Serving HIV-Affected Poor Families
Robert Tufel, MSW, MPH and Geri Brooks, PhD

Analysis of AIDS data in the United States today shows the fastest growing populations with AIDS to be women, children and teens, African Americans, Latinos, and individuals exposed to HIV through heterosexual contact. The majority of these cases occur in urban poor households where one or more family member is living with HIV disease.

This epidemiological profile makes it crucial to develop systems of care for low-income HIV-infected and affected families living with children. The family in which one or more members is HIV infected is not only confronting the effects of a chronic, debilitating, life-threatening illness but also weathering the ravages of poverty: inadequate housing, family disorganization, malnutrition, violence, discrimination, and substance abuse. HIV disease takes its toll by placing unique stresses on the family system, stresses that exacerbate the already devastating effects of poverty. This article looks at the dynamics of poor urban families and how HIV disease changes these dynamics.

Family Dynamics
Poor families, both those with and without HIV disease, are often characterized by extended families, large households, and in many cases, single mothers and absent or unsupportive fathers. Many African-American and Latino families have complex, multigenerational, extended family networks that provide support for children and other family members, and include grandparents, aunts and uncles, cousins and adult children, as well as neighbors, friends, and members of the "church family." HIV infection complicates this family dynamic because it requires an extraordinary response on the part of the extended family, and because within inner-city, African-American and Latino communities, it often affects many generations simultaneously.

Since most HIV-affected families are headed by women living at the extreme margins of society, the position of women in these families is especially relevant to the family dynamic. Women, particularly those caring for HIV-infected family members, are more likely to respond to the needs of other family members before they respond to their own needs. This is exacerbated by the fact that a woman's experience of discrimination, due to factors such as past drug use, racism, or sexism, may make her reluctant to access health care for herself.

Sexual practices among many poor families reflect sex roles that subjugate women's desires to those of their male partners. Women report that, despite fears of HIV transmission, they suggest using condoms infrequently because they fear violence or rejection from their partners. Often this dynamic increases the anxiety of women and causes family relationships to be strained.

Ethnicity and culture influence how a family defines itself, relations and communication among family members, parenting styles, and coping strategies. The concept of the support group, in which individuals share personal experiences with non-family members, may seem inappropriate to someone from a Latino or African-American family. In addition, many African-American and Latino families may be influenced by indigenous, nonmedical healers, well-intentioned grandparents, or other members of the community who present alternatives to Western medicine. Challenging firmly held cultural beliefs is not productive and is likely to alienate family members. Rather, these beliefs
Editorial: Family Values
Robert Marks, Editor

The rhetoric of family values would have us believe that inner-city families are doomed. Focusing attention on structure, rather than content, this perspective idealizes the nuclear family and scorns families that may lack a biological father or mother, that may include working parents, and that may extend to encompass grandparents, uncles and aunts, cousins, neighbors and friends. The rhetoric of family values would have us believe that such families are inherently dysfunctional.

The experience of family therapists contradicts this viewpoint. All families, especially those that are poor, face challenges in a society confronting unemployment and deficient health care and educational systems. But the articles in this issue of FOCUS serve to remind weary counselors that even the most apparently "dysfunctional" families have resources that can be harnessed to aid the counselor, the therapy, and the family.

In their article, Robert Tufel and Geri Brooks describe the psychosocial challenges for poor families confronting HIV disease. Gillian Walker's article focuses on how family therapy can be used to serve families living in poor communities. Walker's piece states it most forcefully, but both articles acknowledge that the client—the family—is the practitioner's greatest ally, a perspective that modifies the common wisdom that poor families can survive HIV disease only with the help of forces from the outside.

The irony of all of this is that the nuclear family—held up by family values advocates—is clearly a liability in these situations. It is because family need to be integrated into systems of care for the family.

The Impact of HIV Disease on the Family

HIV disease adds to the stress of poverty in a variety of ways, complicating issues regarding housing, relations with the extended family and community, planning for the future, dealing with substance abuse, and the psychological well-being of uninfected children. For a majority of poor families, housing is a major issue, whether it manifests itself as the lack of a home, living in unsafe neighborhoods, or overcrowding. Lack of appropriate housing disrupts virtually every aspect of family life, damaging the physical and emotional health of family members, interfering with children's education and development, and resulting in the separation of family members.

For families and children living with HIV infection, homelessness or lack of stable housing adds to their vulnerability to medical problems such as upper respiratory infections, ear disorders, gastrointestinal disorder, chronic physical disorders, and general fatigue. Homelessness also makes it difficult to receive services such as food delivery, support by volunteers from a "buddy" program, and respite care, all of which can help to stabilize a family.

Waiting lists for federal assistance or subsidized housing for families can be years long, and specialized AIDS housing is not always developed with families in mind. AIDS programs have for the most part developed housing to serve single, HIV-infected adults. For those families who are able to access AIDS housing, the death of the HIV-infected member makes the rest of the family ineligible for the housing.

For a mother caring for her HIV-infected adult daughter, her daughter's death means not only grief, but also the loss of housing, diminished income due to loss of Social Security benefits, the added responsibility of being the sole supporter of her granddaughter, and the withdrawal of AIDS-specific medical, psychological, and practical support services. Unless services can assist the grandmother in the transition following her daughter's death, and provide follow-up after the transition, her family system may be stressed to the breaking point. This may exacerbate the psychological challenges both grandmother and granddaughter face.
The stigma of HIV disease complicates relations between the family and the extended family and in the community. Twelve years into the epidemic, families continue to hide the presence of AIDS, HIV-infected children and their siblings are ostracized in schools, and family members continue to shun infected members for fear of casual transmission. Infected family members face not only the experience of social and family rejection, but also the frustration and hopelessness of watching other family members confront anger, hatred, and misunderstanding. These experiences increase feelings of isolation and shame and reduce social support all the more necessary under these circumstances.

Stigma affects the whole family system, regardless of who in the home is aware of a family member's HIV status. A child who does not know in many cases lives with the knowledge that there is a secret, something hidden in the family that cannot be spoken. For some families, stigma brings threats and feelings of being cut off not only from friends and extended family members, but also from proper medical care and other significant support systems. In many cases, it is only when a parent becomes ill and the family is most vulnerable that rejection may be risked through disclosure.

Planning for change is always stressful; for HIV-infected parents planning for a time when they may not be able to care for their children, the stress is compounded. Custody and guardianship planning signifies an important step in a parent's acceptance of his or her own illness; in many cases, however, parents avoid planning due to denial of illness. Sometimes, a parent suddenly begins planning, and this may be a signal that the parent is aware on some level that he or she is beginning the dying process and may indicate the need for other types of supportive services for both the parent and the children. In other cases, denial may be so strong that the parent may be unable to recognize when he or she is no longer able to care for the children. At certain times, service providers in conjunction with medical providers must determine what is in the best interests of the children—for example, foster care, temporary guardianship or permanent guardianship placements—sometimes even when this is contrary to the wishes of parents.

Under any of these conditions, the new family will have to deal with the children's feelings of rejection, abandonment, grief, isolation, and fear during the process of change. When a parent is hospitalized, it is important that the children live in a setting that represents the least disruption of their normal schedules and offers the opportunity to visit the parent. This will help in the children's ability to cope with the illness and feelings of insecurity.

A majority of families living with HIV disease are also confronting the affects of substance abuse. Substance abuse hastens disease progression making it more difficult for parents to care for their children and to deal with the stresses of the illness. Children may also have developmental delays if their mothers were using drugs during pregnancy. For parents in recovery, an illness may provoke a relapse or the start of active use. Children and family members may have to confront abandonment and issues of loss twice—once due to substance use and then again when the parent becomes ill and dies. A child's feelings of blame and anger against a substance abusing parent may become complicated when the parent dies causing increased feelings of guilt and self-blame.

Lastly, because the attention of the family is so focused on the care of those who are ill, the needs of uninfected children are often neglected. These children frequently present with symptoms of depression, anxiety, and severe behavioral problems. A recent study by the National Institute of Mental Health and the Health Resources and Services Administration found that 73 percent of adolescents living in HIV-infected families had problems in school, 58 percent had decreased school grades associated with the illness of the parent, and of adolescents who knew about the illness of parents, none had shared that information with their best friends.

Children are isolated from support systems that give them an opportunity to discuss living with ill or dying parents or siblings. Older children may become "parentified," taking on the responsibilities of the parent, and the parent may become more and more childlike as he or she becomes sicker. The family system may be threatened if there is no support to help family members deal with their changing roles, and their feelings of fear, inadequacy, hopelessness, and grief.

References
Approaches

Given the dynamics of HIV disease in families, what are effective techniques for service providers? First, it is important to view the family as a functioning unit. Past distrust of social service and government agencies creates obstacles in constructing new linkages with these families. Thus, workers need to develop trusting relationships with parents before assuming case management roles. This can be done during the intake process and initial assessment, at which time counselors can create a case record containing information on the history of the parents and children. Intake forms should contain the following: ethnic background, presenting problem, service goals and plan, psychosocial history, medical history, drug-use history, emergency contact information, names of teachers and pediatricians, details regarding future planning for the children, disclosure information, health profiles for the children, and history of parents’ involvement with Child Protective Services.

Providers need to establish close ties not only with parents but also with other family members, especially grandparents, who may be the most able caretakers in the family system and who may be crucial to the resolution of future crises involving the family. By assisting uninfected family members, providers play an important role in maintaining the family system and ensuring that each member functions in the glare of the epidemic.

Secondly, providers must recognize the need to work on issues unrelated to HIV disease. Helping parents arrange child care, medical care for the children, governmental benefits, developmental testing, substance abuse treatment, counseling, advocacy, and even bus passes and food vouchers can ease the family’s burden and help establish the provider-family relationship. Once providers demonstrate their abilities to assist with immediate concerns, the family usually feels more open to pursuing more difficult psychological issues such as loss of control, fear, isolation, grief, bereavement, and planning for the future.

Thirdly, providers need to form relationships not only with AIDS agencies but also with family and child service agencies such as Headstart, child welfare departments, and public school systems. Providers can educate such family agencies about HIV-related issues such as confidentiality, disclosure, and risk assessment. Providers also need to ensure that AIDS agencies appropriately serve families by making these agencies aware of the different issues that confront families.

Finally, due to the lack of appropriate services for families living with HIV disease, providers need to seek to change systems that do not meet the needs of families. For example, the Family and Children’s AIDS Network (FCAN) in Chicago advocated for changes in the state guardianship laws making it easier for HIV-infected parents to plan for their children. Future advocacy might focus on case management programs for grandparents caring for their grandchildren, support and bereavement groups for HIV-affected children, and AIDS agency policies that focus on the needs of families.

Conclusion

As the nature of the HIV epidemic continues to change, as cases among women and children continue to increase, so must AIDS service providers shift their focus to the family system. Despite the obstacles that families confront, they often display incredible courage and strength. Effective providers can help families emphasize these strengths thereby increasing family stability and attaining the goal of any family provider: to increase the family’s ability to cope with the crisis at hand.

Clearinghouse: Family Therapy

References


Eco-Systemic Family Therapy
Gillian Walker, MSW

Healing the relationships between people with HIV disease and people in their intimate networks—families of origin or families of choice—is perhaps the most essential task for counseling. While this challenge is difficult for families in poor communities—who must struggle with basic survival, as well as HIV disease—most families are able to identify resources in extended kin systems and in community institutions that can ease their journey through illness. An "eco-systemic" approach to counseling helps clients by mobilizing natural caregiving networks, drawing on family resources and, in doing so, achieving goals in a cost-effective way.

The Resources of Poor Families
An eco-systemic case management model formally conceptualizes the family as the unit of care. It recognizes four factors as central to providing HIV-related care to poor families. First, AIDS frequently infects more than one family member and always affects the psychosocial functioning of the entire family. Second, the multiple social and medical service needs of both patient and family are the subjects of intervention and dealing with them requires collaborating with other agencies. Third, family members, as well as members of extended kin systems and friendship networks can become problem solvers as well as providers of loving care. Fourth, community members can play key roles in HIV-related program development, leadership, and outreach.

To implement this approach, providers must be willing to challenge their perceptions of culture, including the culture of poverty. For example the terms “multi-problem” and “disorganized” have shaped our thinking about families of poverty. These terms are not only pejorative, but also prophetic as to the outcome of intervention. They conjure up images of the Hydra of Greek mythology; if you help the family solve one problem, inevitably another problem will emerge.

Family therapists such as Salvador Minuchin and Nancy Boyd-Franklin have shown that behind the apparent “disorganization” of many families of poverty exists flexibility, underlying organization, and a rich tapestry of relationships that are fundamental resources for survival. For example, African-American families have a tradition of caring that extends beyond the immediate family, often raising children of other family members and friends. If this group of people was to survive the monstrous disruptions of family life brought about by slavery in the United States, they had to develop a system of care that constantly redefined “family” in accordance with need. As a result many families and extended kin systems, even those with minimum resources, are willing to take in whole families when a parent has AIDS and to care for orphaned children after the death of parents. It is such support that enables families of poverty to survive violence, hunger, disease, and a drug-saturated culture.


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See also references cited in articles in this issue.
Intervening with Families

In the initial phase, eco-systemic family therapy may seem similar to other forms of family intervention. The therapist puts the family at ease, helps identify problems, elicits beliefs and feelings about these problems, and helps determine the impact of HIV disease on family members. The therapist takes note of family dynamics: alliances, conflicts, and "cut-offs," (permanent breaks in relationships).

In an eco-systemic model, however, the therapist emphasizes strengths and resources rather than pathologies. He or she will normalize conflicts as expected responses to the stress of the disease and the disclosure of its causes, and will interpret emotional symptoms as ways of adapting to the illness.

While the therapist facilitates the ventilation of angry, guilty, or shameful feelings about the illness, the major therapeutic task is to seed ideas for the construction of a new narrative that will emphasize hope, survival strategies, and the love of each family member for the others. Because it is important to help the family tap its own unique resources for healing, the therapist does not pose as an expert but rather serves as a consultant who helps the family identify and respect the ways in which it has resolved problems and survived other crises. The therapist also ascertains the practical needs of family members, everything from access to after-school programs to medical intervention.

The Eco-Map

The "eco-map" or "family resource genogram" is a useful tool for establishing both resources available to a family and the nature of the family's relationship with necessary services.\(^3\) Created after a family has established a trusting relationship with the therapist, the eco-map should be approached as a way for the family to share the prideful, as well as the problematic, aspects of its history, as a tool to enable the family to use family and professional resources more effectively.

The eco-map comprises a family tree, including the names, dates of birth, marriage, and death, and the locations of significant family and quasi-family members, and charts the relationships among members over at least three generations. The family tree should indicate the nature of relationships—whether conflictual, close, or cut off—and important dates, for example, the date and time when someone began drug use, went to prison, moved away from home, contracted a serious disease. Assessment of how each family member is doing may turn up unexpected resources and may indicate an area of work, for example, the restoration of an interrupted relationship with a potential support person.

The eco-map also delineates the major professional systems and professional workers involved in the life of the family such as church, welfare, the medical system, school, and social service agencies. The map may show that a child is in trouble in school, but that there has been no contact between the school and an appropriate social service agency, or it may identify that there has been virtually no communication among the counselors involved with the family.

Creating an eco-map is often a clarifying and organizing experience for the family. Frequently family members begin to think about how to heal conflictual relationships. Simple questions such as "Who in the family could help grandmother and her daughter resolve their fight?" or "Who would be the best person to talk to Tony about safer sex?" not only raise unexpected responses but also encourage the family to problem solve. Ultimately, the eco-map helps identify problem solvers, who, coached by the therapist, can maintain their roles over time and maximize the impact of therapy on the family network.

Conclusion

A severe stigmatizing illness such as AIDS is a terrifying, destabilizing, disempowering event that threatens the fabric of relationships. The family's recognition of its own expertise and resources can begin the critical process of healing relationship wounds. It also can reduce the burden on the health care professional as the family and the professional enter into a partnership.

References


Authors

Gillian Walker, MSW was the Co-Director of the AIDS and Families Program of the Ackerman Institute in New York from 1985 to 1991. She is the author of The Midst of Winter: Systemic Family Therapy with Individuals, Couples and Families with AIDS (W. W. Norton, 1991) and co-author with Anita Morawetz of Brief Therapy With Single Parent Families (Brunner Mazel, 1983).

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

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Recent Reports

Culture and Family

A case study of a London Sikh family affected by both HIV disease and hemophilia demonstrates the usefulness of family therapy in transcending both cultural and linguistic barriers. Systemic family therapy led to better communication among family members, challenged traditional Sikh beliefs that blamed female members for HIV infection, and resulted in successful prevention education.

The study focused on a Sikh family that came to London from Punjab. The family of four children included two sons with hemophilia. Marriages for the two sons were arranged in India and neither wife knew about her husband's condition or had any understanding of hemophilia. Both sons received treatment at their local district general hospital, where they were informed that they were HIV-infected. However, a combination of an inadequate knowledge of English (and the absence of Punjabi translation) and of a clear understanding of HIV-related concepts prevented them from comprehending the implications of HIV infection. When one of the son's wives became pregnant, an alert midwife referred the entire family to the Royal Free Hospital Hemophilia Center where they all began their counseling.

In Sikhism, marriages are usually arranged, wives are expected to be obedient to their husbands, and male offspring are valued. As a result of these beliefs, when a Sikh husband falls ill, it is often assumed to be the result of inadequate care by his wife. Such beliefs made it difficult for the HIV-infected brothers and their wives to accept that HIV is sexually transmitted. They also had difficulty believing there was a risk of infection to an unborn fetus. The rest of the family tended to abandon the couples because they saw the illness as the result either of the wives' "loose" behavior or of their failure to care for the husbands. These cultural barriers were compounded by the fact that all the family's information about HIV disease was communicated in English.

The counseling approach used in this case embodied two concepts basic to the idea of family therapy: a systemic view and circularity. The systemic view considers the individual as a member of an entire family system. As such, if anything happens to one member of the family, it automatically affects other members. Similarly, the behavior of family members always affects the individual. Employing circularity, the therapist questions family members to enable them to see how each perceives the family and its relationships, and to observe the variety of perceptions of the family that may coexist. In doing so, family members correct misconceptions and open lines of communication.

Using circularity, the family successfully confronted issues such as the future of the couples' children. Previously, the family would not discuss such matters but once the therapist posed hypothetical questions about what might happen to the children if the parents died, the family began to explore possible solutions. Through numerous sessions of such questioning, the couples improved their understanding of English. Further, the sessions enabled the couples to speak openly with each other about HIV disease and the impact that the illness had on each other and their families, and led the husbands to respect their wives' concerns and opinions.

Family Therapy and Adolescents

Family therapy can play a significant role in reducing high-risk behavior among teenagers, especially since participation in risky activities often correlates with poor communication and troubled relationships among family members.
and other acting-out behaviors; it improves communication within the family; it allows for the dissemination of HIV prevention information to the entire family; it enables the detection of physical or sexual abuse, which has been correlated to high-risk behaviors among adolescents; and it makes use of parental leverage to bring about behavior change.

The 12-session PBFT model was originally developed to treat drug-abusing teens and was derived from structural, strategic, functional, and behavioral family approaches. PBFT has eight major components, including: restraining immediate change to lessen the likelihood of uncomfortable or dangerous consequences; establishing appropriate parental influence to clarify confused or blurred hierarchical boundaries; gathering information about how the behaviors of family members are linked to the adolescent’s risky behaviors; interrupting dysfunctional sequences of behavior; providing assertiveness training to resist peer pressure to engage in risky behaviors; and including peers in family therapy sessions.

The case of a single mother, Jean, with three sons—one of whom was heavily involved in drugs and was sexually active with a number of partners—illustrates some of these components. For example, during therapy it came out that the boys never followed their mother’s rules because she never imposed punishment if rules were broken. In response, the therapist encouraged Jean and the family to recognize Jean’s right and obligation to take a leadership role in the family. The family discussed and agreed on rules and consequences, and Jean was able to follow through on enforcement when Brent, the son who used drugs, broke what were perceived by her sons as the “family’s” rules.

It also became clear that Brent would most often use drugs and have unprotected sex following family arguments. In response, the therapist taught the family problem-solving and communications techniques to resolve conflict more effectively, encouraged Brent to notice what he did when he successfully avoided arguments, and encouraged the family to identify more positive things they might do together.

Family Responses to HIV Disease

Lippmann SB, James WA, Frierson RL. AIDS and the family: Implications for counseling. AIDS Care. 1993; 5(1): 71-80. (University of Louisville.)

Grief, fear of contagion, HIV-related stigma, role reversals resulting from illness, the difficulty of making final arrangements, and suicide are the major challenges for families dealing with HIV disease, according to a brief review article. Family therapy can counteract abandonment and guilt, provide HIV-related information that can result in greater comfort and optimism about disease progression, and provide the family with resource referrals.

The disclosure of HIV infection may reveal previously unknown behaviors such as drug use, homosexuality, or sex outside of a primary relationship. This may raise concerns about trust, abandonment, and the status of intimacy with a primary partner. As the ill person becomes more dependent, role changes in the family create strain and anxiety among family members. Vacillation in disease progression and symptoms may again alter roles, and this can increase tension, especially if family members are unwilling to change roles in response to changing conditions.

Open discussions, including HIV-related information, can alleviate many anxieties. Family input and participation in preparations for death or in decisions regarding life support can assist in processing grief as death draws near, particularly when the HIV-infected family member is well enough to participate in such discussions.