

# Drawing on Experience to Face Evolving Challenges:

## Mental health, HIV and Aging

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January 23, 2019

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POSITIVE CHANGE  
FOR PEOPLE LIVING  
WITH HIV AND OTHER  
EPISODIC DISABILITIES

**réalise** UN MOTEUR  
DE CHANGEMENT POUR  
LES PERSONNES VIVANT  
AVEC LE VIH ET D'AUTRES  
INVALIDITÉS ÉPISODIQUES

# Agenda

- How do we define mental health?
- HIV impacts aging people
- Mental health & HIV vulnerability
- Mental health and aging with HIV
- Cognitive health and aging with HIV
- What does it all mean?
- Q & A



- ⦿ National organization
- ⦿ Research, education, policy and practice
- ⦿ Rehabilitation lens
- ⦿ My focus: HIV and Aging

## Definition of mental health

“A state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.”

World Health Organization, 2014

[http://www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/)

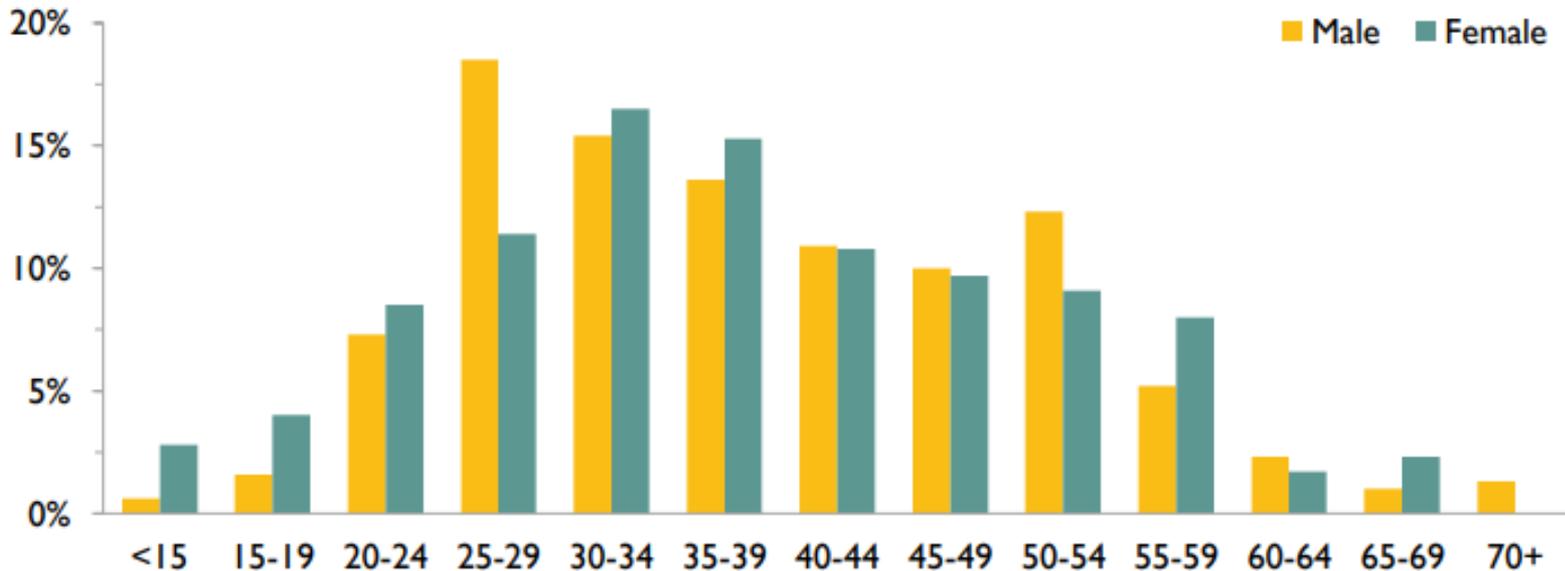
# Why HIV, aging and mental health?

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# 1 in 5 new HIV diagnoses in Ontario is in someone age 50+

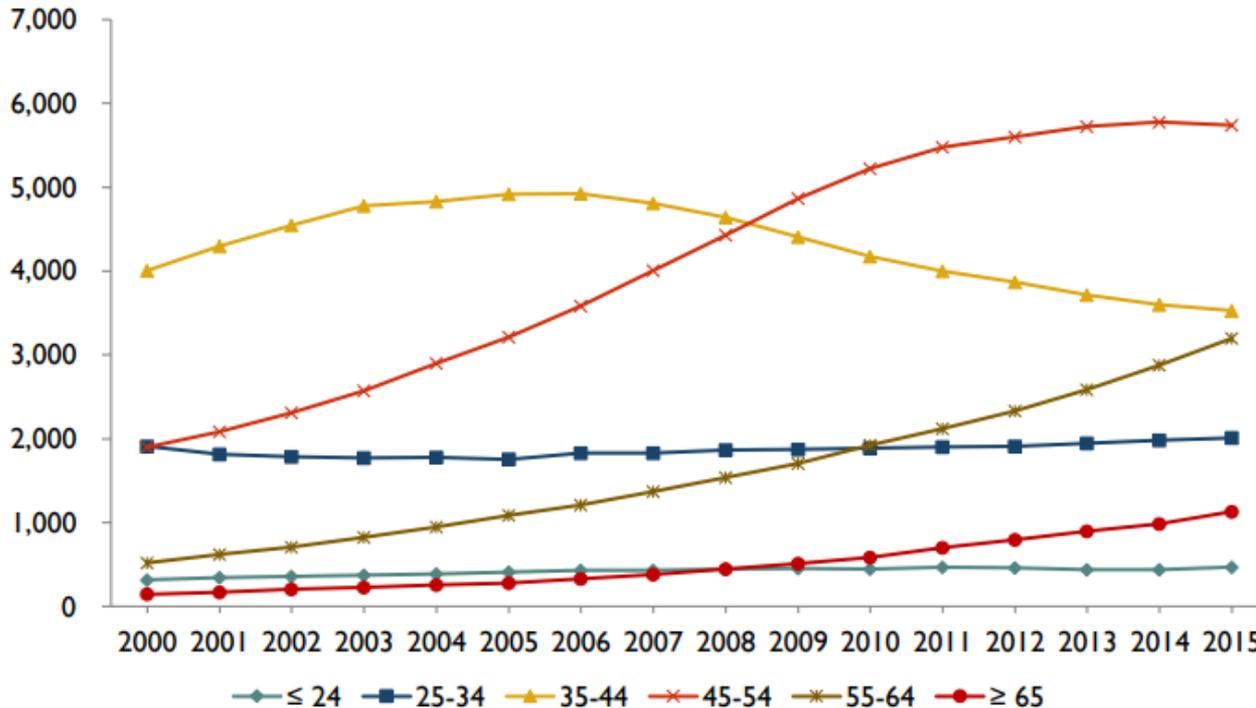
**Figure 3.1** Percent of new HIV diagnoses by age and sex, Ontario, 2016



Wilton J., Liu J., Sullivan A., Sider D., Kroch A. New HIV diagnoses in Ontario: Preliminary Update, 2016. Ontario HIV Epidemiology and Surveillance Initiative, Toronto, Ontario, October 2017.

# 27% of people diagnosed with HIV in Ontario were 55+ years old in 2015

**Figure 2.3** Number of people with diagnosed HIV living in Ontario by age category, 2000 to 2015



Ontario HIV Epidemiology and Surveillance Initiative. HIV care cascade in Ontario by sex, age and health region: Linkage to care, in care, on antiretroviral treatment and virally suppressed, 2015. February 2018.

# Mental health, aging and HIV vulnerability

## The Life Course, Syndemic Theory and Intersectionality

# Determinants of mental health (among older adults)

Mental Health Commission of Canada (2018)

*Guidelines for Comprehensive Mental Health Services for Older Adults in Canada*

- Financial security
- Social isolation
- Physical health
- Sense of purpose / worth
- Safe, suitable housing
- Mobility / transportation
- Access to services
- Community engagement
- Ageism
- Self determination / choice

# Life Course Models

- Critical period
- Accumulation of risk

(Ben-Shlomo & Kuh, 2002)

Table 1 Conceptual life course models

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**Critical period model**

with or with out later life risk factors

with later life effect modifiers

**Accumulation of risk**

with independent and uncorrelated insults

with correlated insults

'risk clustering'

'chains of risk' with additive or trigger effects

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# Adult Mental Health as Maturity

Based on the notion that the brain continues to evolve and unfold over the life course; rather than deteriorating like other parts of the body can

Human development through life experience leads to maturity, and greater maturity = greater mental health

## Steps toward ultimate 'maturity':

- Identity – understanding one's own values
- Intimacy – ability to have reciprocal relationships
- 'Career consolidation' – finding one's 'calling'
- Generativity – guiding the next generation
- "Keeper of the meaning" – passing on traditions
- Integrity – peace and unity with self and world

Positive Mental Health: Is there a Cross-Cultural Definition? (Vaillant, 2012)

*“synergistic epidemics”*

Epidemics of co-occurring problems or adverse experiences that tend to cluster within a population

Do not disappear with HIV diagnosis



# Intersectionality

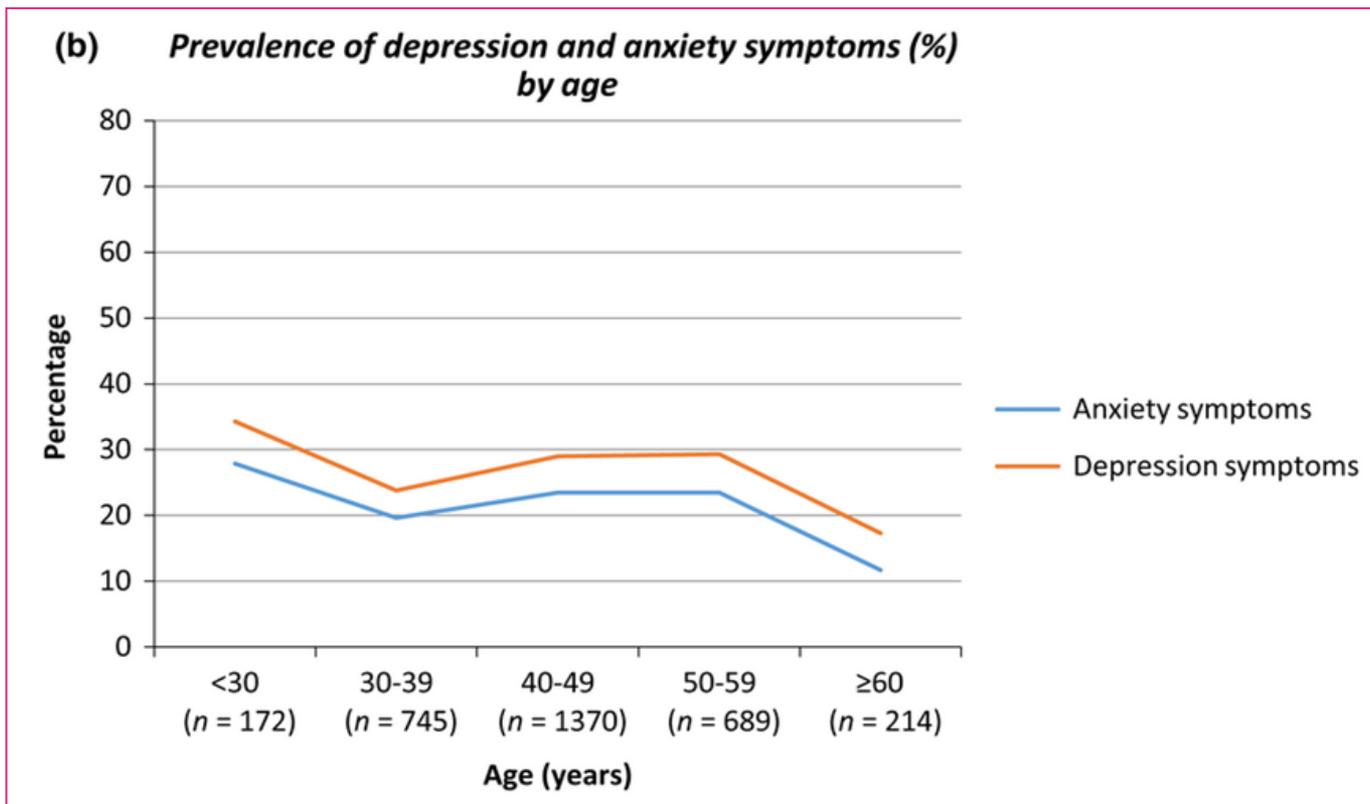
## Factors associated with depression and/or depressive symptoms in older gay men

- “Internalized gay ageism” (Wight et al 2015)
- History of depressive symptoms (Wight et al 2016)
- Aging-related stress (Wight et al 2016)
- Persistent or increasing sexual minority stress (Wight et al 2016)
- HIV-stigma + loneliness (Groves et al 2010)
- Living with HIV (Fredriksen-Goldsen & Emlet 2012)
- High incidence of lifetime victimization (Fredriksen-Goldsen et al., 2013b)
- Income, education, marital status, employment status, poor perceived physical health (Scott et al 2016)

# Mental Health and Aging with HIV

# Aging with HIV

## Impacts on Mental Health



Age, time living with diagnosed HIV infection, and self-rated health  
McGowan et al, HIV Medicine 2016

# LOSS & TRAUMA

**“I’m not ready to get involved with someone. I’m afraid of getting attached to somebody and re-experience what I went through. On the other hand, I don’t want to put anyone else through it either.”  
(Gay man, age 52)**

**- Wallach & Brotman 2018**

Toronto Star (1971-2014); Jul 1, 1983; ProQuest Historical Newspapers: Toronto Star  
pg. A13

# Hysteria grips U.S.



**O** Special to The Globe and Mail  
The Globe and Mail (1936-Current); Aug 10, 1983; ProQuest Historical Newspapers: The Globe and Mail  
pg. 14

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TORONTO STAR, FRIDAY, AUGUST 26, 1983 /A17

# INSIGHT

OTTAWA  
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afraid to work in  
people who are af  
mosquito bites,"  
Sarah Gross.

# AIDS: The terror stalking Metro's gays

\*R  
Most AIDS vict  
drug abusers, Hai  
But faced with  
origins and no kno  
the "risk groups";  
AIDS.

## Killer illness has caused homosexuals to be less promiscuous

By **Elle Tesher** Toronto Star  
Hot night downtown at Corneli-  
us, a cavernous Yonge St. bar and  
this summer's hit spot for  
homosexual men. The glitter-lit  
dance floor jumps to Flashdance  
music; the bar crowd is layers-  
deep, swash in soda and lime and  
beer.  
Leaning at small counters,  
shooting pool, cruising the room,  
homosexual men chat with  
friends, lovers, dates.



AIDS warning: Grabbin' from roster cut out by the... dence the risk of contracting the illness. Although there... epidemics such as the ones that hit New York and San

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# GENERATIVITY

**“I used to volunteer as a patient instructor, teaching the PHAs about, what I referred to as ‘my successes of living with HIV.’... I think that is the most important thing for me because when I was diagnosed with HIV and when my partner died in 1993, at that time I expected to follow him quite soon because back then, things were different. So I’ve learned a lot, and I’ve taught myself a lot.”**  
**(Man living with HIV, age 66)**

**– Emlet and Harris 2018**

# UNCERTAINTY

“So, I have anxieties...related to...the future...you know...financial concerns about not earning enough money, and so therefore, not having as much savings as I should, etc. etc.” (Older woman living with HIV)

– Solomon et al 2018

# Uncertainty

**Table 1: Major themes and associated issues in mental health experiences**

Theme	Participant-identified issues
Uncertainty	<ul style="list-style-type: none"> <li>Unexpected survival</li> <li>Interpreting one's symptoms</li> <li>Medical uncertainty</li> </ul>
Stigma	<ul style="list-style-type: none"> <li>Discrimination in health care interactions</li> <li>Misinformation</li> <li>Physical appearance</li> <li>Compounded stigma</li> <li>Anticipated stigma</li> </ul>
Approaches to resilience	<ul style="list-style-type: none"> <li>Reducing space that HIV takes up in one's life</li> <li>Accommodating HIV</li> <li>Engaging with social support</li> </ul>

Preparing for death that never came

Not dying perceived as a loss

Lack of clarity about what's causing symptoms

Cautious monitoring of lab/test results

Limits to current medical knowledge of HIV and aging



Mental Health Experiences of Older Adults Living with HIV: Uncertainty, Stigma, and Approaches to Resilience, Furlotte & Schwartz (March 2017)

# Uncertainty as a Dimension of Episodic Disability



Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework  
Kelly K O'Brien, Ahmed M Bayoumi, Carol Strike, Nancy L Young and Aileen M Davis  
Health and Quality of Life Outcomes, 2008

# Uncertainty Related to Aging with HIV

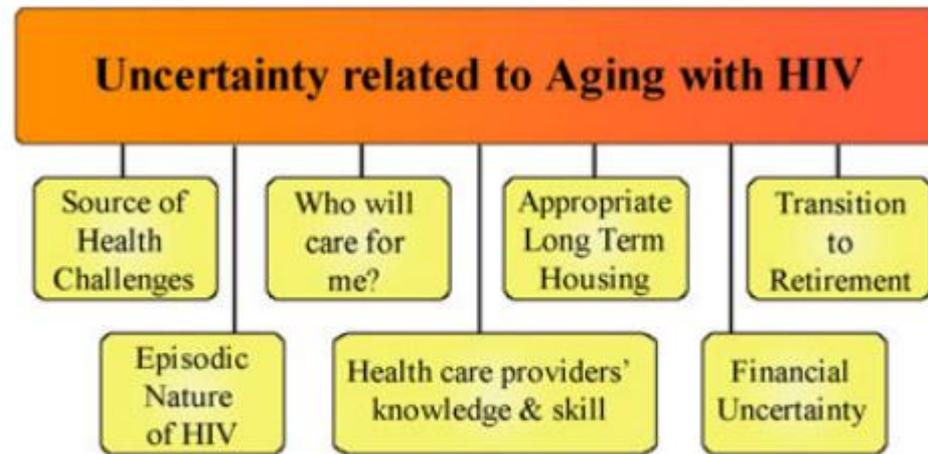


Figure 1. Source of uncertainty related to aging with HIV.

Aging with HIV and disability: The role of uncertainty  
Patricia Solomon, Kelly O'Brien, Seanne Wilkins & Nicole Gervais  
AIDS Care 2014

# Invisibility & Ageism

## Non-descript symptoms of mental health in older persons

(Canadian Psychological Association, 2015)

- No pleasure in activities one once enjoyed
- Less energy/tired
- Aches and pains
- Difficulties concentrating
- Changes in sleep patterns
- Changes in appetite

Assumptions about resilience and ‘limitless coping’ among HIV service providers

# STIGMA

**“I went in to have my surgery; one of the nurses commented, “Oh, I don’t want to change her.”... And I said: “You don’t have to change me at all. I can go change myself, if that’s how you feel.” I was really upset. You’re wearing gloves, what more do you need? Put a mask on if that’s how scared you feel. I don’t care, put an extra coat on. I really don’t give a shit. But I’m a patient here, you took an oath to look after us and not discriminate!”**

**(Woman living with HIV, age 62)**

**- Furlotte & Schwartz 2017**



Gipsy Ray - Diane Jones treats an early AIDS patient at San Francisco General in 1984

Alon Reininger - Contact Press Images  
Thomas Ramos, AIDS Patient, NY hospital, 1987 (NY Times)

**FIGURE 1**  
Nurse Willingness Scale

1. How willing would you be to give Mark a bed bath?
2. How willing would you be to clean up stool or emeses, using gloves?
3. Would you bring a meal tray into Mark's room?
4. Would you change Mark's bed linen?
5. Would you take Mark's vital signs?
6. Would you be willing to change Mark's dressings, using gloves?
7. Would you be willing to clean supplies, using gloves, after the doctor completes a diagnostic procedure?
8. Would you feed dinner to Mark?
9. Would you complete catheter care, using gloves?
10. Would you shave Mark?
11. Would you empty the urinary drainage bag, using gloves?
12. Would you start IV fluids, using gloves?
13. Would you administer a blood transfusion, using gloves?

*'Honey, his mother's not coming. He's been here six weeks. Nobody's coming. Nobody's been here, and nobody's coming.'*

# Stigma

**Table 1: Major themes and associated issues in mental health experiences**

Theme	Participant-identified issues
Uncertainty	Unexpected survival Interpreting one's symptoms Medical uncertainty
Stigma	Discrimination in health care interactions Misinformation Physical appearance ← Compounded stigma Anticipated stigma
Approaches to resilience	Reducing space that HIV takes up in one's life Accommodating HIV Engaging with social support

Discrimination by health care providers on basis of HIV status, behaviours, LGBTQ identity

Misinformation about HIV prognosis/survival

Visible changes to body shape (wasting, lipodystrophy) can lead to social exclusion, distress

Combined effects of being labelled disabled, old, having mental health issues

Fear of stigma limits disclosure

# RESILIENCE

**“I’ve taken a positive constructive approach to my aches and pains ... I just take it for what it is, and I change my schedule to accommodate my body that needs to be resting, and so it hasn’t –like I haven’t suffered. I have suffered so much psychologically that physically there is nothing that can be as bad as the psychological hell I went through, so right now I’m in a good place.”**

**(Woman living with HIV, age 62)**

**- Furlotte & Schwartz 2017**

# Resilience

*Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress (APA)*

- As people age, they are more likely to describe that they are aging successfully, despite any health issues ([Jeste et al 2013](#))
- Older PLWHIV appear to be extremely resilient, many remain optimistic and in control of their lives ([Emlet, Tozay & Raveis 2011](#))

# Resilience

**Table 1: Major themes and associated issues in mental health experiences**

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## Resilience strategies:

- Focusing on other areas of life besides HIV
- Managing pain through rest and pacing
- Connecting with others
- Families of choice
- Spiritual support
- Social pruning
- Activism / volunteering
- Saying no, self care
- Formal support services

# Promising interventions and ideas worth considering

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# General Approaches

## Fostering sense of mastery and individual control

- Client-centered goal setting
- Problem-solving skills may be built over time living with HIV
- Support for working through past victimization

## Building Resilience

- Therapeutic support for reframing adversity

## Social support and community engagement associated with greater mastery and resilience

# Mastery

- Greater perceived control associated with less anxiety about the future among lesbian and gay people age 35+ (Hostetler 2012)
- Buffers against HIV-stigma in people living with HIV (Rueda et al 2012)
- Positively associated with psychological health-related quality of life among older gay and bisexual men living with HIV (Emlet et al 2017)
- Mastery positively associated with length of time living with HIV (Emlet et al 2017)

# Social Interventions

In a meta-analysis, social activities showed more effect on depressive symptoms among older adults than physical activity, skills training, group support, reminiscence and multicomponent interventions.

Longer interventions have positive effects on depressive symptoms

“Meaningful social activities, tailored to the older individual’s abilities, preferences and needs should be considered when aiming to improve mental health among older people.”

- Family-style mealtimes in nursing homes
- Volunteering as ESL tutors
- Weekly singing rehearsal/ performances

Forsman et al 2011

# Counselling Approaches

## Learnings from mental health and aging:

- The Pikes Peak Model for Practice in Professional Geropsychology (Knight et al 2009)
  - Attitudes, knowledge and skill competencies
  - Roots in lifespan developmental psychology – it is important to understand normal aging before working with older adults with psychological disorders
  - Attends to diversity among older adults & importance of understanding unique needs

# COGNITIVE CHANGES

**“If I forget about my doctor’s appointment I feel bad. It’s like I did it intentionally like I didn’t want to go to the doctor. I make sure that I go straight away and tell them that you know what I forgot that I had appointment at this time, that’s why I’m here. Rather than calling them that I forgot my appointment. So they can see me physically.”**

**(Woman living with HIV and mild cognitive disorder)  
– Terpstra et al 2018**

# HIV & Cognition

Andrew Eaton, MSW, RSW, PhD(c)  
brainXchange  
January 23, 2019



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# What is HAND?

## What is HIV-Associated Neurocognitive Disorder (HAND)?

HAND is defined as neurological disorders that cause incurable cognitive impairment, as a result of HIV causing structural damage in the brain's fronto-striatal-thalamatory circuits.

HAND is classified in three forms:

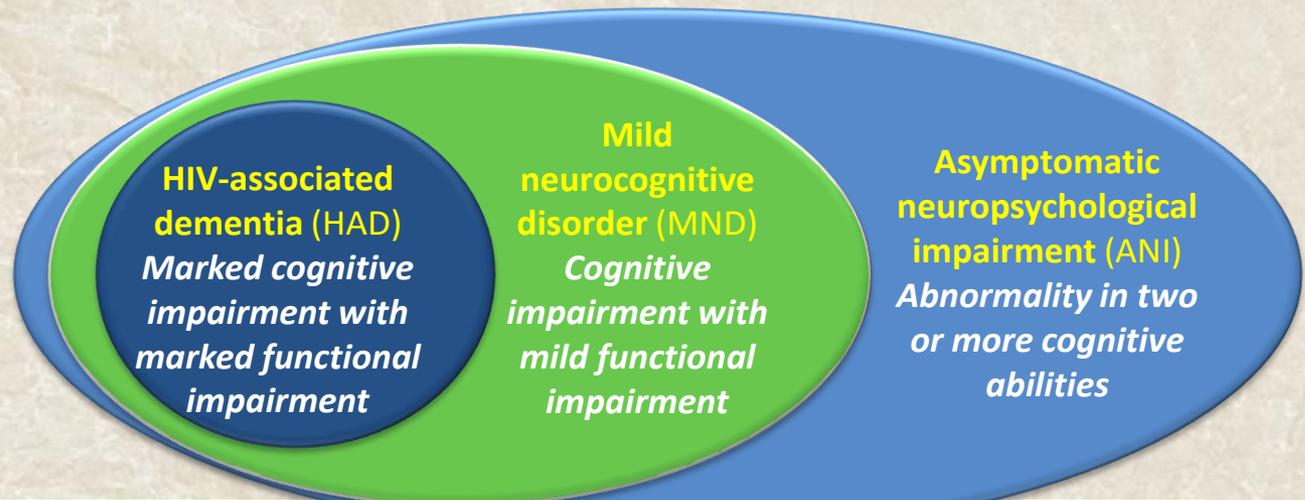
1. Asymptomatic Neurocognitive Impairment (ANI)
2. Mild Neurocognitive Disorder (MND)
3. HIV-Associated Dementia (HAD)

Antinori et al., 2007; Bhaskaran et al., 2008; Greene et al., 2015; Grant et al., 2014; Heaton et al., 2010; Monforte et al., 2004



# What is HAND?

- HAND is classified as neurological disorders that cause cognitive impairment
- Damage is mostly in the brain's fronto-striatal-thalamatory circuits.
- There are three forms:



	ASYMPTOMATIC NEUROPSYCHOLOGICAL IMPAIRMENT (ANI)	MILD NEUROCOGNITIVE DISORDER (MND)	HIV-ASSOCIATED DEMENTIA (HAD)
COGNITIVE IMPAIRMENT	≥ Mild	≥ Mild	≥ Moderate
FUNCTIONAL IMPAIRMENT	None	≥ Mild	≥ Moderate



# Who is affected by HAND?

About 30-50% of people living with HIV may develop neurocognitive impairments; mostly, these impairments will be mild in nature

Risk factors for HAND include:

- Low nadir CD4 (< 200)
- Low hematocrit (red blood cell volume : total blood volume)
- Increased age

Even without these risk factors, some people may still develop HAND

These risk factors can be exacerbated by issues such as low education, malnutrition, low coping skills.

Some factors (e.g., substance use, depression) can confound neuropsychological screening, making it difficult to diagnose HAND.



# Who is affected by HAND?

HAND is of particular concern amongst *long-term survivors*, who:

- Were treated with incompletely suppressive antiretroviral regimens
- Took HIV medications with high rates of mitochondrial toxicity
- Were diagnosed with an AIDS defining illness (e.g., Kaposi's Sarcoma)
- Had a severely compromised immune system for a prolonged period



# Who is affected by HAND?

Anyone living with HIV can be disproportionately affected by HAND if:

- Medication (cART) adherence is poor, or treatment is started late after diagnosis
- Education & literacy levels are low
- They are underhoused and/or underemployed
- They have other physical & mental health issues and/or current/past substance use

Fazeli et al, 2013; Kidder et al, 2015; Ryan et al, 2005; Trujillo, 2010



# Why is HAND a problem?

HAND is characterized by **learning impairments, memory deficits, difficulties in processing new information, executive functioning impairment, problem solving errors, poor decision-making, etc.**



This can lead to **stress, anxiety, social isolation, difficult coping, and may impact *activities of daily living*** (e.g., trouble managing medications, difficulty working, trouble with housing).

Cody, Fazeli, Moneyham, & Vance, 2016; Grant et al., 2014; Illa, Echenique, Bustamante-Avdellaneda, & Sanchez-Martinez, 2014; Spudich, 2013; Tedaldi, Minniti, & Fischer, 2015; Vance et al., 2013



# HAND Testing in Toronto

St. Michael's Hospital in Toronto has a clinic dedicated to HAND:

Neurobehavioral Research Unit

St. Michael's Hospital

Hours: Monday to Friday, 9:00am to 5:00pm

Phone: 416-864-6060 ext. 6484 – Dr. Teri Sota

You can phone this clinic directly, or ask your physician for a referral.



# HAND Prevention & Treatment

- Taking HIV medications (cART) as prescribed is **the most effective form of HAND prevention and treatment.**
- You can also prevent & treat HAND by increasing **cognitive reserve** (i.e., the brain's resistance to cognitive decline) by:
  - Exercising regularly
  - Healthy eating
  - Social supports
  - Managing other issues such as anxiety, depression, substance use
  - Working or volunteering



# Intervention Development

Eaton, Walmsley, Craig, Rourke, & Fallon

Funded by the CIHR Canadian HIV Trials Network – CTN (2017-2019)

MND diagnosis from St. Mike's, age  
40+, 5+ years living with HIV

Cognitive Remediation Group  
Therapy

Living with HAND Support Group  
(Control)

<http://www.hivnet.ubc.ca/clinical-trials/ctnpt-029/>

St. Michael's

Inspired Care.  
Inspiring Science.



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the CTN  
CIHR Canadian  
HIV Trials Network



# People living with HIV worry about HAND

SOCIAL WORK IN HEALTH CARE  
2017, VOL. 56, NO. 8, 733–747  
<https://doi.org/10.1080/00981389.2017.1339759>



## The intersecting cognitive and aging needs of HIV-positive older adults: Implications for social work practice

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### ABSTRACT

Cognitive impairment is a significant health concern for people aging with HIV/AIDS. Using a community-based participatory research (CBPR) framework, we surveyed ( $n = 108$ ) and interviewed ( $n = 20$ ) people living with HIV who were over age 50 about their cognitive concerns and recommendations for social work intervention development. Quantitative findings indicate that our sample was greatly engaged in their HIV care, yet participants had many cognitive concerns. Qualitative findings highlighted fear, shame, and uncertainty concerning HIV and aging alongside a need for increased social work support. This paper provides practical engagement strategies for social workers to support clients concerning HIV, aging, and cognition.

### ARTICLE HISTORY

Received 27 November 2016  
Revised 1 May 2017  
Accepted 4 June 2017

### KEYWORDS

Health care; HIV/AIDS; older adult; psychosocial intervention; social support; social work



# HIV, Social Work, and Brain Health

*Exploring the role of social work in supporting people affected by HIV-Associated Neurocognitive Disorder (HAND).*

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Chantal Mukandoli<sup>1</sup>, Robert Wallace<sup>1</sup>, and David McClure<sup>1</sup>

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Funded by the OHTN (CBR 1043).

Ethics approval from the University of Toronto's HIV/AIDS Research Ethics Board.

The funder is not responsible for this study's findings.

[ohtn.on.ca/hand\\_social\\_work](http://ohtn.on.ca/hand_social_work)



# Methods

- Explanatory sequential mixed-methods design
- Informed by participatory action research (PAR)
- Peer researchers as equitable team members
- Purposive sampling + snowball sampling
- Phase one: Survey (n=108)
  - Data analysis: Descriptive statistics
- Phase two: Interviews (n=20)
  - Data analysis: Manifest and latent coding with three coders and a collaborative, iterative process to determine findings

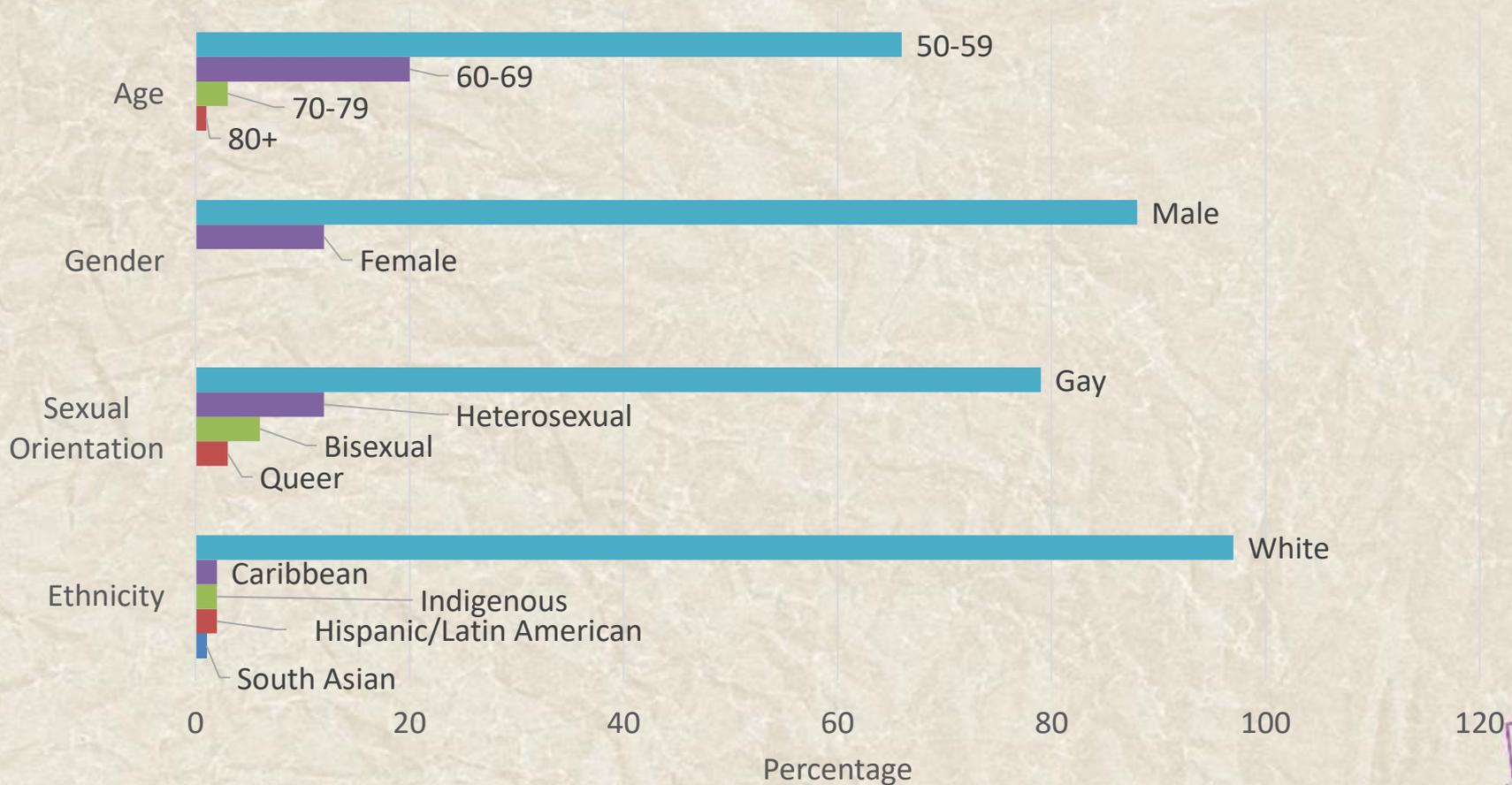


# Research Questions

1. What are the self-identified concerns of HIV-positive older adults affected by HAND in Ontario?
2. How have these concerns been addressed or not addressed through existing programs and services from social workers, hospitals and clinics, and community-based HIV organizations (CBOs or ASOs)?
3. To what extent do clients and community members understand the role of social workers, hospitals and clinics, and CBOs/ASOs?



# Results: Participants (n=108)



# Results: Brain Health Concerns

64.1%	Difficulty remembering	22.3%	Completing daily living tasks
64.1%	Remembering the names of people you've just met	21.4%	Keeping social plans
51.5%	Feeling emotionally overwhelmed	21.4%	Active employment
51.5%	Procrastinating or putting off tasks more than usual	21.4%	Following verbal instructions
50.5%	Maintaining attention	21.4%	Doing simple math in my head
46.6%	Finding words	18.4%	Solving problems
43.7%	Misplacing items	16.5%	Adhering to medication
34%	Expressing yourself clearly	15.5%	Predicting the consequences of my decisions
32%	Remembering the names of people you've known for a long time	14.6%	Calculating a tip at a restaurant
29.1%	Making decisions	10.7%	Reading a map / understanding directions
25.2%	Multitasking	8.7%	Following written instructions
		3.9%	Inappropriate dress/attire



# Results: Brain Health Concerns

Table 1

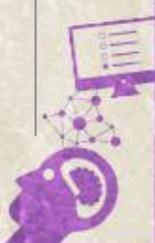
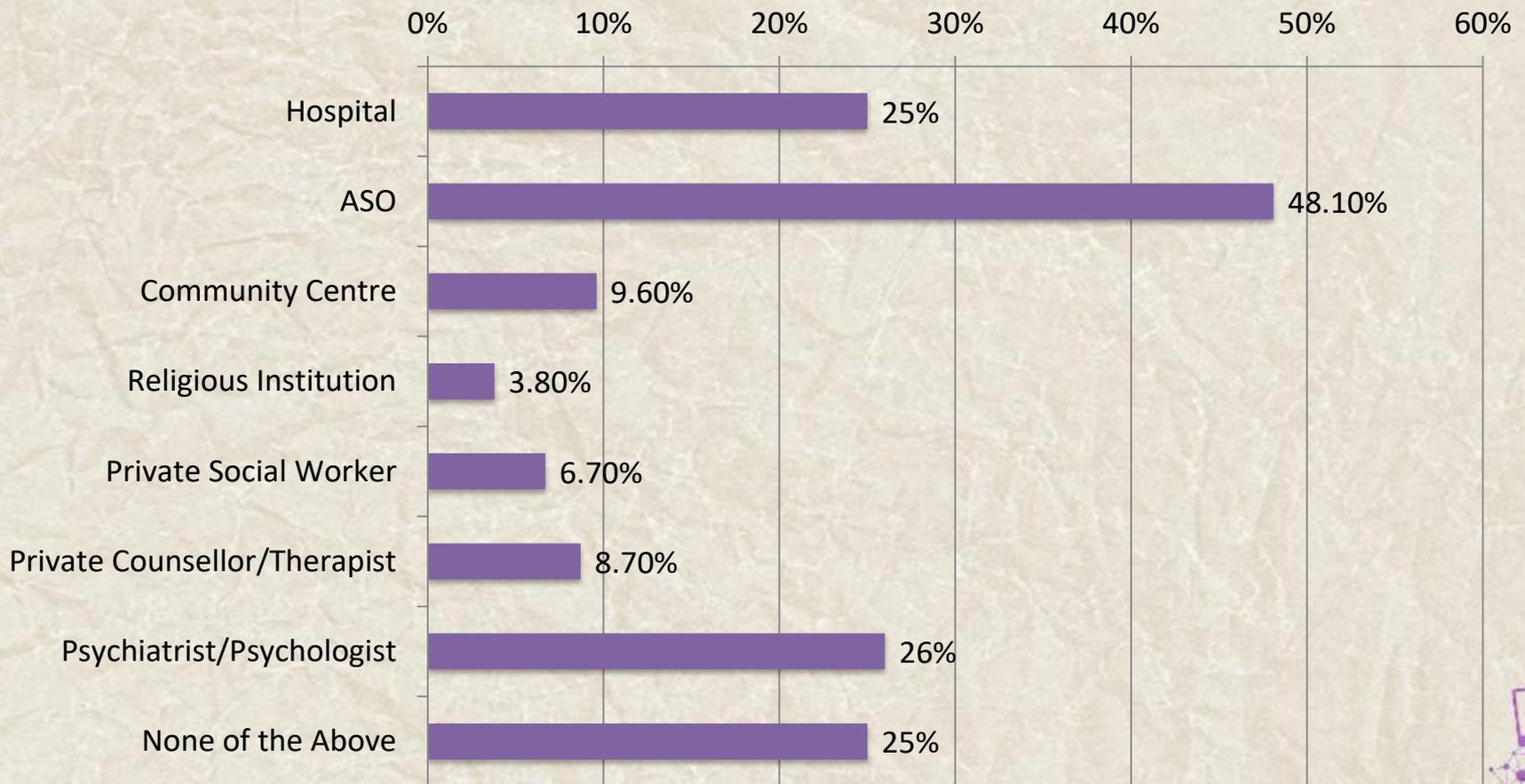
Factors impacting brain health

Question	Yes	No	Unknown
Do you exercise regularly?	54.7%	45.3%	N/A
Do you smoke cigarettes?	27.1%	72.9%	N/A
Do you use substances that could impact your brain health? (e.g. alcohol, cocaine, crystal meth, injection drugs, marijuana)	51.4%	47.7%	0.9%
Are you currently experiencing mental health concerns? (e.g. anxiety, unmanageable stress, depression)	53.8%	38.7%	7.5%
Have you ever been diagnosed with a mental health issue that could impact brain health? (e.g. depression, bipolar)	53.8%	43.4%	2.8%
Have you ever been diagnosed with a health issue, aside from HIV, that could impact brain health? (e.g. cardiovascular disease, MS, diabetes, traumatic brain injury)	30.8%	61.5%	7.7%



# Results: Current Supports

Where do participants access HIV-specific supports?



# Results: Current Supports

1. Do survey respondents talk about brain health with service providers?
  - 46% yes; 54% no
2. If yes, have respondents been referred for HAND screening?
  - 31.8% yes; 68.2% no
3. Have respondents ever tried to get brain health help and been unable to?
  - 82.8% no; 17.2% yes



# Results: CBOs & social work

Table 2

Can CBOs/ASOs, hospitals, and social workers provide support for HIV and brain health?

Question	Yes	No	Unknown
Can CBOs/ASOs support you? (n=63)	79.4%	12.7%	7.9%
Can hospitals support you? (n=52)	73.1%	11.5%	15.4%
Can social workers support you? (n=52)	69.2%	15.4%	15.4%



# Results: CBOs & social work

“Well, I certainly think [ASOs] can have those education sessions where they bring in experts to talk about, what are the newest developments in HAND, what are they finding in HAND research – that’s education and information. But I would like to see more around applications towards the individual that is suffering from HAND and what programs could be put in place for them. Things like maybe brain...well, the testing, setting up or facilitating testing for people who haven’t been tested, re-testing to see progression or regression of those who have been tested. So I guess that would just sort of, you know not only just be through your family doctor but I think there should be a role through ASOs, maybe even having – I don’t know – groups or software, like I noticed people coming here to use the computers and maybe they could have those brain function software programs on computers, a special quiet area where it can be done. Yeah, or software that could be accessed on the website so people who can’t make it out of their homes can access it that way.” (I18, 50-59 years old, male, white/Canadian).



# Results: CBOs & social work

“Do social workers take care of this and everything else? Really? I would prefer someone not to raise my expectations” (S008, 50-59 years old, male, Hispanic/Latin American)

“Are Social Workers qualified in the field of dementia and memory loss. How can Social Workers deal with loss in all aspects..death, economic status, loss of friends and ostrasizing [sic] by family. Assist in making of wills, DNR, Powers of Attorneys.” (S018, 60-69 years old, male, white/western European)



# Results: CBOs & social work

“And that’s why I originally didn’t event want to come to the table to talk about my brain health because I figured okay they’re going to...say somebody’s got a cognitive brain issue okay there’s somehow less of a person. And I didn’t want to do that to myself...I have to learn to deal with it better, yeah. And I think the social workers have to do that too.” (I15, 60-69 years old, male, white/Canadian).



# Social determinants of health associated with greater cognitive reserves: many are within an individual's control

- Social supports which can provide an antidote to real and perceived stigma
- Management of mental health issues such as chronic stress, anxiety and depression
- Literacy and educational levels
- Adult occupation
- Life style issues such as exercise
- Housing – people in better housing are more medication compliant



# Our study findings show that clients are motivated:

- 54.7% exercise
- 48.6% get support from family and friends
- 24.8% get support from partners/spouse
- 24.8% get support from family
- 72.9% are non-smokers



## The flip side...There are some BUTS:

- 43.5% do not exercise
- 51.4% do not get support from friends
- 75.2% do not get support from family
- 24.8% get support from a partner or spouse which may indicate the number who are single
- While just under 60% worry about their cognitive health, only 46% talk to their service providers and only 31.8% of these were referred for testing. This may also reflect resourcing issues outside of Toronto



# Themes from the qualitative data

- Participants struggled to separate what is HAND and what is a normal part of the aging process
  - Impact:
    - Fear and uncertainty about the future, particularly anxiety over what is a symptom to worry about and what is not
- Participants are resilient, independent and cope, but often at a cost
  - A common sense of being on their own to deal with:
    - Anxiety
    - Depression
    - Participants often struggled alone with their fears rather than reach out for support
  - Fear of aging alone



# Themes

- Knowledge reduces anxiety and stress. Those who discussed brain health concerns experienced less anxiety and stress about the future
- The role of social workers and community workers was not well understood and many did not know their service provider's professional identity. However, for those who did, social workers were seen as:
  - “Meat and potatoes” i.e. brokers between clients and resources
  - Holistic in their approach
  - Knowledgeable about interpersonal dynamics



# Just Published

Original Article

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**Questions?**

**Thank you!**

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# What does it all mean?

**realize** FOSTERING  
POSITIVE CHANGE  
FOR PEOPLE LIVING  
WITH HIV AND OTHER  
EPISODIC DISABILITIES

**réalise** UN MOTEUR  
DE CHANGEMENT POUR  
LES PERSONNES VIVANT  
AVEC LE VIH ET D'AUTRES  
INVALIDITÉS ÉPISODIQUES

# Questions and Discussion

**realize** FOSTERING  
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