
2021

A patient's narrative of engaging HIV care: Lessons learned to harness resources and improve access to care

David Lessard

Centre for Health Outcome Research, Research Institute of the McGill University Health Centre, Montreal, Canada, david.lessard2@mail.mcgill.ca

Serge Vicente

Département de Mathématique et Statistique, Université de Montréal, Montreal, Canada, sergeviciante1975@gmail.com

Patrick Keeler

Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA), Montreal, Canada, info@cercleorange.ca

Bertrand Lebouché

Chronic and Viral Illness Service, McGill University Health Centre, Montreal, Canada; Department of Family Medicine, McGill University, Montreal, Canada; Canadian Institutes of Health Research Strategy for Patient-Oriented Research Mentorship Chair in Innovative Clinical Trials, Montreal, Canada, bertrand.lebouche@mcgill.ca

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Community Health Commons](#), [Infectious Disease Commons](#), and the [Medical Humanities Commons](#)

Recommended Citation

Lessard, David; Vicente, Serge; Keeler, Patrick; and Lebouché, Bertrand (2021) "A patient's narrative of engaging HIV care: Lessons learned to harness resources and improve access to care," *Patient Experience Journal*: Vol. 8 : Iss. 2 , Article 5.
DOI: [10.35680/2372-0247.1566](https://doi.org/10.35680/2372-0247.1566)

This Personal Narrative is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

A patient's narrative of engaging HIV care: Lessons learned to harness resources and improve access to care

Cover Page Footnote

Acknowledgment: Authors are supported by the Canadian Institutes for Health Research Strategy for Patient-Oriented Research (CIHR SPOR) Mentorship Chair in Innovative Clinical Trials, owned by BL. Authors would like to thank the CIHR SPOR Quebec Methodology Support Unit. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

A patient's narrative of engaging HIV care: Lessons learned to harness resources and improve access to care

David Lessard, PhD, *Research Institute of the McGill University Health Centre, david.lessard2@mail.mcgill.ca*

Serge Vicente, PhDc, *Département de Mathématiques et Statistique, Université de Montréal, sergivicente1975@gmail.com*

Patrick Keeler, *Coalition des organismes communautaires québécois de lutte contre le sida, info@cercleorange.ca*

Bertrand Lebouché, MD, PhD, *Research Institute of the McGill University Health Centre, bertrand.lebouche@mcgill.ca*

Abstract

In Canada and the USA, about 30% of people with HIV are uninsured or not covered by government-subsidized health insurance. This paper presents a patient's narrative of his experience being diagnosed with HIV and accessing care in the midst of his process of immigrating to and studying in Canada. The narrative explores how Vincent Croft (pseudonym) has coped with the chronicity of the infection and its associated social stigma and the temporary solutions he found to access treatment. Engaging with healthcare providers, researchers, and other people living with HIV has allowed Croft to share his experience, including the barriers he encountered and the solutions he envisioned or attempted, resulting in self-empowerment and reinterpretations of Croft's own trajectory. Patrick Keeler, a community-based intervener, reflects on Croft's narrative as symptomatic of systemic issues in access to care of people living with HIV in Canada. He also illustrates how the experiential knowledge of people with similar lived experiences can trigger simple, innovative, and cost-efficient initiatives with Le Cercle Orange, which connects and mobilizes existing resources for people with HIV with no or limited access to care and treatment.

Keywords

HIV, patient experience, patient engagement, access to therapy, community integration

Introduction

For people recently diagnosed with HIV, timely access to care has been long considered a public health imperative,¹ given benefits like improved quality of life and clinical outcomes,^{2,3} and suppression of risks of forward transmission.⁴ In Canada and the USA, up to 30% of people with HIV are uninsured or not covered by government-subsidized health insurance, accounting for tens of thousands of people.^{5,6} For these people to get access to care and treatment, sustainable solutions and resources do exist but are frequently "hidden" from people who are excluded from traditional health coverage. The body of this paper presents a narrative by Vincent Croft (pseudonym), an international student and patient whose experience illustrates the implications of reduced access to care and treatment, the efforts made to resolve this situation, and the lessons learned in the process. In the last section, a comment by PK, a community intervener, shows how an innovative and cost-efficient program building on existing resources could improve patients' interactions and integration in the healthcare system.

Vincent Croft: A patient's narrative

After growing up, living, and studying in Europe, I realized a dream: I moved to Canada in 2013 to begin a graduate study program. I was then HIV-negative and knew little about this virus. I had heard little about HIV since growing up in the 1980's, and thought it was a lethal disease. I had not experienced severe health problems and it never crossed my mind that I could be infected with HIV. My interactions with the healthcare system in Europe were limited to a few consultations for minor and easily resolved issues. When I arrived in my new home city, I landed in my new study program, and met a new partner.

After a few months, when renewing my passport and study permit, I was asked by immigration authorities to complete a health check-up, which included a routine HIV and hepatitis screening. I was informed a few days later that I had tested positive for HIV and syphilis. I cannot underemphasize the surprise and the emotional disruption that came with the diagnosis. I was convinced that I would die in a few months. This impacted me psychologically and I questioned everything. I went through a difficult separation with my partner and felt I would not be loved or supported again. I lost motivation to study and felt

alienated from my program. I felt disoriented and helpless. I had no idea how to interact with my friends, fellow students, and supervisors or how to manage this situation. I ended up reducing social contacts and isolating myself.

Meeting care providers and beginning treatment

The nurse who gave me my result referred me to an HIV-specialized service in one of the main local hospitals. I went for my first consultation with my physician and a multidisciplinary care team, including nurses and social workers.

Here came a second surprise: my care providers were reassuring and comforting and told me they had tools to handle my condition. The relationships I established with care providers saved my life. They explained to me that effective antiretroviral therapy (or ART) for HIV had existed for several years. ART implies taking a few pills a day. Taking ART as prescribed would manage the medical aspect of my infection: my immune system, my health, my quality of life, and my life expectancy would not be affected. Moreover, I learned that taking the treatment would eventually make me 'undetectable', that is, my viral load would be suppressed, meaning that I would not transmit the virus to my sexual partners. Indeed, a person with HIV who takes treatment and maintains an undetectable viral load cannot transmit HIV to their sex partner.⁴ These are basic principles of current HIV care that, until then, I completely ignored.

As a patient, I first took on a quite 'passive' role. I assumed my healthcare team knew everything and relied on them for the medical management of my condition. My physician gave me a prescription for ART and I consented to take it. I went to the pharmacy and then, came a third surprise: I did not have long-term access to ART. ART was too expensive for me to pay from my pocket, as it is for virtually all people with HIV. In Canada, people's medical costs are generally either covered by a public, private, or collective health insurance. As an international student, my medical coverage only covered, and still only covers to this day, a few months of ART. A social worker advised me to go back to my home country, where ART is completely covered by a public regime. Yet I did not want to abandon my study program, which I had worked so hard to enter. I thus found alternative ways to access ART. A friend sent me my medication from Europe by mail for a few months, but Canada prohibited the international mailing of prescribed drugs. Then, I joined a clinical trial that has covered, and still covers, the cost of ART.

Once I started taking it, I noticed that it needed planning and organization. For example, I did not want to take ART in front of colleagues or other students. When I travelled, I did not know how to adapt my ART-taking schedule to jet lag. During consultations and appointments, I always had several questions and my healthcare providers would

answer me with useful answers oriented towards improving my situation. At times, I could email or call them to discuss my concerns. I listened and followed the instructions. Besides ART, I looked for simple, complementary ways of taking care of myself. I kept a good nutrition and avoided smoking or drinking. More importantly, I re-discovered sports, which I had abandoned when moving to Montreal. Sport helped me maintain my motivation despite my new circumstances. Still, ART could not treat the emotional and social distress I felt since my diagnosis. Although my care providers explained all these facts to me, it took time to integrate them. For example, I still felt and acted as if I would never be able to have a 'normal' sexuality or meet partners.

I decided to apply for permanent residency in Canada, which would give me access to better medical coverage. However, in Canada, immigrants' health status and potential demands on health or social services are evaluated. A person is considered as representing an 'excessive demand' (or 'burden') when their probable usage of health or social services as a permanent resident would negatively affect medical service wait times or cost more than three times the Canadian average for health and social services (per person).⁷ In my case, the cost of ART exceeded the Canadian government 'excessive demand cost threshold,' making me ineligible for permanent residency unless I demonstrate that I can absorb the cost of ART.

Engaging and exploring new roles

During the fall 2015, I accepted an invitation to join a 'patient advisory committee' with nine other people with HIV whose life and care experiences differed from each other. This advisory committee would work with clinical researchers on research projects to develop patient-centered interventions at my clinic. I first had difficulties identifying myself as someone who could contribute to the research and clinical team. It was difficult for me to talk about HIV, and I felt that my experience was too limited. It was about a year and a half since my diagnosis at that moment, and I felt I had spent most of this time in depression and trying to secure my access to ART. I felt shame and guilt. I thought my challenges in getting ART were abnormal.

I still joined the advisory committee. It provided an opportunity to meet other people with HIV and share my experiences. I thought that it would help me overcome my loneliness, integrate what I had learned with my care providers, and let go of my initial perceptions of HIV. Also, my field of study was, to a certain extent, compatible with those of the research team. In other words, clinical research represented a domain in which I could project some of my academic skills. Being a graduate student and lecturer, I felt comfortable sharing knowledge and explaining technical aspects to different audiences. I hoped

that being involved with researchers could re-ignite my motivation for research and my study program and make the best out of this difficult situation.

My involvement with the committee began. With time, we got to know each other and shared our experiences and opinions on research, HIV, and ART, and a great cohesion and support emerged between members amidst technical discussions on research and clinical interventions. Outside of the committee, I felt more positive about living with HIV and willing to talk about it. I became increasingly involved with researchers and I shared my experience with different audiences made up of people concerned by HIV, like researchers or healthcare providers.

Lessons learned

I have overcome many challenges, and overall, this process has been positive, and quite a learning experience. First, engaging care is a step-by-step process, and I learned that winning battles did not mean achieving full victory. Indeed, my access to ART remains unsure and temporary. I feel that this uncertainty is 'eroding'⁸ my motivation to take ART, and I fear eventually being out of solutions.

Second, I learned to better integrate different parts of myself. In other words, my social, academic, and personal selves now cohabit better. It has somehow led me to 'emancipate' myself of the difficulties I experienced in the months following my diagnosis.

Third, I had to take care of the physical, psychic, emotional, and social impacts of the diagnosis before getting involved with others. I had to replace misinformation and misconceptions of HIV with valuable knowledge, learning from my healthcare providers, by myself, or from my peers. Knowledge has been crucial to overcoming challenges.

Comment by PK: Systemic access, linkage of resources, and Le Cercle Orange

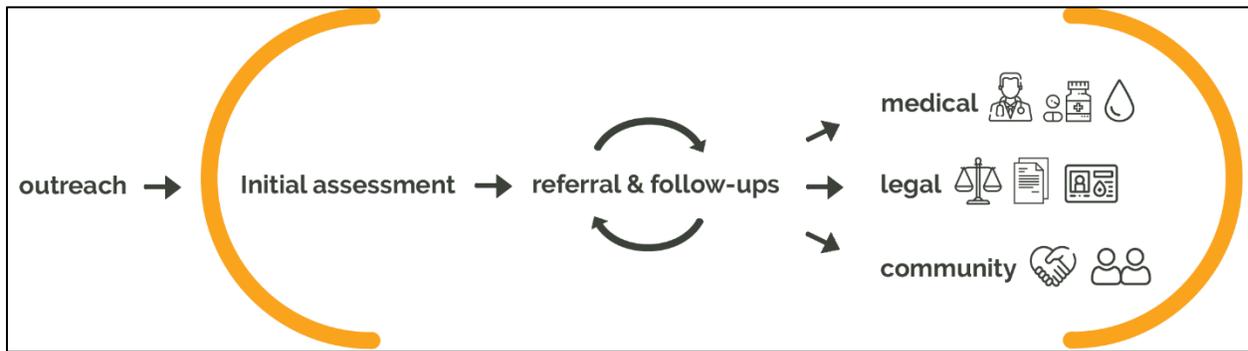
Vincent Croft's narrative draws us into the immeasurable psychological difficulties, including isolation, shame, and fear, that a new and highly stigmatized condition may cause. It also highlights the resilience and emotional courage it takes to overcome such challenges. Croft describes his experience with immigration issues and isolation all while managing a worrying 'time crunch' as he fears medication could potentially run out. People living with HIV without access to care are left with piecemeal solutions – e.g., having to mail medication from overseas or participating in clinical trial. As Croft describes, a person's ability to access health care can be severely impacted by their immigration status and other legal issues, as well as social hurdles such as housing, food security and isolation, and income.

Working in the Canadian HIV community I have often heard stories similar to Croft's. I have also come to realize that solutions and resources do exist. For instance, pharmaceutical companies offer programs covering the cost of ART for individuals with limited means; healthcare professionals can see a number of patients free of charge; several legal clinics answer questions around disclosure and immigration concerns; community organizations offer HIV-specific support services. However, these resources have been chronically disorganized and disconnected from one another. As a result, healthcare may be experienced as a labyrinth of systems, institutions and organizations that, taken individually, provide only segments of care.

A genuine understanding of experiences like Croft's can inspire creative solutions through dialogue and partnerships. For instance, engaging with people living with HIV without access to health care pushed us to create Le Cercle Orange (LCO; cercleorange.ca) – a novel project tailored to provide access to healthcare for all people living with HIV in Montreal, regardless of their legal status. LCO operates by synchronizing, connecting and harmonizing existing resources (such as those described above) facilitating medication access, primary health care, immigration, and community support. Services provided by LCO are free of charge. Participants contact LCO staff by email (info@cercleorange.ca) complete an initial needs assessment, and are then referred to relevant medical (e.g., private or hospital-based clinics), legal (e.g., juridical clinics, specialized lawyers), or community-based (e.g., advocacy groups) resources within a frequently-updated network of partners. Figure 1 showcases the process of linking people to resources.

Patients too often have to navigate the medical, biological, and psychosocial aspects of their health condition alone and blindfolded, while managing legal hurdles (e.g., immigration). Many have little or no prior experience of the healthcare system. Narratives like Croft's reveals the power of resilience, the value of collaboration, and the humanity behind systemic issues. It is important to give patients platforms and forums to voice, share, and learn from their experience. In the context of collaboration and partnerships, sharing personal experiences can inspire creative, collaborative solutions, such as LCO, ensuring access to care.

Figure 1. Process of linking people with HIV to resources with Le Cercle Orange



References

1. Levi, J., *Ensuring timely access to care for people with HIV infection: a public health imperative*. 2002, American Public Health Association.
2. Ford, N., et al., *Benefits and risks of rapid initiation of antiretroviral therapy*. *AIDS*, 2018. **32**(1): p. 17-23.
3. CATIE. *Starting ART on the same day as an HIV diagnosis in British Columbia*. 2015 [cited 2021 07 January]; Available from: <https://www.catie.ca/en/treatmentupdate/treatment-update-210/anti-hiv-therapy/starting-art-same-day-hiv-diagnosis-british-col>.
4. Eisinger, R.W., C.W. Dieffenbach, and A.S. Fauci, *HIV viral load and transmissibility of HIV infection: undetectable equals untransmittable*. *Jama*, 2019. **321**(5): p. 451-452.
5. Snider, J.T., et al., *Nearly 60,000 uninsured and low-income people with HIV/AIDS live in states that are not expanding Medicaid*. *Health Aff (Millwood)*, 2014. **33**(3): p. 386-93.
6. Institut national de santé publique du Québec. *Programme de surveillance de l'infection par le virus de l'immunodéficience humaine (VIH) au Québec: Rapport 2019*. 2020; Available from: https://www.inspq.qc.ca/sites/default/files/publications/2706_programme_surveillance_infection_2019_0.pdf.
7. Immigration, Refugees and Citizenship Canada. *Excessive demand: Calculation of the cost threshold*. 2018, Immigration, Refugees and Citizenship Canada: Ottawa.
8. Lessard, D., et al., *HIV-Positive Patients' Perceptions of Antiretroviral Therapy Adherence in Relation to Subjective Time: Imprinting, Domino Effects, and Future Shadowing*. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, 2018. 17.