Webinar: Growing older with HIV in the Treat-All Era
Instructions for participants

• Please ask questions to presenters and panellists in the Q&A box

• The chat is for any technical issues or general questions

• Access the special issue here: https://bit.ly/HIV_Ageing

• Session recording and slides will be sent to all participants
## Agenda

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<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>People</th>
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<tbody>
<tr>
<td>5 MINS</td>
<td>WELCOME AND INTRODUCTION</td>
<td>Heidi Crane, University of Washington, United States</td>
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<tr>
<td>30 MINS</td>
<td>PRESENTATIONS</td>
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<td></td>
<td>Health and community care and support needs and preferences of older people living with HIV in Ontario, Canada</td>
<td>Kate Murzin, Realize, Canada</td>
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<td></td>
<td>Neurocognitive performance and quality of life of older adults with HIV on antiretroviral treatment in Northern Thailand</td>
<td>Linda Aurbibul, Research Institute for Health Sciences, Chiang Mai University, Thailand</td>
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<td></td>
<td>Priorities for health and wellbeing for older people with and without HIV in Uganda</td>
<td>Zahra Reynolds, Massachusetts General Hospital, United States</td>
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<td>Growing older: The PEPFAR perspective</td>
<td>Katy Godfrey, Office of the Global AIDS Coordinator, United States</td>
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<td>25 MINS</td>
<td>PANEL DISCUSSION – NEXT STEPS</td>
<td>Jules Levin, NATAP, United States</td>
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<td>Moderated by Heidi Crane</td>
<td>Reena Rajasuriar, University of Malaya, Malaysia</td>
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<td></td>
<td></td>
<td>Aggrey Semeere, IDI-Makerere University, Uganda, Ghana</td>
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<td>Kenneth Mayer, JIAS Editor-in-Chief and presenters</td>
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Research as a Tool for Advocacy

Addressing the unmet needs of older people living with HIV

Kate Murzin
National Program Manager
Realize
Themes

- The PANACHE Ontario project
- The dynamism of community-based research
- Research as a tool for advocacy
Preferences and Needs for Aging Care among HIV-positive Elderly people
PANACHE
Project Goal and Sub-Study Objectives

Project Goal:

To gather the data needed to advocate for equitable access to comprehensive services (HIV, aging, healthcare, social) for older people living with HIV and inform new initiatives that respond to the self-identified needs of this cohort.

Sub-study Objectives:

1. To describe the health and community care and social support needs and preferences of a diverse group of older people living with HIV (age 60+)

2. To describe the life course experiences which shape their needs and the extent to which they are being met
What we did and how?
73 participants

64 average age in years

23 median number of years living with HIV

66% identified as men

47% identified sexual orientation as gay

42% identified as being Black, Indigenous or Persons of Colour (BIPOC)

59% lived alone

70% rent their dwelling

84% receiving government and/or private benefits
Current Needs

Practical needs were cited most often
• Affordable, safe, secure housing
• Healthy, plentiful food

Physical and mental health needs
• Medication, medical supplies, mobility aids, dental services, glasses, hearing aids, mental health services
• Having someone to call on in case of illness/injury (e.g., falls)
• More information on ageing (e.g., care options, financial planning)

Social and emotional needs
• Companionship, inclusion in HIV community, emotional/spiritual/peer support
Are these needs being met?

- Participants reported accessing a wide variety of health-related services
- Many spoke of barriers to fulsome service access:
  - social determinants of health
  - provider issues
  - structural challenges
- Workarounds often used to partially address unmet health needs
- Subsidized housing, food programs, community-based HIV orgs important but also problematic
- Needs differ by community size
Triad of Experiences Unique to Older Adults Living with HIV
Uncertainty Makes Planning for Care and Support More Difficult

• Many participants described uncertainty in daily lives
• Ageing is anxiety-provoking; a process of becoming more vulnerable and having insufficient resources to compensate for decreasing personal capacity
• Uncertainty about the availability and accessibility of appropriate formal ageing care and supports
• Unable to exercise control over how current or future needs were met
PANACHE: Guiding Principles

• Community-based participatory research
  • Equitable partnerships
  • Capacity-building
  • Mutual respect for different forms of knowledge

• GIPA/MEPA
  • Community researchers collected the data
  • Participatory analysis team & DEPICT model
The Glasgow Manifesto
Calls to Action

Care

It is with great urgency that we implore *all stakeholders* to *work with us* to implement these CALLS TO ACTION without further delay.

Quality of Life

Empowerment

International Coalition of Older People with HIV (iCOPe HIV)
Neurocognitive Performance and Quality of Life of Older Adults with HIV on Antiretroviral Treatment in Northern Thailand

Linda Aurpibul, Patumrat Sripan, Arunrat Tangmunkongvorakul, Wilawan Chaikan, Saowalak Sarachai, Kriengkrai Srithanaviboonchai

1 Research Institute for Health Sciences, Chiang Mai University, Chiang Mai, Thailand
2 Faculty of Medicine, Chiang Mai University, Chiang Mai, Thailand
Background

- In Thailand, the national scale-up of HIV care began in 2000 and now many patients on ART have survived into their fifties, so-called older adults with HIV (OAHIV).

- Neurocognitive impairment (NCI) is one among several comorbidities associated with a decline in daily living activities, cognitive symptoms, and functional status in people living with HIV.
In the ART era, profound HIV-associated neurocognitive disorders were less frequently seen, but milder form of NCI remained prevalent.

The consequences of NCI include poor medical adherence, disruption of daily functioning, decreased quality of life (QOL), and increased risk of mortality.

The study objectives were to determine:
- The frequency of NCI among Thai OAHIV on antiretroviral treatment
- The correlation between neurocognitive performance and QOL
- Factors associated with NCI in OAHIV
A cross-sectional study was conducted at 12 community hospitals in Chiang Mai, Thailand between September and November 2020.

The study population was OAHIV who were enrolled and followed in the prospective older adult cohort study started in 2015.

They attended HIV care under the national AIDS program covered antiretroviral medication q 2-3 months, CD4 counts and laboratory safety parameters measurement q 6 months, and annual HIV RNA testing.

All participants who showed up during the study follow-up in 2020 were invited to join this study.
Methods

- Cognitive performance was assessed by trained investigators using the Thai version of the Montreal Cognitive Assessment (Thai-MoCA).
  - Scores < 25 was defined as having NCI
  - Scores 16-24 for amnestic mild cognitive impairment (aMCI), and
  - Scores <16 for dementia

- Health-related QOL was assessed using the Thai-validated version of the Medical Outcomes Study HIV (MOS-HIV).
  - Higher scores mean better QOL
  - T-score was calculated; a physical health summary T-score ≥ 50 was defined as good QOL.
## Results

- **A total 269 OAHIV were enrolled.**
- 233 (86.6%) started ART (non-nucleoside reverse transcriptase-based regimens) between 1998 and 2013 while they were immunosuppressed.
- Other 36 (13.4%) started ART after 2013 when it became available for all at any CD4 levels.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex</td>
<td>159 (59.3%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>61.8 (58.9-65.7)</td>
</tr>
<tr>
<td>Age &gt; 60 years</td>
<td>160 (59.5%)</td>
</tr>
<tr>
<td>Formal education</td>
<td></td>
</tr>
<tr>
<td>0-4 years</td>
<td>213 (79.5%)</td>
</tr>
<tr>
<td>5-12 years</td>
<td>46 (17.2%)</td>
</tr>
<tr>
<td>&gt; 12 years</td>
<td>10 (3.7%)</td>
</tr>
<tr>
<td>Monthly income (Thai baht)</td>
<td>4,000 (2,000-10,000)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married or in a relationship</td>
<td>106 (39.4%)</td>
</tr>
<tr>
<td>Single/separated/divorced</td>
<td>163 (60.6%)</td>
</tr>
<tr>
<td>Duration since HIV diagnosis (years)</td>
<td>26.2 (23.3-28.8)</td>
</tr>
<tr>
<td>Duration on ART (years)</td>
<td>10.5 (8.5-13.5)</td>
</tr>
<tr>
<td>Current CD4 cell count, cells/mm3 (n=234)</td>
<td>484 (339-634)</td>
</tr>
<tr>
<td>Current virologic suppression</td>
<td>227/229 (99.1%)</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>119 (44.4%)</td>
</tr>
<tr>
<td>Renal disease</td>
<td>5 (1.9%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>35 (13.1%)</td>
</tr>
<tr>
<td>Dyslipidemia</td>
<td>101 (37.7%)</td>
</tr>
</tbody>
</table>

❖ A total 269 OAHIV were enrolled.
❖ 233 (86.6%) started ART (non-nucleoside reverse transcriptase-based regimens) between 1998 and 2013 while they were immunosuppressed.
❖ Other 36 (13.4%) started ART after 2013 when it became available for all at any CD4 levels.
## Quality of life

<table>
<thead>
<tr>
<th>Quality of life (MOS-HIV), n=269</th>
<th>Total</th>
<th>OAHIV with impaired QOL (29%)</th>
<th>OAHIV with good QOL (71%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health summary T-score</td>
<td>54.97 (48.07-58.46)</td>
<td>41.01 (33.75-46.84)</td>
<td>56.93 (54.59-59.43)</td>
</tr>
<tr>
<td>Mental health summary T-score</td>
<td>58.40 (54.30-61.74)</td>
<td>54.03 (49.02-58.97)</td>
<td>59.54 (56.49-62.75)</td>
</tr>
</tbody>
</table>

### Physical health domain scores

- **Pain**
- **Social functioning**
- **Role functioning**
- **Physical functioning**
- **General health**

### Mental health domain scores

- **Health transition**
- **Quality of life**
- **Health distress**
- **Energy & fatigue (vitality)**
- **Mental health**
- **Cognitive functioning**
# Neurocognitive performance

<table>
<thead>
<tr>
<th>Neurocognitive impairment, n (%)</th>
<th>Total</th>
<th>OAHIV with impaired QOL</th>
<th>OAHIV with good QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurocognitive impairment, n (%)</td>
<td>234 (87.3%)</td>
<td>16 (20.3%)</td>
<td>43 (22.8%)</td>
</tr>
<tr>
<td>aMCI, n (%)</td>
<td>59 (22.0%)</td>
<td>16 (20.3%)</td>
<td>43 (22.8%)</td>
</tr>
<tr>
<td>Dementia, n (%)</td>
<td>175 (65.3%)</td>
<td>47 (59.5%)</td>
<td>128 (67.7%)</td>
</tr>
</tbody>
</table>

**Neurocognitive performance (MoCA scores)**

<table>
<thead>
<tr>
<th>Domain scores</th>
<th>Mean scores</th>
<th>OAHIV with good QOL</th>
<th>OAHIV with impaired QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation</td>
<td>5.7</td>
<td>5.8</td>
<td></td>
</tr>
<tr>
<td>Delayed recall</td>
<td>1.8</td>
<td>1.9</td>
<td></td>
</tr>
<tr>
<td>Abstraction</td>
<td>0.6</td>
<td>0.7</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>0.7</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td>Attention</td>
<td>4.3</td>
<td>4.3</td>
<td></td>
</tr>
<tr>
<td>Naming</td>
<td>2.4</td>
<td>2.5</td>
<td></td>
</tr>
<tr>
<td>Visuospatial/executive</td>
<td>2.9</td>
<td>2.9</td>
<td></td>
</tr>
</tbody>
</table>

**P=0.055**
Discussion

- In our study, a lower median MoCA scores and higher proportion of participants with NCI were seen when compared to the previous studies in Thailand. This might be explained by limited formal education and delayed ART initiation in our participants.

- We believed that apart from age and diseases, the neurocognitive performance was most likely affected by the diversity in geographic, ethnocultural, and education factors.

The low domain scores in language, abstraction, and delayed recall were observed,

However, our participants did not perceive themselves as having memory problems (the median cognitive function domain score in QOL was 90/100). Moreover, they had high role and social functioning (median scores 100/100).

Low perceived difficulty in their daily activities might be due to low instrumental activities involved.

Our participants lived in their familiar community with low technology environment where high cognitive skills were not required. Thus, the NCI did not affect their perceived QOL.
Conclusion

- We documented low neurocognitive performance in a large majority of OAHIV with immune recovery and virologic suppression following delayed ART initiation.

- Now that early ART initiation became a standard practice, more research to identify potentially modifiable factors affecting neurocognitive performance in aging populations is warranted.

- Early detection of NCI among this population would allow healthcare providers to monitor, counsel, or intervene in a timely manner.
Priorities for health and well-being among older people with and without HIV in Uganda: A qualitative methods study

Zahra Reynolds
Medical Practice Evaluation Center, Massachusetts General Hospital
February 2023
Background

- Rapid increase in an aging population of people with HIV (PWH) in Sub-Saharan Africa

- Much known and discussed in guidelines about biomedical care for people with HIV, but almost nothing about determinants of well-being for older PWH

People with HIV age 50+, Eastern and Southern Africa, Aidsinfo
Objectives

- Understand the experiences of older aged Ugandans
  - How do they define their quality of life?
  - What affects functioning and well-being?

- Results informed design of follow-up longitudinal cohort study

- Over-arching goal of understanding the determinants of quality of life for older PWH and to guide their care
Methods

- Semi-structured interviews with people with and without HIV in Mbarara
- Themes guided by conceptual framework
- Inductively coded thematically by two researchers

Siedner, J Aging Health, 2019
PMC6019109
Cohort Characteristics

- 36 total interviews completed, half among PWH
- Median age 57 (range 49-73)
- 61% primary education or less
- Majority (75%) practice subsistence farming
Emergent Themes

1. Overall, PWH see themselves as healthy with a good quality of life
“HIV is like flu or cough; if you are taking your medication as prescribed by the doctor, it does not affect your way of doing things in any way. [Sickness] happens to those who don’t take their medication very well.”

—72-year-old woman with HIV
“I view myself as a normal person and I would not see any change of having HIV because I don’t see any difference; I have developments just like an HIV-negative person only that I see that I don’t have the energy that I had before like now.”

–49-year-old man with HIV
Emergent Themes

2. HIV stigma is declining with ART availability
“Honestly speaking, there is no HIV person that’s treated unfairly! There is no trademark that points out an HIV positive person. Before they were affected by skin rash, and everyone knew the signs. Can you tell that I am HIV by merely looking at my skin?”

–49-year-old man with HIV
Emergent Themes

3. People both aging with and without HIV shared concerns about non-communicable diseases (NCDs) as their greatest health threats as well as vision and hearing loss.

Source: CDC Public Health Image Library
“Cancer [...] claims lives of many people and you hear someone saying that instead of being killed by cancer I'd rather be killed by HIV. One says that with HIV, he or she can access any health facility and get tested and treatment accordingly and become fine. But with cancer, one has to die while in terrible pain.”

–57-year-old woman without HIV
Emergent Themes

4. Shared fears about losses of independence due to declines in cognition, energy, strength, and physical functioning

Source: CDC Public Health Image Library
“I used to remove the banana suckers myself but now I cannot. I would like to slash my compound, but I cannot manage it now, and now I have to use money to hire someone to do it. Now even raising a hoe is becoming a challenge and I may soon fail to dig.”

–54-year-old woman living with HIV
Key findings and next steps

Key findings

• Older people with HIV on ART do not think of HIV as a major health threat, and report declining stigma

• Concerns about NCDs and loss of vision and hearing are shared among older people in rural Uganda

• Loss of cognition and function leading to decreased independence are greatest threats to quality of life

Next steps

• Cognitive function, physical function, vision and hearing testing included in ongoing longitudinal cohort study

• HIV care programs in rural Sub-saharan Africa must start thinking of wrap-around services, beyond ART and OI management, to optimally care for PWH as they age
Acknowledgements

**Study team**
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Growing Older—the PEPFAR perspective

Katy Godfrey Senior technical advisor adult treatment
Main points

• The PEPFAR cohort is ageing; this population is expected to grow
• Mortality is higher in the over 50 group compared to all other adults on treatment; men experience higher mortality than women
• Viral suppression is high in older adults, leading to the inference that mortality is due to something other than undertreated HIV disease
• Comorbidities are prevalent in the older population—in both people with and without HIV
• Treating comorbidities improves the lifespan and the health span.
People supported on ART by age in PEPFAR

Number of clients on ART (TX_CURR)

- <01
- 01-09
- 10-14
- 15-19
- 20-24
- 25-29
- 30-34
- 35-39
- 40-49
- 50+

Female TX_CURR  Male TX_CURR

2022 data
Ageing population

2021 data
Ageing population over time

Ageing populations in the PEPFAR program, 2017-2021

Godfrey et al. 2022
Mortality (on treatment) in 12 PEPFAR countries 2020-2021

Age 15-49

Ages 50+

Fernandez, Godfrey et al
AIDS 2022
Viral Load Suppression by age and sex across PEPFAR
Burden of disease by cause, African Region (WHO), 2019

Total disease burden, measured in Disability-Adjusted Life Years (DALYs) by sub-category of disease or injury. DALYs measure the total burden of disease – both from years of life lost due to premature death and years lived with a disability. One DALY equals one lost year of healthy life.

Neonatal disorders: 69.49 million
Respiratory infections and TB: 57.87 million
Malaria & neglected tropical diseases: 49.32 million
Enteric infections: 47.95 million
HIV/AIDS and STIs: 40.44 million
Other NCDs: 34.5 million
Cardiovascular diseases: 28.6 million
Other infectious diseases: 24.84 million
Cancers: 17.14 million
Mental disorders: 15.57 million
Nutritional deficiencies: 15.07 million
Digestive diseases: 13.25 million
Unintentional injuries: 12.85 million
Transport injuries: 12.21 million
Diabetes and kidney diseases: 11.02 million
Neurological disorders: 10.23 million
Musculoskeletal disorders: 10.03 million
Respiratory diseases: 7.82 million
Maternal disorders: 5.77 million
Skin diseases: 5.77 million
Interpersonal violence: 5.01 million
Self-harm: 3.12 million
Substance use disorders: 2.14 million
Conflict and terrorism: 1.46 million
Natural disasters: 120,795.76

Source: IHME, Global Burden of Disease (2019)  
Note: Non-communicable diseases are shown in blue; communicable, maternal, neonatal and nutritional diseases in red; injuries in grey.
More non-infectious deaths than infectious in South Africa
Comorbidities - Africos

Chang, Godfrey et al 2022
Program review Ethiopia

• Facility based chart review of individuals over 40
• Not comprehensive, charts randomly selected at several sites.
• Looked for HTN, DM, hyperlipidemia, renal insufficiency and obesity and others
• Likely underestimated prevalence of these conditions-data not collected routinely or noted in charts
• HTN occurred in 8.2%, DM 5.3%, CRI 7.3%
• At least 1 NCD: 22%
How to begin?

• PEPFAR is committed to supporting and aligning resources for HIV care with national health priorities and programs
• PEPFAR strategy deliberately calls out person centered care of an ageing population
• COP 23 Guidance: ”Person-centered care focuses on reducing mortality and improving the “health span”—the period of life spent in good health, free of chronic diseases and aging-related disabilities”
• Focus on hypertension as a “pathfinder” for NCD integration
Thank You!