

Rapid Review Response: The Use of Facilitated Peer Support Group Model for People Living with HIV

Question

- 1) What are the benefits of group interventions for persons living with HIV/AIDS (PHAs), and
- 2) What are best practices in administering group intervention programming for PHAs?

The Issue and Why It's Important

Therapeutic interventions utilizing group dynamics have evolved from basic “group therapy” (guided by a therapist and attended by several clients), to complex group interventions tailored to therapeutic needs and contextual factors (e.g., inpatient vs. outpatient, homogeneous vs. heterogeneous groups, and short vs. long term) (see Appendix 1 for a figure that outlines factors in group dynamics) (1). In the domain of health, group interventions have become increasingly popular for supporting persons affected by illness (2). In their special report series for the “International Journal of Group Psychotherapy” Sherman et al (2004) identify the following benefits of group interventions drawn from the literature:

- They serve as forums for peer support, providing a sense of universalism or shared experience, and an opportunity to learn from others facing similar challenges;
- Participants may derive hope by witnessing others face the challenge of illness with resourcefulness, experience renewed self-worth by helping others who are faring more poorly than they are (e.g., via downward and upward social comparison processes);
- Peer support and modeling also may contribute to new coping resources and self-efficacy, perhaps more effectively than is possible in individual therapy.
- Moreover, groups are often regarded by medical patients as less stigmatizing and by health providers as more cost-effective than individual treatment (3).

While there is growing evidence that group interventions and services are helpful, the effectiveness of interventions throughout the disease trajectory has been less clear (3). Specifically, the following limitations and considerations with respect to the effects of group interventions have been noted:

- few studies have explored the important question of *how* groups support adjustment to illness, and although positive inter-group social comparisons has been associated with improved adjustment to illness, negative inter-group social comparisons have resulted in worsening adjustment (4).
- “self-help groups, support groups, therapy groups and patient instruction groups are used at random, both in practice and in research studies” (2).
- Due to inconsistencies in definition and conceptualization, as well as differences in group design and administration, it is challenging to assess their effectiveness (3, 5).

Key Take Home Messages

- Group Interventions are a popular, effective, and cost effective way of improving psychosocial and even some physiological health outcomes for PHAs (3, 5-9).

- There exist a myriad of group designs, and no standardized intervention or delivery protocol exists for the running of an HIV support group (3, 5). However, cognitive behavioral group therapy has proved especially effective (10).
- Treatment effects are influenced by characteristics of the participants (stage of illness, personal beliefs/values, and demographic characteristics) (5, 11) as well as the intervention design (ability of leader, intervention [cognitive, narrative, etc], and length/number of sessions) (3, 7).
- Unlike primary prevention groups, support groups for PHAs require specialised skills and have not been as widely used in community settings (7, 12).

What we found

Delivery models

Peer Support

Peer support (group facilitator has current or former shared experience) has been used in a variety of illnesses and chronic health conditions; arthritis, diabetes, cardiac health, weight loss, pain management, and HIV (13). The “Centre for Review and Dissemination” have identified five popular models of peer support: one-on-one face-to-face, one-on-one telephone, group face-to-face, group telephone, and group Internet (13). In a systematic review of peer-support programs for people with cancer, Hoey et al (2008) found a high level of satisfaction with the groups, but evidence of psychosocial benefit was mixed (14). In another systematic review focusing on the effects of online peer to peer interactions, Eysenbach et al (2004) report “there is no robust evidence exists of consumer led peer to peer communities, partly because most peer to peer communities have been evaluated only in conjunction with more complex interventions or involvement with health professionals”(15). As with traditional approaches, the variety of peer approaches taken in group design and composition results in different beneficial properties across health indications (13).

Group support and HIV

In their series of special reports, Sherman et al (2004) identify cancer and HIV as the two medical conditions about which there was the most scientifically based information about group interventions (6), with important overlap between the two conditions and opportunities for cross learning (3, 5, 6). The authors note the growing evidence in support of group services, but warn the limited understanding of “which interventions are most effective for participants at which phases in the trajectory of disease has been less clear” (3). In other words, a newly diagnosed individual will have different support needs than someone with advanced symptoms of a disease (see Appendix 2 for a table outline the evidence for group support for participants at different stage of disease)

Brashers, Neidig, and Goldsmith (2004) found support from others helps PHAs manage the uncertainty of illness in a number of ways: (a) assisting with information seeking and avoiding, (b) providing instrumental support, (c) facilitating skill development, (d) giving acceptance or validation, (e) allowing ventilation, and (f) encouraging perspective shifts (16). However, respondents also discussed ways in

which supportive others interfered with uncertainty management and how seeking support imposed personal costs and required developing boundary enforcing strategies (16).

Overall, Wood (2007) identifies three key elements which appear to underlie the successful group effort: Power (peer, non-expert, power sharing model), Context (non-clinical setting), and Creativity (“social worker” using their role in a creative way, encouraging, posing questions, etc) (17).

Peer Support and HIV Group Interventions

While peer-to-peer interventions have become increasingly popular in HIV risk and harm reduction strategies (18-24), existing reviews of support group interventions have focused primarily on professionally facilitated groups (3, 5-8, 12). While several of the independent studies reviewed used peer approaches, they usually served as a co-facilitator alongside a trained therapist (12, 25). A pilot study evaluating peer facilitation amongst Chinese PHAs actually observed an initial worsening of psychological functioning immediately post-intervention, but which improved dramatically at follow-up (26). With respect to training needs, Helgeson, Cohen, Schulz, and Yasko (1999, 2001) [cited in Leszcz et al (2004)] warn that peer support groups can have harmful effects if not well facilitated or if the discussion becomes more emotionally complex than can be managed by the peer facilitator (7). However, Harris (2007) found PHAs reported having benefited differently from professional counselling and peer support services, differentiating between the two by suggesting that “sensitive and personal issues were best explored with a professional counsellor in a one-to-one context, rather than with peer support workers or in a group context” (27). The unique benefits of peer support and group sessions as identified by participants included; reducing feelings of isolation, enhanced social and interpersonal skills, a sense of equality through flattened power hierarchies, and role modeling (27).

Psychotherapy and Group Cognitive Behavioural Therapy

A recent systematic review and meta-analysis examining the efficacy of group psychotherapy treatment among PHAs with depressive symptoms concluded that group psychotherapy is efficacious in reducing depressive symptoms among HIV-infected individuals (9). Most groups for PHAs used brief, structured interventions, usually based on cognitive-behavioural approaches (3), which often results in salient impacts on participants’ coping efforts (8).

Although Group Cognitive Behavioural Therapy (GCBT) has been proven effective, there exists no coherent and evaluated GCBT theory accounting for groups processes and differences (10). As such, Oei and Dingle (2008) argue the following important areas are in need of further research: 1) the applicability of GCBT in minority groups and different cultures; 2) the lack of wide spread use of GCBT by mental health workers in community clinics; 3) the need to have better guidelines for training of the next generation of GCBT at institutional levels; 4) the cost benefit of group over individual psychotherapy needs to be clearly shown and 5) the need to develop a coherent GCBT theory (10).

Benefits of Group Interventions and HIV

HIV Health Outcomes: Evidence suggests that in addition to psychosocial functioning, social support may also buffer or decrease negative health outcomes for PHAs (28). The 2nd in the series of review articles by Sherman et al (2004) explores the literature on professionally-led groups and; immune

activity, neuroendocrine function, and survival among patients with cancer or HIV disease. Overall findings from the literature suggest that group interventions, “particularly those that include training in self-regulation skills, are capable of inducing changes in immune and endocrine activity”(5). While individual results are mixed, “a number of well-designed studies have demonstrated changes in an array of cellular immune and neuroendocrine parameters among patients with cancer or HIV disease” (5). Although the majority of evidence has been collected from adults, young people living with HIV have also benefited from group interventions; with decreased negative perceptions of treatment, and an increased number with undetectable viral load as compared to control groups (29). While benefits of group interventions have been suggested for increased mortality (and slowing of disease progression), few studies in the HIV literature have demonstrated clear links (5).

Additional Benefits of HIV Support Groups: In addition to lowered depression and improved coping strategies (28), group interventions have the additional benefit of resulting in increased uptake of medical services/visits for PHAs (30). Although many PHAs are willing to engage with social support services, they may be less likely to utilize mental health and addictions services due to stigma and perceived and actual access barriers. Support groups can serve as opportunities to integrate focused interventions and connect participants with external services (12, 17, 31). While beneficial, group interventions are one component in “a spectrum of psychosocial services, and they are likely to be most effective when they are integrated with other types of patient care”, including but not limited to: substance abuse disorders; individual therapy; family services; psychopharmacological consultation; and pastoral care (7).

Factors to consider when delivering groups interventions

Treatment Duration and Frequency: Determining the optimal “dose” and timing of interventions for patients with different capacities and preferences remains an important area for further inquiry. In HIV, most of the clinical evaluations focused on short-term groups, ranging from 6 to 24 sessions over the course of 6 to 12 weeks (8). Overall, the literature suggests “structured interventions and less structured, more interactive ones have roughly comparable effects for gay men with asymptomatic or somewhat more advanced HIV disease” (3).

Leszcz et al (2004) suggest adapting the decision making framework developed by Cunningham and Edmonds (1996) for cancer care (7):

- Brief educational classes are directed to newly diagnosed patients; these provide helpful information and require little commitment from participants.
- Short-term psycho-educational groups are offered to patients with greater needs or interests; these are designed to provide support, improve health behaviours, and develop a foundation of coping skills.
- Finally, long-term, less directive therapy groups are available for patients needing or wishing more intensive interventions, particularly those facing the ongoing challenges of advanced disease.

Setting - Most studies of group interventions with PHAs have been conducted in clinical settings housed in academic medical centers or teaching hospitals (3). Yet, a recent study found participants attending support groups in non-medical model agencies (77.8%, $n=7$) were significantly more likely to be retained in group (i.e., attend 11 or more sessions) than those at medical model agencies (39.1%, $n=9$) (31). Leszcz et al (2004) recommend “improving strategies for dissemination of effective services from academic institutions to community providers” (7).

Group Leadership: The interventions reviewed were delivered by a range of professionals and trainees, including those with training in psychology, social work, nursing, and psychiatry (with fairly comparable benefits among trained professional leaders) (5). Kalichman, Rompa, and Cage (2005) recommend using “mixed gender teams of co-facilitators for each group, where at least one facilitator is HIV-positive and open about their HIV status” (12).

Effective training for group leaders continues to be debated in the literature, with questions surrounding format of training, layering of complex skills, ecological perspective, evaluation, and group membership requirements for students (see 2004, special issue on training in *The Journal for Specialists in Group Work*) (1). Differentiating between primary prevention and support for PHAs; groups “focusing on adjustment to illness or psychological co-morbidity rather than primary prevention require other areas of clinical proficiency” (7), and “facilitators should be experienced in conducting interactive support groups, as opposed to public health education classes, seminars, and directive drug treatment groups” (12). Again, these are very different undertakings and a lack of effective facilitation can have deleterious effects on group dynamics and outcomes (7).

There are also considerations for HIV group leaders, who may experience “burnout, emotional depletion, or over identification”, and would benefit from “regularly scheduled peer supervision/support, attention to personal limits and therapeutic boundaries, and recognition of and support for normal grieving” (7). Group leaders should also consider effective processes for temporarily remaining themselves from the group (if needed), in ways which will allow the group to continue with a temporary facilitator (32).

Characteristics and Qualities of Group Facilitators Rated by 67 Participants in the Intervention Trial That Tested a Social Cognitive Theory-Based HIV Transmission Risk Reduction Intervention for HIV-Positive Persons (12) *Only items scored positively = or > 80% included.

<ul style="list-style-type: none"> • Able to get group members talking • Understood how the groups should work • Able to adapt to group needs • Capable of fitting in the group • Able to let go of their own agenda • Authentic and genuine • Able to control and manage problems • Appreciated group member life experiences • Open to sharing in group • Willing to maintain eye contact 	<ul style="list-style-type: none"> • Interesting voice and way of saying things • Used humor as part of the group • Understanding and nonjudgmental • Respectful of group members • Aware of differences in the group • Made sure everyone had a chance to talk • Willing to provide direct feedback • Knew about community services • Able to comfort those who were struggling • Followed up on needs that surfaced
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Alternative Service Delivery Formats:

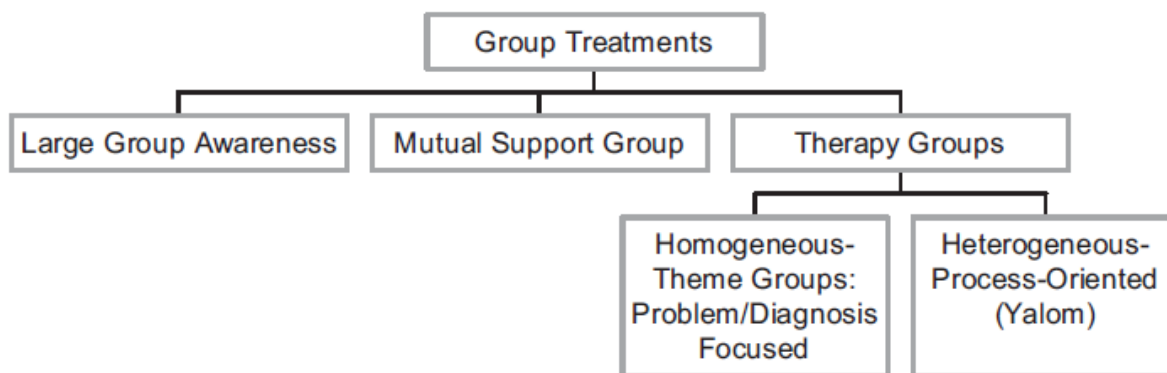
Telephone: In a pilot project assessing the feasibility of a telephone support group intervention for PHAs with haemophilia and their family caregivers, participants reported they had benefitted from sharing information, and that the support group had decreased their feelings of isolation and loneliness (25). Although the use of teleconference technology makes group dynamics more difficult, telephone based groups are an effective strategy to decrease geographic or logistical isolation (33).

Internet-Based: Recent studies have also shown the usefulness of on-line support groups for HIV, with information and emotional and network support being provided between peers (2, 34). Despite what may seem an alienating context, Bar-Lev (2008) argues that by writing detailed descriptions of their illness experiences, “participants in online HIV support groups create emotionally vibrant and empathic communities” (35).

Additional considerations

Although groups comprised of “homogenous” members (with similar symptoms/at similar stages of their illness) are better for creating understanding and support between members, the limitations and constraints of care options and number of available participants may require diverse and mixed groups (7). Ongoing consideration should be given to how group composition may affect participants’ who are at different stages of their illness, so as not to overwhelm or alienate (7).

Group Typologies (1)



(1)

Demographic and Medical Characteristics. In their study of demographic characteristics and perceived barriers to group support, Walch, Roetzer, Minnett (2006) identify attendees of group interventions as predominantly white, male, homosexual/bisexual, diagnosed with HIV within the last five years, had higher educational attainment, and had been diagnosed longer than non-attendees (11). This is supported by the larger body of literature, which indicates group interventions for PHAs have been directed predominantly toward gay men, with attendees being mostly well-educated White or Hispanic men (5).

Personal and Social Factors. The evidence suggests PHAs with varying levels of distress respond differently to group services (5). Although contextual factors affecting PHAs lives (e.g., homophobia, racism) have been taken up in the planning and pilot testing of many interventions, other relevant personality or social factors have received little attention and their role remains unclear (5). Recent groups have attempted to provide specialised care for PHAs presenting with other complex issues, which has been shown to decrease intrusive traumatic stress symptoms for persons who have experienced sexual abuse (36).

* Overall, Sherman et al (2004) argue clinical programs would benefit from following the lead of primary prevention projects, which have done more to “identify and modulate important process variables (e.g., matching of patient and therapist gender, incorporating cultural values) prior to beginning the primary investigation”. As well, they “have done a better job of clearly specifying mediating variables thought to be important (e.g., perceived risk, self-efficacy, sexual communication skills) and measuring these variables over the course of the intervention” (8).

Adherence to the Intervention: Attending group was more consistently associated with positive outcomes in the HIV setting (higher adherence, lower stress, etc) (8).

Factors That May Impact Local Applicability

Jurisdictions studied

Individual studies reviewed were all conducted in western contexts (primarily United States), and English language journals. The reviews used in this summary did not report on country/nation of the

studies, but one identified the lack of inclusion of non-English studies as a gap (3). Jurisdictional issues were presented more in terms of health–care vs. community settings.

Populations Assessed

In the HIV literature, most studies have focused on gay men with early-stage disease, and have not attended to other groups who are overrepresented amongst new infections or “bear a disproportionate burden from this illness (e.g., women, African American and Hispanic patients, adolescents, IV drug users)” (5).

Unlike the prevention group literature, there is less research on diversity amongst people living with HIV and group support interventions (3). Few studies explore interventions with minority ethnic groups (26). Women were nearly absent from group CBT studies (the most common group intervention used) (9), despite benefiting from a range of group services (11, 20, 29-31).

Resources needed

The literature does not identify specific resources needed to provide group interventions, aside from specialized training for group leaders (1). However, additional resources may be needed to support participants (e.g., transportation, childcare, and food at meetings) (17, 37).

A List of Group Resource Guides:

Franciscus A. Hepatitis C: Support Group Manual. San Francisco, CA: Hepatitis C Support Project; 2005. Available on-line: www.hcvadvocates.org

Sarnoff Schiff H. The Support Group Manual: A Session by Session Guide: Penguin; 1996.

Joining People With Diabetes. Support Group Leadership: Training Manual. 2000. Available on-line: www.diabetesinmichigan.org

Health care setting characteristics

Although the majority of studies reviewed in a systemic way were based in university clinical settings, a recommendation identified in the literature is to take these interventions out into the community in an effective manner (7, 31).

What We Did

To identify literature, we hand searched all systematic reviews and protocols from the HIV/AIDS Cochrane review group and the ‘HIV’ and ‘acquired immunodeficiency syndrome’ topic categories on www.health-evidence.ca. We also searched the Cochrane Library, Medline, Embase, Database of Abstracts of Reviews of Effects, CINAHL and Scholars Portal using standardized search terms (HIV AND support group for every database except Scholars Portal for which we used the following terms: Support groups [descriptor] AND (facilitated OR peer) [keywords] AND HIV [keyword]).

After reviewing all the search results we consulted relevant individual studies and systematic reviews of the literature on group interventions for PHAs. In total, we reviewed n=46 articles, which included 5 relevant systematic reviews (9, 10, 13-15) and an especially useful 4 part review series (3, 5-8). The reviews used focused on quantitative evidence gathered from clinical settings, but acknowledged qualitative data as “extremely helpful” in addressing questions of context and process (8). As such, we have included findings and recommendations from the few qualitative studies on the topic. We conducted related articles searches in PubMed using two relevant citations (38, 39).

We excluded studies published before the introduction of Highly Active Retroviral Therapy in 1996 (although such studies are included in the systematic reviews used), and primary prevention group assessments (although considered group interventions, and often evaluated in systematic reviews of group interventions). Although prevention groups are commonly administered in community settings, and have been effectively evaluated for use with diverse populations (8), they do not require the specialized skills needed for therapeutic facilitation, and have different outcome goals than therapeutic interventions with PHAs (7).

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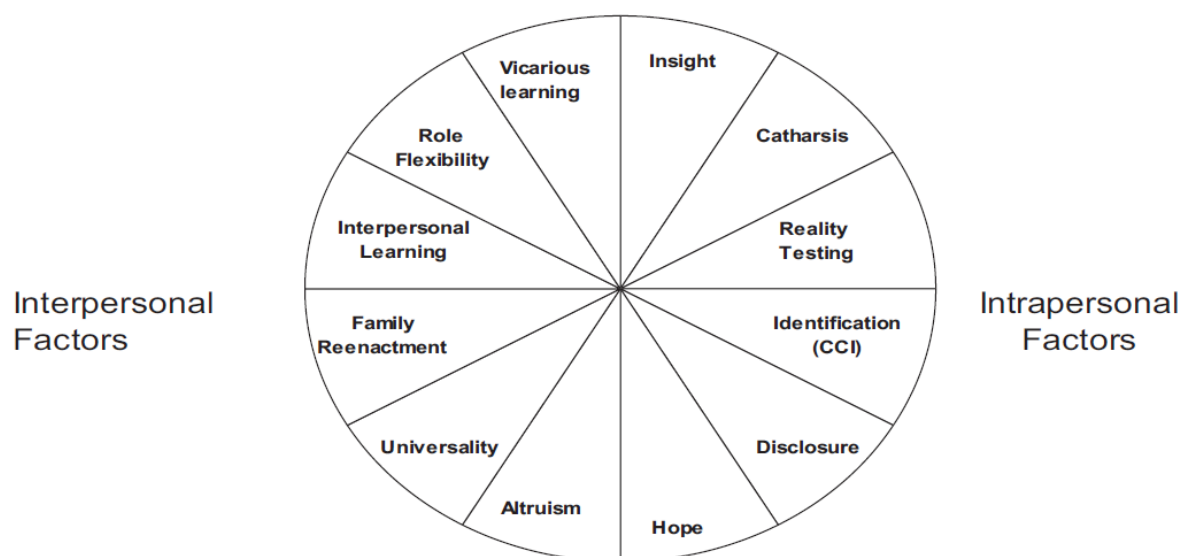
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Appendix 1

Interpersonal and Intrapersonal Therapeutic Factors in Group Dynamics (cohesion, catharsis, and insight) from (1).



Appendix 2: Comparison of evidence for group therapy with participants at different disease stages

<p><i>Adults with Asymptomatic HIV Infection</i></p>	<p>These studies suggest that services may assist homogenous groups of gay men with mild-to-moderate distress in managing the initial crisis of diagnosis and the early stage of asymptomatic infection.</p> <ul style="list-style-type: none"> - the evidence is strongest concerning the value of brief, skills-oriented groups for enhancing adjustment (3).
<p><i>Adults with Advanced Disease</i></p>	<p>HIV-related physical symptoms were reduced in two studies and self-reported healthcare visits were diminished in another investigation. Thus, findings for a number of important outcomes, while limited, are very promising.</p> <ul style="list-style-type: none"> - information is limited concerning group interventions directed exclusively toward patients with AIDS; these services await further study. - for individuals with advanced cancer, on the other hand, the evidence is more compelling for longer-term, existentially oriented, less directive interventions (e.g., supportive-expressive therapy) (3).