuring consistent access to food may be an important and neglected intervention to improve antiretroviral treatment effectiveness...adherence modified the association between food insecurity and HIV RNA suppression; for individuals who were less adherent, severe food insecurity was associated with an 85% reduction in the odds of viral suppression. For individuals with more than 80% adherence, there was still a 66% reduction in the odds of viral suppression for individuals who were severely food insecure, but this association was no longer significant...food insecurity may also impact viral suppression through biologic mechanisms.”^{xxi}

Barrier to Linkage to Care: Stigma:

“Fear and ignorance about the disease and how it is transmitted may result in the isolation and avoidance of PHAs by others in their communities. To avoid such reactions, especially in view of the multiple, overlapping relationships in rural communities which make it difficult to ‘contain’ personal information, some PHAs are understandably reluctant to disclose their situations to others or receive help from local services. In fact, some respondents in our study reported that they chose to rely on services that do not require them to disclose their names or to use services without disclosing their HIV status.”^{xlii}

Hospital Admissions:

“...more recent studies examining the utilization of inpatient services by people living with HIV have described stabilizing or increasing rates of hospital admission, particularly among patients for whom the effects of HIV infection intersect with socially and structurally mediated barriers to care, such as women and people from ethnic minority groups...the proportion of diagnosed cases of HIV infection represented by women has increased substantially from less than 3% in the early years of the epidemic to 25% in 2008. Similarly, the prevalence of HIV among persons immigrating to Ontario from HIV-endemic countries increased 62% from 2003 to 2008. In this context of pronounced change in both the treatment and demography of HIV infection, accurate population-based estimates of health-service utilization are required by clinicians, researchers and policy-makers involved in the provision, evaluation and funding of HIV-related care.”^{xliii}

“Because receipt of cART is associated with a reduced risk of hospital admission for HIV-attributable illness, the occurrence of such admissions may represent inadequate access to outpatient medical care or challenges in initiating or maintaining long-term antiretroviral therapy...persistent differences in rates of total hospital admission for specific groups of people with HIV imply that gaps may exist in the current complement of community-based health and social services, which may render the most marginalized HIV-infected patients vulnerable to poor health outcomes.”^{xliv}

Geographic mobility and its Effect on Treatment Adherence:

“For those living with chronic illness, such as HIV, geographic mobility complicates engagement with care and adherence to treatment. The rise in global population mobility means that barriers to health care for mobile populations impact more people each year...geographic mobility, including travel, migration, and emigration, is associated with poor health outcomes, and highly mobile people are more at risk for acquiring and living with poorly controlled HIV/AIDS. Studies show that immigrants are less likely to be tested for HIV and more likely to present for care with advanced disease. An HIV diagnosis can contribute to greater mobility as HIV-infected (HIV+) individuals move to seek care and away from stigma. Examination of the HIV care cascade reveals that migration also adversely impacts maintenance in HIV care and researchers’ ability to quantify stages in the cascade.”^{xlv}

“Mobility patterns are complex, and motivation for travel impacts the mobility pattern, which, in turn, determines its effect on adherence and engagement in care. Barriers were most often structural, rather than individual, and include HIV-related stigma and the inability to access care or medications at the destination site, particularly for long-stay travelers and transnationals. Mobility rarely facilitated engagement with care, with the exception of individuals traveling to urban clinics because they felt care was better and less stigmatized at an urban site further from home.”^{xlvi}

“Geographic mobility is also associated with patterns of accessing and receiving HIV care. The distance a patient travels to receive care negatively affects adherence to antiretroviral therapy (ART) and overall engagement in HIV care. Nondisclosure of one’s HIV status to others, especially while traveling, may undermine adherence, particularly when immigrants visit their country of origin. Conversely, geographic mobility can have a positive impact. Some individuals will move toward HIV treatment sites or support networks and away from stigma.”^{xlvii}

“...adverse impact on adherence could be caused by mobility-induced interruptions in medication supply, increased difficulty in taking medications in settings with less privacy because of fears of disclosure of HIV status, disruptions in daily schedule, conflicting demands on the mobile individual’s time, and loss of social support if this support was found at home...An alternative hypothesis is that mobility might have a positive impact on adherence to ART if people living with HIV were moving into locations where HIV care or caregivers were more readily available or social supports were improved. It is important to note that different types of mobility may have different impacts on adherence.”^{xlviii}

“Though not included in traditional concepts of ‘mobility’, travel to access medical care can become a significant source of mobility for people living with HIV. Some data demonstrate that difficulty finding money for or time for transportation to and from clinic is a barrier to effective ART. Particularly where dedicated HIV care clinics are scarce, people living with HIV may travel hours or even days to receive medical care. The cost of this mobility, both in terms of payment for transportation and in hours which could be dedicated to other tasks, is usually borne by the HIV+ patient and their family.”^{xlix}

Barriers to Linkage to Care- The Rural/Urban Divide:

“...recent data from the US Centers for Disease Control and Prevention (CDC) and the Public Health Agency of Canada (PHAC) show that the HIV epidemic has migrated from primarily urban centers to more rural locales...in small towns and remote areas in the United States and Canada, persons from minority groups, Indigenous populations, and women are disproportionately represented among new HIV infections. Furthermore, evidence indicates rural residence is a risk factor for lower rates of HIV testing, later HIV diagnosis, later adoption of advances in antiretroviral therapy (ART), and consequently, increased HIV-related mortality. Also, rural residents with HIV infection often face challenges such as stigma, social isolation, long distances to care, limited transportation, and lack of access to providers with HIV expertise. HIV-related stigma can significantly impact care utilization and health outcomes including quality of life and medication adherence and people living in rural regions often experience high levels of HIV-related stigma. People living with HIV (PLWH) in rural and Northern Ontario, Canada report higher levels of perceived HIV-related stigma compared with those living in nonrural or Southern Ontario.”ⁱ

“Disparities in rural-urban population health and access to care are significant problems in many countries, including Canada. Canadians who live in rural areas have shorter life expectancies and higher rates of chronic illness and disability than their urban counterparts, and many face challenges in access to health care as a result of shortages in local health care providers and long distances to travel, particularly for specialized care. Access issues are particularly significant for people living with HIV/AIDS (PHAs) who reside in rural areas. Because HIV/AIDS is treated primarily by specialists, disease-related treatment is usually concentrated in tertiary urban-based centers and, where rural support services do exist, PHAs may be reluctant to use them due to concerns over confidentiality...the stigma associated with HIV/AIDS can pose a significant barrier to such support...knowledge levels about the disease vary from community to community...lack of knowledge about HIV/AIDS can lead not only to intolerance or stigmatization of PHAs, but it also carries its own health risks. Indeed, it has been argued that “inadequate knowledge of HIV and indifference to prevention messages” can contribute to “inaccurate perceptions of personal risk factors.”ⁱⁱ

“...many developed countries face regional shortages of healthcare providers...the delivery of sufficient health care in deprived and remote regions is challenging...Restrictions such as long distances to care points, provider shortages and quality problems due to lacking resources, cultural barriers and other access limitations hamper sufficient health care delivery...rural residents are likely to have different expectations regarding infrastructure and the availability of services compared to urban populations.”ⁱⁱⁱ

“GP’s interpersonal quality...this difference in importance is supported by other rural health care research that hints to a stronger personal attachment to local doctors and an extended value of local health professionals that goes beyond mere health service delivery, but underpins the social structure of rural communities. In rural areas, health service delivery is more relationship-based and whole-person oriented which may explain the relevance of interpersonal aspects.”ⁱⁱⁱⁱ

Barriers to Linkage to Care for Immigrants:

“Studies from Europe, Canada, and the United States have reported substantial increases during the past decade in both the absolute number and the relative percentage of new HIV diagnoses, HIV cases, and AIDS found in migrants... individuals born outside of Canada are among the most heavily over represented in the Canadian HIV/AIDS epidemic.”^{iv}

“HIV infected immigrants and refugees who migrate from a developing to a developed country are known to have different social and medical needs to locally born HIV+ individuals. It is, as yet, unclear how these differences may impact total medical care costs. Timely access to health care for new migrants is well recognised as often being problematic making direct cost comparisons difficult.”^v

“Compared to Canada Born Patients, foreign born patients were more likely to be female (50%), younger at time of HIV diagnosis (median age 33 years...)-, with heterosexual transmission (93%) being the most common HIV risk factor.”^{vi}

“Once engaged in HIV care retention and the health outcomes of foreign born patients and Canada born patients were similar, 77% of foreign born patients remained in care for the duration of the study compared to 74% of Canada born patients...”^{vii}

Barriers for Linkage to Care for Mothers:

“Mothers living with HIV face a complicated dilemma about feeding their babies. Canadian clinical practice guidelines call for formula feeding to avoid transmission of HIV. But is formula the healthiest way? Do mothers even have a choice? The answers are fraught with social pressures, personal risks and heavy costs. Contradictory messages cloud the picture on infant feeding for mothers living with HIV and guidelines vary around the world. Health Canada encourages breastfeeding as the “normal” and best way to ensure protection, growth and development of babies and toddlers. This message is in tension with

HIV clinical practice guidelines, which recommend that mothers with HIV who live in Canada should avoid breastfeeding and use formula in order to prevent HIV transmission, which is possible through the consumption of breast milk. Canada follows World Health Organization (WHO) guidelines that call for mothers living with HIV in high-income countries to avoid breastfeeding and use formula regardless of their circumstances and whether they are on antiretroviral therapy. The notion that breastfeeding is *always* best to promote mother-baby attachment is not supported by sufficient evidence. This belief is supported more by cultural values, beliefs about “natural” parenting, and campaigns promoting breast milk as “nature’s perfect food”. The message that “breast us best” undermines formula feeding as a healthy alternative for children of women living with HIV...women worry formula feeding will expose their HIV status. Social and cultural questions and a general lack of understanding about HIV make threats of losing privacy and safety very real. The possibility of being shamed, shunned, and losing community support has a big effect on the emotional health and well-being of mothers living with HIV...HIV-related stigma may be increased in settings that do not typically provide care to women living with HIV, for example, rural and remote settings and community hospitals. Not all community hospitals have medical staff with expertise and knowledge of the most up-to-date clinical protocols to deliver care to women living with HIV during pregnancy and at the time of childbirth. Some medical staff may also lack HIV-specific training.”^{lviii}

Barriers to Linkage to Care for Sex Workers:

“Many individual-level and structural-level barriers, such as stigma, discrimination, violence and drug-use, often prevent Female Sex Workers (FSWs) from accessing HIV services and practicing HIV prevention and harm reduction, and these barriers may also influence the ability of FSWs to traverse through the HIV care cascade. In two of the studies included in this systematic review, FSWs reported that inability to attend regular medical appointments, potential loss of wages from visiting ART centres, prior negative experiences with the health care system, the stigmatizing attitude of medical staff, and fear of adverse consequences as a result of others knowing their HIV status and occupation, were some of the factors that prevented them from initiating ART. In three of the studies included in this systematic review, FSWs also reported that running out of pills, not being at home to take pills, feelings of sickness when taking pills, and potential loss of clients if seen taking ART during working hours, were factors that prevented them from adhering to treatment...travelling times to health clinics an additional financial cost were also reported as barriers to treatment.”^{lix}

“Overall, there was a high uptake of both primary care (health clinic and mobile health van) and emergency room services among WISH participants. The high rates of emergency room use, in addition to primary care, is likely a reflection of the overall poor health status of women, the highly unstable lifestyle patterns, high rates of addiction, inaccessible clinic hours during evenings, and a lack of women-specific services. In addition, women reported a high level of contact with front-line workers and use of harm reduction initiatives, attesting to a much higher uptake of low-threshold and more easily accessible services among this group.”^{lx}

“Self-reported barriers to HIV care were largely based on misinformation and misconceptions surrounding the potential for simplified once daily therapy...difficulty in maintaining daily medication regimes and making regular medical appointments were also frequently reported as barriers to accessing HAART. Patients’ confidence in their ability to take HAART medication and to incorporate the complex treatment regimes into their daily routine have been consistently shown to be the predictors of enhanced HAART retention...finally, a fear of others suspecting their HIV status was identified as a significant barrier to accessing HAART treatment. Difficulties surrounding trust and confidentiality among women engaged in sex work have been well documented. Issues of privacy and disclosure in an HIV care program would need to be promoted with a high level of sensitivity and would be best bridged through already established client-provider relationships. Also, current social policies surrounding sex trade work increasingly render the practice as illusive and clandestine, which further perpetuates the high level of stigma and devaluation faced by HIV positive women engaged in sex work.”^{lxi}

“Street-based sex workers are embedded in a complex web of social environments that make them a very important population to reach with health and social services. Many are homeless, and drug abuse in this population is common...despite these myriad health and social problems, studies of homeless women and of women drug users highlight numerous barriers to accessing necessary services, including the structure of care systems; provider resistance; prioritization by women of acute over preventive care; learned hopelessness, depression and low self-esteem; and cost and waiting times...the very nature of women sex workers’ income-generating activities keeps them from seeking the protections and services offered by mainstream charitable and governmental organizations...fear of discrimination and arrest has also been cited as a reason these women do not seek out care.”^{lxii}

“MSM, PWID, and sex workers experience high levels of stigma, discrimination, and violence, including criminalization, in many countries. These structural vulnerabilities are associated with fear of seeking healthcare resulting in decreased utilization of health services. PWID and sex workers experience incarceration that often disrupts treatment. Simultaneously, laws often prohibit interventions such as opioid substitution therapy (OST) and other harm reduction for PWID that improve treatment outcomes. Policies and HIV strategic plans have frequently excluded key populations altogether, such as PEPFAR’s early “anti-prostitution pledge”. Often key populations simultaneously belong to more than one risk group (such as sex workers who inject drugs) and frequently experience syndemics, synergistically interacting co-prevalent diseases and psychosocial conditions (e.g. early childhood trauma, depression and substance use), associated with worse HIV care outcomes. Despite these challenges, evidence shows that treatment can be equally effective among MSM, sex workers, and PWID as other populations when these challenges are appropriately addressed with culturally-competent care...”^{lxiii}

Barriers to Linkage to Care for People Who Inject Drugs:

“...numerous studies have demonstrated that HIV-seropositive IDUs are less likely to be prescribed ART, typically begin therapy at later clinical stages, and have poor survival profiles, compared with other HIV-positive groups. A primary determinant of survival for HIV-seropositive individuals is adherence to ART. High levels of adherence are required to guarantee durable clinical benefits, such as suppression of plasma HIV-1 RNA load and reconstitution of immunologic function. IDUs are known to frequently have lower levels of adherence; several behavioural factors have identified as barriers to adherence to ART, including higher-intensity drug use, concern about adverse effects, and lower adherence self-efficacy. Although social- and structural-level exposures are increasingly appreciated as important determinants of many forms of drug-related harm, most studies of HIV treatment adherence and disease progression have focused on individual-level factors. Imprisonment is a common experience for IDUs. In recent years, some optimism has been expressed that correctional facilities can serve as important sites for detecting infections and initiating treatment...the quality of prison-based care and the effect of imprisonment on HIV disease is of central importance to the health of the most vulnerable HIV-seropositive groups, such as the poor, illicit drug users, and ethnic minorities.”^{biv}

“...significant rates of HIV-related morbidity and mortality have persisted, particularly among marginalized populations, such as HIV-positive injection drug users (IDU), as a result of inequitable access to HAART...IDU are known to have lower uptake of HAART compared to other HIV-positive individuals and are more likely to die without ever having received HAART. Typically, IDU are diagnosed at more advanced stages of HIV infection and initiate HAART later compared to individuals without a history of injection drug use...in addition to challenges related to HAART access, IDU also face substantial barriers to continuous engagement in HIV treatment in settings where HAART is widely available to IDU. In Vancouver, Canada for instance, up to 50% of IDU discontinue HAART therapy prematurely...and among those IDU who remain engaged in treatment, 60% have suboptimal levels of adherence...individual barriers to adherence, which have been repeatedly identified, include higher-intensity illicit drug use, lower adherence self-efficacy and co-morbid psychiatric conditions, such as depression and anxiety...the common co-morbidity of hepatitis C infection among HIV-positive IDU, which can increase side effects and limit tolerability of HAART...For example, a sense of responsibility to protect others from HIV and a positive attitude toward HIV medicines have been identified as facilitating adherence...positive influence of social factors such as social support and positive patient-provider relationships...a few studies have identified structural influences such as methadone maintenance therapy...to improve uptake and adherence to HAART.”^{bv}

“Medical complications and behavioural problems that accompany substance abuse can complicate the medical management of human immunodeficiency virus (HIV) – positive individuals, and many IDUs do not receive optimal HIV therapy. This may be in part because of concern that IDUs who are HIV infected may not adhere to treatment plans or that medications may interact if taken concomitantly with “street drugs”. Discomfort in or negative attitudes toward treating IDUs may also be factors. Researchers have studied physician attitudes toward drug users, especially those with HIV infection...experience and expertise generally are important predictors of health care quality for HIV-infected persons and IDUs.”^{bvi}

“Experience caring for particular subsets of patients, such as IDUs, is critical for ensuring that care is of the highest possible quality. Also, patient load is associated with negative attitudes, which are in turn related to selected aspects of care for a subset of patients.”^{bvii}

Importance of the Patient-Provider Relationship for Treatment Adherence:

“Providers play an important role in the continuum of care for PLHIV in that they are seen as the main source of information about living with HIV and recommendations about treatment...patients may be more likely to start...stop...and change treatment...if recommended to do so by a health-care provider.”^{bviii}

“Interpersonal aspects of care rated important by people living with HIV in quantitative studies included professionalism, taking patients seriously, providing emotional support, taking an interest in personal relationships, empathy and enabling patients to feel comfortable, discussing personal issues. Qualitative studies shed further light on the aspects of the HCP-patient relationship that were valued by people with HIV. Patients emphasised the importance of building a good relationship with their HIV doctor, with trust being a key feature of the relationship. Continuity was important- patients preferred to see the same HCP at each appointment to avoid having to repeat their story to someone who did not fully understand their needs.”^{bix}

“...physicians who practice in rural settings often lack specific HIV/AIDS-related training and most have limited experience providing HIV-related care. In general, rural-dwellers have more difficulty finding a physician than those living in urban settings...this problem is exacerbated for PHAs...many PHAs who live in rural areas often choose to, or have little choice but to, rely extensively upon urban providers for care.”^{bx}

“Primary care physicians were perceived as having too little knowledge about HIV and lacking sufficient expertise or experience to treat HIV positive patients. However, it was suggested that primary care physicians in rural settings should be provided with training in HIV in order to combat perceived stigma and isolation among patients in these communities.”^{bxii}

“Patients valued having convenient clinic hours, being able to call the clinic, being able to make an appointment within 24h having access to a walk-in/emergency clinic, as well as transparency...and reliability.”^{lxixi}

“HIV treatment information, including an explanation of treatment side effects in language that the patient could easily understand, information on how to take prescribed medication and an explanation of the advantages and disadvantages of any treatment was particularly important.”^{lxixii}

“...patients valued good communication between the health care professionals involved in their care. Participants in one study reported that changes to health policy had resulted in their care being fragmented between GPs, the HIV clinic and other hospital departments, with poor communication between the various services...fragmentation of the healthcare system as a barrier to engagement with care.”^{lxixiv}

Effects of Incarceration on Treatment Adherence:

“Among HIV-infected individuals who were prescribed HAART between 1997 and 2001, non-adherence was common (43%), particularly among those who had a history of incarceration within 12 months of initiating antiretroviral therapy and a history of injected drug use. Furthermore, this translated into a substantially lower probability of achieving viral suppression compared with individuals without a history of incarceration...it appears that subjects are able to adequately adhere to HAART in the structured setting of the BC provincial prison system but are unable to continue this level of adherence upon release. Among those incarcerated, the longer their sentence, the higher the probability of virological suppression. Furthermore, it appears that initiating HAART while in prison is not done with adequate linkage to prescribing physicians in the community, as evidenced by the lower proportion who adhere to HAART in the first year of starting therapy. Incarceration is most probably a marker of life instability and may identify group of HIV-infected individuals who especially need (i) linkage with a community prescribing physician and (ii) more tangible adherence support upon prison release. Although the BC provincial prison system has been a leader in responding to HIV/AIDS in prison, there is no formalized linkage program after release. A number of studies have highlighted the importance of the link between HIV specialists and correctional health care providers to ensure that HIV-infected patients have optimal care both inside prison and after release.”^{lxixv}

“Recent studies have revealed strong links between incarceration and non-adherence to ART in many settings. Several barriers to treatment within correctional systems have been described, such as sub-standard healthcare facilities, a lack of care for HIV-related co-morbidities such as addiction, and an emphasis on public security over public health...poor continuity of care between correctional and non-correctional care settings is a barrier to maintenance of treatment.”^{lxixvi}

ENDNOTES

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