Are we prepared for an aging HIV population?: A needs assessment identifying the barriers and challenges to care and services

Dr. Amrita Ahluwalia and Keith Hambly

A Lifetime of Care? Factors that influence retention
November 18, 2013 – 3:20 p.m.

OHTN 2013 RESEARCH CONFERENCE
NOVEMBER 17-19, 2013

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

RESEARCH TEAM AND PARTNERSHIPS

Principal Investigator: Dr. Amrita Ahluwalia

Co-Investigator: Michael Blair

Study Co-ordinator: Barbara Lush

Community Partners:
Fife House Foundation
LOFT Community Services/McEwan Housing and Support Services
Casey House
COTA Health
Toronto People with AIDS Foundation
Sherbourne Health Centre
St. Michael's Hospital
Toronto Central Community Care Access Centre
Toronto Community Housing
Saint Elizabeth
Toronto HIV/AIDS Network

FUNDING AND ETHICS

Funded By: AIDS Community Action Program,
Public Health Agency of Canada

Ethics Approval Received From: Public Health Agency of Canada

A “Hidden epidemic”: Aging with HIV

“Toronto’s HIV/AIDS experts and activists are growing increasingly alarmed by “a hidden epidemic” — infected people who have lived decades longer than anyone imagined and are being hit with a host of aging illnesses in their 30s, 40s and 50s. They include dementia, cardiovascular and liver disease, cancers, diabetes, osteoporosis, emphysema and kidney problems.”

– *When HIV Moves into Nursing Homes*, Toronto Star, *27 February 2011*

Needs Assessment-Background

The implications of an increasing aging PHA population are multifaceted as it impacts service users, service providers and health care professionals.

This community-based needs assessment is part of a two-year pilot project being led by Fife House Foundation in collaboration with multi-sectoral partners.

This study aimed to identify issues and challenges of aging PHAs, their care and support needs, and the gaps in care and services.

Study Objectives

Primary Objective:

The main objective of this study is to identify issues of access, quality of care and support and housing services for PHAs who are aging, those with aging related illnesses, complex care, cognition issues and acute health issues.

Secondary Objectives:

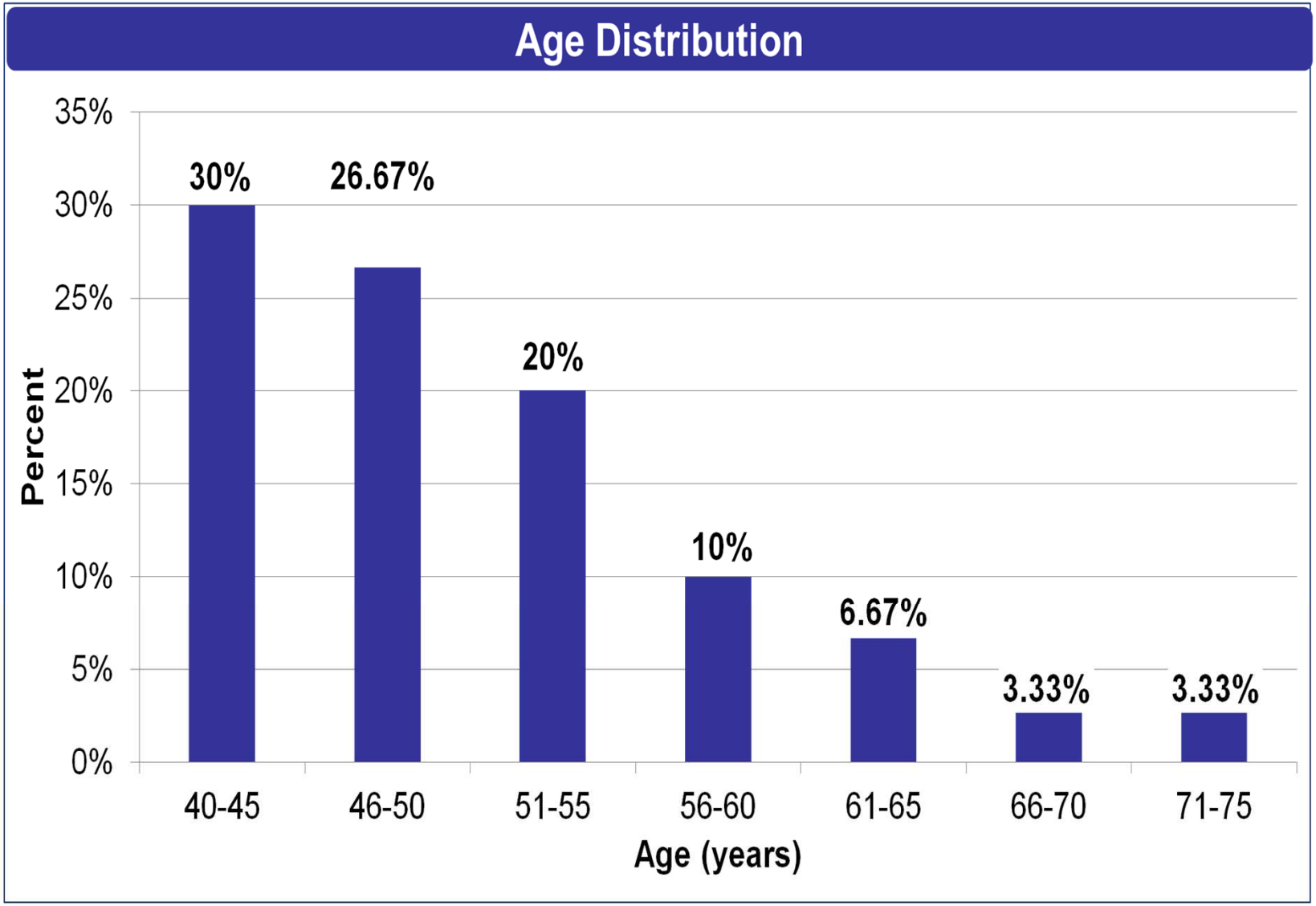
- To identify the issues and challenges that aging PHAs, are experiencing in their everyday life.
- To develop an understanding of what care and support services aging PHAs, are receiving and accessing.
- To explore the changes aging PHAs are experiencing related to their care and service needs.
- To identify the gaps in care and services and explore how these gaps impact their lives.
- To identify strategies to address the gaps in care and services.

Methodology

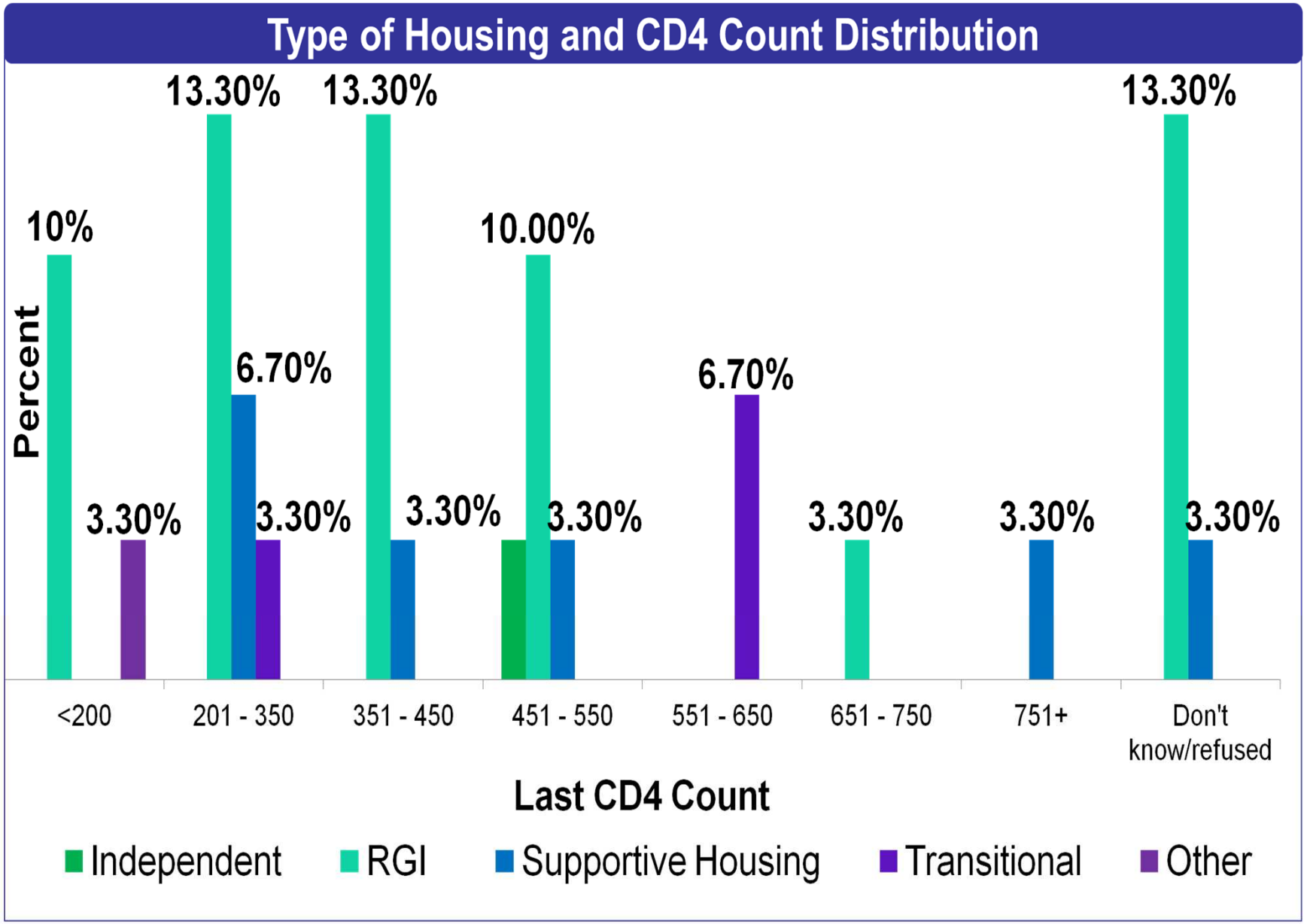
- Quantitative and qualitative methodologies were used to collect data.
- Three peer research assistants (PRAs) were trained in focus group facilitation and data collection skills.
- To gain in-depth information of lived experiences, the questions focused on everyday issues, access to care and services, gaps in care and services and strategies to address these gaps.
- Thirty participants from Toronto (4-6 per focus group) were recruited to participate in six focus groups.

Participant Demographics

Gender & Sexual Orientation					
	Heterosexual	Gay	Bisexual	MSM	Total
Male	6	10	5	2	23 (77%)
Female	6	0	1	N/A	7 (23%)
Total	12 (40%)	10 (33%)	6 (20%)	2 (7%)	30 (100%)


Age Distribution
35%
30%
25%
20%
15%
10%
5%
0%
Percent
30%
26.67%
20%
10%
6.67%
3.33%
3.33%
40-45
46-50
51-55
56-60
61-65
66-70
71-75
Age (years)

FINDINGS


Type of Housing and CD4 Count Distribution
Percent
10%
3.30%
13.30%
6.70%
3.30%
13.30%
3.30%
10.00%
3.30%
6.70%
3.30%
3.30%
13.30%
3.30%
<200
201 - 350
351 - 450
451 - 550
551 - 650
651 - 750
751+
Don't know/refused
Last CD4 Count
Independent
RGI
Supportive Housing
Transitional
Other

Most Common Diagnoses	
Diagnosis:	No. of Participants Diagnosed
Mental Health Issues	15
Substance Use	17
Arthritis	15
Hepatitis B and C	12
Dental Issues	18
Chronic Pain	12
Mobility Issues	10
Bacterial Infections	5
AIDS Associated Cancers	3
Pneumococcal Infections	2
Neurocognitive Impairment	1

Synergistic effect of aging and HIV creates an array of needs, both physical and mental health were interconnected for most participants who struggle with co-morbidities that impact their quality of life.

"...when I was in the hospital, near death, I needed them (various service providers) because I was pretty much useless. I...almost died... plus I had some mental health issues... so I needed them back then to help me get back on my feet..."

Stigma and discrimination based on HIV status, substance use, and/or Native status causes structural barriers impeding access to and quality of care and services

While the majority of participants identified as non-Aboriginal, 30% identified as Métis or First Nations. One participant said:

"One day I went to 8 different places... and got turned down because I'm Native, but on the phone I don't sound Native... so I go to these places and they look at me and it's stigma, stereotyping me, right?"

Inaccessibility of appropriate mental health and substance use programs creates barriers to housing

"...when it came to mental health and addiction, those are like really key elements that were missing from my care... I find a lot of people I spoke to as well... they said those components were missing... like they get their housing, they get everything they need physically or financially, but... those two components, they're the biggest ones that are missing, and that obviously is a big barrier to housing, to getting other services..."

High levels of anxiety about future needs and care

"...in 10 years I'll be 70, who knows if I'll be walking. Where am I going to live?
Do I need to be in palliative care? Do I need to be in a seniors' home – and I
don't think the general medical facilities are prepared for HIV patients."

Complex health issues cause isolation for aging PHAs

Because of decline in mobility and mental health status, isolation becomes a reality for aging PHAs.

"Since I've moved in this building…I've been in St. Michael's more than I have
been here. Surgeries, and different kinds of surgeries, and cirrhosis… so I've
been ill. So I don't really associate with that many people, lonely."

Complex needs due to multiple health issues requires a nexus of care

The existence of multiple health conditions requiring attention indicated the need for developing an integrated care system. As one participant explained:

"...it's my health (it's) diminished: the walking, my hand, I'm not able to use it anymore...things I was doing every day I can't do anymore... I'm having issues mentally – I have dementia... I can't manage drugs, finances, nothing, so... my situation is up in the air."

Recommendations

- Develop a nexus of support and information, and enhance communication between service and health care providers by streamlining information and reporting systems.
- Develop more consistent, coordinated, flexible and client-centered services that are easily accessible.
- Develop and implement intensive training for housing staff in issues of aging, substance use, and mental health.
- Care management and client care should be more inclusive and change with changing needs.
- More accessible long-term supportive housing/geriatric care facilities for aging PHAs with complex care needs.
- Develop programs to give opportunities for social engagement.

For further information:

Contact: Dr. Amrita Ahluwalia
Director of Research and Evaluation
Fife House Foundation
Tel: 416-205-9888 ext. 225
Email: aahluwalia@fifehouse.org

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www.fifehouse.org