Support groups have long been one of the most cost-effective services for people living with HIV, and in today's difficult budgetary climate, they have become even more important. This article reviews the data pertaining to the efficacy of support groups for clients with chronic medical problems and the role of support groups in the AIDS epidemic. It relies on the support groups program at the UCSF AIDS Health Project (AHP), one of the oldest in the nation, to show the ways in which group techniques may be applied and may change in response to changes in the epidemic.

Since the 1970s, researchers have accrued data suggesting that "psychological factors themselves could influence survival" both in general and in the context of HIV. Further, there is a consensus among researchers that "the best chance of using psychosocial methods to improve physical health lies in improving quality of life." The effectiveness of groups in providing this psychological support for individuals with life-threatening medical problems is well documented. A recent meta-analysis of group therapy approaches found that the "average recipient of group treatment is better off than 72 percent of untreated controls." In particular, the study found better outcomes for members of groups focused on a specific medical diagnosis versus groups focused on more than one diagnosis. It also found that group members with depression or eating disorders had better outcomes than members with other disorders. Other research has found that group interventions are not only effective but also cost-efficient.

Features of Group Therapy
Irvin Yalom identified 11 potent features of group work. Among these features are: a forum where members can identify with others, thus decreasing isolation; a place to safely and publicly discuss the experience of living with a stigmatized condition; and an opportunity for altruism, enabling a member who offers support and information to another to increase his or her self-esteem.

Groups normalize the experience of living with HIV by enabling participants to identify with other people with HIV, and this experience can offer hope, support, and solace. Groups also approximate a family experience for those HIV-positive clients who have been shunned by or alienated from their biological families or whose families of choice have been decimated by the epidemic.

Support groups for people with HIV integrate a problem-solving and information-sharing component that is often absent from individual therapy. Members can help each other navigate social services bureaucracies, learn to advocate for themselves with a range of providers and insurers, identify new resources, and discuss risks and benefits of medical and alternative treatments. Finally, support groups can effectively respond to psychiatric conditions.

HIV Group History, Themes, and Structures
At the beginning of the epidemic, AIDS support groups were undifferentiated, using the same approach to treat all clients as these individuals confronted a life-threatening illness about which little was known. As a result, support groups addressed a wide range of social and emotional needs. In this era before effective HIV treatment, these groups dealt prominently with themes of dying, death, loss, and grief. Early groups also enabled the mutual exchange of support and information and provided forums for mental health crisis intervention. Many of these groups were volunteer-run; others were facilitated by mental health professionals and incorporated aspects of group therapy. Groups experienced much attrition due to death, and many simply ended.

It became clear that the condition of some people with AIDS progressed rapidly and
By the time this goes to press, it is likely that for the third year in a row, proposed funding cuts will threaten the AIDS Health Project’s support groups, an integral program of the pioneering San Francisco Model for AIDS care. So far, AHP has saved this program from the chopping block by presenting sufficiently compelling evidence to local policy makers that support groups are both cost-efficient and effective in protecting psychological and physical health.

In this issue of FOCUS, two AHP clinicians—Marc Wallis and John Tighe—present some of these arguments. Wallis reviews the history of support groups and some of the evidence that demonstrates their efficacy and value. Tighe recounts the development and evolution of one particular support group, providing an illustration of the ways in which assessment, planning, facilitation, and flexibility combine to serve the needs of clients.

A few months ago, I heard an interview with Louis Menand, the author of The Metaphysical Club, which won the 2002 Pulitzer Prize for history and which recounts the story of a group of 19th century thinkers. At the risk of misrepresented the book, my memory is that one of the club’s members—either William James, John Dewey, or Oliver Wendell Holmes—said that there are no inalienable rights and that individual rights exist only because there is society: we perceive ourselves as individuals only through the reflection of ourselves in others. There are many ways of thinking about these concepts. But at the time I heard the interview, I was thinking about this issue of FOCUS, and Menand’s words struck me as another way of expressing the value of support groups. It struck me that each group itself represents a society through which each participant may derive a sense of him or herself. Participants not only articulate their distresses and capacities, but also experience these aspects of self through the responses of others. I don’t know whether this reflected self is “truer” than the self any of us experiences directly, but it may be no less true, and experiencing it helps uncover aspects of truth that are often clouded by a person’s proximity to him or herself.

All of this may sound abstract, but in the society of a support group, the dynamic helps people deal with all-too-practical challenges such as adhering to medications, responding to the physical effects of disease and treatment, sustaining healthy behaviors, and dealing with isolation. Such a powerful tool deserves to keep the primary place it has in the pantheon of HIV-related interventions.

References


The development of zidovudine (ZDV; AZT) marked the beginning of better HIV treatment. This increased the motivation to get tested, leading to earlier diagnosis, earlier treatment, and longer and healthier lives for people with HIV. Support groups focused less explicitly on death and dying and more on the challenges of dealing with the range of HIV-related conditions and symptoms. This resulted in complex treatment decisions in the face of growing numbers of treatments, treatment side effects, the uncertainty of disease course, and living with HIV and its psychological and physical consequences.

In 1996, significant treatment advances opened up the possibility that HIV might become a chronic and manageable, rather than an acute and life-threatening, illness. Despite the obvious benefits of these advances, many people faced challenges in managing complex medication regimens and side effects, such as peripheral neuropathy and body fat changes, dealing with the possibility of treatment failure, negotiating uncertain but expansive futures including returning to work, and confronting long-delayed grief for friends who had died and for decimated support systems.
By the late 1990s, the broadening HIV client population—ranging from long-term survivors, who without any treatment remained symptom-free, to people for whom treatment had repeatedly failed—represented a broad spectrum of needs. The AIDS Health Project introduced additional specialized groups to address this diversity of needs, including a Considering Work Program in 2000 and Positive Recovery groups in 1999 focusing on substance abuse issues.

Groups have reflected a diversity not only in terms of diagnosis but also in terms of a range of other characteristics, including gender, sexual orientation, race and ethnicity, substance use history, and other factors. If there ever was a "typical person with HIV," there is not now. This increases the importance of assessing needs in particular communities and among particular subpopulations in order to develop specific types of groups. Likewise, sophisticated individual assessment of clients is essential to determine overall service needs as well as to match clients with the most appropriate groups.

Today, groups provide a unique opportunity for clients to experience non-sexual intimacy, identify with others like themselves, and establish community, an experience that is particularly meaningful to people who belong to marginalized communities or who have a history of substance use or psychiatric illness. One former group member described the process by saying: “It wasn’t about being gay. It was about being human. It transcended clichés. It was about being tired of being lonely and wanting a group of people to connect with.”

Different Groups Serve Different Needs

Since it began in 1984, the AIDS Health Project has created some of the longest running programs in the world including 29 groups last year, serving hundreds of clients annually. A review of these groups—many of which are tailored specifically to meet the needs of gay and bisexual men in San Francisco—provides a good overview of the ways in which group interventions might be developed and integrated into HIV-related services.

Today, AHP’s group interventions can be divided into three general types: support groups, psychoeducational groups, and psychotherapy groups. Support groups aim to facilitate the exchange of support and information among participants. Psychoeducational groups focus primarily on the dissemination of information and skills building. Psychotherapy groups, the most internally focused of the three, aim to contextualize the experience of living with HIV within the member’s individual psychology. Therapy groups, however, do incorporate aspects of information sharing, mutual aid, and skills building.

Support Groups. AHP offers a variety of support groups, each facilitated by two volunteers, all of whom have attended a weekend-long facilitator training, and who must attend annual clinical didactic meetings as well as monthly consultation groups to process countertransference reactions and further hone group facilitation skills. While group members often exchange information, the primary aim of support groups is to develop a community among the members.

Support groups are particularly suited to clients who function well in most realms of their lives and are able to interact well with others. The role of the facilitators is to create an atmosphere of respect and emotional safety in which this exchange can occur.

Support group offerings include groups that are limited to 12 weeks and ongoing groups with no time limit, but to which members are required to make a six-month commitment in order to increase group cohesion and minimize disruption. Time-limited groups often function as a testing ground for those with no previous group experience or as a place for people whose schedules may not permit them to commit to an ongoing group. It is notable that a considerable number of clients who complete time-limited groups then seek placement into ongoing support groups. Many members remain in these ongoing groups far beyond the initial six-month commitment, some for as long as 11 years. It is also significant that many volunteer facilitators are members of support groups themselves.

Psychoeducational Groups. Psychoeducational groups—single-event meetings, such as AHP’s annual, day-long “Just for Women” seminar—offer an efficient means of increasing skills and fostering a sense of community. Each psychoeducational group is focused on a particular purpose and is facilitated by professional staff. While these groups do attend to feelings as they arise, uncovering emotions is not their primary emphasis. Given their minimal time requirement, psychoeducational groups are ideal not only for clients who need specific infor-
mation but also for those who are not yet ready to commit to a more interpersonally intensive group experience. For this reason, psychoeducational groups function as a point of contact for many clients who subsequently seek out other HIV-related services.

**Psychotherapy Groups.** Many AIDS Health Project groups combine elements of both support groups and psychoeducational groups, as well as aspects of crisis intervention, existential psychotherapy, and psychodynamic psychotherapy. These groups are facilitated by professional staff, not volunteers, since the demands they place on facilitators are complex and multi-dimensional. Psychotherapy groups vary in length from a drop-in group, which meets for two hours every week, to 12-week groups and ongoing groups, both with closed membership. This continuum of services allows clients to move toward a deeper level of group exchange and helps staff place clients in the most appropriate groups. For instance, attendance at a drop-in group enables staff to assess which type of group would best fit a particular client’s needs.

Psychotherapy groups at AHP are well suited for clients whose complex problems cannot be addressed by a volunteer-facilitated group. This includes people diagnosed with substance abuse, characterological problems such as borderline or narcissistic personality disorders, or severe affective, anxiety, or psychotic disorders. Psychotherapy group facilitators take a more active and central role in the group than do volunteers, setting firm limits, articulating interpretations, using confrontation, assessing psychosocial risk factors, and providing psychoeducation. The complex interplay of clinical tasks requires not only advanced training but also a willingness to be flexible and creative while remaining firm and supportive.

**Designing a Groups Program**

A sophisticated assessment system is a key element of any successful HIV-related groups program. Careful assessment by trained staff is crucial to match the client with the type of group that best suits his or her needs. While AHP clients are welcome to attend drop-in groups without prior assessment, they must be screened by AHP staff in order for them to join short-term or ongoing support or psychotherapy groups. The process begins with an intake interview, during which staff must conclude that a client requesting a support group is psychiatrically stable and able to interact with others with minimal interpersonal distress. Clients with prominent psychiatric or substance abuse issues are typically referred for further assessment by a clinically trained staff member, who decides whether the client is appropriate for a group and for which type of group.

All potential support group clients are finally referred to the coordinator of AHP’s program, who assigns the client to a group of eight to twelve members, based on scheduling concerns and careful attention to group composition issues such as age, stage of illness, and interpersonal style. The program coordinator then contacts each new member to introduce him or her to the program, assures any client anxieties, and makes a final assessment as to the client’s appropriateness for a support group.

**Conclusion**

In an era of increasingly austere social services budgets, support groups are both highly efficacious and cost-effective. Participation offers numerous benefits, particularly to those with serious medical illnesses. While early in the HIV epidemic support groups served many functions, the evolution of the epidemic has resulted in a parallel evolution in the delivery of HIV-related mental health services, including increasingly specialized group interventions. It is essential for HIV agencies to offer a continuum of group interventions in order to address clients with diverse needs.
Support groups—and support group programs—typically evolve over time to meet the changing needs of the populations they serve. The Sex and Sobriety support group, started in 2002 by the UCSF AIDS Health Project’s Risk Evaluation and Counseling for Health (REACH) Program, is a good example of this process. REACH develops prevention interventions for HIV-negative and HIV-positive gay men.

Substance Use and Sex
For some people with substance abuse histories, the prospect of sex can “trigger” drug use; for others, the idea of having sex without drugs is alien or the prospect of getting emotionally close to someone can be daunting. People who are in recovery from substance abuse or otherwise abstaining from use often have a difficult time navigating sexuality while being “clean and sober.” These conflicts, which are at the forefront for individuals struggling to maintain sobriety, are not necessarily addressed in recovery contexts. In fact, people in recovery often report being discouraged by their sponsors from entering romantic relationships, desire naturally persists and can lead to substance use relapse or to discord in a person’s life. Since the concept of group support is such an integral part of the recovery process, it made sense to use the tool of a support group to help people in recovery confront HIV-related risk and directly address the challenges of sex, intimacy, and dating.

The Origins of the Sex and Sobriety Group
The Sex and Sobriety Group was inspired by another REACH support group: Reality Check. A drop-in group for people who use substances, Reality Check has an explicit harm reduction focus. Participants discuss sex and intimacy challenges such as disclosure of HIV status to partners, ways in which sex and intimacy can trigger substance use, and ways in which substance use can lead to HIV-related sexual risk. Reality Check participants who were not actively using, particularly those with extended periods of “clean” time, were concerned about being “triggered” by group members who were using. These clients asked for a group in which they could talk about their concerns with others who were clean and sober. Further, they suggested that a closed rather than a drop-in group would build group cohesion, intimacy, and trust.

The REACH Program’s desire to respond to these clients—by creating the Sex and Sobriety Group—was not unique. Throughout its history, REACH has initiated new groups or changed the format of existing groups in response to various types of issues of sex, and members of 12-step programs are often discouraged by their sponsors from entering romantic relationships during the early stages of sobriety. While abstaining from sex and dating during the early stages of recovery can be valuable, and even essential, this goal is not always realistic. Regardless of whether or not a person chooses to abstain from sex or dating, desire naturally persists and can lead to substance use relapse or to discord in a person’s life. Since the concept of group support is such an integral part of the recovery process, it made sense to use the tool of a support group to help people in recovery confront HIV-related risk and directly address the challenges of sex, intimacy, and dating.

Since group support is such an integral part of recovery, it made particular sense to use the tool of a support group to help people in recovery confront HIV-related risk.
feedback. These include comments from clients, facilitators, and community focus groups, and written evaluations from group participants, as well as analyses of perceived community needs and of changes in the epidemic. Starting any group requires looking at existing group formats and making modifications to fit newly identified needs; for the Sex and Sobriety Group, REACH identified several changes.

Most REACH groups are peer-based, meet weekly, typically have about 10 members, and are led by two facilitators, either two trained volunteers or a trained volunteer and a staff counselor with a professional counseling degree. Because of the complicating factors of substance abuse and the newness of the Sex and Sobriety Group, REACH matched a staff person with a volunteer. It also made sense to employ the REACH norm of a two-hour group lasting 12 weeks. The group required participants to have been clean and sober from all substances for a minimum of six months (in recovery communities, many people see periods of three, six, nine, and twelve months as significant milestones).

Historically, membership in many HIV-related groups—including those at the AIDS Health Project—has been determined based on HIV status. REACH opened up the Sex and Sobriety Group to members regardless of status. The combination of both HIV-positive and HIV-negative men in an HIV prevention group has created an opportunity for dialogue about some important, albeit emotionally risky, topics such as serostatus disclosure, dating someone of a different HIV status, and engaging in unprotected sex. Such discussions can be difficult, but having a mix of HIV-status in the group gives a chance for participants to hear the voices of the “other” in a safe environment that mirrors real-world experiences.

While the Reality Check clients who requested the new group formed a core of potential participants for Sex and Sobriety, the group’s success was dependent on community outreach and marketing to promote awareness, fill the initial group, and sustain interest for future cycles of the group. Effective outreach was especially important because REACH is not primarily a substance abuse services program, and the recovery community had not previously viewed REACH as a resource. Due to budgetary constraints, REACH typically relies on cheap, yet effective, marketing approaches such as posting flyers in high visibility locations, counselor referral, and word of mouth from satisfied clients. In this case, REACH placed graphically appealing flyers at locations in which 12-step meetings are frequently held. Further, REACH’s substance abuse specialist undertook grassroots outreach within the recovery and substance abuse treatment communities.

Potential participants contacted REACH, completed an intake process, and were interviewed by the staff facilitator to determine whether or not the group appeared to be a useful match. Within less than two months, 10 members had signed up and the group was ready to begin.

The group was structured similarly to other REACH groups: during the initial sessions, members identified topics for discussion over the course of the group, and each member identified individual goals. Along with the overall goal of maintaining sobriety, topics that arose in the first group included: remaining “present in intimate sexual situations,” decreasing compulsivity in sexual behavior, and addressing fears of emotional and physical intimacy. The format of each group session consisted of three parts: a check-in, which included a focus on progress related to group goals and topics each participant wished to discuss that night; group discussion on some of those topics; and a check-out.

**Content of Group Discussion**

Perhaps in part because of the group-oriented nature of the recovery process with which participants had experience, it took little time for participants to identify compelling issues, open up, and begin in-depth dialogues about various subjects. The following three real-life vignettes (with changes to client names and subtle changes to details to preserve confidentiality) suggest the broad range of these discussions. These vignettes reflect the fact that most Sex and Sobriety participants have identified speed as either their drug of choice or their “problematic” drug.

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**Comments and Submissions**

We invite readers to send letters responding to articles published in *FOCUS* or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, *FOCUS*, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
While cultures of use, behaviors, and effects vary among substances, participants who have used other substances have mixed well in the group, acknowledging their differences and focusing on similar themes including isolation, desire for connection, and addictive urges.

Steve, an HIV-positive man with a history of alcohol and other drug use, was terrified of seeing himself as gay. Yet in the group, he acknowledged himself as gay and as someone who someday wanted an intimate relationship with another man. Throughout his life, he had engaged in sex with men but only while high on speed. After achieving several months of clean time, he joined the Sex and Sobriety Group and started considering the possibility of a relationship. Week in and week out, Steve talked about his fears—of intimacy, of sex, of another man knowing him—and came to accept himself as a gay man and to envision what an intimate relationship with a man might look like.

Mario, an HIV-negative man, began to see a pattern in his sex life: he recognized that sex was always related to his relapse to speed use. While his substance abuse recovery had helped him cut down on his “drug binges,” he considered himself successful only to a point: inevitably, when he went on “sex runs,” it was these sex binges, which lasted days, that led him back to drug use. Through the Sex and Sobriety group, Mario started to address his “sex runs” and to come up with a plan to manage these.

The Evolution of a Group

After three 12-week cycles, the popularity of the group and the success of the outreach required REACH to add a second Sex and Sobriety group. As of February 2004, the first group has completed six cycles, and the second has completed three cycles. After the group’s first year, REACH also extended the length of all its groups from 12 weeks to 14 weeks to enhance the experience of group cohesion. Finally, members have often re-enrolled after completion of one cycle of the group to complete additional cycles, and sometimes, members have left group after one cycle, only to return to a later cycle to “readress” issues. At least half of all Sex and Sobriety members participate in two or more cycles, which similar to rates in other REACH time-limited groups.

Finally, the second Sex and Sobriety Group responded to requests from potential participants for a group open to people whose sobriety was greater than three months but less than six months. While the new group appears to be successful, it has experienced more drop out than the six-month group, either because some participants at earlier stages of sobriety may be less emotionally ready for the group’s focus or because of relapse. For example, one group member found that the content of the group was so “charged” that, instead of helping him sustain his sobriety, he was concerned the group might trigger him to lapse. The facilitators validated this member’s decision to leave group, and as he explained his thinking, other group members expressed support for his decision.

In response to this experience, REACH developed a protocol for dealing with relapse. The protocol states that in the case of a participant’s lapse, the group facilitator will review the case and may require the participant to give up his membership in the group. The facilitators would more likely allow a member to stay in group if the member quickly returned to recovery after a lapse and showed integrity by contacting the group facilitators. Facilitators would less likely allow a member to stay if the member had a “full-blown” relapse into his drug of choice and was less responsible in handling the process of “cleaning up” and returning to recovery afterwards. This protocol serves both to help the group avoid triggering relapses among other members and to maintain the group’s focus on the issue of sex while in sobriety.

Conclusion

Sex and Sobriety—and any effective group in the REACH program—has been successful because REACH has paid attention to community and participant needs and has responded to these needs in a way that is consistent with REACH’s mission. We have challenged ourselves to create new programming and to do things in new ways, while at the same time questioning existing approaches, admitting failures, and accepting the limits of our capacities. These perspectives have been essential tools in remaining innovative and dynamic.
Recent Reports

AIDS Groups v. Groups for Other Conditions
Davison KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. *American Psychologist,* 2000; 55(2): 205–217. (University of Texas, Austin; and University of California, Los Angeles.)

People with illnesses seen as stigmatizing, embarrassing, or disfiguring are more likely than people with other diseases to join support groups, according to a study comparing support groups for 20 conditions.

Researchers conducted three studies to determine which disease characteristics are most common among support group participants. The first study identified 12,596 support groups for 20 health problems in four U.S. cities. The 20 diseases included the most prevalent and deadly conditions as well as those with significant psychological and behavioral implications. The second study monitored Internet-based support groups relating to the 20 selected conditions. The third study analyzed both sets of results to determine which disease characteristics related to group participation.

The first study found that AIDS had the second highest number of groups among all cities—comprising 4 percent of all groups—even though it ranked 16th in prevalence compared to the 19 other conditions. Other conditions with a high number of support groups included: alcoholism, which had the most support groups, breast cancer, which had the third most, and prostate cancer, which had the fourth most.

The second study found that multiple sclerosis, chronic fatigue syndrome, breast cancer, and anorexia were the most-posted conditions online. AIDS ranked seventh.

The third study sorted prevalence of both live and online groups by disease characteristics. It found that both types of groups were most common for stigmatizing, embarrassing, or disfiguring diseases, particularly those involving potential alienation from social support. This explains the preponderance of groups focused on alcoholism and AIDS.

This finding conflicts with expectations: an earlier study suggested that embarrassment would diminish support group participation. The study found that participants waiting for a medical procedure that supposedly involved an electric shock preferred to wait in the presence of someone facing the same plight rather than to wait alone. When participants awaiting the same fake procedure were told they would be required to suck bottle nipples while waiting, however, they overwhelmingly chose to wait alone.

The study suggests that people appreciate social support during moments of anxiety unless embarrassment is involved. Participation in face-to-face groups was also associated with terminal conditions and those that are costly to treat, while participation in online forums was oriented around poorly understood conditions or those commonly overlooked by the medical community.

Telephone Support Groups
Nokes KM, Chew L, Altman C. Using a telephone support group for HIV-positive persons aged 50+ to increase social support and health-related knowledge. *AIDS Patient Care and STDs,* 2003; 17(7): 345–351. (Hunter College, City University of New York; and SAGE, New York.)

A small study found that older gay men with HIV benefit from telephone support groups, particularly when discussing ways of dealing with a range of medical issues.

Co-facilitators ran two 10-week support groups composed of up to five gay men with HIV, ages 62 to 71. Weekly conference calls lasted one hour. Conversation focused on coping and symptom management, particularly regarding peripheral neuropathy and diarrhea. Clients also discussed interpreting diagnostic test results; handling chronic illnesses such as diabetes, herina, and hepatitis; and HIV treatment, including complementary therapies. In addition, clients formed social bonds through disclosures regarding loss and other shared experiences.

All participants were disappointed when the project ended, indicating high satisfaction. Though the telephone format allowed anonymity and accessibility for subjects with physical impairments, the inability to assess non-verbal cues presented a problem.

Next Month

Effective HIV prevention may emerge from the biomedical world. Approaches such as vaccines and pre-exposure prophylaxis are being tested, and others such as post-exposure prophylaxis are being used. In the April issue of *FOCUS,* Jonathan Fuchs, MD, MPH and Grant Colfax, MD, researchers at the San Francisco Department of Public Health, describe the range of these interventions and some of the challenges they present.

Also in the May issue, Leslie E. Wolf, JD, MPH and Bernard Lo, MD, medical ethicists at the UCSF Center for AIDS Prevention Studies, discuss the informed consent process in the context of HIV biomedical prevention research.
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