

HIV and/or Hepatitis C and Diabetes: Comorbidities affecting HIV Positive People - A Tip of an Iceberg



Canadian Treatment Action Council
ADVANCING POLICY TO SAVE LIVES

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Executive Summary

Currently, 11 million Canadians are living with prediabetes or diabetes; this means that almost one in three people in Canada are affected by these conditions. In Canada, over 9% of the total population have diabetes mellitus (DM). Diabetes Canada estimates that by 2025, 12% of the population will have diabetes. In 2016, more than 1.6 million people in Ontario were living with diabetes, and another 2.3 million people had prediabetes. In Canada, almost 35-44% of individuals remain unaware that they are living with diabetes, and are not getting the vital education, facts, and care needed to manage this serious disease.

Evidence shows that people living with HIV (PLWH) have a higher incidence of DM relative to the general population. Older age and obesity are associated with the development of DM, but data also shows that PLWH are more likely to develop DM at younger ages (without obesity) when compared to the general population. The risk for DM is also greater in people who have hepatitis C virus (HCV). Plus, certain factors specific to HIV itself, as well as the medications needed to treat HIV, put a person at greater risk of developing diabetes. Both HIV and DM have independent associations with cardiovascular disease, the leading cause of mortality in PLWH.

As a long-lasting disease with serious consequences if left untreated, diabetes requires appropriate and timely intervention. Since people with diabetes generally feel well during the initial stages of the disease, many people are only diagnosed once they have developed complications. Delayed diagnosis results in delayed treatment and the increased potential of developing further complications.

Despite this, diabetes is manageable if individuals, communities, health care providers, and policy-makers are given the information and tools to motivate and support behavioural change. Currently, there is a paucity of programming aimed at educating PLWH about the prevention and maintenance of their diabetes. Strategies for chronic disease management, including for people living with HIV, must be expanded with a view to multimorbidity. Understanding factors that contribute to the risk of multimorbidity is important as this can assist in developing interventions to reduce modifiable factors, which in turn reduces multimorbidity.

As a result of this project, CTAC has uncovered a number of barriers that hamper the ability of PLWH, who are also living with diabetes, to optimally access treatment and care. The following recommendations are essential first steps to addressing these barriers.

Recommendation 1: Eliminate the deductible for Trillium, and the co-payments for the Ontario Disability Benefit (ODB).

Low-income Ontarians struggle with drug benefit plan access, maintaining drug coverage between Ontario Disability Support Program (ODSP) / Ontario Works (OW) and working (or returning to work), meeting basic needs, and accessing Trillium.

The Ontario Drug Benefit (ODB) program and the Trillium Drug Program (TDP) (a program born out of AIDS Activism in the 1990s, but which ended up becoming available to all Ontarians) are the two main programs that assist Ontario residents with covering the costs of expensive prescription drugs and may be able to help cover the high cost of hepatitis C treatment medications.

The Ontario Drug Benefit (ODB) program covers around 4,400 drug products. Drugs that are not listed on the Ontario Drug Benefit Formulary can be considered for coverage through the Ministry's Exceptional Access Program on a case-by-case basis. In addition, individuals who receive social assistance, through either Ontario Works (OW) or the Ontario Disability Support Program (ODSP), may be eligible for prescription drug coverage through the ODB. Adding to this complexity is the fact that, depending on an individual's income level, different deductibles and co-payments will apply under the ODB. It is also necessary for many PLWH to have someone to help them navigate this complex patchwork of coverage.

The Trillium Drug Program is for people who spend approximately 3% to 4% or more of their after-tax household income on prescription drug costs. An individual can qualify for Trillium under certain conditions: a) the individual is not already on ODB; b) is not a resident of a long-term care home; and c) is not someone who receives home care services. With Trillium, an individual is also not able to have private health insurance that covers those drugs in full, but some private insurance is allowed. Also, it is important to note that many focus group participants stated that people who are able to work, or do work but have low-paying jobs, choose to leave the workforce in order to be eligible for the above programs, so that they can afford their HIV and diabetes treatment.

Within Canada, there are 18 different publically funded plans with many more private plans, making the system difficult to understand and navigate. There is also private insurance (some health insurance policies offered through private insurance companies include coverage for prescription drugs. These programs often have their own deductible, or co-pay fee, and may have yearly maximums for prescription drugs). Also, pharmaceutical companies sometimes have funding programs available to help individuals to access the HIV medications that they offer. This all results in a complex system that PLWH have a hard time navigating, a fact that was confirmed during the focus groups, and service provider interviews, conducted as part of this project.

Current access to HIV treatment in Canada is shaped more by where a person lives than what they need. People living with HIV comorbidities are not well served in Canada's patchwork health care system, with separate jurisdictional responsibilities for health in each province and territory, and at the federal level. A complex web of public and private drug coverage, and in some cases lack of coverage, creates inequity, restricting access for many. What medications people can get, at what cost, varies widely, depending on the forms of public and private insurance available to them.

There is an added complexity in terms of being able to access drug plans for people living with multiple comorbidities. This can be linked to the process for approval for access to public drug plans, as well as the eligibility criteria for coverage under these plans (e.g., some doses of certain drugs may be covered, but not others).

In order for PLWH to be able to get the treatment they need, allowing them to remain engaged in care, the deductible and co-payments that are a part of the Trillium and ODB programs need to be eliminated. Also, funding for patient navigators, to help PLWH to navigate Canada's complex system of coverage, is essential.

Recommendation 2: Provide compassionate access to care and treatment for people without status in Canada. Equal and timely access to medications, as clinically appropriate, is important to all individuals living in Canada, especially for those with chronic diseases such as HIV,

diabetes, and related complications.

The immigration and refugee system is complex, confusing, and intimidating for newcomers. People usually become a permanent resident of Canada – and eventually a Canadian citizen – through one of two routes: as an immigrant or as a refugee.

There are people who do not have legal status in Canada because they entered Canada without legal status or have been found to no longer have legal status in Canada. Sometimes people in this situation are referred to as “non-status”.

Refugee claimants in Canada are covered under the Interim Federal Health Program. This program covers the cost of a limited amount of medical treatment, including HIV medication. It is not available to people applying as an immigrant, visitor, student, or to people on work visas. If the refugee claim is successful, then the claimant becomes eligible to apply for healthcare coverage under a provincial, or territorial, health insurance plan. The provincial or territorial health insurance plan should cover the costs of most health services, including medical tests, but not necessarily the cost of all drugs. In order to be covered under a provincial or territorial insurance plan, a person must apply to be enrolled. Generally speaking, provincial or territorial plans have a three-month waiting period before healthcare insurance coverage begins. The three-month period begins on the day a person establishes their residency in that province or territory.

It is important to note that PLWH who are immigrants, or students, can hit roadblocks due to language barriers when they attempt to engage with the health care system. A lack of employment, or stable housing, can also lead to poor health outcomes beyond just that of HIV care. It can affect one’s mental health and the ability to have improved quality of life beyond medications.

It is important that compassionate access to care and treatment be provided for people without status in Canada. Access to care and treatment for people without status in Canada is necessary to aid Canada in reaching the 90-90-90 targets both for HIV and diabetes.

Recommendation 3: Develop diabetes-specific information for PLWH (brochures/videos) that is easy to understand, and leads to participatory diabetes education programs in different, relevant languages.

Through feedback from focus groups and interviews with service providers, CTAC has found that PLWH are not getting standardized care and information regarding the management of their HIV and diabetes, or, if they have been diagnosed as prediabetic, what they need to follow. The development of diabetes-specific information for PLWH (brochures/videos) that is easy to understand, and leads to participatory diabetes education programs in different, relevant languages, will be key to addressing this prominent issue. Promoting access to such resources/workshops for PLWH in AIDS Service Organizations (ASOs), community centres, clinics and at Diabetes Canada events will also be of utmost importance. PLWH, who are prediabetic, can benefit from these resources and make large-scale behaviour changes that will have an impact on whether they go on to have diabetes or not.

Recommendation 4: Increase awareness of the symptoms and long-term complications of diabetes among PLWH, and health care providers, through a variety of methods including basic diabetes education, coping strategies, diabetes self-management education, reading food

labels, healthy cooking classes, exercising etc.

Diabetes self-management is one of the cornerstones of diabetes management. Self-management education contributes to better quality of life and health outcomes for people living with both HIV and diabetes.

For those unaware of any previous risk factors, a diagnosis of DM may come completely out of the blue, adding shock and disbelief to a rollercoaster of other feelings. PLWH may need support to cope with multiple emotional stages, when they handle a new diagnosis of DM. Amongst PLWH depression is relatively common and the double whammy of having diabetes may further add to it. The more equipped with education a PLWH is, the easier the journey with diabetes will be.

Many foods contain carbohydrates, which break down into glucose when they are eaten. This causes blood glucose (sugar) levels to rise. It is therefore important to learn which foods cause blood glucose levels to rise more than others, and to balance food choices. Some foods such as non-starchy vegetables, meats, and alternatives such as fish, legumes, or cheese, have a minimal effect on blood glucose levels. Learning about exercise, portion size, what vegetables to eat, glycemic index (GI) cooking methods, and taking less sugar, carbohydrate, and salt will all help in managing diabetes and leading a healthy productive life.

Recommendation 5: Address the need for the incorporation of diabetic-friendly corners in food banks.

Low-income populations are at an increased risk of diabetes development, and have worse outcomes when they do develop it. PLWH who are in socially disadvantaged groups also experience more difficulty in affording their food and medications. Many are accessing food from the available food banks in their locality, or from ASOs. Service providers have discussed during this project how important it is for PLWH to be able to read labels, to cook certain items properly, and to understand how much sugar and carbohydrates are in certain foods. Awareness of these issues is of vital importance for PLWH living with diabetes, and for those who are predisposed to diabetes. A diabetic-friendly food corner will assist PLWH in being able to choose appropriate foods.

Recommendation 6: Stimulate networking and improved collaborations (ASOs, HIV specialists, endocrinologists, nurses, dieticians, Diabetes Canada etc.) to optimally support PLWH living with comorbidities, in ways that are inclusive of First Nations/Inuit/Métis communities. Management of HIV must gradually expand to include the chronic, and metabolic, complications of the disease, and the adverse effects associated with its treatments.

There is a great and immediate need for comorbidity informed treatment and care that addresses the complexity of living with comorbidities. There is increasing recognition that there should be closer advocacy, policy, and programmatic links between HIV and non-infectious comorbidities as the two epidemics are intertwined. Multimorbidity can have negative impacts on the health of PLWH as it can lower quality of life, increase disability, and increase viremia. The intertwining of programs between ASOs and Diabetes Canada is critical in helping PLWH receive pertinent information for taking care of their health, leading to a better quality of life. Healthcare providers caring for PLWH must be knowledgeable about not only HIV treatment, but also the management of other comorbidities in the context of HIV.

The literature review, focus group discussions, and service provider interviews showed a serious gap in services for PLWH and diabetes. ASOs currently have no programming aimed at diabetes. There are dietitians housed in hospitals and community centres. However, very few organizations have wrap-around services where nurses and dietitians are available to give information. Most of these services are not HIV-specific and cater to the general population.

CTAC feels that there is a window of opportunity available to initiate and start conversations leading to collaboration between the HIV and diabetes sectors. Programs leading to awareness and self-care are becoming increasingly critical for the quality of life of PLWH also living with diabetes. We have gained valuable insight into the multiple challenges faced by PLWH living with diabetes and other comorbidities. This has also opened doors for dialogue between multiple health sectors, revealing opportunities for community-based agencies to organize and promote programmatic and policy change that will broaden access to treatment that can be tailored to suit the various needs of PLWH living with diabetes and other comorbidities. By establishing partnerships and working together, ASOs and these organizations can offer a strong voice to establish diabetes as a high priority issue at both the provincial and federal levels.

Diabetes risk for PLWH should not be considered in isolation, and disease-specific screening/management of other comorbidities, in PLWH and diabetes, should be undertaken. This window of opportunity will be lost if we do not act now!

Introduction

“HIV is manageable, but diabetes is a roller coaster. HIV is a straight line now. I am the centre of my treatment and care: the doctor needs to know our complaints and we have to tell them even if they don’t ask”. Male participant.

The fact that current medications are more effective, and have fewer side effects, has changed the landscape of the human immunodeficiency virus (HIV): “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.”¹

The success of antiretroviral therapy (ART) brings a new set of challenges, including age-related comorbidity and long-term toxicity related to ART.² Everyone is at risk of developing illness related to the decline of important organ-systems, especially as they age. This systemic decline manifests as comorbidities. While the literature regarding the factors that contribute to the prevalence of specific conditions is evolving, it is clear that multimorbidity, (the presence of several of these conditions) is increasingly common for people with HIV.³ People living with HIV (PLWH) appear to be at heightened risk

¹ Ontario Advisory Committee on HIV/AIDS, Toronto, Ontario, “Focusing our efforts: Changing the Course of the HIV Prevention, Engagement and Care Cascade in Ontario- HIV/AIDS Strategy to 2026.” February 2017, pg. 2

² Vance DE, Mugavero M, Willig J, Raper JL, Saag MS. Aging with HIV: a cross-sectional study of comorbidity prevalence and clinical characteristics across decades of life. *J Assoc Nurses AIDS Care*. 2011 Jan-Feb;22(1):17-25.

³ Kendall et al. A cross-sectional, population-based study of HIV physicians and outpatient health care use by people with HIV in Ontario. *BMC Health Services Research* (2015) 15:63

for such illnesses. If left untreated, comorbidities can degrade health-related quality of life and shorten life expectancy.⁴

“More than half of the deaths observed in recent years among ART-experienced PLWH are due to noninfectious comorbidities. These include cardiovascular disease, hypertension bone fractures, renal failure, and diabetes mellitus (DM), diseases that in the general population often coexist and are associated with advancing age.”⁵

A growing proportion of PLWH struggle to cope with one or several of these comorbidities, particularly as they age. Evidence shows that PLWH have a higher incidence of diabetes mellitus (DM) relative to the general population. Older age and obesity are associated with the development of DM, but data also shows that PLWH are more likely to develop DM at younger ages (without obesity) when compared to the general population.⁶ The risk for DM is also greater in people who have hepatitis C.⁷ Both HIV and DM have independent associations with cardiovascular disease, the leading cause of mortality in PLWH.⁸

There is a great and immediate need for comorbidity informed treatment and care that addresses the complexity of living with comorbidities. There is increasing recognition that there should be closer advocacy, as well as policy and programmatic links between HIV and noninfectious comorbidities since the two epidemics are intertwined. Multimorbidity can have a negative impact on the health of PLWH as it can lower quality of life, increase disability, and increase viremia.⁹ Indeed, integrating the disease prevention and management of comorbidities is a growing challenge to clinicians and HIV support services.

The Canadian Treatment Action Council (CTAC) was funded by ViiV Healthcare in 2018 to carry out a project addressing the issues faced by people living with HIV and/or hepatitis C, and diabetes. This comes at a very critical time, since evidence shows that more and more PLWH are being diagnosed with comorbidities, including diabetes. There is a paucity of information about how people living with HIV are experiencing comorbidities, like diabetes, in terms of treatment management, information, and support.

The project has three components:

- A literature review (drawing on literature/evidence from Canada and abroad), and pan-Canadian environmental scan of diabetes-specific supports and services available to positive people.

⁴ CATIE, Comorbidities in selected Canadian Clinics, Treatment Update 228 downloaded from <https://www.catie.ca/en/treatmentupdate/treatmentupdate-228/co-morbidities/co-morbidities-selected-canadian-clinics>

⁵ Guaraldi G, Orlando G, Zona S, Menozzi M, Carli F, Garlassi E, Berti A, Rossi E, Roverato A, Palella F; Premature Age-Related Comorbidities Among HIV-Infected Persons Compared With the General Population, *Clinical Infectious Diseases*, Volume 53, Issue 11, 1 December 2011, Pages 1120–1126, <https://doi.org/10.1093/cid/cir627>

⁶ Hernandez-Romieu AC, Garg S, Rosenberg ES et al. Is diabetes prevalence higher among HIV-infected individuals compared with the general population? Evidence from MMP and NHANES 2009-2010. *BMJ Open Diabetes Res Care* 2017; 5:e000304.

⁷ HIV and Diabetes, understanding HIV/AIDS, Side effects of HIV Medicines, AIDSinfo August, 2018, downloaded from <https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/22/59/hiv-and-diabetes>

⁸ Smith CJ, Ryom L, Weber R et al. D:A:D Study Group Trends in underlying causes of death in people with HIV from 1999 to 2011 (D:A:D): a multicohort collaboration. *Lancet* 2014; 384:241–8. [PubMed]

⁹ Salter ML, Lau B, Go VF, Mehta SH, Kirk GD. HIV infection, immune suppression, and uncontrolled viremia are associated with increased multimorbidity among aging injection drug users. *Clin Infect Dis*. 2011 Dec;53(12):1256-64.

- A needs analysis to better understand how a positive person experiences diabetes and, through focus groups (conducted in Ontario), offer diabetes-specific education and disease awareness. Specific focus was placed on rural/urban, women, and newcomer communities.
- Advocacy – this project identified best practices, gaps, and recommendations for increased access to diabetes treatment for PLWH that meets their needs.

The environmental scan consists of a series of qualitative interviews with service providers (across Canada), and people living with HIV and diabetes in Canada. Interviews with 22 service providers focused on: the scope of their work with people living with HIV, and/or HCV, and diabetes; their role supporting people living with HIV, and/or HCV, and diabetes to access healthcare and to stay on treatment; and barriers that service providers see as impacting access to healthcare.

CTAC worked with Community Partners (Alliance for South Asian AIDS Prevention, AIDS Committee of Durham, and community leaders) to gather focus group participants living in urban and rural areas of Ontario. Three focus groups, as well as one to one interviews with people living with HIV, diabetes, and other comorbidities were conducted with questions exploring: their experiences with healthcare in their city/region; how living with HIV, and/or HCV, and diabetes has changed their experience with healthcare; and lifestyle, awareness of diabetes, and specific challenges that have negatively impacted their access to health services. There were 20 participants (10 from rural settings, and 10 from urban settings with an almost equal distribution of gender).

From this project, we have gained valuable insight into service gaps, and challenges, in the treatment and care of those living with HIV, and HIV/ HCV, and diabetes. During the course of this project we also revealed opportunities for relevant stakeholders (community-based agencies/healthcare professionals/public health/Diabetes Canada) to expand networking, collaborate, organize, and promote programmatic/policy change that will broaden awareness and the scope of information available to service providers and PLWH living with diabetes as a comorbidity.

HIV and Comorbidities: A Complex Mix

“AIDS Service Organizations (ASO’s) do not collect data on comorbidities: HIV and hepatitis C, we do address. There is no focus on non-communicable diseases: huge issue, in reality, people are not dying from HIV, but from other diseases.” Service provider working in an urban area of Ontario.

“When we do intake, we do check for other multiple conditions besides HIV and I know we have clients with diabetes. This is something which has been on my to do list, it is an issue ... it is like I have HIV and I’m a hot mess ...” Service provider working in a rural area of Ontario.

“I have multiple comorbidities. I was diagnosed with HIV from 1989... I have to take warfarin because my blood clots up...it’s used to treat or prevent blood clots in veins or arteries, which can reduce the risk of stroke and heart attack. I also have a rare condition with my sweat glands. I was a smoker and then was diagnosed with PCP (Pneumocystis carinii pneumonia) and had to quit smoking. I gained almost 100 lbs., my primary care physician told me I was pre-diabetic in 2016 and told me to watch my weight ... meantime I had acute kidney failure...I was referred to the positive care clinic but they had no diabetes info to take home. Many of my comorbidities are due to my HIV drugs...lipodystrophy and problems of chronic pain but I can’t take painkillers due to stomach issues. I had to change my medication many

times. Diabetes has complicated my life especially... since I have this love for chocolates and Irish whiskey...but I just can't seem to win. I have 17 different doctors..." 51-year-old male participant.

The widespread introduction of highly effective combination ART for the treatment of the HIV has dramatically decreased HIV-associated morbidity and mortality. Despite marked increases in life expectancy, mortality rates among PLWH remain 3–15 times higher than those seen in the general population. However, as PLWH age, it is predicted that up to 84% will have at least one noncommunicable chronic disease (e.g. diabetes) by the year 2030. Multiple comorbidities, such as HCV, can affect an individual's health, quality of life, and life expectancy. These comorbidities are now the most common causes of death and disability in people living with HIV.¹⁰

Vance et al reviewed electronic medical records of 1,478 adult patients seen in an HIV clinic between May 2006 and August 2007 to examine patterns of comorbidities, and immunological and clinical characteristics across each decade of life.¹¹ With increasing age, patients were found to have lower HIV viral loads, more prescribed medications, and a higher prevalence of comorbid conditions, including coronary artery disease, hypertension, erectile dysfunction, diabetes, peripheral neuropathy, hepatitis C, and renal disease. Complex medication regimes, adverse effects from these medications, interactions among the drugs, and fatigue due to a high pill burden can affect adherence among the many people living with HIV and other comorbidities.¹²

By 2030, 75% of the HIV-positive population will be over 50, and the proportion of those with more than three comorbidities will have increased significantly.¹³ Studies show that up to 60% of PLWH have at least one comorbid condition diagnosed throughout the course of their life and that up to 65% of those with a chronic condition have two or more conditions additionally diagnosed following infection.^{14, 15, 16,}

Downloaded from <http://www.ohntn.on.ca/research-portals/co-morbidities/>

¹¹ Vance DE, Mugavero MGS, James Willig MHS, Raper JL, Saag MS. Aging With HIV: A Cross-Sectional Study of Comorbidity Prevalence and Clinical Characteristics Across Decades of Life, *JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE*, Vol. 22, No. 1, January/February 2011, 17-25

¹² Justice, Amy C. "HIV and Aging: Time for a New Paradigm." *SpringerLink*, Current Science Inc., 13 Apr. 2010, link.springer.com/article/10.1007/s11904-010-0041-9, pg. 69.

¹³ Lopes S, Kirk O, Lundgren J, Laut K, Edwards S, Duvivier C, Stefan C, Sambatakou H, Maciejewska K, Aragão F, Mocroft A for the EuroSIDA study : Gilead Sciences, Centre for Health and Infectious Disease Research, Department of Infectious Diseases, Rigshospitalet, University of Copenhagen, Copenhagen, Denmark, Mortimer Market Centre UK, Hôpital Necker-Enfants Malades France, J.W.Goethe University Hospital Germany, Ippokration General Hospital Greece, Pomeranian Academy of Medicine, Poland, University College London, UK AGING AND THE EVOLUTION OF COMORBIDITIES AMONG HIV PATIENTS IN THE EUROSIDA COHORT, Poster at the HIV Glasgow Drug Therapy 2016 downloaded from https://hivglasgow.s3.amazonaws.com/wp-content/uploads/2016/12/07155115/8.-Co-morbidities-and-Complications-of-Disease-and_or-Treatment-Ageing-Bone-CV_Poster-Book.pdf

¹⁴ Goulet JL, Fultz SL, Rimland D, Butt A, Gibert C, Rodriguez-Barradas M, et al Aging and infectious Diseases: Do patterns of comorbidity vary by HIV status, age and HIV severity? *Clin Infect Dis*. 2007;45(12):1593-601

¹⁵ Kendall CE, Wong J, Taljaard M, Glazier RH, Hogg W, Younger J, et al, A cross sectional population –based study measuring comorbidity among people living with HIV in Ontario. *BMC Public Health* 2014; 14-161

¹⁶ Kim DJ, Westfall AO, Chamot E, Wiling AL, Mugavero MJ, Ritchie C, et al. Multimorbidity patterns in HIV-infected patients: the role of obesity in chronic disease clustering. *J Acquired Immune Defic Syndr*: 2012;61 (5)600-5.

In a sample of 1,000 HIV positive Canadians taking ART, researchers found that almost 75% of the participants had two or more comorbidities, 9% of the participants had type 2 diabetes, 70% were at an elevated risk of kidney disease and 10% were at an elevated risk of cardiovascular disease.²¹ Thus, literature highlights that multimorbidity is steadily increasing and common among PLWH.^{22,23,24,25,26} Women living with HIV are especially affected, having a higher prevalence of comorbidity and multimorbidity than the general population, as shown in an Ontario study.¹³

So why is this happening?

“We say clients are managing their HIV through meds and access to treatment and care but are they focussing on managing other co-medical conditions they have? Diabetes is not projected as a killer ... not to worry about it.” Service provider working in Toronto.

“The fact that I am in the focus group has changed my attitude towards diabetes. Adherence is difficult with so many medications: 24 pills/day and insulin 4-5 times/day. We need to live for ourselves no one wants to die before time. Realize how your body feels, must be connected with your body. Don't forget your body - we know our body the best.” South Asian participant.

While the prevalence of comorbidity in people with HIV is clearly high, there have been inconsistencies regarding which conditions are more or less common in people with HIV. It is likely that the prevalence of individual comorbidities is a result of the complex interplay of aging, behavioral risk factors such as smoking (known to be higher among those with HIV), alcohol use (alcohol associated conditions that are generally seen in older non- HIV adults are now common in younger PLWH who consume alcohol), genetic risk factors, HIV severity, and ART history. Strategies for chronic disease management, including

¹⁷ Guaraldi G, Zona S, Brothers TD, Carli F, Stentarelli C, Dolci G, et al. Aging with HIV vs. HIV Seroconversion at Older Age: A Diverse Population with Distinct Comorbidity Profiles. PLoS ONE. 2015; 10(4): e0118531.

¹⁸ Hasse B, Tarr PE, Marques-Vidal P, Waeber G, Preisig M, Mooser V, Valeri F, Djalali S, Andri R, Bernasconi E, Calmy A, Cavassini M, Vernazza P, Battegay M, Weber R, Senn O, Vollenweider P, Ledergerber B. Strong Impact of Smoking on Multimorbidity and Cardiovascular Risk Among Human Immunodeficiency Virus-Infected Individuals in Comparison With the General Population Open Forum Infect Dis. 2015 Sep; 2(3): ofv108.

¹⁹ Goulet JL, Fultz SL, Rimland D, Butt A, Gibert C, Rodriguez-Barradas M, et al. Aging and infectious diseases: do patterns of comorbidity vary by HIV status, age, and HIV severity? Clin Infect Dis. 2007;45(12):1593-601

²⁰ Crawford TN and Thornton A, AIDS and Behavior , <https://doi.org/10.1007/s10461-018-2242y>

²¹ Fraser C, Wong A, Baril JG, et al. Canadian HIV practice reflective initiative to improve management of patients with co-morbidities. *Canadian Association for HIV Research*, 26-29 April 2018, Vancouver, British Columbia. Poster CSP8.10.

²² Hasse B, Ledergerber B, Furrer H, Battegay M, Hirschel B, Cavassini M, Bertisch B, Bernasconi E, Weber R, Swiss HIVCS: Morbidity and aging in HIV-infected persons: the Swiss HIV cohort study. Clin Infect Dis. 2011, 53: 1130-1139.

²³ Guaraldi G, Orlando G, Zona S, Menozzi M, Carli F, Garlassi E, Berti A, Rossi E, Roverato A, Palella F: Premature age-related comorbidities among HIV-infected persons compared with the general population. Clin Infect Dis. 2011, 53: 1120-1126.

²⁴ Goulet JL, Fultz SL, Rimland D, Butt A, Gibert C, Rodriguez-Barradas M, Bryant K, Justice AC: Aging and infectious diseases: do patterns of comorbidity vary by HIV status, age, and HIV severity? Clin Infect Dis. 2007, 45: 1593-1601.

²⁵ Salter ML, Lau B, Go VF, Mehta SH, Kirk GD: HIV infection, immune suppression, and uncontrolled viremia are associated with increased multimorbidity among aging injection drug users. Clin Infect Dis. 2011, 53: 1256-1264.

²⁶ Guaraldi G, Zona S, Brothers TD, Carli F, Stentarelli C, Dolci G, et al. Aging with HIV versus HIV seroconversion at older age: a diverse population with distinct comorbidity profiles. PLoS ONE, 2015;10(4):e0118531

for people with HIV, must be expanded with a view to multimorbidity.^{27,28} Understanding factors that contribute to the risk of multimorbidity is important as this can assist in developing interventions to reduce modifiable factors, which in turn reduces multimorbidity.

What is the Definition of “Older” with HIV?

“Many are not being able to go to ASOs and are just going to GPs that maybe not aware of their HIV status so they maybe at a greater risk. There is a two-fold response here. The GPs also need to know about the considerations of HIV and diabetes. I was on Triumeq which elevates the risk of heart attack.”
Peer service provider.

“In September 1994, I was diagnosed with HIV as well as diabetes. I went to Victoria to work and came back to Toronto...I was positive after I came back. The primary care physician who was also specialized in HIV phoned and asked me “are you sitting down?” Then spilled the beans: “you have HIV and diabetes”. I would be dead in a few years. Thirteen people died amongst 32 people in the building I live in. I was referred to an endocrinologist, but I did not go since I was going to die anyway. More like 10 years later, I did...I was told to write down everything I ate, was not going to do that – my mother and grandmother had diabetes, so it was genetic, I was dying anyway so why change my diet? HIV meds changed quickly in 1996. I started going to Mt Sinai from 2017 seeing an endocrinologist but not linked with HIV specialist. My kidneys are not in a good shape, never thought of any modifications: I could but I am not pushing it: HIV is first and foremost but at this time and point its diabetes and my kidney because it’s all related. I may live until my 90s....never know. Everything is covered because I am a senior, I get \$170 from the Assisted Devices Care Program (ADP) and needles.” A 78- year-old male focus participant.

“I am 48 years old. In 2015, I came to Toronto and after 3-4 months found out about HIV. Family doctor let me know that I have diabetes a few months back and told me not to take sugar but didn’t tell me any of the consequences.... didn’t ever tell me I will go blind or legs maybe cut off. I have to take metformin, have to do exercise. The pharmacist gave me info on diabetes. I used to take a lot of white bread, I could not digest, too much sugar- I think it was due to diabetes. I used to eat and sleep instantly. Women’s College Hospital there is a program on nutrition... that really helped. I have high cholesterol now so I have to take care of food. I have to think about my diabetes. I do have a monitor but I don’t check. I understand that I have to know myself- I have to follow a lifestyle. I don’t eat anymore before I sleep. My medications are covered by ODSP.” South Asian male participant.

Various studies have shown that PLWH who are older (over the age of 50) and have a longer duration of exposure to ART, have a significantly increased risk for diabetes.^{29,30}

²⁷ Crawford TN, Thornton AC, Alcohol use and multimorbidity among individuals living with HIV, *Aids and Behaviour*, published online <https://doi.org/10.1007/s10461-118-2242-y>

²⁸ Vance DE, Mugavero M, Willig J, Raper JL, Saag MS: Aging with HIV: a cross-sectional study of comorbidity prevalence and clinical characteristics across decades of life. *J Assoc Nurses AIDS Care*. 2011, 22: 17-25. 10.1016/j.jana.2010.04.002.

²⁹ Rasmussen LD et al. Risk of diabetes mellitus in persons with and without HIV: a Danish nationwide population-based cohort study. *PLoS ONE* 2012.7.12. downloaded from <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0044575>

³⁰ Ghislain M et al. Late Antiretroviral Therapy (ART) initiation is associated with long-term persistence of systemic inflammation and metabolic abnormalities. *PLoS ONE*. 2015. 10. e0144317. downloaded from <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0144317>

“As of 2015, almost half of the people living with HIV in Ontario are over age 50; many may experience premature signs of aging, related to the inflammation associated with HIV and to side effects of antiretroviral drugs.”³¹

According to a study of people receiving HIV care in British Columbia, Canada, PLWH over the age of 50 are more likely to have developed type 2 diabetes if they started antiretroviral treatment before 1999, or had a longer exposure to older antiretroviral drugs such as stavudine (d4T) or first-generation protease inhibitors (such as nelfinavir or indinavir,). The onset of diabetes was much less likely in people aged 50 and over who started treatment from 2010 onwards, or who started treatment at a higher CD4 cell count. The study showed that people who started treatment in the period 1997-2004 were almost 50 times more likely to develop diabetes compared to people who started treatment between 2005 and 2009.³²

Researchers at major medical centres in France compared health-related information from more than 13,000 HIV-positive people, some of whom were more than 75 years old. The prevalence of Type 2 diabetes was 11% in the elderly (aged 50 to 75 years) and 22% in the geriatric (aged 75 years and older) group. HCV coinfection was also prevalent (25% and 9% respectively).³³

A study including PLWH from three London outpatient clinics, showed that the prevalence of type 2 diabetes in a significantly older 2015 cohort was 15.1% compared with 6.8% in the 2005 cohort. Whether the high risk of age-related diseases in HIV-infected people is caused by biologic aging, or HIV-associated risk factors such as chronic immune activation and low-grade inflammation, is unknown.^{34, 35}

Oh, Diabetes Mellitus!

What is Diabetes?

Diabetes is a chronic disease in which the body either cannot produce insulin, or cannot properly use the insulin it produces. Insulin is a hormone that controls the amount of glucose (sugar) in the blood. Diabetes leads to high blood sugar levels, which can damage organs, blood vessels, and nerves.³⁶

Types of Diabetes

³¹ Ontario Advisory Committee on HIV/AIDS, Toronto, Ontario. “Focusing our efforts: Changing the Course of the HIV Prevention, Engagement and Care Cascade in Ontario- HIV/AIDS Strategy to 2026” February 2017, pg. 51.

³² Samad F et al. Incidence of diabetes mellitus and factors associated with its development in HIV-positive patients over the age of 50. *BMJ Open Diabetes Research & Care*, 5: e000457, doi: 10.1136/bmjdr-2017-000457, 2017.

³³ Allavena C, Bernaud C, Lariven S, et al. Aging with HIV: emerging importance of chronic comorbidities in patients over 75. Conference on Retroviruses and Opportunistic Infections, 22-25 February 2016, Boston, MA. Abstract 709.

³⁴ Duncan AD, Louise GM, Barry PS, Type 2 diabetes prevalence and its risk factors in HIV : A cross-sectional study. In: *PLoS ONE*. 2018 ; Vol. 13, No. 3.

³⁵ Rasmussen LD, May MT, Kronborg G, Larsen C S, Pedersen C, Gerstoft J, Obel N, Time trends for risk of severe age-related diseases in individuals with and without HIV infection in Denmark: a nationwide population-based cohort study. *The Lancet. HIV*, ISSN: 2352-3018, 2015, Vol: 2, Issue: 7, Page: e288-98

³⁶ Canadian Diabetes Association 2018 downloaded from <https://www.diabetes.ca/>

Type 1 diabetes usually starts during childhood or adolescence. The body makes little or no insulin. The lack of insulin causes glucose to build up in the blood. This causes high blood sugar.

Type 2 diabetes, which typically develops during adulthood, is where the body produces insulin but does not use it properly. Type 2 diabetes is, by far, the most common kind of diabetes among the general population and among people living with HIV. This report will focus on Type 2 diabetes. This type of diabetes accounts for an estimated 90% of diabetes cases, overall. Type 2 diabetes has been recognized internationally, and domestically, as a growing health burden affecting some 285 million people worldwide, and is expected to affect 438 million people by 2030.^{37, 38}

Gestational diabetes develops during pregnancy. Blood sugar levels usually return to normal after the baby is born. There is a risk of gestational diabetes if a woman is being treated for HIV at the same time, and the risk of developing Type 2 diabetes is increased.³⁹

Pre-diabetes is when the blood sugar levels are higher than normal, but are not high enough to be considered diabetes. The condition can be reversed, but nearly 50 percent of people who have it go on to develop type 2 diabetes.⁴⁰

Treatment of type 1 diabetes uses insulin injections, whereas type 2 diabetes is generally treated using medications. The first-line medication for DM is metformin. After lifestyle modification and metformin, if a patient is still not at goal, there are multiple treatment options. With time, if type 2 diabetes progresses, insulin injections may be needed as well. It is beyond the scope of this review to discuss the treatment strategies for diabetes in PLWH.

Diabetes in Canada

Diabetes is one of the most common chronic diseases in Canada.⁴¹ The number of people with DM is rising, both in Canada and around the world. Currently, 11 million Canadians are living with prediabetes, or diabetes: this means that almost one in three people in Canada are affected by these conditions.

The aging of the Canadian population, largely as a result of the baby boomer cohort, has been one of the factors contributing to the increase in the number of Canadians living with diagnosed DM. Statistics Canada defines baby boomers as those born between 1946 and 1965, which means they currently range in age from 50 to 69.⁴² In recent years, the highest increase in the number of individuals with diabetes has been in the 60 to 64 year age group. In addition to the aging baby boomer cohort, the increased

³⁷ World Health Organization. Fact Sheet on Diabetes. (March 2016). Downloaded from <http://www.who.int/mediacentre/factsheets/fs312/en/>

³⁸ World Health Organization. Global Report on Diabetes. Downloaded from http://apps.who.int/iris/bitstream/10665/204871/1/9789241565257_eng.pdf?ua=1

³⁹ Gestational Diabetes. Downloaded from <https://www.cdc.gov/diabetes/pubs/pdf/gestationalDiabetes.pdf>

⁴⁰ CATIE, From a Practical Guide to a Healthy Body for People Living with HIV Diabetes and Blood Sugar Problems. Available online at :<https://www.catie.ca/en/practical-guides/healthy-body/7>

⁴¹ Public Health Agency of Canada, Chronic Diseases, Diabetes in Canada: Facts and figures from a public health perspective downloaded from [https://www.canada.ca/en/public-health/services/chronic-diseases/...](https://www.canada.ca/en/public-health/services/chronic-diseases/)

⁴² Statistic Canada, Census in Brief, Generations in Canada Age and sex, 2011 Census available at <https://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.cfm>

longevity of individuals living with diabetes (due to advancements in treatment and earlier diagnosis) has contributed to the increasing prevalence rates of the disease.

In Canada, about 3.4 million people have DM: that is just over 9% of the total population. The diabetes prevalence in Canada increased by more than 35% between 2009 and 2015.^{43,44} Diabetes Canada estimates that by 2025, 12% of the population will have diabetes. In 2016, more than 1.6 million people in Ontario were living with diabetes, and another 2.3 million people had prediabetes. Almost half remain undiagnosed in Canada and are not getting the vital education, facts, and care they need to manage this serious disease.⁴⁵ It is disturbing to note that 35-44% of people with diabetes do not know they have it. As a long-lasting disease with serious consequences if left untreated, diabetes requires appropriate and timely intervention. In fact, someone may have had diabetes for up to 12 years before diagnosis. Since people with diabetes generally feel well during the initial stages of the disease, many people are only diagnosed once they develop complications. Delayed diagnoses result in delayed treatment, which can be less effective in preventing, or decreasing, further complications.

Diabetes is also costly for those living with the disease. Affordability and accessibility of diabetes medications, devices, and supplies vary depending on where one lives in Canada, and the public programs and services available. While some jurisdictions have increased support, costs continue to be a major barrier for many with diabetes. The increasing rate of diabetes and its complications poses a serious burden to the publicly funded healthcare systems and economies of many provinces.⁴⁶

Diabetes comorbidity is raising more concern as diabetes continues to emerge as a major disease of public health importance in countries with high HIV prevalence.

Despite this, diabetes is manageable if individuals, communities, healthcare providers, and policy-makers are given the information and tools to motivate and support behavioural change.

Impact of Diabetes

"I was diagnosed with HIV 25 years back, comorbidities wasn't a thing then. I have a GP that specializes in HIV. I have had diabetes for the last 10 years. My sugar used to be checked regularly. I went to a generalized workshop at East York General Hospital: got myself informed. I had a heart attack in 2017. I was on protease inhibitors but last June 2017 switched to integrase inhibitors. Diabetes is treated separately. Diabetes and HIV are compartmentalized, no program on healthy eating. CATIE and PWA had nutritional programs but not anymore. Amongst the HIV issues, diabetes is way down the list. It is a "silent killer" and we are not connected to our bodies. We are focussed on HIV. There is clear relationship

⁴³ Canadian Diabetes Association. *Diabetes Charter for Canada Backgrounder*. (May 2015). Downloaded from <https://www.diabetes.ca/getmedia/513a0f6c-b1c9-4e56-a77c-6a492bf7350f/diabetes-charter-backgrounder-national-english.pdf.aspx>

⁴⁴ Hyman I, Gucciardi E, Patychuk D, Rummens JAJ, Shakya Y, Kljujic D, Bhamani M, Boqaileh F. "Self-management, health service use and information seeking for diabetes care among Black Caribbean immigrants in Toronto." *Canadian journal of diabetes* 38, no. 1 (2014): 32-37.

⁴⁵ Cook Douglas: The Diabetes Drill from The Positive Side, Winter 2015 downloaded from <https://www.catie.ca/en/positiveside/winter-2015/diabetes-drill>

⁴⁶ Diabetes Report: Diabetes Canada at the tipping point- Chartering new path 2011, downloaded from <https://www.diabetes.ca/publications-newsletters/advocacy-reports/diabetes-canada-at-the-tipping-point>

between HIV and diabetes but we are not making any links. On ODSP (Ontario Disability Support Program) people have less money, don't understand the consequences of diabetes, the nuances like for example when you say one large potato contains half a cup of sugar, it becomes clear. Root veggies are starch that converts to sugar, so the information has to be given by bits and pieces so the information is not "overwhelming." Thomas Egdorf, Director, AIDS Bereavement and Resiliency Program of Ontario (ABRPO).

"People have to know about the impact, there are so many undiagnosed, not testing for HIV or diabetes." Service provider.

"I ended up in the hospital with a very low CD4 count. I was incoherent and my kidney and liver were out of whack. Things came gradually under control. It was the effects of the diabetes. I had five different doctors. I am careful with diet, exercise and watch what I eat ... my HIV specialist and GP have 100% cooperation as well as great diabetic team and a foot care specialist. So, I have to talk to 8-9 doctors which makes me tired out but this is all a part of living through this." Service provider.

The impact of diabetes cannot be underestimated. High, untreated blood sugar is related to many long-term health problems. The long-term consequences of uncontrolled diabetes are devastating and can include vascular disease (heart attacks and stroke); increased risk of heart attack; and kidney disease (diabetic nephropathy), which may eventually lead to end-stage renal disease requiring dialysis. Diabetic neuropathy can also occur, which causes painful burning and tingling or numbness in the limbs, and can be debilitating. Skin infections, especially of the feet, take longer to heal in diabetics than in non-diabetics, placing diabetics at higher risk of amputation. Diabetes also causes depression as well as erectile dysfunction in men and pregnancy complications in women. Complications can be life threatening: life expectancy for people with type 1 diabetes may be shortened by as much as 15 years and, for those with type 2 diabetes, by five to 10 years.⁴⁷

The Diabetic Associations Clinical Guidelines recommend that PLWH, whom are also living with diabetes and other comorbidities, have close follow up with an interdisciplinary health care team for optimal management. There are three subgroups of people with diabetes and HIV: individuals with preexisting diabetes who contract HIV; those who are diagnosed with diabetes and HIV at the same time; and others who develop diabetes after starting antiretroviral therapy. These subgroups need to be managed differently, as the mechanisms of metabolic dysregulation vary between them.

HCV and Diabetes - What is the Relationship?

"I was HIV positive from 2015. I also had hepatitis C which cleared up with 12 weeks of medications. My blood work was done regularly. I wanted to know more so that is why I came to the focus group. I need to know more about diabetes." Female participant.

An estimated 220,000 - 245,000 Canadians are infected with HCV. Unfortunately, around 44% of those individuals are unaware of their status, and are often only diagnosed incidentally to something else.

⁴⁷ An Economic Tsunami: The Cost of Diabetes in Canada, 2009. Available at: <http://www.diabetes.ca/economicreport/>
Diabetes Charter For Canada 2016, <http://www.diabetes.ca/how-you-can-help/advocate/why-federal-leadership-is-essential/diabetes-statistics-in-canada>

There is a large population of individuals currently aging with HCV, whether diagnosed or not, who are now experiencing complications. Some of these complications are quite severe and can include cirrhosis, liver failure, and death.⁴⁸

A large number of studies report an increased risk for type 2 diabetes and insulin resistance in patients with chronic HCV infection.^{49,50,51,52} The positive association between HCV and diabetes has been substantiated by numerous studies in the past two decades, as well as across different ethnicities and geographic regions, in both developed and developing countries.^{53,54,55,56,57,58,59,}

Epidemiological studies have since specifically linked HCV and HCV cirrhosis with diabetes.^{60,61,62} HCV infection precedes the diagnosis of type 2 diabetes in as many as 73% of cases, further suggesting HCV's pathogenic role in the development of type 2 diabetes.^{63,64,65} It is estimated that up to 33% of chronic HCV patients have type 2 diabetes.^{66,67}

⁴⁸ Fletcher A, Canadian Treatment Action Council "The time has come to eliminate hepatitis C in Canada", 2018 available at <https://ctac.ca/wp-content/uploads/2018/11/Cascade-Paper.pdf>

⁴⁹ White DL, Ratziu V, El-Serag HB. Hepatitis C infection and risk of diabetes: a systematic review and meta-analysis. *J Hepatol* (2008) **49**(5):831–44. doi:10.1016/j.jhep.2008.08.006

⁵⁰ <http://www.diabetesforecast.org/2011/oct/what-s-the-link-between-hepatitis-c-and-type-2.html>

⁵¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4568414/>

⁵² Francesco Negro and Mahnaz Alaei, Hepatitis C virus and Type 2 Diabetes, *World J Gastroenterol* 2009 April 7; **15**(13): 1537-1547

⁵³ Hammerstad SS, Grock SF, Lee HJ, Hasham A, Sundaram N and Tomer Y (2015) Diabetes and hepatitis C: a two-way association. *Front. Endocrinol.* **6**:134. doi: 10.3389/fendo.2015.00134

⁵⁴ Simo R, Hernandez C, Genesca J, Jardi R, Mesa J. High prevalence of hepatitis C virus infection in diabetic patients. *Diabetes Care* (1996) **19**(9):998–1000. doi:10.2337/diacare.19.9.998

⁵⁵ Soma J, Saito T, Taguma Y, Chiba S, Sato H, Sugimura K, et al. High prevalence and adverse effect of hepatitis C virus infection in type II diabetic-related nephropathy. *J Am Soc Nephrol* (2000) **11**(4):690–9

⁵⁶ Guo X, Jin M, Yang M, Liu K. Type 2 diabetes mellitus and the risk of hepatitis C virus infection: a systematic review. *Sci Rep* (2013) **18**(3):2981. doi:10.1038/srep02981

⁵⁷ Vanni E., Bugianesi E, Saracco G., Treatment of type 2 diabetes mellitus by viral eradication on chronic hepatitis C: myth or reality? *Dig Liver Dis Off J Ital Soc Gastroenterol Ital Assoc Study Liver.* 2016;**48**:105-111

⁵⁸ Memon MS, Arain ZI, Naz F, Zaki M, Kumar S, Burney AA. Prevalence of type 2 diabetes mellitus in hepatitis C virus infected population: a Southeast Asian study. *J Diabetes Res* (2013) **2013**:539361. doi:10.1155/2013/539361

⁵⁹ Ozyilkan E, Arslan M. Increased prevalence of diabetes mellitus in patients with chronic hepatitis C virus infection. *Am J Gastroenterol* (1996), **91**(7):1480–1.

⁶⁰ Kruszynska YT, McIntyre N. Carbohydrate metabolism. In: McIntyre N, Benhamou JP, Bircher J, Rizzetto M, Rodes J, editors. *Oxford Textbook of Clinical Hepatology.* Oxford, England: Oxford University press (1991). 129–34.

⁶¹ Allison ME, Wreghitt T, Palmer CR, Alexander GJ. Evidence for a link between hepatitis C virus infection and diabetes mellitus in a cirrhotic population. *J Hepatol* (1994) **21**(6):1135–9.

⁶² Lonardo A, Adinolfi LE, Petta S, Craxi A, Loria P. Hepatitis C and diabetes: the inevitable coincidence? *Expert Rev Anti Infect Ther* (2009) **7**(3):293–308.

⁶³ Romero-Gomez M, Del Mar Vilorio M, Andrade RJ, Salmeron J, Diago M, Fernandez-Rodriguez CM, et al. Insulin resistance impairs sustained response rate to peg interferon plus ribavirin in chronic hepatitis C patients. *Gastroenterology* (2005) **128**(3):636–41.

⁶⁴ Grimbert S, Valensi P, Levy-Marchal C, Perret G, Richardet JP, Raffoux C, et al. High prevalence of diabetes mellitus in patients with chronic hepatitis C. A case-control study. *Gastroenterol Clin Biol*, 1996, **20**(6–7):544–8.

⁶⁵ Mehta SH, Brancati FL, Strathdee SA, Pankow JS, Netski D, Coresh J, et al. Hepatitis C virus infection and incident type 2 diabetes. *Hepatology* (2003) **38**(1):50–6.

⁶⁶ Knobler H, Schihmanter R, Zifroni A, Fenakel G, Schattner A. Increased risk of type 2 diabetes in noncirrhotic patients with chronic hepatitis C virus infection. *Mayo Clin Proc* (2000) **75**(4):355–9.

⁶⁷ Zein NN, Abdulkarim AS, Wiesner RH, Egan KS, Persing DH. Prevalence of diabetes mellitus in patients with end-stage liver cirrhosis due to hepatitis C, alcohol, or cholestatic disease. *J Hepatol* (2000) **32**(2):209–17.

The landmark cross-sectional NHANES III study that surveyed 9,841 adults from the United States concluded that HCV-positive patients older than 40 years old had a threefold increased risk for type 2 diabetes, compared to those without HCV.⁶⁸

The latest study by Provost and team showed that, in PLWH, cirrhosis is associated with an increased risk of diabetes, but not chronic HCV infection, or duration of HCV infection.⁶⁹

The intersection of HIV, HCV, and Diabetes

“Lives are complex, complex health needs, mental health, addiction, hepatitis C ... we try to look into everything but don't go into non-infectious stuff, maybe something we need to look into.” Service provider.

“HIV and diabetes is an important conversation. I was detected with HIV when I was 20, I finished a decade now, I am worried not about HIV but about other comorbidities ... it is more than a pill, what must I do to remain healthy, how do I identify what I need?” Peer service provider.

There are 63,110 individuals living with HIV in Canada.⁷⁰ There are no current statistics on the number of people living with HIV and diabetes in Canada. With the Canadian population aging, the number of older Canadians living with HIV will increase.⁷¹

HIV as a risk factor for diabetes has long been controversial, but evidence shows that people living with HIV have increased diabetes prevalence compared to the general population.⁷² Rates of diabetes have been shown to be higher in people living with HIV than in the general population. People over the age of 40, including people living with HIV and having other comorbidities, are more likely to develop diabetes. One important reason is that many people living with HIV have some of the risk factors for diabetes.⁷³

In an observational study carried out in the USA, the prevalence of diabetes was nearly 4% higher in a nationally representative sample of people living with HIV than among the United States general public, taking into account factors including sex, ethnicity, HCV infection, and poverty.⁷⁴

Certain HIV medications, especially some of the older ones, have been associated with a higher risk of diabetes. Studies have shown that HIV and highly active antiretroviral therapy (HAART) increase the risk

⁶⁸ Mehta SH, Brancati FL, Sulkowski MS, Strathdee SA, Szklo M, Thomas DL. Prevalence of type 2 diabetes mellitus among persons with hepatitis C virus infection in the United States. *Ann Intern Med* (2000) 133(8):592–9.

⁶⁹ Piroth L, Wittkop L, Lacombe K, et al Efficacy and safety of direct-acting antiviral regimens in HIV/HCV co infected patients-French ANRS CO13 HEPAVIH cohort. *J Hepatol.* 2017; 67:23-31

⁷⁰ Public Health Agency of Canada. “Infographic: HIV in Canada” *Canada.ca*, 16 Jul. 2018, downloaded from <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/hiv-canada.html>.

⁷¹ HIV and Aging in Canada, downloaded from http://www.cdn aids.ca/wp-content/uploads/HIV_aging_4-Prevention-Fact-Sheet.pdf

⁷² People living with HIV may be more at risk of diabetes, AVERT, 2nd February 2017 downloaded from <http://www.aidsmap.com/Type-2-diabetes-and-HIV/page/1327149/>

⁷⁴ BMJ. "People infected with HIV may be more susceptible to diabetes: Prevalence nearly 4 percent higher than among US general public, and often in absence of obesity." *ScienceDaily*, 30 January 2017. <www.sciencedaily.com/releases/2017/01/170130224712.htm>.

of prediabetes and type 2 diabetes by 1.5 to 4-fold compared to the general population.³⁸ This is compounded by an increase in associated comorbidities in PLWH, including HCV and cardiovascular disease.^{75,76,77} Most researchers have demonstrated that HIV/HCV-coinfected patients are even more likely to develop diabetes than patients with either virus alone. Similar to HIV coinfection, diabetics experience more severe HCV-related outcomes. The World Health Organization estimates the prevalence of diabetes mellitus in persons over 25 years of age to be 10%, similar to the prevalence of HIV infection in HCV-infected persons.^{78,79,80,81}

It is important to understand that the development of diabetes is complex and influenced by many factors.

Data from some Clinical Studies

The **Multicenter AIDS Cohort Study (MACS)** enrolled 5,622 men over 17 years and was the first study to assess the incidence of diabetes in HIV-infected men.

Of 1,278 men from this study, 47 of 411 men with HIV using HAART (14%) had diabetes at baseline compared with 33 of 710 men without HIV (5%). PLWH on HAART are up to five times more likely to develop diabetes than HIV-negative individuals. This increased risk is due to the effectiveness of HAART regimens and some of the HAART medications themselves. Incidence of medication-related diabetes increases as the duration of therapy increases. Furthermore, some medications commonly used to treat patients' adverse events related to HAART also increase the risk for the development of diabetes.

The highest, most studied risk factor for PLWH and the development of diabetes is associated with protease inhibitors (PIs). PIs are the only class of HIV medications that have a direct effect on glucose metabolism. However, this adverse effect on glucose metabolism is not the same for all PIs. The protease inhibitors most associated with the adverse events are indinavir (Crixivan), ritonavir (Norvir), and amprenavir (Agenerase). These three effect glucose levels through multiple mechanisms. Among the noted PIs, indinavir has been reported as having both rapid and dramatic effects on patient's glucose metabolism resulting from as little as one dose. Meanwhile, the nucleoside reverse transcriptase inhibitor (NRTI) known as stavudine increases the risk of developing diabetes indirectly.

⁷⁵ : Kalra et al.: Understanding diabetes in patients with HIV/AIDS. *Diabetology & Metabolic Syndrome* 2011 3:2.

⁷⁶ Althoff KN, McGinnis KA, Wyatt CM, Freiberg MS, Gilbert C, Oursler KK, et al. (2015) Comparison of risk and age at diagnosis of myocardial infarction, end-stage renal disease, and non-AIDS-defining cancer in HIV-infected versus uninfected adults. *Clinical Infectious Diseases* 60: 627–638. <https://doi.org/10.1093/cid/ciu869> PMID: 25362204

⁷⁷ Platt L, Easterbrook P et al, *The Lancet Infectious Diseases*, Prevalence and burden of HCV co-infection in people living with HIV: a global systemic review and meta-analysis, July 1, 2016, 16, 7, 797-808.

⁷⁸ Shafran et al (PDF) HIV Co-infected Have Similar SVR Rates as... Available from: https://www.researchgate.net/publication/278044606_HIV_Co-infected_Have_Similar_SVR_Rates_as_HCV_Mono-infected_with_DAAs_It%27s_Time_to_End_Segregation_and_Integrate_HIV_Patients_into_HCV_Trials [accessed Aug 16 2018].

⁷⁹ Huang YW, Yang SS, Fu SC, et al. Increased risk of cirrhosis and its decompensation in chronic hepatitis C patients with new-onset diabetes: A nationwide cohort study. *Hepatology* 2014; 60:807–14.56.

⁸⁰ Elkrief L, Chouinard P, Bendersky N, et al. Diabetes mellitus is an independent prognostic factor for major liver-related outcomes in patients with cirrhosis and chronic hepatitis C. *Hepatology* 2014; 60:823–31.

⁸¹ CATIE: A Practical Guide to a Healthy Body for People Living with HIV Available available at: <http://www.catie.ca/en/practical-guides/healthy-body/7>

This study did correlate well with previous studies that showed an increased risk for diabetes in HIV-infected women on HAART. MACS also showed an increased risk for diabetes among HIV-infected individuals not taking HAART.^{82,83}

The **Data collection on adverse effects of anti-HIV drugs (D:A:D)** is a multinational, prospective, observational study with data collected from 212 clinics in Europe, the U.S., Australia, and Argentina.

Of the positive 33,389 study patients, 952 had diabetes at baseline, for a prevalence of 2.85%. During the follow-up period, diabetes was diagnosed in 744 patients. In this study, the incidence of diabetes had increased with cumulative exposure to combination antiretroviral treatment. In the study group, men were more likely to develop diabetes than women were; other factors included older age, and African ancestry.⁸⁴

The Swiss HIV cohort study: 123 of 6,513 persons included in the follow up developed diabetes. This study has reported an increased incidence rate ratio among male study subjects and among those who use protease inhibitors and some nucleoside reverse transcriptase inhibitors (NRTI).⁸⁵

The Women's Interagency HIV study: conducted in six cities in the United States and tracked the disease progression of women with/at risk for HIV using semi-annual study visits. The investigators compared women in three groups: those who used PIs in a regimen containing one PI and at least one NRTI and/or NNRTI; those who used NRTIs and/or NNRTIs but no PIs; and those who received no antiretroviral therapy at all. In this study, cumulative exposure to NRTI was associated with an increased incidence of diabetes.⁸⁶

Cohort study: this study evaluated the incidence and determinants of diabetes in HIV-infected adults initiated with combination antiretroviral treatment (cART) in 1997-1999 and followed up to 2009. The incidence rate in this study was 14.6 in men and 12.6 in women.⁸⁷

In summary, the prevalence of DM in HIV-infected patients has been reported to range from 2% to 14% and varies depending on the cohort studied, how the DM diagnosis is established, and how DM risk factors are accounted for in the analysis.

Despite the conflicting evidence on the independent role of HIV in DM, certain factors are clearly associated with DM including increasing age, obesity, and genetic factors. Other factors influence DM

⁸² Brown TT et al, Antiretroviral therapy and the prevalence and incidence of diabetes mellitus in the Multicenter AIDS Cohort Study. *Archives of Internal Medicine* 165(10):1179-84. May 23, 2005.

⁸³ Brow, T. et al, Cumulative exposure to nucleoside analogue reverse transcriptase inhibitors is associated with insulin resistance markers in the Multicenter AIDS Cohort Study. *Acquired Immune Deficiency Syndrome* 19(13):1375-83. September 2, 2005.

⁸⁴ De Wit S. et al, Incidence and risk factors for new onset diabetes mellitus in HIV infected patients: the Data Collection on Adverse Events of Anti-HIV Drugs (D:A:D) study. *Diabetes Care* 31(6):1224-29. June 2008.

⁸⁵ Ledergerber, B. et al, Factors associated with the incidence of type 2 diabetes mellitus in HIV-infected participants in the Swiss HIV Cohort Study. *Clinical Infectious Diseases* 45(8):111-19. April 15, 2007.

⁸⁶ Tien, P. et al, Antiretroviral therapy exposure and incidence of diabetes mellitus in the Women's Interagency HIV Study. *Acquired Immune Deficiency Syndrome* 21(13):1739-45. August 20, 2007.

⁸⁷ Capeau J, Bouteloup V, Katlama C, Bastard JP, Guiyedi V, Salmon-Ceron J, Protopopescu C, Lepout C, & Raffi F, Chêne G (2011). Ten-year diabetes incidence in 1046 HIV-infected patients started on a combination antiretroviral treatment. *AIDS (London, England)*. 26. 303-14. 10.1097/QAD.0b013e32834e8776.

incidence in the general population, but are more common in HIV-infected patients: HCV infection, use of certain medications and opiate use, and low testosterone. Furthermore, ART-associated lipodystrophy, visceral fat accumulation/lipohypertrophy, and HIV-related inflammation are DM risk factors in HIV-infected patients.⁸⁸

Where HIV and Diabetes Intersect - Populations at Greater Risk

Traditionally, diabetes can affect people who are overweight, or experiencing obesity caused by sedentary lifestyles and eating habits; people who have low incomes, or live in poverty; people aged 40 and older; and those who have a family history of diabetes.

Diabetes can vary in terms of incidence and severity within different populations. We find that certain populations with HIV are also at increased risk of developing type 2 diabetes.

Low - Income Families

“There are significant numbers of women living under the poverty line. So, follow up and suggestions are difficult. Gangrene can occur (had a client that lost her leg). There are populations who are also ashamed of asking for food. The diet is mainly rice based. Obesity and fatty liver are high, depression, and other comorbidities of which, number one is mental health and depression. You have diabetes you have to exercise, and there are eating restrictions. They do not meet goals, so they do not go to see the nurse, or dietician. There are also people who are in denial.” Service provider in Toronto working for a women’s organization.

Low-income populations are at increased risk for the development of diabetes and have worse outcomes when they do develop it. PLWH who are in socially disadvantaged groups also experience more difficulty in affording their medications. Low-income women are particularly at risk. While more men than women have diabetes, diabetes rates are higher in women within high-risk and marginalized populations.⁸⁹ The burden of diabetes on women is unique because the disease can affect both mothers and their unborn children.⁹⁰

Ethnic Groups

“I was diagnosed with HIV in 2001. Nine months ago, my primary care physician told me that I have diabetes. I have to control diet, I have to do exercise, but linking up and getting information is difficult for me because I don’t know English very well.” South Asian male participant.

“HIV started in 1990 for me. My mother and aunt had diabetes, and my brother had diabetes from

⁸⁸ Monroe AK, Glesby MJ, Brown TT; Diagnosing and Managing Diabetes in HIV-Infected Patients: Current Concepts, *Clinical Infectious Diseases*, Volume 60, Issue 3, 1 February 2015, Pages 453–462, <https://doi.org/10.1093/cid/ciu779>

⁸⁹ Diabetes Canada, Diabetes Statistics in Canada downloaded from <https://www.diabetes.ca/how-you-can-help/advocate/why-federal-leadership-is-essential/diabetes-statistics-in-canada>

⁹⁰ Diabetes 360^o: A Framework for a Diabetes Strategy for Canada Recommendations for Governments, July 2018 http://www.diabetes.ca/getmedia/a4d52b4c-85fa-4cf2-aa4d-e15103f16ec3/Diabetes_360_Recommendations_1.pdf.aspx

childhood. I had to take medications for mental health and that caused my blood sugar to raise. Two years ago, I was referred to an endocrinologist and diabetic medications started. So, from October 2017, I started medications, but the side effects were that it curbs the appetite and a lot of vaginal infections. Every time the endocrinologist gave a new medication, he would tell me to ask my HIV clinic if I could take it or not. When the nurse at my HIV clinic said go ahead, I would start taking it. My doctors are all separated, no one gives information to each other, I had to program my mind: I have what I have: I had to watch what I eat and put the right food in my mouth. Since I was a diabetes caregiver for my family I had to learn. Knowledge is important.” Afro-Asian woman participant.

“My husband has diabetes. I am very careful with his diet and I am his caregiver so I came today to know and learn more about diabetes and how I can help my husband.” African woman participant.

According to 2014 national estimates, people from HIV-endemic countries living in Canada have HIV incidence rates 6.3 times higher than people of other ethnicities living in Canada. The risk of diabetes is also higher in recent immigrants and certain ethnic groups, such as those of South Asian, African, and Hispanic descent.⁹¹

While the high prevalence of diabetes amongst the African Caribbean and Black (ACB) communities has long been recognized by health researchers in Canada and other multiethnic countries, ACB communities continue to have some of the worse diabetes outcomes compared to other ethnoracial groups.^{92,93,94,95,96,97}

Also, recent PLWH who are immigrants may experience problems in accessing care because of language barriers and inexperience in navigating the health care system.

Although the disproportionate burden of diabetes is partly driven by a genetic predisposition to diabetes, this biological facet merely operates against a backdrop of more complex historical and social factors faced by this community, which includes disenfranchisement(s), economic alienation, and structural discrimination. These factors continue to influence their health outcomes to this day.⁹⁸

⁹¹ Kelly C, and Booth GL. “Diabetes in Canadian Women.” *BMC Women’s Health* 4.Suppl 1 (2004): S16. PMC. Web. 30 Aug. 2018.

⁹² Chiu M, Maclagan L C, Tu, J V, & Shah BR(2015). Temporal trends in cardiovascular disease risk factors among white, South Asian, Chinese and black groups in Ontario, Canada, 2001 to 2012: a population-based study. *BMJ open*, 5(8), 1-10.

⁹³ Liburd LC, Namageyo-Funa, A, Jack L., & Gregg E. (2004). Views from within and beyond: illness narratives of African-American men with type 2 diabetes. *Diabetes Spectrum*, 17(4), 219-224.

⁹⁴ Liburd, Leandris C, Namageyo-Funa A, and Leonard J Jr. "Understanding" masculinity" and the challenges of managing type-2 diabetes among African-American men." *Journal of the national medical association* 99, no. 5 (2007): 550-558.

⁹⁵ Griffith DM, Metz J, & Gunter K (2011). Considering intersections of race and gender in interventions that address US men’s health disparities. *Public health*, 125(7), 417-423.

⁹⁶ Shaw S J, Armin J, Torres, CH, Orzech, KM, & Vivian J. (2012). Chronic disease self-management and health literacy in four ethnic groups. *Journal of health communication*, 17(sup3), 67-81.

⁹⁷ Creatore MI, Polsky JY, Weyman JT, Tynan AM, Gozdyra P, Zahn W, Booth GL, Glazier RH. “Ethnicity, Immigration, and Diabetes”. *Diabetes Atlas for Peel Region*. Peel Public Health, 2014.

⁹⁸ Liburd, L.C, Namageyo-Funa, A, Jack L., & Gregg, E. (2004). Views from within and beyond: illness narratives of African-American men with type 2 diabetes. *Diabetes Spectrum*, 17(4), 219-224.

First Nations, Inuit and Métis community members

“Not just HIV or Hep C, but diabetes (which) greatly trumps those epidemics in all of those communities.” Dr. Stuart Skinner at the 2017 Highlights in Medicine Alumni Reunion Conference on June 23, Alumni Panel, HIV: A conversation on a Saskatchewan Epidemic.

“I had HIV in 1989. Three years back I was told, I have diabetes and began Metformin, then gradually insulin and I take a new drug once a week. I use coupons for my insulin injections (free Toujeo coupon). It is different for indigenous people. I take nine other drugs including insulin. Therefore, I have premature aging and brittle bones. All the pharmacists say is lose the weight and you will be better. My mobility is a great challenge since I have sciatica and my bones are crushed at the lower back. I am so tired of going without; I do not eat processed food and cook soups. There are no pamphlets or resources for diabetes and HIV. I try to watch what I eat and eat more veggies and fruit. If I eat more, it affects the next day. Actually, I avoided meetings and talking to people but it helps, you can get recipes. For me HIV was just the beginning.” An Indigenous male participant.

“There are many living with both (HIV and diabetes). It is common, awareness of the dangers, education level is very low, the biggest barrier is housing. Since diabetes has no immediate effect, people are not focussed on it. People here don’t give a shit about their diet: primary source is bread and they eat whatever they can get.” Service provider working in Saskatoon.

“The doctors are really judgmental, especially to the Aboriginal people. The first time I went to the building, one of the ladies told the other lady (and I heard it), ‘She has HIV!’ That’s not right, and in front of the whole room. So, I was like, ‘Excuse me! You cannot disclose that’. She was like, ‘I have to tell’.” Quote taken from a focus group participant from CTAC’s Project, *Gaps and Policy Barriers to Engagement with the HIV Cascade of Care In Ontario*.

Among the Aboriginal population of Canada (which includes First Nations, Inuit, and Metis), DM and HIV contribute significantly to their higher morbidity and increased health disparity when compared to non-Aboriginal Canadians. Aboriginal populations have HIV incidence rates 2.7 times higher than people of other ethnicities, increased risk of HCV co-infection, and are three to five times more likely to develop

⁹⁹ Griffith DM, Metz J, & Gunter, K. (2011). Considering intersections of race and gender in interventions that address US men’s health disparities. *Public health, 125*(7), 417-423.

¹⁰⁰ Shaw, S, Armin J, Torres CH, Orzech, KM, & Vivian J. (2012). Chronic disease self-management and health literacy in four ethnic groups. *Journal of health communication, 17*(sup3), 67-81.

¹⁰¹ Creatore MI, Moineddin R, Booth G, Manuel DH, DesMeules M, McDermott S, and Glazier RH. "Age-and sex-related prevalence of diabetes mellitus among immigrants to Ontario, Canada." *Canadian Medical Association Journal* 182, no. 8 (2010): 781-789.

¹⁰² Creatore MI, Polsky JY, Weyman JT, Tynan AM, Gozdyra P, Zahn W, Booth GL, Glazier RH. "Ethnicity, Immigration, and Diabetes". *Diabetes Atlas for Peel Region*. Peel Public Health, 2014.

¹⁰³ Canadian Diabetes Association. "Diabetes: Canada at the tipping point—charting a new path." Diabetes Québec; Canadian Electronic Library (Firm) (2011).

type 2 diabetes than the general population.^{104,105}

In contrast to the general Canadian population (in which the prevalence is higher in men than women), First Nations women bear a heavier diabetes burden than First Nations men across most age groups. Among Aboriginal Canadians, two-thirds of affected individuals are women. Aboriginal women have over 5 times the rate of diabetes compared to women in the general population, and Aboriginal men have over 3 times the rate of diabetes compared to men in the general population. Up to 18% of Aboriginal women are diagnosed with gestational diabetes, increasing the likelihood that mother and child will experience diabetes at some stage in their life.

For First Nations individuals living on reserve, diabetes prevalence is 3-5 times greater than in the general population, and their rates of complications are higher. The age/sex standardized prevalence of diabetes for Métis individuals was 11.2%, nearly 25% higher than that of the general Ontario population as shown by a study examining diabetes prevalence and care in 14,480 Métis of Ontario.¹⁰⁶ The socio-cultural, biological, environmental, and lifestyle changes seen in the First Nations, Inuit, and Métis populations in the last half-century have contributed significantly to increased rates of diabetes and its complications.¹⁰⁷

“There are barriers specific to First Nations, Inuit, and Métis individuals who try to access healthcare which include: issues stemming from the legacy of colonialism, racist policies and discrimination by healthcare providers, and a lack of integration of traditional aspects into the healthcare system that create additional barriers in engaging in their HIV and diabetes care and treatment.”^{108, 109}

It is also important to note that the Federal Government of Canada launched the Aboriginal Diabetes Initiative (ADI) in 1999 as part of the bigger Canadian Diabetes Strategy to provide a better framework for surveillance, public education, and community-based diabetes management.¹¹⁰ However, these programs are not linked with any HIV programs.

¹⁰⁴ Public Health Agency of Canada. Chapter 3: Diabetes in Canada: Facts and figures from a public health perspective – Health system and economic impact downloaded <https://www.canada.ca/en/public-health/services/chronic-diseases/reports-publications/diabetes/diabetes-canada-facts-figures-a-public-health-perspective/chapter-3.html>

¹⁰⁵ Mortality due to diabetes - The Conference Board of Canada downloaded from <https://www.conferenceboard.ca/hcp/Details/Health/mortality-diabetes.aspx>

¹⁰⁶ Shah BR, Cauch-Dudek K, Pigeau L, Diabetes Prevalence and Care in the Métis Population of Ontario, Canada Diabetes Care Dec 2011, 34 (12) 2555-2556; DOI: 10.2337/dc11-0945

¹⁰⁷ PHAC Report Public Health Agency of Canada. Diabetes in Canada: Diabetes in Canada: Facts and figures from a public health perspective: First Nations, Inuit, and Métis. Ottawa, ON: Public Health Agency of Canada; 2015

¹⁰⁸ Gahagan J and Ricci C. HIV/AIDS Prevention for Women in Canada: A Meta-Ethnographic Synthesis. 11 Mar. 2018, www.academia.edu/5061637/HIV_AIDS_Prevention_for_Women_in_Canada_A_Meta-Ethnographic_Synthesis, pg. 22.

¹⁰⁹ Goodwin Irene, Diabetes, Mental Health & Aboriginal People Literature Review: Health Policy Analyst Native Women's Association of Canada 3/31/2011

¹¹⁰ Beckett M, Firestone MA, McKnight CD, Smylie J, Rotondi MA, A cross-sectional analysis of the relationship between diabetes and health access barriers in an urban First Nations population in Canada, BMJ Open. 2018; 8(1): e018272. Published online 2018 Jan 21.

The Cascade of Care for HIV and Diabetes

“It is our hope that the federal government will invest the necessary and critical resources into supporting a strategy that will lead to the implementation of a pan-Canadian approach to the prevention and management of diabetes in Canada ... such an initiative should establish collective leadership among all key stakeholders, including Indigenous communities, provincial and territorial policy-makers, health-care providers, and persons living with diabetes. This could put Canada in a position of global leadership in the treatment of diabetes in time for the 100th anniversary of the discovery of insulin in 2021.” Dr. Jan Hux, President, Diabetes Canada.

“This is a tsunami and if we don’t grapple with this, it will be very draining on our health care system”: Diabetes Canada.

In recent years, HIV has gone from a being a potentially life-threatening illness to a manageable chronic disease due to advances in clinical treatment options; social and behavioural advancements; and models of care that help to improve and extend quality of life among people living with HIV.

Within the HIV realm, the Cascade of Care has been used as a way to monitor PLWH through each stage of care (from infection and diagnosis through to ART initiation and viral suppression), “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.”¹¹¹

The Public Health Agency of Canada has recently released updated statistics regarding Canada’s progress towards the 90-90-90 targets. These statistics showed that, of the estimated 63,110 individuals living with HIV in Canada, 86% of these individuals had been diagnosed, 81% of those diagnosed were on treatment, and 91% of those on treatment had a suppressed viral load.¹¹² Diabetes Canada is building on this successful model, implemented in the HIV/AIDS community, which has been credited for transformational breakthroughs in the treatment and management of HIV/AIDS. This adaptation, by Diabetes Canada, is known as Diabetes 360°. The all-party Diabetes Caucus also supports it.¹¹³

The Diabetes Canada 90-90-90-90 targets are: 90 per cent of Canadians would live in an environment that does not promote the development of diabetes; 90 per cent of Canadians would know whether they’re at risk for, or living with, diabetes; 90 per cent of those with prediabetes, or diabetes, would be engaged in appropriate interventions to avoid developing diabetes, or its complications. As a result of

¹¹¹ Schafer, Katherine et al. “The Continuum of HIV Care in Rural Communities in the United States and Canada: What is Known and Future Research Directions.” *J Acquir Immune Defic Syndr*, vol. 75, no.1, May 2017, p.35-44

¹¹² Public Health Agency of Canada, Summary: Estimates of HIV incidence, prevalence and Canada’s progress on meeting the 90-90-90 HIV targets, 2016 downloaded from <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-90.html>

¹¹³ Diabetes Canada, Diabetes Canada presents innovative new approach to tackling diabetes epidemic downloaded from <https://diabetes.ca/newsroom/search-news/diabetes-360>

this, 90 per cent of them would be achieving improved health outcomes.

This approach to diabetes could help ensure the sustainability of Canada's healthcare system, according to Diabetes Canada. New research on diabetes suggests that nearly 30% of adults with diabetes remain undiagnosed - the same rate as people with HIV - and only about 20% of diabetes patients are treated satisfactorily.¹¹⁴ Diabetes Canada estimates that, within 10 years, the cost of treating diabetes will increase by 40 per cent to \$5 billion annually. In July 2018, on behalf of more than 100 stakeholder groups involved in the development of the Canadian Diabetes Strategy, and the Diabetes 360° initiative, Diabetes Canada released a major report and recommendations for a much-needed national diabetes strategy. They also urged commitment on the behalf of the Government to fund the strategic framework before the burden of diabetes gets worse.

Intrapersonal and Extrapersonal Barriers to Staying Engaged in Care for PLWH who also live with Diabetes

Mental Health

"I have to look into the mirror and say again and again: I love you, I love you, I love you, that gives me self worth. Self-care and information help, but my mental health needs to be attended to." African female participant.

"There was a boundary line of ... wanting to live and not wanting to live. I used to tell the doctor for a pill, I wanted to die ... I did try to commit suicide after my mother died. I got up with a tube in my throat ... I look back to that and think how lucky I am." Elderly male participant.

Depression has been implicated in many studies as having an adverse impact on primary care patients relative to diabetes, diabetes self-care, adherence to medication regimes, functioning and healthcare costs.^{115,116} Screening for depression among PLWH with diabetes is vital in primary care settings.^{117,118,119}

Awareness and Perception of the Effects of Diabetes

"Prevention is better than cure: it is better to learn about it now so that I can handle it in the future, since my granddaughter has HIV. I would like to be prepared in case, in the future, she gets it." African grandmother.

¹¹⁴ Ali MK, Bullard KM, Gregg EW, Del Rio C. A Cascade of Care for Diabetes in the United States: Visualizing the Gaps. *Ann Intern Med.* ;161:681–689. doi: 10.7326/M14-0019

¹¹⁵ Gonzalez JS, Safren SA, Cagliero E, et al. Depression, self-care, and medication adherence in type 2 diabetes: relationships across the full range of symptom severity. *Diabetes Care.* 2007;30(9):2222-7.

¹¹⁶ Costa E, Giardini A, Savin M, et al. Interventional tools to improve medication adherence: review of literature. *Patient Prefer Adherence.* 2015;9:1303-14. Published 2015 Sep 14. doi:10.2147/PPA.S87551

¹¹⁷ WW Eaton, H Armenian, J Gallo, L Pratt, and DE Ford. 1996 87 Impact of Depressive Symptoms on Adherence, Function and Costs by Ciechanowski, Katon and Russo

¹¹⁸ Goodwin I, Diabetes, Mental Health & Aboriginal People Literature Review: Health Policy Analyst Native Women's Association of Canada 3/31/2011

¹¹⁹ Bădescu SV, Tătaru C, Kobylinska L, et al. The association between Diabetes mellitus and Depression. *J Med Life.* 2016;9(2):120-5.

“My cousin passed away due to diabetes, lost kidneys, and was on dialysis. I understood that I have to change my lifestyle living with both HIV and diabetes. For 8 years I have not smoked ... no ... no ... I had no information pamphlets ... I learnt myself, I walk.” South Asian male.

“I had HIV from 2003. I became prediabetic 6 years back and diabetic 3-4 years back. My HIV specialist diagnosed me. So, I was told to exercise. The HIV specialist only treated my HIV, not my diabetes. My family doctor started me on four medications for diabetes. The dietician was not helpful for me, too much information in one go ... it is too much to digest. I knew nothing about diabetes. I also have psychiatric problems. I take around 15-20 medications. I go to four doctors, everyday testing for diabetes is not possible. I got to face it, no running away, have to deal with it.” Elderly male participant.

Perception of the complications of diabetes was low in many of the participants, especially those newly diagnosed, and the common perception was that current symptoms are not severe enough to commit to life and/or diet changes. Again, there were participants who felt the need to learn more about diabetes.

Unstable Housing

“We have two persons managing their HIV and diabetes in two ways. One is housed and managing his HIV and diabetes well, one lacks stable housing and sometimes lives on the streets and is not managing his HIV or diabetes well ... his life is chaotic and we see him once in a while.” Service provider working in Edmonton.

Research shows strong associations between unstable housing and deleterious adherence patterns, increased rates of drug and alcohol abuse, higher rates of HIV infection and HIV/AIDS related morbidity and stigma, poor physical and mental health, inability to access medications, lack of routine, privacy and storage for medications.¹²⁰

The Shortage of Physicians and Specialists

The current lack of general practitioners, and HIV specialists, have had a profound effect on the ability of PLWH living with comorbidities to become linked to and remain engaged in care in Ontario, as illustrated by the following quotes:

“Many clients don’t have primary care physician: sometimes cost is involved for dietician, some nurses do give advice, the population is still small for HIV and diabetes but challenging ... people living in poverty, they don’t have the choice so eating whatever they get” Service provider.

“Many are not being able to go to ASOs and are just going to GPs that maybe not aware of their HIV status so they maybe at a greater risk.” Service provider.

¹²⁰ Brenden J et al. “Factors Linked to Transitions in Adherence to Antiretroviral Therapy among HIV-Infected Illicit Drug Users in a Canadian Setting.” *AIDS care*, vol. 27, no. 9, (2015): pp. 1128–1136. PMC. Web. 30 May 2018.

Stigma

“When my family doctor found out I have HIV, there was a shift in his behaviour towards me. It was like ... you’re going to die anyway so why are you disturbing me? I don’t know why I felt that but it was like he didn’t care so much or even listened to me properly. I had to go to him 7 times to fill up a form because he was just not paying attention.” South Asian participant.

“I was at an outpatient clinic in 2012. The doctor came to tell me that I have HIV and diabetes. He left the room ... I was sitting there ... he never came back. I went out to look for him and another doctor told me that he had left ... I blew my stack.” Service provider.

“You have medication for HIV, but no medication for stigma ... educating ourselves about HIV is the only way out of stigma.” African participant.

“No focus on comorbidities at all ... HIV, HCV, mental health, being incarcerated, food insecurity, housing ... we are not even close ... we are just scratching the surface, there is so much deep rooted stuff happening in the community, funding has changed. Don’t even know if HIV will be in the focus after a few years.” Service provider working in Regina.

“I know ... I know ... there are issues with HIV and diabetes, but I can’t really to do anything about it since there are too many other demanding issues, and I am the only one supporting PLWH ... ” Service provider working in Saskatoon.

Stigma can play a role in the decision of whether someone will be tested for HIV, or whether someone will seek prevention and/or support services. CTAC’s ‘Identifying and Plugging the Leaks: Gaps and Policy Barriers to Engagement with the HIV Cascade of Care’ project has reported that PLWH chose to rely on services that do not require them to disclose their names, or to use services without disclosing their HIV status.⁴⁸

People often do not differentiate between the different diabetes types, or they believe that diabetes results from an unhealthy lifestyle. That is just the tip of the iceberg.

Some common stigmas related to type 1 diabetes include the belief that you can “outgrow” diabetes, it is considered the “bad kind of diabetes” or that you can manage the disease by making lifestyle changes. Other stigmas include frowning upon injections, or blood testing, with your glucose monitor in public, believing that medical issues may interfere with the ability to work.

People with diabetes type 2 may feel that people believe they got diabetes by living an unhealthy lifestyle and that it is entirely their fault (which is far from the truth as genetics, ethnicity, and age play a far greater role), and that they are “undisciplined” if they eat sugar-containing foods. Another common stigma is that this type of diabetes is “no big deal”.¹²¹ Some people may avoid insulin injections and testing their blood sugar in public - which can have very serious consequences. People routinely face challenges in their social lives and workplace, and are at increased risk for depression. Many people

¹²¹ Grunhaus LJ, Dario Health, The Social Stigma Surrounding Diabetes, 2018 downloaded from <https://mydario.com/social-stigma-surrounding-diabetes/>

blame themselves for developing the disease. Such negative emotions can affect the way people view their disease and approach their diabetes management.

Education is the best way to overcome stigma. People are slowly becoming more aware of diabetes, its implications, and the huge mental burden that comes with it. However, there is still a long way to go. Service providers in some provinces are also grappling with funding cuts, which have led to staff and program cuts.

Too Much Information

“That is another barrier to care: feeling very overwhelmed and being bombarded by a long list of things that they need to do or follow up on. An individual might not go back for their next appointment because they realized that the healthcare provider might say, “Hey! At the last appointment we made the list of things for you to do.” They are setting up people to fail and fall through the cracks in the system because the service providers were not always helping people follow up on the case management pieces. There’s a system navigation piece that is easier, as service providers, to navigate so, I guess, another barrier could be as service managers we don’t have enough caseworkers to do the advocacy.” Service provider

“My family doctor started me on 4 medications for diabetes. The dietician was not helpful for me, too much information in one go ... it is too much to digest. I knew nothing about diabetes.” South Asian participant.

Living with additional comorbidities like diabetes and having to go to multiple healthcare providers can lead to additional stress and anxiety for many PLWH. Information from healthcare providers, and accepting and following up on that information accordingly, is essential for the health of PLWH. Many PLWH can accept large amounts of information, but many cannot. They become overwhelmed by the sheer complexity or volume of information. When people are under extreme stress, every task can seem overwhelming. It is important for service providers to understand and gauge how much, and in what way, they can give information that will be acceptable to the person in question.

The Urban/Rural Divide

Whether one lives in an urban or rural community can have a profound effect on one’s experience with treatment and care. People who live in rural areas can face additional barriers to accessing care than those faced by people located in urban areas. These issues include such things as confidentiality around one’s HIV status in smaller communities where everyone may know each other, long distances to travel in order to access care, as well as less access to healthcare providers with HIV and comorbidity expertise.

Although General Practitioners (GPs) can/do care for those with HIV, the disease is still primarily the purview of specialists. In order to reach the majority of these specialists, many people living in rural communities will have to travel to larger urban centres, “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.”¹²²

Lifestyles

“1996 family doctor checkup, I was losing weight, so found out I have HIV and in 1998 started HIV meds. 1999 for 6 months I was at home not working. My brother was working at Kentucky Fried Chicken and was bringing home and I was eating a lot of that. Then my blood pressure, high cholesterol, and diabetes was detected. I had to pay \$65.00 to see the dietician. He gave me a chart about food. I want to live but I don’t know much about the effects of diabetes on my body. I have diabetes and herpes also. I know now ... a person who has HIV and diabetes, must change lifestyle, change food, do exercise and walk and walk ...” South Asian participant.

“People living in poverty, they don’t have the choice, so eating whatever they get.” Service provider.

“Looking at food served in conferences or retreats, you can understand that there isn’t any thoughts or consideration for people living with diabetes.” Service provider living with HIV.

“Oh, the food at Christmas parties ... all sweets ... what do I eat?” African women participant.

“Patients who are overweight and obese, elevated cholesterol, age more than 45, take lots of sugar, everyone of the clients have limited access and people on poverty so high fat diet. Blood work is done, kidney function, random blood sugar, doesn’t show much - more comprehensive testing should be done.” Service provider.

Despite the various difficulties in being able to adjust one’s lifestyle to incorporate diabetes in a healthier way, diabetes is manageable if individuals, communities, healthcare providers, and policy-makers are given the information and tools to motivate and support behavioural change.

Environmental Scan

Methodology

CTAC used a mixed-methods approach, which included online information sharing, focus groups, and key informant interviews to gather data for the environmental scan. CTAC also reached out to Diabetes Canada about this project. A short synopsis of the project outlining our objectives and purpose was sent out to almost 40 AIDS Service Organizations (ASOs) and health centres across Canada. CTAC carried out 23 interviews with service providers across Canada about services related to HIV and diabetes. CTAC searched through 50 ASOs across Canada through the Canadian AIDS Society’s member list for diabetes programs, services, or resources.

¹²²Veinot TC, Harris R, “Talking about, knowing about HIV/AIDS in Canada: a rural-urban comparison.” *J Rural Health* 27(3)(2011):310-8.

Diabetes Canada

Diabetes Canada has programs all across Canada. Across the country, Diabetes Canada's regional office staff and volunteers conduct programs and provide support to help people living with, or affected by, diabetes, navigate their care and self-management.

AIDS Service Organizations (ASOs)

There are significant variances in the rates of diabetes and prediabetes across Canada, with the highest rates in the Atlantic provinces. The Atlantic provinces also have higher rural populations compared to other provinces in Canada – accessing care for people with diabetes is more challenging in rural areas than in urban areas.^{123,124}

There are no programs at the ASO level in the Atlantic region. There is a program in Nova Scotia (NS) for African Canadians called The Matter of Black Health, which is a free program to anyone of African descent aged 19 and over, and is a partnership between the Health Association of African Canadians, Diabetes Canada, and the Medavie Health Foundation. The project leverages a proven health-coaching model into a culturally specific, strength-based approach to living well, supporting the prevention and management of chronic disease to support behaviour and lifestyle changes for African descended people in targeted communities in NS. The unique approach guides participants through stages of change, while connecting participants with community resources and supporting self-determination. The Matter of Black Health initiative is only offered within Nova Scotia. However, this program is not linked with any ASOs and ASOs are unaware of the program.

In Winnipeg, there are a number of diabetes education programs. However, there are no groups aimed at people living with HIV specifically. One service that addresses part of what's needed to manage HIV and diabetes is Nine Circles Community Health Centre in Winnipeg, which has an HIV dietitian that helps clients manage diabetes.

Nine Circles Community Health Centre offered a diabetes education series in October 2014 and March 2015 to clients of **Nine Circles and the Manitoba HIV Program**, which was not exclusive to people living with HIV. Each series consisted of four sessions, two hours in length, once per week for four weeks. Only two participants completed each of the two series offered. Nine Circles attempted to decrease the number of sessions to two to see if this would impact interest in the fall of 2015. Despite this, the group was cancelled due to lack of participants.

Other programs have peer coordinators or counselors who provide advice and guidance about how to interact with the health system to find treatment or care. For example, **Vancouver Island Persons Living With AIDS Society's peer navigators** help clients find key services (and service providers) in Canada's health systems.¹²⁵

“Diabetes is a significant challenge. We try to link up with other service providers.” AIDS Victoria Island.

¹²³ Canadian Diabetes Association. (2011). *Diabetes: Canada at the Tipping Point – Charting a New Path*. Pp. 10-11.

¹²⁴ Statistics Canada. (2012). Population, urban and rural, by province and territory, 2011 Census. Available at: <http://www.statcan.gc.ca/tables-tableaux/sum-som/I01/cst01/demo62a-eng.htm>

¹²⁵ Vancouver Island PWA Society - Newly diagnosed: What you need to know <http://vpwas.com/hiv aids-info/newly-diagnosed/>

“There are people who have been diagnosed with diabetes, but there are no programs. It would really benefit the people if there was a program about living with HIV and diabetes and how to take care of yourself.” African male participant living in Vancouver.

Women’s Health in Women’s Hands (WHIWH) in Toronto has a diabetes education program run by diabetes nurses/dietitians but it is not exclusive for PLWH.¹²⁶ WHIWH serves women from African, Caribbean and Black (ACB), South Asian, and Latino communities. Since they have wrap-around services, prediabetic and diabetic patients are linked up with physicians and nurses once they are diagnosed. WHIWH has a food bank and a ‘how to make healthy food’ program, as well as classes around healthy eating and reading food labels. WHIWH carries out outreach at satellite clinics, temples, and mosques, as well as at large events like Black Expo. This program has been identified as a best practice model.

Harm reduction services are available at **Toronto People with AIDS Foundation (PWA)**. They have diabetic needles for insulin users and make sure their clients have coverage for medications and needles. They refer clients to Sherbourne Health Centre for nutritional counselling. PWA has a brochure titled “Diabetes and HIV: What you need to know.”

Community health centers (CHCs) in Canada, are non-profit, community-governed community health organizations that provide primary health care, health promotion, and community development services, using inter-disciplinary teams of health providers. These teams include physicians, nurse practitioners, dietitians, health promoters, counsellors, and others. In addition, CHCs provide a variety of health promotion, and illness prevention services that focus on addressing and raising awareness of the broader determinants of health such as employment, education, environment, isolation, and poverty. A team of Certified Diabetes Educators (registered nurses and registered dietitians) provide one-on-one appointments, education sessions, and support groups to help clients navigate healthy lifestyle behaviours, prevent or learn to self-manage diabetes, reduce their risk for developing complications, and maintain a high quality of life. There are over 300 CHCs across Canada, and there are over 80 CHCs in Ontario alone. ASOs sometimes refer their clients to CHC services.

Best Practices

Lakeridge Health Centre in Whitby is a ‘one stop shop’ for clients seeking HIV, AIDS and hepatitis C care. The clinic is staffed by an interdisciplinary team that includes infectious diseases specialists, registered nurses, a social worker, a dietitian, a pharmacist, and administrative support. The Positive Care Clinic here has programs for aging people who have kidney failure. There are also diabetes educational programs (e.g. diabetes and heart failure), but these programs are not specific to HIV and diabetes.

The HIV/AIDS Resources and Community Health (ARCH) is an ASO based in Guelph with a specialized clinic. The ARCH Clinic is a community-based outpatient HIV clinic offering effective and compassionate care and treatment for people living with HIV/AIDS who reside in Guelph-Wellington-Dufferin, Kitchener-Cambridge-Waterloo, and Grey-Bruce Counties. The health care team of doctors and nurses provide a

¹²⁶ Women’s Health in Women’s Hands - Community Services and Programs <http://www.whiwh.com/community-services-programs>

continuum of care and give needs-based counselling to PLWH with diabetes. However, ASOs associated with wrap-around clinic services are very rare here. As such, they have no specific program for PLWH and diabetes.

Casey House in Toronto carries out case-by-case counselling with patients who have HIV and diabetes, and links them up with a dietician from St. Michael's Hospital (practicing once a week at Casey House). Their in-house kitchen menu also caters to PLWH and diabetes.¹²⁷ This is the kind of comprehensive health service needed to most effectively manage these comorbidities. This level of specific care may not be accessible to many people who are living with these comorbidities, either because of physical distance, wait-lists, lack of access to navigators to link them to these services, economics, or other barriers.

It was uncovered that some ASOs have medical professionals on staff. However:

- The number of ASOs with medical professionals on staff are few, and usually only in major cities (Toronto, Vancouver).
- A medical professional on staff at an ASO often works there only once a week, and may not have a high level of knowledge about comorbidities involving HCV and/or diabetes.

Unfortunately, across all the provinces and territories of Canada, programs linking HIV directly with diabetes are virtually non-existent. The literature review, focus group discussions, and service provider interviews showed a serious gap in services for PLWH and diabetes: that there are no programs at any of the AIDS Service Organizations. There are dieticians housed in hospitals and community centres. Very few organizations have wrap around services where nurses and dieticians are available to give information. Most of these services are not HIV-specific and cater to the general population.

Policy and Programmatic Recommendations

Over the course of this project (literature review, environmental scan of services, focus groups, and individual interviews), CTAC has uncovered a number of barriers that hamper the ability of PLWH, who are also living with diabetes, to optimally access treatment and care. The following recommendations are an essential first step in being able to address these barriers.

Recommendation 1: Eliminate the deductible for Trillium, and the co-payments for the Ontario Disability Benefit (ODB).

“My private insurance only pays for medications for 30 days which can start anytime in the month since I take 17 types of medications. If I travel, I sometimes can't get the medications on time. I go without it then... Then for some I have to go through Trillium and there is co-payment. This is very difficult for me.”
Male participant living in rural Ontario.

Low-income Ontarians struggle with drug benefit plan access, maintaining drug coverage between Ontario Disability Support Program (ODSP) / Ontario Works (OW) and working (or returning to work),

¹²⁷ Casey House – Inpatient program downloaded from <https://www.caseyhouse.com/how-we-help/inpatient-program/>

meeting basic needs, and accessing Trillium. Government coverage of diabetes medications, devices, and supplies varies across jurisdictions, leaving some costs for these supports to be borne directly by people living with diabetes in order to effectively manage their disease. As a result of this, 57% of Canadians with diabetes say they do not comply with their prescribed therapy because they cannot afford their medications, devices, and supplies, thus potentially compromising their diabetes management. Less access to public or private insurance means greater out-of-pocket expenses.

The Ontario Drug Benefit Program (ODB) program and the Trillium Drug Program (TDP) (a program born out of AIDS Activism in the 1990s, but which ended up becoming available to all Ontarians) are the two main programs that assist Ontario residents with covering the costs of expensive prescription drugs and may be able to help cover the high cost of hepatitis C treatment medications.

The Ontario Drug Benefit (ODB) program covers around 4,400 drug products. Drugs that are not listed on the Ontario Drug Benefit Formulary can be considered for coverage through the Ministry's Exceptional Access Program on a case-by-case basis. In addition, individuals who receive social assistance, either through Ontario Works (OW) or the Ontario Disability Support Program (ODSP), may be eligible for prescription drug coverage through the ODB. Adding to this complexity is the fact that, depending on an individual's income level, different deductibles and co-payments will apply under the ODB. It is also necessary for many PLWH to have someone to help them navigate this complex patchwork of coverage.

The Trillium Drug Program is for people who spend approximately 3% to 4% or more of their after-tax household income on prescription-drug costs. An individual can qualify for Trillium under certain conditions: a) the individual is not already on ODB; b) is not a resident of a long-term care home; and c) is not someone who receives home care services. With Trillium, an individual is also not able to have private health insurance that covers those drugs in full, but some private insurance is allowed. Also, it is important to note that many focus group participants stated that people who are able to work, or do work but have low-paying jobs, choose to leave the workforce in order to be eligible for the above programs, so that they can afford their HIV and diabetes treatment.

Within Canada, there are 18 different publically funded plans with many more private plans, making the system difficult to understand and navigate. There is also private insurance (some health insurance policies offered through private insurance companies include coverage for prescription drugs. These programs often have their own deductible, or co-pay fee, and may have yearly maximums for prescription drugs.) Also, pharmaceutical companies sometimes have funding programs available to help individuals to access the HIV medications that they offer. This results in a complex system that PLWH have a hard time navigating, a fact that was confirmed during the focus groups, and service provider interviews, conducted as part of this project.

Current access to HIV treatment in Canada is shaped more by where a person lives than what they need. People living with HIV comorbidities are not well served in Canada's patchwork healthcare system, with separate jurisdictional responsibilities for health in each province and territory, and at the federal level. A complex web of public and private drug coverage, and in some cases lack of coverage, creates inequity, restricting access for many. What medications people can get, at what cost, varies widely, depending on the forms of public and private insurance available to them.

There is an added complexity in terms of being able to access drug plans for people living with multiple comorbidities. This can be linked to the process for approval for access to public drug plans, as well as the eligibility criteria for coverage under these plans (e.g., some doses of certain drugs may be covered,

but not others).

In order for PLWH to be able to get the treatment they need, allowing them to remain engaged in care, the deductible and co-payments that are a part of the Trillium and ODB programs need to be eliminated. Also, funding for patient navigators, to help PLWH to navigate Canada's complex system of coverage, is essential.

Recommendation 2: Provide compassionate access to care and treatment for people without status in Canada. Equal and timely access to medications as clinically appropriate, is important to all individuals living in Canada, especially for those with chronic diseases such as HIV, diabetes and related complications.

"My husband has diabetes from 1984 and from 1990 he had high blood pressure. From 2009 kidney problems started. We came to Canada in 2015 and we waited for 6 months for his card ... for 6 months he did not get any medications ... you see he was on insulin we could not afford it so I was just limiting his food. He had angiogram 7 months ago and he is on dialysis." African woman participant.

The immigration and refugee system is complex, confusing and intimidating for newcomers. People usually become a permanent resident of Canada – and eventually a Canadian citizen – through one of two routes: as an immigrant or as a refugee.

There are people who do not have legal status in Canada because they entered Canada without legal status or have been found to no longer have legal status in Canada. Sometimes people in this situation are referred to as "non-status".

Refugee claimants in Canada are covered under the Interim Federal Health Program. This program covers the cost of a limited amount of medical treatment, including HIV medication. It is not available to people applying as an immigrant, visitor, student, or to people on work visas. If the refugee claim is successful, then the claimant becomes eligible to apply for healthcare coverage under the provincial, or territorial, health insurance plan. The provincial or territorial health insurance plan should cover the costs of most health services, including medical tests, but not necessarily the cost of all drugs. In order to be covered under a provincial or territorial insurance plan, a person must apply to be enrolled. Generally speaking, provincial or territorial plans have a three-month waiting period before healthcare insurance coverage begins. The three-month period begins on the day a person establishes their residency in that province or territory.

If anyone is applying as an immigrant, student or visitor, they will not be eligible for either the Interim Federal Health program or provincial healthcare coverage. They will need to pay for health services and drugs either through private insurance or out of their own pocket.

It is important to note that PLWH, who are immigrants, or students, can hit roadblocks due to language barriers when they attempt to engage with the healthcare system. A lack of employment, or stable housing, can also lead to poor health outcomes beyond just that of HIV care. It can affect one's mental health and the ability to have improved quality of life beyond medications.

It is important that compassionate access to care and treatment be provided for people without status in Canada. Access to care and treatment for people without status in Canada is necessary to aid Canada in

reaching the 90-90-90 targets both for HIV and diabetes.

Recommendation 3: Develop diabetes-specific information for PLWH (brochures/videos) that is easy to understand, and leads to participatory diabetes education programs in different, relevant languages.

“So does diabetes affect the body? Does it affect every organ? I didn’t know.” South Asian male participant.

Through feedback from focus groups and interviews with service providers, CTAC has found that PLWH are not getting standardized care and information regarding the management of their HIV and diabetes, or, if they have been diagnosed as prediabetic, what they need to follow. The development of diabetes-specific information for PLWH (brochures/videos) that is easy to understand, and leads to participatory diabetes education programs in different, relevant languages, will be key to addressing this prominent issue. Promoting access to such resources/workshops for PLWH in ASOs, community centres, clinics and at Diabetes Canada events will also be of utmost importance. PLWH, who are prediabetic, can benefit from these resources and make large-scale behaviour changes that will have an impact on whether they go on to have diabetes or not.

Recommendation 4: Increase awareness of the symptoms and long-term complications of diabetes among PLWH, and health care providers, through a variety of methods including basic diabetes education, coping strategies, diabetes self-management education, reading food labels, healthy cooking classes, exercising etc.

“Definitely awareness is needed. Dangers of diabetes and impact of meds on the same body. Newcomers finances are very limited and very little money for healthy food options.” Service providers from Edmonton.

Many foods contain carbohydrates, which break down into glucose when they are eaten. This causes blood glucose (sugar) levels to rise. It is therefore important to learn which foods cause blood glucose levels to rise more than others, and to balance food choices. Some foods, such as non-starchy vegetables, meats, and alternatives such as fish, legumes, or cheese, have a minimal effect on blood glucose levels.

Learning about portion size, what vegetables to eat, glycemic index (GI) cooking methods, and exercise will help PLWH to manage their diabetes. Diabetes self-management is one of the cornerstones of diabetes management. Self-management education contributes to better quality of life and health outcomes for people living with both HIV and diabetes.

For those unaware of any previous risk factors, a diagnosis of DM may come completely out of the blue, adding shock and disbelief to a rollercoaster of other feelings. PLWH may need support to cope with multiple emotional stages when they handle a new diagnosis of DM. Amongst PLWH, depression is relatively common, and the double whammy of having diabetes may further add to it. The more equipped with education a PLWH is, the easier the journey with diabetes will be.

Recommendation 5: Address the need for the incorporation of diabetic-friendly corners in food banks.

“Our food bank is the most popular and most used programme ... but many can’t read the labels or know how to cook the items properly ... or even that they should not take them if they have diabetes. They don’t know how much sugar or carbs are in certain foods...no awareness.” Service provider in Toronto.

Low-income populations are at an increased risk of diabetes development, and have worse outcomes when they do develop it. PLWH who are in socially disadvantaged groups also experience more difficulty in affording their food and medications. Many are accessing food from the available food banks in their locality, or from ASOs. Service providers have discussed during this project how important it is for PLWH to be able to read labels, to cook certain items properly, and to understand how much sugar and carbohydrates are in certain foods. Awareness of these issues is of vital importance for PLWH living with diabetes, and for those who are predisposed to diabetes. A diabetic-friendly food corner will assist PLWH in being able to choose appropriate foods.

Recommendation 6: Stimulate networking and improved collaborations (ASOs, HIV specialists, endocrinologists, nurses, dieticians, Diabetes Canada etc.) to optimally support PLWH living with comorbidities in ways that are inclusive of First Nations/Inuit/Métis communities. Management of HIV must gradually expand to include the chronic, and metabolic, complications of the disease, and the adverse effects associated with its treatments.

“My HIV Specialist takes care of only my HIV, nothing else.” Male participant.

*“People who are living with HIV really need a GP. The HIV specialist looks at the HIV, and the GP looks at everything else. Issues like diabetes pain management. It was easier for the GP to deal with those things, versus the HIV specialist.”*¹²¹

“Systemic costs make people fall through the crack. ‘Competing priorities’ diabetes is a silent killer: important to have conversations acknowledging it. ‘Own your health’, it becomes challenging, there has to be shift from HIV to comorbidities: clinicians must change their approach to holistic approach.” Service provider.

There is a great and immediate need for comorbidity informed treatment and care that addresses the complexity of living with comorbidities. There is increasing recognition that there should be closer advocacy, policy and programmatic links between HIV and noninfectious comorbidities as the two epidemics are intertwined. Multimorbidity can have negative impacts on the health of PLWH as it can lower quality of life, increase disability, and increase viremia. The intertwining of programs between ASOs and Diabetes Canada is critical in helping PLWH receive pertinent information for taking care of their health, leading to a better quality of life. Healthcare providers caring for PLWH must be knowledgeable about not only about HIV treatment, but also the management of other comorbidities in the context of HIV.

The literature review, focus group discussions and service provider interviews showed a serious gap in services for PLWH and diabetes. ASOs currently have no programming aimed at diabetes. There are dieticians housed in hospitals and community centres. However, very few organizations have wrap-around services where nurses and dieticians are available to give information. Most of these services are not HIV-specific and cater to the general population.

Future Steps: Window of Opportunity!

The complexity of living with comorbidities of diabetes and HIV, and of diabetes and HIV-HCV co-infection, can lead to significant barriers to accessing treatment. CTAC suggests that a response is urgently needed. Through lifestyle changes and monitoring, HIV positive people can avoid the complications of uncontrolled diabetes and, instead, concentrate on living well with HIV.

Viral suppression for 90% of those receiving antiretroviral therapy is currently the end-point of the UNAIDS 90-90-90 goals but, ultimately, viral suppression cannot be the focus of what the healthcare system delivers PLWH. It fails to take into account the needs of PLWH who have achieved viral suppression, but still must contend with other intense challenges such as serious non-communicable diseases, depression, anxiety, financial stress, and HIV-related discrimination and stigma. We must challenge ourselves to take up the 'fourth 90' and ensure that 90% of people with viral load suppression have good health-related quality of life, as a central guiding objective in the next stage of the march to end HIV.

The population of people living with HIV is aging, and experiencing increasing numbers of comorbidities that not only complicate their HIV care but also complicate their lives and threaten their autonomy. The time is now. The window of opportunity is open to initiate and start conversations leading to collaboration between the HIV and diabetes sectors. Programs leading to awareness and self-care are becoming increasingly critical to improve the quality of life for PLWH living with diabetes. Many past advances in patient rights and services have been the result of community-based action and experience created by the demands of the HIV epidemic. Today, community-based organizations, particularly in smaller centres, are struggling to support larger populations over widespread geographic areas, with broader responsibility. Focused, strategic attention on creating an integrated service environment for PLWH that includes, and supports, holistic services is urgently needed.

From this project, we have gained valuable insight into the multiple challenges faced by PLWH who are also living with diabetes and other comorbidities. This has also opened doors for dialogue between multiple health sectors, revealing opportunities for community-based agencies to organize and promote programmatic and policy change that will broaden access to treatment that could be tailored to suit the various needs of PLWH living with diabetes and other comorbidities. By establishing partnerships and working together, ASOs and diabetes-specialized organizations (e.g. Diabetes Canada, Juvenile Diabetes Foundation, and the Diabetes Council of Canada) can offer a strong voice for diabetes concerns, and establish diabetes as a high priority issue especially for PLWH, at both the provincial and federal levels.

CTAC feels that there is an opportunity to successfully implement interventions for PLWH living with diabetes through ASOs, because they are often the first point of contact for people diagnosed with HIV. The promotion of joint programming between ASOs, Diabetic Canada, and Public Health will lead to a comprehensive support network.

The next steps for this project will include:

- The dissemination of the valuable insights and knowledge gathered throughout the course of this project in order to help service providers and service utilizers more effectively advocate for their needs

- Identifying and negotiating partnerships between ASOs and Diabetes Canada; and identify further areas of policy and programmatic work with communities most affected by HIV, HIV/HCV co-infection, and diabetes.

CTAC would again like to acknowledge the importance of partnerships and collaborations within the community, without which this project would not have been able to succeed.

HIV and/or Hepatitis C and Diabetes: Comorbidities affecting HIV Positive People - A Tip of an Iceberg



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