

“He’s got HIV. Well he’s basically like a diabetic.”: Service provision for HIV as a long-term chronic illness

Soo Chan Carusone, PhD

Casey House, McMaster University

Jessica Cattaneo, MA

AIDS Committee of Toronto

HIV and Aging

November 19, 2013 – 10:50am



OHTN 2013
RESEARCH
CONFERENCE

NOVEMBER 17-19, 2013

CHANGING THE COURSE OF THE
HIV PREVENTION, ENGAGEMENT AND
TREATMENT CASCADE

Outline

- 1 • Study overview
- 2 • Results
- 3 • Implications
- 4 • Next steps

Living with HIV over the Long term



Canadian Institutes
of Health Research

Instituts de recherche
en santé du Canada

Canada



CASEY HOUSE

Objective:

Develop a knowledge base related to long-term survivorship of HIV to guide and support research and program development

Study Questions

1. How is the concept of long-term survivor used and understood in the context of HIV in Toronto?
- 2. What are the care and service needs, challenges, and priorities for people who have lived long term with HIV?**
- 3. What experiences have people living with HIV had in relation to the long-term use of programs and services?**
- 4. What can the experiences of people living long term with HIV tell us about developing programs and services for HIV as a chronic and episodic illness?**

Focus Groups (n=4; 31 pp)

Individuals self-identified as living long term with HIV

Demographics	N (%) / Mean (range)
Age	47 years (20 – 68)
Years living with HIV	18 years (6 – 30)
Gender	23 (74%) male 7 (23%) female 1 transgendered person
Ethnicity (self-identified, n=26)	14 (45%) Caucasian 5 (16%) African/Caribbean/Black 4 (13%) Aboriginal
Annual income	23 (74%) < \$20,000

Key Informant Interviews (n=14; 17 pp)



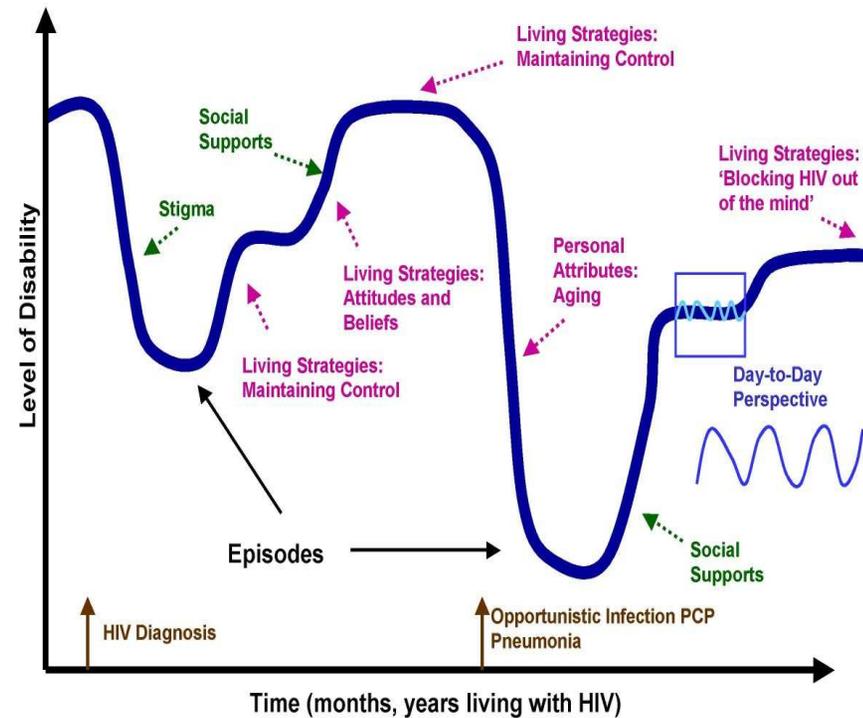
11 Organizations
(Clinics, hospitals, ASOs)



7 Front-line workers
+
10
Managers/Directors

Over the long term

- Fluctuations in health and uncertainty about the future
- Impacts accumulate over time
- Healthwork constant and pervasive
 - ❖ Challenges to ongoing holistic healthwork



Episodic Disability Framework: An example of a person's disability experience illustrating the episodic nature of disability that occurs on a daily basis and over the entire course of living with HIV. Episodes of disability may be triggered by life events (brown), and exacerbated or alleviated by extrinsic contextual factors (green) and intrinsic contextual factors (pink).

(O'Brien *et al.* *Health and Quality of Life Outcomes* 2008
6:76 doi:10.1186/1477-7525-6-76)

Healthwork

I access my doctor every three months. I access the laboratories that do my blood work every three months, one more if necessary. I access the pharmacy in order to get my meds. I access [ASO] for food, for haircuts, for financial assistance. I access [ASO] for counselling, support groups. I volunteer at both those organizations.

(Male 5, FG3)

I've lived this long, I've worked really damn hard to be healthy, to take care so that I don't have to go to the dentist, so that I don't have...you know, not that I don't when that happens, I have to. But the issue is that I'm working really hard, and then they're going to cut my special allowance for food off the menu kind of routine because you're too healthy...you have to be sick in order to get it. Well, you know, I've worked this hard...

(Male 1, FG3)

Accumulated Impacts

All of us can advocate for ourselves and coordinate ourselves out of a paper bag...

(Female 2, FG1)

Income & Employment

When one piece goes often another piece goes, often another piece goes. And oftentimes we can see just a decompensation in a person's depression can lead to poor sleeping habits, poor diet and eventually the meds go...

(KI, A4)

Social Support

Physical and Mental Health

(Male 3 FG2)

I see a lot more people that are developing a cognitive dysfunction. And I know a few of my friends, they self isolate because they recognize what's happening and they are too proud to let other people see what's happening, so therefore they shut themselves away.

Population Health Promotion Model



<http://www.phac-aspc.gc.ca/ph-sp/php-psp/php3-eng.php>

★ = Participant identified

Implications

- Importance of **understanding** the burden of illness and its management on individuals and their social networks
- Importance of individualized, flexible and holistic support
- Role of peer support programs
- Need for support for ongoing efforts to maintain health and wellness – not just responding to crises

Upcoming



“You see when they designed the programs they didn’t think people were going to live that long anyway”: Rethinking service provision for people living long-term with HIV

Panelists: Winston Husbands (ACT), Ann Stewart (Casey House), Ken King (PHA), Kelly O’Brien (University of Toronto)

Acknowledgements

- Research Team: *Jessica Cattaneo, Soo Chan Carusone, Winston Husbands, Stephanie Karapita, Kenneth King, Lydia Makoroka, Kate Murzin*
- Community Advisory Committee
- Our funder, CIHR
- Everyone who participated in this research project

For information regarding this project please contact:

Soo Chan Carusone, schancarusone@caseyhouse.on.ca

Jessica Cattaneo, jcattaneo@actoronto.org