

Final Report to CWGHR

Challenging Depression and HIV

Submitted by: The HIV/AIDS Interagency Coalition
On Mental Health

Rationale for the Project

The project arose out of a series of discussions in early 1999 among five service providers and two PHA community members focusing on the mental health needs of people living with HIV/AIDS. The four of the original five service providers that subsequently formed the Coalition for HIV and Mental Health include; the AIDS Committee of Toronto, St. Michael's Hospital HIV Psychiatry Program, The David Kelley HIV/AIDS Community Counselling Program of The Family Service Association and Sunnybrook and Women's College Health Sciences Centre HIV Outpatient Clinic.

The Coalition felt that depression was, and remains, a major factor influencing the coping capacity of a significant number of clients with HIV/AIDS. The psychosocial impact of illness, medication regimes, medication side effects, poverty, isolation and marginalization were all identified as major determinants of mental health. Feelings of powerlessness and helplessness that accompany depression have reduced the ability of many of the clients of the Coalition organizations to engage meaningfully in the world. Rehabilitation efforts cannot hope to succeed unless they address the impact of depression on these clients.

Our aim was to develop a therapeutic response to depression which would specifically address the relationship between the psychosocial context of those living with HIV/AIDS and depression, and which would enhance the ability of depressed clients to engage meaningfully in the world.

Specifically the Coalition's project had the following objectives:

- Identify major determinants of mental health for people living with HIV/AIDS as they relate to depression
- Develop a pilot group program using the social group work model which incorporates the determinants as outlined above
- Deliver 3 co-facilitated groups over a one year period aiming for a total sample size of 36
- Evaluate the efficacy of the treatment model through the use of pre-test and post-test measures of depression and social functioning
- Produce a written manual and research report to permit the export of the model to other HIV/AIDS service providers

Methodology

The project involved the design and delivery of group therapy using the social group work model to address the experience of depression for clients with HIV/AIDS. The project was designed as a collaborative effort of both community and institution-based organizations. Input from people living with HIV/AIDS was integral to the Coalition and was incorporated into all aspects of the project from design development, to delivery and through the ongoing evaluation.

The therapeutic model the Coalition developed incorporated cognitive and skills-building interventions within a social group work model. The content of the group sessions was specifically linked to issues affecting those experiencing depression within the context of HIV/AIDS. These included such issues as; coping with the increasingly unpredictable trajectory of HIV/AIDS, dealing with survival guilt and multiple loss over time, methods of building effective support networks, dealing with the loss of meaning and the difficulty in engaging with the world in meaningful ways in the context of HIV/AIDS.

The Coalition developed and implemented three groups that ran for 20 weeks over the course of this past year. Our initial aim was to include up to 12 participants in each group. However, due to the length of the intake process, we were unable to meet the goal of 12 members in each group while still beginning the group in a timely manner. We elected to initiate the groups when a sufficient number of group members was available to meet, thus reducing our initial sample size estimate from 36 to 31. Each of the groups was co-facilitated by two Coalition members. Each of the facilitators was trained in the social group work model prior to beginning the sessions.

Clients for this project were recruited from a number of different sources. While the groups were designed for HIV positive individuals who suffer from depression, it was not necessary for an individual to have a formal diagnosis of depression in order to take part. While a number of clients were referred by their physician or therapist, many clients were self-referred. Thus, an important element of the intake interview was to determine the severity of depression the individual experienced. In a number of cases, clients were referred by a therapist involved in the study. These individuals were not placed in those groups that were run by their referring therapist.

Throughout the course of our project recruitment notices were sent to a variety of sources. These included the offices of physicians on the AIDS list in Toronto, psychiatrists, counsellors, and psychologists. Advertisements were also printed bi-weekly in two Toronto newspapers, Now and Xtra. Sponsoring agencies posted notices on-site and posters were set up at a local AIDS conference. Handouts were also left in local Doctors offices. Potential clients were asked to contact our research coordinator who set up interview times and explained the initial process for group membership.

In order to determine whether the intervention was appropriate for a client, a formal list of questions was developed for an intake interview. The primary goals of the assessment tool were to determine the severity of depression that the individual experienced as well as to assess the individual's capacity to participate in a group intervention. We also wished to explore with the client the relationship between HIV and depression, as well as gain information on their experience with HIV. A number of exclusion criteria were determined which were felt to affect whether an individual would benefit from the group intervention. These

included active suicidal or homicidal behaviour or ideation, psychosis, substance use as the primary presenting issue, and cognitive impairment or dementia. In addition, individuals were required to have a diagnosis of HIV for greater than one year prior to the intake interview. This was to ensure that the experience of depression was not solely linked to a recent diagnosis. The use of the assessment tool allowed therapists to determine whether an individual should be excluded based on any of these criteria. The interview also allowed therapists to determine whether the individual had adequate social skills to participate in the group and determine whether or not the client had the capacity to engage with the therapist.

Every attempt was made for the interview to be conducted by both of the therapists who would be facilitating the group. This provided the client with an opportunity to meet each therapist. As well it allowed both therapists to assess the client's suitability as a group member. One therapist acted as the primary interviewer while the second therapist took notes. While the assessment tool provided a formal list of specific questions to elicit information from the client, interviews were conducted informally

Interviews typically lasted one hour. In a number of cases, the therapists were uncertain whether the client would benefit from the intervention or be able to participate in the group and a second interview was scheduled for further assessment. If the client was deemed appropriate for the group and agreed to participate, he was asked to meet with the research coordinator who obtained consent for the research study and administered the research questionnaires. The research coordinator also provided an overview of the study, and explained the purpose of conducting the research and what commitment was expected from the participant. If the client chose not to participate in the group, or was deemed by the therapists as not to be suitable for group therapy, suggestions of alternative services were provided. Once the appropriate number of individuals was found, the research coordinator contacted each individual and informed them of the startup date.

Groups ran from the fall of 2000 through to the summer of 2001. Participants completed the Beck Depression Inventory, the MOS-HIV Survey and the Social Support Questionnaire prior to starting the sessions for a baseline, at the end of the group program (20 weeks) and finally three months after the program was completed. Participants were also asked to complete a qualitative survey at the end of the program. This survey enabled participants to identify components of the program that met their needs and areas where they felt the sessions could be improved.

Facilitators met as a group bi-weekly for consultation sessions while group sessions ran from September 2000 through to end of July 2001. These sessions ensured that there was standardization of process among the groups. Facilitators could also provide each other with feedback, encouragement and support. The

meeting also ensured that the social group work model could be reinforced throughout the course of the group sessions.

Results

Group Composition

At the start of the study there were 31 participants. A full 90% of the participants were male despite activities targeted to recruit women. All but two participants completed high school and over 30% also had some form of university education. Two-thirds were not employed at the time of entry into the study. 60% of participants lived alone; the remainder lived with roommates, partners or family. Three quarters of the subjects indicated that they were homosexual, 13% were heterosexual and 10% were bisexual. 80% of subjects were white, the remainder being Asian, Black, Hispanic and East Indian. We did not have a large enough group size to conduct factor analysis to ascertain if any of these components were statistically related to depression.

Subjects were asked about their psychiatric/psychological history. 50% were currently receiving some form of counselling for a mental health concern. Nine participants were taking anti-depressive medications at the start of the sessions.

60% of subjects indicated that they were currently suffering from physical health concerns related to their HIV status. Aside from HIV-related health concerns, forty percent of the participants indicated that they were currently suffering from other health concerns.

One subject indicated that he felt he had a current problem with alcohol use. 40% of participants indicated that they considered themselves to have had alcohol problems in the past. 70% now considered themselves social drinkers, the remainder did not drink at all. Half of the participants drank less than 2.5 drinks per week.

Three subjects felt they had a problem with drugs and eight or 28% felt that they had drug problems in the past.

Over the course of the 20 week sessions a number of participants dropped out. By the end of the program, 20 participants were available to complete the post-test set of questionnaires, however average attendance amongst the sessions was generally higher than 20, for an average of seven or eight individuals per group.

The dropouts did not seem to differ in any discernable way from those who remained until the end of the program in terms of gender, sexual orientation, race or living arrangements. However, they differed in terms of employment, where

91% of those (10 of 11 people) not completing the full 20 sessions were unemployed. We had an even split in employment/unemployment for those that remained for the full 20 sessions. Additionally, 50% of the dropouts considered themselves to have had a past drinking problem, where only 30% of those remaining felt this way. The one individual who had indicated that he was currently suffering from a problem with alcohol dropped out of the sessions. Finally, those individuals remaining for the full 20 weeks were more likely to have a university education than those dropping out of their groups were.

Feedback from Participants on the Process

According to the participants the groups were highly successful. Of the 19 responses, a full 18 felt that the group's discussions and ways of interacting helped them manage their depression. In fact, verbal feedback was excellent and some group members continued to meet months after the group had ended.

What was mentioned most often as beneficial was the provision of coping skills. Participants were taught to recognize triggers such as negative self talk and make use of techniques to aid in stress management and problem solving.

Participants also indicated that the recognition that each individual was not alone in the way they felt as being particularly helpful. Listening to others describe similar feelings and their mechanisms to solve problems made participants realize that they too would get through the depression.

Group members felt the supportive and encouraging environment was a key component to the success of the program. One member noted that it "forced me to confront, empathize, encourage, acknowledge and generally deal with others."

The one participant for whom the sessions were not helpful liked the group and could not find any elements that he would change despite continuing feelings of depression.

Group members felt there were two components of the group experience that made it particularly successful. First, the climate of openness and honesty within the groups ensured that the members could speak freely and feel safe. There was no sense of being judged and naturally discussion within each group was confidential.

The second component of the group that made it helpful was the facilitation. Members credited the facilitators with creating a safe environment for discussion. No less useful was the facilitators' ability to elicit discussion from all members.

We also asked participants what they didn't like about the groups. Most indicated they had no dislikes, however, some individuals indicated that they were uncomfortable with the concept of the group self-directing. As one member

indicated, “I didn’t like the sensation of the group being set free to progress along its own path at its own pace so freely, despite understanding the rationale behind it.” This facet of the group experience was mentioned anecdotally during the course of the sessions. Some group members indicated a preference for stronger direction.

We asked group members what they would have liked more of during the sessions. Many respondents did not provide any feedback. Of those that did, the most frequent response was a greater number of sessions (more than 20). Additionally, several participants felt that the sessions could have been longer than 2 hours.

When asked about topics they would like to have covered, participants indicated; dealing with death, suicide, sexual ethics, more coping skills and information from other professionals in the field. While these topics had been discussed during the group sessions, this may indicate the importance of these issues for our clients.

Quantitative Outcomes

Three quantitative measures were used: the Beck Depression Inventory, the MOS-HIV Survey and the Social Support Questionnaire. Participants completed the scales at baseline, at post-treatment and three months after the sessions ended.

Analysis of the data was conducted using SPSS™. The Beck Depression Inventory (BDI) is scored out of 63 points with 0 indicating no discernable depression. For this scale, we had normal distribution of the data collected at pre, post and three month follow-up. Average scores for the groups ranged from 18 to 28 in week 1, from 11 to 17 at week 20 and 7 to 22 at three month follow-up. Using ANOVA we found no significant differences between the groups at either pre, post or follow-up. Data for all three groups were then combined and a paired T-test was used to analyze the data. We found an average drop of 8.53 points from pre to post-treatment testing. This was considered a significant change in the Beck scores ($t=2.393$, $df=16$, $p<0.05$). Total BDI scores did not change significantly from post treatment to the three month follow-up period ($t=0.515$, $df=12$, $p<0.616$). Therefore, the benefit of treatment was maintained.

The MOS-HIV Scale is comprised of two parameters, the Physical Health summary score and the Mental Health summary score. Each is scored separately on five parameters and aggregated on a 0 to 100-point scale with 100 indicating excellent physical or mental health. On the Physical Health summary score of the MOS-HIV, the data for each group was normally distributed and there were no significant differences between the groups. Average group scores at baseline ranged from 42 to 68 points. Using ANOVA we found that there were no significant differences between the groups. Scores from the groups were then

combined for week 1 and again for week 20 and a paired T-test conducted. We found an average increase of 4.88 points in the scores over the 20 weeks. However, this was not a significant change. From the end of treatment (week 20) to the three month follow-up there continued to be no significant change.

For the MOS-HIV Mental Health summary score, the data was not normally distributed. There were no significant differences between the groups. Data was subsequently log transformed, which corrected the distribution. A paired T-test was performed on the transformed data that showed an average increase of 9.88 points over the course of the sessions. This was considered a significant increase in scores ($t=2.618$, $df=17$, $p<0.018$). This agrees with the Beck Depression Inventory findings. This improvement in Mental Health scores was maintained at three month follow-up ($t=-.304$, $df=13$, $p<0.766$).

Our final scale was the Social Support Questionnaire as modified by Hays. This scale is also measured on two parameters, a numbers scale and a satisfaction scale. On the number scale one simply takes an average of the total number of people that a respondent feels would be supportive of him/her in 12 different situations. On the satisfaction scale one takes an average of the level of satisfaction the respondents feel with the numbers of supportive individuals they have in their lives. This latter score runs from 1 to 4, with 1 being very satisfied.

On the number portion of the Social Support Questionnaire we did not have normal distribution of the data, and therefore we log transformed the data. In addition, there were significant differences between the groups. Consequently we could not aggregate the data from the three groups. We analyzed this data by group using the Wilcoxon Signed Rank Test. The numbers in the groups were very small and consequently not very valuable, however, we found no significant change in the numbers scale over the 20 weeks for any group, or at three month follow-up.

For the satisfaction portion of the Social Support Questionnaire we did have normally distributed data and there were no significant differences between the groups. Scores ranged from 1.8 to 2 between the groups at week 1, decreased over the course of the 20 weeks (respondents felt less satisfied) and there was minimal change at follow-up. We combined scores for all groups and conducted a paired T-test. However, changes were not significant from week 1 to week 20 ($t=-1.292$ $df=11$, $p<0.214$), or from week 20 to three month follow-up ($t=1.063$, $df=11$, $p<0.310$).

Overall our findings lend support to our original hypothesis. The respondents had a change in their mental health over the course of the sessions as supported by significant changes in both the Beck Depression Inventory and the Mental Health summary score of the MOS-HIV. We did not expect to see a change in physical health. We might have expected the groups to feel more social support over the course of the sessions; however, it is likely that the sessions highlighted the

absence of good social support in the lives of the respondents which may have accounted for the scores. At any rate, the social support findings were not significant.

The above analyses were conducted using data from all pre, post and follow-up data that were completed by participants. In addition, we conducted repeated measures ANOVA tests on a cohort of participants who had completed all three data collection points.

Analysis of the BDI scores showed no significant effect for a subgroup of 12 ($F=2.057$, $df=2,10$, $p<0.179$). The Mental Health summary score of the MOS-HIV survey (log transformed score) were not significant for a subgroup of 14 ($F=1.985$, $df=2,12$, $p<0.180$). The Physical Health summary score of the MOS-HIV survey did not show a significant effect for a subgroup of 14 ($F=0.450$, $df=2,12$, $p<0.648$). On the numbers portion of the Social Support Questionnaire (log transformed), there was a trend, but not significant effect for a subgroup of 11 ($F=3.277$, $df=2,9$, $p<0.085$). For the satisfaction portion of the Social Support Questionnaire (log transformed), no significant effect was found for a subgroup of 12 participants ($F=0.819$, $df=2,10$, $p<0.468$).

In sum, no measure showed a significant difference across time when the smaller cohort (participants who had scores at all three time points) was examined. The loss of power in the data analysis results from having a much smaller cohort.

Our results are in no way definitive. We cannot say that it was our sessions that caused the change in scores because we did not strictly control for such factors as starting antidepressant medications or beginning individual counseling during the course of the sessions. Notwithstanding these factors, we were conducting pilot research and these results give us confidence to go forward with more rigorous research.

Evaluation

Our Coalition feels that this project was a tremendous success. Not only were the desired results achieved, but this project also led to the development of a strong service delivery team from individuals working at various agencies, institutions and from the PHA community; to our knowledge the first such grouping in Toronto. The Coalition provided an opportunity to enhance skill sets of members through sharing and training. Members were able to expand their peer-support system. Most importantly, they were able to develop both community-based research skills and an enthusiasm for the research process, which they will carry forward into future projects.

This project would not have been successful without two key elements. First, we had strongly committed volunteer members in the Coalition. This commitment extended over the years of planning through project execution and evaluation. One of the volunteers was a co-facilitator for training members in the social group work model utilized in the project, leading the bi-weekly consultation sessions and providing expertise and encouragement for other Coalition members in use of the model. Several volunteers also facilitated groups, lending time and support to a lengthy intake process and 20 weeks of sessions, in addition to the consultation and administration meetings. Our project would not have been possible without their unrelenting commitment and the Coalition is indebted to these individuals.

The second key factor in the project's success was the enormous support of the community agencies in providing in-kind contributions to ensure the project could move forward with a limited budget. Rooms were provided for free for all meetings and group sessions. Office space and equipment was provided for the research coordinator. In-house expertise was freely supplied for developing advertisements for the group and for the layout of the manual. Advertising space was provided for free. These are all elements we would have been unable to pay for and the Coalition recognizes that this project would not have been possible had this support not been provided.

In our evaluation phase we reviewed the project stages and discussed elements within each that we felt were particularly important to both the successful completion of the project, and which were found to be challenging in retrospect and we would change in future endeavors.

Our planning stage was incredibly lengthy. Initial discussions regarding the need for service delivery for persons with HIV/AIDS suffering from depression began in March of 1999. Time was needed to coalesce and build trust as a group. Once the opportunity for funding arose, the group was able to rely on its strong cohesion to modify the project as a research project and move forward. However, had the group not already been through the formation stages there undoubtedly would have been further delays.

Being new to community-based research, the coalition did not anticipate the time involved in the ethics review process. As Coalition members were drawn from two Toronto teaching hospitals, ethics approval was required from each. This process took over a year and obviously delayed start up of the project. While ethics review will still be required for future projects, familiarity with the process might shorten this phase in the future.

Recruitment took slightly longer than originally anticipated. This was more likely due to our unfamiliarity with the recruitment process leading to an underestimation of the time involved to complete this component. The one facet of recruitment that the Coalition would try to modify in the future was the difficulty

accessing marginalized HIV/AIDS groups. Participants were predominantly white males. Only three of the original thirty participants were women. While the recruiting process included service organizations and therapists who might have access to marginalized groups, it appears evident that this was not an effective method for recruitment in these cases. Perhaps holding smaller groups under the umbrella of organizations directly accessing individuals within those groups might be an effective mechanism of recruitment in the future.

The intake process for group members, as described under the methods section of this report, was lengthy. Despite this, Coalition members felt that the intake interviews were of an appropriate length and necessary to ensure that prospective clients would benefit from the group process.

The service delivery aspects of this project ran very smoothly. The consultation process was considered to be vital to the success of the groups. As previously mentioned, service delivery was contingent on the provision of rooms and office space at no cost to the Coalition.

Our dropout rate throughout the sessions was one third of participants, from 31 to 20. It should be noted that throughout the twenty weeks, individuals in each of the three groups would often miss one or two sessions. Members were only considered a dropout if they failed to attend the final session wherein they would complete the second series of questionnaires.

The feedback from our participants, as discussed in the Results section above, indicates that the Coalition was successful in meeting the needs of the clients. Feedback was uniformly positive and there were no suggestions for modifications to the process aside from lengthening individual sessions and holding sessions for more than twenty weeks.

Overall, the Coalition members were enthusiastic about the project and more than satisfied with the process and the outcomes. Their introduction to community-based research was so positive that a subcommittee was formed to consider moving from the pilot project to further formal research on the efficacy of the therapeutic model. Several aspects of the research were highlighted for consideration in future projects. The Coalition felt that a reassessment of the outcome measures used would be in order. While they felt that the measures were suitable for this first research project, it was felt that a measure of resiliency in subjects pre and post sessions would be useful. However, it was also noted that the Coalition requires research expertise in order to move forward and will actively seek out a member with this skill set for future projects. Since the completion of the pilot project, the coalition has welcomed two additional organizations to its membership. Casey House and The Riverdale Hospital are committed to both working towards improved and innovative service delivery and to ongoing research into this area.

The Coalition will definitely move forward in three areas; continued service delivery building on the success of this project, highlighting continued need for mental health services for HIV/AIDS clients, and continued research on the model and dissemination of the results and materials developed for this project.

Meeting the CWGHR Priorities

The Challenging Depression and HIV project met each of the priorities for CWGHR-funded projects. The project fell into two of the priority areas as identified by CWGHR, the Treatments and Complementary Therapies area and the Physical, Psychological and Social Issues area.

This project represents an advance in the field of HIV rehabilitation through research on the provision of group therapy in the treatment of depression in individuals suffering from HIV/AIDS. To our knowledge, within Toronto, there are few facilities providing this much needed service to the HIV/AIDS community. Often service is provided individually. However, given that social isolation may be a factor of and a catalyst for further depression, a group therapy represents a step forward in treatment. Our pilot research project results give us confidence that this approach shows promise to be successful in decreasing the feelings of depression in individuals and empowering them in making changes from a position of hope and an internal locus of control.

The project addressed a practical rehabilitation issue for clients as depression is experienced by a significant number of HIV/AIDS clients seeking services. In total we interviewed nearly 60 individuals for this project over 4 months who either self-referred or were encouraged to join by their therapist. As a comparison this represents over 80% of the total support group population of one of the community agencies involved. This implies the magnitude of depression, whether formally diagnosed or not, within the HIV/AIDS population and highlights the need for this type of rehabilitative service.

As previously discussed, this project involved, and continues to involve, individuals with HIV/AIDS in all project stages, from design to dissemination of findings. These individuals have also generously *donated* their time, energy and expertise to this project. Further service delivery and continued research would not be possible without their continued assistance, nor would the success of this original project.

This project was conceptualized, designed, implemented and evaluated by a Coalition comprised of individuals from community agencies, hospitals and individuals from the PHA community. This allowed us to bring together individuals with shared interests and skills in order to provide service where a gap had been identified, as well as to capitalize on the breadth of ideas,

expertise and resources that a diverse group can bring. The effort to bring together community members and service providers from institutions and community organizations is a unique initiative and can serve as a national model.

Our project promotes access to and information about rehabilitation opportunities for people living with HIV/AIDS through the dissemination of the manual, which will familiarize other service providers with the concepts and information needed to provide group services themselves. In addition, we hope to have our research published, which will broaden access to information regarding this project and might serve as a catalyst for similar studies.

The Challenging Depression and HIV project places interventions in HIV in the context of broader social and systemic issues in illness, disability and rehabilitation. It addressed the relationship between the psychosocial context of those living with HIV/AIDS and depression and ultimately enhanced the ability of depressed clients to engage meaningfully with the world.

Dissemination of Project Information

The Coalition intends to disseminate the results of this project through a variety of avenues. We will 'launch' the manual and project results at a community forum in the greater Toronto area.

Nationally, we will be sending an executive summary of the project/manual to AIDS service providers. The full manual will be made available to any organization that is interested in more specific details.

Coalition members would also like to attend various conferences and symposia to discuss the project as time and individual resources permit. Ideas include the CASS Skills Building Workshop and the American Association of Advancement of Social Work with Groups conference.

The Coalition has formed a subcommittee that will deal exclusively with the dissemination of the project results as well as act as a contact resource for service providers who might require further information and advice.

The group also hopes to develop materials that deal with the successful formation of the HIV/AIDS Interagency Coalition on Mental Health, including writing of papers and presentations. We feel that this was a vital component of the success of the project and that our experiences, including lessons learned through the process, will assist other groups forming such alliances.

