Adapting Cognitive Remediation Group Therapy Online: Focus Groups with People Aging with HIV

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Andrew D. Eaton, PhD, MSW^{1,2}, Jenny Hui, MEd^{1,3}, Marvelous Muchenje, MSW^{1,2}, Taylor Kon, BSW¹, Kate Murzin, MPH⁴, Soo Chan Carusone, PhD5, Nuelle Novik, PhD1, Adria Quigley, PhD6,7, Kristina Kokorelias, PhD^{2,8,9,10}, and Francisco Ibáñez-Carrasco, PhD¹¹

Abstract

Cognitive health is a significant concern for people aging with HIV/AIDS. Psychosocial group therapies may help people aging with HIV who experience cognitive challenges cope with their symptoms. The COVID-19 pandemic revealed in-person group therapies need adaptation for technology-mediated delivery. Peer-led focus groups discussed adapting cognitive remediation group therapy (CRGT) as an online intervention. CRGT combines mindfulness-based stress reduction and brain training activities. Purposive sampling recruited people aging with HIV (40+) who self-identified cognitive concerns and resided in one of two Canadian provinces. Thematic content analysis was employed on transcripts by seven independent coders. Ten, 2-hour focus groups were conducted between August and November 2022. Participants (n=45) responded favorably to CRGT's modalities. Alongside support for its continued implementation in-person, participants requested online synchronous and online asynchronous formats. Preferred intervention facilitators were peers and mental health professionals. We also discuss how to adapt psychosocial HIV therapies for technology-mediated delivery.

Keywords

HIV & AIDS, group therapy, cognition, aging, intervention adaptation

Plain Language Summary

Changing an in-person support group about cognitive health to an online support group via focus group consultations with middle-aged and older adults living with HIV/AIDS

Cognitive health concerns are common for people living with HIV as they grow older. Support groups may help individuals make connections with each other and develop ways to manage symptoms of cognitive impairment. In-person support groups need to have online adaptations for many reasons, including access for rural and remote communities. We conducted ten focus groups, led by people living with HIV, to discuss how to change an in-person support group to be online. The support group uses mindfulness and brain training activities. Forty-five people over age 40+ who are living with HIV in Ontario and Saskatchewan, Canada, and concerned about cognitive health participated in these focus groups. Seven researchers analysed the focus group transcripts. Participants liked the idea of the support group, both in-person and online. They specifically requested two forms of an online

Corresponding Author:

Andrew D. Eaton, Faculty of Social Work, University of Regina, Regina, SK, Canada. Email: andrew.eaton@uregina.ca



¹ Faculty of Social Work, University of Regina, Regina, SK, Canada

² Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, ON, Canada

³ Ontario Institute for Studies in Education, University of Toronto, Toronto, ON, Canada

⁴ Realize, Toronto, ON, Canada

⁵ Collaborative for Health and Aging, McMaster University, Hamilton, ON,

School of Physiotherapy, Dalhousie University, Halifax, NS, Canada

⁷ Nova Scotia Health Authority, Halifax, NS, Canada

⁸ Department of Occupational Science & Occupational Therapy, Temerty Faculty of Medicine, University of Toronto, Toronto, ON, Canada

⁹ Toronto Rehabilitation Institute, University Health Network, Toronto, ON, Canada

¹⁰ Department of Medicine, Sinai Health Systems, Toronto, ON, Canada

Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

support group: synchronous, where everyone attends together at the same time, and asynchronous, where people attend at different times. This paper discusses how to change other in-person counselling and support group options for HIV to online formats.

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Background

HIV, Aging, and Cognition

Forty-five years into the HIV/AIDS epidemic, aging with the virus is a priority, due to growing numbers of individuals who are living with HIV and are aged 50+. This trend is driven by greater life expectancy for people living with HIV due to widespread access to combination antiretroviral therapy (cART), as well as increases in new HIV diagnoses among older adults.² Approximately half of Canadians living with HIV are now over 50 years of age³; in 2021, this age group accounted for 20.6% of new HIV diagnoses reported in Canada.⁴ In Ontario, between 2000 and 2015, new HIV diagnoses among people aged 45+ increased from 2551 to 10,063; by 2015, this age group comprised 62.6% of all Ontarians with diagnosed HIV. Another province of note is Saskatchewan, where since 2017: (a) the rate of new HIV infections has been over double the national rate; (b) the majority of new HIV infections are attributed to injection drug use; and (c) in particular, men aged 40+ in Saskatchewan reported the highest proportion of new infections at 36.8/100,000.⁵

As people living with HIV age, they face outsized risks for physical and psychological comorbidities relative to their seronegative peers. 6 There is an increased prevalence for comorbid conditions such as cardiovascular disease, liver diseases, frailty, diabetes, bone and joint disorders, and neurocognitive disorders —which may also present at an earlier age—for people living with HIV, compared to people who are seronegative. ^{7,8} Among these comorbidities, difficulties associated with cognition (ranging from mild symptoms like forgetfulness to diagnosed cognitive impairment) is a common issue with significant consequences for the well-being and quality of life of people aging with HIV. 9-11 Thirty to 50% of people living with HIV—even patients receiving cART—may experience mild-to-moderate or asymptomatic forms of HIV-associated neurocognitive disorders (HAND), which impact cognitive domains such as memory, attention, and speed of processing. 12,13

Cognitive Remediation Group Therapy

Cognitive health is a major concern for people aging with HIV, both in terms of prevalence as well as negative impacts on an individual's quality of life. However, pharmacological interventions have shown limited success in improving cognition. Psychosocial supports thus offer a critical opportunity for alleviating symptoms associated with cognitive impairment, for example by reducing stress and anxiety associated with chronic health conditions 14,15—yet there is currently a dearth

of psychosocial interventions targeting cognitive health for people aging with HIV.¹⁶ People living with HIV have more unique needs for cognitive health support than the general population. This is due to the dual stigma of HIV and cognitive concerns, ¹⁶ as well as the earlier onset of cognitive concerns among people living with HIV; issues with cognition commonly arise in their 40's-60's rather than in geriatric age. 16-18 In existing literature, people living with HIV have highlighted the importance of group therapies for addressing cognitive difficulties, as groups can encourage social connections and community building in the face of stigma. ^{17–19} There is also evidence that psychosocial interventions combining multiple strategies or modalities may demonstrate improved outcomes relative to those reliant on a single technique such as talk therapy. ^{20,21} Moreover, emergent research suggests that social support is associated with improved cognitive functioning among middleaged and older people living with HIV who also identify as sexual minorities (eg. gay or bisexual men).²² This further underscores the importance of developing group interventions for individuals from underserved communities.

In response to this critical gap, our research team developed a cognitive remediation group therapy (CRGT), a combination psychosocial intervention that is grounded in the needs of people aging with HIV and cognitive concerns. 23,24 CRGT blends mindfulness-based stress reduction (MBSR) with braintraining activities (BTAs) and was piloted as an in-person intervention in Canada in 2019.^{23,24} The pilot evaluated CRGT against mutual aid group therapy (an active control) in a randomized controlled trial (RCT) for people diagnosed with mild-to-moderate HAND. 23,24 When CRGT was delivered in person, it consisted of nine 3-hour sessions delivered once weekly.^{23,24} Participants attended an initial 3-hour orientation to set goals for the intervention, make participant-facilitator introductions, establish group norms and guidelines, learn principles of MBSR and BTA, and set up the BTA software. Eight weekly intervention sessions then occurred, each comprised of (a) 2 h of MBSR to teach meditation, body scans, deep breathing, and other exercises to relieve stress; and (b) 1 h of BTA to discuss training progress and challenges, alongside time for individual practice. 23,24 MBSR utilizes a published curriculum of mindfulness and meditation activities, delivered in-session and via weekly homework assignments, 25 which help reduce anxiety and stress associated with cognition.²⁶ Meanwhile, BTA consist of games or activities completed on paper or via software—PositScience by BrainHO, in this instance—that can improve cognitive functioning when practiced for >2 h per week for >8 weeks.²⁷ Each of these strategies has been individually found helpful among people living with HIV.27,28

Results showed that CRGT performed better or equal to mutual aid on outcomes of feasibility, acceptability, fidelity, stress, anxiety, and coping. 23,24 However, the pilot utilized a small sample size (n=12), which was chiefly due to the requirement that participants be formally diagnosed with HAND, a condition that is difficult to determine.²⁹ The small sample limited the conclusions that could be drawn from the results encouraged consideration of alternative screening measure for cognition. Consequently, a sufficiently powered trial was needed after the pilot to determine intervention efficacy. Moreover, the onset of the COVID-19 pandemic ceased all in-person group therapy at the time; since then, psychosocial interventions are increasingly being adapted as online or hybrid initiatives, and these shifts in healthcare delivery formats appear to be persisting. 30,31 As such, the present study aimed to determine how to adapt CRGT for online or hybrid modes of delivery, by conducting focus groups with people aging with HIV and cognitive concerns.

Methods

This was a community-based, participatory research (CBPR) study comprised of a demographic questionnaire and technology-mediated focus groups with people aging with HIV. CBPR in this context means that people living with HIV and cognitive concerns have co-designed, -delivered, and -evaluated CRGT in partnership with community partners and researchers since 2017, ^{23,24} and the partnership is continuing in the present study. ³² The study protocol is published elsewhere. ³² No changes were made from protocol to completion. Ethics approval was obtained from the University of Regina's Research Ethics Board (2022-035). This study was conducted in accordance with the consolidated criteria for reporting qualitative research (COREQ); refer to supplementary file 1 for the COREQ checklist. ³³

Recruitment

People living with HIV were eligible to participate in this study if they were at least 40 years of age, resided in Ontario or Saskatchewan, Canada, and had self-identified cognitive health concerns. The inclusion criteria for age were determined based on research showing that people living with HIV may experience cognitive concerns in their 40's 16-18,34 and that participants in their 40's may be years older before the adapted CRGT interventions are widely available. Moreover, in terms of self-identified cognitive concerns, participants completed a brief demographics survey that asked them to indicate concerns related to an area of cognition (eg, memory, attention, focus), and all participants identified at least one cognitive health concern. Ontario and Saskatchewan were selected as sampling regions because they are two provinces with notable HIV-related statistics. In 2020, the Public Health Agency of Canada³⁵ identified Ontario and Saskatchewan as two provinces with the highest estimated number of new HIV infections. In 2016, Saskatchewan reported an HIV diagnosis rate 15.1 per 100,000, more than two times the overall Canadian rate.³ Meanwhile, Ontario comprised the highest number and proportion of reported HIV cases in Canada in 2016 (n = 881, 37.6%).³

To recruit participants, purposive sampling was used to increase the depth—as opposed to breadth—of understanding about a phenomenon of interest.³⁶ In this sampling method, researchers identify and select specific individuals who hold differing and important views about the issue at hand.³⁷ The study authors leveraged their networks of people living with HIV and HIV organizations to share the study materials via email for recruitment. The authors include people living with HIV, service providers, and researchers who identify as male, female, and nonbinary—and many members of the team hold multiple identities. The team has graduate degrees (eg, PhD) and decades of training experience in community-based HIV research. To sample purposively, peer researchers engaged in outreach with people living with HIV at community events and meetings. Members of the research team promoted the study through organizational websites and social media, and engaged in outreach to gerontological and HIV organizations in Ontario and Saskatchewan.

Data Collection

To collect data, we administered a brief survey questionnaire and then conducted focus groups with people aging with HIV in Ontario and Saskatchewan. The groups discussed CRGT and considerations for adapting it to an online or hybrid format, as well as other issues related to HIV, aging, and cognition. Facilitators prompted participants to expand on points, encouraged differences of opinion, and checked for understanding of participant contributions. As part of the CBPR approach,³⁸ peer researchers—people aging with HIV and with self-identified concerns about cognition—were trained using the research team's curriculum for peer researchers engaged in HIV-related CBPR.³⁹ Critically, peer researchers and community partners played an essential role in our study, as they helped to recruit participants, co-facilitate focus groups, analyze data, co-author knowledge mobilization activities, and prepare the proposal for a subsequent efficacy trial.

Demographic Questionnaire. Prior to taking part in focus group interviews, participants completed a 15-min online survey questionnaire via Qualtrics, which elicited information about their demographics such as age, gender, ethnicity, and length of time living with HIV. The surveys were designed to use accessible wording for individuals of Grade 4-5 reading level, determined through an online readability evaluation software called byreadable.com. Each participant was individually presented with the questionnaire at an initial Zoom meeting with the first author, where they were invited to ask questions about the study, review the consent form, provide oral consent, and complete the questionnaire. At this meeting, participants also scheduled attendance at a future focus group.

Focus Groups. Ten, 2-hour focus groups were conducted between August and November 2022. The facilitators (first,

second, and third authors) discussed the topic of data saturation at the conclusion of each focus group. At the conclusion of the ninth group, the facilitators agreed that no new information had emerged. The tenth group was already scheduled, and when completed confirmed the facilitators' opinion that data saturation had been achieved. Each group comprised of three to seven participants and followed a semi-structured interview guide. The guide (refer to supplementary file 2) contained questions about: (a) CRGT's components; (b) how CRGT could support cognitive health; (c) suggested changes or improvements; and (d) recommendations for future research. The questionnaire was not pre-tested. In this study, each focus group commenced with facilitators describing the study and providing background information about CRGT, including the results of the 2019 in-person pilot RCT.²³ Then, the first portion of focus group questions sought participants' feedback on current components of CRGT: an 8-session weekly 3-h intervention consisting of 2 h of MBSR⁴⁰ and 1 h of BTAs.^{23,24} Participants were asked how these components of CRGT could be modified for an online or hybrid intervention, and which components would preferably be delivered synchronously or asynchronously. Additionally, participants were asked for their preferences regarding the length of the CRGT program and individual sessions, as well as where they would most likely engage with recruitment information for CRGT.

Sample Size

In total, 105 people completed the screening survey. Fifty-three were ineligible due to location (ie, residing outside of Ontario or Saskatchewan, Canada). Seven did not respond to an email inviting them to a group. Forty-five participants completed the entire study and comprise the sample for this article. There was no overlap between the participants who completed this study, and those who took part in the CRGT pilot study. Refer to Figure 1 for a flow chart showing participant eligibility and enrollment.

Data Analysis

Descriptive Statistics. Frequencies of participant demographics were derived from the online survey questionnaires. This included percentages and averages of characteristics such as age, location, gender, sexual orientation, ethnicity, employment, substance use, clinical diagnoses, and information related to HIV diagnosis.

Thematic Content Analysis. Each focus group was audiorecorded and transcribed verbatim. With the 10 resulting transcripts, the seven-member analysis team—consisting of people aging with HIV, service providers, and researchers—utilized a participatory approach to content analysis. 41,42 Each transcript was analyzed by three coders. Each coder was provided the interview guide and the Consolidated Standards of Reporting Trials (CONSORT) checklist for reporting necessary components of a trial, 43 in preparation for designing a future

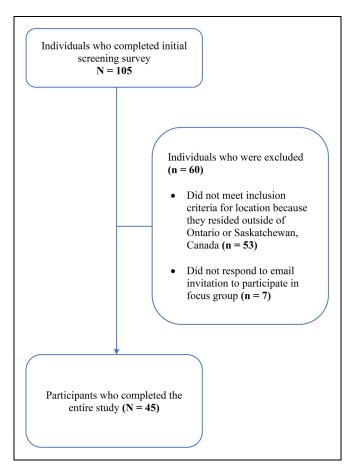


Figure 1. Participant flowchart.

clinical trial of the adapted CRGT intervention. Coders immersed themselves in the data by carefully reading and reviewing the transcripts. Then, each coder extracted and organized codes and supporting quotes into a separate document; codes reflecting similar concepts or themes were grouped together. Independent coding of the data facilitated individual conceptualizations of participants' preferences for an adapted CRGT and an efficacy trial. Upon completion of the individual coding stage, team meetings were held to discuss convergence and divergence of identified themes; the goal of these meetings was to achieve consensus regarding concepts and themes to include in an adapted intervention plan and RCT proposal. 44,45 To mitigate issues of hierarchy or inequitable input within the analysis team, we ensured each team member had an opportunity to review an equal number of transcripts; prepare a written document; and voice feedback during discussion to reach consensus of themes. Prior to disseminating the results of the analyses, we utilized member-checking to discuss findings with focus group participants via email.

Results

Participant demographics are listed below, followed by descriptions of the two key themes that emerged through qualitative

content analysis of focus group transcripts. Each key theme is comprised of three sub-themes and supported by illustrative participant quotations.

Participant Demographics

Demographic characteristics of the focus group participants (n = 45) were derived from the survey questionnaire. Participants' ages ranged from 41 to 71 years, with an average age of 53. Nearly three-quarters of participants resided in Ontario, while the other individuals were based in Saskatchewan. Just over half of the total participants were from Toronto specifically; outside of Toronto, 10 individuals described their location as a large center (population >100,000), five individuals were from a medium center (population 30,000-99,999), and six came from a small center (population <29,999). In terms of gender, participants identified as cis women (44.4%), cis men (42.2%), trans men (4.4%), non-binary (4.4%), two-spirit (2.2%), and gender non-conforming (2.2%). Most participants identified as gay (42.2%) or heterosexual (40.0%), and others as bisexual (8.9%), queer (4.4), two-spirit (2.2%), or lesbian (2.2%). Participants reported their ethnicity as White (44.4%), Black (33.3%), Indigenous (13.3%), mixed-race (4.4%), Hispanic (2.2%), or another unlisted identity (2.2%). Refer to supplementary file 3 for further information about participants' demographic characteristics including information related to employment, HIV diagnoses and support networks, and clinical diagnoses of psychological and neurocognitive disorders.

Qualitative Findings

Two distinct themes emerged from content analysis of the focus group data, capturing participants' perspectives on adapting CRGT for online or hybrid delivery. These two themes—(a) Benefits and Importance of CRGT, and (b) Intervention Delivery and Logistics—each consist of three sub-themes.

Theme One: Benefits and Importance of CRGT. Participants described myriad ways that they could benefit from attending CRGT. They also discussed how CRGT can help people who are getting older with HIV. Respondents valued mindfulness activities that result in relaxation, improved focus, and reduced stress. Brain-training activities were perceived to enhance memory, focus, and attention, providing mental stimulation and flexibility. In addition, group sessions could combat isolation and loneliness. Overall, participants saw mindfulness, brain-training, and group engagement as valuable tools for addressing cognitive challenges and improving well-being in the context of HIV.

Sub-Theme One: Benefits of Mindfulness. Several individuals expressed appreciation for the benefits of mindfulness activities, which comprise one part of CRGT. Participants believed that mindfulness was helpful for relaxing, keeping oneself grounded in the moment, managing attentional difficulties by focusing on one thing instead of multiple things, improving thought clarity,

and reducing stress and anxiety—and that CRGT provided valuable opportunities to practice mindfulness. One participant who had prior experience with mindfulness opined:

I think it's [mindfulness is] amazing. And it's amazing because... It can change the way you react to things. It can help you to fall asleep and help you calm down if you're upset and crying or whatever, to focus on, if you're worried about yesterday or today well then you're not focusing on the present moment.

Mindfulness was identified by some participants as particularly useful for people with cognitive issues, including HAND. For instance, one individual stated:

[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.

Another participant explained that while mindfulness could be challenging or unhelpful at times—for example, when someone "suffers from a lot of anxiety or stress or even depression... [and has] a hard time focusing on the present moment"—there were parts of mindful practice that were useful for them, chiefly "physical mindfulness" involving breathing exercises, attending to bodily sensations, or grounding techniques.

Sub-Theme Two: Benefits of BTA. Another component of CRGT, BTA, was described by participants as helpful for their cognitive health—particularly by providing tools to improve memory, focus, and attention. As one participant shared:

I personally do a lot of like games and stuff like that to keep my mind focused. So, because I have a little better memory loss sometimes, so I try to keep on top of that. So it helps me, so I'm not losing more memory. So, by participating in a little game that's just like word searches or stuff like that or finding objects within a picture to match the object that's being shown, it helps me a lot with my memory.

Participants felt that BTA could help "keep your mind... active," which could be especially helpful "because you are using parts of your mind that you don't use every day." One person mentioned that the games may be a little frustrating at first (eg, if they cannot locate the objects in the BTA task that involves identifying objects), but would be ultimately beneficial. Participants also shared that they liked the accessibility of BTA games, which are portable on one's mobile phone and able to be completed on one's own schedule. Others highlighted how BTA could be enjoyable in their own right, or "a fun way to learn"; as one person put it, "the exercises would certainly be fun. I fiddle and play on my computer and do crossword puzzles and like that kind of thing... So these [BTA]

play right into that." As with mindfulness, some participants highlighted how BTA could have "direct" benefits specifically for people with cognitive issues. One person shared:

I think both the brain HQ and the meditation and mindfulness are really, really important because they very directly address issues being experienced, issues around focusing, issues around remembering, issues around not being distracted and so on. So it's a very direct interaction.

Sub-Theme Three: Benefits of Group Intervention. Participants felt that the group format of CRGT was especially important for several reasons. First and foremost, taking part in a group intervention provides social support and the opportunity to forge new connections, which is critical for addressing the isolation and loneliness shared by many individuals across focus group interviews. Participants highlighted that social isolation is a key issue for older adults aging with HIV and cognitive concerns, who face intersecting stigma based on multiple marginalized identities. Moreover, isolation among people aging with HIV was exacerbated by the COVID-19 pandemic. One participant shared, "[T]here was a time that depression was killing everyone... during COVID or something like that. And most times my physician noted not to stay alone... Just for myself, me being alone is simply not enough for myself."

Elements of mutual aid were also discussed. As one individual opined, "[A]llowing that opportunity to... share your frustrations, our experiences doing the games and, you know, helping each other through that, that's a very important part..." Second, participants believed that completing activities as a group would increase motivation and involvement in the intervention, as group members can help keep each other accountable. As one person explained:

For me, if I'm given exercises on mindfulness or yoga to do it by myself at home, I won't have any motivation to do it. But when you're in a group, it not only reduces isolation, but, like, a lot of fun comes with it.

Additionally, participants discussed the benefits of hearing new and diverse perspectives from people who take part in group activities, including facilitators as well as peers. They mentioned that they would be able to learn new skills and coping mechanisms by becoming aware of others' opinions and "different ways of sitting with people." Some participants explained that this is why they would prefer to have multiple group facilitators from varied backgrounds, as "you learn from different people... [s]o you get different opinions from everybody."

Theme Two: Intervention Delivery and Logistics. The second key theme emerged as participants discussed different considerations for adapting CRGT into a technology-mediated intervention, including participant recruitment, mode and synchronicity of intervention delivery, length of overall program and individual sessions, as well as facilitator identity. Across these discussions about intervention logistics, participants underscored the importance of three factors: (a) Accessibility, or the ability to

feasibly access CRGT and understanding how it works; (b) *Utility*, or the usefulness of the intervention and how to measure progress; and (c) *Flexibility*, or the ability to make choices regarding how one wishes to engage with the intervention.

Sub-Theme Four: Accessibility of Intervention. Participants highlighted that the adaptation of CRGT must be available and accessible to a wide range of individuals aging with HIV and cognitive concerns, including those who live in remote or rural areas, may not have reliable access to technology (eg, Wi-Fi), or have specific needs related to transportation, mobility, or health and safety. Given the diverse needs of people who may wish to take part in CRGT, several participants recommended offering in-person as well as online groups. As one participant explained:

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.

Participants mentioned that the accessibility of in-person CRGT would also depend on the location of the site; although several individuals preferred taking part in an in-person group, long commutes to the delivery site may hinder their ability to attend the group, in which case they would rather attend an online group. One person acknowledged that technology-mediated groups could address certain issues of access while also imposing serious barriers, particularly for someone who is unfamiliar with computers, or resides in an area with wireless services that are unreliable or expensive:

When you bring up this online stuff, you really cut a cord. As a new senior who's not computer trained, who has had no [wireless] service in three months and their bill doubled... I think it's great that all you guys love it, but I don't know how to use computers. The service is inconsistent. I can't afford it... I see the convenience of doing it [online], but I'm used to doing things in person the old-fashioned way...

Sub-Theme Five: Utility of Intervention. In addition to accessibility concerns, participants emphasized that it was important to understand how CRGT is useful or beneficial for them, especially in terms of cognitive health issues. Participants expressed a desire for clarity regarding the purpose of CRGT and its different components, the positive and negative impacts that these activities may have on one's cognitive health, indicators of progress, as well as what to expect in terms of a timeline for change. One person requested, "I would like to know how much my brain can be strengthened and my memory by doing those things [ie, BTA, mindfulness]." Participants preferred to have this information provided prior to starting CRGT, as well as during the intervention. Understanding the purpose of different activities could strengthen participants' engagement with CRGT; as one participant shared, "I'm open

to try new things, but... I just don't want to do anything that's a waste of my time," while another stated, "If you tell me just do it without a purpose after a while... I will lose my interest and my interests will go away at some point because I find it's just redundant."

Participants made different recommendations for improving the utility of the online intervention for their needs. For example, participants discussed methods for ensuring that group members remained engaged and attentive during the virtual sessions. They mentioned that each session should be as interactive as possible and should not exceed 2 hours, as people may have difficulty staying still or focused for longer periods of time due to restlessness, reduced attentive capacity, ADHD, or physical conditions such as digestive issues.

Sub-Theme Six: Flexibility of Intervention. There was consensus among participants that it was crucial for them to individually decide how they would like to engage with CRGT, as well as be able to express their own personal preferences. For example, participants expressed preference for group facilitators who—regardless of profession—are aware of different learning styles and able to flexibly tailor online CRGT activities to meet individual needs. Of note, participants highlighted that delivering CRGT as a hybrid intervention provides flexibility for people to attend online or in person. Then they could choose how to participate in the intervention (eg, online or in person), participants felt a greater sense of control. As one person put it:

I think it should be a self-choice. If someone wants to be in person, let them be in person. If they want to be on Zoom let them be on Zoom. I think it should be... whatever is comfortable for that person.

Some participants raised the option of making online and in-person sessions of CRGT available for a longer period of time, during which group members could flexibly "drop in" based on personal preference, or attend follow-up sessions after completion of the primary intervention. For example, one person proposed a "graduated system" involving several weeks of attending CRGT, followed by a few weeks off, and then an opportunity to return to CRGT for follow-up sessions. In discussing the benefits of a flexible, drop-in program, another participant expressed,

It would be nice to have, you know, the availability... you can try out by yourself, you can go by yourself, it doesn't work, you're stuck, you go back, you get some reinforcement, reassurances, maybe talk to others, maybe confer with others again.

Discussion

This study's main findings are that people aging with HIV are interested in both in-person and online CRGT interventions. Some preferred the social connection of in-person sessions, especially after experiencing isolation due to COVID-19. Others favored online options due to access challenges and

concerns about air-borne illness. Some wanted synchronous online sessions (with a facilitator at the same time), while others preferred asynchronous ones (self-paced). Below we situate findings within literature regarding how: (a) in-person CRGT continues to be of interest to people aging with HIV and (b) online synchronous and asynchronous forms, alongside the in-person iteration offered previously, may be preferable for some people in some contexts.

Resuming In-Person CRGT

Participants highlighted a certain loss of community during the COVID-19 pandemic and a desire to gather with their peers once again. The HIV/AIDS epidemic has long been understood as exceptional, 46 and a key component of that exceptionalism is the existence of community-based HIV services (eg, AIDS Committee of Toronto, AIDS Programs South Saskatchewan) in many cities worldwide. Community-based services help people living with HIV to connect with each other and access programs and services for health and well-being. 47,48 While a systematic review and meta-analysis has determined that, overall, HIV infection did not significantly increase risk of COVID-19 mortality, 49 there were fears that the immunodeficiency virus could exacerbate COVID-19 infection. Discrete studies showed upwards of 38% greater risk of severe illness and death due to COVID-19 among people living with HIV compared to the general population. 50 As a result, in-person HIV community support services were moved to online formats (eg, Zoom) during the pandemic years.⁵¹ This study found that these service closures made participants yearn for in-person connection, and that isolation resulting from COVID-19 heightened some respondents concerns about their cognitive health. This may be related to the dual stigma of HIV and cognitive health concerns, 16,17 which can exacerbate the difficulties of isolation. These factors contributed to participants' overall interest in CRGT, and preference for the in-person form specifically.

Introducing Online CRGT

While all participants expressed interest in and enthusiasm for CRGT, some made it clear that they would exclusively attend an online iteration. Factors guiding this preference included service access issues and concerns arising from the COVID-19 pandemic. There is a risk/benefit calculation regarding HIV services that has arisen from the COVID-19 pandemic;⁵² in this study, participants were balancing the risk of coronavirus infection against the health impacts of isolation, which may have applications during other illness outbreaks. It may be more difficult to provide certain types of social support in an online group environment, which could in turn impact the efficacy of delivering online CRGT. For instance, some studies suggest that group cohesion may be reduced in the absence of bodily interactions and nonverbal cues.⁵³ Concurrently, extant literature has clearly demonstrated that it is more difficult to live with HIV in rural and remote environments than in urban centers. 54,55 For the most part, healthcare systems lacked options for remote or online engagement—particularly in group format—prior to the COVID-19 pandemic, which greatly quickened the adoption of telehealth and virtual care in both individual and group formats.⁵⁶ Study participants who desired peer connection similar to in-person CRGT—but would only attend online sessions—expressed preference for online synchronous CRGT delivered via a web conference platform (eg, Zoom Healthcare). Based on participants' consensus, the format of online synchronous CRGT would consist of twice weekly 1.5-h sessions over 8 weeks (for 16 sessions or 24 h, the same hours as in-person CRGT), and each session would be equally divided between MBSR and BTA. Respondents who found it difficult to schedule consistent time for a weekly group, or who preferred a different experience regarding the intervention's elements, requested online asynchronous CRGT. This would consist of eight self-directed online MBSR modules and BTA practice facilitated by a forum whereby participants can discuss progress and challenges with each other and facilitators in a text-based format.

Implications for Research

These findings necessitated reflection on the ideal design for an efficacy trial of CRGT. Noting participants' strong preferences for either in-person CRGT, online synchronous CRGT, or online asynchronous CRGT, designing a RCT whereby participants would be allocated to one of these forms arbitrarily appeared to conflict with what people aging with HIV were requesting. Another way HIV is exceptional compared to other illnesses is how people living with the virus have impacted the conduct of clinical trials since the earliest years of the epidemic.⁵⁷ This has included questioning and—in some instances—redesigning traditional RCT elements such as randomization, use of placebo, and blinding.⁵⁸ Innovative clinical trials (iCTs) are emerging as alternatives to traditional RCTs, 59 and people living with HIV are again on the vanguard of improvements to research designs. 60 Therefore, a partially randomized patient preference trial (RPPT) may best evaluate CRGT's efficacy. RPPT is a form of iCT that has been found to enhance external validity while maintaining the internal validity of RCTs, 60 and bolstering retention. 61 An RPPT of CRGT could incorporate preference for in-person or online CRGT (which could be based on location, concerns about in-person groups, or other factors) while permitting randomization for those with no preference.

This study contributes to the literature on behavioral interventions regarding HIV and comorbidity management. During the COVID-19 pandemic, behavioral interventions rapidly moved to technology-mediated forms, ³¹ yet this study shows that some people living with HIV prefer to remain online while others wish to convene in-person. Since people living with HIV are at increased risk of age-related comorbidities, ^{8,10} there is debate on whether behavioral interventions

should focus on discrete comorbidities or the broader construct of healthy aging. ⁶² Participants in this study focused specifically on cognitive health, which may suggest that some comorbidities would benefit from distinct interventions.

Limitations

This study has several limitations. Data collection solely in English may have limited participation. Participants in the focus groups are likely not representative of people living with HIV over the age of 40 in Ontario and Saskatchewan. The study is at risk of social desirability bias whereby respondents may have provided responses they perceived as being favorable. 63 While completion of a survey and focus group indicate some interest in the CRGT model, this may not translate to enrollment in a multi-week group intervention. Thick description of numerous responses across 10 focus groups may mitigate some of these concerns. During data analysis, the focus group transcripts were de-identified such that information that may identify an individual participant was removed or anonymized. Consequently, we could not analyze the focus group data for differences in participants' responses based on demographic variables (eg, ethnoracial identity, sexual orientation, and gender). The focus group facilitators shared that they did not perceive any discernible trends in our data, in terms of differences in participants' responses based on ethnicity, gender, sexual orientation, and other demographic variables. In other words, participants' preferences about adapting the CRGT intervention were not consistent with any specific demographic categories. Inter-rater reliability was not calculated. Employing multiple coders, including community members, on a small budget meant that software that facilitates inter-rater coefficient calculation (eg, NVIVO) was not feasible. Further, the coding team has been working together for over ten years and as a result may interpret the data in similar ways.64

Conclusion

This study presents results from a qualitative, community-based participatory study to adapt CRGT into online forms for people aging with HIV and cognitive concerns. This paper details the experiences of people aging with HIV coming out of the COVID-19 pandemic, considering how best to access behavioral support for cognitive health. In conclusion, our study highlighted that individuals aging with HIV have a strong interest in both in-person and online interventions that support their cognitive health. The social connection provided by in-person sessions is especially valued, given experiences of isolation during the COVID-19 pandemic. Meanwhile, online alternatives are preferred by those facing access challenges and worries of airborne illness. Notably, participants exhibit varying preferences for synchronous or asynchronous online sessions. These findings are compelling as we consider the lasting impacts of the COVID-19 pandemic and how to best design behavioral interventions for people living with HIV.

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ORCID iD

Andrew D. Eaton https://orcid.org/0000-0003-1331-1222

Supplemental Material

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