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## Views from the front lines: Getting to undetectable

We spoke to three service providers to find their views and insights on the challenges facing their clients in getting an undetectable viral load:

- [Norma Rabbitskin](#), Senior Health Nurse, Sturgeon Lake First Nation Health Centre, Saskatchewan
- [Sem Teklemariam](#), Women's Support Coordinator, Black Coalition for AIDS Prevention (Black CAP), Toronto, Ontario
- [Deanna Macdonald, RN \(c\), BSN](#), Interior Health Clinical Care Coordinator – HIV and Health Outreach Team, Kelowna, British Columbia

### Norma Rabbitskin

#### **What do the HIV-positive people that you work with know about undetectable viral load? Is having an undetectable viral load a priority in their lives?**

I am employed as Senior Health Nurse overseeing community health, home and community care and primary care programs in Sturgeon Lake First Nation. Our Health Centre mission is to provide prompt care and provide access to improve health outcomes. Our team works with our community members who have recently been diagnosed or have been living with HIV chronically to get prompt access to care and treatment of their infection. We have all the streams being delivered at the community to provide holistic care. We have been working with building on relationships with individuals, family and community. Our nurses work one on one with clients, providing support and education so they can make an informed decision on the treatment process. Initially they are not aware of what undetectable viral load is. Education and being there to assist them is our main priority. As a team we work with individuals and families providing care and case management. We develop close relationships with them. We don't want to overwhelm them initially with information about treatment or undetectably so, initially, we just provide support. We make subsequent appointments to talk about treatment.

Eventually, after a number of sessions, clients do come to understand what undetectable viral load is. Once they know about it, yes, it is a priority for them. It reinforces their role in managing their own health! They understand the health *and* prevention benefits of HIV treatment and adherence, and they attend appointments, they take their medication.

#### **For the community that you work with, what are the greatest barriers to having and maintaining an undetectable viral load?**

Barriers to maintaining undetectable viral loads for our community members who are already vulnerable are due to a range of health, social and economic inequities. The social determinants of health that impact risks of acquiring HIV, especially injection drug use, include factors such as: poverty, inadequate housing, and lack of education, job training or employment. As well, the impacts of Colonization, unresolved grief from residential schools, and intergenerational trauma, are all reasons why some clients are not able to maintain an undetectable viral load. We

come across individuals who don't have a home and are couch surfing. It is certainly challenging for our team to maintain continuum of care for client who are under our case load. Many of our clients are unemployed; living on a fixed income creates other issues – many can't afford quality, nutritious food in an ongoing way. This is a barrier to health – everything is interconnected.

Our clients face stigma and discrimination continually. They don't feel safe to tell others about their status. I am grateful we have a team that is caring and committed to providing a safe environment and is responsive to the clients' needs.

Jurisdictional issues are another barrier that impacts our community and other First Nations Peoples in Canada. This is a major barrier to having and maintaining an undetectable viral load. We are lucky in that our community fought to have their health funding be transferred to the community level. Transferred health services is self-determination at its best, and lets the community design a healthcare system that integrates culture and based on the needs of the community and the trends that we are seeing. This is often not the case in other communities, leading to many unique service delivery models for First Nations Peoples (including those living with HIV), which have different positive and negative impacts on people's health. Before we designed our own health services, nurses would have to send patients out of community to get care for sexually transmitted infections and other blood-borne infections (STBBIs). Now, they can stay in their home community and access holistic care, because we designed it that way.

### **What role do you play in supporting your clients to access HIV treatment when ready and stay on HIV treatment over the long term?**

My role is making sure the programs are responsive to the needs of our people. Our team provides health education to individuals, families and community. We see our biggest role is to be the resource for our clients when they seek help. It is up to them if they choose to access care and support within the community or we can refer them to Access Place in Prince Albert (the nearest big city).

It is important for our nurses to take these conversations slowly, over a series of visits, and simplify the language and jargon associated with HIV. For example, we learned from our infectious disease doctor that the best way to describe viral suppression is to use simple language, such as “putting the virus to sleep with medication.” This makes it easier for the client to digest. We also talk to clients about people who have been managing and living with HIV for many years and are the “role models.”

We also refer clients to a traditional health program upon request, where they can have access to traditional medicines. The informed, motivated individual understands the disease process, and recognizes his/her role in self-care. It is essential to establish and maintain a proactive healthcare team, including a primary care physician, traditional healer, and interdisciplinary staff members, working together in a collaborative model and utilizing a holistic approach that addresses all aspects of an individual – the physical, the mental, the emotional and the spiritual – that must be addressed in order to promote health and healing.

I also engage in a lot of advocacy work as a manager, to address the barriers to treatment related to the social determinants of health. A lot of my work is in advocacy, particularly related to the racism within our healthcare system in general. Many clients face stigma on and off reserve and report racial discrimination in the health system. I work to advocate for culturally safe care, including building competency around trauma-informed care within our own Sturgeon Lake Health Centre.

### **Sem Teklemariam**

#### **What do the HIV-positive people that you work with know about undetectable viral load? Is having an undetectable viral load a priority in their lives?**

The clients that I work with are primarily newcomers and immigrants from Africa and the Caribbean. How much they know about undetectable viral load typically depends on how long they have lived in Canada.

The women who know about viral load are those who have lived in Canada for a long time, been clients of or volunteered with community-based organizations, and have been engaged in HIV care. For these women, having an undetectable viral load is a very important thing in their life. They tell me when they are undetectable and we talk about viral load. But, here is the thing: most of these women don't know the prevention implications of having an

undetectable viral load. They haven't heard of "Undetectable = Untransmittable" and they don't know the prevention science. They see 'undetectability' in terms of their own health. They see it as controlling their virus, preventing opportunistic infections, and living a healthy and long life.

Women who are newcomers to Canada, speak a language other than English, or have strong religious and cultural backgrounds tend to know far less about HIV. These women tend not to know or understand what the virus is and how it works in their body.

I speak to all my clients about HIV treatment and care, viral load, and undetectability. Conversations about treatment and the virus can be challenging for my clients who are new to Canada and have particularly strong religious backgrounds. There are still many myths and misconceptions about HIV. Some of my clients really believe that their faith will cure HIV; it is hard to challenge this belief and connect people to medical care and treatment. It takes time and trust. I explain to these women and their families what the virus and viral load are, and the importance of HIV treatment for their own health. Sometimes I am successful. One strategy that can work is engaging with religious leaders to speak to their followers about HIV and HIV treatment within the worldview of the religion in question. Black CAP has partnered with the Ontario HIV Treatment Network (OHTN) and the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) on the Black Praise Project that engages faith-based leaders to raise the issue of HIV and stigma with members in their religious communities.

**For the community that you work with, what are the greatest barriers to having and maintaining an undetectable viral load?**

For the women I work with, things like language, level of education, HIV stigma, and immigration status and process are the primary barriers to HIV treatment and undetectability.

For many clients, whether they are new to Canada or not, language is a barrier because often, when a client does not speak English, they lack access to even basic information about HIV and HIV treatment. They can't read information; they can't communicate with a healthcare provider. Often, because of HIV stigma, these women are not even willing to work with an interpreter - interpreters are often from their own community or home country - because of a fear of HIV stigma. They often choose not to get the information they need over the risk of being exposed as HIV positive in their own communities. Educational level can also be a barrier. For some of the clients I work with, scientific and medical information and jargon are new to them; they have not engaged with this type of information before. Simply not understanding what viruses are, for example, is a huge barrier.

New immigrants to Canada face a number of other barriers to HIV treatment access and undetectability. First, many newcomers learn of their HIV status at immigration, when they are alerted by a public health nurse that they are living with HIV. Many of my clients reveal the nature of these discussions: they tend to focus on the protection of the public. These conversations have actually had the effect of *detering* clients from seeking care. Support and referral through the immigration process must be improved. Second, it isn't easy to get access to medical care. For newcomers who do not come to Black CAP or another AIDS Service Organization, it can be difficult to understand how to navigate the healthcare system and engage with a doctor. Third, even once linked to care, it can be a challenge to access treatment. This is important: often, with my clients, I learn that doctors are not offering women treatment when they first visit. While guidelines currently advise linkage to treatment right away, many clients are not offered HIV treatment until their CD4 counts are quite low.

Even when women are successfully linked to support and care, other barriers may exist. For newcomers, the immigration process is the first and foremost thing in their minds. Accessing housing, preparing for hearings: these are the issues that people think about and devote energy towards, not HIV.

**What role do you play in supporting your clients to access HIV treatment when ready and stay on HIV treatment over the long term?**

Referral to medical care is the first and most important thing that I will do when I initially meet with a client. Many of my clients come to me newly diagnosed and need a lot of support to access care. Others, who have been aware of their HIV status for some time, are often not yet on treatment when we first meet. For both types of clients, linkage to medical care is an urgent need. After a client is successfully linked to care, I focus on supportive counselling and the woman's more immediate needs around settlement, housing, immigration and income supports.

## **Deanna Macdonald**

### **What do the people with HIV that you work with know about undetectable viral load? Is having an undetectable viral load a priority in their lives?**

Clients who are referred to our program live in urban and rural communities and may have additional challenges such as mental health and substance use, unstable housing, financial problems and food insecurity.

Many of the people we work with know about and place value on having an undetectable viral load. For our clients, having an undetectable viral load is very much about personal health and wellness. It represents the efforts that they have put towards their health, because it requires adherence; for some, it also represents feeling safe within their relationships as it removes the risk of transmitting the virus.

Many of our clients have lives that are chaotic; the concept of undetectable viral load really seems to provide a sense of control over the virus. Viral load and the goal of undetectability provide an opportunity for clients to quantify improvements in or the maintenance of their health. Clients talk about the actual *number*. Taking medication and reaching or maintaining an undetectable viral load is an opportunity to maintain control in their lives. It gives people a goal related to their own health that they can measure; its great positive feedback on their efforts to engage with us and take their medication when they know they are undetectable.

For people who are newly diagnosed, the concept of being undetectable seems to be a great indicator of how important HIV treatment is. Clients can *see* their health improve, even if they don't *feel* different, when they start to take treatment.

Having an undetectable viral load is definitely a priority in our clients' lives...until it isn't. Priorities often come down to the social determinants of health and the client's stability. When a person is homeless and struggling with substance use or food insecurity, HIV medication and viral load are not a top priority. But, for the most part, when life situations are more stable, it is a priority. For people in serodiscordant relationships, however, maintaining an undetectable viral load seems to remain a priority, regardless of other circumstances; it just removes the incredible stress that can be associated with concerns around transmission.

### **Throughout the treatment cascade or continuum of care, what are the greatest barriers to having and maintaining an undetectable viral load for the community you work with?**

Mental health, substance use, homelessness, HIV stigma, and the realities of living in a rural region are examples of barriers to treatment for the clients that we work with.

Many of our clients face issues of homelessness and unstable housing. Many stay in places that are not very safe. There have been a number of situations where a person is successfully on treatment, carries their treatment in their backpack, and then their backpack is lost or stolen at the shelter where they're staying. Because HIV medications are centrally dispensed in British Columbia (from Vancouver) it can actually be quite difficult and take some time for a person in this situation to get back on medication.

In our large region, many clients live in small communities and rural areas. It can be difficult to feel safe in terms of confidentiality and their HIV status. Despite the new knowledge we have about HIV, stigma still persists in communities. In some communities there is only one pharmacy and the client may know the pharmacist and not want to share their status. Significant concerns about others in the community learning their status and feeling unsafe for this reason creates important barriers to treatment.

Transportation can also pose a barrier to treatment. It can be a challenge for individuals to get to larger centres to receive HIV care or access medications. In some communities, there is limited internet and cell phone reception, which can make it challenging to connect with healthcare providers and our nursing team.

Finally, some of our clients face barriers to care and treatment post-incarceration. When people living with HIV are released, they are provided two weeks' worth of ARVs. Often, these individuals do not know where to go for HIV care post-release and they are then lost to care.

### **What role do you play in supporting your clients to access HIV treatment when ready and to stay on HIV treatment over the long term?**

The biggest thing that we do to support clients in accessing HIV treatment is to assess and support issues related to the social determinants of health. We do a lot of work that is focused on the broad supports to staying on treatment: housing, food security, income security, mental health and substance use. In this way, advocacy is an important part of our nursing practice. We engage in client-centred case management to help set people up for success when they do start treatment.

In terms of directly supporting access to treatment, our nurses link people living with HIV to primary care and specialist care as needed. Given that in British Columbia, all medications are centrally provided through Vancouver, we need to work with clients to develop a plan for how they will access their drugs: in Vancouver, people will visit a pharmacy, but in our region, people may have medication delivered to a doctor or nurse's office, a health centre, or a pharmacy, depending on where they live. In small communities, we will occasionally partner with local community agencies to engage with clients and hold their medication. For example, we partner with drop-in centres where people who are homeless may drop in daily for meals. At the same time, the drop-in centre staff will offer them their medication. This all happens with the consent of the client, of course.

We also offer practical supports such as transportation to appointments and accompaniment during appointments. Sometimes, we are the only person who knows their HIV status, the only person that they have to speak openly with about HIV.

### **Related article**

For more detailed information on undetectable viral load, see [Getting to undetectable: Population differences in Canada](#)

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