



ADAPTING COGNITIVE REMEDIATION GROUP THERAPY (CRGT) FOR PEOPLE LIVING WITH HIV: COMMUNITY REPORT

ACKNOWLEDGMENTS

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EXECUTIVE SUMMARY



People living with HIV are living longer, and in overall better health, than ever before. Cognitive health concerns are a common issue experienced by people aging with HIV, may first present in middle age, and can be a significant source of stress and anxiety. There is no pharmacological remedy.

Cognitive remediation group therapy (CRGT), developed by Dr. Andrew Eaton and colleagues over a decade of community-based participatory research, is a promising strategy for alleviating the challenges associated with cognitive concerns amongst people living with HIV.

CRGT combines mindfulness-based stress reduction and brain training activities in a group format to cultivate calmness, practice remedial cognitive strategies, and encourage community-building and social connectivity.

This report presents ways to adapt CRGT to online forms, to provide more options and flexibility for people living with HIV. This report also presents an understanding of uncertainty and unmet healthcare needs related to HIV and cognitive concerns, with healthcare recommendations emerging.

KEY TERMS & CONCEPTS

HIV-associated neurocognitive disorder (HAND): an organic mental disorder (i.e., not caused by psychological or psychiatric illness) that can cause cognitive symptoms for people living with HIV, including challenges with memory, concentration, and organization.

- HAND can present like other forms of cognitive impairment, because it interferes with domains of functioning such as a person's memory or speed of processing information.
- But one characteristic that sets HAND apart is that people living with HIV can experience mild-to-moderate impairment at an earlier age—in their 40s and 50s—compared to the general population (who are usually at similar risk of cognitive symptoms in their 60s and beyond)
- There is currently no established gold standard for diagnosing HAND. The condition is most commonly diagnosed using the Frascati criteria.¹

Cognitive remediation group therapy (CRGT): a group-based program developed to support people who are aging with HIV and experiencing concerns about their cognition. CRGT combines mindfulness skills with brain-training activities (BTA).

- So far, CRGT has been delivered in person in Toronto with people aging with HIV, who reported less anxiety and stress—and increased use of mindfulness and BTA—after taking part in the group. This group ran from 2018-2019 and consisted of 8 weekly sessions that were each 2 hours long.

Community-based participatory research (CBPR): an approach that actively involves and centers the input of participants at each stage of the research process.^{2,3} For example, participants may help with determining the research question (i.e., what we are investigating); creating interview guides and co-facilitating focus groups; analyzing data; and sharing findings from the research.

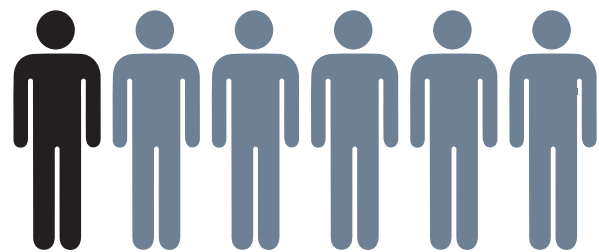
- This approach is an alternative to more conventional forms of research, which may view and treat participants as separate from the research process.³



BACKGROUND

About half of Canadians living with HIV are now over fifty years of age.⁴ In 2021, this age group accounted for 20.6% of new HIV diagnoses reported in Canada.⁵ Now in the fifth decade of the HIV/AIDS epidemic, aging with the virus is a growing priority in light of the increasing population of people living with HIV over the age of 50.⁶ In fact, by 2025, it has been estimated that globally **1 in 6 people** living with HIV will be over 50 years old.⁶ Thanks to widespread access to combination antiretroviral therapy and increases in new HIV diagnoses among older adults, there is growing interest in understanding and supporting the needs and experiences of people aging with HIV.^{7,8}

Since the HIV epidemic, multiple co-morbidities and chronic co-conditions have been linked to an HIV-positive diagnosis, including mental health concerns, viral infections, and cognitive impairments.^{9,10} Through the development and implementation of medication for HIV, the health outcomes of individuals diagnosed with HIV have improved significantly, resulting in longer lives, reaching into their senior years.¹¹ As people living with HIV age, they face increased risk for physical and psychological comorbidities.¹²



By 2025, it has been estimated that 1 in 6 persons with HIV will be over 50 Years old (Sok, 2019)

“
Comorbidity occurs when a person has more than one disease or condition at the same time. Conditions described as comorbidities are often chronic or long-term conditions.”¹³

As such, people living with HIV are more likely to also be living with a diagnosis of:

- cardiovascular disease
- liver diseases
- frailty
- diabetes
- bone and joint disorders
- neurocognitive disorders

Among these co-morbidities, **cognitive concerns** are a common issue experienced by individuals aging with HIV, with significant impacts on their wellbeing and quality of life.¹⁴⁻¹⁶ Among people living with HIV, one common cause of cognitive concerns is **HIV-Associated Neurocognitive Disorder (HAND)**. This condition is most commonly diagnosed when it's found that a person is experiencing dementia that is directly related to HIV replication in the brain. However, there is currently no gold-standard process for diagnosing HAND, and the prevalent existing diagnosis criteria, the Frascati criteria for example, requires an intensive and time-consuming process to determine the diagnosis. The cognitive impairments and symptoms associated with HAND are a significant source of stress and anxiety for

people living with HIV, and it can be difficult to cope with on a daily basis.¹⁴

Furthermore, the impact of aging and associated medical considerations results in uncertainties for both an individual's health and psychosocial wellbeing. Uncertainty can stem from “incomplete or missing information about... outcomes that may occur... which influences how people make decisions”.¹⁸ This kind of uncertainty can result in distress, particularly when left unaddressed or not communicated between patient and practitioner, and impacts the care that an individual receives.¹⁹ Many individuals and their healthcare providers are faced with medical uncertainty, struggling to manage and conceptualize multiple health conditions or co-morbidities.¹⁹ For aging adults, this can lead to particular distress when leaving a hospital or healthcare setting after receiving care, including feeling confusion about how they should respond to their new diagnoses or progression of their conditions.²⁰

What can be done?

Biomedical interventions, such as use of cART, show limited success in improving people's cognition.¹⁶ As an alternative, programs that support an individual's mental and social needs (i.e., **psychosocial** interventions) can alleviate cognitive symptoms. This can be accomplished, for example, by reducing stress and anxiety for people living with chronic health conditions.^{21,22} Despite this evidence, there is currently a lack of psychosocial supports designed to improve the cognitive health of those aging with HIV.²³

In existing publications, people living with HIV have demonstrated and highlighted the importance of group therapies to address cognitive concerns. This is in part due to how groups can encourage social connections and community-building in the face of stigma.²⁴⁻²⁶ There have also been evidence demonstrating that combining multiple types of support/ intervention strategies may lead to improved outcomes, when compared to an individual-based intervention such as talk therapy.^{27,28}

What is CRGT?

As stated, we lack psychosocial interventions specifically for cognitive health amongst persons aging with HIV. Existing research has demonstrated an interest and need for group therapies to address cognitive difficulties, as peer groups can **encourage community-building** and **social connectivity** in the face of historical and present stigma.²⁴⁻²⁶ Furthermore, it has been demonstrated that combining multiple approaches can be effective in facilitating improved outcomes for aging individuals relying on a single treatment, such as talk therapy.²⁷⁻²⁸ For older adults experiencing cognitive impairment in aging, for example, talk therapies have been suggested to increase effectiveness through activity-based approaches such as worksheets, meditation, games, or non-verbal models.^{29,30}

In response to this gap in supports for people aging with HIV experiencing cognitive concerns, Eaton et al. developed the Cognitive Remediation Group Therapy (CRGT) approach, which combines mindfulness-based stress reduction (MBSR) and brain training activities (BTA) and was piloted as an in-person intervention in 2018-2019.^{31,32} The piloted therapy used a combination psychosocial approach, with its focus on supporting the needs of persons aging with HIV and experiencing cognitive concerns.

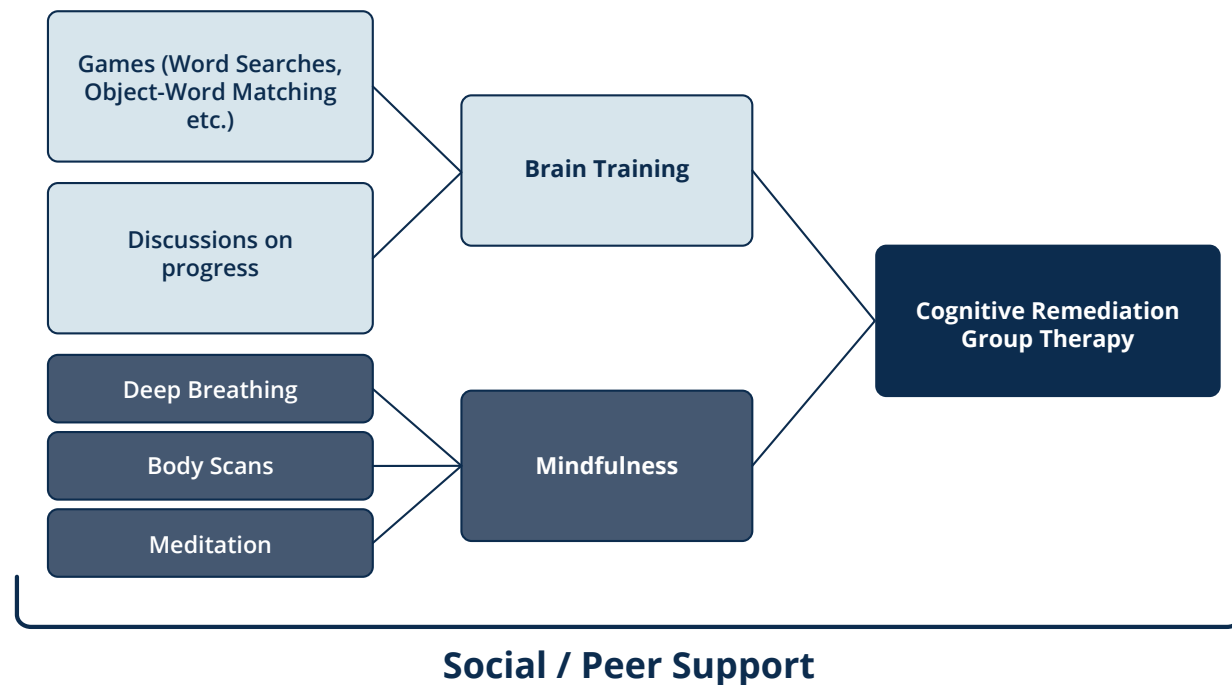
The pilot study for CRGT compared the feasibility of this new intervention with that of mutual aid group therapy (a more conventional form of support group) for people living with a mild-to-moderate HIV-Associated Neurocognitive Disorder (HAND).^{31,32} Eight sessions were held weekly, with two hours focused on MSBR (sessions teaching meditation, body scans, deep breathing, and other stress-relief techniques). These MSBR techniques were utilized through a series of published **mindfulness and meditation activities** that were delivered in the sessions as well as with worksheets to be sent home with participants aimed at reducing stress³³

BACKGROUND

and anxiety³⁴ associated with cognition. Furthermore, one hour each session was focused on individual time to practice BTA, as well as time to have a discussion on training and progress and subsequent challenges experienced by the participants. BTA consisted of games and/or activities completed with pen and paper, or via software (such as PositScience by BrainHQ), which has been suggested to improve mental function when practiced for more than two hours a week, over 2 months or more.³⁵

The results of the initial CRGT groups were promising: CRGT performed better or equally well when compared to mutual aid therapies. Our participants reported less anxiety and stress, and more use of mindfulness skills and brain training activities during and after the study.³² These results were encouraging and suggested that CRGT would be effective for older adults living with HIV and associated

cognitive concerns; yet the study had certain limitations, which speak to the importance of doing further research about CRGT and about the experiences of people aging with HIV and cognitive concerns. One limitation of the pilot was its small number of participants, which may be linked to the fact that a diagnosis of HAND was required in order to participate in the study. This suggests that it may be critical to offer low-barrier HAND screening in future studies. Furthermore, the pilot intervention was delivered in person prior to the onset of the COVID-19 pandemic. Since the start of the pandemic, healthcare delivery has shifted toward offerings of hybrid or totally online initiatives.^{36,37} As such, the present study was designed in order to determine how to best proceed with adapting CRGT for hybrid or fully online modes of service delivery through the use of focus groups with participants aging with HIV and its associated cognitive concerns.



PARTICIPANT DASHBOARD:

Who was part of this project?

Forty-five people took part in online focus groups for this study. Our participants were all people over the age of 40 who were living with HIV, and who reported experiencing concerns about their cognitive health (e.g., memory, attention, organization). Participants either lived in Ontario or in Saskatchewan.

The ages of our participants ranged from 41 to 71, with an average age of 53. The largest cohort of this population identified as gay (42.2%), with the second most common sexual orientation being straight/heterosexual (40.0%). Moreover, a majority relied on disability as their main source of income, and were not employed in the labour market. Only 8.9% were formally diagnosed with an organic mental disorder, such as HAND.





HIV, AGING & COGNITION

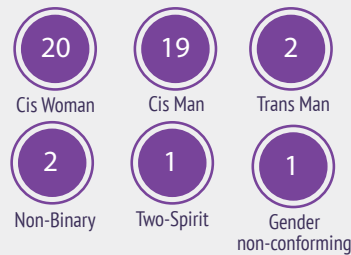
Focus Groups with People Aging with HIV in ON & SK Canada



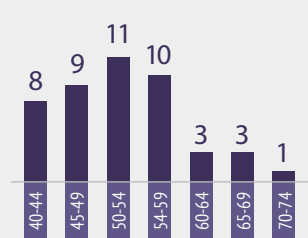
45 participants



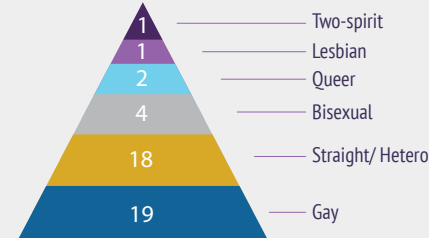
Gender



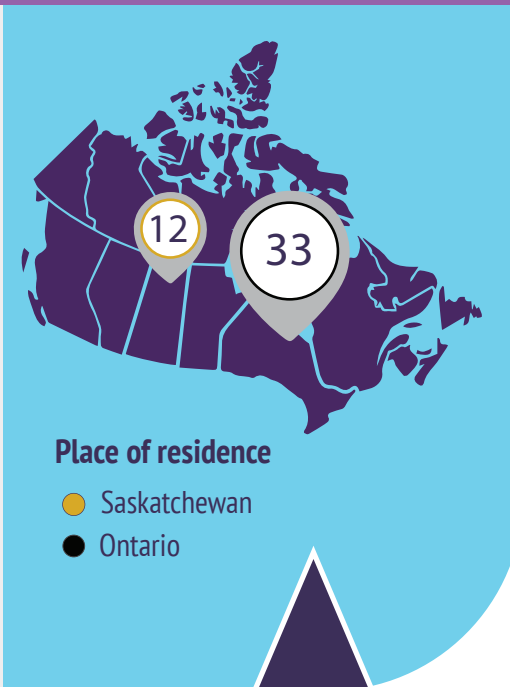
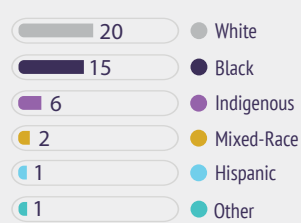
Age



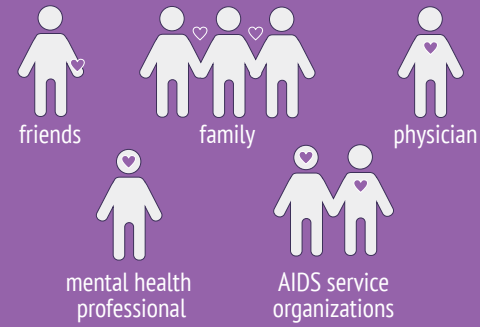
Sexual Orientation



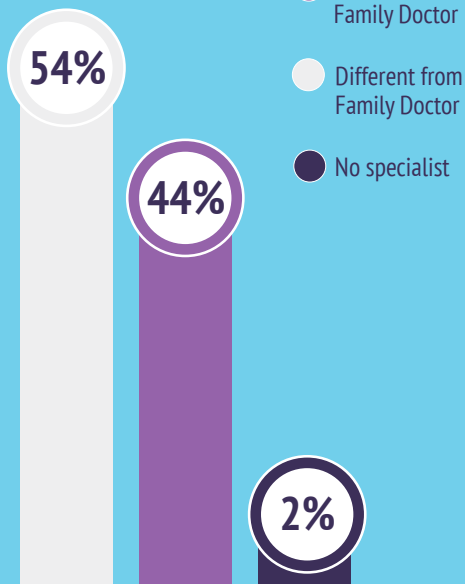
Ethnicity



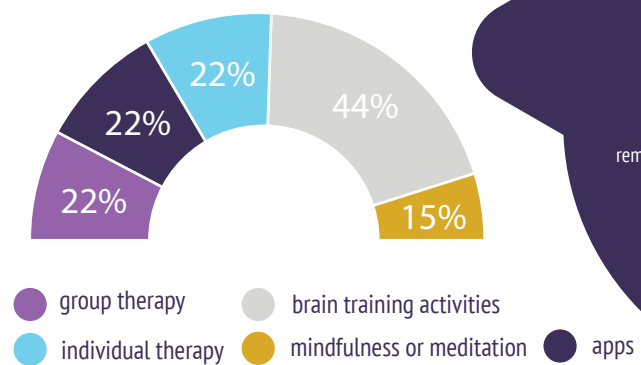
Participants try to find support through:



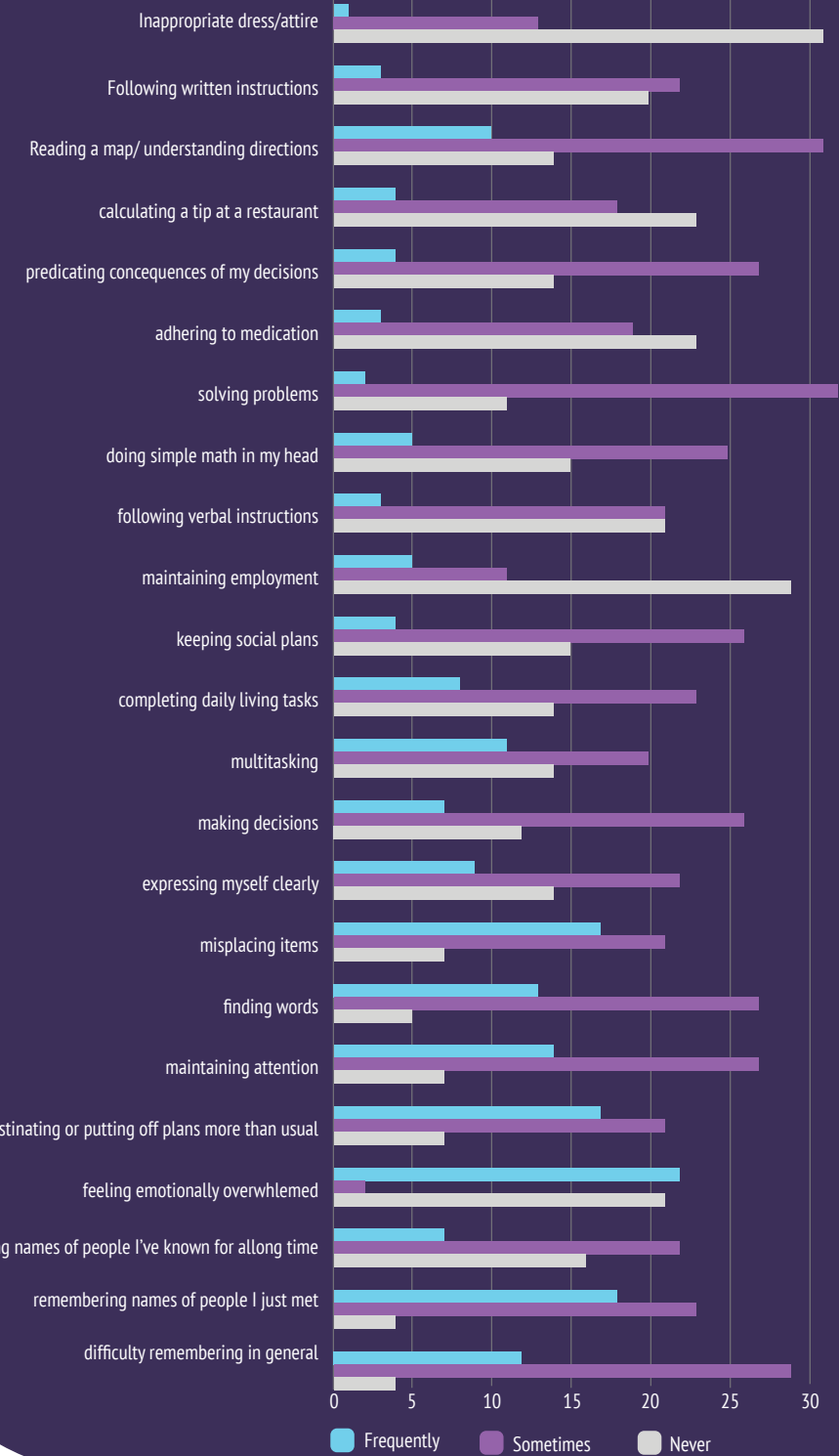
HIV Specialist



Participants compensate for cognitive concerns by:



Cognitive Concerns



HIV social support network



86%

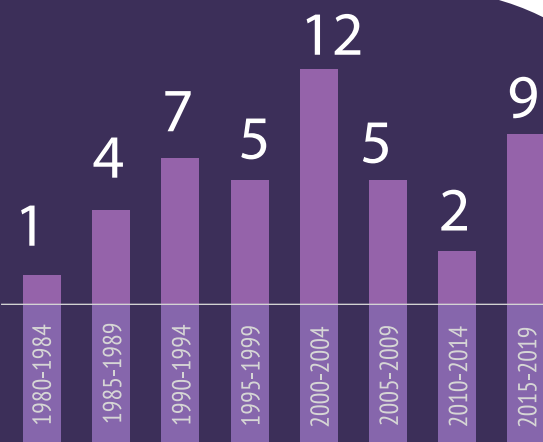
of participants noticed cognitive concerns themselves first



98%

of participants have a family doctor

Year of HIV Diagnoses



31%

of participants indicate that supports have listened and offered help

46%

of participants have accessed an AIDS support service organization in the past 3 months



STUDY DESIGN:

What methods did we use for this research?

Step 1: Recruit people aging with HIV (aged 40+) and cognitive concerns who are interested in participating in the study, living in Ontario or Saskatchewan. Forty-five individuals ended up taking part in our research.

Step 2: Collect data. Participants completed a 15-minute online survey questionnaire and attended a 2-hour Zoom focus group interview. We hosted 10 focus groups.

Step 3: Analyze Data. The focus groups were audio-recorded and transcribed. We used *thematic content analysis* to identify key themes across all 10 focus group transcripts

Findings for Study 1

Participants' preferences for adapting CRGT for online or hybrid delivery

Findings for Study 2

Participants' cognitive concerns, feelings of uncertainty, and resources for coping with cognitive concerns while aging with HIV.

Collecting Data

First, participants met with Dr. Andrew Eaton over Zoom to ask questions about the study, review the consent form, and give verbal consent to participate in the study. During this meeting, they completed an **online survey questionnaire** (15 minutes long) that asked about their demographics, information related to HIV (e.g., year of diagnosis, whether they were taking medications), and cognitive health concerns.

Second, participants attended a **focus group interview** (2 hours long) over Zoom, which were co-facilitated by a peer researcher who is living with HIV. Each focus group had between 3-5 participants, with two co-facilitators. During the focus groups, participants were asked open-ended questions about CRGT, concerns about cognitive health, supports they've accessed, and interest in being screened for HAND. We hosted 10 focus groups in December 2022.

Analyzing Data

Once the data was collected from the survey questionnaires and focus groups, we used a method called **thematic content analysis** to understand and analyze the data so far.

Each focus group was audio-recorded and transcribed verbatim. With the 10 resulting transcripts, our team used **thematic content analysis** to analyze the data.

- In Study 1, the team consisted of people aging with HIV, service providers, and researchers.
- In Study 2, the team consisted primarily of researchers, with input from people aging with HIV and service providers.

Thematic content analysis is a method for understanding qualitative (i.e., non-numerical) data. Researchers each read and reviewed the transcripts independently, then identified and organized key themes that emerged from the data. We also found supporting quotes in the transcripts to illustrate these key themes.

- In Study 1, the themes and quotes captured participants' preferences for adapting CRGT for online or hybrid delivery.
- In Study 2, the themes and quotes captured participants' concerns regarding their cognitive health; feelings of uncertainty about aging with HIV and cognitive concerns; any resources they use to cope with cognitive concerns; and unmet needs and ideas for how they could be better supported.



STUDY 1: WHAT DID WE FIND?

Adapting cognitive remediation group therapy (CRGT) for online or hybrid delivery

Two key themes emerged from the focus groups with people aging with HIV and cognitive concerns, specifically regarding their preferences for adapting CRGT for online or hybrid delivery. Participants talked about (1) the **benefits and importance of CRGT** for people aging with HIV and cognitive concerns; and also discussed (2) **logistics about the intervention** itself, including how it could be delivered, for what length of time, and by whom.

“

[M]editation and mindfulness both are the exact opposite of the symptoms I'm experiencing, which are... difficulty focusing, difficulty paying attention, and forgetting what I'm doing, being easily distracted and so on. So, I think these are perfect exercises... for people with HAND, because it flies right in the face of the difficulties that we're having there - opportunities to practice, getting better at the things we're struggling with.

—Focus group participant describing a benefit of CRGT

”

Theme 1: Benefits and importance of CRGT

Participants believed that CRGT would be helpful for them in different ways. They emphasized the benefits of

- (1) mindfulness;
- (2) brain-training activities (BTA); and
- (3) group intervention.

Participants believe that the mindfulness activities involved in CRGT promotes staying grounded, improves clarity of thought and minimizes the impact of distractions, and reduces stress and anxiety. Moreover, participants find that BTAs improves their memory, focus and attention. They find the BTA games accessible and fun, which helps to motivate them to play. Last, participants, many of whom are socially isolated, appreciate the group format of CRGT, as it provides social support and encourages connection with peers. Participants also believe that the group format keeps them motivated and accountable; this encourages learning from others' experiences and perspectives.

Theme 2: Intervention Delivery and Logistics

Intervention delivery and logistics describe the recruitment of participants, mode of delivery (online or hybrid programming), length of sessions, and identity of the facilitator (mainly concerning whether the facilitator was a peer or professional). Participants identify three major factors that could shape the success of

the intervention delivery: (1) accessibility—the ability to access CRGT (informed by location, technological access, literacy, time, etc.); (2) utility—how useful the intervention is; (3) flexibility—the ability to make decisions independently during the intervention.

According to participants, accessibility concerns/constraints for the CRGT program include access to technology, location, transportation needs, mobility, health, and safety. Regarding utility, participants stress the importance of understanding the program's impact on their brains and cognitive function. Participants believe that it is crucial for them to understand the purpose and impact of the program to engage with the program. Moreover, it is important for participants to choose how they engage in/participate in the intervention; this flexibility gives participants a greater sense of control.

“

There might be people with mobility issues. They can't get around as easily or they have breathing issues themselves... for example, like being in your home where you're comfortable and relaxed it, it would probably work better for a lot of people. A hybrid scenario... based on people at home or some people, people in a room... it makes it more accessible.

—Focus group participant discussing accessibility considerations for CRGT

”

STUDY 2: WHAT DID WE FIND?

Cognitive concerns and uncertainty experienced by people aging with HIV

In addition to describing their preferences for adapting the CRGT intervention, participants in our 10 focus groups also shared about **different issues affecting their cognition**.

They also discussed the **uncertainty** they felt about aging with HIV while also experiencing cognitive concerns, including in **interactions with healthcare providers**. Uncertainty is a significant concern for people aging with HIV.³⁸ To cope and to thrive in the face of these challenges, participants described the **existing supports** that help them manage their cognitive concerns while aging with HIV. Lastly, they also illustrated key unmet needs and **envisioned ways that they could be better supported** in their cognitive health as people living and aging with HIV.

Theme 1: Cognitive concerns

In our focus groups, people aging with HIV described different concerns related to their cognitive or psychological health.

Memory issues

- Participants in 6/10 focus groups mentioned difficulties with memory, such as forgetting tasks and objects (e.g., bringing money to do laundry). One person described their experience as “short-term memory loss”.

Concentration issues

- Participants in 6/10 focus groups mentioned difficulties with concentration, including difficulty focusing on a task and being easily distracted.

Mental health issues

- Participants in 7/10 focus groups mentioned mental health issues—including depression and anxiety—that complicated their experiences of aging with HIV and cognitive concerns.

“*Because sometimes you get distracted and then at the same time you will lose focus as well, so you can concentrate on one thing and think you can do multiple things when you can't. So your brain gets overwhelmed... with a lot of things at the same time.*”

—Focus group participant describing issues with concentration

Theme 2: Uncertainty related to aging with HIV and cognitive concerns

Participants described **uncertainty** about navigating their cognitive concerns while aging with HIV. They felt uncertain about **what was causing** their cognitive concerns, which was

linked to feelings of uncertainty about **how to treat** or manage these symptoms. Notably, there were participants across all 10 focus groups who reported that they **had never heard of HAND**, and the lack of knowledge about HAND and other cognitive disorders was associated with uncertainty.

“*I worry about my brain. I worry that I'm forgetting too much. I don't know if it's the medication. I don't know if it's the virus. I don't know if it's the age, the aging... there's so much complexity in not knowing what is causing this.*”

—Focus group participant sharing feelings of uncertainty

Theme 3: Interactions with healthcare providers

Across several focus groups, participants described their experiences interacting with healthcare providers in the context of HIV, aging, and cognitive health.

- Participants felt that they were not receiving adequate—or any—knowledge and resources from providers about cognitive health.
- Participants felt that there was no time to bring up cognitive concerns, and several individuals mentioned that mental health was not addressed by their HIV healthcare providers.

- Participants also often felt dismissed by healthcare providers when they did voice concerns about their own cognitive functioning, for example when providers assumed or suggested that the person's cognitive concerns were due to stress. One participant shared, “When I confront my practitioners with my concerns, they say it's just stress go on vacation, that sort of thing.”

- On the flip side, when participants felt validated and heard by their provider, it was a positive experience.

Theme 4: Existing supports for managing cognitive health while living with HIV

Participants described the existing resources that they have accessed to support or manage their cognitive concerns while aging with HIV.

Healthcare Provider

- People aging with HIV described approaching their family doctor, HIV specialist, and/or psychiatrist for support with managing cognitive concerns.

Support Groups

- People aging with HIV also shared that it was helpful and enjoyable to attend support groups, and that these groups were often led by peers living with HIV. They noted that these support groups did not necessarily focus on HIV, aging, or cognition, but were nonetheless still beneficial for supporting mental health and fostering social connection.

Self-Management

- People aging with HIV also used self-care strategies to help manage cognitive concerns. For example, participants mentioned that it was helpful to practice mindfulness, take vitamins, go on walks, and spend time in nature.

“

I like nature... just taking a walk... or going by the lake, it helps to relax me... I can relax my mind and think clearly and see things a little bit better that way.

—Focus group participant describing one way that they manage cognitive concerns

”

Theme 5: Unmet needs and ideas for the future

As well, participants in our focus groups discussed their unmet needs and shared ideas about how they could be better supported to manage cognitive concerns while aging with HIV.

Educating healthcare providers and receiving more referrals/resources

- Participants felt that it would be important for physicians to take initiative in providing information about HIV, HAND, and cognitive disorders—or else the burden may fall on the patient to come prepared with a “list” of concerns to the appointment.

Developing more support groups focused on aging, HIV, and cognition

- People aging with HIV expressed interest in and appreciation for group-based interventions such as CRGT, which they felt would also be helpful for addressing experiences of social isolation and loneliness.

Providing regular screening for cognitive issues

- On the whole, participants were interested in being **assessed for HAND**, especially as part of the CRGT program.
- They also emphasized that it would be important to have opportunities for **consistent check-ups for their cognitive health** (e.g., annual assessments similar to breast cancer screening)—for people of all ages to access.



CONCLUSION & RECOMMENDATIONS

In our first study, people aging with HIV and cognitive concerns shared their thoughts, ideas, opinions, and feedback on how we could adapt cognitive remediation group therapy (CRGT) for virtual or hybrid delivery. The key findings that emerged from this first study were: (1) older people living with HIV continue to be interested in in-person CRGT; and (2) hybrid or online programming is appealing to participants along with in-person programming.

In-person CRGT

Many participants, after years of isolation during the COVID-19 pandemic (also considering that many older adults are socially isolated beyond the pandemic) wanted in-person programming to facilitate social connection and to bond with peers. Participants view group CRGT as a way to connect with other older adults living with HIV, experiencing the same challenges as themselves.

Introducing online CRGT

While, like participants who prefer in-person programming, many participants express the desire for peer connection, the preference to have an online option, or the interest to attend exclusively online is significant. Location is a large factor in this, particularly for individuals in rural communities. Some participants hope for CRGT programming that resembles telehealth and virtual care that became more common during and post the COVID-19 pandemic.

In our second study, people aging with HIV shared about their cognitive health concerns, as well as uncertainty and unmet needs related to their cognitive concerns. Participants also illustrated how they cope in the face of these challenges and described ways in which they could be better supported in their cognitive health while aging with HIV.

Recommendations from Study 2:

- Primary care physicians may wish to ask older adults living with HIV about their memory, concentration, and focus during routine visits.
- It may also be helpful for healthcare providers to have resources or referrals on hand to provide to older adults living with HIV (e.g., referral to medical professional for diagnostic assessment; community services or programming to support people living with HIV; further reading about cognitive concerns and HIV). As a starting point, our resource list at the end of this report may be helpful.
- It is important to develop group-based interventions for people aging with HIV and cognitive concerns. Participants in our research found it helpful and enjoyable to take part in group-based programming (e.g., groups could help them feel less lonely and more connected to others, or learn more coping skills)—yet few such programs exist to support individuals in managing their cognitive health while living with HIV.

RESOURCES

This report does not contain medical advice. If you are concerned about your cognitive health or seeking cognitive screening, please speak with your family physician or HIV specialist.

CATIE. HIV and Aging. <https://www.catie.ca/managing-your-health/hiv-and-aging>



Memory and Aging Center, Weill Institute for Neurosciences, University of California, San Francisco. A healthcare provider's guide to HIV-associated neurocognitive disorder (HAND). https://memory.ucsf.edu/sites/memory.ucsf.edu/files/wysiwyg/UCSF_HIV%20Dementia_Providers_11-6-17.pdf



Realize. HIV and Aging. <https://www.realizecanada.org/our-work/hiv-and-aging/>



HIV, aging, and cognition and CRGT publications: <https://www.eaton-lab.com/hiv-aging-and-cognition.html>



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