Group Support for Caregivers
Ken Pinhero, LCSW and Cathy Cassel, LCSW

People with HIV disease frequently rely upon formal caregivers—including medical and other health professionals, social service agencies, psychotherapists, and clergy—and informal caregivers, including friends, families, and partners. To the relief and encouragement of mental health professionals who work with HIV disease, discussion of the psychological complexities related to caregiving has recently appeared in psychology and social work literature.1,2 This article continues the discussion by describing a support group model for informal caregivers, who offer emotional, practical, spiritual, or financial help to people with HIV disease.

Psychological Challenges for Caregivers
Caregivers encounter many of the same issues faced by people with HIV disease. The specter of AIDS raises a host of feelings, including anticipatory loss and grief, helplessness and hopelessness, fear and shame, and homophobia. The stigmatizing and life-threatening nature of AIDS exposes both people with HIV disease and caregivers to social isolation. In places where the epidemic is widespread, both groups rely on networks of support to guard their own physical health while responding to the needs of people with HIV disease. As is apparent with addiction and recovery, the reasonable concern for the well-being of another can evolve instead into an attempt to control behavior, a pattern identified in the substance abuse field as "codependency." Because the life-threatening nature of HIV disease and its physical and emotional manifestations can cause severe anxiety among caregivers, they, more than those caring for people with other conditions, risk exhibiting codependent behavior.

Goals and Organization of Support Groups
The psychological challenges of social isolation and support system depletion make group treatment particularly suitable for caregivers. Groups enable clients to compare stories with others who know from experience what HIV caregiving entails and to work together to prevent burn-out.

It is important to distinguish support groups for caregivers from psychotherapy groups. Helen Northen3 identifies common goals of support groups, including:

- Reducing stress and social isolation;
- Enhancing coping skills;
- Providing chances for venting and universalizing feelings;
- Increasing self-esteem and lessening feelings of stigma.

The overall objective of these groups is to strengthen psychological defenses in the face of tremendous hardship. Therefore, functional behavioral change, rather than the uncovering of unresolved psychological issues, is the primary focus of the group. Problem solving is typically practical and concrete: clients explore how to talk to their significant others, to seek help from friends, and to approach doctors. Group leaders encourage members to share educational information and resources and to maintain outside contact with other participants. At times, leaders, themselves, have outside consultations with members. Practices like these would challenge the integrity of group boundaries and norms if they occurred in a psychotherapy group.

Groups strengthen psychological defenses by focusing intervention on functional behavior change rather than uncovering unresolved psychological issues.

Group leaders deliver interpretations gently and respect their clients' limited capacity to change in the midst of anticipatory grief. Clients learn to recognize parallels between relationship dynamics inside and outside the group. Occasionally, to enhance group process, group leaders will carefully disclose personal feelings and reactions to the group. As a rule, however, leaders encourage members to look to each other for feedback and support.

Prior to the first meeting, group leaders conduct individual interviews to assess the level of coping of a caregiver, the amount of care needed by the person whom the caregiver is tending, the strength and breadth of the caregiver's social support network, the caregiver's history of group experience, and other psychosocial stressors affecting the caregiver. Careful screening allows group leaders to refer those clients who would not benefit from the group model, for example, clients who are actively psychotic, who exhibit suicidal tendencies with a potential for acting on these impulses, and who abuse substances.

Membership in the group is kept between five and eight people. Groups are co-facilitated, so that therapists may share with each other the weight of their personal feelings and reactions. An hour and a half in length, groups run for a period of 10 weeks, which allows enough time for interpersonal bonding, yet accommodates the need for providing services to a larger number of people. All of these group organization guidelines were developed to serve a generic population and are applicable, possibly with some refinement, to more specialized groups such as ones for biological families or caregivers of racial and ethnic diversity.

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Group Process

Ariadne Beck's model for group therapy forms a foundation for the developmental process of the caregiver support group. Briefly, this model identifies nine developmental phases through which groups progress, given adequate time and successful resolution of conflicts. In order to be effective, a group must pass through each phase in succession, although a group can be successful without completing all nine. In caregiver groups, it appears that the first three phases and the final phase (termination) are both necessary and sufficient for establishing effective support.

In the first phase, individual group members express and attempt to master their anxiety, while the group as a whole takes on the task of solidifying membership. A working "contract," which outlines goals, expectations, and group rules, and defines the commitment of each group member, is developed by the end of this phase. Typically, in the first few weeks of a group, as participants share initial and often distressing stories, they tend to assume that all group members are equally overwhelmed. As a result, participants may treat each other with undue delicacy and deliberateness, a phenomenon referred to as "attributing fragility." It is useful to defuse such anxiety by acknowledging it as a normal response, and by eliciting clear, accurate descriptions of the specific stresses affecting each individual.

In phase two, individual members begin to express anger, competition, and conflict with one another. While in many kinds of groups these interactions are overt and explicit, in caregiver groups they are often subtle and hard to detect. In this phase, the group struggles to tolerate differences between members.

It is common during this stage for the group to try to "fix" someone, to get him or her to shift from a stance that may be perceived as psychologically unhealthy, emotionally painful, or too "different." For example, the group may respond, "Phil, have you tried ...?" when he says he feels helpless when his partner is of abandoning clients, their resistance to facing loss, and their own group leaders to manage, since it forces them to confront the dread themes and provides important material for discussion during the developmental process of the caregiver support group. Group facilitators encourage the use of group time to explore the possibility of future contact. While some groups disband altogether, more often members continue to meet informally in each others' homes or formally with a private facilitator.

Conclusion

Effective informal caregiving shortens the time people with HIV disease need to spend in hospital and institutional settings. It is particularly important to consider ways to strengthen informal caregiver networks as the epidemic increasingly stresses health-care delivery systems. Brief support groups provide a cost-effective mental health intervention that addresses the isolation, frustration, and helplessness felt by many HIV caregivers.

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References


Request for Submissions and Comments

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, including a summary of the idea and a detailed outline of the article. Send correspondence to:

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Clarifying the Caregiver-Client Relationship

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In order to optimally care for patients with HIV disease and to avoid exhaustion and incapacitating grief, caregivers must examine their relationships to their patients. The primary caregiving goal must be the effective and humane treatment of people with HIV disease. Such care is bound to be difficult because HIV infection brings with it the anticipation of pain and the looming threat of death. It also brings with it patients with whom doctors may identify, indeed overidentify patients who are often young, educated, and apparently courageous. One of the places where these issues arise most frequently is within agencies that provide direct patient care to people with HIV disease. It is these agencies that can offer caregivers their best support.

The Importance of Defined Roles

It is natural for caregivers to develop feelings about patients during the course of treatment. Clients may be endearing or infuriating, solicitous or angry, compliant or argumentative. In any event, all deserve to receive the same efficient and caring service. To best provide equitable services, caregivers must define roles for themselves in which they are involved enough with clients to offer effective care yet not so involved that they cannot accomplish the objective tasks of administering to their clients' needs. For example, when a caregiver's grief, following the death of client, makes it impossible for him or her to work, this caregiver cannot be expected to provide for the needs of his or her other clients.

Similarly, caregivers may unintentionally confuse clients with consistent intimacy or personal involvement or give clients unclear messages. For instance, a client may believe that the therapist who visits him or her at home and inquires about sexual functioning in the informal setting may actually be expressing interest in a sexual relationship rather than professional concern. Caregivers who work with clients with HIV disease face special challenges when trying to define roles. HIV disease, because it can so dramatically affect physical health and mental state, may leave clients confused, grasping, frightened, hostile, seductive, or demanding. Clients have the right to expect that their responses to pain, grief, and fear will not be misunderstood by caregivers. Caregivers must avoid taking these changing emotional states personally. For example, as clients break down denial about illness, their anger at AIDS, society, and fate is often aimed at their caregivers. If caregivers are friends, clients may attempt to stifle their emotions, and clients who believe that care is provided as a favor may feel obliged to repay caregivers in some way, or even worse, may feel they are not entitled to make further demands.

Interventions to Clarify Boundaries

A balanced personal life is important for caregivers coping with the demands of working with very ill patients. It is through these outside friendships that caregivers should seek emotional fulfillment and support. Clients too are best served when they have primary friendships apart from their relationships with caregivers. In such situations, clients are relieved of undue feelings of obligation to caregivers, who are then seen as professionals doing their jobs.

Agencies that employ professional caregivers can aid them in maintaining clear roles by offering support in four ways. First, they should develop clear-cut rules of behavior for counselors. Policy should be established to address issues such as whether caregivers should see clients on their days off, whether clients should be given caregivers' home telephone numbers, and whether casual socialization with a patient's family and friends is allowed. The exact way each agency handles these issues is not as important as the existence of clear guidelines. Also, while guidelines are not stone walls, if there is a need to violate them, their existence alerts both caregivers and their supervisors to an unusual circumstance.

Second, agencies can ensure that they employ enough caregivers to provide feedback and support for each other. Overburdened workers, laboring without time for discussion of clients and feedback about appropriate roles, are more inclined to make errors or develop job burnout. Third, agencies can provide staff with access to approachable senior consultants who are experienced in the area of role definition. Finally, agencies should sponsor periodic retreats where staff can reflect on and discuss the role of the agency, caregiver stresses, and changing patient needs.

When caregivers find themselves thinking about clients a disproportionate amount of time, it is a signal to discuss this situation with colleagues or supervisors.

In the final analysis, even with guidelines, feedback and supervision, caregivers must develop their own skills in maintaining clear and helpful roles with clients. One rule of thumb in this self-monitoring process is that if caregivers find themselves thinking about clients a disproportionate amount of time, especially when they are off duty, it is a signal for them to discuss the situation with colleagues or supervisors. This is especially true if patients arouse strong emotions, whether positive responses such as empathy or attraction or negative ones like avoidance or anger.

Volunteer Caregivers

The principles outlined above for professional caregivers also pertain to volunteer caregivers. Agency administrators, however, must provide closer supervision to volunteer staff. Volunteers should be offered realistic training and complete explanations of the tasks they are undertaking. Agencies should enforce realistic time limits and be cautious in asking volunteers to commit to more than one client at a time. Respite time should be given to volunteers after the death or separation from a client.

The situation of self-motivated volunteers—friends, lovers, or family members—who work with people with HIV disease without the training or support of agencies raises special issues. Informal caregivers must guard against the possibility of isolation or "heroic" behavior. Mental health and medical professionals should impress on informal caregivers the importance of taking time off from caregiving, continuing other activities, including employment, and maintaining their friendships. In addition, informal caregivers will likely experience not only burnout, but also the grief that accompanies the death of a close friend or family member.

Conclusion

Caregivers must clearly define their roles with clients—by understanding professional responsibilities and agency policies—particularly when working with people with HIV disease. This allows them to minimize emotional fatigue and increase emotional support. In the face of a burgeoning epidemic, such role clarification can preserve increasingly valuable patient care resources.

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References

Recent Reports


Peer led support groups were as effective as professionally led support groups for improving caregivers' abilities to cope with specific behavioral problems, increasing their perceptions of self-efficacy, and improving their relationships with care receivers.

Researchers reviewed two peer led and two professionally led groups taken from a larger study of 14 groups comprising a total of 130 caregivers tending older, frail individuals. Tape transcripts of group sessions were evaluated using analytical scales to describe content, work style, and content style, and using an independent qualitative content analysis by project staff. Since the study was small, data was not subjected to statistical analysis.

The groups, which met for eight weekly, two-hour sessions, focused on caregiving, and on the relationship between the caregiver and the care receiver. Peer led groups included more information-sharing and discussion about caregiving. Professionally led groups had more personal discussion, analysis, and exploration. While professional leaders were more active in keeping groups focused, they did not dominate interaction.

Differences between peer and professionally led groups were not significantly reflected in group outcome measures. Both types of groups performed similarly in encouraging participants to explore issues, in offering hope, in providing information, and in reducing isolation. Professional leaders were more likely to help members gain insights into coping skills and to build more cohesive groups. Peer leaders, however, were more effective at encouraging social interaction and were stronger role models.

**Caregivers’ Social Support, Self-Esteem, and Burden.** University of Louisville (Journal of Advanced Nursing, July 1990).

Caregivers with a large amount of available social support had better social skills than those with little social support, and caregivers who had relatively little social support, affirmation, and affection had low self-esteem, according to a survey of 31 caregivers who spent time with older people with irreversible dementia.

The caregivers, most of whom were women and older people, were usually spouses or adult children of care receivers. Most caregivers spent from one to 16 hours a day as caregivers and had been providing care for a mean of 2.6 years.

Researchers found no relationship between social skills and objective burden, the disruption in caregivers’ lives caused by caregiving. However, social skills were correlated with subjective burden—the individual attitudinal or emotional response to the caregiving experience—and unassertive caregivers experienced lower caregiving burden than assertive individuals. The researchers speculate that assertive caregivers may become frustrated when they are not able to control illness.

There was also a significant negative relationship between loss and self-esteem. Caregivers who reported losing a greater number of relationships in the previous year, through death or relocation, had lower self-esteem.

**Therapist-Client Relationships.** University of California Los Angeles (Professional Psychology: Research and Practice, October 1989).

In a large, national study, mental health professionals considered most outside roles and relationships with clients to be unethical. Few professionals had engaged in these activities, especially those of a sexual or financial nature.

Of 4,800 questioned, 2,133 subjects returned usable surveys regarding incidental, social, financial, and sexual involvement with clients. The sample, roughly half men and half women, had a mean age of 48 years. Most participants were married, and the largest percentage were in private practice. Almost half were psychologists, almost one-third were social workers, and about one-quarter were psychiatrists. Roughly half of the subjects were asked about their beliefs regarding the ethics of 20 specific practices, while the other half were asked if they had engaged in these practices, and if so, with what proportion of their clients.

Under almost all scenarios, more respondents defined behaviors as “never ethical” or ethical under “rare” or “some” conditions than defined them as ethical. A majority of respondents rated five of the behaviors as “never ethical”: sexual activity with a current client, or with a client after termination, selling a product to a client, inviting a client to a social event, and providing therapy to an employee. A majority rated as ethical under at least “some” conditions the following behaviors: accepting a client’s invitation to a special occasion, accepting a gift worth less than $10, and providing individual therapy to a relative, friend, or lover of a client. Of subjects who were asked if they had engaged in specific behaviors, a majority said yes to only two: accepting a gift worth less than $10 and providing therapy to a client’s significant other.

Next Month

The AIDS epidemic has not only revealed deficiencies in health and social systems throughout the world, it has also raised questions about how we define health, and forced us to consider a new paradigm, a new model, for health care. In the February issue of FOCUS, Jonathan Mann, MD, MPH, former Director of the World Health Organization Global Programme on AIDS and currently Director of the International AIDS Center of the Harvard AIDS Institute, examines these changes. He defines the old and new health care paradigms, their conflicting approaches of coercion versus solidarity, and how to foster the new paradigm.

Dr. Mann’s article challenges the international community to adopt a global approach to health care. Also in the February issue, Michael Helquist, founding editor of FOCUS and Regional Coordinator for Latin America/Caribbean at AIDS.COM, looks at the developing world and the obstacles it poses to the establishment of solidarity.

In Memoriam

Larry Cichosz, a volunteer for the AIDS Health Project, died on December 17. He was a valuable member of the FOCUS team, involved in graphic design, desktop publishing, and proofreading. Larry was a rare find, someone who knew what he was doing and did it well, who brought to our workplace not only intelligence, but also quiet humor and a gentle disposition. We will miss him.