

# «Economic Realities»

of people living with HIV in Québec

A community-based research project by le **Portail VIH-sida du Québec** (2021)



## Methodology

- Exploratory, qualitative design;
- 14 PLHIV from Quebec interviewed, totalling 264 years of living with HIV;
- 939 minutes of testimonial recorded, transcribed, and anonymized;
- Qualitative thematic analysis.

## Background

- 12 % approximately of people in Canada are currently living in poverty
- 50 % approximately of PLHIV in Canada are currently living in poverty
- 62 % of participants in the "Quebec HIV Stigma Index" [1] reported an income of less than \$20,000/year

The negative effects of poverty on health have a significant impact on people's social participation and on their likelihood of accessing a decent income, which in turn creates a «vicious cycle» that exacerbates the disabling effects of illness on health, and leads to further social isolation.

## Participants' Financial Profile

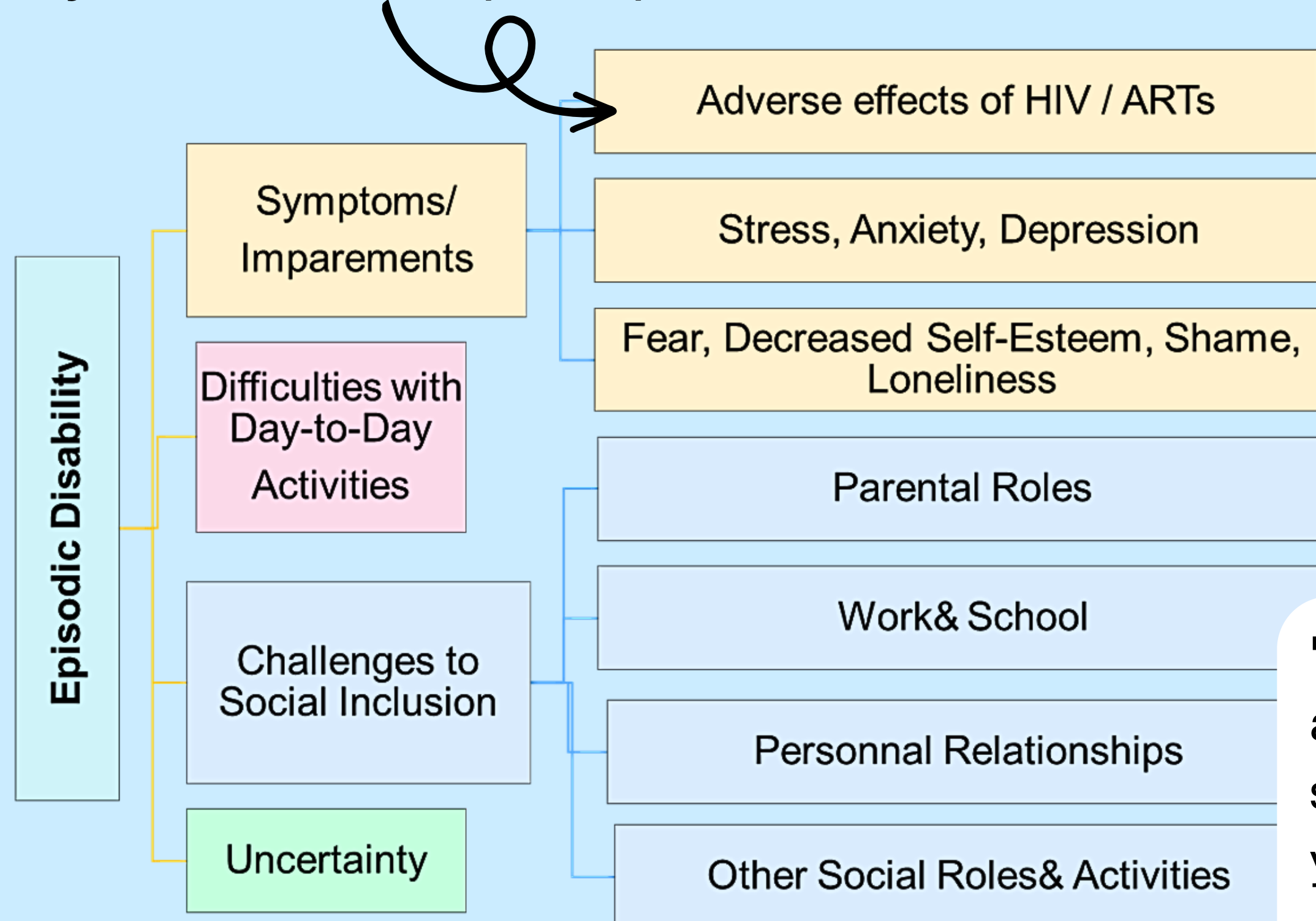
"Generally, I can afford ..."	Yes	No
Housing	7	5
Food	5	7
Transportation	6	6
Hobbies	6	6
Phone	11	0
Web services	8	4
TV	7	3
Insurances (life, car, home)	7	5
Seasonally-Appropriate Clothing	3	9
Eye Care	1	8
Dental Care	0	8
Drugs Co-Payment	5	4
Other Health Related Expenses	0	12
Childcare	1	0
Taxes	4	2
Saving Plans (RRSP, etc.)	0	12
Emergency Funds (3x monthly expenses)	0	12

"I really try to make it a priority, but there have been times where I haven't been able to get my medication. There were times when I had to skip my meds for a couple of days..." (L)

- Some said that they sometimes had to postpone getting their HIV meds, or go without them altogether for a while because they didn't have the money for it.
- All mentioned difficulties accessing health services not covered by Quebec's health insurance program (RAMQ); many reported that they had to postpone or give up needed care because the costs were too high.
- All participants, regardless of their sources of income, reported that they were unable to save money; at the time of their interview, 3 employed individuals had less than \$1 to themselves.
- The vast majority were currently experiencing, or had experienced in the past, debt-related struggles.

## «Episodic Disability Framework»

by O'Brien & al. (2008)



- Participants described negative HIV-related health effects that were consistent with O'Brien's & al. (2008) "episodic disability" model [2].
- WHO defines disability as "the sum of interactions between a person's health and their context which adversely affect their activities and social participation" [3].

"[When I first had my HIV diagnosis] I experienced a pretty major burn out, and I had to deal with serious depression episodes pretty much every year since... Psychologically, physically, its been extremely taxing."(F)

- The impairing effects of HIV on global health can vary significantly both in number and intensity throughout a person's life, hence the "episodic" aspect of the disability.
- Participants also noted that their personal journey with HIV had enabled them to develop strategies that now helped them manage the disabling effects of HIV on their health. Even if older now, most felt that they were, in fact, in better physical and mental health at the time of their interview, than they were when first diagnosed.

"It took me 2 years to truly accept my diagnosis. Two years of hell, really." (D)

## Inflexible Statuses

"Well, actually I worked «under the table» [illegally] for quite a long time. But yeah, I had been declared «severely disabled», so... in my mind, i though I could never work again, you know... ? " (A)

- Many mentioned that acquiring a disability status was a necessary step in order to financially achieve a healthier quality of life. However, this status locked them into an "all-or-nothing" definition of health that did not allow for a gradual return to employment as their health improved.
- The definition of 'disability' used by our systems does not support an adequate health-work balance. To protect their status, people are therefore forced to unnecessarily restrict their work hours, work illegally, or opt not to be compensated for their work.

## Insufficient Incomes

	Sustainable Income (IRIS): 28 783\$	MBM: 21 132\$
Minimum Wage (35h): 20 307 \$	-8 476 \$	-825 \$
Social Solidarity: 16 903 \$	-11 880 \$	-5 039 \$
Social Assistance: 10 423 \$	-18 360 \$	-10 709 \$
Qc Pension Plan: 20 231 \$	- 8 552 \$	-901\$

Difference between estimated annual income and Qc poverty measures, by economic situations for 2021 (single person, Montréal region)

- Many employees reported that, despite being employed full time, they were unable to adequately provide for themselves on their current income. People were thus confronted with situations of poverty, despite being actively involved in the workforce.

"My job doesn't pay much. If I didn't have my pension on top of my salary, I wouldn't even be able to afford decent housing. [I need both], and even then, I'm struggling." (J)

- Instead of enabling PLHIV to regain a health status favorable to their social participation, actual support systems initiate a negative cycle that keeps vulnerable people in extreme financial precariousness, which in turn contributes to poor health.

- Many turned to community-based services as a way to address the challenges created by current support and employment systems. The resources and the flexibility that could be found in these spaces allowed many to meet some of their material needs, but also to find a place among their peers and to acquire new skills and strengths, which they were eventually able to mobilize in order to reintegrate an employment situation compatible with their health.

"I did some work [in a community-based org.], and it made me want to get back in action! At some point I thought, « Hey, I can do that kind of job! I'm here already, and I'm already doing the work !»... I realized that I had potential too, you know ?" (D)

## Structural Poverty

- Fear of losing their government issued health insurance plan, or fear of not having access to a salary sufficient to cover their health care costs, represent sources of doubt for PLHIV. These concerns contribute to the "uncertainty" dimension of the 'episodic disability' model, adding to the overall negative health effects of HIV.
- The "episodic" nature of the HIV-related disability is not recognized by Quebec's current support systems: the "all or nothing" approach to disability adopted by support programs, and the rigid format and strict schedules often associated with employment settings, do not allow for a realistic health/activities balance. As a result, individuals are unable to access sufficient and health-enhancing income.
- By depriving folks of their ability to make the choices required to achieve and maintain an adequate standard of living, the "bare minimum" approach of Quebec's support policies is in direct contradiction with Canada's Poverty Reduction Strategy (2018) [4].

"Like, if I was teaching 3 hours a week, spread over several days... I could manage that, you know? But to go out and work in a school for 40 hours a week, that was a whole different story..." (C)

## Recommendations

- Let's call for an unconditional access to an income support program for every Canadian living with an annual income inferior to the threshold established by the Canadian Market Basket Measure (MBM).
- Dental and vision health is not an option! Let's demand that ALL health care be covered by our public insurances.
- Let's fight against prejudices related to poverty, and promote actions that allow people to regain their health and to live in dignity, rather than measures that lead to more poverty, exclusion and illness.
- Social contribution is not limited to paid work, and should be encouraged and acknowledged for its true value; let's advocate for actions that foster the development and the sustainability of our community strengths and resources.

Ref:  
 [1] COCQ-sida, (2020) « Moi, toi et le VIH - Résultats de l'Index de la stigmatisation des personnes vivant avec le VIH au Québec »  
 [2] Gouvernement du Canada (2018), «Une chance pour tous : la première Stratégie canadienne de réduction de la pauvreté»  
 [3] O'Brien & al. (2008), «Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework»  
 [4] OMS-Organisation mondiale de la santé (2011), «Rapport mondial sur le handicap»