Group Work with People with ARC: A Conceptual Framework

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In developing a conceptual model for doing group work with people with AIDS Related Complex (ARC), it is important to identify the biases inherent in the approaches we use. At the UCSF AIDS Health Project, we combine a cognitive/behavioral educational support group format with a brief therapy, problem-solving orientation. This model was developed during three years of experience working primarily with gay-identified men, 20 to 50 years of age, who are HIV seropositive and have symptoms related to HIV infection. As other populations (for example, heterosexuals, women, ethnic minority groups, I.V. drug users) develop ARC and are affected by the AIDS epidemic, models should be developed to meet their specific needs.

Within the grey zone of uncertainty surrounding ARC, our approach emphasizes the importance of self-definition of illness and wellness, the multi-dimensional quality of health, and the need to develop coping skills within an educationally oriented and socially supportive atmosphere.

Group Services

The literature suggests that psychological states play an important role in an individual’s sense of well-being, and that social support and stress may be important modulators of physical illness. Drawing on previous experience and knowledge gained from the medical self-help movement and cognitive behavioral psychology, we use a short-term group model as well as a drop-in format to help people with ARC learn to cope with their illness.

After an individual psychosocial assessment, clients are referred to the group that best meets their needs. The 8-session ARC group is comprised of 8 to 12 participants. Each weekly two-hour session includes didactic and experiential learning. The ARC drop-in group follows the format:

- **(1)** immediate service for people awaiting an 8-session group.
- **(2)** adjunctive services to individuals requiring more than once-a-week intervention.
- **(3)** “as needed” support for people who due to their illness are unable to commit to an 8-session group.

Clients with major psychiatric disorders and/or addictions to substances are referred to other community resources.

The objectives of the ARC groups include:

1. providing education regarding the bio-psychosocial aspects of ARC,
2. improving stress management, coping, and communication skills, and
3. expanding the individual’s social support and use of community resources.

Each session includes announcements, a brief stress management exercise, structured check-in, presentation of educational material, discussion and processing. The session ends with a longer exercise implementing relaxation, guided imagery, and visualization.

**We learn that ... what is required is the authentic presence of the facilitator and that what we get back from clients is more than what we give.**

The ARC drop-in group follows a similar format, although the participants determine the focus of each session by reacting to the check-in process. The drop-in group differs also in that there is no intake or screening to enter the group. Additionally, a ten-minute break is included prior to the relaxation and visualization exercise as a means of prompting interaction among members. The facilitators are available for one-half hour after the drop-in group ends to offer brief individual consultations and to provide information and referral services. Depending on the size of the group and differing issues, the group has the option to sub-divide and then reintegrate. The size of the group has varied from 8 to 18 people.

In the 8-session group the following themes become the focus of each session:

- **Week 1** - introduction and ground rules and a discussion of “what is ARC?”;
- **Week 2** - coping with stress;
- **Week 3** - coping with depression;
- **Week 4** - coping with anger;
- **Week 5** - sexual issues;
- **Week 6** - relationship issues;
- **Week 7** - planning for the future;
- **Week 8** - review, closure, and termination.

The following psychological criteria are used as general guidelines for appropriate referrals to ARC groups: non-psychotic, non-suicidal, non-acting out, not currently addicted to abusing substances, and motivation for participation in the group. We recommend that people with ARC be under the medical care of a physician and that people with ARC who have severe symptoms be involved in individual therapy.

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I.V. Drug User...

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Over the past two years, several cities in the U.S., Western Europe, and Australia have initiated outreach projects for I.V. drug users. Many of these efforts incorporate active participation of former I.V. users responsible for delivering specific AIDS prevention messages in an accurate, credible, and ongoing fashion. The impact of these projects to date has been extremely promising, but the long-range effects of such interventions will not be felt for some time.

The HERO Outreach Program
In early 1986 the Maryland Drug Abuse Administration provided funding to the Health Education Resource Organization (HERO) to operate in Baltimore a five month pilot project targeted at active I.V. drug abusers not in treatment. (HERO is the primary AIDS prevention organization for the Baltimore metropolitan area). The Street Outreach AIDS Prevention (SOAP) project was designed to reduce the spread of HIV within this population using indigenous, ex-addict community health educators. Due to the uncertain feasibility of such a program in a city like Baltimore, HERO conducted an evaluation of the outreach effort in cooperation with the Harvard School of Public Health under the supervision of William McAuliffe, Ph.D. Program areas under study included recruitment and training methods, the likelihood for drug relapse by workers if they are continually placed in a high-risk environment, the impact of such an intervention on active addicts, and the community's willingness to endorse such efforts.

SOAP selected outreach workers according to specific criteria including knowledge of the streets and drug culture, interpersonal communication skills, length of time in treatment, and the recommendations of treatment counselors. Seven prospective workers attended a two-day orientation and training session conducted by HERO and the state Drug Abuse Administration. Upon completion, four of the seven participants began a four-week "internship" period as SOAP outreach workers to test their education skills on the streets under the close supervision of the project's director.

Each day for one month teams of two or three outreach workers canvassed selected sites. The project director (a social worker with extensive drug treatment experience) and the outreach workers selected target areas known for their high drug use activity. Such sources often relied on inside reports about the frequency, amount, and quality of the drugs available as well as the level of police surveillance. The intent was both to disseminate AIDS prevention information to integrate workers into the neighborhood, thus increasing their level of acceptance and credibility.

SOAP workers used a variety of educational techniques in their outreach efforts. In addition to providing literature and posters to neighborhood businesses and organizations serving the target population, the "ten minute AIDS rap" became the hallmark of the project. On street corners, in store fronts, at bus stops, and in doorways, SOAP workers would approach passers-by with a prepared opening statement about AIDS and engage them in a brief personalized risk assessment and risk reduction lesson. The intervention would then conclude with the distribution of both educational literature and condom samples.

Program Evaluation
SOAP workers interviewed one or two users each day before providing them with any information to determine the level of baseline knowledge on the street. One month later outreach workers conducted follow-up phone interviews with those who offered their names and phone numbers. Eighty-three percent of all individuals were re-interviewed.

The study found that the use of indigenous outreach workers is an extremely operational and cost-effective educational technique. Proper selection, training, and supervision of the workers were noted as the most significant contributions to the success of the project. The pre- and post-survey of participants' AIDS knowledge indicated significant improvements in awareness. Although measures of behavior change were positive, differences did not prove statistically significant.

Recommendations from the study team included:
1) expanding the program to match better the scope of the drug problem in Baltimore,
2) intensifying the impact of the intervention by increasing the number of visits to an area and offering small bottles of bleach with instructions for cleaning needles,
3) performing periodic serologic testing of addicts to determine better the impact of behavioral changes on seropositivity rates, and
4) expanding the level of community networking performed by the program staff to augment available resources.

Program Administration
At present the SOAP project still operates according to its original model while successfully incorporating some of the recommendations from the evaluation. The project has developed into a comprehensive outreach program with strong community linkages. The program director oversees all administrative management of the program's staff and activities. An outreach team leader (a member of the original outreach worker staff) is responsible for supervising four full-time outreach workers while a case manager assigned to the program responds to requests for social case work and counseling services by the ever-increasing pool of addicts in need of AIDS-related services.

In addition to the monthly street contacts, outreach workers have been invited to conduct educational presentations to clients awaiting intake in a number of drug treatment programs in the area. This has become so popular that weekly scheduled presentations are now provided, allowing AIDS risk awareness to begin early in the treatment process. In addition, outreach to adolescents at risk has been begun via regularly scheduled educational presentations and "fun days" sponsored at local community centers that serve this population.

Concerned about the risk of infection and transmission for prostitutes, outreach staff have also conducted several "Women's Health Days" in areas of high activity. Services offered include blood pressure screening, breast examinations, pap smears, anonymous antibody testing and counseling, as well as information and condom distribution. These programs have proven extremely popular and are now scheduled regularly.

Indications of Success
Since the initiation of the special outreach programs in 1986, HERO has learned several lessons about how to intervene effectively with I.V. drug users. These can be summarized as follows:
1) As innovative interventions continue to be developed, professionals must re-evaluate their attitudes regarding addicts' ability to change behaviors in the face of the AIDS epidemic;
2) Similar to the response observed within the gay community, active participation of individuals with I.V. drug use as a risk factor is an important aspect of successful AIDS prevention messages among I.V. drug users. In addition to the extremely positive response by addicts to the outreach workers, the responsibility assumed by the outreach workers themselves has had a profound
Diagnosis/Treatment/Prevention

Group Interventions for AIDS Prevention: An Evaluation

Jeffrey Moulton, PhD, David Sweet, MA, Gamze Gurbuz, BA, and James W. Dilley, MD

The urgency of the AIDS epidemic has precluded a systematic evaluation of prevention programs that appear to serve the needs of people with HIV infection and of the “worried well.” Yet evaluation is a necessary component of any successful health promotion effort. Already health officials around the world—convinced now that something must be done about HIV transmission—have posed the basic questions that all AIDS prevention programs must face: “Does AIDS education work, and, if so, what works best?”

The AIDS Health Project of San Francisco has developed a model group program for AIDS prevention and risk reduction. The program involves an eight-week educational support group format designed for participants in three different areas of concern: support for people with ARC, “hot and healthy sex,” and “transitions” or developing the means to cope with the ongoing AIDS epidemic. Reported here are the preliminary results of an outcome evaluation of these group interventions conducted during the past year.

During the evaluation period 160 consecutive gay and bisexual male clients participated in the above three group formats. A mental health clinician led each of the groups of 10 to 12 individuals over an eight-week period. Group members completed pre- and post-intervention questionnaires which considered the following variables: psychological distress, knowledge of AIDS risk activities, social support, coping skills, current mental health needs, alcohol and drug use, and sexual practices. The respondents represented a group of largely white (87%), gay men in their mid-30s who were knowledgeable about their antibody status or the current status of their health. More than one quarter of the respondents were HIV antibody positive; another one quarter had been diagnosed with ARC. More than one third did not know their antibody status, and the remaining individuals (11%) reported a seronegative status.

Effect on Sexual Practices

Prior to the intervention we asked the respondents about the extent to which they engaged in high- and low-risk sexual practices in the past year. Approximately 60% reported “almost always” or “always” engaging in safe sex activities. Slightly more than 30% said they practiced safe sex “seldom” or “half the time.” A small percentage of the men (15%) said they continued with high-risk activities “half the time” to “always.” Nine percent reported abstaining from sex altogether. These data are consistent with other recent studies of change in gay male sexual behavior.

When asked what factors had influenced a compromise of safe sex standards in the previous 12 months, respondents endorsed the following reasons:

a) I lack self-control (40%);
b) I was aroused more than usual (37%);
c) My partner was more of a “turn on” than usual (32%);
d) I was lonely (32%).

Substance use was another reason given, although it was reported to be a less frequent factor. However, drug and alcohol problems were major issues for this group of clients. More than half reported current or past substance use problems as measured by the Michigan Alcohol Screening Test.

Impact on Psychological Distress

Clients reported feeling at high risk for infection with HIV and for progression of infection to clinical manifestations over the next two years. Respondents rated their perceived degree of risk on a scale of one to ten, where one was “no risk,” five was a “50/50 chance,” and ten was “certain to develop AIDS or ARC.” Excluding clients with AIDS or ARC, nearly half rated their chances of developing ARC as a five or greater. Excluding persons with AIDS, two-thirds rated the likelihood of their developing AIDS as greater than five.

Several clients had developed methods for coping with distress before they entered the educational groups. Active behavioral and active cognitive methods correlated positively to a significant degree with reductions in hopelessness. Behavioral coping strategies included improving diets, forming a personal plan of action about AIDS, political activities, and learning more about HIV antibody testing and possible treatments. Cognitive strategies involved thinking about AIDS concerns on a one-day-at-a-time basis, thinking more about the meaning of life, and considering how others in similar situations might be responding. Another important and significant correlate was taking responsibility for maintaining and possibly improving one’s health status.

To assess changes over time in psychological distress, knowledge about AIDS, and risk behavior, we compared pre- and post-intervention scores on our scales. Across all measures of psychological distress, statistically significant reductions occurred at the post-intervention assessment, even for those individuals who had undertaken coping strategies already. For example, we found reductions in hopelessness as measured by the Beck Hopelessness Scale as well as reductions in all sub-scales of the Profile of Mood States measuring depression, confusion, fatigue/inertia, tension, anxiety, and anger/hostility.

No significant increases in the already high level of knowledge about HIV transmission were noted after the intervention. Statistically significant increases in the practice of safe sex and reductions in unsafe sex practices were reported at the post-group assessment.

Summary

Certain methodological issues must be considered when examining this type of evaluation research data. For example, the lack of a control group limits our ability to determine with certainty that changes in distress and behavior are due to the group intervention and not to some other influence. In addition, the data reflect self-reported changes by the participants; it was not possible to determine more objectively whether the group intervention resulted in reductions of HIV transmission or in the development of clinical manifestations.

Preliminary results indicate that the group intervention model studied here is effective in ameliorating psychological distress and in assisting in behavior change and in encouraging health promotion practices. These data and the clinical experience of the AIDS Health Project staff suggest that the majority of these clients need supportive interventions to assist them in maintaining their commitments to HIV risk reduction. A minority of clients may need interventions focused more intensively on the adoption of safe sex behaviors. Most interventions with this population must consider the effect of substance use and abuse on the type of intervention used. An important focus of these groups is the empowerment of participants, teaching active coping methods and encouraging involvement in one's health maintenance.

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BRIEFS

Recent Reports

CDC Revision of Surveillance Definition for AIDS

Following months of discussion, the Centers for Disease Control (CDC) in collaboration with the Council of State and Territorial Epidemiologists has revised the case definition for Acquired Immunodeficiency Syndrome. The need to expand the definition has long been an issue for clinicians who have care for patients who were clinically felt to be people with AIDS but whose symptoms fell outside of the previous case definition. This earlier definition has caused significant social and psychological consequences for individuals who have been denied benefits from Federal, State and local programs because they have not fulfilled the requirements for a diagnosis of AIDS.

The expanded definition will improve this situation and will also: a) more accurately reflect the disabling morbidity associated with HIV infection; b) simplify reporting of AIDS cases; c) improve the sensitivity of diagnosis through greater use of serological tests for HIV (including AIDS antibody and T-cell testing results); and, d) include "presumptively" diagnosed cases (those that are made without confirmed laboratory evidence) of diseases that are indicative of an AIDS condition, e.g., the diagnosis of Kaposi's sarcoma by an experienced clinician without a confirmatory biopsy. (See the August 14, 1987, Morbidity and Mortality Weekly Report (MMWR) Vol. 36, No. 15, for a detailed description of the expanded definition.)

The major changes in the new definition apply to patients with laboratory evidence of HIV infection. Thus, patients who are seropositive and fulfill criteria for HIV encephalopathy, display the HIV wasting syndrome, and/or exhibit one of a broader range of AIDS-indicative diseases, for example, primary lymphoma of the brain, will now be included as AIDS cases according to the expanded guidelines.

The new definition for children differs from that for adults in two ways. First, multiple or recurrent serious bacterial infections and lymphoid interstitial pneumonia/lymphoid hyperplasia are accepted as indicative of AIDS in children but not in adults. Second, for children less than 15 months of age whose mothers are thought to have had HIV infection during the child's pregnancy, the laboratory criteria for HIV infection are more strict. These more stringent criteria are needed because the presence of the antibody in a child 15 months of age or less may simply reflect the persistence of passively acquired maternal antibodies.

The anticipated impact of these changes on the total number of AIDS cases reported is unknown. However, to evaluate the impact of the revised case definition on long-term trends, future data analyses by the CDC will include separate tallies for cases meeting the previous and the revised case definitions.

Guidelines for Facilities Treating Chemically Dependent Patients at Risk for AIDS or Infected by HIV. The AIDs and Chemical Dependency Committee of the American Medical Society on Alcoholism and Other Drug Dependencies (AMSAODD) has prepared guidelines to help staff in chemically dependency treatment programs respond to the needs of patients at risk for AIDS.

1) Provide services that do not discriminate against chemically dependent patients at risk for or infected with HIV.
2) Do not use HIV antibody testing as a screening criterion for admission.
3) Develop a full spectrum of services by working in conjunction with local AIDS/ARC service agencies.
4) Train staff in assessment, counseling, and referral skills specific to the needs of patients at risk for AIDS.
5) Educate staff and chemically dependent patients about AIDS and the risks of transmitting HIV. It is best to do so before admitting the first infected or at-risk patients. Provide education about AIDS, ARC, and HIV testing especially as it relates to chemical use on a regular and continual basis. Provide services to allow staff and patients to deal with their emotional reactions to the presence of people with AIDS and those who are HIV seropositive.
6) Provide counseling about safer sex, high risk behavior, and potential perinatal transfer of HIV.
7) Provide educational and emotional support services to families, close friends, and partners or patients at risk for AIDS.
8) Provide counseling about safer sex, high risk behavior, and potential perinatal transfer of HIV.

Next Month

In the United States and abroad, the rising number of pediatric AIDS cases adds yet another tragedy to the toll of the AIDS epidemic. In the U.S., alone, scientists estimate that by 1991 there may be 10-20,000 infants and children with HIV infection. For developing countries, AIDS threatens to undermine decades of work to establish childhood health programs.

In the November issue of FOCUS, William A. Smith, EDD and Gary B. MacDonald will analyze the impact of HIV infection on these worldwide programs. Dr. Smith is the Executive Vice-President of the Academy for Educational Development (AED), a Washington, D.C.-based non-profit company that has been involved in public health communication in developing countries for the past 25 years. Mr. MacDonald has served as Senior Technical Advisor on AIDS to AED; he formerly was the executive director of the AIDS Action Council in Washington, D.C.

Also in the November issue will be a discussion by Lewis Katoff, PhD of the problems and counseling issues encountered by those who work with children with AIDS and their families. Dr. Katoff is the Director of Client Services for the Gay Men's Health Crisis in New York City.