Research Update

The American Psychiatric Association estimates that 15 million people in the United States participate in one of 750,000 support groups.1 There are many reasons for people, both those with HIV infection and those at risk for infection, to attend support groups. Researchers have found that relationships formed as part of the support group experience can improve quality of life and, for those facing life-threatening illness, extend life expectancy.2 A study of women with terminal breast cancer found that those who participated in a group lived twice as long—an average of 18 months longer—than those who did not.3

The process of relating to others and sharing life experiences seems to be fundamentally healing and empowering. A survey of 232 support group participants from 65 different groups that focused on life-threatening disease found that 70 percent of participants reported less emotional stress and 62 percent said they were less afraid of a disease crisis. In addition, 39 percent said that life had taken on a new meaning since they had begun participating in a support group and more than half the members reported increased self-confidence when dealing with physicians.4 A study of depressed, HIV-infected people found support groups beneficial in reducing depression, hostility, physical symptoms, and the incidence of unprotected receptive anal sex.5 Support groups have also been found to inspire activism and community involvement among members.6,7

People who test HIV-negative can focus on a variety of concerns that may arise from being uninfected in a community in which most of the people they know may be infected with HIV. Uninfected gay men, in particular, may suffer from “survivor guilt” about living in the midst of the epidemic while remaining uninfected. While some publicity about people with HIV provides role models and inspiration for others who are infected, it may lead uninfected men to believe that HIV infection is inevitable or even admirable.8 Support groups designed for uninfected people may have roles and usefulness that can help clients change unsafe behaviors or maintain low-risk behaviors. Support groups can also help clients “normalize” their feelings, gain a sense of peer norms regarding safer behaviors, and solve problems. In addition, after a positive result, groups can assist clients with coping skills.

This issue of PERSPECTIVES explains the roles and usefulness of different types of support groups. The Implications for Counseling section provides direction for assessing whether group support would be useful for a particular client, and if so, how to encourage a client to attend.
Survey of a Support Group for People with HIV

- 100% said they were able to discuss life experiences and feelings
- 82% said it was useful to share experiences and feelings
- 0% felt pressured to speak

fected gay men can instill a sense of community and peer norms that encourage safer sex behaviors.

These support group benefits can be important in avoiding unsafe behaviors, both for those who are infected with HIV and those who are uninfected. Lack of appropriate support can lead to increased depression and a failure to negotiate safer sex. A 1993 study found that those subjects who did not receive risk reduction and assertiveness training in a support group were less effective at initiating safer sex discussions or refusing to engage in unprotected intercourse than those who did participate in the groups.9

**Types of Support Groups**

The term “support group” commonly refers to a gathering of peers sorting through concerns or problems together, with or without a leader. Types of support groups include:

- Self-help groups, which may have various levels of structure and are generally facilitated either by peers with limited training or by participants themselves.
- Psychotherapy groups, in which professional counselors facilitate group interactions that help members explore, understand, and perhaps change long-standing interpersonal patterns.
- Instructional groups, in which a leader—typically a professional—provides instruction and facilitates skills-building about a particular topic, such as managing stress.

Support groups can take many forms. They can be specific to certain populations, for example, by gender or race, or they can be all-inclusive. They may focus on a specific topic or more generally on social support. They may run for a limited number of sessions or be ongoing and continue indefinitely. And they may be labeled as “open” or “closed.” Open groups allow new members and visitors to attend; groups in which members can “drop-in” without going through an intake or appointment process are a form of an open group. Closed groups keep the same members throughout the duration of the group. Members in a closed group may be required to commit to attending a minimum number of sessions. Research has shown all of these approaches to be effective.

Groups can also vary greatly in their affiliation to other groups or organizations. Friends or work colleagues may start self-help groups that are not affiliated with any professional organization. Members in these groups may help each other by informally sharing their own reactions and solutions to problems. In contrast, some managed groups use professional knowledge to set-up and operate groups; they often have pre-established topics for discussion and operate for a limited course of time, for instance over a period of six weeks or for 12 sessions. In managed groups, facilitators control membership standards, but don’t necessarily participate in the group activities.10 Psychotherapists also offer groups in their private practices.

**The Role of Support Groups in Changing Behaviors**

Research shows that while standard HIV test counseling interventions are valuable, they may not be enough in themselves to lead people to change risky behaviors, especially for those who test HIV-negative.11

Over time, support groups can help a person develop the motivation to change behaviors and build skills to make changes. By providing information, creating or changing social norms, and encouraging positive change, participants are better able to eliminate long-standing behaviors such as unsafe sexual or drug-using behavior. In addition, participants can make lifestyle improvements such as healthier eating, regular exercise, relaxation, or meditation.

To help curb high-risk behaviors, some groups combine training in assertiveness, problem-solving, and managing and taking responsibility for one’s behaviors. A study of one such group found that participants rapidly decreased risky behaviors after sharing ideas and problem-solving strategies. Group interaction was shown to improve self-image, which in turn led members to have more confidence in negotiating for safer sex.9

Even if groups do not stress behavior or lifestyle changes, these are often by-products of support group activity. In a study of support groups for people facing serious disease, 92 percent of group members said they learned a new behavior and more than half said they discovered new capabilities and became more attentive to their own interests and needs.4

**Resistance to Groups**

Some people are reluctant to attend support groups. They may believe that attendance takes a heavy emotional toll or, for people with HIV, that it involves preoccupation with illness. In one small
study, however, only five percent of group members said they experienced being in a group as an emotional burden.4

Social factors may lead some people to resist attending groups. Because HIV-related groups often target specific audiences—such as gay or bisexual men, injection drug users, or female partners of people with HIV—people who attend support groups may fear being “found out,” particularly by their employers or health care providers. People also may avoid groups out of fear that they will be forced to expose sexual or drug-using activity. In addition, homophobia, classism, or racism may deter a person from being in a group. These factors and others may lead someone who joins a group not to make personal disclosures within the group.12

People may resist support groups because they view groups as not being worthwhile. While one study found that those in a group reported benefits such as receiving information about mental illness and solutions to problems, those who were not in a group anticipated the group would involve an unreasonable expenditure of time and emotional stress of not fitting in with other members.7 Some people may interpret membership in a group as a sign of personal “weakness.” In one study of bereavement groups, non-members and, to a lesser extent, members viewed those who participate in groups as needy, lonely, and dependent.13 Even if a person decides to attend a support group, he or she may drop out because of what that person or a group’s leader considers a “lack of good fit.” For example, a heterosexual man infected with HIV as a result of unsafe injection drug use may not feel comfortable participating in a group with gay men who do not have a history of injection drug use. Or, an African-American person may feel his or her needs are overlooked in an HIV prevention group made up primarily of non-African Americans.

### Positive Effects of Support Groups

232 support group members reported the following benefits:

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Reduced emotional stress</td>
<td>70%</td>
</tr>
<tr>
<td>Reduced fear of a disease crisis</td>
<td>62%</td>
</tr>
<tr>
<td>Learned new behavior</td>
<td>92%</td>
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<tr>
<td>Increased self-confidence</td>
<td>58%</td>
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<tr>
<td>Learned more about treatment and services</td>
<td>66-69%</td>
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### Related Issue: One-Time Group Interventions

One-time, theme-focused workshops, which might deal with such topics as safer sex, grief, or disability, are an important group support option. Because single-session groups require a commitment to attend only once, they are perhaps the least invasive intervention. People who are uncomfortable making a commitment to a longer-term group or who resist a focus on emotional support may be willing to attend a one-time educational group.

Some people may need only one session to gain the skills to avoid unsafe behaviors, to establish a social connection to others, or to feel confident in a decision to leave a job as a result of a progression in disease. A one-time group discussion may provide the extra motivation toward making decisions and acting on them. For those who are only contemplating change, a one-time intervention may help them understand the possibilities, and lead them to further contemplation of change and further support.

Single session workshops are most effective when they have as clear and simple a focus as possible. For instance, one group might focus on exploring the decision to take treatments for HIV infection; another might focus on the possibility of applying for disability benefits. But it would likely be less productive to include both of these topics in a single group. Because of the limited time of a single-session group, it is especially important for participants to understand beforehand the purpose of the group. This may give them the chance to develop some ideas about what they desire or expect from the workshop.
Implications for Counseling

Counselors are a useful resource in relation to support groups. Counselors can explain to clients the nature of groups, assess their usefulness for each client, provide referrals, and support clients in making decisions about being in a group.

Getting help in a support group can be a logical progression after a test counseling session. For example, a support group can provide further help to a client who expresses motivation to avoid unsafe sex but is unclear at the end of a counseling session whether this is possible.

Many clients have a limited understanding of the nature of support groups and their relevance. People who have never been in a group might view the group process as mysterious or threatening. They may see the prospect of attending a group as an admission that they are severely troubled or that they are too weak to take care of themselves. Some may believe that support groups focus only on suffering and complaining. In addition, people may incorrectly view any type of support group environment as a form of psychotherapy and see this as harmful.

Even those who have participated in groups before may not understand what they might gain from being in a group now. For instance, a female client may have been in a support group during pregnancy that was focused on caring for a newborn. This client may not realize that a group could now help her remain committed to safer sex. In addition, previous experiences may have been unfulfilling.

Begin a discussion of support groups by asking clients their ideas about groups. Explain that group involvement generally gives members a chance to see that others have concerns similar to theirs, and that, as a result, group participants can help each other feel less alone with their concerns. In a group, a person can listen to how others have responded to various situations and therefore better understand his or her own concerns. Explain that groups can give people a chance to share with others their solutions to problems. Finally, explain that groups can be a source from which to learn concrete information, such as the names of “good” doctors or the “cheapest” place to get safer sex supplies.

Be aware that clarifying the group process may raise new concerns. For instance, upon hearing that other group members might share their concerns, clients may become afraid that group members will try to solve their problems or control their lives.

Assessing Need and Desire for a Group

While nearly any client might be a candidate for a support group, groups might be especially beneficial for the following:

- Those who feel isolated, who feel that no one else shares or understands their concerns;
- Those with a history of HIV risk behaviors or who appear vulnerable to these behaviors;
- Those who express a need for

Related Issue: Guiding Members to Groups

When explaining support groups to clients, provide specific information and instructions. The following are adapted from an intervention to support people in attending Alcoholics Anonymous 12-step meetings.

1. Attending a support group may help you deal with your HIV concerns. Most people who participate in support groups have increased self-esteem, greater social connection, and more effective skills in negotiating and maintaining safer behaviors.
2. Making a commitment to attend a group is a proactive way of taking care of yourself.
3. Socializing with other members before and after group sessions, if appropriate within group guidelines, can be an enjoyable way to meet others and receive support.
4. You do not have to actively participate in discussions when you are uncomfortable doing so.
5. When you attend a group, try to focus on what other members are saying. Others may be discussing experiences that will help you deal with your concerns.
6. If you are fearful of others’ judgments, keep in mind that other group members are likely to be most interested in talking about their own experiences, not in judging you.
7. If you don’t feel comfortable in a group, discuss this in the group. Remain open to other types of groups.
8. Be careful not to concentrate on the end result; enjoy the process. Think of the group experience as an opportunity to grow and learn about yourself.
When it appears that a client might benefit from a group, assess whether the client is receptive to receiving follow-up services in general and a support group specifically. Find reasons clients might be motivated to be in a group. These might include a desire to avoid unsafe sex or to feel more fulfilled or less lonely. For someone who tests positive, a group can be a resource for integrating the knowledge of the result. Recognize that each client’s motivations will be different and that clients may need encouragement in order to consider a group.

Help clients determine realistic expectations about outcomes of a group. Some clients might wish to stop having unsafe sex and see this as attainable; others may not be able to make this commitment, but might want to improve their negotiating skills with partners. Help clients understand that expectations may change once they enter a group. For instance, initially a client may express desire to improve social skills. Once in the group, however, he or she may begin to acknowledge a history of substance abuse, and halting the abuse may become the primary goal.

A support group might be useful when clients come forth with a barrage of questions during a disclosure session. This may indicate the client is overwhelmed with the disclosure of the test result. The counselor can serve this client most effectively by focusing on the client’s immediate feelings of receiving the result and suggesting a support group as a place where the client can pose and get answers to questions over time.

**Types of Groups: Making a Match**

After assessing needs and desires for support, assess the type of group that might be most appropriate for a specific client. In doing this, learn the following:

1) **History of group involvement.** Has the client been in a support group before? What was this experience like? If a client has not been in support groups, what are his or her feelings about other group experiences, perhaps as a member of an athletic team or a work group in a job or school setting?

2) **History of commitment.** Ask the client about his or her willingness to commit to a group. For instance, does he or she feel capable of making and following through with a 12-week commitment to attend a group? If not, ask whether he or she wishes to be able to make a commitment at some future point. Explore whether a one-time or drop-in group might be a more realistic option.

3) **Financial issues.** Does the client have resources, either money or insurance, to be in a group that has a fee? Is he or she willing to spend money to be in a group?

4) **Logistics.** Are there obstacles that might keep a client from attending a group, such as transportation difficulties or time conflicts?

Some clients want groups in which they share similarities with other members. Ask a client if he or she desires this, while not making assumptions about the client’s desires. For instance, a counselor may incorrectly believe that a heterosexual male client wants to be in a group with other heterosexuals, when in fact this client may be most interested in a group with others of his race or ethnicity, rather than sexual orientation.

Other factors also affect clients’ decisions about the type of group to join. Some people like groups where there is a definite leader, while others do not want this. Some people like groups operated through their churches, while others do not. There are people who do not like feedback in groups, while others thrive on feedback.

**Making Referrals**

In making referrals, provide specifics. Give a group contact name and telephone number, the location and time of the group, if this is known, and information about the focus of the group and the way it is facilitated. Explain the intake or interview process a client might need to go through to get into a group. Explain what the client might expect during the first group session.

Prepare clients for challenges they might encounter. For instance, when providing a referral for a group that may have a waiting list, inform the client of this possibility, and provide a referral for a drop-in group to attend in the meantime.

To improve the likelihood that a client will pursue a referral for a support group, learn whether friends will support a client in joining a group. Determine also if people might be an obstacle to the client entering a group. A person may have friends or partners who fear changes that the client might make as a result of being in a group. Or, if a client is in an abusive relationship, the client’s partner may try to prevent the client from seeking support.

In some cases, there may be no groups that fit a client’s needs or desires. For instance, in most places there are few, if any, groups offering support in behavior change for heterosexual women. When there is no group for a person’s specific needs, assess other options. For instance, in this example, a community may have a health clinic that offers a general-focus group for women.

In the absence of groups, look for options that might provide clients with similar benefits. For instance, student health services and local churches, social organizations, and workplace employee assistance programs often provide useful non-group support services. In addition, test counselors can
Advocate for funding for additional support groups, solicit volunteers who might join or organize a group, or consider being involved with colleagues in starting groups.

Responding to Resistance

People sometimes resist entering support groups even when they see the benefits of being in a group. Assess this possibility and ask clients if they are aware of reasons for not wanting to be in a group.

Some clients may believe their concerns are either too great or too small—or, paradoxically, both—to be dealt with in a support group. They may view groups as being either full of troubled people, or they might see themselves as the only troubled person in the group. Learn more about these feelings and clarify conflicting information. Remind these clients that by raising an issue in a test counseling session, it appears they are at least somewhat willing to discuss the issue and that it has some importance to them.

Clients might be uncomfortable with support groups because such groups are made up of people they do not know. Clients may fear that joining a group will be a sign that their friendships are inadequate. Explain that it is not unusual for a person to have support needs that are not being met by friends, regardless of the nature of those friendships, and that groups complement friendships. Note that friends may not discuss with one another some topics because they fear a lack of objectivity or the loss of a friendship. In support groups, people often feel freer to broach subjects because members do not necessarily depend upon others in the group for day-to-day friendship.

Clients may fear the prospect of change that group support may foster. Acknowledge that changing unproductive behaviors is often a part of group involvement. Explain that group members are not required to make changes unless they want to do so and that groups will help members deal with challenges. Acknowledge a client’s resistance. For instance, the counselor may state, “I understand the concerns you have expressed, and I am also really struck with what the research about support groups tells us—that people can benefit immensely from groups, often in ways people never imagined. It can be valuable support and an important option for someone like you to consider.” When resistance persists after exploration, it may be useful to change the focus of the session to another topic and perhaps return to support issues later in the session.

A Counselor’s Perspective

“I think a lot of clients feel no one else will understand their concerns. I point out that clients aren’t alone and that others share their concerns and can support and understand them.”

When Groups Might Not Be worthwhile

There are occasions when groups might not be a useful intervention. Those with concerns about trust may not feel enough safety or comfort to be in a group. They may feel others will not respect them or the confidentiality of what they say. Some clients may find that group involvement does not give them the individual attention they need. They may be too strongly influenced by others and feel a loss of their own identity in groups. Those in early stages of recovery from substance use may not be a good match for a group that includes people who are actively using substances.

Groups may not be appropriate for some clients with poor interpersonal skills, and for those with limited control of emotions, such as anger or rage. Some clients may be hostile toward other people and therefore inappropriate for certain groups. In addition, people who are mentally ill may not fit in with a group of higher functioning people. Beyond these things, in some cultures people do not see group support as being useful. Keep in mind that these issues are dealt with more thoroughly during the intake interview that generally occurs before a person joins a managed group.

Respect clients’ views and experiences, acknowledge that groups might not be an appropriate option for them, and offer other options. People might be open to individual counseling and support, perhaps from a psychotherapist or minister. Some people can increase the support they receive from friends or they might try to meet new people who can be supportive. Recognize, too, that groups may become a more useful option in the future.

A Counselor’s Perspective

“While it’s important for me to encourage clients to consider support groups, I need to respect that clients might not want a support group. Then I have to provide other options for support.”
Case Study

Lou has engaged in unprotected sex with various partners on several occasions in the past year. He would like to change his behavior, but feels he cannot. Sometimes his episodes of unsafe sex are preceded by what he considers moderate consumption of alcohol. Lou has never participated in a support group, but he sees that group involvement can help some people. While he says he does not want to engage in unsafe sex, Lou says his situation is not serious enough to warrant intervention.

Counseling

Discuss further Lou’s history of unsafe sex. Learn how he views the unprotected sex in which he has engaged. Assess why he feels these behaviors are not serious enough to warrant intervention, and empathize with his views. Make sure he understands that through unprotected sex he is at risk for becoming infected, and explain that by visiting the test site he is receiving outside intervention.

Attempt to find a reason he might view his unsafe behavior as deserving of outside attention or why he might be motivated to avoid unsafe sex. With this motivation in mind, explain that there are options other than unsafe sex. Explore the apparent contradiction between Lou’s view of his behaviors as harmful and his feeling that intervention is not necessary. See if Lou recognizes this as a contradiction.

Assess further his knowledge of and views toward groups. Explain that groups involve a simple process of people coming together to take care of themselves, and that the process of talking with others in a support group setting has been beneficial to many in changing unsafe behaviors. Help him see that others in groups share his concerns about unsafe sex, and explain that many people have found reasons to try support groups even though they have believed their unsafe sex was not serious enough to warrant intervention.

Because Lou has said that groups can benefit others, learn more about why he believes this and, given this, ask whether there are other factors that lead him to believe groups might not benefit him.

Remain open to reasons for his resistance to joining a group, including issues of self-esteem, the view that behavior change is not possible, and the idea that he may be reluctant to address the issue of substance use in his life or face criticism from others about it.

Explore Lou’s substance use further and the fact that substance use can lead a person to engage in unsafe behaviors. Explain that support groups can be useful for recognizing relationships between various activities, such as substance use and unsafe sex.

If Lou continues to view groups as not being beneficial for him, consider other options such as one-time interventions and one-on-one counseling. Offer referrals to these as well.

References

Test Yourself

**Review Questions**

1. True or False: Support groups are valuable only for those who are HIV-positive.

2. What kind of group allows new people to “drop in” without an interview or intake process? a) open groups, b) closed groups, c) both of the above, d) neither of the above.

3. True or False: Support groups can help a person change harmful behaviors, such as drug use or unprotected intercourse, that may be difficult for a person to change on his or her own.

4. True or False: Information about how to avoid HIV infection is enough to keep a person from engaging in unsafe behaviors.

5. True or False: Research has shown that people without support and training have a difficult time initiating discussions about sex or insisting upon safer sex.

6. True or False: Participating in a support group often takes a heavy emotional toll and is likely to depress participants or create a preoccupation with illness and death.

7. True or False: All support groups have the same structure and are of the same type.

8. True or False: Support groups are appropriate for every client seeking testing services.

**Discussion Questions**

1. How can counselors respond when clients express a lack of interest in being in a group and are uncertain of any reasons for this?

2. How can counselors respond when clients discuss having bad group experiences in the past? How can counselors respond when clients say that groups are only for people who are too weak to deal with their problems on their own?

3. How can counselors explain the benefits that may come to clients in a support group, especially with clients who have little understanding of the role of groups?

4. How can counselors respond when clients express that they feel unable to commit to regularly attending a support group, but still desire to be in a group?

5. How can counselors maintain current information about available groups? How can counselors learn more about the benefits of particular groups?

**Answers**

1. False. Support groups can be helpful in keeping a person from getting infected.

2. A. Open groups allow new members to “drop in.”

3. True.

4. False. Once a person knows behaviors that are considered safer or unsafe, he or she must also be able to enact those behaviors.

5. True.

6. False. In one survey of 232 support group participants, only 5 percent said discussing their problems was a heavy burden.

7. False. There are various types of support groups, and groups have various structures. Some groups involve a great deal of structure, while others are largely unstructured. Some groups restrict who may participate—groups may be only for people with HIV—while other groups are open to all.

8. False. There are some clients for whom support groups are not appropriate.
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