BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-033183
Article Type:	Protocol
Date Submitted by the Author:	24-Jul-2019
Complete List of Authors:	Eaton, Andrew; University of Toronto, Factor-Inwentash Faculty of Social Work Walmsley, Sharon; Toronto General Hospital, Toronto General Research Institute Craig, Shelley; University of Toronto, Factor-Inwentash Faculty of Social Work Rourke, Sean; St. Michael's Hospital Sota, Teresa; St. Michael's Hospital McCullagh, John; Ontario AIDS Network (OAN) Fallon, B; University of Toronto, Social Work
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Dementia < NEUROLOGY, SOCIAL MEDICINE, Clinical trials < THERAPEUTICS

Cognitive remediation group therapy for people aging with HIV-Associated Neurocognitive Disorder (HAND): Protocol for a pilot randomized, controlled trial

Andrew D. Eaton[1]*, Sharon L. Walmsley[2], Shelley L. Craig[1], Sean B. Rourke[3], Teresa Sota[3], John W. McCullagh[4], Barbara A. Fallon[1]

[1]Factor-Inwentash Faculty of Social Work, University of Toronto; Toronto, ON, Canada

[2]Toronto General Research Institute; Toronto, ON, Canada

[3] St. Michael's Hospital; Toronto, ON, Canada

[4]Ontario AIDS Network (OAN); Toronto, ON, Canada

*Corresponding author. Factor-Inwentash Faculty of Social Work, University of Toronto. 246 Bloor St. W., Toronto, ON, Canada, M5S1V4 Phone: +1-416-978-8895. Email: andrew.eaton@utoronto.ca.

Word count: 3,453

Abstract

Objective: To pilot test Cognitive Remediation Group Therapy (CRGT) for people aging with HIV-Associated Neurocognitive Disorder (HAND), and to compare outcomes against an active control group.

Study design: A pilot, parallel design, two-arm randomized, controlled trial. Community-based participatory research was utilized to design this protocol.

Settings: Recruiting site is a neurobehavioural research unit at a tertiary care hospital in Toronto, Canada. Interventions will be held at community-based organizations.

Participants: Participants will be recruited from amongst those who were diagnosed with the Mild Neurocognitive Disorder (MND) form of HAND, provided consent to be contacted for further research, and had last clinic visit after January 1, 2016. Eligibility criteria includes age ≥ 40 years, known HIV status for 5+ years, English fluency, able to consent to the protocol, and able to attend eight weeks of group therapy.

Interventions: Eligible participants will be randomized to one treatment arm. Both arms consist of eight-session group interventions delivered once weekly at three hours per session. Arm 1 (novel) is CRGT, combining Mindfulness-Based Stress Reduction with Brain Training Activities. Arm 2 (active control) is Mutual Aid Group Therapy, an established intervention for people living with HIV and dementia.

Outcomes: Feasibility, measured by proportions of the sampling frame that consent, enrol, begin, and complete the study. Acceptability, assessed by a questionnaire comprised of a standardized satisfaction scale for support groups and questions about session length, number of sessions, activities used, and evaluation of therapy facilitators. Intervention fidelity, assessed through facilitator session reports. Exploratory outcomes of change in stress, anxiety, coping, and use of intervention activities, measured at three time points.

Anticipated Results: This study could provide insight into study design (e.g., recruitment, measures) and intervention considerations (e.g., structure, content) for a larger trial to lessen the burden of cognitive decline amongst people living with HIV.

Keywords

HIV & AIDS; Dementia; Social medicine; Clinical trials

Strengths and limitations of this study

- This protocol's community-based participatory research approach prioritized patient and public involvement as people aging with HIV co-designed the study, will deliver the interventions, and will be involved in analysis and dissemination of results.

- Cognitive impairment may be the most prevalent comorbidity for people aging with HIV, and a lack of interventions exist to address the stress and anxiety caused by HIV-Associated Neurocognitive Disorder (HAND).

- Studies that test psychosocial interventions are often quasi-experimental or compare an intervention to an inactive control. This pilot trial's active design permits comparison between two distinct interventions.

- The key limitations of this protocol are: a small target sample, lack of participant blinding, a single recruiting site, limiting entry criteria to anglophones, no long-term follow-up, potential confounders (e.g., stage of HIV, concurrent comorbidities, etc.), requirement to know how to use a tablet and the internet for brain training activities, and a need for consistent availability for eight sessions of weekly three-hour group therapy.

1.0 Introduction

1.1 Background and rationale

Cognitive impairment is a significant comorbidity for people aging with HIV; 30-50% may be affected to some degree by HIV-Associated Neurocognitive Disorder (HAND) [1-3]. HAND is thought to result from structural damage to fronto-striatial-thalamatory circuits in the brain (neural pathways that mediate cognitive, motor, and behavioural functions); hence, there is no cure [3-8]. HAND is diagnosed in three categories of graded severity based on the Frascati criteria determined by the CHARTER cohort study of people aging with HIV and neurological challenges [3, 4]. The Frascati categories (with estimated prevalence from CHARTER in brackets) are: (a) Asymptomatic Neurocognitive Impairment (ANI – 33%); (b) Mild Neurocognitive Disorder (MND – 12 – 20%); and (c) HIV-Associated Dementia (HAD - < 2 – 3%) [4]. These categorizations are determined by neuropsychological testing of the degree of abnormality in cognitive domains (e.g., speed-of-processing, executive functioning, etc.) and by level of impairment to activities of daily living [4, 5]. Without effective HIV medication, people living with HIV may rapidly progress through these stages, demonstrated by high rates of the most severe form (HAD) prior to the introduction of successful cART regimens [2-5]. HAND may be a result of uncontrolled HIV replication in the brain [4-7]. The development and widespread use of modern cART, and the trend towards earlier treatment initiation, has reduced HAND's severity and its consequences; however, it remains a significantly debilitating issue [3, 9, 10]. It is seen more commonly, and is of particular concern, in AIDS survivors – people aging with HIV who were treated with incompletely suppressive antiretroviral regimens and with medications that had higher rates of mitochondrial toxicity, often late in disease such as after an AIDS defining illness or when the immune system was very weak [6-8]. The shift in prevalence from severe to moderate HAND, and the higher risk amongst AIDS survivors, may suggest that uncontrolled replication of HIV in the brain is causative, and that there is less opportunity for replication when effective treatment is initiated early [5].

HAND symptoms include memory deficits, problem solving errors, difficulties in processing new information, executive function impairment, and poor decision making [3-8]. This in turn leads to stress, anxiety, social isolation, difficult coping, and impacts daily activities (e.g., medication adherence) [11-13]. HAND differs from Alzheimer's disease and other cognitive impairments in numerous clinical areas [7]. Perhaps the most distinguishing characteristic is that people living with HIV are at similar risk of mild HAND in their 40's and 50's as the general population is at risk of mild dementia in their geriatric years [10, 11]. With cognitive decline from normal aging and other syndemic factors (e.g., intersecting HIV and aging comorbidities), HAND symptoms are amplified and further impair the aging HIV-infected adult's ability to cope [13]. With the earlier age of impairment and syndemic factors associated with HIV, HAND may be a condition in need of specific psychosocial intervention distinct from what is currently being tested in geriatric adults with dementia [12, 14]. Yet despite exploratory research on the unique challenges of HAND and a stated community need [11, 12, 15-17], HAND intervention research in the era of modern cART is limited and the optimal intervention is unclear [13, 14].

Psychosocial factors (i.e., social networks, mood) have predicted the ability to cope with HAND symptoms when demographics (i.e., gender, age, education, and ethnicity) and neurocognitive results are controlled [18], so interventions which improve psychosocial factors may enhance coping with HAND. Mindfulness-Based Stress Reduction (MBSR) group therapy has decreased stress and anxiety, and improved coping for people with dementia [19]. Computerized brain training activities (BTA) have had similar benefit in middle-aged and older adults with HAND, but participants have requested emotional support (such as MBSR) to complement BTA [20]. Further, a scoping review found that a combination approach (i.e., mindfulness, cognitive training techniques, and group therapy) to psychosocial interventions may have better health outcomes for people living with HIV than a single technique approach [21]. Using community-based participatory research to engage people aging with HIV and HAND researchers, this study will pilot cognitive remediation group therapy (CRGT) – combining MBSR and BTA – in a pilot randomized, controlled trial (RCT) of feasibility and acceptability. CRGT will be against an active control – mutual aid group therapy – chosen as an established intervention in both the HIV [22] and dementia [23] fields that mimics the form (i.e., support group) of CRGT while controlling for the inherent benefit (i.e., social connection) of group therapy [24].

1.2 Objectives

The primary objective of this pilot RCT is to test cognitive remediation group therapy (CRGT) for a sample of people aging with HIV who have been diagnosed with mild-to-moderate HAND (i.e., MND), and to compare feasibility and acceptability outcomes against an active control of mutual aid group therapy. The secondary objective is to assess implementation fidelity of both trial arms. Exploratory objectives are to compare stress, anxiety, coping, and use of mindfulness and brain training activities.

1.3 Trial design

This is a pilot, parallel group design RCT that will recruit people aging with HIV (≥ 40 years old) who have been diagnosed with MND-HAND since January 1, 2016 from a neurobehavioural research unit in Toronto, Canada. The trial uses a refinement framework to assess, in a preliminary sense, whether therapy of this nature is feasible and acceptable to this population [25]. The recruited sample (target n = 12-16) will be randomized to either eight weekly three-hour sessions of CRGT or eight weekly three-hour sessions of mutual aid group therapy.

2.0 Methods: Participants, interventions, and outcomes

2.1 Study setting

Participants will be recruited from St. Michael's Hospital's Neurobehavioral Research Unit, a clinic dedicated to HAND assessment in downtown Toronto, Canada. This clinic uses Frascati criteria [3] to assess cognitive impairment via neuropsychological testing conducted by two psychologists. The intervention arms will be at community-based organizations in downtown Toronto, Canada. The novel CRGT arm will be at the Centre for Mindfulness Studies, a facility that owns the necessary equipment for MBSR (e.g., yoga mats). The control mutual aid arm will be at the AIDS Committee of Toronto (ACT), who have been offering mutual aid groups for people living with HIV for over twenty years.

2.2 Patient and public involvement

Community-based participatory research (CBPR) and implementation science guided an approach to engage people aging with HIV and affected by HAND, alongside service providers and HAND researchers, as the protocol was being developed. First, an exploratory CBPR study surveyed (n=108) and interviewed (n=20) people aging with HIV in Ontario; approximately one-eighth of participants had been diagnosed with HAND and the entirety of the sample self-identified recently reduced function and ability in more than one cognitive domain (e.g., memory, speed-of-processing) [12]. The purpose of this initial study was to determine direction for psychosocial interventions in HIV and cognition, with a focus on social work due to the profession's history of effective engagement with people living with HIV [26, 27]. The initial study also sought to understand the impacts of peer service provision and peer research from people affected by HAND themselves [28,29]. The results of this study suggested that a cognitive remediation intervention, combining emotional and practical coping skills training in a group setting, may help people living with HAND manage their symptoms and improve their wellbeing [12].

Second, the first author conducted key informant interviews with six HAND researchers from Canada, the United States, Spain, and Australia. These interviews discussed work-in-progress and design considerations for intervention research, an example of which is Brain Training Activities (BTA). BTA, comprised of online and offline games and activities targeted for cognition, shows promise in helping people with cognitive impairment improve their function at specific tasks and activities (e.g., remembering sequences, responding quickly) through repeated practice [20]. BTA has been predominantly administered as an individual activity, such as software installed on a person's home computer with clinic follow-up on progress. This may contribute to relatively low uptake of BTA as a promising intervention technique [30].

Third, the first and sixth authors held two focus groups in downtown Toronto: one with people aging with HIV and concerned about HAND (n=10) and one of social workers in the HIV field (n=8). These consultations were conducted to finalize trial components, including intervention selection, appropriate questionnaires, and a sensitive method of data collection. These activities supported CBPR's aim of co-constructing new interventions with people most affected by the issue under study [31], and implementation science's recommendation of preliminary consultation to improve the potential for scale-up should the study determine promising results [32].

2.3 Eligibility criteria

Inclusion criteria: People who: (a) are aged ≥ 40 years; (b) have a documented HAND diagnosis of Mild Neurocognitive Disorder (MND); (c) were diagnosed with HIV ≥ 5 years ago; (d) provided consent to St. Michael's Hospital to be contacted for future research studies; and (e) could feasibly attend eight weeks of group therapy in downtown Toronto. Exclusion criteria: Participants who: (a) have a documented HAND diagnosis of Asymptomatic Neurocognitive Impairment (ANI) or HIV-Associated Dementia (HAD); (b) have been hospitalized in the past month; (c) are unable to communicate in English; (d) are unable to use a tablet for BTA; or (e) are assessed by the research coordinator to be disruptive to a group therapy setting (e.g., due to discriminatory remarks). Justification: MND is chosen instead of ANI or HAD due to the potential for unacceptably high false positive error rates in ANI [33] and the potential null effect from psychosocial interventions for people with HAD [14]. As the two arms will address HAND and not HIV, a limit of ≥ 5 years since HIV diagnosis is set to mitigate the risk that some participants may want to discuss issues associated with a recent HIV diagnosis instead of issues associated with HAND. Forty years of age is chosen as the lower limit as it is approximately one standard deviation below the mean of MND diagnosis in the CHARTER cohort [3, 4] and at the recruiting clinic. Other criteria were set in accordance with the study's context. For example, recent hospitalization could suggest poor health and could bar participation in an eight-week group.

2.4 Interventions

Both interventions consist of nine, three-hour weekly sessions (an orientation session and eight group sessions) and will be at community-based organizations in downtown Toronto, Canada.

2.4.1 Cognitive remediation group therapy (novel arm)

Cognitive Remediation Group Therapy (CRGT) is a blend of two emerging interventions – Mindfulness-Based Stress Reduction (MBSR) and Brain Training Activities (BTA) that will be combined for the first time for people with HAND in this study. MBSR will comprise two-thirds of each weekly session and will be facilitated by a physician and a social worker using the MBSR manual that includes meditation, body scans, deep breathing, and other exercises to relieve stress and regulate emotions [34]. BTA will comprise the remaining one-third of each group session and will be facilitated by a peer aging with HIV. Participants will have access to Samsung tablets and a one-year license to BrainHQ training by PositScience. BrainHQ tailors training (i.e., games) to participant's deficit domains (e.g., speed-of-processing, memory) via a screening exercise and then offers activities of increasing difficulty. If people practice for a minimum of three hours per week for eight weeks, they may self-report a positive change in coping [30]. As this may be the first time BTA is offered in a group setting, the peer facilitator will use a participatory approach by soliciting participants' input on how to structure sessions (e.g., individual practice, group discussion on training progress and challenges, or some combination).

2.4.2 Mutual aid group therapy (control arm)

Mutual aid groups consist of facilitated discussion of challenges and coping strategies associated with an illness or issue [24]. Mutual aid groups may be the most recognizable form of group therapy, as Alcoholics Anonymous has popularized the model [35]. These groups use the principle that people can help one another overcome their health and social challenges when trained facilitators – often social workers – help the group maintain respect, stay on topic, and explicate connection and shared experience between participants [36]. For this study, mutual aid will be facilitated by a social worker and a peer aging with HIV. Refer supplementary file 1 for the facilitators' manual of this model.

2.4.3 Discontinuation criteria

Participants may cancel their participation at any time. Intervention arms will be discontinued if, due to cancellations, the total number of participants registered to an arm is three or less.

2.4.4 Protocol adherence strategies

The study sponsor has access to the participant database and will monitor the timeline of protocol procedures. Facilitators of each intervention arm will submit weekly session reports that will be checked to ensure that interventions are progressing as designed.

2.4.5 Concomitant care and interventions

Co-enrollment in another HAND or mindfulness treatment study is not permitted.

2.5 Outcomes

Outcomes and measures are listed in table 1. As a pilot study, feasibility and acceptability are primary outcomes to assess whether a larger trial could further test group therapy for people with HAND. Intervention fidelity (i.e., how closely the facilitators adhere to each arm's therapy model) is a secondary outcome to assess whether the interventions are delivered as planned. Exploratory outcomes of stress, anxiety, coping, and use of brain training and mindfulness activities will also be assessed.

Table 1: Outcomes and measures

Outcomes	Measures	Description
Feasibility	Participant recruitment and retention	Proportion of eligible participants who agree to participate, complete the pre-test, attend the first group session, complete the full group series, and complete the study
	Chart abstraction of participant demographics	The sampling frame's demographics (i.e., age, gender, ethnicity, length of time living with HIV, length of HAND diagnosis) will be described in terms of those who agree and decline to participate
Acceptability	Helping Characteristics of Self-Help and Support Groups Measure [37]	22-item Likert measure where higher scores indicate greater group satisfaction, administered in sessions four and eight of each arm
	Reasons for withdrawal (if applicable)	If participants withdraw from the study, they will be asked if they consent to having the reason for withdrawal described
Intervention fidelity	Facilitators' session reports	Facilitators will submit weekly session reports that will include checklists of therapy components and open-ended questions about group activities, dynamics, and challenges
Stress	HIV/AIDS Stress Scale [38]	29-item Likert measure where higher scores indicate greater HIV-related stress
Anxiety	Anxiety in Cognitive Impairment and Dementia Scale [39]	26-item dyadic measure where higher scores indicate greater cognition-related anxiety
Coping	Coping Self-Efficacy Scale of Health Problems [40]	10-item Likert measure where higher scores indicate greater coping with health problems
Use of mindfulness strategies	Five Facet Mindfulness Questionnaire – Short Form [41]	24-item Likert measure where higher scores indicate greater use of mindfulness strategies
Use of brain training activities	Novel arm – PositScience progress reports Control arm – self-report	The brain training software provided to participants in the novel arm tracks their activity. For the control arm, participants will self-report use of brain training activities

2.6 Participant timeline

Refer to table 2 for the schedule of events. The timeline consists of three distinct periods: a) screening, where eligibility will be confirmed, the research coordinator will obtain consent and participants will complete baseline questionnaires; b) study, where intervention arms will be administered; c) and follow-up, where participants complete questionnaires at the interventions' conclusion and a 3-month follow-up.

Table 2: Schedule of events

Visit Details	**Screening Period**			**Study Period**			**Follow-up Period**	
Visit Name	Screening Call	Screening Visit	Baseline Visit	Orientation	Sessions 1-7	Sessions 4 & 8	Follow-up Visit	End of Study Visit
Visit #	-3	-2	-1	0	1,2,3,4,6,7	4 & 8	9	10
Week #			-1	0-8			9	21
Day #	-56 to -7 days		-7	0-56			63	153
Day Window	+/- 7	+/- 7	+/- 7	+/- 7	+/- 0	+/- 0	+/- 7	+/- 7
Procedures								
Informed Consent		X						
Entry Criteria Assessment	X	X						
Chart Abstraction (demographics)		X						
Randomization			X[1]					
Group Sessions				X[2]	X	X		
Facilitator Session Reports					X	X		
Helping Characteristics of Self-Help and Support Groups Measure						X		
HIV/AIDS Stress Scale			X				X	X
Anxiety in Cognitive Impairment and Dementia Scale			X				X	X
Coping Self-efficacy of Health Problems Scale			X				X	X
Five Facet Mindfulness Questionnaire – Short Form			X				X	X

[1] To occur once all participants have been enrolled and eligibility confirmed

[2] Acquaintance with group only; no therapy will be administered during this session

2.7 Sample size

A sample size of 12-16 participants (6-8 in each study arm) has been selected as: (a) 6-8 participants have been found to be an ideal size for eight weeks of group therapy [42]; and (b) this number can provide preliminary insight into the feasibility and acceptability of the novel CRGT arm, before initiating a larger study. Further, 12-16 participants are 30% to 40% of the sampling frame (n=40). So, if this pilot's results prove promising, scale-up to a larger study with similar recruitment proportions would feasibly require a sample of 90-120 from approximately 300 potential participants.

2.8 Recruitment

A clinical psychologist from the recruiting site will attempt to contact all participants in the sampling frame (n=40) at their last known phone number and email. Three distinct contact attempts will be made for each individual. This contact will briefly explain the study and determine whether a participant elects to meet with the study coordinator to confirm eligibility and review the consent form.

3.0 Methods: Assignment of interventions

3.1 Allocation

Concealed allocation will be used for this study. The first author will provide the study sponsor with unique identifiers of each enrolled participant. The sponsor will then randomize participants in a 1:1 fashion using blocks of size two to either the novel or control arm. Individual allocation results will then be communicated to each participant.

3.2 Blinding

Facilitators of the study arms will be blind to outcome assessments; otherwise, this study is not blinded. Blinding participants to psychosocial trials is difficult, as participants are actively involved in their therapy [43]. Blinding of this nature often requires deception, which raises ethical concerns [44]. The limitations to this approach and mitigating strategies will be discussed in the results paper.

4.0 Methods: Data collection, management, and analysis

4.1 Data collection methods

Demographics will be abstracted from participant charts at the recruiting site. A research coordinator will collect self-reported data for exploratory outcomes from participants at three times (baseline, postintervention, and 3-month follow-up). Further, the coordinator will collect acceptability data via a questionnaire at the midpoint and endpoint of the interventions. Group facilitators will write structured session reports to be submitted weekly following each group session. Refer to supplementary file 2 for consent and data collection forms.

4.2 Participant retention plans

To promote participant retention in group sessions, the study coordinator will send weekly reminders to participants. To promote completion of questionnaires, three distinct contact attempts will be made to schedule study visits. If a participant withdraws from the study, the coordinator will ask for permission to report the reason for withdrawal.

4.3 Data management

All data collected will be labelled with a unique identifier for each participant. The study coordinator will enter data into REDCap (Research Electronic Data Capture), a browser-based database; this data will be verified by the principal investigator.

4.4 Analysis

The stakeholders (people aging with HIV, service providers, and researchers) who provided initial consultation to study design will reconvene to collectively analyze the de-identified results, to inform the design of a larger study of group therapy for people aging with HIV who are experiencing cognitive challenges. For intervention fidelity, content analysis will be performed by two independent coders familiar with the models of group therapy [45]. With a small target sample, analysis of the exploratory outcomes will be limited. With a Kenward-Roger adjustment for small sample size (i.e., scaling F by factor λ and determining denominator degrees of freedom m for an approximate expectation and variance of a $F_{l,m}$ distribution) [46] to the covariance matrix, a between-groups treatment effect may be detected while minimizing false positive error risk in these exploratory outcomes [47].

5.0 Safety considerations

Group therapy poses risk of psychological and social distress when participants feel uncomfortable discussing sensitive concerns and when they believe their confidentiality may be jeopardized. To mitigate these potential risks, the nature of a group setting and the limits of confidentiality will be discussed with participants at the consent stage. Facilitators will also meet with participants individually in an orientation meeting prior to the group's commencement to discuss norms and guidelines for group behaviour. Additionally, participants may withdraw their participation at any time, without any impact on their current standard of care. Further services and resources will be provided to participants who withdraw. Conducting the intervention arms at community-based sites that currently offer other types of support services to people living with HIV (such as counselling) may provide an opportunity for participants to access additional supports if necessary.

6.0 Ethics and dissemination

The study sponsor will monitor the trial, and audit the data at their discretion. Consent forms and data will be stored separately on secure, encrypted servers for seven years following study completion. The study protocol and consent form have been approved by the Research Ethics Boards of St. Michael's Hospital (#17-334) and the University of Toronto (#35860). The trial was registered on clinicaltrials.gov (#NCT03483740) before recruitment commenced. Protocol amendments, if applicable, will be communicated to the study sponsor, ethics boards, and registry prior to implementation. Outputs from this study will include journal publications, conference presentations, and community reporting. Outputs will not identify participants.

7.0 Discussion

This pilot RCT may provide preliminary insight into how the novel CRGT as a combination intervention (i.e., MBSR, BTA, and group therapy) compares to the mutual aid standard of group therapy that comprises the active control. The community-based approach may also provide insight into how patient and public involvement can inform the design and analysis of psychosocial intervention trials [48], with implications for other social researchers seeking to design rigorous and community-informed intervention studies of a similar nature.

CRGT may offer participants practical and emotional coping strategies alongside the inherent social connection benefit that participants can receive from the mutual aid control. This will build on existing research showing that combination approaches are preferable to people living with HIV [21] and people with dementia [19], while addressing the gap in psychosocial interventions for people with HAND. This refinement pilot trial will provide insight into the feasibility and acceptability of CRGT and a study of this nature, to inform the development of a larger study. A pilot is needed, given HAND's complexity and the lack of existing interventions for this condition, to preliminarily assess these interventions before a larger trial is designed. Based on other psychosocial intervention pilot trials [49, 50] a sample of 12-16 completing the study with positive acceptability results and strong intervention fidelity could potentially justify upscaling this pilot into a full-scale trial.

There has been little research conducted that provides people living with HAND the opportunity to interact with one another in a confidential group setting. It is possible that this group experience could be helpful for people living with HAND, as exploratory research has identified a dual stigma associated with the condition [11, 17]. The dual stigma is people feel that they cannot speak about HAND to their HIV-positive community due to dementia stigma, nor could they discuss it with HIV-negative friends and service providers who are familiar with cognitive impairment due to HIV stigma. Such community-building and shared support around the stress and uncertainty of aging with HIV may ameliorate the damaging effects of stigma [51, 52].

Author contributions

ADE conceived and developed the protocol, and drafted the manuscript. **SLW** provided expertise with trial design. **SLC** provided expertise with intervention design. **SBR** and **TS** provided expertise in HAND. **JWM** and **BAF** contributed to protocol refinement. All authors edited and approved the final version of the manuscript.

Competing interests

There are no competing interests for any author.

Funding

This work is funded by the CIHR Canadian HIV Trials Network (CTN) through a Pilot Study Grant (PT029). ADE and SLW hold salary awards from the Ontario HIV Treatment Network (OHTN). SLC and BAF are Canada Research Chairs. The funders did not have a role in the design of the study, nor in the decision to submit the study for publication. This study was approved by the Research Ethics Boards of St. Michael's Hospital (#17-334) and the University of Toronto (#35860). The trial was registered on clinicaltrials.gov (#NCT03483740) before recruitment commenced.

Data sharing statement

Data resulting from this protocol (i.e., de-identified surveys) may be available, pending consultation with the Research Ethics Boards (REBs) of St. Michael's Hospital and the University of Toronto. Data requests may be sent to the principal investigator at andrew.eaton@utoronto.ca, who will consult with the REBs.

Acknowledgements

We wish to thank all of the people living with HIV and other stakeholders for their contributions to the study’s design. Thanks to Dr. Judy Needham at the CTN for excellent project management, and to Dr. Lauren McInroy and Jenny Hui for assistance with this article.

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SUPPORT GROUP FACILITATION TRAINING MANUAL

AIDS COMMITTEE OF TORONTO
February 2018

Acknowledgements:

Many thanks to Paul Cogan for his assistance in creating an electronic version of this manual (2009).

Published 1998
Maureen Carnegie
Chuck Marino
Scott Pope

Adapted 2009
Jocelyn Watchorn
Kate Murzin

Updated 2016
Andrew Eaton
Marsha Malbari
Constantine Cabarios

TRAINING OVERVIEW

1. TRAINING SESSION ONE
    a. Getting to know each other
    b. Agenda for the Session
    c. Training Guidelines
    d. Group Norms
    e. Review of Active Listening
    f. Structured Feedback
    g. Introduction to Support Groups
    h. Check-Ins & Check-Outs
    i. Content & Process
    j. Bridging & Connecting

2. TRAINING SESSION TWO
    a. Agenda for the Session
    b. Skills Review & Toolbox
    c. Review of Working with Emotion
    d. Reflecting Feelings

3. TRAINING SESSION THREE
    a. Agenda for the Session
    b. Skills Review & Toolbox
    c. Dealing with Challenging Situations in Groups
    d. Closure
    e. Self Care
    f. Working with a Co-Facilitator
    g. Self Disclosure
    h. Working with Silence

4. TRAINING SESSION FOUR
    a. Agenda for the Session
    b. Skills Review & Toolbox
    c. Meet & Greets
    d. Group Logistics

5. APPENDICES
    a. Suggested Readings
    b. Facilitator Toolbox

TRAINING SESSION NUMBER ONE

- SESSION ONE AGENDA
- TRAINING GUIDELINES
- ROLE PLAYS: PURPOSE & GUIDELINES
- GROUP NORMS
- ACTIVE LISTENING
- STRUCTURED FEEDBACK
- THE FACILITATED PEER SUPPORT GROUP MODEL
- KEY ELEMENTS OF SUPPORT GROUPS
- EFFECTIVE VS. INEFFECTIVE GROUPS
- GROUP ATMOSPHERE
- STAGES OF GROUP DEVELOPMENT

Support Group Facilitator Training

Session One

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Intro ‘Sandbox’ Activity

    - Move around the room and get quickly into pairs.
    - One partner asks the other to discuss their hopes for the facilitator training.
    - Discuss for two minutes.
    - When the bell rings, switch partners and repeat!

    Group discussion: What did you learn about your own/the group’s hopes and expectations?

After this session, participants will:

- have a better idea of who is participating in the facilitator training;
- be more aware of their personal expectations of the facilitator training and those of the group.

2. Introductions

3. Review Goals for the Evening

4. Agreements
    a. Housekeeping
    b. Training Guidelines
    c. Training Norms
        i. Universal Norms
        ii. What else do you need to feel safe in the training environment?
        iii. Accountability to one another

5. Listening Exercise

    - Find a partner. Please choose someone you don’t already know.
    - Instructions to follow!

Group discussion : What makes it easy or difficult to listen?
What kinds of things do people need support with?
What makes it easy or difficult for people to get support?

After this session, participants will:

- be more aware of the factors which impact their ability to listen;
- have a better understanding of what is involved in giving/receiving support.

6. Active Listening

After this session, participants will be able to:

- Define active listening;
- demonstrate a variety of verbal and non-verbal active listening techniques.

7. Group Norms

After this session, participants will be able to:

- Define ‘norms’;
- identify the types of norms and differences between them;
- recognize the facilitator’s role in establishing and modeling norms.

8. Structured Feedback

After this session, participants will be able to:

- Give feedback that results in positive change.

9. Introduction to Support Groups

After this session, participants will:

- Understand the facilitated peer support group model including:
    - the definition of a facilitated peer support group;
    - the role of the support group facilitator;
    - the goals/purpose/benefit of support groups;
    - the values/key elements of support groups;
    - how this type of group differs from a therapy group;
    - be able to contrast the qualities of effective and ineffective groups.
- Recognize the stages of group development.

Group Discussion

- What experiences do people here have with groups?
- What do you think a facilitator does?
- What are the goals/purpose/benefit of support groups?

10. Evaluations

TRAINING GUIDELINES

Some Things To Expect and Not To Expect from Facilitator Training

Everyone comes to this training with different learning needs and expectations. Here are a few things that you can expect to experience, and a few you can expect not to experience in this training program.

DO EXPECT:

1. To gain basic skills in facilitating support groups. Our aim is to help you build a foundation which you can then expand on over time, with experience.
2. To spend different amounts of time on each topic. Due to varying skill levels, some people may require more or less time, depending on the area.
3. To have an opportunity to practice the skills within small groups.
4. To potentially still feel unprepared to facilitate groups by the end of the training, especially if you have never done so before. Your sense of preparedness will probably improve when you begin to facilitate ‘real life’ groups.
5. To experience some frustration when our time limits prevent extended discussion or practice.
6. To have fun and be challenged by learning new things and interacting with others in the training!

DON’T EXPECT:

1. To be an expert group facilitator by the time you have finished the training.
2. To cover specific types of issues/topics that groups discuss - i.e., the impact of care giving, spirituality, medications, etc. Our focus is on group skills, not group issues.
3. To utilize the training sessions as if this were a support group; participants are here to **learn group skills**, and must keep this in mind throughout the duration of the training.
4. To have unlimited time to voice your opinions.
5. To stay late — we will begin and end each session on time.

TRAINING GUIDELINES

The following guidelines apply to all facilitator training sessions, and all participants are expected to adhere to them. These guidelines are intended to assist in creating a positive, respectful learning environment. **They are non-negotiable.**

Confidentiality - Each participant has signed a confidentiality agreement as a condition of attending this training. What this means is that nobody inside of the training group is identified to anybody outside of the training group. Anything of a personal nature discussed in the sessions is not to be discussed outside of the sessions.

Respect for differences - Each participant has different life experiences, affiliations, values, etc. Respect for this diversity is expected by interacting with each other in a considerate and courteous manner.

Use of "I" statements - Each participant will take ownership for her/his opinions/assertions by using "I" statements, (as opposed to "you", "we", etc.). For example, "I think...", "I feel..." I believe...".

Time and attendance - Each participant is expected to attend every session and to be on time. Trainers will start and end sessions on time. Further, each participant takes responsibility for ensuring they return on time from break-out exercises, and realizes that the work of the session will resume at the appointed time, regardless of absence.

If a participant is unable to attend a particular session (with reason), ACT's Group Programming Coordinator should be informed ahead of time. A decision to withdraw from the training should be relayed to the trainers (and fellow participants, if possible) at the earliest opportunity.

Limit the length of time you speak when you have the floor - Each participant agrees to be mindful that there are many participants in the training, all of whom have the right to actively participate. So that everyone has an equal opportunity to do this, please monitor yourself when you are speaking in the training group to ensure you are leaving time for others to contribute.

ROLE PLAYS: PURPOSE & GUIDELINES

Role playing is a vital and major component of the AIDS Committee of Toronto Facilitator Training Program. Role playing creates an opportunity for training participants to build confidence, generate problem-solving strategies, utilize core facilitator skills, confront challenges and develop a personalized style of facilitating. Role playing also provides an opportunity for the trainers to monitor the skill development of the training participants.

Role playing, for many participants, can be very challenging, uncomfortable and cause anxiety. That said, it is important for the *trainers and participants* to create and ensure a safe, positive and enhancing learning environment.

The purpose of the role plays is not to “outwit, outsmart, or outlast" the other training participants. When participating in a role play as a group member, the goal is not to ambush the facilitator.

When you participate in role play, please observe the following guidelines:

- take a turn at different roles, including facilitator (take a risk);
- if you are playing a group member, it’s o.k. to be difficult, but not too difficult. Be *realistically* challenging and be prepared to shift into non- resistance;
- keep focused on process;
- when giving feedback, emphasize what went well, what seemed to work, what you learned, etc. Avoid criticism or dwelling on what was `wrong’.

Remember, role plays are a brief moment in time of a make-believe group session. Role plays are an opportunity to learn from each other, and identify our areas of strength and challenge.

THE ESTABLISHMENT OF NORMS IN A SUPPORT GROUP

Every group, whether social, familial, supportive, etc., is regulated by ‘rules’ of behavior which can be either implicit or explicit. In a support group, these ‘rules’ are known as norms. The underlying purpose of group norms is to establish a ‘culture’ in the group. Norms provide a guide for interaction between members, and as such may be a prescription for as well as a prescription against certain kinds of behavior.

In a support group context, group norms are both explicit and implicit. The explicit norms are those which are verbalized and established within the first session. The implicit norms are those which are understood, but not directly expressed, and develop over time. An example of an implicit norm would be group members consistently relying on one member to express controversial opinions in group meetings.

The establishment of explicit norms provides the important first step towards creating an atmosphere of safety in the group. Explicit norms help to provide members with guidelines and establish expectations about how the group will ‘operate’. As well, positive explicit norms contribute to the development of positive implicit group norms. While support groups generally benefit from the establishment of certain universal norms, (presented by the group facilitators), it is important that group members have the opportunity to decide upon additional norms which are important to the unique culture they wish to create. Facilitators might choose to elicit input from group members about norms with a statement like, “What do you need to have happen in this group so that you can feel safe and are prepared to participate?"

Support group facilitators play an important role not only in assisting members with establishing group norms, but in modeling the behavior associated with the norms. For example, facilitators model the use of “I" statements when expressing their ideas and opinions. Facilitator adherence to, and modeling of, group norms provides a reference point for group members.

UNIVERSAL NORMS

Confidentiality

Respect for differences

Use of "I" statements

Participation

GROUND RULES FOR SUPPORT GROUPS

One key to developing the safety that is so important for support groups is to establish ground rules that are discussed, agreed upon and adhered to by everyone in the group. Some ground rules might include the following.

Confidentiality

What is discussed in the group stays in the group, particularly anything that could identify any member.

Start and end on time

By starting and ending promptly, members develop trust and learn what they can expect from the group. This also respects members' busy schedules, which might include medical appointments or returning home to care for a loved one.

Be present or let someone know you won't be

Members need to know that their fellow members will attend the group or that they will call the facilitator or another member to inform the group of their upcoming absence.

Responsibility to raise issues

Facilitators won't be able to guess what the members may want to share. Members are responsible for getting their needs met in the group. Important issues should be put out on the table in a timely way.

Alcohol or drug use during the sessions

Group members are expected to come to the group without being impaired by alcohol or other non-prescription drugs.

No sex between facilitators and members

Sexual contact between a facilitator and a member can be detrimental to the group process. Sexual behavior has the potential to be destructive to the member as well as the group as a whole. Knowing from the start that sex and romance with the facilitator are not possibilities, can allow some members to feel safer and more comfortable.

Sex between members is also discouraged. With the need for safety and trust, the added complication of special relationships between members can be difficult for the group.

Informal, outside-of-group support among members

Ideally, support among members will continue outside of group meetings. This may include phone calls, visits or other shared activity. Meetings can also continue informally after the conclusion of time-limited groups.

No secrets or special outside contact between members and facilitators

Facilitators should be clear about not having any special relationships with certain members. Favoritism, or the appearance of it, will lessen the facilitator's effectiveness.

Set guidelines for entering and leaving the group

In open groups, members will come and go. When adding new members, it helps to let current members know that new people will be joining. If possible, let members know at least a week in advance. Suggest that members who decide to leave should try to complete any unfinished business that may exist with other members or with the group and give at least one week's notice of their intention to leave the group.

Differences and disagreements are OK

Allow members to voice disagreements as long as they happen in a respectful way. Stress to members that disagreements can often be a source of growth.

Discuss non-sexual physical contact

Each group member is unique in how they view touching and hugging. Cultural or gender differences, boundary or abuse issues, loneliness, simple likes and dislikes can influence how comfortable someone is with physical touch. For some groups, a member may give a hug or put a hand on the shoulder of a member who has revealed something painful or shared an emotional issue or seems to be hurting. This response can be both natural and beneficial. However, no matter how well-intentioned and innocent the gesture, some people might feel violated and unsafe with any form of physical contact. Encourage the group to discuss this before anyone spontaneously and unknowingly oversteps another's boundaries.

"Check in' should be brief

Check in is a tool to use at the beginning of each group session. During check in, each group member briefly shares what happened to them between meetings, how they are feeling at the moment, what they'd like to talk about that session, etc. Check in works as a transition for group members from their day-to-day situations to the "culture" of the group. Check in is a time for facilitators and other group members to get a sense of the general mood and feelings of each group member. (Facilitators should check in). It's important for facilitators to ensure that check in doesn't become a series of extended monologues (which take up all the time).

Establish a ground rule that check in will be time limited and that the time will be gently enforced by facilitators. Politely interrupt members who are taking too much time during check in. Redirect an extended check in to the purpose of the group. Let members know that if they raise an important issue during check in, the group will come back to it later and allow them to fully explore their issue.

Adapted from NATIONAL HIV/AIDS VOLUNTEER TRAINING KIT (1998: AIDS Committee of Toronto), Training Module 2: Support Group Facilitation: Support Group Manual (p.8-11)

UNIVERSAL GROUP NORMS (SAMPLE GROUP HANDOUT)

CONFIDENTIALITY:

Volunteers, ACT staff and service providers who run programs at ACT are expected to uphold the highest standards of confidentiality in their work. Similarly, it is expected that all support group participants will respect the privacy and confidentiality of other group members and volunteers. This is a non-negotiable group norm.

OTHER GUIDELINES:

Please be on time!

The time the group spends together is limited, so it is very important to maintain regular attendance. Please plan to arrive in advance so that the group can begin promptly at 6:30pm.

Keep us informed!

While we stress that attending all meetings will yield the best results for you and other members of the group, we understand that absences happen from time to time. If you are going to miss a session due to illness or other unexpected circumstances, please call the facilitator in advance of the meeting you will miss, so that we know that you are ok. Yes, we will worry about you and make attempts to locate you if you do not show up!

Participate!

Talking about some of these issues can be difficult, but ultimately the benefit you gain from being in a group is related to the effort you put in to participate. Participation takes many different forms: listen carefully to other group members, contribute to group discussions, or suggest topics of conversation. Who knows, you may find that you are not alone in what concerns you!

Respect each other and yourselves!

We will start the group by asking you to identify what you wish to achieve and helping you determine norms for the group. Treat each other with respect; the way you wish to be treated. Respect yourself and your own boundaries, and please let us know when you need help to maintain them.

Use “I” Statements!

When sharing your opinion, thoughts, feelings and experiences, use “I” statements. These statements start with “I think….”, “I feel…..”, “In my experience….”, or “When that happened to me I……”. Many times, others in the group or outside it have different points of view or have experienced something in a different way than you have. Using “I” statements gives everyone an opportunity to share what things are like for them.

OTHER NORMS FOR THIS GROUP:

ACTIVE LISTENING

Active listening is an essential component of group facilitation. Generally, active listeners defer their own judgment about the speaker, resist giving feedback until the speaker is finished speaking, seek clarification, and paraphrase and check their understanding of the speaker's message.

Active listening has two parts: looking like you are listening and sounding like you are listening. Everything which follows is culture-bound whether that culture is based on nationality, gender, sexual orientation, age, or whatever. "Matching" the person you are listening to is a good (not perfect) general starting point.

Looking like you are listening is communicated non-verbally through position, posture, facial expressions, eye contact, etc.

A rough guide would be to:

1. Face the person who is speaking more or less directly and
2. At the same level (don't stand over the speaker) with a
3. Distance of about two arm's lengths between.
4. Maintain a relaxed (not slouched) posture.

The most important facial expression (apart from keeping your eyes open) is probably appropriate smiling. A fixed, expressionless face interferes with good listening. Head nods are encouraging.

In the absence of bodily contact, eye contact is probably the most important dimension of communication in active listening. Matching the eye contact of the speaker is a good place to start. Be sure not to completely avoid eye contact.

Sounding like you are listening is essential. This would include "minimal encouragers" (uh huh, yes, mmhh hmm, I see, etc.); repetition of a key word or phrase also communicates good listening.

Other ways of sounding like you are listening and encouraging the speaker are:

1. **Rephrasing** something in your own words without adding anything and
2. Asking, "Is that right?" (called "**checking out**" or a "**perception check**")
3. When 1 and 2 are done together it is called **paraphrasing.**
4. **Summarizing** what has been said is another verbal listening skill (often used with a perception check) as is
5. **Clarifying** which is best done with
6. **Open-ended questions** (who, what, when, where, etc ....) which put the focus on the speaker as opposed to

7. **Close-ended questions** (which can be answered with one word like ’yes' or ‘no‘ or are multiple choice/either-or questions) usually reflect what the *listener* is thinking.

STRUCTURED FEEDBACK

Chuck Marino

So what is effective feedback? Effective feedback is feedback that results in change. It really isn't very difficult to give feedback in the usual way:

- by criticizing
- by pointing out what's wrong
- by asking questions
- by telling someone a better way to do it
- etc.

It's pretty obvious that generally it doesn't feel good to be criticized in this way. Most of the time when someone is given this kind of feedback they are stifled rather than encouraged to speak up or to try something new.

Effective feedback results in positive change. For this to happen, the criticism must be heard and acted upon. To maximize the chances of this happening it is necessary for the critic to demonstrate:

- **respect** for the person being criticized;
- **understanding** of whatever is being criticized;
- the skills to **identify the positive parts**; and
- ability to indicate **a useful change**.

Structured feedback is a way of doing this. It is a very short, personal evaluation which contains your assessment of the positive and negative aspects of a meeting, an opinion, an idea, something someone has said or done, etc. **It is also a way for co-facilitators to evaluate each other and their groups so that they learn how to be more effective.**

Structured Feedback

Briefly state at least two or three positive things about whatever it is you want to give feedback on or criticize. Two or three things you liked, learned, understood in a new way, want more of, found useful, interesting, etc.

Briefly state the single most important thing which you think should he change. Say something like, "I see the main problem as how to..." or "I wish that..." **NOT** "I didn't like,.." or "You didn't..." or "You should..." or 'I really like that idea but..."

HIGHLIGHTS OF THE FACILITATED PEER SUPPORT GROUP MODEL

Focus of the model:

The model of group work we will be working from is facilitated peer support.

A facilitated peer support group may be defined as:

A group of people who usually share common issues/problems/goals/life experiences and who join together for the purpose of mutual aid. The group is facilitated by a person(s) who has skill in group process and assists members in the structuring of, and communication within, the group.

Support group members, *not* the facilitators, are accepted as the experts on their situation/issues/problems. The aim of facilitators is to assist group members in bringing into awareness their strengths and knowledge, and to assist in creating opportunities to learn from each other and appropriate external resources.

The formulation of the content or agenda for the peer support group is usually not the *primary* focus of facilitators; for the most part, the agenda is set and driven by group members. Thus facilitators are more concerned with how the group is functioning, and less with **what** is being discussed in group.

Goals of the Facilitated Peer Support Group:

The goals of the peer support group are to:

1. Create safety, understanding and support amongst group members;
2. create connections or a sense of community between group members that will last beyond the duration of the group;
3. to empower group members.

Empowerment in this context means the acquisition of useful and relevant information, knowledge of one‘s personal and external resources, and an increased capacity and desire to use these skills. Facilitators foster empowerment in the peer support group by providing as safe an environment as possible which encourages learning from each other, supports positive risk, and always emphasizes the strengths (as opposed to the deficits) of group members.

It is important to be aware that emphasizing group member’s strengths and abilities does not mean ignoring the difficulties and pain they may be experiencing. Group members must have opportunities to share these experiences. An emphasis on strengths means exploring the coping strategies and knowledge group members have developed as a result of their experiences. Regardless of how *we* may judge *them*, people employ diverse strategies to manage problematic situations every day.

Inherent Vales of Facilitated Peer Support Model:

There are many-different ways of structuring facilitated peer support groups. Regardless of the structure of the group, there are certain core values or beliefs which guide and support the process. These values and beliefs include:

- peer support is an important and valuable strategy in confronting the complex issues which affect people's lives;
- individuals are experts on their own circumstances and state of being;
- peer support groups can and do enhance individual coping and self esteem;
- peer support empowers groups, and the individuals in those groups. This results from the focus on strengths and abilities, the broadening and acquisition of relevant and useful information, and the 'community building function of group;
- the diminishment of isolation through membership in a peer support group is of value in and of itself regardless of what other benefits group members may derive from the experience;
- group members have ownership of the group;
- the capacity of a facilitated peer support group to become a self-help group is recognized, encouraged, and supported.

Expertise and Advice-Giving:

Facilitators have expertise in guiding group process - they do not necessarily have solutions to the problems presented by group members.

Because facilitators are frequently peers to group members, and/or because they are often very well informed about issues related to the focus of the group, it can be tempting to offer group members solutions or expert information. This is contrary to the goals of a facilitated peer support group.

It is important to remember that facilitators are usually viewed by group members as authority figures; therefore any advice or information you provide may be construed as the final, authoritative answer and discourage further investigation. Furthermore, group members may be reluctant to offer alternative opinions or options which differ from those of the facilitator.

Providing answers and/or presenting one‘s self as the expert denies the abilities of group members to know what is best for them. Providing solutions does not empower people. Assisting them to discover how they can come up with their own solutions does. As one facilitator of a group for HIV-positive people stated, "If I want to truly foster empowerment of the group, it is important that I tell members 'I have HIV and I'm here as the group facilitator, but this doesn't mean I do HIV better than you do."

Advice-giving is discouraged amongst group members as well as facilitators. We ask group members to use 'I' statements to avoid advice-giving (i.e. "I tried x…" rather than "You should try x…").

It is important to be aware of the difference between information provision and advice-giving. Group facilitators often have resource information, etc. that could be of great value to group members. If you have a piece of knowledge you believe group members would benefit by, you must be conscious of why, how, and when you offer it.

Example: Group members are talking about an issue that you have personally experienced. You had great success in dealing with the problem by using 'x' strategy. You think that group members should know about this strategy.

Advice-giving response: "When I had that problem, I did x. X involves…. (goes on at length to describe the strategy in detail). This was the best way of dealing with it, and I had great results. You should all try it - I bet you'll find it works great for you too!"

Information provision response: "I've had some experience dealing with this problem. It may be worthwhile to become informed about strategy x. Does anyone here have experience with strategy x? Is the group interested in finding out more about strategy x? Any ideas on how/where we could get that kind of information?"

Key points to remember:

Be clear about your role as a facilitator, both to yourself and to group members.

There is great strength and wisdom in each group — when the group is grappling with an issue, look to the group first as the best resource.

If the group needs expert information, ask the group how they want to go about getting the information; will a group member do research and report back to the group? Will a guest speaker be invited to speak to the group? Will the group go on an outing to discover the answers?

If you are working with a co-facilitator, seek feedback from her/him on your interventions with the group to ensure that they are within appropriate boundaries.

Assessment & Evaluation:

As a final note, facilitators/organizations which provide facilitated peer support groups benefit by having group members assess, or evaluate, the group experience and facilitation (a written evaluation form is often used for this purpose). This can provide invaluable feedback on what works and what doesn't work. A request for feedback can occur either at the completion of group, or periodically throughout the sessions.

Member evaluations reinforce the values associated with the facilitated peer support model in that they place importance on the opinions and experiences of the members, and emphasize the ownership that members have of the group. Evaluations by group members are a learning tool which facilitators can utilize to assess their effectiveness, strengths, and areas for continued work.

KEY ELEMENTS OF A SUPPORT GROUP

1. **Mutual Aid**
   An alliance of individuals who benefit from working with each other on certain common problems or who need each other to work on those problems.

2. **Empowerment**
   a. Becoming aware of the power dynamics operating in your life space.
   b. Learning the skills necessary for controlling what can be controlled in your life.
   c. Exercising those skills without infringing on the rights of others, and
   d. Supporting the empowerment of others.

3. **Connection**
   Moving from the disconnection that results from facing a traumatic stressor to connection with self and with community.

4. **Leader/Co-Leader**
   a. Maintains a safe environment or a safe space;
   b. Facilitates connections between group members through active listening;
   c. Keeps the focus of the group upon the agreed upon goals of the group.

EFFECTIVE VS. INEFFECTIVE GROUPS

EFFECTIVE GROUPS	INEFFECTIVE GROUPS
Goals are clarified and changed to give the best possible match between individual and competitively structured group goals. Goals are co-operatively structured.	Members accept imposed goals. Goals are competitively structured.
Communication is two-way: the open and accurate expression of both ideas and feelings expressed.	Communication is one-way and only ideas are expressed. Feelings are suppressed or ignored.
Participation and leadership are shared by all group members. Both 'task' and 'maintenance' roles are present.	Leadership is delegated and based on authority. Membership/participation is unequal, with high-authority members dominating. Only "task" roles present.
Decision making matches the situation - different methods at different times. Consensus is encouraged.	Decisions are made by the highest authority with little group discussion. Members' involvement is minimal.
Ability and information determine influence and power. Power is shared. 'Contracts' built to ensure individual goals/needs are met.	Position determines influence and power. Power is concentrated in authority positions. Obedience to authority is the rule.
Challenge and conflict seen as positive keys to members' involvement in decision making and good group work.	Challenge and conflict are ignored, denied, avoided or suppressed.
Interpersonal group behavior is emphasized. Cohesion is advanced through inclusion, acceptance, support and trust.	Individual roles are emphasized. Cohesion ignored, members controlled by force.
Members evaluate the effectiveness of the group and decide how to improve its functioning. Maintenance is an important component.	The highest authority evaluates the effectiveness and decides how goal accomplishment may be improved. Maintenance is ignored.
Interpersonal effectiveness, innovation and individuality is encouraged. Diversity is welcomed.	Organization, stability, and structure rigidly adhered to.

GROUP ATMOSPHERE

Certain notable impressions usually result from a particular group meeting. One might have the impression that not much work was done due to a general inability to ‘get started’ on the part of group members. Or, one might have the impression that a lot of work was accomplished but that in the course of that work, tempers flared or members were on edge or touchy.

These types of impressions describe the group atmosphere. Some terms to describe the group atmosphere are:

Tense: When pressures are felt, sometimes because of time limitations, or conflict between members, or personally threatening topics, the atmosphere may be tense.

Flight: When the group pursues ‘inappropriate’ or outside topics or horseplay as a means of avoiding the real task at hand (which might be threatening or unpleasant), the group atmosphere may be one of flight.

Fight: Often group members will find themselves in disagreement with the topic, decisions to be made, or action to be taken. This intra-group conflict may be described as fight.

Work: When the group devotes itself to its task in a purposeful manner the atmosphere is one of work.

Play: The opposite of work may be play. This situation exists when the group avoids doing its work, and can’t shake off being lighthearted.

Competitive: When several members seem out to win their own points, with the result that the group action can only proceed out of a win-lose situation, the session might be described as competitive.

Co-operative: As opposed to the competitive atmosphere, group members may work together harmoniously. When members seem to share goals and support one another in attaining group goals, the atmosphere may be described as co-operative.

Sluggish: Sometimes a group will try hard to deal with its task but just can't seem to get going. When members enter the session with low energy and do not gain momentum, the atmosphere can be described as sluggish.

Rewarding: When group members have worked together well and have accomplished the task they set for themselves they may feel a sense of satisfaction and that they have gained from the experience. The atmosphere may thus be described as rewarding.

STAGES OF GROUP DEVELOPMENT (Tuckman, 1967)

Stage 1: Forming

- becoming oriented to the group
- wanting to belong
- gathering information and impressions about each other
- likely avoidance of conflict
- may look to facilitator for leadership

Stage 2: Storming

- communication patterns will begin to emerge
- may see challenging of the facilitator
- challenging other members
- will look to norms/guidelines for clarity of rules
- group members may express dissatisfaction behaviourally (missing meetings, arriving late)
- opportunity for facilitators to empower the group

Stage 3: Norming

- will begin to confront issues, not each other
- establishment of group agreements
- “honeymoon” period

Stage 4: Performing

- working towards group goals
- open communication
- roles and responsibilities in group are flexible
- high degree of comfort
- disagreement can occur without conflict

Stage 5: Adjourning/Transforming/Deforming

- about completion and disengagement
- opportunity to experience closure/goodbye in a new way
- anxiety or fear may present
- possible regression to earlier stages of group development

TRAINING SESSION NUMBER TWO

- SESSION TWO AGENDA
- CHECK-INS
- CONTENT AND PROCESS
- BRIDGING AND CONNECTING

Support Group Facilitator Training
Session Two

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Check-Ins & Check-Outs

After this session, participants will:

- know the purpose of a check-in;
- will be able to contrast what a check-in is and what it isn't;
- understand the format of and be able to facilitate a group check-in.

a) Group discussion
  - What does 'check in' mean to you?
  - What is the purpose of 'check in'?

b) Group exercise
  - Go around and do a brief group check in

4. Content and Process

After this session, participants will:

- be able to define content and process as they relate to group interactions
- recognize the facilitator's role with regards to process-observing;
- be able to recognize and demonstrate process-observing skills.

a) Group Exercise - "Fishbowl"
  - Half of the group will participate, half will observe.

5. Bridging and Connecting

<u>After this session, participants will:</u>

- be able to define what bridging and connecting are;
- be aware of methods/approaches to bridging and connecting.

6. Role Plays

<u>Skills for practice:</u>

- check in;
- norm-setting;
- bridging & connecting group members.

7. Evaluations

THE NATURE AND PURPOSE OF CHECK-INS IN A SUPPORT GROUP

As a starting point to each meeting, support groups often use a ‘check-in’ format. The main purpose of the check-in is to re-orient members to the group environment and to determine who in the group needs time that session.

The format for check-ins usually consists of each member speaking in turn about how she/he is feeling that session in relation to issues relevant to the group context. This point is crucial for two reasons:

1. if the content is not relevant to the group context, members are bringing in extraneous issues which will side-track the group from its purpose and focus;
2. an agenda for the meeting is naturally formulated through individual requests for time and highlighting of emerging issues.

Check-ins should be brief and centered in the here-and-now. They should be brief because they are not the focus of the meeting; when members get caught up in lengthy check-ins; focus is often centered on one individual to the exclusion of others. Check-ins should be centered in the here-and-now in order to establish the focus on ‘live’ issues.

An example of a brief, here-and-now focused check-in might sound something like, “Tonight I am feeling angry. I’ve made a lot of realizations based on what we talked about last meeting, about how I feel being infected with HIV. I need some time to discuss this tonight." Note that even though this person refers to the last session, the comments are here-and-now focused because they are relevant to the group context, and the feelings are being experienced in the moment.

The role of the facilitators during check-in primarily involves the use of active listening skills. This means responding verbally and non-verbally to each member so mat she/he knows she/he is being heard. Verbal responses may include a brief paraphrase: i.e. “So you’re feeling a lot of anger about being infected, and tonight you need some time to work on this in the group."

Check-in is not a time for probes and invitations to expand on expressed issues. The opportunity for this will come later as members begin to engage in the ‘work’ of the meeting.

It is important to note that in a support group context, group facilitators often take a turn in the check-in. Because facilitators are not participants in the group in the same way other members are, check-in is not an opportunity to comment on personal issues you may be experiencing.

For example, this is not the time to make a comment such as “I’m finding it difficult to be here tonight because a lot of the things we’ve been talking about are relevant to my issues. I’m just beginning to get in touch with my own anger about being HIV-positive". If this is indeed the case for you, you do not have to risk your authenticity by denying that it is difficult for you to be there; you might instead say something like, "My energy is not as high as I would like it to be tonight. It may be a bit of a challenge for me to stay focused during our meeting." But when you begin to disclose your own issues, the focus is taken away from the group members, for whom the group exists. If the group is raising issues for you; consider speaking with your co-facilitator, supervisor, or another supportive person outside of the group context.

CONTENT AND PROCESS IN A SUPPORT GROUP

Content - is what the group is talking about. It refers to what is being said or talked about.

Process - is what is happening in the moment. It refers to the impact or effect of what is being talked about.

For example, if the group member is talking about a death and group members are silently listening or quietly crying, the **WHAT** that is being talked about is a death (content), and **HOW** this is affecting the group is that some members are listening silently or quietly crying (process, or the impact of what is being said).

Successful support group facilitators focus on the process most of the time (although not all of the time), as opposed to content. This requires focusing on what is happening in the group and not getting lost in the content. As with all group skills, maintaining a focus on the group process and not getting lost in the group content takes practice and attention.

A focus on process means emphasizing the ‘how’. "How?" questions keep the focus on what is happening in the moment. "Why?" questions focus on the past. "Why?" questions are the hallmark of leaders who focus on content, keep group members from talking about feelings, and, emphasize their own authority and control.

For example, if John says that his partner is refusing to take his medication because it makes him feel sick (content) and Mary begins to cry (process), the facilitator could ask the group for ideas to help John's partner conform to his drug taking routine (content), or the facilitator could ask Mary why she is crying (content); or the facilitator could remind the group that the topic for tonight is ‘positive thinking’ (content).

On the other hand the facilitator could ask John how he feels about his partner‘s choice (process), or the facilitator could ask the group how they are feeling about what John is talking about (process) or the facilitator (a really good facilitator) could simply point out what is happening and invite responses from the group. Like this, "John is telling us about his partner's non-compliance and I am noticing that Mary is crying and the rest of the group seems to be silent. I guess I‘m wondering what is going on for everyone right now."

An easy way to begin to focus on process instead of content is for the leader to simply identify what is going on right now in the group and to invite responses from the group. The formula is: "What’s happening right now is ________and I am wondering how people are feeling about that", or "I am wondering how what we are talking about is affecting everyone.”

CONTENT AND PROCESS EXERCISE

Below are statements made by group members, and corresponding responses made by group facilitators. Each statement is followed by a content response and a process response. Mark a “C” beside the response you believe is a content response, and a “P” beside the response you believe is a process response.

1. Group Member “I don't know why we have to accept new members into the group - we're getting along quite well and a new member would just change everything."

Group Facilitator: "A couple of people have expressed reluctance to have a new member join the group. Could we take some time and talk about how the idea of having a new person start is affecting everyone?"

Group Facilitator: "Well, we all agreed when the group started that we would accept new members. It wouldn‘t be fair to change the rules now.”

2. Group Member: "Sorry I’m late again. I had to drop something off at the hospital for Pete and then pick up a prescription for myself. I‘m now depleted, but it just couldn’t be helped.”

Group Facilitator: "Sounds like you were having a really busy day. No wonder you’re flustered."

Group Facilitator: "How is caring for Pete and yourself affecting you?"

3. Group Member: "After I eat I feel so sick, so I tend to stick close to home. Now my friends think I’m abandoning them because they don’t know the truth."

Group Facilitator: "How are you coping with feeling so ill and not having your friends know?”

Group Facilitator: "Why don’t you try telling your friends of your illness?"

4. Group Member: "I just hate coming to this group week after week. I have better things to do.”

Group Facilitator: "Well, that is legitimate, why don`t you check your schedule and let us know if it’s going to work for you."

Group Facilitator: "It sounds like you have a lot going on. How is coming here every week affecting you?"

5. Group Member: "I really think the group should be longer than 10 weeks. It just seems too short."

Group Facilitator: "Yeah, a lot of people in these groups want them to be longer. Maybe we should look into changing the policy."

Group Facilitator: "It makes sense that you would be thinking about the group ending. How do you feel knowing that there are 2 sessions left?"

6. Group Member: (with raised voice to another group member) "Who the hell do you think you are telling me how to live my life?"

Group Facilitator: "Frank just yelled at Jean and I'm noticing that everyone is very quiet. I'm wondering what is going on for everyone."

Group Facilitator: "Calm down, you are very upset. Yelling your comments is not going to help resolve this."

BRIDGING & CONNECTING

In a support group, common themes/issues/opinions/perceptions/feelings/etc. usually arise between members. Recognition and identification of these commonalties is one way in which members of the group move toward cohesion, and ultimately empowerment.

Throughout the duration of the group, and especially in the early stages, when members may have not yet decided how they will include themselves, bridging or connecting is an important facilitator function. Bridging may be defined as identifying and summarizing for the group the common themes, issues, etc. which have emerged. A bridging statement may be one of three things:

1. A paraphrase;
2. a summary of content; or
3. a reflection of feelings.

It is important to note that bridging statements are not interpretations of what you are hearing from group members; in other words they are not statements about what you think the underlying issues are. Bridging comments reflect what you have heard group members say.

Bridging can involve pointing out connections between two group members, for example: "Mary, you just talked about feeling a lot of confusion around treatment options, Fred was relating similar feelings earlier when he was talking about the decisions he's struggling with."

It also consists of summarizing expressed themes common to several or all group members, for example: "Everyone in this group has lost someone to AIDS, and several people have talked about their feelings of loss. We're beginning to express some of the feelings of grief shared by people in the group."

As in any paraphrase or summary (which is a main element of bridging), it is important to check out your perceptions with group members. It is not necessary to do this every time you make a bridging statement, and when you do, you might say something like, "Am I hearing some of you say .... ", or "The sense I'm getting is several people in the group are saying .... Is that right?"

After making a bridging statement, you may want to follow up with an open-ended question as a way of re-engaging the group in dialogue. For example, "There seems to be a theme emerging here of ...I wonder if someone else can say what they are thinking about this theme?"

Finally, as the support group evolves members will ideally begin to pattern themselves after the lead of the facilitators, spontaneously making bridging/connecting statements themselves. For example, "I can really relate to what you were saying Tom, about your feelings of uncertainty right now. This seems like something a lot of us here are trying to cope with." When support group members begin to do their own bridging, this is a cue to facilitators to relinquish some of their responsibility for this task.

TRAINING SESSION NUMBER THREE

- SESSION THREE AGENDA
- SKILLS REVIEW & TOOL BOX
- WORKING WITH EMOTION
- REFLECTING FEELINGS

Support Group Facilitator Training
Session Three

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Skills Review

After this session, participants will have a heightened awareness of:
- Active listening - definition and techniques;
- Structured feedback skills;
- Content and process - definitions, facilitator's role in process-observing;
- Bridging and connecting - definitions, approaches.

4. Working with Emotion — (review from core skills)

After this session, participants will:
- understand the importance of emotion in a support group environment;
- recognize factors which affect their comfort level when dealing with emotion;
- recognize 'emotion words';
- possess the skills needed for working with emotion in a group.

5. Reflecting Feelings

After this session, participants will:
- understand the facilitator's role in reflecting feelings;
- be aware of techniques for exploring feelings.

6. Role plays: Feelings/Emotion

- Working with Emotion
- Reflecting feelings

7. Evaluations

WORKING WITH EMOTION

An important function of a support group is to help participants identify and express the feelings associated with their experiences. While feelings may not be the sole focus of a support group is important that facilitators encourage the creation of an atmosphere which allows for and encourages emotion.

When we avoid emotion in a support group context, we send a message that feelings are not safe or valued.

The result is that group members may deny the existence of and/ or suppress the expression of their feelings. Consequently, the group may stay on a superficial level, never going beyond an intellectual expression of individual experience. When this happens, the group ceases to become a support group and is instead a discussion group.

In all human endeavors, the element of emotion is always present, and how we deal with expressed emotion is culture-bound. In a support group context, we are often confronted with very deep and intense feelings. For both facilitators and group members, the expression of intense emotion can be frightening and/or anxiety- producing for a number of reasons, including:

1. the expressed emotion may echo emotions which we are not yet ready to explore or have not resolved;
2. the expressed emotion may evoke responses in ourselves which we feel uncomfortable with;
3. we may have concerns that the expression of strong emotion will “open the flood gates", resulting in an outpouring from group members that will become overwhelming or ‘out of control’;
4. as facilitators, we may feel that making space for the exploration of group members feelings may “trigger’ an emotional response in ourselves;
5. we may feel responsible for making the expresser feel ‘better’;
6. we may believe we will be unable to respond to the emotion.

It is absolutely essential that support group facilitators become comfortable with the expression of emotion in the group, and are prepared to encourage its expression. How one reaches this comfort level is highly individualized and beyond the scope of facilitator training. However, there are a few key elements which are helpful in working with emotion as it emerges in group. If you sense that your group has ‘shut down’, that it is going in circles, not moving beyond the surface, etc., you may want to refer to this checklist:

Checklist for Working with Emotion

- have I encouraged group members to name their feelings?
- have I ‘allowed’ group members to express feelings and stay with them?
- have I stayed focused on the person(s) expressing strong emotion?
- have I offered encouragement by paraphrasing, summarizing, empathizing?
- have I used bridging skills when more than one member is expressing an emotion?
- have I been respecting members’ boundaries/limits of exploring emotion?
- have I sought support for myself outside of the group context (i.e. ensured that I have time to debrief with my co-facilitator after meetings, utilized supervision/ consultation opportunities, talked with someone who I know is understanding and supportive, etc)?
- have I been ignoring expressions of feeling instead of acknowledging them?
- have I been stifling the expression of feelings by reassuring, questioning the feeling, or changing the topic?
- have I been turning feeling expressions into intellectual statements?
- have I been pushing group member(s) to express more than they are comfortable with in the moment?
- have I been interpreting/labeling members feelings (i.e. “I think you have a lot of anger underneath your issues"), instead of asking the person to describe what s/he is experiencing (i.e. "You’ve been saying a lot about what you think about...I wonder if you can talk about the feelings that go along with that")?

WORKING WITH FEELINGS

1. Very seldom
2. Occasionally
3. Sometimes
4. Often
5. Most of the time

______I am aware of my feelings
______I am able to name my feelings
______I am able to express my feelings
______I am able to sustain a conversation about my feelings

______I notice other people's feelings
______I am able to encourage others to talk about their feelings
______I am able to reflect other people's feelings without interpreting them
______I am comfortable conversing with other people about their feelings

______I initiate conversations with others about my feelings
______People initiate conversations with me about their feelings

Comments:
____
____
____
____
____
____
____
____
____
____

REFLECTING FEELINGS

When you are working with emotions, the most important facilitator intervention is to reflect those feelings back to the group member(s). Reflecting feelings opens up the exploration of felt experiences, sends a signal that feelings are acknowledged, and can move the group beyond a discussion of ‘facts’.

Of primary importance when working on reflecting feelings is the avoidance of interpretations. What this means is that you do not express your theories about what a person is feeling or experiencing. Instead, you encourage the group member(s) to describe or name what s/he is feeling. Even when it may seem obvious (i.e. a person is crying/yelling/etc.), we do not truly know what the person is experiencing until we ask. As you will know from your own experience, tears do not always mean sadness, yelling does not always signify anger, silence does not always equal disinterest, etc.

There are four elements which can be utilized to work with feelings in the support group context which avoid interpretation and encourage members to express what they are experiencing:

1. When a member is speaking, listen for feeling words. Playback the feeling words you heard in a paraphrase. Example:

   Member: “I’ve been thinking a lot about John lately. He’s been dead for a year now, and I should probably be moving on with my life. I just get so overwhelmed with sadness sometimes and I can’t seem to get past it."

   Facilitator: "So there are times when you just feel overwhelmed with sadness, and you just can’t seem to get past it."

2. Play back the feeling and check out the accuracy of your paraphrase. Following on the above example:

   Facilitator: “So there are times when you feel overwhelmed with sadness, and you just can’t seem to get past it. Did I get that right?"

3. Encourage and assist the member to explore the feelings through clarification and summary. Following on the above example:

   Facilitator: "You feel overwhelmed with sadness - tell us some more about the sadness, what that’s like for you."

   Member: "Yeah, you know I become so emotional, I just cry and cry. When I think about his death, I’m filled with this ache, this sense of utter emptiness."

   Facilitator: "So that overwhelming sadness is an ache, a feeling of just utter emptiness inside. Tell us some more about the emptiness."

4. As a way of bringing it back to the group, once the member has had an opportunity to share her/his experience, you may want to utilize your bridging/ connecting skills. For example:

   Facilitator: “Frank, you’ve been telling us about the overwhelming feelings of sadness and emptiness you have sometimes when you think about John and his death. I wonder if anyone else in the group can connect with these feelings?”

Core Skills Training- Communication -Feeling Words

Accepted
Affectionate
Afraid
Angry
Anxious
Ashamed
Attracted
Bored
Competitive
Confused
Defensive
Desperate
Disappointed
Embarrassed
Free
Frustrated
Grateful
Guilty
Happy
Hopeful
Hurt
Inferior
Interested
Intimate
Jealous
Joyful
Livid
Lonely
Loving
Rejected
Respected
Sad
Satisfied
Shocked
Shy
Superior
Suspicious
Trusting

* this is not an exhaustive list *

TRAINING SESSION NUMBER FOUR

- SESSION FOUR AGENDA
- SKILLS REVIEW & TOOL BOX
- WORKING WITH CHALLENGING SITUATIONS
- CLOSURE
- SELF CARE

Support Group Facilitator Training
Session Four

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Review of skills learned

4. Dealing with Challenging Situations in Groups

    - What are "challenging situations" to you?
    - Who are they challenging for?
    - What are your fears/challenges?
    - How can we manage these situations?

After this session, participants will:

- be able to recognize and identify challenging situations;
- be aware of how to deal with challenging situations as a group;
- know the role of the facilitator in dealing with challenging situations;
- demonstrate their ability to deal with challenging situations.

5. Closure

After this session, participants will:

- recognize the purpose/importance of group closure;
- know when to address group closure;
- recognize the role of group facilitators in closure.

6. Self-Care

After this session, participants will:

- know what self care is;
- recognize the importance of self care;
- be aware of strategies for self care.

7. Evaluations

DEALING WITH CHALLENGING SITUATIONS IN A GROUP

Like nearly everything else that goes on in the group, the difficult behavior of specific members is something that the whole group allows to happen, and the group itself can respond to any challenge.

The facilitator, rather than "fixing it", makes it safe for the group to address challenges. Sometimes, the "problem" also provides a way for the group to protect itself or to avoid what feels like a more uncomfortable scene.

For example, superficial conversations might keep people from facing the pain of their situation. Always being angry and non-accepting of one member who stands out as the most different can be a way to avoid being criticized. The facilitator can point out what they see is happening and gently ask the group if this is OK with them.

Facilitators should not assume to know the real reason something is going on. Do not get into analyzing. Instead, you, as the facilitator, can ask the group how they want to handle the situation.

The following are some challenges that might be encountered in a group:

One person does most of the talking

Consider what keeps other members from speaking up, what might they fear, what could make it safe for more people to talk?

Fighting between members

Differences and conflicts are natural and can help people learn about themselves and grow stronger. First, you, as the facilitator, might do some self examination to make sure that you are OK with conflict. In the group, keep calm, avoid taking sides and encourage “I" statements while discouraging put downs and judgments. As the conflict continues, perhaps focus on commonalities, and encourage other members to broaden the discussion.

People coming late

It’s important for the group as a whole to enforce the ground rule of starting on time. If a pattern develops where the group never knows when the meeting has actually started (because it feels like they are always waiting for someone to get there) the group won’t feel as sure of itself as a group.

"Dumping’’ just before the end of the session

Members may wait to share their heaviest problems until the end of the session for many reasons: perhaps they’re anxious, they’re hoping the group will meet longer, they’re trying to control the group, etc. Whatever the reason (and often the reason is not clear), make sure the group ends on time. Suggest that members bring up their concerns early in the meeting so they will be sure to get the time they need.

Denial

Though this may feel like a problem to the facilitators, it may or may not be a problem for the group. When it seems like "something’s in the air" or some key issue has not been spoken about (like sex, death, suicide, love, etc.), it may help if the facilitator mentions that it’s OK to talk about the issue if it’s important to anyone.

Member in crisis

Sometimes, the normal rhythm of a group is disrupted when a member becomes enraged, overwhelmed, panicked and/ or hopeless because of sudden or unexpected changes in their life. These crisis feelings can "snowball" in the group (as member after member feels out of control. The calmness of the facilitator can alleviate this tendency.

Facilitators should stay calm, breathe deeply, speak slowly and encourage members of the group to do the same. Allow the extreme emotions to be expressed and respond to them with calm acceptance. If it seems necessary, one facilitator can take the member in crisis out of the room to spend some individual time with them. If it appears someone’s life is in immediate danger, call for help. Encourage the member to contact their therapist, crisis hotline or 911 if the emergency calls for it.

Since the group will be affected by the crisis, and, at some level, each member may identify with the person in pain, it’s crucial to encourage the group to talk about the experience.

GROUP CLOSURE

Every group has a life span which includes a beginning, middle and end. Although each person experiences them uniquely, endings are meaning-laden. For many, the ending of group is experienced as a loss and therefore represents some of life's most crucial and painful issues.

Because each of us encounters endings throughout the course of our lives and because endings are so meaningful, it is absolutely essential to work with group members on closure. Working on closure provides opportunities for members to reflect on their experience in group, determine what they got from the group, and make plans on how to utilize group learnings in an ongoing way. The facilitator can aid this process by assuming the following closure tasks:

***Regularly remind group members that the group will be ending*.** Group members may deny or ignore the fact that the group will end, and it is important that facilitators keep this in awareness. One way to achieve this is to keep members focused on what they have determined they want to work on. For example, “We have three more sessions left, and there are a few issues the group had said they wanted to address which we haven't yet covered. Can we take some time tonight to review what we want to cover in our remaining sessions?"

Encourage the transfer of learning from the group to the member's personal environment. The underlying goal of any support group is to help members become aware of, and better utilize, their personal and environmental resources. Facilitators can assist in this task by providing opportunities to reflect on the group experience throughout the course of the group, and especially at closure. At closure, some pertinent questions might include, “What's different for you now than when you started the group?", "What has changed that might help you deal differently with the issues that brought you here?", "What have you learned about yourself/the issues we've talked about/what's available to you while being in this group?". This is an excellent opportunity to help members acknowledge and appreciate their personal and environmental resources.

Encourage the expression of feelings about the ending of group. Facilitators can take on a modeling role here by reflecting on what the group has meant for them and how they feel about it ending.

Have faith that group participants will continue to grow once group has ended. Sometimes it is difficult for facilitators to let go of the group because we worry that members are not ‘ready' for it to end. It is important to remember that group participants had resources before the group started, and will continue to have them once it ends. Even when we think someone has not had enough time to get something significant from the group experience, it is important to remember that we often have no idea of what the true personal impact and meaning of an experience is for an individual. For some, it may not be until later that s/he significantly benefits from the group experience.

Some additional notes:

Working on closure should not be left until the last session. At the very least, facilitators should begin encouraging group members to actively talk about the group ending by the second last session. As noted above, regular reminders that the group will be ending should be given throughout the course of the group, and can be used as a way to keep the group focused on what they want to accomplish.

Closure exercises at each group meeting are a good way to get group members (and facilitators) into a routine of addressing endings. How this is accomplished varies from group to group, but your group might decide to end each meeting with a process similar to a check-in exercise.

Some ideas for closing exercises are:

- Have each member say how s/he is feeling in the moment, i.e. “Right now, I’m feeling energized by what we talked about in group tonight."
- Have each member say what s/he got from this meeting, i.e. "Tonight I got a better sense of what’s really been bothering me. I’m now aware that I’m angry about..."
- Have each member say what s/he learned in this meeting, i.e. "I learned a lot about strategies people are using to deal with medication side effects."
- Have each member say what s/he wants to talk about next meeting, i.e. "At our next meeting, I really want us to talk about how we can have sex, and keep ourselves safe both physically and emotionally?”

Consider having members complete a written evaluation at the end of a group. This can assist members with starting to think about what the group experience has meant for them, as well provide you with valuable feedback on the group structure/format and your facilitation skills. If possible, evaluation forms should not be left to the last moment if you want thoughtful responses.

SELF CARE FOR FACILITATORS

Providing supportive service to others can be extremely rewarding. At times, it can also be difficult and personally challenging.

As a support group facilitator, you are in a position to hear and witness people's pain and triumphs — this is a position which, in various ways, will undoubtedly have a personal impact. If you are in any way personally connected to the issues addressed in your groups, the impact may be even greater. To be able to effectively facilitate and maintain your own well-being, it is essential that you develop practices for your own self-care.

No one can tell you what you need to do to take care of yourself, but here are a few basic principles which make sense to consider:

- look after your physical well-being as best you can; try to eat healthy, get plenty of rest, exercise, etc.;
- figure out what you need to feel good, and find ways to get those needs met;
- establish a support system for yourself and utilize it — partner, family, friends, therapist, whoever;
- acknowledge and accept both your strengths and your limitations as a facilitator and as a human being;
- set realistic goals for yourself.

Specifically when you are facilitating:

- have a preparatory/check-in meeting with your co-facilitator before each meeting;
- debrief with your co-facilitator after each session — make sure to talk about how you felt about the facilitation experience, not just what happened for group members (the structured feedback format can come in really handy here);
- utilize 'supervision'/ consultation opportunities and other related resources to work out problematic areas;
- be proactive - if you are having difficulties in the group, and/or if facilitating the group is having a negative impact on you, don't wait for it to resolve itself. Utilize the supports at your disposal before you burnout;
- remind yourself that the well-being of the group is not solely your responsibility - you add a piece, but you do not have the power to control how people experience the group, or what they ultimately take with them from the experience.

TRAINING SESSION NUMBER FIVE

- SESSION FIVE AGENDA
- WORKING WITH CO-FACILITATORS
- SELF DISCLOSURE
- WORKING WITH SILENCE
- GROUP LOGISTICS
    - Facilitator Responsibilities
    - Timeline of an ACT Support Group
    - Meet & Greets
    - Session Reporting
    - Facilitator Supervision

Support Group Facilitator Training
Session Five

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping
2. Review Goals
3. Parking Lot
4. Working with Co-Facilitators

After this session, participants will:

- have a better understanding of their own facilitation style and how their experiences/background affect it;
- be prepared to deal with the dynamics of working with a co-facilitator;
- have the skills necessary to coordinate work with a co-facilitator.

Group discussion

  - Co-facilitation

5. Self-Disclosure

After this session, participants will:

- be able to define self-disclosure;
- know the significance of self-disclosure;
- be able to recognize appropriate situations in which to self-disclose;
- be aware of strategies for self-disclosure;
- be able to recognize effective self-disclosure.

6. Group Logistics

After this session, participants will:

- Have a better understanding of the administrative tasks associated with facilitating support groups at ACT;
- Be prepared to deal with emergencies/crises in the group setting, including knowing when to seek assistance from ACT staff or outside organizations;
- Understand better their role and responsibilities as part of the Support Group program;
- Understand how they will be supervised, supported and receive feedback from the Group Programming Coordinator.

a) Volunteer Responsibilities
b) The Role of the Group Programming Coordinator
c) Administrative/logistical details for the Support Group Program

7. Graduation & Group Closure

8. Evaluations

QUESTIONS FOR CO-FACILITATORS

(Adapted from The Skilled Facilitator (1994), by Reger M. Schwarz)

Orientation/Style

1. The major values, beliefs, and principles that guide my facilitation are...
2. The major values, beliefs, and principles that other facilitators hold and that I strongly disagree with are…
3. At the beginning of a support group meeting, I usually...
4. At the end of a support group meeting, I usually...
5. When a group member talks too much, I usually...
6. When the group is silent, I usually...
7. When an individual group member is silent, I usually...
8. When a group member gets upset, I usually…
9. When a group member comes late, I usually
10. When a group member leaves early, I usually…
11. When group members are excessively polite and do not confront each other, I usually...
12. When there is conflict in the group, I usually…
13. When the group attacks one member, I usually...
14. When a group member takes a cheap shot at me or implies I am ineffective, I usually...
15. When a group member attempts to force other group members to accept her/his opinion, I usually...
16. When members are off track, I usually...
17. When a group member criticizes another group member, I usually...
18. My favorite group interventions are...
19. Interventions that a support group usually needs but that I don‘t often make are...
20. The things that I find most satisfying about facilitating support groups are...
21. The things that I find most frustrating about facilitating support groups are…
22. The things that I find most uncomfortable in facilitating support groups are...
23. On a continuum ranging from passive to very active, my intervention style is...
24. My typical intervention rhythm is (fast/slow)...

Experiences and Background

1. Discuss your experiences as a facilitator/co-facilitator. What types of groups have you facilitated? What were the content and process issues in the groups?
2. Discuss your best facilitation and co-facilitation experiences. What was it about these experiences that made them so successful?
3. Discuss your worst facilitation and co-facilitation experiences. What was it about these experiences that made them so unsuccessful?
4. Describe some of your facilitation behaviors that a co-facilitator might find idiosyncratic.
5. Describe the issues that have arisen between you and other co-facilitators.

6. Describe the areas in which you are trying to improve your facilitation. How would you like the co-facilitator to help you improve?
7. What personal issues do you have that might hinder the ability of you and the co-facilitator to work with each other or with group members?
8. Given what you know about the co-facilitator, what concerns do you have about working with that person?

Co-facilitator Co-ordination

1. How will the pre-group tasks be divided?
2. How will pre-session planning happen?
3. How will post-group debriefings happen?
4. Who will sit where in group meetings?
5. Who will start the meeting? Who will finish it?
6. How will you divide the labour?
7. What kind of facilitator interventions and behavior are inside and outside the zone of deference that each of you will grant the other?
8. Where, when, and how will you deal with the issues between you?
9. What kinds of disagreements between you are you willing and not willing to show in front the group?
10. What is non-negotiable for each of you as a co-facilitator?

SELF DISCLOSURE

Chuck Marino

Here is a good guideline: it is important that support group facilitators be genuine. Playing a role like the expert, the wise person, the sympathetic listener, etc. is phony. Being you, not hiding behind a role, is genuine.

Facilitators who never disclose anything about themselves are showing their group how to be cautious, impersonal, and closed.

Facilitators who reveal too much blur the distinction between themselves and their group; they would rather be a friend than facilitate the group. They burden the group with their own opinions, reactions, and memories.

An important part of being you is using your own feelings and reactions as a group facilitator. The question becomes when is it appropriate to disclose your own feelings and reactions?

1. A first indicator that self-disclosure may be called for is when you experience a persistent feeling or reaction to what is going on in the group. Perhaps you are feeling bored or irritated; maybe you feel uncertain or uneasy. If this is the case it is very likely that you are not the only one having this feeling and it becomes very important for you to disclose it. The key words here are persistent (it keeps coming back) and feeling (not a fleeting thought or memory). If you experience a persistent or recurring feeling this is an indicator that self-disclosure might be necessary or appropriate.

2. Unrehearsed disclosures about what you are experiencing right now are usually much more effective and facilitative than disclosures about your past or your memories. Putting this guideline in reverse; if it is too easy to reveal, or it is something you reveal often; or if it sounds rehearsed, it is probably not a good self-disclosure. A good self-disclosure is fresh, unrehearsed, and a little difficult to put out there. “I have had that experience myself” is not likely to be as good a disclosure as “I’m feeling a little anxious about what we are talking about and I am wondering if anyone else is sharing that feeling?”

3. The final guideline is to ask “What do I expect to happen if I disclose what’s going on with me and will that empower the group or focus the group on me?” This is an important question to ask and answer. Predicting the effects of your self-disclosure will increase the chances that it will be effective. By observing the effects of your self-disclosure you can become better and better able to use this as an effective tool.

Here is how to evaluate a facilitator’s disclosure: It was a good self disclosure if the next thing that happened was the group explored what they had been talking about more fully or at a deeper level.

Working with Silence

Constantine Cabarios

What is silence? According to the Merriam-Webster (2015) dictionary definition, silence (is a noun) “that lacks sound or noise; it is a situation, state or period of time in which people do not talk; a situation or state which someone does not talk about or answer questions about something.”

What does silence mean? Silence has different meanings for people. It can be an uncomfortable experience and it can also provide a sense of relief. In *counselling*, silence is used as therapeutic tool by trained counsellors to allow their clients time to reflect, process emotions and/or retrieve memories and experiences that may add further insights into their therapeutic goals. The counsellor may use this technique to elicit *non-verbal* or *verbal* responses, depending on the level of therapeutic alliance between the counsellor and client.

For North American or Western European cultures, use of silence in communication can be an uncomfortable experience and yet according to social scientists, 70% of communication is *non-verbal* (Jaworski &Sachdev, 1998). North Americans may perceive effective communication as verbal (Knapp, 1975) and thus most forms of communication involve some form of conversing (e.g. small talk) or rhetoric (i.e. to persuade) and can present the speaker as confident, knowledgeable, engaging, expedient and effective (Davidson, 2009). In Asian or in Eastern cultures, *silence* may be viewed as a sign of respect, strength and wisdom (Davidson, 2009). Depending on various contexts, silence can have different meanings for people.

Silence Quotes	What does it mean?
Silence is a source of great strength. - Lao Tzu	
Nothing strengthens authority so much as silence. - Leonardo da Vinci	
Silence is a true friend who never betrays. - Confucius	
Silence is the sleep that nourishes wisdom. - Francis Bacon	
Silence is the most perfect expression of scorn. - George Bernard Shaw	
Tis better to be silent and be thought a fool, than to speak and remove all doubt. - Abraham Lincoln	
He who does not know how to be silent will not know how to speak. - Ausonius	

Productive use of silence. In group work, silence can be a chance for group participants to rest, reflect, find balance or organize their thoughts and feelings after an emotion-filled moment (Vriend and Dyer, 1975). Conversely, it can provide group facilitators a chance to observe the group dynamics through non-verbal cues and monitor the reactions of the group participants and determine when to ‘break the silence.’

Non-productive use of silence. This can manifest in group participants as a form of resistance to go against the ‘leader’ of the group (Vriend and Dyer, 1975). In other words, there might be a group member who is always leading the topic discussion and therefore other group members may feel resentful, anxious or fearful. Group members may be cognizant of ‘taking up too much space’ or perceived as ‘ganging up’ on the leader (Vriend and Dyer, 1975).

Knowing when to break silence. It is important for group facilitators to remind themselves and group members that silence is part of non-verbal communication and that they always have the choice to talk or not, as we are all unique individuals with different methods of expression. Group facilitators should be able to get sense of each group members’ personalities and therefore determine if a group member is feeling anxious or distressed with the lack of verbal dialogue (Vriend and Dyer, 1975). There should be enough time for contemplation for all group members during the session and then the group facilitator should be able to bring the group back to a group discussion. However, the group facilitator should be careful with the tendency to influence the direction of the conversation. Rather, the group members should be able to take the initiative and ‘break the silence’ on their own.

Example of how to break the silence without being directive or suggestive:

Group facilitator: We’ve been silent for some time now. I’m wondering how people are feeling.

Activity: “Mirrors”

- Need one leader, one follower and observer(s)
- The leader will initiate a non-verbal behaviour (e.g. clapping hand, bowing head, looking up, yawning, etc.)
- The follower will follow the action(s) of the leader
- The observer (facilitator) will monitor reactions of the group

Description: The mirroring exercise is another actor warm-up that's adapted easily for any team-building activity. It can be performed in pairs or with everyone standing in a circle. One person leads by making slow movements with her arms, hands, head and body. Her partner or the others in the circle try to imitate her exactly. The trick to this exercise is to avoid hesitating, then following the leader. Everyone should try to time their actions as close together as possible -- a mirror image -- so it's difficult to distinguish who's leading and who's following. The leader must make sure that her movements can be imitated. Eye contact can help the other people anticipate the next move.

Purpose: use of non-verbal cues, observation skills and being present in a group; ‘listening’ to group dynamic cues; builds awareness; use of non-verbal mirroring.

References

Jaworski, A. and Sachdev, J. (1998). Beliefs and Silence in the Classroom. *Language and Education,* 12 (4) pp. 273-292.

Knapp, H. (2007). *Therapeutic communication: Developing professional skills*. Los Angeles: Sage Publications.

Vriend, J. and Dyer, W. W. (1975). Effectively handling silence in counseling groups. *Canadian Counsellor*, Vol. 9, No. 1, pp. 2-8.

VOLUNTEER CODE OF CONDUCT
Human Resources Manual
Policy 9-23

1. CONFIDENTIALITY

We will honor the confidentiality of service users, clients, volunteers, staff, sponsors and donors and adhere to the established precepts of confidentiality of ACT Policies & Procedures and government legislation. We agree to consider information pertaining to medical conditions, family relations, phone numbers and addresses, sexual orientation and other facts of a highly personal nature as confidential and therefore we understand that we are not to disclose this information to any person who is not authorized by ACT to have access to such information without the specific permission of the individual concerned.

2. NON-DISCRIMINATION/EQUITY

In keeping with ACT's philosophies and policies, ACT will neither practice nor tolerate discrimination or harassment against any staff member, volunteer or service-user on the ground of race, creed, color, place of origin, ethnic origin, ancestry, citizenship, political or religious affiliation, gender, sexual orientation, age, marital status, family relationship, HIV status, economic status, identity, disability or record of offences. We will treat each other, staff and service users with dignity, care and respect. We will be sensitive to and educate ourselves about individual and group differences. We will honor all clients' rights to self-determination and agree to support people in making their own personal choices.

3. CONFLICT OF INTEREST

We commit to our understanding and upholding of the Conflict of Interest policy. We agree to discuss any potential conflict with our supervisors and commit to being truthful in all matters to do with our volunteer relationship with ACT.

4. RELATIONSHIPS – BOUNDARIES

ACT encourages friendly relations between volunteers and those they serve. However, it is important to remain aware of appropriate boundaries. As with paid staff, ACT discourages relationships of a romantic or sexual nature between supervisors and those they supervise or volunteers and those they serve. We agree to maintain respectful and professional relationship boundaries during the course of our volunteer work and agree to speak with our supervisors should any relationship develop which makes it difficult for us to remain objective and fulfill our volunteer obligations.

5. LIMITS

We agree to maintain the limits we have set for ourselves with respect to the emotional and physical resources we are willing to provide. We understand that our own training and education may limit our ability to service clients and we recognize the need to ask for assistance or refer when appropriate. If we feel we are being asked to do something outside of our job description, or are having difficulty saying no to a staff member, volunteer or client, we will ask for support and coaching from our supervisors and/or peers.

6. ACCOUNTABILITY

We agree to participate in supervision that is acceptable, reasonable, regular and visible according to the guidelines of the individual programs we are assigned to. Supervision guarantees accountability for the performance of assigned responsibilities, provides an opportunity for feedback and guidance, and assistance and support in my role as a volunteer.

7. TRAINING AND CONTINUING DEVELOPMENT

We understand that in accepting a volunteer position with ACT, we are agreeing to undertake and complete the necessary training before, during and in the course of our volunteer assignment as outlined by the Volunteer Coordinator and as indicated in our program agreements. We value our own continuing development and understand that it is essential as a volunteer. We will do this by keeping updated on new information, attend monthly meetings and relevant in-services, and by taking advantage of opportunities such as seminars and workshops offered both within and outside of ACT.

8. ALCOHOL/DRUG USE

We understand that being under the influence of alcohol or drugs may interfere with our ability to deliver service. We therefore agree: not to perform our volunteer duties while under the influence of drugs or alcohol; not to provide a client with illegal substances or encourage their use; not to participate with a client in alcohol consumption to the point where our effectiveness is impaired.

9. SCENTS

Many people living with HIV/AIDS and also those who suffer from environmental allergies, are extremely sensitive to strong scents. In order to make ACT as comfortable as possible for all people who are affected by this, staff and volunteers agree to moderate their use of colognes and perfume while working in the office or performing duties on behalf of ACT in the community.

10. NON-COMPLIANCE

We understand that failure to adhere to any and all parts of this code may result in suspension from our volunteer duties and/or termination of our volunteer relationship with The AIDS Committee of Toronto (ACT).

RESPONSIBILITIES OF SUPPORT GROUP FACILITATORS

1. All volunteers with ACT are representatives of the organization and, as such, agree to adhere to the policies and procedures outlined in the Volunteer Code of Conduct.

2. Confidentiality

Your responsibility to the members of your group includes:

- Safeguarding the confidentiality of group members' identities, names and contact information
- Returning ALL documents related to the group to the Group Programming Coordinator upon completion of the group

Tips on keeping information confidential:

- Use only first names when taking group notes, including session reports
- Keep all documents related to the group on the ACT premises
- Do not acknowledge group members when you see them outside the group setting, unless they acknowledge you first. When making conversation, do not make any mention of ACT or the group
- When leaving messages for group members, be discreet. Do not say what organization you're calling from.
- Use the assigned ACT mailbox to receive messages/calls from group members. Safeguard the password to this mailbox.

3. Safety

Confidentiality of client information does not extend to communication between volunteers and the Group Programming Coordinator, especially when issues of safety are involved.

Specifically, you **MUST** report to the Group Programming Coordinator as soon as possible any situation involving intent to cause harm to self or others, including disclosure of intent to commit suicide, harm another person or admission of or intent to harm a child.

4. Session Reporting

Volunteer Support Group Facilitators are required to fill out weekly session reports regarding group activities and submit them to the Group Programming Coordinator before the next weekly group session.

These reports are important as they keep the Group Programming Coordinator informed of what is happening in the groups, identify emerging trends and issues affecting the communities ACT serves, and assist us in evaluating the Support Group Program.

5. Training

All volunteers in the Support Group program are required to program-specific meetings/trainings. In addition, Support Group Program volunteers are strongly encouraged to take part in other training opportunities within the organization.

6. Commitment

As a Support Group Facilitator, you are accountable to the Group Programming Coordinator, your co-facilitator and your group members to be present, on time and prepared to facilitate all scheduled meetings of the group. If you are ill, or unexpectedly cannot attend a group meeting, you must provide advanced notice to the Group Programming Coordinator and your co-facilitator.

7. Support and Supervision

Participation in the supervision process, outlined below, is a requirement of all volunteers in the Support Group Program:

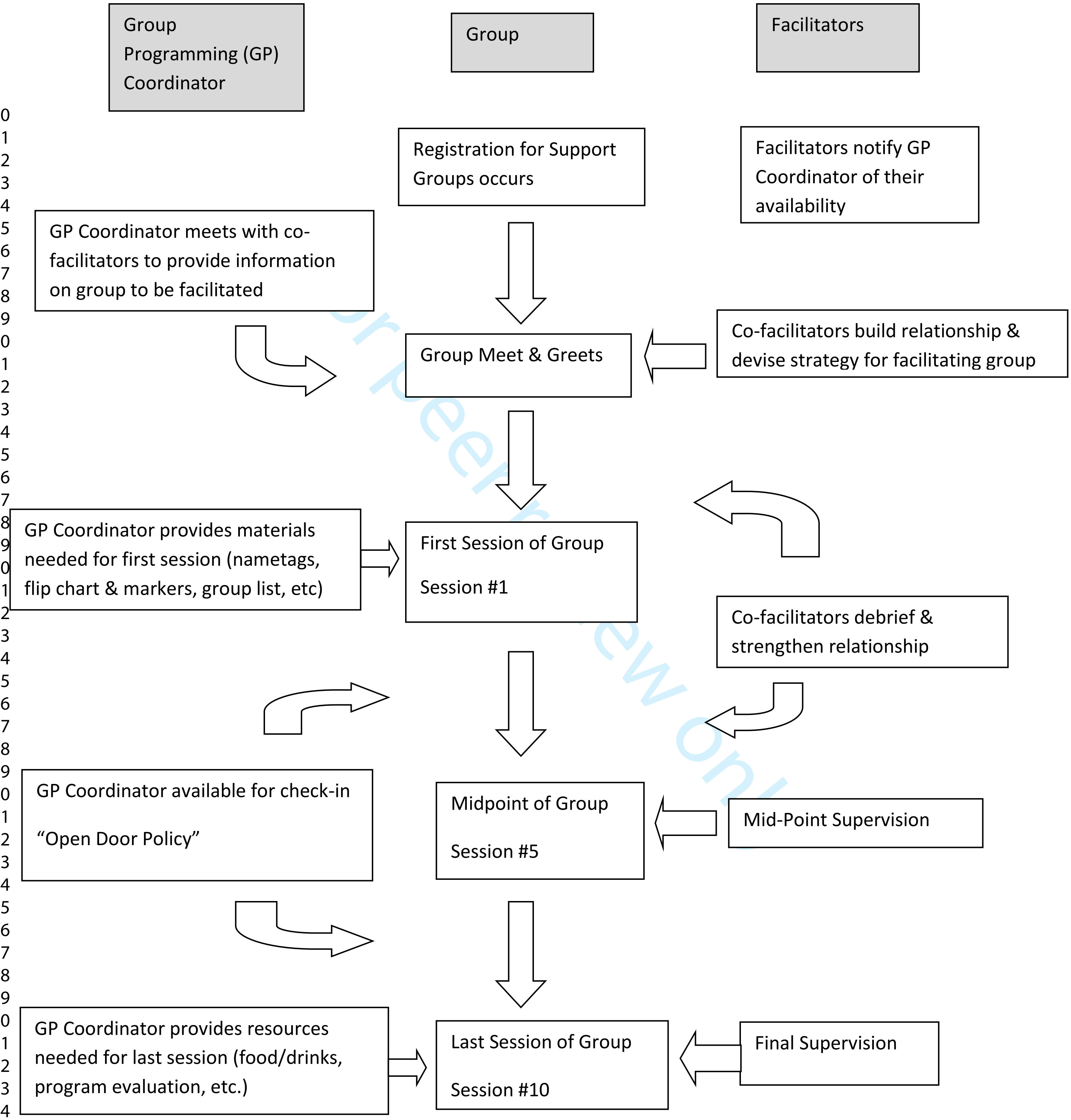
- Volunteer facilitators meet with the Group Programming Coordinator on a regular basis while the group they are facilitating is in progress. The Group Programming Coordinator is also available outside of regularly scheduled supervision meetings for consultation and problem solving regarding any issues that may arise during the course of their work.

- Facilitators of short-term groups will have supervision meetings with the Group Programming Coordinator at the middle (4-6 week mark) and end (after last session) of the group.

- Facilitators of on-going groups will informally check in with the Group Programming Coordinator on a regular basis and will have supervision meetings approximately quarterly.

8. Boundaries
   - Gifts
   - Relationships with group members

TIMELINE OF A SHORT-TERM ACT SUPPORT GROUP



“MEET & GREETS”

“Meet & Greets” are 15-minute meetings that the group facilitators hold with each participant individually before the first group session. Social group work theory has a term for this process: Role Induction.

“Meet & Greets” are not an assessment of the group participant’s eligibility to be part of the group. That assessment has already been completed by ACT’s Group Programming Coordinator.

“Meet & Greets” are an opportunity for the group facilitators to introduce themselves to each group participant. The purpose of this meeting is to discuss the roles of group participant and group facilitator, the process of the group, and how the group participant could feel safe in a support group setting.

Possible discussion topics during group “Meet & Greets”:

Group processes:
- Check in — how it works, why it’s done
- Where do discussion topics come from?
- Importance of group norms
- Timing — start & end times, breaks
- Calling in for absences

Group communication:
- Listening
- Sharing the air/taking turns talking
- Giving advice to fellow group members vs. sharing and relating personal experiences — "I statements"

Group philosophies:
- Talking about feelings/emotions is encouraged
- Respect for differences is expected
- Goals: exchange of information, support, ideas

Role of facilitators:
- Facilitating discussion among group members
- Focus on process, not content of discussion
- Do not provide all of the answers
- Do provide resources, referrals on where to look for information and encourage group members to do the same

Role of Group Programming Coordinator (distribute cards):
- Withdrawal from group
- Concerns/questions related to this or other programming

MEET & GREET QUESTIONNAIRE (SAMPLE)

Monday Evening Support Group

Monday October 19 – Monday December 21, 2009

Facilitators' Names, Ext. 408

Have you ever participated in a support group before? If YES, what was the experience like for you? If NO, how did you come to choose to participate in a support group?

What appeals to you about this group?

What are three things you hope to get out of this group?

1)

2)

3)

What can we as facilitators do to help you achieve your goals and make you feel that your participation in this group was a success?

Are there any worries or concerns you have about participating in this group?

Are there any specific issues or topics you would like to have addressed in this group?

Do you have any questions for us?

Support Group Session Report (SAMPLE)

Group:	**Session #:**
Facilitators:	**Date:**
Topic:	**Guest Speaker:**
Members present:	**Members absent:**

Topics/issues covered in this session:

Are there any issues or concerns that arose in this session?

Comment on this session's group process – what worked well, what difficulties arose, conflict between group members, connections between group members, facilitation issues, etc.:

Are there any resources your group needs?

Are you encountering any situations which could be addressed through further training opportunities (skills and/or information-based)?

Volunteer Support Group Facilitator Supervision (SAMPLE)

Volunteer Name: ____

Supervisor Name: ____

Date of Supervision: ____

Current Volunteer Status: ____________________________________

Areas of Strength **Areas of Potential Growth**

Part One: Volunteer Feedback (To be completed by the volunteer)

What I am doing well as a facilitator: 1. 2. 3.	What concerns/wishes I have for myself as a facilitator: 1. 2. 3.
What works well for me about the support group program: 1. 2.	What concerns/wishes I have about the support group program: 1. 2.

Part Two: Supervisor Feedback (To be completed by the Group Programming Coordinator)

What I see you doing well as facilitator: 1. 2.	My wishes for you as a facilitator are: 1. 2.

3.	3.
Training and Professional Development Opportunities Completed: 1. 2.	Training and Professional Development Opportunities Recommended: 1. 2.

Part Three: Comments (to be completed during supervision)

Volunteer Signature: ____

Group Programming Coordinator Signature:_________________________________

Date & Time of Next Supervision: ____

APPENDICES

- SUGGESTED READINGS
- FACILITATOR TOOL BOX

SUGGESTED READINGS

There are lots of books and articles about groups, group process, and group skills. Here are a few resources worth checking out:

Irvin D. Yalom, *The Theory and Practice of Group Psychotherapy*. 4th ed. Basic Books. New York, 1995.

Although this book is about psychotherapy groups, it is an excellent source of information, much of which can be appropriately modified to suit support groups. Yalom is widely considered to be the authority on group psychotherapy, but he has a definite psychoanalytic bias. If you are not a fan of psychoanalysis, prepare yourself for a provocative read!

Lawrence Shulman, *The Skills of Helping Individuals and Groups*. PE. Peacock Publishers Inc. U.S.A., 1984. (There may be newer editions)

This is a great book with clear, usable descriptions of various communication skills and group work. Lots of 'case' examples help to illustrate skills and theories.

David W. Johnson and Prank P. Johnson, *Joining Together - Group Theory and Group Skills*. 6th ed. Allyn & Bacon. USA., 1997.

A good overview of group theory and skills with lots of facilitation skill-building exercises.

Harvey J. Bertcher, *Group Participation - Techniques for Leaders and Members*. Sage Publications. USA., 1979.

An oldie but a goodie! Clear, basic descriptions of the skills and tasks related to group work.

Alex Gitterman and Lawrence Shulman, *Mutual Aid Groups and the Life Cycle*. PB. Peacock Publishers Inc. USA., 1986.

The first chapter of this book describes some of the basic theoretical components associated with the Mutual Aid model. Case examples of group work with a variety of populations are presented.

TOOLS AND TIPS FOR SUPPORT GROUP FACILITATORS
"TOOL BOX"

Active listening

- Rephrasing
- Checking out/asking
- Paraphrasing
- Summarizing
- Clarifying
- Open- & closed-ended questions
- Body language/facial expressions
- Helps members to feel heard and understood

Bridging & Connecting

- Pointing out connections between group members
- Summarizing common themes
- Re-engaging the group in discussion
- Reduces isolation and helps to normalize experiences

Working with emotion & reflecting feelings

- Encouraging expression and exploration
- Respecting personal boundaries
- Listening for feeling words
- Naming the feelings and clarifying, then putting it to the group

Process Comments/Putting it back to the group

- Focusing on the "how" in the group
- Puts the power back to the group

Norms

- Redirects/focuses group
- Reinforces a structure
- Can often help with challenging situations in groups
- Helps to create safety in the group

Check Ins

- Can help to set agenda topics for evening
- Indicator of emotion in the room
- Brings everyone into the "here and now"

Structured Feedback

- Sets a tone for how to talk to each other
- Encourages a strength-based approach by pointing out helpful traits
- Helps members to "own" their words

Closure

- Using regular reminders
- Connecting the group experience to the personal environment
- Supporting/encouraging emotion around loss/closure
- Offers an opportunity to explore "unfinished business"

Working with a Co-Facilitator

- Can help to balance out skills
- Can help if there is a safety or security issue in the space
- Can offer support to each other
- Can offer more attention to the group

the CTN
CIHR Canadian
HIV Trials Network

le Réseau
Réseau canadien
pour les essais VIH des IRSC

UHN

act

St. Michael's
Inspired Care.
Inspiring Science.

PARTICIPANT INFORMATION AND CONSENT FORM

Study Title:	IN HAND - Cognitive remediation group therapy to improve older adults' ability to cope with HIV-Associated Neurocognitive Disorder (HAND): A pilot randomized, controlled trial
Protocol Number:	CTNPT 029
Principal Investigator:	Mr. Andrew D. Eaton, MSW, RSW PhD Candidate & Research Director Factor-Inwentash Faculty of Social Work, University of Toronto 416-978-8895 (Monday to Friday 9am-5pm)
St. Michael's Hospital Investigator:	Dr. Sean B. Rourke, MD, PhD, FCAHS Clinical Neuropsychologist, St. Michael's Hospital Scientist, Li Ka Shing Knowledge Institute Professor of Psychiatry, University of Toronto 416-878-2779 (Monday to Friday 9am-5pm)
Co-Investigator(s):	Dr. Sharon L. Walmsley, Toronto General Research Institute (TGRI) University, Health Network (UHN) Dr. Shelley L. Craig, Factor-Inwentash Faculty of Social Work, University of Toronto Dr. Barbara A. Fallon, Factor-Inwentash Faculty of Social Work, University of Toronto
Study Sponsor:	St. Michael's Hospital
Study Funder:	CIHR Canadian HIV Trials Network (CTN)
Study Coordinator:	Mr. Alex Wells AIDS Committee of Toronto (ACT) 416-340-8484 ext. 283 (Monday to Friday 9am-5pm)
24-HOUR CONTACT:	(416) 864-5431 (Hospital Locating)

INTRODUCTION

You are being asked to take part in a research study involving group therapy because you are living with HIV-Associated Neurological Disorder (HAND), more specifically, Mild Neurocognitive Disorder (MND).

Before deciding to take part in this study, it is important that you read and understand the following explanation about the study and its risks and benefits. Participation is voluntary. Please ask the study investigator or study staff to explain any words you don't understand. If you have any questions please ask a study investigator or study staff for more information. If you wish to take part in this study, you will be asked to sign this form.

If the study doctor is also your treating doctor, this will be discussed with you.

Please take time to read the following information carefully and if you wish discuss it with your family, friends, and doctor before you decide.

BACKGROUND

Approximately half of the aging HIV-positive population will be affected by HAND. People with HAND can experience memory impairment and issues with processing new information, problem solving and decision making. With the development, access to, and early initiation of modern antiretroviral therapy (ART), HAND is less severe and less common than it once was. However, people who were treated with old therapies, ones that were less effective and with higher rates of toxicity compared to current regimens, or who experienced AIDS defining illnesses, may be affected by HAND more frequently and more severely.

In the general aging population Mindfulness-Based Stress Reduction (MBSR) and brain training activities (BTA) have been shown to decrease stress and depression and improve coping and quality of life. Mindfulness-Based Stress Reduction (MBSR) involves meditation and breathing exercises. Brain training activities (BTA) involve practice with games on computers and mobile devices that are designed to help improve memory, attention, and organizational skills. These types of therapies can vary widely they have not been fully tested in people aging with HAND.

In this study we will explore the use of cognitive remediation group therapy (CRGT) in aging HIV-positive adults affected by Mild Neurocognitive Disorder. CRGT will combine Mindfulness-Based Stress Reduction (MBSR) and brain training activities (BTA) in a group setting.

PURPOSE OF THE STUDY

The purpose of this research study is to determine if it is possible to conduct cognitive remediation group therapy (CRGT) in older HIV-positive adults living with mild-to-moderate HAND and if this type of therapy is acceptable. Researchers will compare this experimental group therapy to the standard of care group therapy that is available to persons living with HIV. As part of the study researchers will also evaluate if there are any changes in your stress, anxiety, and coping from the beginning to the end of the research study.

If you agree to take part in this study you will be one of approximately 16 participants recruited from St. Michael's Hospital.

WHO CAN TAKE PART IN THE STUDY

You may be able to participate in this study if:

- You are aged 40 or older

- You have received a documented HAND diagnosis of MND
- You have been living with HIV for 5 or more years
- You provided consent to St. Michael's Hospital to be contacted for future research studies
- You are available to attend 10 weeks of group therapy in downtown Toronto

You will not be eligible to participate in this study if:

- You have been diagnosed with another significant psychiatric condition (i.e. schizophrenia, bipolar disorder, etc.) and/or past traumatic brain injury
- You have a documented HAND diagnosis of asymptomatic neurocognitive impairment (ANI) or HIV-associated dementia (HAD)
- You have active intravenous or crystal meth drug use
- You have been hospitalized within the past month
- You are unable to communicate in English
- You are unable to use a tablet
- You are currently participating in another HAND, or mindfulness treatment study

DESIGN OF THE STUDY

If you are eligible to take part in this study you will be randomized, which means you will be selected by chance (like a flip of a coin) to one of two therapy groups described below. The randomization for this study is in a 1:1 ratio, which means you will have an equal chance of being in either group. There will be approximately 8 participants in each group.

Participants in each group will be asked to attend 10 weekly 3-hour group therapy sessions:

Group A: (Experimental Cognitive remediation group therapy)

If you are assigned to Group A your group therapy sessions will be led by a Mindfulness-Based Stress Reduction (MBSR)-certified social worker and a peer (person aging with HIV) at Toronto General Hospital. For about one hour you will complete brain training exercises on a tablet using PositScience software by BrainHQ. Study participants will support each other working through these activities. For about two hours you will take part in mindfulness-based stress reduction activities such as meditation and breathing exercises. This type of therapy is research and is not the standard of care for persons living with HIV-Associated Neurological Disorder (HAND).

Group B: (Active Control-Living with HIV Support Group Therapy)

If you are assigned to Group B your therapy sessions will be led by a certified social worker at the AIDS Committee of Toronto (ACT). This group involves peer-based discussion on the effects of living with HIV, with topics determined by the group in the meeting. This is the standard care therapy for persons living with HIV.

DURATION OF THE STUDY

The total length of your participation in the study will be about 6 months. There will be a screening period (to confirm your eligibility to take part in this study) which may last 1 to 2 weeks. Once you are confirmed to be eligible to take part in this study you will attend a baseline visit to complete a study questionnaire. After all the participants in the study have been enrolled you will be randomized to one of the two therapy groups and you will be asked to meet with the group facilitator and then attend 10 therapy sessions once a week for 10 weeks. At the end of the therapy sessions you will visit the study center for follow-up at about one week after the therapy sessions end and again about 3 months later.

STUDY PROCEDURES

Screening Visit (30 minutes)

Once you have agreed to take part in the study and signed the informed consent form study staff will ask you about:

- Your demographic information, medical history and alcohol/drug use
- Any changes in your cognition (memory, problem solving, coping) since your last clinic visit
- Your preferred schedule to attend a 10-week group therapy program
- Your access to a mobile device (i.e., smartphone, tablet) for the purpose of using brain training games from PositScience by BrainHQ.

After the screening visit study staff will access your patient chart at St. Michaels Hospital to collect information about your medical history, medications and clinic visits to see if you meet the specific requirements to be in the study. Your demographics (age, ethnicity, gender etc.) will also be collected from your patient chart.

If you meet the study entry criteria you will be asked to visit the study center for a baseline visit.

Baseline Visit (40 minutes)

At this visit you will be asked to complete a study questionnaire that asks about your emotions and thoughts surrounding living with HIV and HAND. This survey will be completed on a computer but if you prefer you can complete it on paper. Study staff will be available to help you with any questions you do not understand.

Group Assignment (Randomization)

Once all the study participants have been enrolled in the study you will be randomly assigned to one of the two therapy groups:

Group A: Experimental Cognitive Remediation Group Therapy **or**
Group B: Active Control-Living with HIV Support Group Therapy (standard of care group therapy)

Facilitator Meeting (20 minutes)

After you have been assigned to a group you will be asked to meet with your group facilitator before the therapy sessions begins. The facilitator will give you more information on what to expect at the therapy sessions.

Therapy Sessions (Visit 1-10, 3 hours each)

You will be asked to attend 10 group therapy sessions for 10 weeks in a row. Each session will last about 3 hours. This is a total of 30 hours of group therapy.

Visit 5 and 10 Questionnaires (10 minutes each)

At the end of therapy sessions 5 and 10 you will also be asked to complete a questionnaire about your satisfaction with the session’s length, content and facilitators. This will be completed on paper.

Follow-up Visit (40 minutes)

You will be asked to visit the study center 1-2 weeks after the group therapy sessions have ended. At this visit you will be asked to complete a study questionnaire that asks about your emotions and thoughts surrounding living with HIV and HAND. This is the same questionnaire that you completed at the baseline visit. This survey will be completed on a computer but if you prefer you can complete it on paper. Study staff will be available to help explain any questions you do not understand. This visit will take about 40 minutes to complete.

End of Study Visit (40 minutes)
You will be asked to visit the study center about 3 months after the follow-up visit. At this visit you will be asked to complete a study questionnaire that asks about your emotions and thoughts surrounding living with HIV and HAND. This is the same questionnaire that you completed at the baseline and follow-up visits. This survey will be completed on a computer but if you prefer you can complete it on paper. Study staff will be available to help explain any questions you do not understand.

After this, you will have finished all of the study visits and your participation in the study will be completed.

POTENTIAL HARMS AND DISCOMFORTS

We do not think you will be harmed in any way during this study, but there is a chance that you could find some parts of the study uncomfortable.

- You may feel anxious, upset or sad when answering questions or completing questionnaires. You are not required to answer any questions that make you feel uncomfortable.
- During the group therapy you will be asked some personal questions about your experiences with HIV and HAND. We need to ask these questions for the study to understand the impact of the program, and what could be done better in the future. This may make you experience discomfort, anxiety, and/or unease from disclosing sensitive information about yourself to other participants during the group therapy.

If you have any concerns about your feelings during the study please contact the study team and they can direct you to the appropriate support service. You can also follow-up with your social worker or other health care professional.

There is potential for research participants/group members to expose sensitive information about the group and/or other group members. Research participants/group members will be asked during the consent process and throughout the group therapy sessions to maintain the confidentiality of the group, however group members are not bound by professional obligations to maintain the confidentiality of the group. Facilitators are bound by professional obligations to maintain the confidentiality of the group. Research participants/group members will be advised to practice some caution before sharing personal and sensitive information. All participants will only be referred to by a first name, and will be offered the possibility of using a pseudonym (false name) in the group.

POTENTIAL BENEFITS

We do not know whether being in this study will benefit you. It is possible that you may learn new skills that may help you cope with HAND but this is not certain.

This is a "pilot study" which is done to test the study plan and to find out whether enough participants will join a larger study and accept the study procedures. The results may be used as a guide for larger studies, although there is no guarantee that they will be conducted. Knowledge gained from pilot studies may be used to develop future studies that may benefit others.

ALTERNATIVES TO PARTICIPATION

You do not have to join this study to receive services related to HAND. If you decide not to take part in this study you will still be able to receive any standard of care treatment you are already receiving, or are due to receive.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this study is voluntary. You may withdraw from this study at any time without giving reasons. Your decision will not affect your or your family's ability to receive medical care at St. Michael's Hospital or any of the other study sites, and you will not lose any benefits to which you are otherwise entitled.

The study investigator may also stop your participation in the study without your consent if it is in your best interest or if you do not follow the requirements of the study. If you are asked to leave the study, the reasons for this will be explained to you and you will have the opportunity to ask questions about this decision.

The data you provide up to the point of withdrawal may still be used in the analysis. No further information will be collected from you.

NEW INFORMATION

If any new information becomes available during the study that could affect your willingness to continue to participate, it will be supplied to you.

COSTS TO PARTICIPATION AND COMPENSATION

There will be no cost to you for taking part in this study. You will not be paid for your participation in this study. However, you will be provided with a maximum of $300 in compensation for your time and travel. Compensation will be provided according to the following schedule:

- $20 for attending the Screening Visit
- $20 for attending the Baseline Visit
- $20 for attending the Facilitator Meeting
- $20 for attending each therapy session (10 sessions x $20 = $200)
- $20 for completing the Follow-up Visit
- $20 for completing the End of Study Visit

RIGHTS AS A PARTICIPANT

If you are harmed as a result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

PROTECTING YOUR HEALTH INFORMATION: PRIVACY AND CONFIDENTIALITY

If you agree to join this study, the study investigator and his/her study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your

- Name and age
- Address
- Hospital ID,
- Date of birth,
- New or Existing medical records, including types, dates and results of medical tests or procedures

All persons involved in the study, including the study investigators, coordinators, nurses and delegates (hereby referred to as "study personnel"), are committed to respecting your privacy. No other persons will have access to your personal health information or identifying information without your consent, unless required by law. The study personnel and the study sponsor will make every effort to keep your personal health information private and confidential in accordance with all applicable privacy legislations, including the Personal Health Information Protection Act (PHIPA) of Ontario.

The following groups or people may come to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

- University Health Network (the study sponsor) or its representative
- Representatives of St Michaels Hospital and University Health Network Research Ethics Boards

Any personal identifying information (such as your name) will be "de-identified" by replacing your personal identifying information with a "study number". This number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will be available to St. Michael's Hospital investigator Dr. Sean Rourke and the study staff. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

Your coded study data will be sent to and accessed by study personnel at the AIDS Committee of Toronto (ACT), University Health Network (UHN), and the CIHR Canadian HIV Trials Network (CTN). This data will not include your name or address, date of birth or any information that directly identifies you. To protect your privacy, data will be password protected and access to study data will be limited to authorized persons and transmission of the data will be encrypted.

The data collected for this study will not be part of your medical record, however your participation in this study may be recorded in your medical record. You have the right to review your personal data and request changes if not correct. However, access to your study data during the study may be limited if it weakens the integrity of the study.

All study data will be kept in a locked and secure area by the study investigator. Electronic files will be stored securely on the hospital network. Study data will be kept for 7 years after the end of the study at which time paper study documents will be shredded and electronic data will be destroyed.

STUDY REGISTRATION AND RESULTS

A description of this clinical trial will be available on http://www.hivnet.ubc.ca/clinical-trials/ctnpt-029/, as required. This website will not include information that can identify you. At most, the Website will include a summary of the results. You can search this Website at any time.

The study results may be published in medical literature or presented at conferences, seminars or other public forums, but you will not be identified by name or any other identifying information.

COMMUNICATION WITH YOUR FAMILY DOCTOR OR SPECIALIST

If you consent, we will be informing your primary treating doctor and/or specialist of your study participation. We will send your primary physician and/or specialist a letter which will include a brief summary of the study so they can provide proper medical care.

RESEARCH ETHICS BOARD CONTACT

If you have questions regarding your rights as a research participant, you may contact the Director, Sharon Freitag, Research Ethics, St. Michael's Hospital, at 416-864-6060 ext. 2385 during business hours.

This research project and information and consent form have been reviewed and approved by the Research Ethics Board (REB) at St. Michael's Hospital. The REB is a group of scientists, medical staff, individuals from other backgrounds (including law and ethics), as well as members from the community. The committee is established by the hospital to review studies for their scientific and ethical merit. The Board pays special attention to the potential harms and benefits involved in participation to the research participant, as well as the potential benefit to society. This group is also required to do periodic review on ongoing research studies. As part of this review, someone may contact you from the REB to discuss your experience in the research study.

STUDY CONTACTS AND EMERGENCY CONTACT

If you have any questions about this study at any time, or if you experience a research-related injury, you should contact:

Principal Investigator:	Mr. Andrew Eaton 416-978-8895 / andrew.eaton@utoronto.ca
St. Michael's Investigator:	Dr. Sean Rourke 416-878-2779 / sean.rourke@utoronto.ca
Research Coordinator:	Mr. Alex Wells 416-340-8484, ext. 283 / awells@actoronto.ca

STATEMENT OF CONSENT

Study Title: IN HAND - Cognitive remediation group therapy to improve older adults' ability to cope with HIV-Associated Neurocognitive Disorder (HAND): A pilot randomized, controlled trial

This research study has been explained to me, and my questions have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I have the right not to participate and the right to withdraw without affecting the quality of medical care at St. Michael's Hospital for me and for other members of my family. As well, the potential harms and benefits (if any) of participating in this research study have been explained to me.

I have been told that I have not waived my legal rights nor released the study investigators, study sponsor, or involved institutions from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. I have been told that records relating to me and my care will be kept confidential and that no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

Consent to notify primary care physician (s) or specialist(s) of your participation in this study This is not a consent to release medical information.

Initial: ______ Yes, I want the study investigator to advise my primary care physician(s) or specialist(s) of my participation in this study.

Initial: ______ No, I do not want the study investigator to advise my primary care physician(s) or specialist(s) of my participation in this study.

Consent to participate in the study
I hereby consent to participate in this study. I have been told I will be given a copy of this signed consent form.

Participant's Name (Print)	Participant's Signature	Date [MM/DD/YYYY]

I have explained the study to the above-named participant. I have explained the nature and purpose, the potential benefits, and possible risks associated with participation in this research study. I have answered all questions that have been raised about the study.

Name and Position of Person Obtaining Consent (Print)	Signature of Person Obtaining Consent	Date [MM/DD/YYYY]

APPENDIX A (Study Visit Schedule)

Visit Details	**Screening Period**			**Study Period**			**Follow-up Period**	
Visit Name	Screening Call	Screening Visit	Baseline Visit	Orientation	Sessions 1-7	Sessions 4 & 8	Follow-up Visit	End of Study Visit
Visit #	-3	-3	-1	0	1,2,3,4,6,7	4 & 8	9	10
Week #			-1	0-8			9	21
Day #	-56 to -7 days		-7	0-56			63	153
Day Window	+/- 7	+/- 7	+/- 7	+/- 7	+/- 0	+/- 0	+/- 7	+/- 7
Procedures								
Informed Consent		X						
Entry Criteria Assessment	X	X						
Chart Abstraction (demographics)		X						
Randomization			X[1]					
Group Sessions				X[2]	X	X		
Facilitator Session Reports					X	X		
Helping Characteristics of Self-Help and Support Groups Measure						X		
HIV/AIDS Stress Scale			X				X	X
Anxiety in Cognitive Impairment and Dementia Scale			X				X	X
Coping Self-efficacy of Health Problems Scale			X				X	X
Five Facet Mindfulness Questionnaire – Short Form			X				X	X

[1] To occur once all participants have been enrolled and eligibility confirmed

[2] Acquaintance with group only; no therapy will be administered during this session

Inclusion/Exclusion Criteria Confirmation

Inclusion Criteria	Yes	No
1) Participant Age ≥40	☐	☐
2) ≥5 years living with HIV	☐	☐
3) MND (Mild Neurocognitive Disorder) diagnosis	☐	☐
4) Consented to future contact for research from St. Michael's Hospital	☐	☐
5) Can attend 8 weeks of group therapy in downtown Toronto	☐	☐
If # **No** ≥1, cannot enroll into study	☐	☐

Exclusion Criteria	Yes	No
1) ANI / HAD diagnosis	☐	☐
2) Hospitalization within past 30 days	☐	☐
3) Inability to communicate in English	☐	☐
4) Cannot use a tablet	☐	☐
5) Would be disruptive to a group setting		
If # **Yes** ≥1, cannot enroll into study	☐	☐

If participant does not meet Inclusion/Exclusion Criteria, Please specify #: ___________________________

*If **OTHER** Please specify ____If eligible, proceed with ICF Process. After ICF is signed, continue to 3.*

2. Participant Availability (Mark when typically available)

May-June 2018

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
9:00 AM – 12:00 PM	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*
12:00 PM – 3:00 PM	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*
3:00 PM – 6:00 PM	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*
6:00 PM – 9:00 PM	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*

Fall 2018 (August-December)

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
9:00 AM – 12:00 PM	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*
12:00 PM – 3:00 PM	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*
3:00 PM – 6:00 PM	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*
6:00 PM – 9:00 PM	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*

Times unavailable in Spring or Fall: ____

4. **Mobile Device Access**

Do you have access to the following mobile devices?

Computer	Yes	No
Tablet	Yes	No
Smartphone	Yes	No

IN HAND
Cognitive remediation group therapy to improve older adults' ability to cope with HIV-Associated Neurocognitive Disorder (HAND): A pilot randomized, controlled trial

Questionnaire: **Baseline Visit, Post-Intervention, 3-month Follow-up**

Participant ID: ______________ Date: ______________

Hi there, I'm a study coordinator with the IN HAND research study. I have some questions about your emotions and thoughts surrounding HIV and HAND- your experiences with stress, anxiety, and coping. I'm going to ask you some survey-like questions, some yes or no, some on a scale of 0-4, and some on a scale from 1-5. You can choose not to answer any question, and we can pause, or stop the questionnaire at any time you like.

Would you like to begin?

HIV/AIDS Stress Scale

Below is a list of problems that people living with HIV sometimes have. For each question, there are two examples to describe the problem. Your own examples may differ from the ones provided, so long as they seem to fit within the problem category. Please circle a number to the right of each question that best describes how troublesome that problem has been for you during the past month.

How much were you troubled by:	Not at all	A bit (once or twice in the past month)	Moderate (once or twice a week for the past month)	A lot (three to six times a week for the past month)	Extreme (daily)
1. **Distressing emotions related to HIV** (e.g., you feel angry or fearful; you feel anxious or depressed)	0	1	2	3	4
2. **Relationship difficulties related to HIV** (e.g., you have arguments with your support person about how to best care for your health; you have difficulty establishing a relationship)	0	1	2	3	4
3. **Grief/bereavement related to HIV** (e.g., you are concerned about your own losses such as loss of independence; you are grieving for the loss of a loved one from AIDS)	0	1	2	3	4

4. **Confidentiality/privacy concerns related to HIV** (e.g., you are concerned about your HIV status breached; you are reluctant to disclose your status to others)	0	1	2	3	4
5. **Sexual difficulties related to HIV** (e.g., you're finding it hard to maintain safe sex behaviours; you are sexually frustrated)	0	1	2	3	4
6. **Difficulties in coming to terms with your HIV status** (e.g., you can't accept that you have HIV; you refuse to even think about HIV)	0	1	2	3	4
7. **Concerns about death related to HIV** (e.g., you are preoccupied with dying; you don't think about the possibility that you may die from HIV)	0	1	2	3	4
8. **Isolation related to HIV** (e.g., you have less contact with others because of HIV; you don't get invited out much now that you have HIV)	0	1	2	3	4
9. **Suicidal thoughts/attempts related to HIV** (e.g., you have thoughts of ending your life; you have actually attempted to end your life)	0	1	2	3	4
10. **Increased drug/alcohol intake related to HIV** (e.g., you use drugs and/or alcohol more now; you are often high or drunk)	0	1	2	3	4
11. **Discrimination/stigma concerns related to HIV** (e.g., you are concerned that you will be discriminated against because of HIV; you feel as if you have not been treated with respect)	0	1	2	3	4
12. **Religious/existential difficulties related to HIV** (e.g., you are having difficulty searching for meaning in your life; you are struggling to make sense of the predicament you are in)	0	1	2	3	4
13. **Overly attentive to bodily functions or changes** (e.g., you are constantly checking for HIV-related symptoms; you are overly attentive to any new physical changes such as appearance of a rash)	0	1	2	3	4
14. **Difficulties in telling others of your HIV status** (e.g., you don't know who, how, or when to tell of your HIV status; you have only told one or two people)	0	1	2	3	4
15. **Boredom related to HIV** (e.g., you are unable to use your free time doing things you would normally enjoy; you often find yourself sitting about doing nothing)	0	1	2	3	4

16. **Difficulty dealing with HIV-related symptoms of illness** (e.g., you often have difficulty dealing with fatigue or nausea; you have pain and physical discomfort most of the time)	0	1	2	3	4
17. **Difficulty in enhancing your health** (e.g., your attempts to maintain adequate nutrition, or a positive mental attitude often are short-lived)	0	1	2	3	4
18. **Difficulty with health care system** (e.g., you have difficulties in getting access to health services such as dentists or home care)	0	1	2	3	4
19. **Difficulties with HIV treatment** (e.g., you have difficulties managing side effects from HIV treatments; you can't adhere to HIV treatment)	0	1	2	3	4
20. **Transport difficulties related to HIV** (e.g., you have difficulty getting appropriate transport to places; public transport is physically demanding)	0	1	2	3	4
21. **Financial difficulties related to HIV** (e.g., you are unable to pay debts; you have problems with superannuation payouts)	0	1	2	3	4
22. **Daily living difficulties related to HIV** (e.g., you can't always do the shopping or cleaning; you can't keep up with the basic day-to-day chores)	0	1	2	3	4
23. **Reducing risk of infection** (e.g., you are preoccupied with thoughts about transmitting HIV to others; you can concerned that some of your behaviours may put others at risk)	0	1	2	3	4
24. **Difficulty in accessing information related to HIV** (e.g., you have received conflicting information on HIV; you can't get adequate treatment information)	0	1	2	3	4
25. **Employment difficulties related to HIV** (e.g., you can't obtain/maintain employment because of illness; you are concerned about work-related stress)	0	1	2	3	4
26. **Legal problems related to HIV** (e.g., you are involved in a legal process; you don't know who to assign power of attorney to)	0	1	2	3	4
27. **Planning difficulties related to HIV** (e.g., uncertaint with your health makes career planning difficult; you don't know whether to start new projects)	0	1	2	3	4

28. **Difficulties with thinking processes related to HIV** (e.g., you forget things more than usual; you can't concentrate as well as usual)	0	1	2	3	4
29. **Dealing with declining health related to HIV** (e.g., you have difficulty in dealing with increasing physical restrictions due to declining health; you have difficulty dealing with the change from being well to having illness)	0	1	2	3	4

Anxiety in Cognitive Impairment and Dementia Scale

Please circle yes or no for the following questions, thinking about the past 24 hours. If you answer yes to the numbered questions, please answer the corresponding letter question below it.

In the past 24 hours:

1. Have you experienced worry? (e.g., about health, memory of cognitive functioning, friends and family, etc.)	yes	no
a. If so, did worrying bother you?	yes	no
2. Have you experienced anxiety? (e.g., about health, memory of cognitive functioning, friends and family, etc.)	yes	no
a. If so, did the anxiety bother you?	yes	no
3. Have you been startled? (e.g., sudden scare, no sense of time and place, etc.)	yes	no
a. If so, did the startle bother you?	yes	no
4. Have you experienced insomnia? (e.g., sleeplessness, etc.)	yes	no
a. If so, did the insomnia bother you?	yes	no
5. Have you experienced irritability? (e.g., low patience, expression of frustration, etc.)	yes	no
a. If so, did the irritability bother you?	yes	no
6. Have you experienced muscle tension?	yes	no
a. If so, did the muscle tension bother you?	yes	no
7. Have you experienced restlessness? (e.g., fidgeting, etc.)	yes	no
a. If so, did the fidgeting bother you?	yes	no
8. Have you experienced fatigue? (e.g., overly tired, not as much energy as normal etc.)	yes	no
a. If so, did the fatigue bother you?	yes	no
9. Have you experienced cardiovascular issues? (e.g., chest pain, etc.)	yes	no

a. If so, did the cardiovascular issues bother you?	yes	no
10. Have you experienced respiratory issues? (e.g., shortness of breath, etc.)	yes	no
a. If so, did the respiratory issues bother you?	yes	no
11. Have you experienced gastrointestinal issues? (e.g., diarrhea, excessive flatulence, etc.)	yes	no
a. If so, did the gastrointestinal issues bother you?	yes	no
12. Have you experienced other somatic issues? (e.g., pain, depression, etc.)	yes	no
a. If so, did the somatic issues bother you?	yes	no
13. Have you experienced any avoidance behaviours? (e.g., denial, not wanting to attend appointments, etc.)	yes	no
a. If so, did the avoidance behaviour bother you?	yes	no

Five Facet Mindfulness Questionnaire – Short Form (FFMQ-SF)

Below is a collection of statements about your everyday experience. Using the 1–5 scale below, please indicate, in the box to the right of each statement, how frequently or infrequently you have had each experience in the last month (or other agreed time period). Please answer according to what really reflects your experience rather than what you think your experience should be.

Never or Very Rarely True **1**	*Not often true* **2**	*Sometimes True Sometimes Not True* **3**	*Often True* **4**	*Very often or Always True* **5**

1	I'm good at finding the words to describe my feelings	*DS*	
2	I can easily put my beliefs, opinions, and expectations into words	*DS*	
3	I watch my feelings without getting carried away by them	*NR*	
4	I tell myself that I shouldn't be feeling the way I'm feeling	*/NJ*	
5	it's hard for me to find the words to describe what I'm thinking	*/DS*	
6	I pay attention to physical experiences, such as the wind in my hair or sun on my face	*OB*	
7	I make judgments about whether my thoughts are good or bad.	*/NJ*	

8	I find it difficult to stay focused on what's happening in the present moment	/AA	
9	when I have distressing thoughts or images, I don't let myself be carried away by them	NR	
10	generally, I pay attention to sounds, such as clocks ticking, birds chirping, or cars passing	OB	
11	when I feel something in my body, it's hard for me to find the right words to describe it	/DS	
12	it seems I am "running on automatic" without much awareness of what I'm doing	/AA	
13	when I have distressing thoughts or images, I feel calm soon after	NR	
14	I tell myself I shouldn't be thinking the way I'm thinking	/NJ	
15	I notice the smells and aromas of things	OB	
16	even when I'm feeling terribly upset, I can find a way to put it into words	DS	
17	I rush through activities without being really attentive to them	/AA	
18	usually when I have distressing thoughts or images I can just notice them without reacting	NR	
19	I think some of my emotions are bad or inappropriate and I shouldn't feel them	/NJ	
20	I notice visual elements in art or nature, such as colors, shapes, textures, or patterns of light and shadow	OB	
21	when I have distressing thoughts or images, I just notice them and let them go	NR	
22	I do jobs or tasks automatically without being aware of what I'm doing	/AA	
23	I find myself doing things without paying attention	/AA	
24	I disapprove of myself when I have illogical ideas	/NJ	

Coping Self-Efficacy Scale of Health Problems

Presented below are 10 statements about you and your state of health. Please read each one of them and express if you totally disagree (column marked with 1), disagree (column marked with 2), agree (column marked with 3), or totally agree (column marked with 4). For each question, circle only one answer from the four mentioned. There are no right or wrong answers; what is important is your opinion, so we ask for your honesty.

Questions	Totally Disagree	Disagree	Agree	Totally Agree
1. I largely believe that the ability to overcome an illness of disease depends on me	1	2	3	4
2. I am a healthy person, and I do not commonly suffer ailments	1	2	3	4
3. The majority of people are in worse health than I am	1	2	3	4
4. I avoid going to health services and I try to solve my health problems by myself	1	2	3	4
5. I feel optimistic about my state of health	1	2	3	4
6. When faced with a health problem, I first think about how I can solve it for myself	1	2	3	4
7. I think that telling others about one's own health problems does not help to overcome them	1	2	3	4
8. I feel happy	1	2	3	4
9. I believe I have problems in my life, but not as many as others	1	2	3	4
10. I have many things to worry about, and health is not a main one	1	2	3	4

Use of Brain Training Activities

Do you currently practice brain training activities on your computer, mobile device, or pen and paper?

Yes No

1. If yes, how frequently do you practice this activities?
   - ○ More than 3 hours per week
   - ○ 1-3 hours per week
   - ○ Less than 1 hour per week

Group Therapy Satisfaction
Sessions #4 and #8

1. **Please indicate the degree to which you agree or disagree with the statements below:**

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I feel the facilitators remained respectful and non-judgmental.	1	2	3	4	5
I feel the facilitators managed communication well within the group.	1	2	3	4	5
I feel the facilitators maintained a safe environment.	1	2	3	4	5

2. **Please read the statements below and circle the number that best indicates your feelings about each statement. For example, if you strongly disagree with a statement, circle "1". If you are neutral, circle "2", and if you strongly agree, circle "5".**

	Strongly disagree				Strongly agree
Since I started coming to this group, I have begun to have more faith in my ability to change myself.	1	2	3	4	5
Since I started coming to this group, I have begun to cope much better with my life.	1	2	3	4	5
The group helps me find new coping strategies.	1	2	3	4	5
The group has helped me learn ways of solving my problems.	1	2	3	4	5
The group has helped me find ways of controlling myself.	1	2	3	4	5
The group makes me feel I'm not alone with my difficulties.	1	2	3	4	5
The group takes me out of my loneliness.	1	2	3	4	5
A professional could never understand me the way group members can.	1	2	3	4	5
The group helps me evaluate my coping strategies.	1	2	3	4	5
The group makes me feel I can function as well as anyone else.	1	2	3	4	5
Other group members' knowledge and experience helps me as much as the help I could get from professionals.	1	2	3	4	5
I share my life experiences with other members of the group.	1	2	3	4	5

I share my troubles with other members of the group.	1	2	3	4	5
Members of the group disclose personal and intimate details of their lives.	1	2	3	4	5
The group helps me to release tension.	1	2	3	4	5
I contribute my own knowledge and experience to the other members.	1	2	3	4	5
I help the members of the group a lot through my own knowledge and experience.	1	2	3	4	5
The knowledge and experience I acquired as a result of my situation contribute to the group at least the same as the knowledge of a professional.	1	2	3	4	5
When something bothers me, members of the group treat me kindly.	1	2	3	4	5
Group members care about each other.	1	2	3	4	5
I give group members "tips" on how to cope with daily situations.	1	2	3	4	5
The group offers me "tips" on how to cope with daily situations.	1	2	3	4	5

3. How did you feel about the size of the group?

☐ Too many people ☐ Too few people ☐ Just right

4. Overall, how did you feel about the length of each group session (3 hours)?

☐ Too short ☐ Too long ☐ Just right

a) Any other comments about group size and/or session length?

5. Is there anything else you would like to tell us about working within a group?

SPIRIT

STANDARD PROTOCOL ITEMS: RECOMMENDATIONS FOR INTERVENTIONAL TRIALS

SPIRIT 2013 Checklist: Recommended items to address in a clinical trial protocol and related documents*

Section/item	Item No	Description	Reported on Page
Administrative information			
Title	1	Descriptive title identifying the study design, population, interventions, and, if applicable, trial acronym	1
Trial registration	2a	Trial identifier and registry name. If not yet registered, name of intended registry	11
	2b	All items from the World Health Organization Trial Registration Data Set	See registry
Protocol version	3	Date and version identifier	See registry
Funding	4	Sources and types of financial, material, and other support	12-13
Roles and responsibilities	5a	Names, affiliations, and roles of protocol contributors	12
	5b	Name and contact information for the trial sponsor	12-13
	5c	Role of study sponsor and funders, if any, in study design; collection, management, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication, including whether they will have ultimate authority over any of these activities	12-13
	5d	Composition, roles, and responsibilities of the coordinating centre, steering committee, endpoint adjudication committee, data management team, and other individuals or groups overseeing the trial, if applicable (see Item 21a for data monitoring committee)	11
Introduction			
Background and rationale	6a	Description of research question and justification for undertaking the trial, including summary of relevant studies (published and unpublished) examining benefits and harms for each intervention	4-5
	6b	Explanation for choice of comparators	5
Objectives	7	Specific objectives or hypotheses	5

Trial design	8	Description of trial design including type of trial (eg, parallel group, crossover, factorial, single group), allocation ratio, and framework (eg, superiority, equivalence, noninferiority, exploratory)	5
Methods: Participants, interventions, and outcomes			
Study setting	9	Description of study settings (eg, community clinic, academic hospital) and list of countries where data will be collected. Reference to where list of study sites can be obtained	5
Eligibility criteria	10	Inclusion and exclusion criteria for participants. If applicable, eligibility criteria for study centres and individuals who will perform the interventions (eg, surgeons, psychotherapists)	6-7
Interventions	11a	Interventions for each group with sufficient detail to allow replication, including how and when they will be administered	7
	11b	Criteria for discontinuing or modifying allocated interventions for a given trial participant (eg, drug dose change in response to harms, participant request, or improving/worsening disease)	8
	11c	Strategies to improve adherence to intervention protocols, and any procedures for monitoring adherence (eg, drug tablet return, laboratory tests)	8
	11d	Relevant concomitant care and interventions that are permitted or prohibited during the trial	8
Outcomes	12	Primary, secondary, and other outcomes, including the specific measurement variable (eg, systolic blood pressure), analysis metric (eg, change from baseline, final value, time to event), method of aggregation (eg, median, proportion), and time point for each outcome. Explanation of the clinical relevance of chosen efficacy and harm outcomes is strongly recommended	8-9
Participant timeline	13	Time schedule of enrolment, interventions (including any run-ins and washouts), assessments, and visits for participants. A schematic diagram is highly recommended (see Figure)	9-10
Sample size	14	Estimated number of participants needed to achieve study objectives and how it was determined, including clinical and statistical assumptions supporting any sample size calculations	11
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	11

Methods: Assignment of interventions (for controlled trials)

Allocation:			
Sequence generation	16a	Method of generating the allocation sequence (eg, computer-generated random numbers), and list of any factors for stratification. To reduce predictability of a random sequence, details of any planned restriction (eg, blocking) should be provided in a separate document that is unavailable to those who enrol participants or assign interventions	11
Allocation concealment mechanism	16b	Mechanism of implementing the allocation sequence (eg, central telephone; sequentially numbered, opaque, sealed envelopes), describing any steps to conceal the sequence until interventions are assigned	11
Implementation	16c	Who will generate the allocation sequence, who will enrol participants, and who will assign participants to interventions	11
Blinding (masking)	17a	Who will be blinded after assignment to interventions (eg, trial participants, care providers, outcome assessors, data analysts), and how	11
	17b	If blinded, circumstances under which unblinding is permissible, and procedure for revealing a participant's allocated intervention during the trial	N/A

Methods: Data collection, management, and analysis

Data collection methods	18a	Plans for assessment and collection of outcome, baseline, and other trial data, including any related processes to promote data quality (eg, duplicate measurements, training of assessors) and a description of study instruments (eg, questionnaires, laboratory tests) along with their reliability and validity, if known. Reference to where data collection forms can be found, if not in the protocol	11
	18b	Plans to promote participant retention and complete follow-up, including list of any outcome data to be collected for participants who discontinue or deviate from intervention protocols	12
Data management	19	Plans for data entry, coding, security, and storage, including any related processes to promote data quality (eg, double data entry; range checks for data values). Reference to where details of data management procedures can be found, if not in the protocol	12
Statistical methods	20a	Statistical methods for analysing primary and secondary outcomes. Reference to where other details of the statistical analysis plan can be found, if not in the protocol	12

	20b	Methods for any additional analyses (eg, subgroup and adjusted analyses)	12
	20c	Definition of analysis population relating to protocol non-adherence (eg, as randomised analysis), and any statistical methods to handle missing data (eg, multiple imputation)	12
Methods: Monitoring			
Data monitoring	21a	Composition of data monitoring committee (DMC); summary of its role and reporting structure; statement of whether it is independent from the sponsor and competing interests; and reference to where further details about its charter can be found, if not in the protocol. Alternatively, an explanation of why a DMC is not needed	12
	21b	Description of any interim analyses and stopping guidelines, including who will have access to these interim results and make the final decision to terminate the trial	12
Harms	22	Plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects of trial interventions or trial conduct	12
Auditing	23	Frequency and procedures for auditing trial conduct, if any, and whether the process will be independent from investigators and the sponsor	12
Ethics and dissemination			
Research ethics approval	24	Plans for seeking research ethics committee/institutional review board (REC/IRB) approval	12-13
Protocol amendments	25	Plans for communicating important protocol modifications (eg, changes to eligibility criteria, outcomes, analyses) to relevant parties (eg, investigators, REC/IRBs, trial participants, trial registries, journals, regulators)	13
Consent or assent	26a	Who will obtain informed consent or assent from potential trial participants or authorised surrogates, and how (see Item 32)	9
	26b	Additional consent provisions for collection and use of participant data and biological specimens in ancillary studies, if applicable	N/A
Confidentiality	27	How personal information about potential and enrolled participants will be collected, shared, and maintained in order to protect confidentiality before, during, and after the trial	12
Declaration of interests	28	Financial and other competing interests for principal investigators for the overall trial and each study site	14

Access to data	29	Statement of who will have access to the final trial dataset, and disclosure of contractual agreements that limit such access for investigators	14
Ancillary and post-trial care	30	Provisions, if any, for ancillary and post-trial care, and for compensation to those who suffer harm from trial participation	N/A
Dissemination policy	31a	Plans for investigators and sponsor to communicate trial results to participants, healthcare professionals, the public, and other relevant groups (eg, via publication, reporting in results databases, or other data sharing arrangements), including any publication restrictions	13
	31b	Authorship eligibility guidelines and any intended use of professional writers	N/A
	31c	Plans, if any, for granting public access to the full protocol, participant-level dataset, and statistical code	14
Appendices			
Informed consent materials	32	Model consent form and other related documentation given to participants and authorised surrogates	Suppl file
Biological specimens	33	Plans for collection, laboratory evaluation, and storage of biological specimens for genetic or molecular analysis in the current trial and for future use in ancillary studies, if applicable	N/A

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*It is strongly recommended that this checklist be read in conjunction with the SPIRIT 2013 Explanation & Elaboration for important clarification on the items. Amendments to the protocol should be tracked and dated. The SPIRIT checklist is copyrighted by the SPIRIT Group under the Creative Commons "Attribution-NonCommercial-NoDerivs 3.0 Unported" license.

Protocol for a pilot randomized, controlled trial evaluating feasibility and acceptability of cognitive remediation group therapy compared to mutual aid group therapy for people aging with HIV-Associated Neurocognitive Disorder (HAND) in Toronto, Canada

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-033183.R1
Article Type:	Protocol
Date Submitted by the Author:	02-Oct-2019
Complete List of Authors:	Eaton, Andrew; University of Toronto, Factor-Inwentash Faculty of Social Work Walmsley, Sharon; Toronto General Hospital, Toronto General Research Institute Craig, Shelley; University of Toronto, Factor-Inwentash Faculty of Social Work Rourke, Sean; St. Michael's Hospital Sota, Teresa; St. Michael's Hospital McCullagh, John; Ontario AIDS Network (OAN) Fallon, B; University of Toronto, Social Work
Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Neurology, Research methods, Patient-centred medicine
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Dementia < NEUROLOGY, SOCIAL MEDICINE, Clinical trials < THERAPEUTICS

Protocol for a pilot randomized, controlled trial evaluating feasibility and acceptability of cognitive remediation group therapy compared to mutual aid group therapy for people aging with HIV-Associated Neurocognitive Disorder (HAND) in Toronto, Canada

Andrew D. Eaton[1]*, Sharon L. Walmsley[2], Shelley L. Craig[1], Sean B. Rourke[3], Teresa Sota[3], John W. McCullagh[4], Barbara A. Fallon[1]

[1]Factor-Inwentash Faculty of Social Work, University of Toronto; Toronto, ON, Canada

[2]Toronto General Research Institute; Toronto, ON, Canada

[3] St. Michael's Hospital; Toronto, ON, Canada

[4]Ontario AIDS Network (OAN); Toronto, ON, Canada

*Corresponding author. Factor-Inwentash Faculty of Social Work, University of Toronto. 246 Bloor St. W., Toronto, ON, Canada, M5S1V4 Phone: +1-416-978-8895. Email: andrew.eaton@utoronto.ca.

Word count: 3,644

Abstract

Introduction: HIV-Associated Neurocognitive Disorder (HAND) may affect 30-50% of people aging with HIV. HAND may increase stress and anxiety, and impede coping. Psychosocial group therapy may ameliorate HAND's symptoms, yet the ideal intervention is unclear. This protocol outlines a pilot randomized, controlled trial (RCT)—designed using community-based participatory research–to pilot Cognitive Remediation Group Therapy (CRGT) against an active comparator.

Methods and analysis: This is a pilot, parallel design, two-arm RCT that will recruit participants diagnosed with the Mild Neurocognitive Disorder (MND) form of HAND from a neurobehavioural research unit at a tertiary care hospital in Toronto, Canada. Eligibility criteria includes age ≥ 40 years, known HIV status for 5+ years, English fluency, able to consent, and able to attend eight weeks of group therapy. Eligible participants will be randomized to one of two treatment arms, each consisting of eight-session group interventions delivered once weekly at three hours per session. Arm 1 (novel) is CRGT, combining Mindfulness-Based Stress Reduction with Brain Training Activities. Arm 2 (active control) is Mutual Aid Group Therapy. The primary outcomes are feasibility, measured by proportions of recruitment and completion, and acceptability, determined by a satisfaction questionnaire. The secondary outcome is intervention fidelity, where content analysis will be used to assess facilitator session reports. A between-groups analysis will be conducted on exploratory outcomes of stress, anxiety, coping, and use of intervention activities that will be collected at three time points.

Ethics and dissemination: Ethical approval was obtained from the Research Ethics Boards of St. Michael's Hospital and the University of Toronto. Findings will be disseminated through peer-reviewed publications, conference presentations, and community reporting. This study could provide insight into design (e.g., recruitment, measures) and intervention considerations (e.g., structure, content) for a larger trial to lessen the burden of cognitive decline amongst people aging with HIV.

Registration: clinicaltrials.gov #NCT03483740

Keywords

HIV & AIDS; Dementia; Social medicine; Clinical trials

Strengths and limitations of this study

- Patient and public involvement was prioritized in this protocol as people aging with HIV co-designed the study, will deliver the interventions, and will be involved in analysis and dissemination of results.
- There are a lack of proven interventions to address the stress and anxiety caused by HIV-Associated Neurocognitive Disorder (HAND).
- Interventions for complex comorbidities need to be pilot tested to ensure feasibility and acceptability before conducting a large-scale trial
- This protocol's active design permits comparison between two distinct interventions, as evaluations of psychosocial trials are often limited by inactive controls.
- The key limitations of this protocol are: a small target sample, lack of participant blinding, a single recruiting site, restriction to anglophones, lack of long-term follow-up, potential confounders (e.g., stage of HIV, concurrent comorbidities, depression, etc.), requirement to know how to use a tablet and the internet for brain training activities, and the ability to commit to eight weekly three-hour group therapy sessions.

1.0 Introduction

1.1 Background and rationale

Cognitive impairment is a significant comorbidity for people aging with HIV; 30-50% may be affected to some degree by HIV-Associated Neurocognitive Disorder (HAND) [1-3]. HAND is thought to result from structural damage to fronto-striatial-thalamatory circuits in the brain (neural pathways that mediate cognitive, motor, and behavioural functions); hence, there is no cure [3-8]. HAND is diagnosed in three categories of graded severity based on the Frascati criteria determined by the CHARTER cohort study of people aging with HIV and neurological challenges [3, 4]. The Frascati categories (with estimated prevalence from CHARTER in brackets) are: (a) Asymptomatic Neurocognitive Impairment (ANI – 33%); (b) Mild Neurocognitive Disorder (MND – 12 – 20%); and (c) HIV-Associated Dementia (HAD - < 2 – 3%) [4]. These categorizations are determined by neuropsychological testing of the degree of abnormality in cognitive domains (e.g., speed-of-processing, executive functioning, etc.) and by level of impairment to activities of daily living [4, 5]. Without effective HIV medication, people living with HIV may rapidly progress through these stages, demonstrated by high rates of the most severe form (HAD) prior to the introduction of successful cART regimens [2-5]. HAND may be a result of uncontrolled HIV replication in the brain [4-7]. The development and widespread use of modern cART, and the trend towards earlier treatment initiation, has reduced HAND's severity and its consequences; however, it remains a significantly debilitating issue [3, 9, 10]. It is seen more commonly, and is of particular concern, in AIDS survivors – people aging with HIV who were treated with incompletely suppressive antiretroviral regimens and with medications that had higher rates of mitochondrial toxicity, often late in disease such as after an AIDS defining illness or when the immune system was very weak [6-8]. The shift in prevalence from severe to moderate HAND, and the higher risk amongst AIDS survivors, may suggest that uncontrolled replication of HIV in the brain is causative, and that there is less opportunity for replication when effective treatment is initiated early [5].

HAND symptoms include memory deficits, problem solving errors, difficulties in processing new information, executive function impairment, and poor decision making [3-8]. This in turn leads to stress, anxiety, social isolation, difficult coping, and impacts daily activities (e.g., medication adherence) [11-13]. HAND differs from Alzheimer's disease and other cognitive impairments in numerous clinical areas [7]. Perhaps the most distinguishing characteristic is that people living with HIV are at similar risk of mild HAND in their 40's and 50's as the general population is at risk of mild dementia in their geriatric years [10, 11]. With cognitive decline from normal aging and other syndemic factors (e.g., intersecting HIV and aging comorbidities), HAND symptoms are amplified and further impair the aging HIV-infected adult's ability to cope [13]. With the earlier age of impairment and syndemic factors associated with HIV, HAND may be a condition in need of specific psychosocial intervention distinct from what is currently being tested in geriatric adults with dementia [12, 14]. Yet despite exploratory research on the unique challenges of HAND and a stated community need [11, 12, 15-17], HAND intervention research in the era of modern cART is limited and the optimal intervention is unclear [13, 14].

Psychosocial factors (i.e., social networks, mood) have predicted the ability to cope with HAND's symptoms amongst people with varying levels of cognitive impairment and amongst diverse demographics (i.e., gender, age, education, and ethnicity) [18], so interventions which improve psychosocial factors may enhance coping with HAND's symptoms. Mindfulness-Based Stress Reduction (MBSR) group therapy has decreased stress and anxiety, and improved coping for people with dementia [19]. Computerized brain training activities (BTA) have had similar benefit in middle-aged and older adults with HAND, but participants have requested emotional support (such as MBSR) to complement

BTA [20]. In the general population with dementia, a systematic review synthesis found that these group-based, multi-component strategies improve global cognitive functioning and activities of daily living to a greater extent than a single-component therapy [21]. Similar evidence for people living with HIV is still emerging, however a recent scoping review found that combination approaches (i.e., mindfulness, cognitive training techniques, and group therapy) to psychosocial interventions may have better health outcomes for people living with HIV than a single technique approach [22]. People with the emotional stability and practical coping strategies can more successfully adapt to the challenges of aging, such as cognitive decline [23-25]. Combination approaches that facilitate emotional wellbeing (i.e., MBSR) and practical tasks to improve coping with cognitive impairments (i.e., BTA) may therefore be better suited to ameliorating the effects of HAND for people aging with HIV than a single therapy approach.

Using community-based participatory research to engage people aging with HIV and HAND researchers, this study will pilot cognitive remediation group therapy (CRGT) – combining MBSR and BTA – in a pilot randomized, controlled trial (RCT) of feasibility and acceptability. CRGT will be against an active control – mutual aid group therapy – chosen as an established intervention in both the HIV [26] and dementia [27] fields that mimics the form (i.e., support group) of CRGT while controlling for the inherent benefit (i.e., social connection) of group therapy [28].

1.2 Objectives

The primary objective of this pilot RCT is to test cognitive remediation group therapy (CRGT) for a sample of people aging with HIV who have been diagnosed with mild-to-moderate HAND (i.e., MND), and to compare feasibility and acceptability outcomes against an active control of mutual aid group therapy. The secondary objective is to assess implementation fidelity of both trial arms. Exploratory objectives are to compare stress, anxiety, coping, and use of mindfulness and brain training activities.

1.3 Trial design

This is a pilot, parallel group design RCT that will recruit people aging with HIV (≥ 40 years old) who have been diagnosed with MND-HAND since January 1, 2016 from a neurobehavioural research unit in Toronto, Canada. The trial uses a refinement framework to assess, in a preliminary sense, whether therapy of this nature is feasible and acceptable to this population [29]. The recruited sample (target n = 12-16) will be randomized to either eight weekly three-hour sessions of CRGT or eight weekly three-hour sessions of mutual aid group therapy.

2.0 Methods: Participants, interventions, and outcomes

2.1 Study setting

Participants will be recruited from St. Michael's Hospital's Neurobehavioral Research Unit, a clinic dedicated to HAND assessment in downtown Toronto, Canada. This clinic uses Frascati criteria [3] to assess cognitive impairment via neuropsychological testing conducted by two psychologists. The intervention arms will be at community-based organizations in downtown Toronto, Canada. The novel CRGT arm will be at the Centre for Mindfulness Studies, a facility that owns the necessary equipment for MBSR (e.g., yoga mats). The control mutual aid arm will be at the AIDS Committee of Toronto (ACT), who have been offering mutual aid groups for people living with HIV for over twenty years.

2.2 Patient and public involvement

Community-based participatory research (CBPR) and implementation science guided an approach to engage people aging with HIV and affected by HAND, alongside service providers and HAND researchers, as the protocol was being developed. First, an exploratory CBPR study surveyed (n=108) and interviewed (n=20) people aging with HIV in Ontario; approximately one-eighth of participants had been diagnosed with HAND and the entirety of the sample self-identified recently reduced function and ability in more than one cognitive domain (e.g., memory, speed-of-processing) [12]. The purpose of this initial study was to determine direction for psychosocial interventions in HIV and cognition, with a focus on social work due to the profession's history of effective engagement with people living with HIV [23, 30]. The initial study also sought to understand the impacts of peer service provision and peer research from people affected by HAND themselves [31,32]. The results of this study suggested that a cognitive remediation intervention, combining emotional and practical coping skills training in a group setting, may help people living with HAND manage their symptoms and improve their wellbeing [12].

Second, the first author conducted key informant interviews with six HAND researchers from Canada, the United States, Spain, and Australia. These interviews discussed work-in-progress and design considerations for intervention research, an example of which is Brain Training Activities (BTA). BTA, comprised of online and offline games and activities targeted for cognition, shows promise in helping people with cognitive impairment improve their function at specific tasks and activities (e.g., remembering sequences, responding quickly) through repeated practice [20]. BTA has been predominantly administered as an individual activity, such as software installed on a person's home computer with clinic follow-up on progress. This may contribute to relatively low uptake of BTA as a promising intervention technique [33].

Third, the first and sixth authors held two focus groups in downtown Toronto: one with people aging with HIV and concerned about HAND (n=10) and one of social workers in the HIV field (n=8). These consultations were conducted to finalize trial components, including intervention selection, appropriate questionnaires, and a sensitive method of data collection. These activities supported CBPR's aim of co-constructing new interventions with people most affected by the issue under study [34], and implementation science's recommendation of preliminary consultation to improve the potential for scale-up should the study determine promising results [35].

2.3 Eligibility criteria

Inclusion criteria: People who: (a) are aged ≥ 40 years; (b) have a documented HAND diagnosis of Mild Neurocognitive Disorder (MND); (c) were diagnosed with HIV ≥ 5 years ago; (d) provided consent to St. Michael's Hospital to be contacted for future research studies; and (e) could feasibly attend eight weeks of group therapy in downtown Toronto. Exclusion criteria: Participants who: (a) have a documented HAND diagnosis of Asymptomatic Neurocognitive Impairment (ANI) or HIV-Associated Dementia (HAD); (b) have been hospitalized in the past month; (c) are unable to communicate in English; (d) are unable to use a tablet for BTA; or (e) are assessed by the research coordinator to be disruptive to a group therapy setting (e.g., due to discriminatory remarks). Justification: MND is chosen instead of ANI or HAD due to the potential for unacceptably high false positive error rates in ANI [36] and the potential null effect from psychosocial interventions for people with HAD [14]. As the two arms will address HAND and not HIV, a limit of ≥ 5 years since HIV diagnosis is set to mitigate the risk that some participants may want to discuss issues associated with a recent HIV diagnosis instead of issues associated with HAND. Forty years of age is chosen as the lower limit as it is approximately one standard deviation below the mean of MND diagnosis in the CHARTER cohort [3, 4] and at the recruiting clinic. Therefore, forty years of age may be an appropriate lower limit for a study of this nature so that participants can still bond over the shared experience of aging with HIV while being inclusive of the age range of people most likely to be diagnosed with HAND. Other criteria were set in accordance with the study's context. For example, recent hospitalization could suggest poor health and could bar participation in an eight-week group. There are no eligibility criteria for viral load, other comorbidities, and alcohol and substance use.

2.4 Interventions

Both interventions consist of nine, three-hour weekly sessions (an orientation session and eight group sessions) and will be at community-based organizations in downtown Toronto, Canada.

2.4.1 Cognitive remediation group therapy (novel arm)

Cognitive Remediation Group Therapy (CRGT) is a blend of two emerging interventions – Mindfulness-Based Stress Reduction (MBSR) and Brain Training Activities (BTA) that will be combined for the first time for people with HAND in this study. MBSR will comprise two-thirds of each weekly session and will be facilitated by a physician and a social worker using the MBSR manual that includes meditation, body scans, deep breathing, and other exercises to relieve stress and regulate emotions [37]. BTA will comprise the remaining one-third of each group session and will be facilitated by a peer aging with HIV. Participants will have access to Samsung tablets and a one-year license to BrainHQ training by PositScience. BrainHQ tailors training (i.e., games) to participant's deficit domains (e.g., speed-of-processing, memory) via a screening exercise and then offers activities of increasing difficulty. If people practice for a minimum of three hours per week for eight weeks, they may self-report a positive change in coping [33]. As this may be the first time BTA is offered in a group setting, the peer facilitator will use a participatory approach by soliciting participants' input on how to structure sessions (e.g., individual practice, group discussion on training progress and challenges, or some combination).

2.4.2 Mutual aid group therapy (control arm)

Mutual aid groups consist of facilitated discussion of challenges and coping strategies associated with an illness or issue [28]. Mutual aid groups may be the most recognizable form of group therapy, as Alcoholics Anonymous has popularized the model [38]. These groups use the principle that people can help one another overcome their health and social challenges when trained facilitators – often social workers – help the group maintain respect, stay on topic, and explicate connection and shared experience between participants [39]. For this study, mutual aid will be facilitated by a social worker and a peer aging with HIV. Refer supplementary file 1 for the facilitators' manual of this model.

2.4.3 Discontinuation criteria

Participants may cancel their participation at any time. Intervention arms will be discontinued if, due to cancellations, the total number of participants registered to an arm is three or less.

2.4.4 Protocol adherence strategies

The study sponsor has access to the participant database and will monitor the timeline of protocol procedures. Facilitators of each intervention arm will submit weekly session reports that will be checked to ensure that interventions are progressing as designed.

2.4.5 Concomitant care and interventions

Co-enrollment in another HAND or mindfulness treatment study is not permitted.

2.5 Outcomes

Outcomes and measures are listed in table 1. As a pilot study, feasibility and acceptability are primary outcomes to assess whether a larger trial could further test group therapy for people with HAND. Intervention fidelity (i.e., how closely the facilitators adhere to each arm's therapy model) is a secondary outcome to assess whether the interventions are delivered as planned. Exploratory outcomes of stress, anxiety, coping, and use of brain training and mindfulness activities will also be assessed.

Table 1: Outcomes and measures

Outcomes	Measures	Description
Feasibility	Participant recruitment and retention	Proportion of eligible participants who agree to participate, complete the pre-test, attend the first group session, complete the full group series, and complete the study
	Chart abstraction of participant demographics	The sampling frame's demographics (i.e., age, gender, ethnicity, length of time living with HIV, length of HAND diagnosis) will be described in terms of those who agree and decline to participate
Acceptability	Helping Characteristics of Self-Help and Support Groups Measure [40]	22-item Likert measure where higher scores indicate greater group satisfaction, administered in sessions four and eight of each arm
	Reasons for withdrawal (if applicable)	If participants withdraw from the study, they will be asked if they consent to having the reason for withdrawal described
Intervention fidelity	Facilitators' session reports	Facilitators will submit weekly session reports that will include checklists of therapy components and open-ended questions about group activities, dynamics, and challenges
Stress	HIV/AIDS Stress Scale [41]	29-item Likert measure where higher scores indicate greater HIV-related stress
Anxiety	Anxiety in Cognitive Impairment and Dementia Scale [42]	26-item dyadic measure where higher scores indicate greater cognition-related anxiety
Coping	Coping Self-Efficacy Scale of Health Problems [43]	10-item Likert measure where higher scores indicate greater coping with health problems
Use of mindfulness strategies	Five Facet Mindfulness Questionnaire – Short Form [44]	24-item Likert measure where higher scores indicate greater use of mindfulness strategies
Use of brain training activities	Novel arm – PositScience progress reports Control arm – self-report	The brain training software provided to participants in the novel arm tracks their activity. For the control arm, participants will self-report use of brain training activities

2.6 Participant timeline

The study started on August 6, 2018 and is expected to end by December 31, 2019. Refer to table 2 for the schedule of events. The timeline consists of three distinct periods: a) screening, where eligibility will be confirmed, the research coordinator will obtain consent and participants will complete baseline questionnaires; b) study, where intervention arms will be administered; c) and follow-up, where participants complete questionnaires at the interventions' conclusion and a 3-month follow-up.

Table 2: Schedule of events

Visit Details	**Screening Period**			**Study Period**			**Follow-up Period**	
Visit Name	Screening Call	Screening Visit	Baseline Visit	Orientation	Sessions 1-7	Sessions 4 & 8	Follow-up Visit	End of Study Visit
Visit #	-3	-2	-1	0	1,2,3,4,6,7	4 & 8	9	10
Week #			-1	0-8			9	21
Day #	-56 to -7 days		-7	0-56			63	153
Day Window	+/- 7	+/- 7	+/- 7	+/- 7	+/- 0	+/- 0	+/- 7	+/- 7
Procedures								
Informed Consent		X						
Entry Criteria Assessment	X	X						
Chart Abstraction (demographics)		X						
Randomization			X[1]					
Group Sessions				X[2]	X	X		
Facilitator Session Reports					X	X		
Helping Characteristics of Self-Help and Support Groups Measure						X		
HIV/AIDS Stress Scale			X				X	X
Anxiety in Cognitive Impairment and Dementia Scale			X				X	X
Coping Self-efficacy of Health Problems Scale			X				X	X
Five Facet Mindfulness Questionnaire – Short Form			X				X	X

[1] To occur once all participants have been enrolled and eligibility confirmed

[2] Acquaintance with group only; no therapy will be administered during this session

2.7 Sample size

A sample size of 12-16 participants (6-8 in each study arm) has been selected as: (a) 6-8 participants have been found to be an ideal size for eight weeks of group therapy [45]; and (b) this number can provide preliminary insight into the feasibility and acceptability of the novel CRGT arm, before initiating a larger study. Further, 12-16 participants are 30% to 40% of the sampling frame (n=40). So, if this pilot's results prove promising, scale-up to a larger study with similar recruitment proportions would feasibly require a sample of 90-120 from approximately 300 potential participants.

2.8 Recruitment

A clinical psychologist from the recruiting site will attempt to contact all participants in the sampling frame (n=40) at their last known phone number and email. Three distinct contact attempts will be made for each individual. This contact will briefly explain the study and determine whether a participant elects to meet with the study coordinator to confirm eligibility and review the consent form.

3.0 Methods: Assignment of interventions

3.1 Allocation

Concealed allocation will be used for this study. The first author will provide the study sponsor with unique identifiers of each enrolled participant. The sponsor will then randomize participants in a 1:1 fashion using blocks of size two to either the novel or control arm. Individual allocation results will then be communicated to each participant.

3.2 Blinding

Facilitators of the study arms will be blind to outcome assessments; otherwise, this study is not blinded. Blinding participants to psychosocial trials is difficult, as participants are actively involved in their therapy [46]. Blinding of this nature often requires deception, which raises ethical concerns [47]. The limitations to this approach and mitigating strategies will be discussed in the results paper.

4.0 Methods: Data collection, management, and analysis

4.1 Data collection methods

Demographics will be abstracted from participant charts at the recruiting site. A research coordinator will collect self-reported data for exploratory outcomes from participants at three times (baseline, postintervention, and 3-month follow-up). Further, the coordinator will collect acceptability data via a questionnaire at the midpoint and endpoint of the interventions. Group facilitators will write structured session reports to be submitted weekly following each group session. Refer to supplementary file 2 for consent and data collection forms.

4.2 Participant retention plans

To promote participant retention in group sessions, the study coordinator will send weekly reminders to participants. To promote completion of questionnaires, three distinct contact attempts will be made to schedule study visits. If a participant withdraws from the study, the coordinator will ask for permission to report the reason for withdrawal.

4.3 Data management

All data collected will be labelled with a unique identifier for each participant. The study coordinator will enter data into REDCap (Research Electronic Data Capture), a browser-based database; this data will be verified by the principal investigator.

4.4 Analysis

The stakeholders (people aging with HIV, service providers, and researchers) who provided initial consultation to study design will reconvene to collectively analyze the de-identified results, to inform the design of a larger study of group therapy for people aging with HIV who are experiencing cognitive challenges. For intervention fidelity, content analysis will be performed by two independent coders familiar with the models of group therapy [48]. With a small target sample, analysis of the exploratory outcomes will be limited. With a Kenward-Roger adjustment for small sample size (i.e., scaling F by factor λ and determining denominator degrees of freedom m for an approximate expectation and variance of a $F_{l,m}$ distribution) [49] to the covariance matrix, a between-groups treatment effect may be detected while minimizing false positive error risk in these exploratory outcomes [50].

5.0 Safety considerations

Group therapy poses risk of psychological and social distress when participants feel uncomfortable discussing sensitive concerns and when they believe their confidentiality may be jeopardized. To mitigate these potential risks, the nature of a group setting and the limits of confidentiality will be discussed with participants at the consent stage. Facilitators will also meet with participants individually in an orientation meeting prior to the group's commencement to discuss norms and guidelines for group behaviour. Additionally, participants may withdraw their participation at any time, without any impact on their current standard of care. Further services and resources will be provided to participants who withdraw. Conducting the intervention arms at community-based sites that currently offer other types of support services to people living with HIV (such as counselling) may provide an opportunity for participants to access additional supports if necessary.

6.0 Ethics and dissemination

The study sponsor will monitor the trial, and audit the data at their discretion. Consent forms and data will be stored separately on secure, encrypted servers for seven years following study completion. The study protocol and consent form have been approved by the Research Ethics Boards of St. Michael's Hospital (#17-334) and the University of Toronto (#35860). The trial was registered on clinicaltrials.gov (#NCT03483740) before recruitment commenced. Protocol amendments, if applicable, will be communicated to the study sponsor, ethics boards, and registry prior to implementation. Outputs from this study will include journal publications, conference presentations, and community reporting. Outputs will not identify participants.

7.0 Discussion

This pilot RCT may provide preliminary insight into how the novel CRGT as a combination intervention (i.e., MBSR, BTA, and group therapy) compares to the mutual aid standard of group therapy that comprises the active control. The community-based approach may also provide insight into how patient and public involvement can inform the design and analysis of psychosocial intervention trials [51], with implications for other social researchers seeking to design rigorous and community-informed intervention studies of a similar nature.

CRGT may offer participants practical and emotional coping strategies alongside the inherent social connection benefit that participants can receive from the mutual aid control. This will build on existing research showing that combination approaches are preferable to people living with HIV [22] and people with dementia [19], while addressing the gap in psychosocial interventions for people with HAND. This refinement pilot trial will provide insight into the feasibility and acceptability of CRGT and a study of this nature, to inform the development of a larger study. A pilot is needed, given HAND's complexity and the lack of existing interventions for this condition, to preliminarily assess these interventions before a larger trial is designed. Based on other psychosocial intervention pilot trials [52, 53] a sample of 12-16 completing the study with positive acceptability results and strong intervention fidelity could potentially justify upscaling this pilot into a full-scale trial.

There has been little research conducted that provides people living with HAND the opportunity to interact with one another in a confidential group setting. It is possible that this group experience could be helpful for people living with HAND, as exploratory research has identified a dual stigma associated with the condition [11, 17]. The dual stigma is people feel that they cannot speak about HAND to their HIV-positive community due to dementia stigma, nor could they discuss it with HIV-negative friends and service providers who are familiar with cognitive impairment due to HIV stigma. Such community-building and shared support around the stress and uncertainty of aging with HIV may ameliorate the damaging effects of stigma [54, 55].

Author contributions

ADE conceived and developed the protocol, and drafted the manuscript. **SLW** provided expertise with trial design. **SLC** provided expertise with intervention design. **SBR** and **TS** provided expertise in HAND. **JWM** and **BAF** contributed to protocol refinement. All authors edited and approved the final version of the manuscript.

Competing interests

There are no competing interests for any author.

Funding

This work is funded by the CIHR Canadian HIV Trials Network (CTN) through a Pilot Study Grant (PT029). ADE and SLW hold salary awards from the Ontario HIV Treatment Network (OHTN). SLC and BAF are Canada Research Chairs. The funders did not have a role in the design of the study, nor in the decision to submit the study for publication. This study was approved by the Research Ethics Boards of St. Michael's Hospital (#17-334) and the University of Toronto (#35860). The trial was registered on clinicaltrials.gov (#NCT03483740) before recruitment commenced.

Data sharing statement

Data resulting from this protocol (i.e., de-identified surveys) may be available, pending consultation with the Research Ethics Boards (REBs) of St. Michael's Hospital and the University of Toronto. Data requests may be sent to the principal investigator at andrew.eaton@utoronto.ca, who will consult with the REBs.

Acknowledgements

We wish to thank all of the people living with HIV and other stakeholders for their contributions to the study's design. Thanks to Dr. Judy Needham at the CTN for excellent project management, and to Dr. Lauren McInroy and Jenny Hui for assistance with this article.

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SUPPORT GROUP FACILITATION TRAINING MANUAL

AIDS COMMITTEE OF TORONTO
February 2018

Acknowledgements:

Many thanks to Paul Cogan for his assistance in creating an electronic version of this manual (2009).

Published 1998
Maureen Carnegie
Chuck Marino
Scott Pope

Adapted 2009
Jocelyn Watchorn
Kate Murzin

Updated 2016
Andrew Eaton
Marsha Malbari
Constantine Cabarios

TRAINING OVERVIEW

TRAINING SESSION NUMBER ONE

- SESSION ONE AGENDA
- TRAINING GUIDELINES
- ROLE PLAYS: PURPOSE & GUIDELINES
- GROUP NORMS
- ACTIVE LISTENING
- STRUCTURED FEEDBACK
- THE FACILITATED PEER SUPPORT GROUP MODEL
- KEY ELEMENTS OF SUPPORT GROUPS
- EFFECTIVE VS. INEFFECTIVE GROUPS
- GROUP ATMOSPHERE
- STAGES OF GROUP DEVELOPMENT

Support Group Facilitator Training

Session One

Overall Goal of Facilitator Training
To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Intro 'Sandbox' Activity

    - Move around the room and get quickly into pairs.
    - One partner asks the other to discuss their hopes for the facilitator training.
    - Discuss for two minutes.
    - When the bell rings, switch partners and repeat!

    Group discussion: What did you learn about your own/the group's hopes and expectations?

After this session, participants will:

- have a better idea of who is participating in the facilitator training;
- be more aware of their personal expectations of the facilitator training and those of the group.

2. Introductions

3. Review Goals for the Evening

4. Agreements
    a. Housekeeping
    b. Training Guidelines
    c. Training Norms
        i. Universal Norms
        ii. What else do you need to feel safe in the training environment?
        iii. Accountability to one another

5. Listening Exercise

    - Find a partner. Please choose someone you don't already know.
    - Instructions to follow!

Group discussion : What makes it easy or difficult to listen?
What kinds of things do people need support with?
What makes it easy or difficult for people to get support?

After this session, participants will:

- be more aware of the factors which impact their ability to listen;
- have a better understanding of what is involved in giving/receiving support.

6. Active Listening

After this session, participants will be able to:

- Define active listening;
- demonstrate a variety of verbal and non-verbal active listening techniques.

7. Group Norms

After this session, participants will be able to:

- Define 'norms';
- identify the types of norms and differences between them;
- recognize the facilitator's role in establishing and modeling norms.

8. Structured Feedback

After this session, participants will be able to:

- Give feedback that results in positive change.

9. Introduction to Support Groups

After this session, participants will:

- Understand the facilitated peer support group model including:
    - the definition of a facilitated peer support group;
    - the role of the support group facilitator;
    - the goals/purpose/benefit of support groups;
    - the values/key elements of support groups;
    - how this type of group differs from a therapy group;
    - be able to contrast the qualities of effective and ineffective groups.
- Recognize the stages of group development.

Group Discussion

- What experiences do people here have with groups?
- What do you think a facilitator does?
- What are the goals/purpose/benefit of support groups?

10. Evaluations

TRAINING GUIDELINES

Some Things To Expect and Not To Expect from Facilitator Training

Everyone comes to this training with different learning needs and expectations. Here are a few things that you can expect to experience, and a few you can expect not to experience in this training program.

DO EXPECT:

1. To gain basic skills in facilitating support groups. Our aim is to help you build a foundation which you can then expand on over time, with experience.
2. To spend different amounts of time on each topic. Due to varying skill levels, some people may require more or less time, depending on the area.
3. To have an opportunity to practice the skills within small groups.
4. To potentially still feel unprepared to facilitate groups by the end of the training, especially if you have never done so before. Your sense of preparedness will probably improve when you begin to facilitate 'real life' groups.
5. To experience some frustration when our time limits prevent extended discussion or practice.
6. To have fun and be challenged by learning new things and interacting with others in the training!

DON'T EXPECT:

1. To be an expert group facilitator by the time you have finished the training.
2. To cover specific types of issues/topics that groups discuss - i.e., the impact of care giving, spirituality, medications, etc. Our focus is on group skills, not group issues.
3. To utilize the training sessions as if this were a support group; participants are here to **learn group skills**, and must keep this in mind throughout the duration of the training.
4. To have unlimited time to voice your opinions.
5. To stay late — we will begin and end each session on time.

TRAINING GUIDELINES

The following guidelines apply to all facilitator training sessions, and all participants are expected to adhere to them. These guidelines are intended to assist in creating a positive, respectful learning environment. **They are non-negotiable.**

Confidentiality - Each participant has signed a confidentiality agreement as a condition of attending this training. What this means is that nobody inside of the training group is identified to anybody outside of the training group. Anything of a personal nature discussed in the sessions is not to be discussed outside of the sessions.

Respect for differences - Each participant has different life experiences, affiliations, values, etc. Respect for this diversity is expected by interacting with each other in a considerate and courteous manner.

Use of "I" statements - Each participant will take ownership for her/his opinions/assertions by using "I" statements, (as opposed to "you", "we", etc.). For example, "I think...", "I feel..." I believe...".

Time and attendance - Each participant is expected to attend every session and to be on time. Trainers will start and end sessions on time. Further, each participant takes responsibility for ensuring they return on time from break-out exercises, and realizes that the work of the session will resume at the appointed time, regardless of absence.

If a participant is unable to attend a particular session (with reason), ACT's Group Programming Coordinator should be informed ahead of time. A decision to withdraw from the training should be relayed to the trainers (and fellow participants, if possible) at the earliest opportunity.

Limit the length of time you speak when you have the floor - Each participant agrees to be mindful that there are many participants in the training, all of whom have the right to actively participate. So that everyone has an equal opportunity to do this, please monitor yourself when you are speaking in the training group to ensure you are leaving time for others to contribute.

ROLE PLAYS: PURPOSE & GUIDELINES

Role playing is a vital and major component of the AIDS Committee of Toronto Facilitator Training Program. Role playing creates an opportunity for training participants to build confidence, generate problem-solving strategies, utilize core facilitator skills, confront challenges and develop a personalized style of facilitating. Role playing also provides an opportunity for the trainers to monitor the skill development of the training participants.

Role playing, for many participants, can be very challenging, uncomfortable and cause anxiety. That said, it is important for the *trainers and participants* to create and ensure a safe, positive and enhancing learning environment.

The purpose of the role plays is not to “outwit, outsmart, or outlast" the other training participants. When participating in a role play as a group member, the goal is not to ambush the facilitator.

When you participate in role play, please observe the following guidelines:

- take a turn at different roles, including facilitator (take a risk);
- if you are playing a group member, it’s o.k. to be difficult, but not too difficult. Be *realistically* challenging and be prepared to shift into non- resistance;
- keep focused on process;
- when giving feedback, emphasize what went well, what seemed to work, what you learned, etc. Avoid criticism or dwelling on what was `wrong’.

Remember, role plays are a brief moment in time of a make-believe group session. Role plays are an opportunity to learn from each other, and identify our areas of strength and challenge.

THE ESTABLISHMENT OF NORMS IN A SUPPORT GROUP

Every group, whether social, familial, supportive, etc., is regulated by ‘rules’ of behavior which can be either implicit or explicit. In a support group, these ‘rules’ are known as norms. The underlying purpose of group norms is to establish a ‘culture’ in the group. Norms provide a guide for interaction between members, and as such may be a prescription for as well as a prescription against certain kinds of behavior.

In a support group context, group norms are both explicit and implicit. The explicit norms are those which are verbalized and established within the first session. The implicit norms are those which are understood, but not directly expressed, and develop over time. An example of an implicit norm would be group members consistently relying on one member to express controversial opinions in group meetings.

The establishment of explicit norms provides the important first step towards creating an atmosphere of safety in the group. Explicit norms help to provide members with guidelines and establish expectations about how the group will ‘operate’. As well, positive explicit norms contribute to the development of positive implicit group norms. While support groups generally benefit from the establishment of certain universal norms, (presented by the group facilitators), it is important that group members have the opportunity to decide upon additional norms which are important to the unique culture they wish to create. Facilitators might choose to elicit input from group members about norms with a statement like, “What do you need to have happen in this group so that you can feel safe and are prepared to participate?"

Support group facilitators play an important role not only in assisting members with establishing group norms, but in modeling the behavior associated with the norms. For example, facilitators model the use of “I" statements when expressing their ideas and opinions. Facilitator adherence to, and modeling of, group norms provides a reference point for group members.

UNIVERSAL NORMS

Confidentiality

Respect for differences

Use of "I" statements

Participation

GROUND RULES FOR SUPPORT GROUPS

One key to developing the safety that is so important for support groups is to establish ground rules that are discussed, agreed upon and adhered to by everyone in the group. Some ground rules might include the following.

Confidentiality

What is discussed in the group stays in the group, particularly anything that could identify any member.

Start and end on time

By starting and ending promptly, members develop trust and learn what they can expect from the group. This also respects members' busy schedules, which might include medical appointments or returning home to care for a loved one.

Be present or let someone know you won't be

Members need to know that their fellow members will attend the group or that they will call the facilitator or another member to inform the group of their upcoming absence.

Responsibility to raise issues

Facilitators won't be able to guess what the members may want to share. Members are responsible for getting their needs met in the group. Important issues should be put out on the table in a timely way.

Alcohol or drug use during the sessions

Group members are expected to come to the group without being impaired by alcohol or other non-prescription drugs.

No sex between facilitators and members

Sexual contact between a facilitator and a member can be detrimental to the group process. Sexual behavior has the potential to be destructive to the member as well as the group as a whole. Knowing from the start that sex and romance with the facilitator are not possibilities, can allow some members to feel safer and more comfortable.

Sex between members is also discouraged. With the need for safety and trust, the added complication of special relationships between members can be difficult for the group.

Informal, outside-of-group support among members

Ideally, support among members will continue outside of group meetings. This may include phone calls, visits or other shared activity. Meetings can also continue informally after the conclusion of time-limited groups.

No secrets or special outside contact between members and facilitators

Facilitators should be clear about not having any special relationships with certain members. Favoritism, or the appearance of it, will lessen the facilitator's effectiveness.

Set guidelines for entering and leaving the group

In open groups, members will come and go. When adding new members, it helps to let current members know that new people will be joining. If possible, let members know at least a week in advance. Suggest that members who decide to leave should try to complete any unfinished business that may exist with other members or with the group and give at least one week's notice of their intention to leave the group.

Differences and disagreements are OK

Allow members to voice disagreements as long as they happen in a respectful way. Stress to members that disagreements can often be a source of growth.

Discuss non-sexual physical contact

Each group member is unique in how they view touching and hugging. Cultural or gender differences, boundary or abuse issues, loneliness, simple likes and dislikes can influence how comfortable someone is with physical touch. For some groups, a member may give a hug or put a hand on the shoulder of a member who has revealed something painful or shared an emotional issue or seems to be hurting. This response can be both natural and beneficial. However, no matter how well-intentioned and innocent the gesture, some people might feel violated and unsafe with any form of physical contact. Encourage the group to discuss this before anyone spontaneously and unknowingly oversteps another's boundaries.

"Check in' should be brief

Check in is a tool to use at the beginning of each group session. During check in, each group member briefly shares what happened to them between meetings, how they are feeling at the moment, what they'd like to talk about that session, etc. Check in works as a transition for group members from their day-to-day situations to the "culture" of the group. Check in is a time for facilitators and other group members to get a sense of the general mood and feelings of each group member. (Facilitators should check in). It's important for facilitators to ensure that check in doesn't become a series of extended monologues (which take up all the time).

Establish a ground rule that check in will be time limited and that the time will be gently enforced by facilitators. Politely interrupt members who are taking too much time during check in. Redirect an extended check in to the purpose of the group. Let members know that if they raise an important issue during check in, the group will come back to it later and allow them to fully explore their issue.

Adapted from NATIONAL HIV/AIDS VOLUNTEER TRAINING KIT (1998: AIDS Committee of Toronto), Training Module 2: Support Group Facilitation: Support Group Manual (p.8-11)

UNIVERSAL GROUP NORMS (SAMPLE GROUP HANDOUT)

CONFIDENTIALITY:

Volunteers, ACT staff and service providers who run programs at ACT are expected to uphold the highest standards of confidentiality in their work. Similarly, it is expected that all support group participants will respect the privacy and confidentiality of other group members and volunteers. This is a non-negotiable group norm.

OTHER GUIDELINES:

Please be on time!

The time the group spends together is limited, so it is very important to maintain regular attendance. Please plan to arrive in advance so that the group can begin promptly at 6:30pm.

Keep us informed!

While we stress that attending all meetings will yield the best results for you and other members of the group, we understand that absences happen from time to time. If you are going to miss a session due to illness or other unexpected circumstances, please call the facilitator in advance of the meeting you will miss, so that we know that you are ok. Yes, we will worry about you and make attempts to locate you if you do not show up!

Participate!

Talking about some of these issues can be difficult, but ultimately the benefit you gain from being in a group is related to the effort you put in to participate. Participation takes many different forms: listen carefully to other group members, contribute to group discussions, or suggest topics of conversation. Who knows, you may find that you are not alone in what concerns you!

Respect each other and yourselves!

We will start the group by asking you to identify what you wish to achieve and helping you determine norms for the group. Treat each other with respect; the way you wish to be treated. Respect yourself and your own boundaries, and please let us know when you need help to maintain them.

Use "I" Statements!

When sharing your opinion, thoughts, feelings and experiences, use "I" statements. These statements start with "I think….", "I feel…..", "In my experience….", or "When that happened to me I……". Many times, others in the group or outside it have different points of view or have experienced something in a different way than you have. Using "I" statements gives everyone an opportunity to share what things are like for them.

OTHER NORMS FOR THIS GROUP:

ACTIVE LISTENING

Active listening is an essential component of group facilitation. Generally, active listeners defer their own judgment about the speaker, resist giving feedback until the speaker is finished speaking, seek clarification, and paraphrase and check their understanding of the speaker's message.

Active listening has two parts: looking like you are listening and sounding like you are listening. Everything which follows is culture-bound whether that culture is based on nationality, gender, sexual orientation, age, or whatever. "Matching" the person you are listening to is a good (not perfect) general starting point.

Looking like you are listening is communicated non-verbally through position, posture, facial expressions, eye contact, etc.

A rough guide would be to:

1. Face the person who is speaking more or less directly and
2. At the same level (don't stand over the speaker) with a
3. Distance of about two arm's lengths between.
4. Maintain a relaxed (not slouched) posture.

The most important facial expression (apart from keeping your eyes open) is probably appropriate smiling. A fixed, expressionless face interferes with good listening. Head nods are encouraging.

In the absence of bodily contact, eye contact is probably the most important dimension of communication in active listening. Matching the eye contact of the speaker is a good place to start. Be sure not to completely avoid eye contact.

Sounding like you are listening is essential. This would include "minimal encouragers" (uh huh, yes, mmhh hmm, I see, etc.); repetition of a key word or phrase also communicates good listening.

Other ways of sounding like you are listening and encouraging the speaker are:

1. **Rephrasing** something in your own words without adding anything and
2. Asking, "Is that right?" (called "**checking out**" or a "**perception check**")
3. When 1 and 2 are done together it is called **paraphrasing.**
4. **Summarizing** what has been said is another verbal listening skill (often used with a perception check) as is
5. **Clarifying** which is best done with
6. **Open-ended questions** (who, what, when, where, etc ....) which put the focus on the speaker as opposed to

7. **Close-ended questions** (which can be answered with one word like ’yes' or ‘no‘ or are multiple choice/either-or questions) usually reflect what the *listener* is thinking.

STRUCTURED FEEDBACK

Chuck Marino

So what is effective feedback? Effective feedback is feedback that results in change. It really isn't very difficult to give feedback in the usual way:

- by criticizing
- by pointing out what's wrong
- by asking questions
- by telling someone a better way to do it
- etc.

It's pretty obvious that generally it doesn't feel good to be criticized in this way. Most of the time when someone is given this kind of feedback they are stifled rather than encouraged to speak up or to try something new.

Effective feedback results in positive change. For this to happen, the criticism must be heard and acted upon. To maximize the chances of this happening it is necessary for the critic to demonstrate:

- **respect** for the person being criticized;
- **understanding** of whatever is being criticized;
- the skills to **identify the positive parts**; and
- ability to indicate **a useful change**.

Structured feedback is a way of doing this. It is a very short, personal evaluation which contains your assessment of the positive and negative aspects of a meeting, an opinion, an idea, something someone has said or done, etc. **It is also a way for co-facilitators to evaluate each other and their groups so that they learn how to be more effective.**

Structured Feedback

Briefly state at least two or three positive things about whatever it is you want to give feedback on or criticize. Two or three things you liked, learned, understood in a new way, want more of, found useful, interesting, etc.

Briefly state the single most important thing which you think should he change. Say something like, "I see the main problem as how to..." or "I wish that..." **NOT** "I didn't like,.." or "You didn't..." or "You should..." or 'I really like that idea but...'

HIGHLIGHTS OF THE FACILITATED PEER SUPPORT GROUP MODEL

Focus of the model:

The model of group work we will be working from is facilitated peer support.

A facilitated peer support group may be defined as:

A group of people who usually share common issues/problems/goals/life experiences and who join together for the purpose of mutual aid. The group is facilitated by a person(s) who has skill in group process and assists members in the structuring of, and communication within, the group.

Support group members, *not* the facilitators, are accepted as the experts on their situation/issues/problems. The aim of facilitators is to assist group members in bringing into awareness their strengths and knowledge, and to assist in creating opportunities to learn from each other and appropriate external resources.

The formulation of the content or agenda for the peer support group is usually not the *primary* focus of facilitators; for the most part, the agenda is set and driven by group members. Thus facilitators are more concerned with how the group is functioning, and less with **what** is being discussed in group.

Goals of the Facilitated Peer Support Group:

The goals of the peer support group are to:

1. Create safety, understanding and support amongst group members;
2. create connections or a sense of community between group members that will last beyond the duration of the group;
3. to empower group members.

Empowerment in this context means the acquisition of useful and relevant information, knowledge of one‘s personal and external resources, and an increased capacity and desire to use these skills. Facilitators foster empowerment in the peer support group by providing as safe an environment as possible which encourages learning from each other, supports positive risk, and always emphasizes the strengths (as opposed to the deficits) of group members.

It is important to be aware that emphasizing group member’s strengths and abilities does not mean ignoring the difficulties and pain they may be experiencing. Group members must have opportunities to share these experiences. An emphasis on strengths means exploring the coping strategies and knowledge group members have developed as a result of their experiences. Regardless of how *we* may judge *them*, people employ diverse strategies to manage problematic situations every day.

Inherent Vales of Facilitated Peer Support Model:

There are many-different ways of structuring facilitated peer support groups. Regardless of the structure of the group, there are certain core values or beliefs which guide and support the process. These values and beliefs include:

- peer support is an important and valuable strategy in confronting the complex issues which affect people's lives;
- individuals are experts on their own circumstances and state of being;
- peer support groups can and do enhance individual coping and self esteem;
- peer support empowers groups, and the individuals in those groups. This results from the focus on strengths and abilities, the broadening and acquisition of relevant and useful information, and the 'community building function of group;
- the diminishment of isolation through membership in a peer support group is of value in and of itself regardless of what other benefits group members may derive from the experience;
- group members have ownership of the group;
- the capacity of a facilitated peer support group to become a self-help group is recognized, encouraged, and supported.

Expertise and Advice-Giving:

Facilitators have expertise in guiding group process - they do not necessarily have solutions to the problems presented by group members.

Because facilitators are frequently peers to group members, and/or because they are often very well informed about issues related to the focus of the group, it can be tempting to offer group members solutions or expert information. This is contrary to the goals of a facilitated peer support group.

It is important to remember that facilitators are usually viewed by group members as authority figures; therefore any advice or information you provide may be construed as the final, authoritative answer and discourage further investigation. Furthermore, group members may be reluctant to offer alternative opinions or options which differ from those of the facilitator.

Providing answers and/or presenting one‘s self as the expert denies the abilities of group members to know what is best for them. Providing solutions does not empower people. Assisting them to discover how they can come up with their own solutions does. As one facilitator of a group for HIV-positive people stated, "If I want to truly foster empowerment of the group, it is important that I tell members 'I have HIV and I’m here as the group facilitator, but this doesn’t mean I do HIV better than you do.”

Advice-giving is discouraged amongst group members as well as facilitators. We ask group members to use ‘I’ statements to avoid advice-giving (i.e. "I tried x…" rather than "You should try x…”).

It is important to be aware of the difference between information provision and advice-giving. Group facilitators often have resource information, etc. that could be of great value to group members. If you have a piece of knowledge you believe group members would benefit by, you must be conscious of why, how, and when you offer it.

Example: Group members are talking about an issue that you have personally experienced. You had great success in dealing with the problem by using ‘x’ strategy. You think that group members should know about this strategy.

Advice-giving response: "When I had that problem, I did x. X involves…. (goes on at length to describe the strategy in detail). This was the best way of dealing with it, and I had great results. You should all try it - I bet you’ll find it works great for you too!”

Information provision response: “I’ve had some experience dealing with this problem. It may be worthwhile to become informed about strategy x. Does anyone here have experience with strategy x? Is the group interested in finding out more about strategy x? Any ideas on how/where we could get that kind of information?"

Key points to remember:

Be clear about your role as a facilitator, both to yourself and to group members.

There is great strength and wisdom in each group — when the group is grappling with an issue, look to the group first as the best resource.

If the group needs expert information, ask the group how they want to go about getting the information; will a group member do research and report back to the group? Will a guest speaker be invited to speak to the group? Will the group go on an outing to discover the answers?

If you are working with a co-facilitator, seek feedback from her/him on your interventions with the group to ensure that they are within appropriate boundaries.

Assessment & Evaluation:

As a final note, facilitators/organizations which provide facilitated peer support groups benefit by having group members assess, or evaluate, the group experience and facilitation (a written evaluation form is often used for this purpose). This can provide invaluable feedback on what works and what doesn‘t work. A request for feedback can occur either at the completion of group, or periodically throughout the sessions.

Member evaluations reinforce the values associated with the facilitated peer support model in that they place importance on the opinions and experiences of the members, and emphasize the ownership that members have of the group. Evaluations by group members are a learning tool which facilitators can utilize to assess their effectiveness, strengths, and areas for continued work.

KEY ELEMENTS OF A SUPPORT GROUP

1. **Mutual Aid**
   An alliance of individuals who benefit from working with each other on certain common problems or who need each other to work on those problems.

2. **Empowerment**
   a. Becoming aware of the power dynamics operating in your life space.
   b. Learning the skills necessary for controlling what can be controlled in your life.
   c. Exercising those skills without infringing on the rights of others, and
   d. Supporting the empowerment of others.

3. **Connection**
   Moving from the disconnection that results from facing a traumatic stressor to connection with self and with community.

4. **Leader/Co-Leader**
   a. Maintains a safe environment or a safe space;
   b. Facilitates connections between group members through active listening;
   c. Keeps the focus of the group upon the agreed upon goals of the group.

EFFECTIVE VS. INEFFECTIVE GROUPS

EFFECTIVE GROUPS	INEFFECTIVE GROUPS
Goals are clarified and changed to give the best possible match between individual and competitively structured group goals. Goals are co-operatively structured.	Members accept imposed goals. Goals are competitively structured.
Communication is two-way: the open and accurate expression of both ideas and feelings expressed.	Communication is one-way and only ideas are expressed. Feelings are suppressed or ignored.
Participation and leadership are shared by all group members. Both ‘task’ and ‘maintenance’ roles are present.	Leadership is delegated and based on authority. Membership/participation is unequal, with high-authority members dominating. Only “task” roles present.
Decision making matches the situation - different methods at different times. Consensus is encouraged.	Decisions are made by the highest authority with little group discussion. Members’ involvement is minimal.
Ability and information determine influence and power. Power is shared. ‘Contracts' built to ensure individual goals/needs are met.	Position determines influence and power. Power is concentrated in authority positions. Obedience to authority is the rule.
Challenge and conflict seen as positive keys to members’ involvement in decision making and good group work.	Challenge and conflict are ignored, denied, avoided or suppressed.
Interpersonal group behavior is emphasized. Cohesion is advanced through inclusion, acceptance, support and trust.	Individual roles are emphasized. Cohesion ignored, members controlled by force.
Members evaluate the effectiveness of the group and decide how to improve its functioning. Maintenance is an important component.	The highest authority evaluates the effectiveness and decides how goal accomplishment may be improved. Maintenance is ignored.
Interpersonal effectiveness, innovation and individuality is encouraged. Diversity is welcomed.	Organization, stability, and structure rigidly adhered to.

GROUP ATMOSPHERE

Certain notable impressions usually result from a particular group meeting. One might have the impression that not much work was done due to a general inability to ‘get started’ on the part of group members. Or, one might have the impression that a lot of work was accomplished but that in the course of that work, tempers flared or members were on edge or touchy.

These types of impressions describe the group atmosphere. Some terms to describe the group atmosphere are:

Tense: When pressures are felt, sometimes because of time limitations, or conflict between members, or personally threatening topics, the atmosphere may be tense.

Flight: When the group pursues ‘inappropriate’ or outside topics or horseplay as a means of avoiding the real task at hand (which might be threatening or unpleasant), the group atmosphere may be one of flight.

Fight: Often group members will find themselves in disagreement with the topic, decisions to be made, or action to be taken. This intra-group conflict may be described as fight.

Work: When the group devotes itself to its task in a purposeful manner the atmosphere is one of work.

Play: The opposite of work may be play. This situation exists when the group avoids doing its work, and can’t shake off being lighthearted.

Competitive: When several members seem out to win their own points, with the result that the group action can only proceed out of a win-lose situation, the session might be described as competitive.

Co-operative: As opposed to the competitive atmosphere, group members may work together harmoniously. When members seem to share goals and support one another in attaining group goals, the atmosphere may be described as co-operative.

Sluggish: Sometimes a group will try hard to deal with its task but just can't seem to get going. When members enter the session with low energy and do not gain momentum, the atmosphere can be described as sluggish.

Rewarding: When group members have worked together well and have accomplished the task they set for themselves they may feel a sense of satisfaction and that they have gained from the experience. The atmosphere may thus be described as rewarding.

STAGES OF GROUP DEVELOPMENT (Tuckman, 1967)

Stage 1: Forming

- becoming oriented to the group
- wanting to belong
- gathering information and impressions about each other
- likely avoidance of conflict
- may look to facilitator for leadership

Stage 2: Storming

- communication patterns will begin to emerge
- may see challenging of the facilitator
- challenging other members
- will look to norms/guidelines for clarity of rules
- group members may express dissatisfaction behaviourally (missing meetings, arriving late)
- opportunity for facilitators to empower the group

Stage 3: Norming

- will begin to confront issues, not each other
- establishment of group agreements
- “honeymoon” period

Stage 4: Performing

- working towards group goals
- open communication
- roles and responsibilities in group are flexible
- high degree of comfort
- disagreement can occur without conflict

Stage 5: Adjourning/Transforming/Deforming

- about completion and disengagement
- opportunity to experience closure/goodbye in a new way
- anxiety or fear may present
- possible regression to earlier stages of group development

TRAINING SESSION NUMBER TWO

- SESSION TWO AGENDA
- CHECK-INS
- CONTENT AND PROCESS
- BRIDGING AND CONNECTING

Support Group Facilitator Training
Session Two

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Check-Ins & Check-Outs

After this session, participants will:

- know the purpose of a check-in;
- will be able to contrast what a check-in is and what it isn't;
- understand the format of and be able to facilitate a group check-in.

a) Group discussion
  - What does 'check in' mean to you?
  - What is the purpose of 'check in'?

b) Group exercise
  - Go around and do a brief group check in

4. Content and Process

After this session, participants will:

- be able to define content and process as they relate to group interactions
- recognize the facilitator's role with regards to process-observing;
- be able to recognize and demonstrate process-observing skills.

a) Group Exercise - "Fishbowl"
  - Half of the group will participate, half will observe.

5. Bridging and Connecting

After this session, participants will:

- be able to define what bridging and connecting are;
- be aware of methods/approaches to bridging and connecting.

6. Role Plays

Skills for practice:

- check in;
- norm-setting;
- bridging & connecting group members.

7. Evaluations

THE NATURE AND PURPOSE OF CHECK-INS IN A SUPPORT GROUP

As a starting point to each meeting, support groups often use a ‘check-in’ format. The main purpose of the check-in is to re-orient members to the group environment and to determine who in the group needs time that session.

The format for check-ins usually consists of each member speaking in turn about how she/he is feeling that session in relation to issues relevant to the group context. This point is crucial for two reasons:

1. if the content is not relevant to the group context, members are bringing in extraneous issues which will side-track the group from its purpose and focus;
2. an agenda for the meeting is naturally formulated through individual requests for time and highlighting of emerging issues.

Check-ins should be brief and centered in the here-and-now. They should be brief because they are not the focus of the meeting; when members get caught up in lengthy check-ins; focus is often centered on one individual to the exclusion of others. Check-ins should be centered in the here-and-now in order to establish the focus on ‘live’ issues.

An example of a brief, here-and-now focused check-in might sound something like, “Tonight I am feeling angry. I’ve made a lot of realizations based on what we talked about last meeting, about how I feel being infected with HIV. I need some time to discuss this tonight." Note that even though this person refers to the last session, the comments are here-and-now focused because they are relevant to the group context, and the feelings are being experienced in the moment.

The role of the facilitators during check-in primarily involves the use of active listening skills. This means responding verbally and non-verbally to each member so mat she/he knows she/he is being heard. Verbal responses may include a brief paraphrase: i.e. “So you’re feeling a lot of anger about being infected, and tonight you need some time to work on this in the group."

Check-in is not a time for probes and invitations to expand on expressed issues. The opportunity for this will come later as members begin to engage in the ‘work’ of the meeting.

It is important to note that in a support group context, group facilitators often take a turn in the check-in. Because facilitators are not participants in the group in the same way other members are, check-in is not an opportunity to comment on personal issues you may be experiencing.

For example, this is not the time to make a comment such as “I’m finding it difficult to be here tonight because a lot of the things we’ve been talking about are relevant to my issues. I’m just beginning to get in touch with my own anger about being HIV-positive". If this is indeed the case for you, you do not have to risk your authenticity by denying that it is difficult for you to be there; you might instead say something like, "My energy is not as high as I would like it to be tonight. It may be a bit of a challenge for me to stay focused during our meeting.” But when you begin to disclose your own issues, the focus is taken away from the group members, for whom the group exists. If the group is raising issues for you; consider speaking with your co-facilitator, supervisor, or another supportive person outside of the group context.

CONTENT AND PROCESS IN A SUPPORT GROUP

Content - is what the group is talking about. It refers to what is being said or talked about.

Process - is what is happening in the moment. It refers to the impact or effect of what is being talked about.

For example, if the group member is talking about a death and group members are silently listening or quietly crying, the **WHAT** that is being talked about is a death (content), and **HOW** this is affecting the group is that some members are listening silently or quietly crying (process, or the impact of what is being said).

Successful support group facilitators focus on the process most of the time (although not all of the time), as opposed to content. This requires focusing on what is happening in the group and not getting lost in the content. As with all group skills, maintaining a focus on the group process and not getting lost in the group content takes practice and attention.

A focus on process means emphasizing the ‘how’. "How?" questions keep the focus on what is happening in the moment. "Why?" questions focus on the past. "Why?" questions are the hallmark of leaders who focus on content, keep group members from talking about feelings, and, emphasize their own authority and control.

For example, if John says that his partner is refusing to take his medication because it makes him feel sick (content) and Mary begins to cry (process), the facilitator could ask the group for ideas to help John's partner conform to his drug taking routine (content), or the facilitator could ask Mary why she is crying (content); or the facilitator could remind the group that the topic for tonight is ‘positive thinking’ (content).

On the other hand the facilitator could ask John how he feels about his partner‘s choice (process), or the facilitator could ask the group how they are feeling about what John is talking about (process) or the facilitator (a really good facilitator) could simply point out what is happening and invite responses from the group. Like this, "John is telling us about his partner's non-compliance and I am noticing that Mary is crying and the rest of the group seems to be silent. I guess I‘m wondering what is going on for everyone right now."

An easy way to begin to focus on process instead of content is for the leader to simply identify what is going on right now in the group and to invite responses from the group. The formula is: "What’s happening right now is ________and I am wondering how people are feeling about that", or "I am wondering how what we are talking about is affecting everyone.”

CONTENT AND PROCESS EXERCISE

Below are statements made by group members, and corresponding responses made by group facilitators. Each statement is followed by a content response and a process response. Mark a “C” beside the response you believe is a content response, and a “P” beside the response you believe is a process response.

1. Group Member “I don't know why we have to accept new members into the group - we're getting along quite well and a new member would just change everything."

Group Facilitator: "A couple of people have expressed reluctance to have a new member join the group. Could we take some time and talk about how the idea of having a new person start is affecting everyone?"

Group Facilitator: "Well, we all agreed when the group started that we would accept new members. It wouldn‘t be fair to change the rules now.”

2. Group Member: "Sorry I’m late again. I had to drop something off at the hospital for Pete and then pick up a prescription for myself. I‘m now depleted, but it just couldn’t be helped.”

Group Facilitator: "Sounds like you were having a really busy day. No wonder you’re flustered."

Group Facilitator: "How is caring for Pete and yourself affecting you?"

3. Group Member: "After I eat I feel so sick, so I tend to stick close to home. Now my friends think I’m abandoning them because they don’t know the truth."

Group Facilitator: "How are you coping with feeling so ill and not having your friends know?”

Group Facilitator: "Why don’t you try telling your friends of your illness?"

4. Group Member: "I just hate coming to this group week after week. I have better things to do.”

Group Facilitator: "Well, that is legitimate, why don`t you check your schedule and let us know if it’s going to work for you."

Group Facilitator: "It sounds like you have a lot going on. How is coming here every week affecting you?"

5. Group Member: "I really think the group should be longer than 10 weeks. It just seems too short."

Group Facilitator: "Yeah, a lot of people in these groups want them to be longer. Maybe we should look into changing the policy."

Group Facilitator: "It makes sense that you would be thinking about the group ending. How do you feel knowing that there are 2 sessions left?"

6. Group Member: (with raised voice to another group member) "Who the hell do you think you are telling me how to live my life?"

Group Facilitator: "Frank just yelled at Jean and I'm noticing that everyone is very quiet. I'm wondering what is going on for everyone."

Group Facilitator: "Calm down, you are very upset. Yelling your comments is not going to help resolve this."

BRIDGING & CONNECTING

In a support group, common themes/issues/opinions/perceptions/feelings/etc. usually arise between members. Recognition and identification of these commonalties is one way in which members of the group move toward cohesion, and ultimately empowerment.

Throughout the duration of the group, and especially in the early stages, when members may have not yet decided how they will include themselves, bridging or connecting is an important facilitator function. Bridging may be defined as identifying and summarizing for the group the common themes, issues, etc. which have emerged. A bridging statement may be one of three things:

1. A paraphrase;
2. a summary of content; or
3. a reflection of feelings.

It is important to note that bridging statements are not interpretations of what you are hearing from group members; in other words they are not statements about what you think the underlying issues are. Bridging comments reflect what you have heard group members say.

Bridging can involve pointing out connections between two group members, for example: "Mary, you just talked about feeling a lot of confusion around treatment options, Fred was relating similar feelings earlier when he was talking about the decisions he’s struggling with."

It also consists of summarizing expressed themes common to several or all group members, for example: "Everyone in this group has lost someone to AIDS, and several people have talked about their feelings of loss. We’re beginning to express some of the feelings of grief shared by people in the group."

As in any paraphrase or summary (which is a main element of bridging), it is important to check out your perceptions with group members. It is not necessary to do this every time you make a bridging statement, and when you do, you might say something like, "Am I hearing some of you say .... ", or "The sense I’m getting is several people in the group are saying .... Is that right?"

After making a bridging statement, you may want to follow up with an open-ended question as a way of re-engaging the group in dialogue. For example, “There seems to be a theme emerging here of ...I wonder if someone else can say what they are thinking about this theme?”

Finally, as the support group evolves members will ideally begin to pattern themselves after the lead of the facilitators, spontaneously making bridging/connecting statements themselves. For example, "I can really relate to what you were saying Tom, about your feelings of uncertainty right now. This seems like something a lot of us here are trying to cope with." When support group members begin to do their own bridging, this is a cue to facilitators to relinquish some of their responsibility for this task.

TRAINING SESSION NUMBER THREE

- SESSION THREE AGENDA
- SKILLS REVIEW & TOOL BOX
- WORKING WITH EMOTION
- REFLECTING FEELINGS

Support Group Facilitator Training
Session Three

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Skills Review

After this session, participants will have a heightened awareness of:
- Active listening - definition and techniques;
- Structured feedback skills;
- Content and process - definitions, facilitator's role in process-observing;
- Bridging and connecting - definitions, approaches.

4. Working with Emotion — (review from core skills)

After this session, participants will:
- understand the importance of emotion in a support group environment;
- recognize factors which affect their comfort level when dealing with emotion;
- recognize 'emotion words';
- possess the skills needed for working with emotion in a group.

5. Reflecting Feelings

After this session, participants will:
- understand the facilitator's role in reflecting feelings;
- be aware of techniques for exploring feelings.

6. Role plays: Feelings/Emotion

- Working with Emotion
- Reflecting feelings

7. Evaluations

WORKING WITH EMOTION

An important function of a support group is to help participants identify and express the feelings associated with their experiences. While feelings may not be the sole focus of a support group is important that facilitators encourage the creation of an atmosphere which allows for and encourages emotion.

When we avoid emotion in a support group context, we send a message that feelings are not safe or valued.

The result is that group members may deny the existence of and/ or suppress the expression of their feelings. Consequently, the group may stay on a superficial level, never going beyond an intellectual expression of individual experience. When this happens, the group ceases to become a support group and is instead a discussion group.

In all human endeavors, the element of emotion is always present, and how we deal with expressed emotion is culture-bound. In a support group context, we are often confronted with very deep and intense feelings. For both facilitators and group members, the expression of intense emotion can be frightening and/or anxiety- producing for a number of reasons, including:

1. the expressed emotion may echo emotions which we are not yet ready to explore or have not resolved;

2. the expressed emotion may evoke responses in ourselves which we feel uncomfortable with;

3. we may have concerns that the expression of strong emotion will “open the flood gates", resulting in an outpouring from group members that will become overwhelming or ‘out of control’;

4. as facilitators, we may feel that making space for the exploration of group members feelings may “trigger’ an emotional response in ourselves;

5. we may feel responsible for making the expresser feel ‘better’;

6. we may believe we will be unable to respond to the emotion.

It is absolutely essential that support group facilitators become comfortable with the expression of emotion in the group, and are prepared to encourage its expression. How one reaches this comfort level is highly individualized and beyond the scope of facilitator training. However, there are a few key elements which are helpful in working with emotion as it emerges in group. If you sense that your group has ‘shut down’, that it is going in circles, not moving beyond the surface, etc., you may want to refer to this checklist:

Checklist for Working with Emotion

- have I encouraged group members to name their feelings?
- have I ‘allowed’ group members to express feelings and stay with them?
- have I stayed focused on the person(s) expressing strong emotion?
- have I offered encouragement by paraphrasing, summarizing, empathizing?
- have I used bridging skills when more than one member is expressing an emotion?
- have I been respecting members’ boundaries/limits of exploring emotion?
- have I sought support for myself outside of the group context (i.e. ensured that I have time to debrief with my co-facilitator after meetings, utilized supervision/ consultation opportunities, talked with someone who I know is understanding and supportive, etc)?
- have I been ignoring expressions of feeling instead of acknowledging them?
- have I been stifling the expression of feelings by reassuring, questioning the feeling, or changing the topic?
- have I been turning feeling expressions into intellectual statements?
- have I been pushing group member(s) to express more than they are comfortable with in the moment?
- have I been interpreting/labeling members feelings (i.e. “I think you have a lot of anger underneath your issues"), instead of asking the person to describe what s/he is experiencing (i.e. "You’ve been saying a lot about what you think about...I wonder if you can talk about the feelings that go along with that")?

WORKING WITH FEELINGS

1. Very seldom
2. Occasionally
3. Sometimes
4. Often
5. Most of the time

______I am aware of my feelings
______I am able to name my feelings
______I am able to express my feelings
______I am able to sustain a conversation about my feelings

______I notice other people's feelings
______I am able to encourage others to talk about their feelings
______I am able to reflect other people's feelings without interpreting them
______I am comfortable conversing with other people about their feelings

______I initiate conversations with others about my feelings
______People initiate conversations with me about their feelings

Comments:

REFLECTING FEELINGS

When you are working with emotions, the most important facilitator intervention is to reflect those feelings back to the group member(s). Reflecting feelings opens up the exploration of felt experiences, sends a signal that feelings are acknowledged, and can move the group beyond a discussion of 'facts'.

Of primary importance when working on reflecting feelings is the avoidance of interpretations. What this means is that you do not express your theories about what a person is feeling or experiencing. Instead, you encourage the group member(s) to describe or name what s/he is feeling. Even when it may seem obvious (i.e. a person is crying/yelling/etc.), we do not truly know what the person is experiencing until we ask. As you will know from your own experience, tears do not always mean sadness, yelling does not always signify anger, silence does not always equal disinterest, etc.

There are four elements which can be utilized to work with feelings in the support group context which avoid interpretation and encourage members to express what they are experiencing:

1. When a member is speaking, listen for feeling words. Playback the feeling words you heard in a paraphrase. Example:

   Member: "I've been thinking a lot about John lately. He's been dead for a year now, and I should probably be moving on with my life. I just get so overwhelmed with sadness sometimes and I can't seem to get past it."

   Facilitator: "So there are times when you just feel overwhelmed with sadness, and you just can't seem to get past it."

2. Play back the feeling and check out the accuracy of your paraphrase. Following on the above example:

   Facilitator: "So there are times when you feel overwhelmed with sadness, and you just can't seem to get past it. Did I get that right?"

3. Encourage and assist the member to explore the feelings through clarification and summary. Following on the above example:

   Facilitator: "You feel overwhelmed with sadness - tell us some more about the sadness, what that's like for you."

   Member: "Yeah, you know I become so emotional, I just cry and cry. When I think about his death, I'm filled with this ache, this sense of utter emptiness."

   Facilitator: "So that overwhelming sadness is an ache, a feeling of just utter emptiness inside. Tell us some more about the emptiness."

4. As a way of bringing it back to the group, once the member has had an opportunity to share her/his experience, you may want to utilize your bridging/ connecting skills. For example:

   Facilitator: “Frank, you’ve been telling us about the overwhelming feelings of sadness and emptiness you have sometimes when you think about John and his death. I wonder if anyone else in the group can connect with these feelings?”

Core Skills Training- Communication -Feeling Words

Accepted
Affectionate
Afraid
Angry
Anxious
Ashamed
Attracted
Bored
Competitive
Confused
Defensive
Desperate
Disappointed
Embarrassed
Free
Frustrated
Grateful
Guilty
Happy
Hopeful
Hurt
Inferior
Interested
Intimate
Jealous
Joyful
Livid
Lonely
Loving
Rejected
Respected
Sad
Satisfied
Shocked
Shy
Superior
Suspicious
Trusting

* this is not an exhaustive list *

TRAINING SESSION NUMBER FOUR

- SESSION FOUR AGENDA
- SKILLS REVIEW & TOOL BOX
- WORKING WITH CHALLENGING SITUATIONS
- CLOSURE
- SELF CARE

Support Group Facilitator Training
Session Four

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Review of skills learned

4. Dealing with Challenging Situations in Groups

    - What are "challenging situations" to you?
    - Who are they challenging for?
    - What are your fears/challenges?
    - How can we manage these situations?

After this session, participants will:

- be able to recognize and identify challenging situations;
- be aware of how to deal with challenging situations as a group;
- know the role of the facilitator in dealing with challenging situations;
- demonstrate their ability to deal with challenging situations.

5. Closure

After this session, participants will:

- recognize the purpose/importance of group closure;
- know when to address group closure;
- recognize the role of group facilitators in closure.

6. Self-Care

After this session, participants will:

- know what self care is;
- recognize the importance of self care;
- be aware of strategies for self care.

7. Evaluations

DEALING WITH CHALLENGING SITUATIONS IN A GROUP

Like nearly everything else that goes on in the group, the difficult behavior of specific members is something that the whole group allows to happen, and the group itself can respond to any challenge.

The facilitator, rather than "fixing it", makes it safe for the group to address challenges. Sometimes, the "problem" also provides a way for the group to protect itself or to avoid what feels like a more uncomfortable scene.

For example, superficial conversations might keep people from facing the pain of their situation. Always being angry and non-accepting of one member who stands out as the most different can be a way to avoid being criticized. The facilitator can point out what they see is happening and gently ask the group if this is OK with them.

Facilitators should not assume to know the real reason something is going on. Do not get into analyzing. Instead, you, as the facilitator, can ask the group how they want to handle the situation.

The following are some challenges that might be encountered in a group:

One person does most of the talking

Consider what keeps other members from speaking up, what might they fear, what could make it safe for more people to talk?

Fighting between members

Differences and conflicts are natural and can help people learn about themselves and grow stronger. First, you, as the facilitator, might do some self examination to make sure that you are OK with conflict. In the group, keep calm, avoid taking sides and encourage “I" statements while discouraging put downs and judgments. As the conflict continues, perhaps focus on commonalities, and encourage other members to broaden the discussion.

People coming late

It’s important for the group as a whole to enforce the ground rule of starting on time. If a pattern develops where the group never knows when the meeting has actually started (because it feels like they are always waiting for someone to get there) the group won’t feel as sure of itself as a group.

"Dumping'' just before the end of the session

Members may wait to share their heaviest problems until the end of the session for many reasons: perhaps they're anxious, they're hoping the group will meet longer, they're trying to control the group, etc. Whatever the reason (and often the reason is not clear), make sure the group ends on time. Suggest that members bring up their concerns early in the meeting so they will be sure to get the time they need.

Denial

Though this may feel like a problem to the facilitators, it may or may not be a problem for the group. When it seems like "something's in the air" or some key issue has not been spoken about (like sex, death, suicide, love, etc.), it may help if the facilitator mentions that it's OK to talk about the issue if it's important to anyone.

Member in crisis

Sometimes, the normal rhythm of a group is disrupted when a member becomes enraged, overwhelmed, panicked and/ or hopeless because of sudden or unexpected changes in their life. These crisis feelings can "snowball" in the group (as member after member feels out of control. The calmness of the facilitator can alleviate this tendency.

Facilitators should stay calm, breathe deeply, speak slowly and encourage members of the group to do the same. Allow the extreme emotions to be expressed and respond to them with calm acceptance. If it seems necessary, one facilitator can take the member in crisis out of the room to spend some individual time with them. If it appears someone's life is in immediate danger, call for help. Encourage the member to contact their therapist, crisis hotline or 911 if the emergency calls for it.

Since the group will be affected by the crisis, and, at some level, each member may identify with the person in pain, it's crucial to encourage the group to talk about the experience.

GROUP CLOSURE

Every group has a life span which includes a beginning, middle and end. Although each person experiences them uniquely, endings are meaning-laden. For many, the ending of group is experienced as a loss and therefore represents some of life’s most crucial and painful issues.

Because each of us encounters endings throughout the course of our lives and because endings are so meaningful, it is absolutely essential to work with group members on closure. Working on closure provides opportunities for members to reflect on their experience in group, determine what they got from the group, and make plans on how to utilize group learnings in an ongoing way. The facilitator can aid this process by assuming the following closure tasks:

***Regularly remind group members that the group will be ending*.** Group members may deny or ignore the fact that the group will end, and it is important that facilitators keep this in awareness. One way to achieve this is to keep members focused on what they have determined they want to work on. For example, “We have three more sessions left, and there are a few issues the group had said they wanted to address which we haven’t yet covered. Can we take some time tonight to review what we want to cover in our remaining sessions?"

Encourage the transfer of learning from the group to the member’s personal environment. The underlying goal of any support group is to help members become aware of, and better utilize, their personal and environmental resources. Facilitators can assist in this task by providing opportunities to reflect on the group experience throughout the course of the group, and especially at closure. At closure, some pertinent questions might include, “What’s different for you now than when you started the group?", "What has changed that might help you deal differently with the issues that brought you here?", "What have you learned about yourself/the issues we’ve talked about/what’s available to you while being in this group?". This is an excellent opportunity to help members acknowledge and appreciate their personal and environmental resources.

Encourage the expression of feelings about the ending of group. Facilitators can take on a modeling role here by reflecting on what the group has meant for them and how they feel about it ending.

Have faith that group participants will continue to grow once group has ended. Sometimes it is difficult for facilitators to let go of the group because we worry that members are not ‘ready’ for it to end. It is important to remember that group participants had resources before the group started, and will continue to have them once it ends. Even when we think someone has not had enough time to get something significant from the group experience, it is important to remember that we often have no idea of what the true personal impact and meaning of an experience is for an individual. For some, it may not be until later that s/he significantly benefits from the group experience.

Some additional notes:

Working on closure should not be left until the last session. At the very least, facilitators should begin encouraging group members to actively talk about the group ending by the second last session. As noted above, regular reminders that the group will be ending should be given throughout the course of the group, and can be used as a way to keep the group focused on what they want to accomplish.

Closure exercises at each group meeting are a good way to get group members (and facilitators) into a routine of addressing endings. How this is accomplished varies from group to group, but your group might decide to end each meeting with a process similar to a check-in exercise.

Some ideas for closing exercises are:

- Have each member say how s/he is feeling in the moment, i.e. “Right now, I’m feeling energized by what we talked about in group tonight."
- Have each member say what s/he got from this meeting, i.e. "Tonight I got a better sense of what’s really been bothering me. I’m now aware that I’m angry about..."
- Have each member say what s/he learned in this meeting, i.e. "I learned a lot about strategies people are using to deal with medication side effects."
- Have each member say what s/he wants to talk about next meeting, i.e. "At our next meeting, I really want us to talk about how we can have sex, and keep ourselves safe both physically and emotionally?”

Consider having members complete a written evaluation at the end of a group. This can assist members with starting to think about what the group experience has meant for them, as well provide you with valuable feedback on the group structure/format and your facilitation skills. If possible, evaluation forms should not be left to the last moment if you want thoughtful responses.

SELF CARE FOR FACILITATORS

Providing supportive service to others can be extremely rewarding. At times, it can also be difficult and personally challenging.

As a support group facilitator, you are in a position to hear and witness people's pain and triumphs — this is a position which, in various ways, will undoubtedly have a personal impact. If you are in any way personally connected to the issues addressed in your groups, the impact may be even greater. To be able to effectively facilitate and maintain your own well-being, it is essential that you develop practices for your own self-care.

No one can tell you what you need to do to take care of yourself, but here are a few basic principles which make sense to consider:

- look after your physical well-being as best you can; try to eat healthy, get plenty of rest, exercise, etc.;
- figure out what you need to feel good, and find ways to get those needs met;
- establish a support system for yourself and utilize it — partner, family, friends, therapist, whoever;
- acknowledge and accept both your strengths and your limitations as a facilitator and as a human being;
- set realistic goals for yourself.

Specifically when you are facilitating:

- have a preparatory/check-in meeting with your co-facilitator before each meeting;
- debrief with your co-facilitator after each session — make sure to talk about how you felt about the facilitation experience, not just what happened for group members (the structured feedback format can come in really handy here);
- utilize 'supervision'/ consultation opportunities and other related resources to work out problematic areas;
- be proactive - if you are having difficulties in the group, and/or if facilitating the group is having a negative impact on you, don't wait for it to resolve itself. Utilize the supports at your disposal before you burnout;
- remind yourself that the well-being of the group is not solely your responsibility - you add a piece, but you do not have the power to control how people experience the group, or what they ultimately take with them from the experience.

TRAINING SESSION NUMBER FIVE

- SESSION FIVE AGENDA
- WORKING WITH CO-FACILITATORS
- SELF DISCLOSURE
- WORKING WITH SILENCE
- GROUP LOGISTICS
    - Facilitator Responsibilities
    - Timeline of an ACT Support Group
    - Meet & Greets
    - Session Reporting
    - Facilitator Supervision

Support Group Facilitator Training
Session Five

Overall Goal of Facilitator Training

To provide a fun and challenging environment in which participants can learn and practice basic group facilitation skills and gain the confidence needed to co-facilitate support groups.

Agenda

1. Housekeeping

2. Review Goals

3. Parking Lot

4. Working with Co-Facilitators

After this session, participants will:

- have a better understanding of their own facilitation style and how their experiences/background affect it;
- be prepared to deal with the dynamics of working with a co-facilitator;
- have the skills necessary to coordinate work with a co-facilitator.

Group discussion

  - Co-facilitation

5. Self-Disclosure

After this session, participants will:

- be able to define self-disclosure;
- know the significance of self-disclosure;
- be able to recognize appropriate situations in which to self-disclose;
- be aware of strategies for self-disclosure;
- be able to recognize effective self-disclosure.

6. Group Logistics

After this session, participants will:

- Have a better understanding of the administrative tasks associated with facilitating support groups at ACT;
- Be prepared to deal with emergencies/crises in the group setting, including knowing when to seek assistance from ACT staff or outside organizations;
- Understand better their role and responsibilities as part of the Support Group program;
- Understand how they will be supervised, supported and receive feedback from the Group Programming Coordinator.

  a) Volunteer Responsibilities
  b) The Role of the Group Programming Coordinator
  c) Administrative/logistical details for the Support Group Program

7. Graduation & Group Closure

8. Evaluations

QUESTIONS FOR CO-FACILITATORS

(Adapted from The Skilled Facilitator (1994), by Reger M. Schwarz)

Orientation/Style

1. The major values, beliefs, and principles that guide my facilitation are...
2. The major values, beliefs, and principles that other facilitators hold and that I strongly disagree with are…
3. At the beginning of a support group meeting, I usually...
4. At the end of a support group meeting, I usually...
5. When a group member talks too much, I usually...
6. When the group is silent, I usually...
7. When an individual group member is silent, I usually...
8. When a group member gets upset, I usually…
9. When a group member comes late, I usually
10. When a group member leaves early, I usually…
11. When group members are excessively polite and do not confront each other, I usually...
12. When there is conflict in the group, I usually…
13. When the group attacks one member, I usually...
14. When a group member takes a cheap shot at me or implies I am ineffective, I usually...
15. When a group member attempts to force other group members to accept her/his opinion, I usually...
16. When members are off track, I usually...
17. When a group member criticizes another group member, I usually...
18. My favorite group interventions are...
19. Interventions that a support group usually needs but that I don‘t often make are...
20. The things that I find most satisfying about facilitating support groups are...
21. The things that I find most frustrating about facilitating support groups are…
22. The things that I find most uncomfortable in facilitating support groups are...
23. On a continuum ranging from passive to very active, my intervention style is...
24. My typical intervention rhythm is (fast/slow)...

Experiences and Background

1. Discuss your experiences as a facilitator/co-facilitator. What types of groups have you facilitated? What were the content and process issues in the groups?
2. Discuss your best facilitation and co-facilitation experiences. What was it about these experiences that made them so successful?
3. Discuss your worst facilitation and co-facilitation experiences. What was it about these experiences that made them so unsuccessful?
4. Describe some of your facilitation behaviors that a co-facilitator might find idiosyncratic.
5. Describe the issues that have arisen between you and other co-facilitators.

6. Describe the areas in which you are trying to improve your facilitation. How would you like the co-facilitator to help you improve?
7. What personal issues do you have that might hinder the ability of you and the co-facilitator to work with each other or with group members?
8. Given what you know about the co-facilitator, what concerns do you have about working with that person?

<u>Co-facilitator Co-ordination</u>

1. How will the pre-group tasks be divided?
2. How will pre-session planning happen?
3. How will post-group debriefings happen?
4. Who will sit where in group meetings?
5. Who will start the meeting? Who will finish it?
6. How will you divide the labour?
7. What kind of facilitator interventions and behavior are inside and outside the zone of deference that each of you will grant the other?
8. Where, when, and how will you deal with the issues between you?
9. What kinds of disagreements between you are you willing and not willing to show in front the group?
10. What is non-negotiable for each of you as a co-facilitator?

SELF DISCLOSURE

Chuck Marino

Here is a good guideline: it is important that support group facilitators be genuine. Playing a role like the expert, the wise person, the sympathetic listener, etc. is phony. Being you, not hiding behind a role, is genuine.

Facilitators who never disclose anything about themselves are showing their group how to be cautious, impersonal, and closed.

Facilitators who reveal too much blur the distinction between themselves and their group; they would rather be a friend than facilitate the group. They burden the group with their own opinions, reactions, and memories.

An important part of being you is using your own feelings and reactions as a group facilitator. The question becomes when is it appropriate to disclose your own feelings and reactions?

1. A first indicator that self-disclosure may be called for is when you experience a persistent feeling or reaction to what is going on in the group. Perhaps you are feeling bored or irritated; maybe you feel uncertain or uneasy. If this is the case it is very likely that you are not the only one having this feeling and it becomes very important for you to disclose it. The key words here are persistent (it keeps coming back) and feeling (not a fleeting thought or memory). If you experience a persistent or recurring feeling this is an indicator that self-disclosure might be necessary or appropriate.

2. Unrehearsed disclosures about what you are experiencing right now are usually much more effective and facilitative than disclosures about your past or your memories. Putting this guideline in reverse; if it is too easy to reveal, or it is something you reveal often; or if it sounds rehearsed, it is probably not a good self-disclosure. A good self-disclosure is fresh, unrehearsed, and a little difficult to put out there. “I have had that experience myself” is not likely to be as good a disclosure as “I’m feeling a little anxious about what we are talking about and I am wondering if anyone else is sharing that feeling?”

3. The final guideline is to ask “What do I expect to happen if I disclose what’s going on with me and will that empower the group or focus the group on me?” This is an important question to ask and answer. Predicting the effects of your self-disclosure will increase the chances that it will be effective. By observing the effects of your self-disclosure you can become better and better able to use this as an effective tool.

Here is how to evaluate a facilitator’s disclosure: It was a good self disclosure if the next thing that happened was the group explored what they had been talking about more fully or at a deeper level.

Working with Silence

Constantine Cabarios

What is silence? According to the Merriam-Webster (2015) dictionary definition, silence (is a noun) “that lacks sound or noise; it is a situation, state or period of time in which people do not talk; a situation or state which someone does not talk about or answer questions about something.”

What does silence mean? Silence has different meanings for people. It can be an uncomfortable experience and it can also provide a sense of relief. In *counselling*, silence is used as therapeutic tool by trained counsellors to allow their clients time to reflect, process emotions and/or retrieve memories and experiences that may add further insights into their therapeutic goals. The counsellor may use this technique to elicit *non-verbal* or *verbal* responses, depending on the level of therapeutic alliance between the counsellor and client.

For North American or Western European cultures, use of silence in communication can be an uncomfortable experience and yet according to social scientists, 70% of communication is *non-verbal* (Jaworski &Sachdev, 1998). North Americans may perceive effective communication as verbal (Knapp, 1975) and thus most forms of communication involve some form of conversing (e.g. small talk) or rhetoric (i.e. to persuade) and can present the speaker as confident, knowledgeable, engaging, expedient and effective (Davidson, 2009). In Asian or in Eastern cultures, *silence* may be viewed as a sign of respect, strength and wisdom (Davidson, 2009). Depending on various contexts, silence can have different meanings for people.

Silence Quotes	What does it mean?
Silence is a source of great strength. - Lao Tzu	
Nothing strengthens authority so much as silence. - Leonardo da Vinci	
Silence is a true friend who never betrays. - Confucius	
Silence is the sleep that nourishes wisdom. - Francis Bacon	
Silence is the most perfect expression of scorn. - George Bernard Shaw	
Tis better to be silent and be thought a fool, than to speak and remove all doubt. - Abraham Lincoln	
He who does not know how to be silent will not know how to speak. - Ausonius	

Productive use of silence. In group work, silence can be a chance for group participants to rest, reflect, find balance or organize their thoughts and feelings after an emotion-filled moment (Vriend and Dyer, 1975). Conversely, it can provide group facilitators a chance to observe the group dynamics through non-verbal cues and monitor the reactions of the group participants and determine when to 'break the silence.'

Non-productive use of silence. This can manifest in group participants as a form of resistance to go against the 'leader' of the group (Vriend and Dyer, 1975). In other words, there might be a group member who is always leading the topic discussion and therefore other group members may feel resentful, anxious or fearful. Group members may be cognizant of 'taking up too much space' or perceived as 'ganging up' on the leader (Vriend and Dyer, 1975).

Knowing when to break silence. It is important for group facilitators to remind themselves and group members that silence is part of non-verbal communication and that they always have the choice to talk or not, as we are all unique individuals with different methods of expression. Group facilitators should be able to get sense of each group members' personalities and therefore determine if a group member is feeling anxious or distressed with the lack of verbal dialogue (Vriend and Dyer, 1975). There should be enough time for contemplation for all group members during the session and then the group facilitator should be able to bring the group back to a group discussion. However, the group facilitator should be careful with the tendency to influence the direction of the conversation. Rather, the group members should be able to take the initiative and 'break the silence' on their own.

<ins>Example of how to break the silence without being directive or suggestive</ins>:

Group facilitator: We've been silent for some time now. I'm wondering how people are feeling.

Activity: "Mirrors"

- Need one leader, one follower and observer(s)
- The leader will initiate a non-verbal behaviour (e.g. clapping hand, bowing head, looking up, yawning, etc.)
- The follower will follow the action(s) of the leader
- The observer (facilitator) will monitor reactions of the group

<ins>Description</ins>: The mirroring exercise is another actor warm-up that's adapted easily for any team-building activity. It can be performed in pairs or with everyone standing in a circle. One person leads by making slow movements with her arms, hands, head and body. Her partner or the others in the circle try to imitate her exactly. The trick to this

exercise is to avoid hesitating, then following the leader. Everyone should try to time their actions as close together as possible -- a mirror image -- so it's difficult to distinguish who's leading and who's following. The leader must make sure that her movements can be imitated. Eye contact can help the other people anticipate the next move.

Purpose: use of non-verbal cues, observation skills and being present in a group; ‘listening’ to group dynamic cues; builds awareness; use of non-verbal mirroring.

References

Jaworski, A. and Sachdev, J. (1998). Beliefs and Silence in the Classroom. *Language and Education,* 12 (4) pp. 273-292.

Knapp, H. (2007). *Therapeutic communication: Developing professional skills*. Los Angeles: Sage Publications.

Vriend, J. and Dyer, W. W. (1975). Effectively handling silence in counseling groups. *Canadian Counsellor*, Vol. 9, No. 1, pp. 2-8.

VOLUNTEER CODE OF CONDUCT

Human Resources Manual

Policy 9-23

1. CONFIDENTIALITY

We will honor the confidentiality of service users, clients, volunteers, staff, sponsors and donors and adhere to the established precepts of confidentiality of ACT Policies & Procedures and government legislation. We agree to consider information pertaining to medical conditions, family relations, phone numbers and addresses, sexual orientation and other facts of a highly personal nature as confidential and therefore we understand that we are not to disclose this information to any person who is not authorized by ACT to have access to such information without the specific permission of the individual concerned.

2. NON-DISCRIMINATION/EQUITY

In keeping with ACT's philosophies and policies, ACT will neither practice nor tolerate discrimination or harassment against any staff member, volunteer or service-user on the ground of race, creed, color, place of origin, ethnic origin, ancestry, citizenship, political or religious affiliation, gender, sexual orientation, age, marital status, family relationship, HIV status, economic status, identity, disability or record of offences. We will treat each other, staff and service users with dignity, care and respect. We will be sensitive to and educate ourselves about individual and group differences. We will honor all clients' rights to self-determination and agree to support people in making their own personal choices.

3. CONFLICT OF INTEREST

We commit to our understanding and upholding of the Conflict of Interest policy. We agree to discuss any potential conflict with our supervisors and commit to being truthful in all matters to do with our volunteer relationship with ACT.

4. RELATIONSHIPS – BOUNDARIES

ACT encourages friendly relations between volunteers and those they serve. However, it is important to remain aware of appropriate boundaries. As with paid staff, ACT discourages relationships of a romantic or sexual nature between supervisors and those they supervise or volunteers and those they serve. We agree to maintain respectful and professional relationship boundaries during the course of our volunteer work and agree to speak with our supervisors should any relationship develop which makes it difficult for us to remain objective and fulfill our volunteer obligations.

5. LIMITS

We agree to maintain the limits we have set for ourselves with respect to the emotional and physical resources we are willing to provide. We understand that our own training and education may limit our ability to service clients and we recognize the need to ask for assistance or refer when appropriate. If we feel we are being asked to do something outside of our job description, or are having difficulty saying no to a staff member, volunteer or client, we will ask for support and coaching from our supervisors and/or peers.

6. ACCOUNTABILITY

We agree to participate in supervision that is acceptable, reasonable, regular and visible according to the guidelines of the individual programs we are assigned to. Supervision guarantees accountability for the performance of assigned responsibilities, provides an opportunity for feedback and guidance, and assistance and support in my role as a volunteer.

7. TRAINING AND CONTINUING DEVELOPMENT

We understand that in accepting a volunteer position with ACT, we are agreeing to undertake and complete the necessary training before, during and in the course of our volunteer assignment as outlined by the Volunteer Coordinator and as indicated in our program agreements. We value our own continuing development and understand that it is essential as a volunteer. We will do this by keeping updated on new information, attend monthly meetings and relevant in-services, and by taking advantage of opportunities such as seminars and workshops offered both within and outside of ACT.

8. ALCOHOL/DRUG USE

We understand that being under the influence of alcohol or drugs may interfere with our ability to deliver service. We therefore agree: not to perform our volunteer duties while under the influence of drugs or alcohol; not to provide a client with illegal substances or encourage their use; not to participate with a client in alcohol consumption to the point where our effectiveness is impaired.

9. SCENTS

Many people living with HIV/AIDS and also those who suffer from environmental allergies, are extremely sensitive to strong scents. In order to make ACT as comfortable as possible for all people who are affected by this, staff and volunteers agree to moderate their use of colognes and perfume while working in the office or performing duties on behalf of ACT in the community.

10. NON-COMPLIANCE

We understand that failure to adhere to any and all parts of this code may result in suspension from our volunteer duties and/or termination of our volunteer relationship with The AIDS Committee of Toronto (ACT).

RESPONSIBILITIES OF SUPPORT GROUP FACILITATORS

1. All volunteers with ACT are representatives of the organization and, as such, agree to adhere to the policies and procedures outlined in the Volunteer Code of Conduct.

2. Confidentiality

Your responsibility to the members of your group includes:

- Safeguarding the confidentiality of group members' identities, names and contact information
- Returning ALL documents related to the group to the Group Programming Coordinator upon completion of the group

Tips on keeping information confidential:

- Use only first names when taking group notes, including session reports
- Keep all documents related to the group on the ACT premises
- Do not acknowledge group members when you see them outside the group setting, unless they acknowledge you first. When making conversation, do not make any mention of ACT or the group
- When leaving messages for group members, be discreet. Do not say what organization you're calling from.
- Use the assigned ACT mailbox to receive messages/calls from group members. Safeguard the password to this mailbox.

3. Safety

Confidentiality of client information does not extend to communication between volunteers and the Group Programming Coordinator, especially when issues of safety are involved.

Specifically, you **MUST** report to the Group Programming Coordinator as soon as possible any situation involving intent to cause harm to self or others, including disclosure of intent to commit suicide, harm another person or admission of or intent to harm a child.

4. Session Reporting

Volunteer Support Group Facilitators are required to fill out weekly session reports regarding group activities and submit them to the Group Programming Coordinator before the next weekly group session.

These reports are important as they keep the Group Programming Coordinator informed of what is happening in the groups, identify emerging trends and issues affecting the communities ACT serves, and assist us in evaluating the Support Group Program.

5. Training

All volunteers in the Support Group program are required to program-specific meetings/trainings. In addition, Support Group Program volunteers are strongly encouraged to take part in other training opportunities within the organization.

6. Commitment

As a Support Group Facilitator, you are accountable to the Group Programming Coordinator, your co-facilitator and your group members to be present, on time and prepared to facilitate all scheduled meetings of the group. If you are ill, or unexpectedly cannot attend a group meeting, you must provide advanced notice to the Group Programming Coordinator and your co-facilitator.

7. Support and Supervision

Participation in the supervision process, outlined below, is a requirement of all volunteers in the Support Group Program:

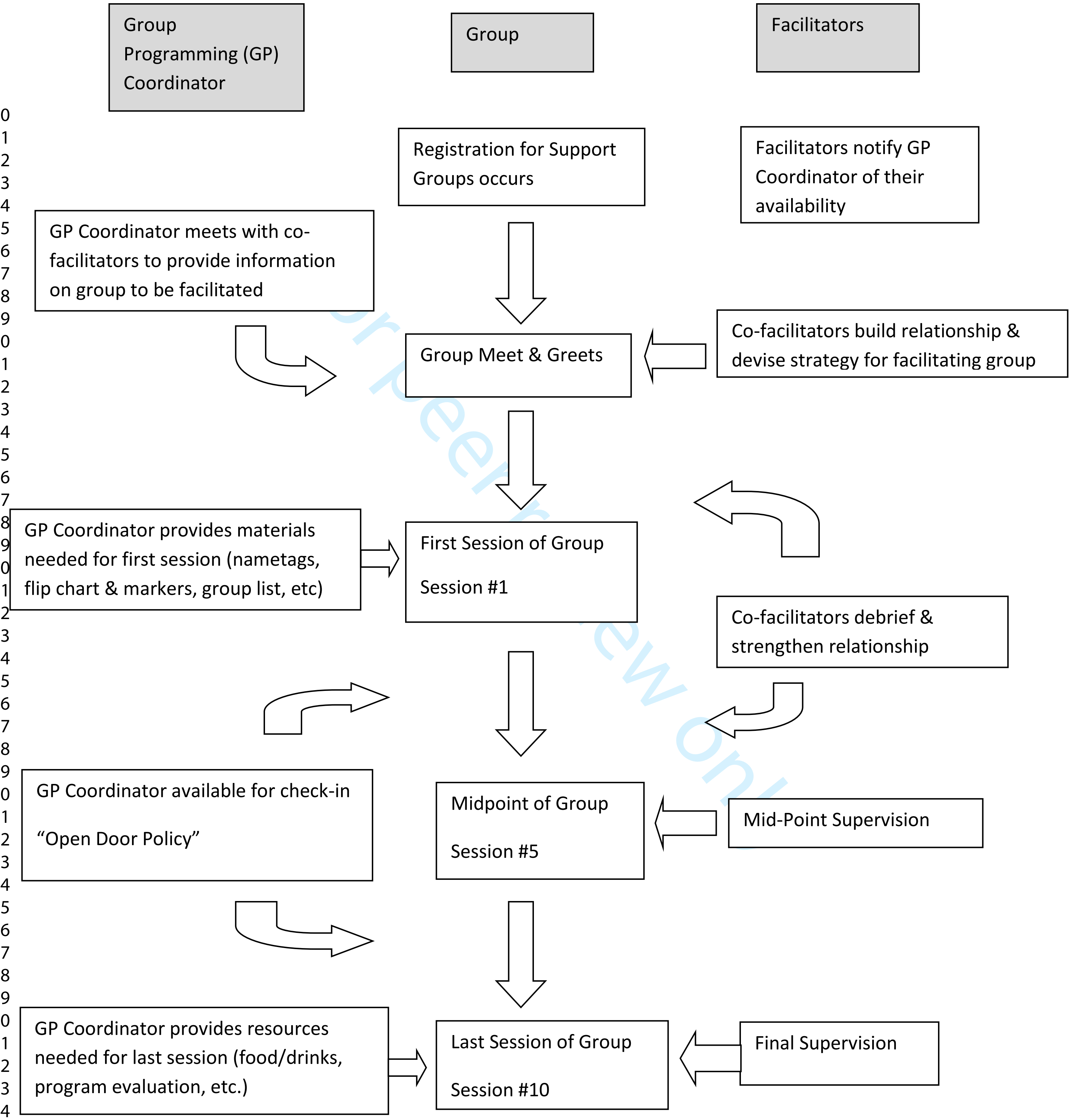
- Volunteer facilitators meet with the Group Programming Coordinator on a regular basis while the group they are facilitating is in progress. The Group Programming Coordinator is also available outside of regularly scheduled supervision meetings for consultation and problem solving regarding any issues that may arise during the course of their work.

- Facilitators of short-term groups will have supervision meetings with the Group Programming Coordinator at the middle (4-6 week mark) and end (after last session) of the group.

- Facilitators of on-going groups will informally check in with the Group Programming Coordinator on a regular basis and will have supervision meetings approximately quarterly.

8. Boundaries
    - Gifts
    - Relationships with group members

TIMELINE OF A SHORT-TERM ACT SUPPORT GROUP



“MEET & GREETS”

“Meet & Greets” are 15-minute meetings that the group facilitators hold with each participant individually before the first group session. Social group work theory has a term for this process: Role Induction.

“Meet & Greets” are not an assessment of the group participant’s eligibility to be part of the group. That assessment has already been completed by ACT’s Group Programming Coordinator.

“Meet & Greets” are an opportunity for the group facilitators to introduce themselves to each group participant. The purpose of this meeting is to discuss the roles of group participant and group facilitator, the process of the group, and how the group participant could feel safe in a support group setting.

Possible discussion topics during group “Meet & Greets”:

Group processes:
- Check in — how it works, why it’s done
- Where do discussion topics come from?
- Importance of group norms
- Timing — start & end times, breaks
- Calling in for absences

Group communication:
- Listening
- Sharing the air/taking turns talking
- Giving advice to fellow group members vs. sharing and relating personal experiences — "I statements"

Group philosophies:
- Talking about feelings/emotions is encouraged
- Respect for differences is expected
- Goals: exchange of information, support, ideas

Role of facilitators:
- Facilitating discussion among group members
- Focus on process, not content of discussion
- Do not provide all of the answers
- Do provide resources, referrals on where to look for information and encourage group members to do the same

Role of Group Programming Coordinator (distribute cards):
- Withdrawal from group
- Concerns/questions related to this or other programming

MEET & GREET QUESTIONNAIRE (SAMPLE)

Monday Evening Support Group

Monday October 19 – Monday December 21, 2009

Facilitators' Names, Ext. 408

Have you ever participated in a support group before? If YES, what was the experience like for you? If NO, how did you come to choose to participate in a support group?

What appeals to you about this group?

What are three things you hope to get out of this group?

1)

2)

3)

What can we as facilitators do to help you achieve your goals and make you feel that your participation in this group was a success?

Are there any worries or concerns you have about participating in this group?

Are there any specific issues or topics you would like to have addressed in this group?

Do you have any questions for us?

Support Group Session Report (SAMPLE)

Group:	**Session #:**
Facilitators:	**Date:**
Topic:	**Guest Speaker:**
Members present:	**Members absent:**

Topics/issues covered in this session:

Are there any issues or concerns that arose in this session?

Comment on this session's group process – what worked well, what difficulties arose, conflict between group members, connections between group members, facilitation issues, etc.:

Are there any resources your group needs?

Are you encountering any situations which could be addressed through further training opportunities (skills and/or information-based)?

Volunteer Support Group Facilitator Supervision (SAMPLE)

Volunteer Name: ____

Supervisor Name: ____

Date of Supervision: ____

Current Volunteer Status: ______________________________________

Areas of Strength **Areas of Potential Growth**

Part One: Volunteer Feedback (To be completed by the volunteer)

What I am doing well as a facilitator: 1. 2. 3.	What concerns/wishes I have for myself as a facilitator: 1. 2. 3.
What works well for me about the support group program: 1. 2.	What concerns/wishes I have about the support group program: 1. 2.

Part Two: Supervisor Feedback (To be completed by the Group Programming Coordinator)

What I see you doing well as facilitator: 1. 2.	My wishes for you as a facilitator are: 1. 2.

3.	3.
Training and Professional Development Opportunities Completed: 1. 2.	Training and Professional Development Opportunities Recommended: 1. 2.

Part Three: Comments (to be completed during supervision)

Volunteer Signature: ____

Group Programming Coordinator Signature:_________________________________

Date & Time of Next Supervision: ____

APPENDICES

- SUGGESTED READINGS
- FACILITATOR TOOL BOX

SUGGESTED READINGS

There are lots of books and articles about groups, group process, and group skills. Here are a few resources worth checking out:

Irvin D. Yalom, *The Theory and Practice of Group Psychotherapy*. 4th ed. Basic Books. New York, 1995.

Although this book is about psychotherapy groups, it is an excellent source of information, much of which can be appropriately modified to suit support groups. Yalom is widely considered to be the authority on group psychotherapy, but he has a definite psychoanalytic bias. If you are not a fan of psychoanalysis, prepare yourself for a provocative read!

Lawrence Shulman, *The Skills of Helping Individuals and Groups*. PE. Peacock Publishers Inc. U.S.A., 1984. (There may be newer editions)

This is a great book with clear, usable descriptions of various communication skills and group work. Lots of 'case' examples help to illustrate skills and theories.

David W. Johnson and Prank P. Johnson, *Joining Together - Group Theory and Group Skills*. 6th ed. Allyn & Bacon. USA., 1997.

A good overview of group theory and skills with lots of facilitation skill-building exercises.

Harvey J. Bertcher, *Group Participation - Techniques for Leaders and Members*. Sage Publications. USA., 1979.

An oldie but a goodie! Clear, basic descriptions of the skills and tasks related to group work.

Alex Gitterman and Lawrence Shulman, *Mutual Aid Groups and the Life Cycle*. PB. Peacock Publishers Inc. USA., 1986.

The first chapter of this book describes some of the basic theoretical components associated with the Mutual Aid model. Case examples of group work with a variety of populations are presented.

TOOLS AND TIPS FOR SUPPORT GROUP FACILITATORS
"TOOL BOX"

Active listening

- Rephrasing
- Checking out/asking
- Paraphrasing
- Summarizing
- Clarifying
- Open- & closed-ended questions
- Body language/facial expressions
- Helps members to feel heard and understood

Bridging & Connecting

- Pointing out connections between group members
- Summarizing common themes
- Re-engaging the group in discussion
- Reduces isolation and helps to normalize experiences

Working with emotion & reflecting feelings

- Encouraging expression and exploration
- Respecting personal boundaries
- Listening for feeling words
- Naming the feelings and clarifying, then putting it to the group

Process Comments/Putting it back to the group

- Focusing on the "how" in the group
- Puts the power back to the group

Norms

- Redirects/focuses group
- Reinforces a structure
- Can often help with challenging situations in groups
- Helps to create safety in the group

Check Ins

- Can help to set agenda topics for evening
- Indicator of emotion in the room
- Brings everyone into the "here and now"

Structured Feedback

- Sets a tone for how to talk to each other
- Encourages a strength-based approach by pointing out helpful traits
- Helps members to "own" their words

Closure

- Using regular reminders
- Connecting the group experience to the personal environment
- Supporting/encouraging emotion around loss/closure
- Offers an opportunity to explore "unfinished business"

Working with a Co-Facilitator

- Can help to balance out skills
- Can help if there is a safety or security issue in the space
- Can offer support to each other
- Can offer more attention to the group

the CTN
CIHR Canadian
HIV Trials Network

le Réseau
Réseau canadien
pour les essais VIH des IRSC

UHN

act

St. Michael's
Inspired Care.
Inspiring Science.

PARTICIPANT INFORMATION AND CONSENT FORM

Study Title:	IN HAND - Cognitive remediation group therapy to improve older adults' ability to cope with HIV-Associated Neurocognitive Disorder (HAND): A pilot randomized, controlled trial
Protocol Number:	CTNPT 029
Principal Investigator:	Mr. Andrew D. Eaton, MSW, RSW PhD Candidate & Research Director Factor-Inwentash Faculty of Social Work, University of Toronto 416-978-8895 (Monday to Friday 9am-5pm)
St. Michael's Hospital Investigator:	Dr. Sean B. Rourke, MD, PhD, FCAHS Clinical Neuropsychologist, St. Michael's Hospital Scientist, Li Ka Shing Knowledge Institute Professor of Psychiatry, University of Toronto 416-878-2779 (Monday to Friday 9am-5pm)
Co-Investigator(s):	Dr. Sharon L. Walmsley, Toronto General Research Institute (TGRI) University, Health Network (UHN) Dr. Shelley L. Craig, Factor-Inwentash Faculty of Social Work, University of Toronto Dr. Barbara A. Fallon, Factor-Inwentash Faculty of Social Work, University of Toronto
Study Sponsor:	St. Michael's Hospital
Study Funder:	CIHR Canadian HIV Trials Network (CTN)
Study Coordinator:	Mr. Alex Wells AIDS Committee of Toronto (ACT) 416-340-8484 ext. 283 (Monday to Friday 9am-5pm)
24-HOUR CONTACT:	(416) 864-5431 (Hospital Locating)

INTRODUCTION

You are being asked to take part in a research study involving group therapy because you are living with HIV-Associated Neurological Disorder (HAND), more specifically, Mild Neurocognitive Disorder (MND).

Before deciding to take part in this study, it is important that you read and understand the following explanation about the study and its risks and benefits. Participation is voluntary. Please ask the study investigator or study staff to explain any words you don't understand. If you have any questions please ask a study investigator or study staff for more information. If you wish to take part in this study, you will be asked to sign this form.

If the study doctor is also your treating doctor, this will be discussed with you.

Please take time to read the following information carefully and if you wish discuss it with your family, friends, and doctor before you decide.

BACKGROUND

Approximately half of the aging HIV-positive population will be affected by HAND. People with HAND can experience memory impairment and issues with processing new information, problem solving and decision making. With the development, access to, and early initiation of modern antiretroviral therapy (ART), HAND is less severe and less common than it once was. However, people who were treated with old therapies, ones that were less effective and with higher rates of toxicity compared to current regimens, or who experienced AIDS defining illnesses, may be affected by HAND more frequently and more severely.

In the general aging population Mindfulness-Based Stress Reduction (MBSR) and brain training activities (BTA) have been shown to decrease stress and depression and improve coping and quality of life. Mindfulness-Based Stress Reduction (MBSR) involves meditation and breathing exercises. Brain training activities (BTA) involve practice with games on computers and mobile devices that are designed to help improve memory, attention, and organizational skills. These types of therapies can vary widely they have not been fully tested in people aging with HAND.

In this study we will explore the use of cognitive remediation group therapy (CRGT) in aging HIV-positive adults affected by Mild Neurocognitive Disorder. CRGT will combine Mindfulness-Based Stress Reduction (MBSR) and brain training activities (BTA) in a group setting.

PURPOSE OF THE STUDY

The purpose of this research study is to determine if it is possible to conduct cognitive remediation group therapy (CRGT) in older HIV-positive adults living with mild-to-moderate HAND and if this type of therapy is acceptable. Researchers will compare this experimental group therapy to the standard of care group therapy that is available to persons living with HIV. As part of the study researchers will also evaluate if there are any changes in your stress, anxiety, and coping from the beginning to the end of the research study.

If you agree to take part in this study you will be one of approximately 16 participants recruited from St. Michael's Hospital.

WHO CAN TAKE PART IN THE STUDY

You may be able to participate in this study if:

- You are aged 40 or older

- You have received a documented HAND diagnosis of MND
- You have been living with HIV for 5 or more years
- You provided consent to St. Michael's Hospital to be contacted for future research studies
- You are available to attend 10 weeks of group therapy in downtown Toronto

You will not be eligible to participate in this study if:

- You have been diagnosed with another significant psychiatric condition (i.e. schizophrenia, bipolar disorder, etc.) and/or past traumatic brain injury
- You have a documented HAND diagnosis of asymptomatic neurocognitive impairment (ANI) or HIV-associated dementia (HAD)
- You have active intravenous or crystal meth drug use
- You have been hospitalized within the past month
- You are unable to communicate in English
- You are unable to use a tablet
- You are currently participating in another HAND, or mindfulness treatment study

DESIGN OF THE STUDY

If you are eligible to take part in this study you will be randomized, which means you will be selected by chance (like a flip of a coin) to one of two therapy groups described below. The randomization for this study is in a 1:1 ratio, which means you will have an equal chance of being in either group. There will be approximately 8 participants in each group.

Participants in each group will be asked to attend 10 weekly 3-hour group therapy sessions:

Group A: (Experimental Cognitive remediation group therapy)

If you are assigned to Group A your group therapy sessions will be led by a Mindfulness-Based Stress Reduction (MBSR)-certified social worker and a peer (person aging with HIV) at Toronto General Hospital. For about one hour you will complete brain training exercises on a tablet using PositScience software by BrainHQ. Study participants will support each other working through these activities. For about two hours you will take part in mindfulness-based stress reduction activities such as meditation and breathing exercises. This type of therapy is research and is not the standard of care for persons living with HIV-Associated Neurological Disorder (HAND).

Group B: (Active Control-Living with HIV Support Group Therapy)

If you are assigned to Group B your therapy sessions will be led by a certified social worker at the AIDS Committee of Toronto (ACT). This group involves peer-based discussion on the effects of living with HIV, with topics determined by the group in the meeting. This is the standard care therapy for persons living with HIV.

DURATION OF THE STUDY

The total length of your participation in the study will be about 6 months. There will be a screening period (to confirm your eligibility to take part in this study) which may last 1 to 2 weeks. Once you are confirmed to be eligible to take part in this study you will attend a baseline visit to complete a study questionnaire. After all the participants in the study have been enrolled you will be randomized to one of the two therapy groups and you will be asked to meet with the group facilitator and then attend 10 therapy sessions once a week for 10 weeks. At the end of the therapy sessions you will visit the study center for follow-up at about one week after the therapy sessions end and again about 3 months later.

STUDY PROCEDURES

Screening Visit (30 minutes)

Once you have agreed to take part in the study and signed the informed consent form study staff will ask you about:

- Your demographic information, medical history and alcohol/drug use
- Any changes in your cognition (memory, problem solving, coping) since your last clinic visit
- Your preferred schedule to attend a 10-week group therapy program
- Your access to a mobile device (i.e., smartphone, tablet) for the purpose of using brain training games from PositScience by BrainHQ.

After the screening visit study staff will access your patient chart at St. Michaels Hospital to collect information about your medical history, medications and clinic visits to see if you meet the specific requirements to be in the study. Your demographics (age, ethnicity, gender etc.) will also be collected from your patient chart.

If you meet the study entry criteria you will be asked to visit the study center for a baseline visit.

Baseline Visit (40 minutes)

At this visit you will be asked to complete a study questionnaire that asks about your emotions and thoughts surrounding living with HIV and HAND. This survey will be completed on a computer but if you prefer you can complete it on paper. Study staff will be available to help you with any questions you do not understand.

Group Assignment (Randomization)

Once all the study participants have been enrolled in the study you will be randomly assigned to one of the two therapy groups:

Group A: Experimental Cognitive Remediation Group Therapy **or**
Group B: Active Control-Living with HIV Support Group Therapy (standard of care group therapy)

Facilitator Meeting (20 minutes)

After you have been assigned to a group you will be asked to meet with your group facilitator before the therapy sessions begins. The facilitator will give you more information on what to expect at the therapy sessions.

Therapy Sessions (Visit 1-10, 3 hours each)

You will be asked to attend 10 group therapy sessions for 10 weeks in a row. Each session will last about 3 hours. This is a total of 30 hours of group therapy.

Visit 5 and 10 Questionnaires (10 minutes each)

At the end of therapy sessions 5 and 10 you will also be asked to complete a questionnaire about your satisfaction with the session's length, content and facilitators. This will be completed on paper.

Follow-up Visit (40 minutes)

You will be asked to visit the study center 1-2 weeks after the group therapy sessions have ended. At this visit you will be asked to complete a study questionnaire that asks about your emotions and thoughts surrounding living with HIV and HAND. This is the same questionnaire that you completed at the baseline visit. This survey will be completed on a computer but if you prefer you can complete it on paper. Study staff will be available to help explain any questions you do not understand. This visit will take about 40 minutes to complete.

End of Study Visit (40 minutes)
You will be asked to visit the study center about 3 months after the follow-up visit. At this visit you will be asked to complete a study questionnaire that asks about your emotions and thoughts surrounding living with HIV and HAND. This is the same questionnaire that you completed at the baseline and follow-up visits. This survey will be completed on a computer but if you prefer you can complete it on paper. Study staff will be available to help explain any questions you do not understand.

After this, you will have finished all of the study visits and your participation in the study will be completed.

POTENTIAL HARMS AND DISCOMFORTS

We do not think you will be harmed in any way during this study, but there is a chance that you could find some parts of the study uncomfortable.

- You may feel anxious, upset or sad when answering questions or completing questionnaires. You are not required to answer any questions that make you feel uncomfortable.
- During the group therapy you will be asked some personal questions about your experiences with HIV and HAND. We need to ask these questions for the study to understand the impact of the program, and what could be done better in the future. This may make you experience discomfort, anxiety, and/or unease from disclosing sensitive information about yourself to other participants during the group therapy.

If you have any concerns about your feelings during the study please contact the study team and they can direct you to the appropriate support service. You can also follow-up with your social worker or other health care professional.

There is potential for research participants/group members to expose sensitive information about the group and/or other group members. Research participants/group members will be asked during the consent process and throughout the group therapy sessions to maintain the confidentiality of the group, however group members are not bound by professional obligations to maintain the confidentiality of the group. Facilitators are bound by professional obligations to maintain the confidentiality of the group. Research participants/group members will be advised to practice some caution before sharing personal and sensitive information. All participants will only be referred to by a first name, and will be offered the possibility of using a pseudonym (false name) in the group.

POTENTIAL BENEFITS

We do not know whether being in this study will benefit you. It is possible that you may learn new skills that may help you cope with HAND but this is not certain.

This is a “pilot study” which is done to test the study plan and to find out whether enough participants will join a larger study and accept the study procedures. The results may be used as a guide for larger studies, although there is no guarantee that they will be conducted. Knowledge gained from pilot studies may be used to develop future studies that may benefit others.

ALTERNATIVES TO PARTICIPATION

You do not have to join this study to receive services related to HAND. If you decide not to take part in this study you will still be able to receive any standard of care treatment you are already receiving, or are due to receive.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this study is voluntary. You may withdraw from this study at any time without giving reasons. Your decision will not affect your or your family's ability to receive medical care at St. Michael's Hospital or any of the other study sites, and you will not lose any benefits to which you are otherwise entitled.

The study investigator may also stop your participation in the study without your consent if it is in your best interest or if you do not follow the requirements of the study. If you are asked to leave the study, the reasons for this will be explained to you and you will have the opportunity to ask questions about this decision.

The data you provide up to the point of withdrawal may still be used in the analysis. No further information will be collected from you.

NEW INFORMATION

If any new information becomes available during the study that could affect your willingness to continue to participate, it will be supplied to you.

COSTS TO PARTICIPATION AND COMPENSATION

There will be no cost to you for taking part in this study. You will not be paid for your participation in this study. However, you will be provided with a maximum of $300 in compensation for your time and travel. Compensation will be provided according to the following schedule:

- $20 for attending the Screening Visit
- $20 for attending the Baseline Visit
- $20 for attending the Facilitator Meeting
- $20 for attending each therapy session (10 sessions x $20 = $200)
- $20 for completing the Follow-up Visit
- $20 for completing the End of Study Visit

RIGHTS AS A PARTICIPANT

If you are harmed as a result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

PROTECTING YOUR HEALTH INFORMATION: PRIVACY AND CONFIDENTIALITY

If you agree to join this study, the study investigator and his/her study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your

- Name and age
- Address
- Hospital ID,
- Date of birth,
- New or Existing medical records, including types, dates and results of medical tests or procedures

All persons involved in the study, including the study investigators, coordinators, nurses and delegates (hereby referred to as "study personnel"), are committed to respecting your privacy. No other persons will have access to your personal health information or identifying information without your consent, unless required by law. The study personnel and the study sponsor will make every effort to keep your personal health information private and confidential in accordance with all applicable privacy legislations, including the Personal Health Information Protection Act (PHIPA) of Ontario.

The following groups or people may come to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

- University Health Network (the study sponsor) or its representative
- Representatives of St Michaels Hospital and University Health Network Research Ethics Boards

Any personal identifying information (such as your name) will be "de-identified" by replacing your personal identifying information with a "study number". This number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will be available to St. Michael's Hospital investigator Dr. Sean Rourke and the study staff. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

Your coded study data will be sent to and accessed by study personnel at the AIDS Committee of Toronto (ACT), University Health Network (UHN), and the CIHR Canadian HIV Trials Network (CTN). This data will not include your name or address, date of birth or any information that directly identifies you. To protect your privacy, data will be password protected and access to study data will be limited to authorized persons and transmission of the data will be encrypted.

The data collected for this study will not be part of your medical record, however your participation in this study may be recorded in your medical record. You have the right to review your personal data and request changes if not correct. However, access to your study data during the study may be limited if it weakens the integrity of the study.

All study data will be kept in a locked and secure area by the study investigator. Electronic files will be stored securely on the hospital network. Study data will be kept for 7 years after the end of the study at which time paper study documents will be shredded and electronic data will be destroyed.

STUDY REGISTRATION AND RESULTS

A description of this clinical trial will be available on http://www.hivnet.ubc.ca/clinical-trials/ctnpt-029/, as required. This website will not include information that can identify you. At most, the Website will include a summary of the results. You can search this Website at any time.

The study results may be published in medical literature or presented at conferences, seminars or other public forums, but you will not be identified by name or any other identifying information.

COMMUNICATION WITH YOUR FAMILY DOCTOR OR SPECIALIST

If you consent, we will be informing your primary treating doctor and/or specialist of your study participation. We will send your primary physician and/or specialist a letter which will include a brief summary of the study so they can provide proper medical care.

RESEARCH ETHICS BOARD CONTACT

If you have questions regarding your rights as a research participant, you may contact the Director, Sharon Freitag, Research Ethics, St. Michael's Hospital, at 416-864-6060 ext. 2385 during business hours.

This research project and information and consent form have been reviewed and approved by the Research Ethics Board (REB) at St. Michael's Hospital. The REB is a group of scientists, medical staff, individuals from other backgrounds (including law and ethics), as well as members from the community. The committee is established by the hospital to review studies for their scientific and ethical merit. The Board pays special attention to the potential harms and benefits involved in participation to the research participant, as well as the potential benefit to society. This group is also required to do periodic review on ongoing research studies. As part of this review, someone may contact you from the REB to discuss your experience in the research study.

STUDY CONTACTS AND EMERGENCY CONTACT

If you have any questions about this study at any time, or if you experience a research-related injury, you should contact:

Principal Investigator:	Mr. Andrew Eaton 416-978-8895 / andrew.eaton@utoronto.ca
St. Michael's Investigator:	Dr. Sean Rourke 416-878-2779 / sean.rourke@utoronto.ca
Research Coordinator:	Mr. Alex Wells 416-340-8484, ext. 283 / awells@actoronto.ca

STATEMENT OF CONSENT

Study Title: IN HAND - Cognitive remediation group therapy to improve older adults' ability to cope with HIV-Associated Neurocognitive Disorder (HAND): A pilot randomized, controlled trial

This research study has been explained to me, and my questions have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I have the right not to participate and the right to withdraw without affecting the quality of medical care at St. Michael's Hospital for me and for other members of my family. As well, the potential harms and benefits (if any) of participating in this research study have been explained to me.

I have been told that I have not waived my legal rights nor released the study investigators, study sponsor, or involved institutions from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. I have been told that records relating to me and my care will be kept confidential and that no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

Consent to notify primary care physician (s) or specialist(s) of your participation in this study This is not a consent to release medical information.

Initial: ______ Yes, I want the study investigator to advise my primary care physician(s) or specialist(s) of my participation in this study.

Initial: ______ No, I do not want the study investigator to advise my primary care physician(s) or specialist(s) of my participation in this study.

Consent to participate in the study
I hereby consent to participate in this study. I have been told I will be given a copy of this signed consent form.

Participant's Name (Print)	Participant's Signature	Date [MM/DD/YYYY]

I have explained the study to the above-named participant. I have explained the nature and purpose, the potential benefits, and possible risks associated with participation in this research study. I have answered all questions that have been raised about the study.

Name and Position of Person Obtaining Consent (Print)	Signature of Person Obtaining Consent	Date [MM/DD/YYYY]

APPENDIX A (Study Visit Schedule)

Visit Details	**Screening Period**			**Study Period**			**Follow-up Period**	
Visit Name	Screening Call	Screening Visit	Baseline Visit	Orientation	Sessions 1-7	Sessions 4 & 8	Follow-up Visit	End of Study Visit
Visit #	-3	-3	-1	0	1,2,3,4,6,7	4 & 8	9	10
Week #			-1	0-8			9	21
Day #	-56 to -7 days		-7	0-56			63	153
Day Window	+/- 7	+/- 7	+/- 7	+/- 7	+/- 0	+/- 0	+/- 7	+/- 7
Procedures								
Informed Consent		X						
Entry Criteria Assessment	X	X						
Chart Abstraction (demographics)		X						
Randomization			X[1]					
Group Sessions				X[2]	X	X		
Facilitator Session Reports					X	X		
Helping Characteristics of Self-Help and Support Groups Measure						X		
HIV/AIDS Stress Scale			X				X	X
Anxiety in Cognitive Impairment and Dementia Scale			X				X	X
Coping Self-efficacy of Health Problems Scale			X				X	X
Five Facet Mindfulness Questionnaire – Short Form			X				X	X

[1] To occur once all participants have been enrolled and eligibility confirmed

[2] Acquaintance with group only; no therapy will be administered during this session

Inclusion/Exclusion Criteria Confirmation

Inclusion Criteria	Yes	No
1) Participant Age ≥40	☐	☐
2) ≥5 years living with HIV	☐	☐
3) MND (Mild Neurocognitive Disorder) diagnosis	☐	☐
4) Consented to future contact for research from St. Michael's Hospital	☐	☐
5) Can attend 8 weeks of group therapy in downtown Toronto	☐	☐
If # **No** ≥1, cannot enroll into study	☐	☐

Exclusion Criteria	Yes	No
1) ANI / HAD diagnosis	☐	☐
2) Hospitalization within past 30 days	☐	☐
3) Inability to communicate in English	☐	☐
4) Cannot use a tablet	☐	☐
5) Would be disruptive to a group setting		
If # **Yes** ≥1, cannot enroll into study	☐	☐

If participant does not meet Inclusion/Exclusion Criteria, Please specify #: ___________________________

*If **OTHER** Please specify ____ If eligible, proceed with ICF Process. After ICF is signed, continue to 3.*

2. Participant Availability (Mark when typically available)

May-June 2018

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
9:00 AM – 12:00 PM	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*
12:00 PM – 3:00 PM	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*
3:00 PM – 6:00 PM	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*
6:00 PM – 9:00 PM	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*

Fall 2018 (August-December)

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
9:00 AM – 12:00 PM	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*	*9:00 AM – 12:00 PM*
12:00 PM – 3:00 PM	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*	*12:00 PM – 3:00 PM*
3:00 PM – 6:00 PM	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*	*3:00 PM – 6:00 PM*
6:00 PM – 9:00 PM	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*	*6:00 PM – 9:00 PM*

Times unavailable in Spring or Fall: ____

4. **Mobile Device Access**

Do you have access to the following mobile devices?

Computer	Yes	No
Tablet	Yes	No
Smartphone	Yes	No

IN HAND
Cognitive remediation group therapy to improve older adults' ability to cope with HIV-Associated Neurocognitive Disorder (HAND): A pilot randomized, controlled trial

Questionnaire: Baseline Visit, Post-Intervention, 3-month Follow-up

Participant ID: ______________ Date: ______________

Hi there, I'm a study coordinator with the IN HAND research study. I have some questions about your emotions and thoughts surrounding HIV and HAND- your experiences with stress, anxiety, and coping. I'm going to ask you some survey-like questions, some yes or no, some on a scale of 0-4, and some on a scale from 1-5. You can choose not to answer any question, and we can pause, or stop the questionnaire at any time you like.

Would you like to begin?

HIV/AIDS Stress Scale

Below is a list of problems that people living with HIV sometimes have. For each question, there are two examples to describe the problem. Your own examples may differ from the ones provided, so long as they seem to fit within the problem category. Please circle a number to the right of each question that best describes how troublesome that problem has been for you during the past month.

How much were you troubled by:	Not at all	A bit (once or twice in the past month)	Moderate (once or twice a week for the past month)	A lot (three to six times a week for the past month)	Extreme (daily)
1. **Distressing emotions related to HIV** (e.g., you feel angry or fearful; you feel anxious or depressed)	0	1	2	3	4
2. **Relationship difficulties related to HIV** (e.g., you have arguments with your support person about how to best care for your health; you have difficulty establishing a relationship)	0	1	2	3	4
3. **Grief/bereavement related to HIV** (e.g., you are concerned about your own losses such as loss of independence; you are grieving for the loss of a loved one from AIDS)	0	1	2	3	4

4. **Confidentiality/privacy concerns related to HIV** (e.g., you are concerned about your HIV status breached; you are reluctant to disclose your status to others)	0	1	2	3	4
5. **Sexual difficulties related to HIV** (e.g., you're finding it hard to maintain safe sex behaviours; you are sexually frustrated)	0	1	2	3	4
6. **Difficulties in coming to terms with your HIV status** (e.g., you can't accept that you have HIV; you refuse to even think about HIV)	0	1	2	3	4
7. **Concerns about death related to HIV** (e.g., you are preoccupied with dying; you don't think about the possibility that you may die from HIV)	0	1	2	3	4
8. **Isolation related to HIV** (e.g., you have less contact with others because of HIV; you don't get invited out much now that you have HIV)	0	1	2	3	4
9. **Suicidal thoughts/attempts related to HIV** (e.g., you have thoughts of ending your life; you have actually attempted to end your life)	0	1	2	3	4
10. **Increased drug/alcohol intake related to HIV** (e.g., you use drugs and/or alcohol more now; you are often high or drunk)	0	1	2	3	4
11. **Discrimination/stigma concerns related to HIV** (e.g., you are concerned that you will be discriminated against because of HIV; you feel as if you have not been treated with respect)	0	1	2	3	4
12. **Religious/existential difficulties related to HIV** (e.g., you are having difficulty searching for meaning in your life; you are struggling to make sense of the predicament you are in)	0	1	2	3	4
13. **Overly attentive to bodily functions or changes** (e.g., you are constantly checking for HIV-related symptoms; you are overly attentive to any new physical changes such as appearance of a rash)	0	1	2	3	4
14. **Difficulties in telling others of your HIV status** (e.g., you don't know who, how, or when to tell of your HIV status; you have only told one or two people)	0	1	2	3	4
15. **Boredom related to HIV** (e.g., you are unable to use your free time doing things you would normally enjoy; you often find yourself sitting about doing nothing)	0	1	2	3	4

16. **Difficulty dealing with HIV-related symptoms of illness** (e.g., you often have difficulty dealing with fatigue or nausea; you have pain and physical discomfort most of the time)	0	1	2	3	4
17. **Difficulty in enhancing your health** (e.g., your attempts to maintain adequate nutrition, or a positive mental attitude often are short-lived)	0	1	2	3	4
18. **Difficulty with health care system** (e.g., you have difficulties in getting access to health services such as dentists or home care)	0	1	2	3	4
19. **Difficulties with HIV treatment** (e.g., you have difficulties managing side effects from HIV treatments; you can't adhere to HIV treatment)	0	1	2	3	4
20. **Transport difficulties related to HIV** (e.g., you have difficulty getting appropriate transport to places; public transport is physically demanding)	0	1	2	3	4
21. **Financial difficulties related to HIV** (e.g., you are unable to pay debts; you have problems with superannuation payouts)	0	1	2	3	4
22. **Daily living difficulties related to HIV** (e.g., you can't always do the shopping or cleaning; you can't keep up with the basic day-to-day chores)	0	1	2	3	4
23. **Reducing risk of infection** (e.g., you are preoccupied with thoughts about transmitting HIV to others; you can concerned that some of your behaviours may put others at risk)	0	1	2	3	4
24. **Difficulty in accessing information related to HIV** (e.g., you have received conflicting information on HIV; you can't get adequate treatment information)	0	1	2	3	4
25. **Employment difficulties related to HIV** (e.g., you can't obtain/maintain employment because of illness; you are concerned about work-related stress)	0	1	2	3	4
26. **Legal problems related to HIV** (e.g., you are involved in a legal process; you don't know who to assign power of attorney to)	0	1	2	3	4
27. **Planning difficulties related to HIV** (e.g., uncertaint with your health makes career planning difficult; you don't know whether to start new projects)	0	1	2	3	4

28. **Difficulties with thinking processes related to HIV** (e.g., you forget things more than usual; you can't concentrate as well as usual)	0	1	2	3	4
29. **Dealing with declining health related to HIV** (e.g., you have difficulty in dealing with increasing physical restrictions due to declining health; you have difficulty dealing with the change from being well to having illness)	0	1	2	3	4

Anxiety in Cognitive Impairment and Dementia Scale

Please circle yes or no for the following questions, thinking about the past 24 hours. If you answer yes to the numbered questions, please answer the corresponding letter question below it.

In the past 24 hours:

1. Have you experienced worry? (e.g., about health, memory of cognitive functioning, friends and family, etc.)	yes	no
a. If so, did worrying bother you?	yes	no
2. Have you experienced anxiety? (e.g., about health, memory of cognitive functioning, friends and family, etc.)	yes	no
a. If so, did the anxiety bother you?	yes	no
3. Have you been startled? (e.g., sudden scare, no sense of time and place, etc.)	yes	no
a. If so, did the startle bother you?	yes	no
4. Have you experienced insomnia? (e.g., sleeplessness, etc.)	yes	no
a. If so, did the insomnia bother you?	yes	no
5. Have you experienced irritability? (e.g., low patience, expression of frustration, etc.)	yes	no
a. If so, did the irritability bother you?	yes	no
6. Have you experienced muscle tension?	yes	no
a. If so, did the muscle tension bother you?	yes	no
7. Have you experienced restlessness? (e.g., fidgeting, etc.)	yes	no
a. If so, did the fidgeting bother you?	yes	no
8. Have you experienced fatigue? (e.g., overly tired, not as much energy as normal etc.)	yes	no
a. If so, did the fatigue bother you?	yes	no
9. Have you experienced cardiovascular issues? (e.g., chest pain, etc.)	yes	no

a. If so, did the cardiovascular issues bother you?	yes	no
10. Have you experienced respiratory issues? (e.g., shortness of breath, etc.)	yes	no
a. If so, did the respiratory issues bother you?	yes	no
11. Have you experienced gastrointestinal issues? (e.g., diarrhea, excessive flatulence, etc.)	yes	no
a. If so, did the gastrointestinal issues bother you?	yes	no
12. Have you experienced other somatic issues? (e.g., pain, depression, etc.)	yes	no
a. If so, did the somatic issues bother you?	yes	no
13. Have you experienced any avoidance behaviours? (e.g., denial, not wanting to attend appointments, etc.)	yes	no
a. If so, did the avoidance behaviour bother you?	yes	no

Five Facet Mindfulness Questionnaire – Short Form (FFMQ-SF)

Below is a collection of statements about your everyday experience. Using the 1–5 scale below, please indicate, in the box to the right of each statement, how frequently or infrequently you have had each experience in the last month (or other agreed time period). Please answer according to what really reflects your experience rather than what you think your experience should be.

Never or Very Rarely True **1**	*Not often true* **2**	*Sometimes True Sometimes Not True* **3**	*Often True* **4**	*Very often or Always True* **5**

1	I'm good at finding the words to describe my feelings	*DS*	
2	I can easily put my beliefs, opinions, and expectations into words	*DS*	
3	I watch my feelings without getting carried away by them	*NR*	
4	I tell myself that I shouldn't be feeling the way I'm feeling	*/NJ*	
5	it's hard for me to find the words to describe what I'm thinking	*/DS*	
6	I pay attention to physical experiences, such as the wind in my hair or sun on my face	*OB*	
7	I make judgments about whether my thoughts are good or bad.	*/NJ*	

8	I find it difficult to stay focused on what's happening in the present moment	/AA	
9	when I have distressing thoughts or images, I don't let myself be carried away by them	NR	
10	generally, I pay attention to sounds, such as clocks ticking, birds chirping, or cars passing	OB	
11	when I feel something in my body, it's hard for me to find the right words to describe it	/DS	
12	it seems I am "running on automatic" without much awareness of what I'm doing	/AA	
13	when I have distressing thoughts or images, I feel calm soon after	NR	
14	I tell myself I shouldn't be thinking the way I'm thinking	/NJ	
15	I notice the smells and aromas of things	OB	
16	even when I'm feeling terribly upset, I can find a way to put it into words	DS	
17	I rush through activities without being really attentive to them	/AA	
18	usually when I have distressing thoughts or images I can just notice them without reacting	NR	
19	I think some of my emotions are bad or inappropriate and I shouldn't feel them	/NJ	
20	I notice visual elements in art or nature, such as colors, shapes, textures, or patterns of light and shadow	OB	
21	when I have distressing thoughts or images, I just notice them and let them go	NR	
22	I do jobs or tasks automatically without being aware of what I'm doing	/AA	
23	I find myself doing things without paying attention	/AA	
24	I disapprove of myself when I have illogical ideas	/NJ	

Coping Self-Efficacy Scale of Health Problems

Presented below are 10 statements about you and your state of health. Please read each one of them and express if you totally disagree (column marked with 1), disagree (column marked with 2), agree (column marked with 3), or totally agree (column marked with 4). For each question, circle only one answer from the four mentioned. There are no right or wrong answers; what is important is your opinion, so we ask for your honesty.

Questions	Totally Disagree	Disagree	Agree	Totally Agree
1. I largely believe that the ability to overcome an illness of disease depends on me	1	2	3	4
2. I am a healthy person, and I do not commonly suffer ailments	1	2	3	4
3. The majority of people are in worse health than I am	1	2	3	4
4. I avoid going to health services and I try to solve my health problems by myself	1	2	3	4
5. I feel optimistic about my state of health	1	2	3	4
6. When faced with a health problem, I first think about how I can solve it for myself	1	2	3	4
7. I think that telling others about one's own health problems does not help to overcome them	1	2	3	4
8. I feel happy	1	2	3	4
9. I believe I have problems in my life, but not as many as others	1	2	3	4
10. I have many things to worry about, and health is not a main one	1	2	3	4

Use of Brain Training Activities

Do you currently practice brain training activities on your computer, mobile device, or pen and paper?

Yes No

1. If yes, how frequently do you practice this activities?
   - ○ More than 3 hours per week
   - ○ 1-3 hours per week
   - ○ Less than 1 hour per week

IN HAND – Group Therapy Satisfaction Questionnaire ID: _____ Date:_____

Group Therapy Satisfaction
Sessions #4 and #8

1. Please indicate the degree to which you agree or disagree with the statements below:

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I feel the facilitators remained respectful and non-judgmental.	1	2	3	4	5
I feel the facilitators managed communication well within the group.	1	2	3	4	5
I feel the facilitators maintained a safe environment.	1	2	3	4	5

2. Please read the statements below and circle the number that best indicates your feelings about each statement. For example, if you strongly disagree with a statement, circle "1". If you are neutral, circle "2", and if you strongly agree, circle "5".

	Strongly disagree				Strongly agree
Since I started coming to this group, I have begun to have more faith in my ability to change myself.	1	2	3	4	5
Since I started coming to this group, I have begun to cope much better with my life.	1	2	3	4	5
The group helps me find new coping strategies.	1	2	3	4	5
The group has helped me learn ways of solving my problems.	1	2	3	4	5
The group has helped me find ways of controlling myself.	1	2	3	4	5
The group makes me feel I'm not alone with my difficulties.	1	2	3	4	5
The group takes me out of my loneliness.	1	2	3	4	5
A professional could never understand me the way group members can.	1	2	3	4	5
The group helps me evaluate my coping strategies.	1	2	3	4	5
The group makes me feel I can function as well as anyone else.	1	2	3	4	5
Other group members' knowledge and experience helps me as much as the help I could get from professionals.	1	2	3	4	5
I share my life experiences with other members of the group.	1	2	3	4	5

IN HAND – Group Therapy Satisfaction Questionnaire ID: _____ Date:_____

I share my troubles with other members of the group.	1	2	3	4	5
Members of the group disclose personal and intimate details of their lives.	1	2	3	4	5
The group helps me to release tension.	1	2	3	4	5
I contribute my own knowledge and experience to the other members.	1	2	3	4	5
I help the members of the group a lot through my own knowledge and experience.	1	2	3	4	5
The knowledge and experience I acquired as a result of my situation contribute to the group at least the same as the knowledge of a professional.	1	2	3	4	5
When something bothers me, members of the group treat me kindly.	1	2	3	4	5
Group members care about each other.	1	2	3	4	5
I give group members “tips” on how to cope with daily situations.	1	2	3	4	5
The group offers me “tips” on how to cope with daily situations.	1	2	3	4	5

3. **How did you feel about the size of the group?**
   ☐ Too many people ☐ Too few people ☐ Just right

4. **Overall, how did you feel about the length of each group session (3 hours)?**
   ☐ Too short ☐ Too long ☐ Just right
   a) Any other comments about group size and/or session length?

5. **Is there anything else you would like to tell us about working within a group?**

SPIRIT

STANDARD PROTOCOL ITEMS: RECOMMENDATIONS FOR INTERVENTIONAL TRIALS

SPIRIT 2013 Checklist: Recommended items to address in a clinical trial protocol and related documents*

Section/item	Item No	Description	Reported on Page
Administrative information			
Title	1	Descriptive title identifying the study design, population, interventions, and, if applicable, trial acronym	1
Trial registration	2a	Trial identifier and registry name. If not yet registered, name of intended registry	11
	2b	All items from the World Health Organization Trial Registration Data Set	See registry
Protocol version	3	Date and version identifier	See registry
Funding	4	Sources and types of financial, material, and other support	12-13
Roles and responsibilities	5a	Names, affiliations, and roles of protocol contributors	12
	5b	Name and contact information for the trial sponsor	12-13
	5c	Role of study sponsor and funders, if any, in study design; collection, management, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication, including whether they will have ultimate authority over any of these activities	12-13
	5d	Composition, roles, and responsibilities of the coordinating centre, steering committee, endpoint adjudication committee, data management team, and other individuals or groups overseeing the trial, if applicable (see Item 21a for data monitoring committee)	11
Introduction			
Background and rationale	6a	Description of research question and justification for undertaking the trial, including summary of relevant studies (published and unpublished) examining benefits and harms for each intervention	4-5
	6b	Explanation for choice of comparators	5
Objectives	7	Specific objectives or hypotheses	5

Trial design	8	Description of trial design including type of trial (eg, parallel group, crossover, factorial, single group), allocation ratio, and framework (eg, superiority, equivalence, noninferiority, exploratory)	5
Methods: Participants, interventions, and outcomes			
Study setting	9	Description of study settings (eg, community clinic, academic hospital) and list of countries where data will be collected. Reference to where list of study sites can be obtained	5
Eligibility criteria	10	Inclusion and exclusion criteria for participants. If applicable, eligibility criteria for study centres and individuals who will perform the interventions (eg, surgeons, psychotherapists)	6-7
Interventions	11a	Interventions for each group with sufficient detail to allow replication, including how and when they will be administered	7
	11b	Criteria for discontinuing or modifying allocated interventions for a given trial participant (eg, drug dose change in response to harms, participant request, or improving/worsening disease)	8
	11c	Strategies to improve adherence to intervention protocols, and any procedures for monitoring adherence (eg, drug tablet return, laboratory tests)	8
	11d	Relevant concomitant care and interventions that are permitted or prohibited during the trial	8
Outcomes	12	Primary, secondary, and other outcomes, including the specific measurement variable (eg, systolic blood pressure), analysis metric (eg, change from baseline, final value, time to event), method of aggregation (eg, median, proportion), and time point for each outcome. Explanation of the clinical relevance of chosen efficacy and harm outcomes is strongly recommended	8-9
Participant timeline	13	Time schedule of enrolment, interventions (including any run-ins and washouts), assessments, and visits for participants. A schematic diagram is highly recommended (see Figure)	9-10
Sample size	14	Estimated number of participants needed to achieve study objectives and how it was determined, including clinical and statistical assumptions supporting any sample size calculations	11
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	11

Methods: Assignment of interventions (for controlled trials)

Allocation:			
Sequence generation	16a	Method of generating the allocation sequence (eg, computer-generated random numbers), and list of any factors for stratification. To reduce predictability of a random sequence, details of any planned restriction (eg, blocking) should be provided in a separate document that is unavailable to those who enrol participants or assign interventions	11
Allocation concealment mechanism	16b	Mechanism of implementing the allocation sequence (eg, central telephone; sequentially numbered, opaque, sealed envelopes), describing any steps to conceal the sequence until interventions are assigned	11
Implementation	16c	Who will generate the allocation sequence, who will enrol participants, and who will assign participants to interventions	11
Blinding (masking)	17a	Who will be blinded after assignment to interventions (eg, trial participants, care providers, outcome assessors, data analysts), and how	11
	17b	If blinded, circumstances under which unblinding is permissible, and procedure for revealing a participant's allocated intervention during the trial	N/A

Methods: Data collection, management, and analysis

Data collection methods	18a	Plans for assessment and collection of outcome, baseline, and other trial data, including any related processes to promote data quality (eg, duplicate measurements, training of assessors) and a description of study instruments (eg, questionnaires, laboratory tests) along with their reliability and validity, if known. Reference to where data collection forms can be found, if not in the protocol	11
	18b	Plans to promote participant retention and complete follow-up, including list of any outcome data to be collected for participants who discontinue or deviate from intervention protocols	12
Data management	19	Plans for data entry, coding, security, and storage, including any related processes to promote data quality (eg, double data entry; range checks for data values). Reference to where details of data management procedures can be found, if not in the protocol	12
Statistical methods	20a	Statistical methods for analysing primary and secondary outcomes. Reference to where other details of the statistical analysis plan can be found, if not in the protocol	12

	20b	Methods for any additional analyses (eg, subgroup and adjusted analyses)	12
	20c	Definition of analysis population relating to protocol non-adherence (eg, as randomised analysis), and any statistical methods to handle missing data (eg, multiple imputation)	12
Methods: Monitoring			
Data monitoring	21a	Composition of data monitoring committee (DMC); summary of its role and reporting structure; statement of whether it is independent from the sponsor and competing interests; and reference to where further details about its charter can be found, if not in the protocol. Alternatively, an explanation of why a DMC is not needed	12
	21b	Description of any interim analyses and stopping guidelines, including who will have access to these interim results and make the final decision to terminate the trial	12
Harms	22	Plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects of trial interventions or trial conduct	12
Auditing	23	Frequency and procedures for auditing trial conduct, if any, and whether the process will be independent from investigators and the sponsor	12
Ethics and dissemination			
Research ethics approval	24	Plans for seeking research ethics committee/institutional review board (REC/IRB) approval	12-13
Protocol amendments	25	Plans for communicating important protocol modifications (eg, changes to eligibility criteria, outcomes, analyses) to relevant parties (eg, investigators, REC/IRBs, trial participants, trial registries, journals, regulators)	13
Consent or assent	26a	Who will obtain informed consent or assent from potential trial participants or authorised surrogates, and how (see Item 32)	9
	26b	Additional consent provisions for collection and use of participant data and biological specimens in ancillary studies, if applicable	N/A
Confidentiality	27	How personal information about potential and enrolled participants will be collected, shared, and maintained in order to protect confidentiality before, during, and after the trial	12
Declaration of interests	28	Financial and other competing interests for principal investigators for the overall trial and each study site	14

Access to data	29	Statement of who will have access to the final trial dataset, and disclosure of contractual agreements that limit such access for investigators	14
Ancillary and post-trial care	30	Provisions, if any, for ancillary and post-trial care, and for compensation to those who suffer harm from trial participation	N/A
Dissemination policy	31a	Plans for investigators and sponsor to communicate trial results to participants, healthcare professionals, the public, and other relevant groups (eg, via publication, reporting in results databases, or other data sharing arrangements), including any publication restrictions	13
	31b	Authorship eligibility guidelines and any intended use of professional writers	N/A
	31c	Plans, if any, for granting public access to the full protocol, participant-level dataset, and statistical code	14
Appendices			
Informed consent materials	32	Model consent form and other related documentation given to participants and authorised surrogates	Suppl file
Biological specimens	33	Plans for collection, laboratory evaluation, and storage of biological specimens for genetic or molecular analysis in the current trial and for future use in ancillary studies, if applicable	N/A

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*It is strongly recommended that this checklist be read in conjunction with the SPIRIT 2013 Explanation & Elaboration for important clarification on the items. Amendments to the protocol should be tracked and dated. The SPIRIT checklist is copyrighted by the SPIRIT Group under the Creative Commons "Attribution-NonCommercial-NoDerivs 3.0 Unported" license.