

# CHAPTER 4

## FAMILY ISSUES FOR PATIENTS WITH HIV/AIDS

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### GENERAL RECOMMENDATIONS:

**Practitioners should assess family configuration, functioning, and existing social support as part of the routine evaluation of patients who are primary caretakers of children. These assessments should ideally be done during times of stability.**

**Practitioners should be aware of the impact of single parent homes, same sex parent homes, and teenage parent homes where there is little to no adult presence.**

**Practitioners should refer children who present with behavioral changes in response to illness of a family member for mental health evaluation.**

As more women of childbearing age become HIV infected, HIV/AIDS increasingly becomes a disease that involves the family. Primary care practitioners working with HIV-infected parents should, therefore, be aware of the needs of their patients' families, as the burden of HIV infection becomes much greater when children are involved. By providing treatment and solutions for common problems found in HIV-affected families, primary care practitioners help ease the pressure on these patients.

Family members of an HIV-infected person also may face particular difficulties. When confronted with the knowledge of a person's illness or lifestyle, family members can become confused or angry. If not addressed, these emotions can be turned against the HIV-infected person. Children who are infected must cope with and adapt to their own chronic and perhaps terminal illness. They often lack the emotional maturity that can help adults, yet they still must try to deal with the psychological effects that the disease can have on them and their families. Similarly, children who live with an HIV-infected family member must bear the psychological impact of this situation. The impact can be especially traumatic if the infected family member is the child's parent or sibling.

Assessing the family's configuration, functioning, and existing social support should be a routine part of evaluating an HIV-infected patient who is the primary caretaker of children. Determining how a family functioned and how family members interacted before the patient was diagnosed with HIV infection will allow primary care practitioners to assess more effectively family problems that may develop over the course of HIV disease.

Components of a basic assessment can be compiled by asking the following questions:

- *Who makes up the household (including adults and children)? What are the relationships among household members?*
- *What are the ages of children and adolescents? If they don't live with the parents being assessed, with whom do they live?*
- *How do the patient's children and adolescents function? Are there problems at home or at school or during times of parent's illness?*
- *Are there people in the patient's extended families or social networks who can be called on during times of crisis?*

## **I. COMMUNICATING HIV STATUS**

### **RECOMMENDATIONS:**

**Practitioners should encourage patients with HIV infection to communicate with their children, family members, and significant others about the disease. If patients are reluctant to engage in these discussions, however, practitioners should respect their wishes** (see Section V: *Domestic Violence and HIV Infection*).

**Practitioners should consider referring patients with HIV infection for mental health or social services if they present with advanced HIV/AIDS without having informed their children and other relations about their disease.**

Communicating with children and extended family members can be very difficult for parents with HIV infection. Many parents appropriately choose to defer discussing their illness during the early stages of infection when health problems are minimal or nonexistent. As the disease progresses, parents may feel increased pressure to talk about the illness with children and family members, especially during times when parental functioning is disrupted (e.g., during hospitalizations or when the illness becomes debilitating).

Because parents may feel guilt or shame about behaviors associated with HIV infection (e.g., drug use, choice of partner), they may have difficulty communicating with their children and families about the disease. In addition, many adults believe that not telling children painful facts will somehow reduce the impact. Ultimately, children cannot be protected from the realities of parental illness and loss. Children need their parents to acknowledge the illness and to indicate, particularly as parents' health worsens, that the children's needs will continue to be met. Emphasis is usually placed on parents simply disclosing their HIV status to their children; however, children need ongoing communication concerning parents' health status and prognosis. Such communication could play an important role in decreasing children's anxiety and increasing their ability to adapt to parental illness.

Nevertheless, health care providers should respect the wishes of parents who are either unwilling or unable to explain the nature of their illness to their children. Parents should be encouraged to discuss the more general issues surrounding illness and prognosis with their children. If, however, during the late stages of HIV disease, parents are still unable to discuss the situation with family members, primary care practitioners should consider referring patients to mental health or social services. Often the complex mental health and psychosocial issues holding parents back from revealing the truth about their illness require ongoing mental health intervention before parents can open up to their children or families.

## **II. ARRANGING FOR FUTURE CARE OF CHILDREN**

### **RECOMMENDATIONS:**

**Primary care practitioners should refer parents to social service providers for assistance with formal and informal options, each having unique advantages and disadvantages, for the placement of children.**

**Primary care practitioners should also be aware of the permanency planning resources available to their patients** (see Appendix VI).

When preparing for the possibility of death, HIV-infected parents face the difficult task of planning for their children's living arrangements. Any such planning is best done by taking into account family wishes and resources. Options that involve family court or children's services can take months to implement and, therefore, should be considered early enough in the course of the disease so that the plan may be operative and available when needed. In general, this planning is best carried out with the help of personnel familiar with the various options available to parents.

## **III. SUBSTANCE USE**

### **RECOMMENDATIONS:**

**Practitioners should look for psychiatric problems, abuse, neglect, and trauma in families in which HIV-infected parents or other household members use substances.**

**For patients who are substance users, treatment planning should include the input of substance abuse counselors.**

Substance use and the resulting guilt, shame, and complicated family dynamics may significantly impair parents with HIV infection. When children and adolescents are involved, the communication and planning necessary to support the family during this critical time can become overwhelmingly challenging. To primary care practitioners, parents with advanced HIV/AIDS who have never addressed the issues that involve their children and other relations may present as having the most disorganized families with the greatest burden of psychiatric and substance use. Children and adolescents from this type of background may be at greatest risk for behavior problems and may need to be referred

for mental health evaluation. Children from more stable backgrounds may act out under the stress of living with an ill parent and may also require referral.

Families affected by substance use should be of special concern to primary care practitioners. Within these families, there is a strong possibility of pre-existing psychiatric disorders, abuse, neglect, and trauma, which are all difficult problems to treat, particularly when associated with HIV illness. As parents' health declines, pressures increase, and the family members' ability to cope in these situations can be severely compromised. Referral for assessment and care by a mental health professional may be necessary to maintain family integrity and stability. For more information, see *Evaluation and Management of Substance Use in HIV Primary Care*. Albany, NY: New York State Department of Health, AIDS Institute, 1995.

#### **IV. RECOGNIZING AND MANAGING ABUSE AND NEGLECT IN HIV-AFFECTED FAMILIES**

##### **RECOMMENDATIONS:**

**Practitioners should be aware of and should attempt to explore in a calm and respectful manner the possibility of abuse and/or neglect in HIV-infected families.**

**Whether or not the parent will become involved in attempts to ameliorate child maltreatment, primary care practitioners must report all cases of suspected abuse or neglect for further investigation to the New York State Central Registry at 1-800-635-1522.**

**If no physical evidence exists to support the suspicion of child abuse yet abuse is still suspected, primary care practitioners should enlist the aid of child protection teams, child and adolescent mental health clinicians, or social work staff with child protection expertise to help assess the case. Clinicians can call child protective services (Administration for Children's Services in New York City, Office of Children and Family Services in New York State) to consult whether or not they should report something when presentation is unclear.**

**Children who report or present with physical evidence of abuse or neglect should be referred immediately to pediatric personnel or to the pediatric emergency room in a hospital setting.**

Since abuse and neglect of children is more prevalent in families in which caregivers are actively and chronically using drugs and/or alcohol, practitioners should be focused on the signs of such trauma:

- **Physical abuse**—which may present as unexplained bruises or fractures.
- **Sexual abuse**—which is defined as any sexual act between an adult and a child or an older child and a younger child and which may present as urinary tract infection or sexually transmitted infection.

- **Neglect**—which is by far the most prevalent form of maltreatment and which is characterized by failure to provide basic needs, such as food, shelter, medical care, or schooling.

Because some caregivers will lie to cover up abuse or neglect, primary care practitioners should be observant in dealing with families in which abuse is suspected. Conclusions concerning abuse can be reached based on direct reports from children, observations of parents interacting with children, evidence of physical injury or neglect, or failure to thrive in infants. When primary care practitioners report cases of suspected abuse or neglect to the New York State Central Registry, they will be assigned a registry number and will be asked to complete the Report of Suspected Child Abuse or Maltreatment form (DSS-2221-A) including the assigned registry number. In New York City, this form must be forwarded to the Administration for Children's Services.

If necessary, the child who reports or presents with physical evidence of abuse or neglect may be separated from the abusive caregiver to ensure the child's safety. Steps such as having security guards accompany families to the emergency room may be taken to enforce cooperation.

## V. DOMESTIC VIOLENCE AND HIV INFECTION

### RECOMMENDATIONS:

**Practitioners should look for evidence of both physical and psychological abuse in relationships in which one or both of the partners are HIV infected** (see Table 4-1).

**Practitioners should respond to the victims of domestic violence in such a way that mental and medical needs are addressed without endangering the victims' lives.**

**Practitioners should use simple questions when screening for risk of domestic violence** (see Table 4-2).

**Treatment planning for patients who are victims of domestic violence should include the input of domestic violence advocates but only with the patient's consent.**

People who access HIV-related services are at high risk for violence, related both to disclosure of their HIV status and to their risk-reduction efforts. Individuals who are ill or disabled are also very vulnerable to an abusive partner's tactics. HIV service providers are often well positioned to offer both referrals and direct services to victims and to those at risk for domestic violence who may not contact other medical or social service professionals. Assessment for domestic violence is being recognized increasingly as a standard of care in providing HIV-related services.

Domestic violence may be either psychological (e.g., economic control, verbal degradation) or physical (e.g., rape, assault). Domestic violence occurs in both heterosexual and homosexual relationships at a similar rate. However, a higher proportion of victims of domestic violence sustain mental

health problems, particularly depression, suicide attempts, substance use/dependency, and post-traumatic stress disorder (PTSD), than that of the general population.

<b>TABLE 4-1 COMMON BEHAVIORS OF BATTERERS</b>	
If batterer is not the HIV patient	<ul style="list-style-type: none"> <li>• attributing violent behaviors to stress of caring for a partner with HIV/AIDS</li> <li>• intentionally isolating the partner by revealing or threatening to reveal his/her HIV status</li> <li>• denying the partner access to nutrition, services, assistance, or health care</li> <li>• refusing to let the partner be treated for injuries caused by battering</li> <li>• forcing the partner to undergo unnecessary treatment (including psychiatric referrals or hospitalization)</li> <li>• refusing to fill prescriptions or disposing of medication</li> </ul>
If the batterer is HIV infected	<ul style="list-style-type: none"> <li>• evincing no responsibility to the partner</li> <li>• using HIV/AIDS to control the partner by demanding excessive caregiving or playing on feelings of guilt</li> <li>• intentionally trying to infect the partner by refusal to engage in risk-reduction behaviors or to practice safe sex or by not informing the partner of the HIV infection</li> <li>• trying to get the practitioner to see the violence as a cry for help and sympathy (e.g., as a response to the illness, solely a mental health problem, a result of substance use or of earlier victimization).</li> <li>• blaming the partner for infecting the batterer, even if the batterer was actually the source of infection</li> </ul>

Simple questions should be used when screening for risk of domestic violence. Table 4-2 contains questions that are part of a screening tool jointly developed and widely circulated within New York State through a collaboration among the New York State Department of Health, the Office for the Prevention of Domestic Violence, and the Medical Society of the State of New York. They are consistent with screening questions recommended by the American Medical Association and others.

<b>TABLE 4-2 SCREENING QUESTIONS TO DETERMINE RISK OF DOMESTIC VIOLENCE</b>
<ul style="list-style-type: none"> <li>• Do you ever feel unsafe at home?</li> <li>• Are you in a relationship in which you have been physically hurt or felt threatened?</li> <li>• Have you ever been or are you currently concerned about harming your partner or someone close to you?</li> </ul>

## A. Referring Patients With HIV/AIDS Who Are Victims of Domestic Violence

### RECOMMENDATION:

**Practitioners should be aware that living with an abusive partner is not, in itself, a symptom of an underlying mental health problem and that many of the concerns of the victim are legitimate safety issues.**

Some victims of domestic violence find that the mental health problems abate when the abuse stops, whereas others need ongoing therapeutic assistance.

Safety should be the primary goal of all interventions. No action should be taken that places the patient in danger, regardless of its potential benefits. A practitioner's ability to respond to a patient's medical and mental health needs, without endangering the patient, will be enhanced if the practitioner remembers the following:

- Symptoms often reflect safety issues. Practitioners should not attribute these symptoms, or the fact that the patient stays in a relationship with a batterer, to underlying mental health problems.
- The practitioner should offer information about local domestic violence services whenever it is suspected or confirmed that a patient is being battered. With the patient's consent, the practitioner should collaborate with domestic violence service providers.
- Not all victims of domestic violence need therapy. The practitioner should not refer for therapy in lieu of domestic violence services. Referral for mental health services should be made if victims need or request them, but victimization should not necessarily be treated as a mental health problem.
- If there seems to be indication for mental health referral, the practitioner should refer the patient to individual therapy, not couples' counseling. Couples' counseling has great potential to endanger the victim (who may be beaten for saying "the wrong thing" in therapy) and reinforce the batterer's controlling tactics.
- The practitioner should always interview a patient privately, out of sight and hearing of his/her partner and children. It should not be assumed that an adult accompanying the patient is not his/her partner.
- The practitioner should ask patients directly whether their partner is hurting or threatening them.

- The practitioner should empathize with the patient's fear and confusion. Reassurance should be given that the patient's feelings are legitimate and normal, and he/she should be reminded that he/she does not deserve to be abused.
- The practitioner should not act without the patient's consent, including calling the police. New York State law does not mandate reporting of adult domestic violence; doing so without the victim's consent violates patient confidentiality. If, however, a practitioner is mandated to make a child abuse report, this should be done with the patient's knowledge and with attention to the patient's safety.
- The practitioner should avoid victim-blaming language in documentation.
- The practitioner cannot solve the problem, but he/she can provide ongoing support. The practitioner should support the patient's right to make his/her own decisions, including those with which the practitioner disagrees.

## **B. Referring Patients With HIV/AIDS Who Are the Perpetrators of Domestic Violence**

A practitioner's ability to respond to the medical and mental health needs of a patient who is the batterer without endangering his/her partner will be enhanced if the practitioner remembers the following:

- Most domestic violence service providers work with victims, not with batterers. However, because some batterers present themselves as victims, suspected batterers should be referred only to specialized batterers' programs. This is especially important in the case of lesbian batterers who can gain entry to shelters because they are women.
- Patients who are batterers should be referred for mental health (and substance use) services if they need them for other reasons, but battering should not necessarily be treated as a mental health problem. Batterers commonly use their attendance at counseling or substance use services as ways to manipulate their partners into dropping charges or remaining in the relationship. Being referred for mental health services when domestic violence is the only identified problem also supports batterers' attempts to deny responsibility for their behavior by implicitly attributing it to factors other than their own choice.
- When domestic violence is identified, practitioners should make the safety of the victimized partner the primary goal of all interventions.

Individuals who are battered will frequently deny any difficulties both out of fear of the batterer and a misguided wish to protect him/her. The patient's history and behavior may provide confirmation of the diagnosis (see Table 4-3).



**TABLE 4-3**  
**COMMON INDICATIONS OF DOMESTIC VIOLENCE**

<p>Common Presenting Problems and History in Patients Involved in Domestic Violence</p>	<ul style="list-style-type: none"> <li>• Stress and anxiety disorders including PTSD and panic attacks</li> <li>• Alcohol or substance dependence or use</li> <li>• Insomnia</li> <li>• Eating disorders</li> <li>• Fatigue, malaise, and vague or psychosomatic complaints</li> <li>• Chronic pain</li> <li>• Severe headaches</li> <li>• Depression</li> <li>• Trauma-related injuries</li> <li>• Suicidal ideation or attempts</li> <li>• Relationship problems</li> <li>• Exacerbation of chronic illnesses (e.g., asthma, migraines)</li> </ul>
<p>Behavioral Cues of Domestic Violence Victims</p>	<ul style="list-style-type: none"> <li>• Change in appointment pattern</li> <li>• Flat or incongruent affectation</li> <li>• Fearfulness toward partner</li> <li>• Apologizes for or rationalizes partner's behavior (even non-abusive behavior)</li> <li>• Bases plans and decisions on what partner wants rather than on his/her own wishes</li> <li>• Performs degrading, inhumane, or inappropriate tasks</li> <li>• Refers to partner's temper frequently</li> <li>• Focuses on how he/she harmed partner</li> <li>• Flees from home or seeks shelter frequently</li> </ul>
<p>Batterer's History and Behavior</p>	<ul style="list-style-type: none"> <li>• Suicide attempts</li> <li>• Intoxication, alcoholism, drug use</li> <li>• Aggressive or abusive toward partner, practitioner, or other staff</li> <li>• Overly attentive to partner</li> <li>• Cancels partner's appointments</li> <li>• Aggressively presents self as victim</li> <li>• Visible defensive injury pattern</li> <li>• Refuses/resents needed medical or mental health care for partner</li> </ul>

