Although several authors have addressed the matter of how children are affected when an adult caretaker has AIDS, most have focused on younger children, ages 3 to 10, rather than on adolescents. Even fewer authors have addressed the specific ways in which adolescents of different ethnic and socioeconomic groups respond to having a parent who is HIV-positive, or has developed full-blown AIDS. This case study examines the various therapeutic strategies used in working with the family of an adolescent Hispanic male street gang member whose mother was HIV positive, and whose father had already developed AIDS.

I first met Manny Lopez at a residential treatment center for males. Like most of the boys who came to our facility, he was placed with us by the juvenile court (in his case, for selling marijuana in school while under the influence of alcohol). He was in seventh grade, and barely 14 years old.

During our first few sessions, Manny responded to most questions with shrugs and one-word answers. He didn’t want to talk about his family, his neighborhood, or his life, claiming that he couldn’t remember anything before age 12.

Several telephone conversations with Manny’s mother revealed that his parents had little social support, and no transportation. When home based services were offered, she responded with some trepidation. “Okay...” she said, with a hint of reservation in her voice, “but did Manny tell you that his Dad and I are sick?” When I told her that Manny hadn’t mentioned their illness, there was a long pause before she said, “My husband has AIDS and I’m HIV positive, and I’m also recovering from stomach cancer.” She agreed to allow a home visit.

The home visit revealed that the Lopez family lived in the middle of the most crime-ridden district of the city. Mr. and Mrs. Lopez welcomed me by offering a glass of Kool-Aid. When I said I wasn’t thirsty I realized I had made a mistake by the look on Mr. Lopez’ face. I accepted the glass and noticed that Mr. and Mrs. Lopez both stared intently at me. When I took a sip, they smiled and began to talk about their lives. I later learned the significance of this interaction, when they told me they had friends and relatives who would not have touched their lips to the glass for fear of getting AIDS.
During the first session, I learned both of Manny’s parents had been addicted to heroin and crack cocaine for most of his life. They had both quit taking drugs “cold turkey” about a year and a half before, after learning that Mr. Lopez had developed AIDS and Mrs. Lopez was HIV-positive. During the past year, Mrs. Lopez had a tumor removed from her stomach, and had only recently ended chemotherapy treatments.

In addition to their health concerns, the Lopez’s were socially isolated because they had stopped associating with their drug using circle when they became sober. Mrs. Lopez’ family of origin had distanced themselves, considering Mr. and Mrs. Lopez “dope addicts.” Mr. Lopez had no available extended family. Both of his parents were deceased. Two of his brothers had also been heroin addicts, and had already died from AIDS. A third brother was serving an 8-year prison term for attempted murder, and the fourth brother had moved to another city and had no contact with him for nearly twenty years. Manny had two siblings. His older brother had been placed by the court with an aunt in another city. His 17-year-old sister had dropped out of high school and lived with her boyfriend, a 20-year-old gang member. The family’s genogram was filled with broken and jagged lines, and marked in all directions with substance abuse.

Mr. Lopez had made his living selling drugs, and he was a lifetime member of a well-known Hispanic street gang. Manny had been “born” into the gang, and had started selling drugs for his father when he was 9 years old. In addition, Mr. Lopez admitted that when he was drinking heavily, he had often been physically abusive to Mrs. Lopez, twice beating her so badly that she had to be hospitalized. Manny had witnessed many of these beatings.

“We were lousy parents,” Mr. Lopez admitted, “actually not really parents at all. We were high all the time, or sleeping. Our kids just ran the streets. It’s amazing that Manny got to seventh grade. We never made him come home at any particular time, made him do his homework, or made him go to bed on school nights or anything good parents do. We feel like it’s our fault that he’s in trouble now.”

Mr. and Mrs. Lopez wanted to learn to “try to be good parents for Manny, for once in our lives.” When we discussed ways to progress toward this goal, Mr. Lopez stated, “Well, you’re going to have to do it fast, because my doc says that with my white cell count I’m not going to make it for more than a year.”

Manny’s family faced multiple challenges, many of which, like spokes emanating from the hub of a wheel, revolved around the physical condition of the parents, and the nature of their illness (HIV/AIDS). The family faced severe social isolation at a time they needed assistance and support. They struggled to manage their grief associated with the multiple losses incurred by their illnesses. The reality that Mr. Lopez was likely to die in the next year was a bitter pill. These challenges had cast the family into the raging emotional river that Rolland (1994), describes as ‘anticipatory loss’.

The family also struggled to live under the stress of poverty and inner-city life. As Boyd-Franklin (1989) has noted, the challenges of poor inner-city families—unemployment, crime, violence, and so forth—is often accompanied by the intrusion of numerous outside systems and agencies into their lives. For families coping with HIV/AIDS, the medical system is also added to the mix. For many families this array of individuals and organizations coming into their lives can be overwhelming (Boyd-Franklin & Boland, 1995), particularly if the family is, in structural terms, underorganized (Minuchin, 1974).

At the beginning of our work, the Lopez family had three physicians, three home-based mental health counselors, and a social worker, nurse, and child welfare
worker. They were suffering from 'multi-systems fatigue.' The family dreaded another intrusion into their private lives. They often found that people who “wanted to help” made more demands on them rather than helping them cope with the demands they already faced. In addition, there was inadequate consultation and coordination between various providers, a common problem for HIV/AIDS patients (Bor, Perry, & Miller, 1989).

The Lopez family’s needs were overwhelming, and the various treatment providers struggled to find a way to connect with the family, and with each other. It was a problem to be addressed later in treatment.

Three months after Manny entered the treatment facility he was preparing to go home for his first overnight pass. His parents had come to campus earlier in the day for a family session. During the family session, they had laid out the ground rules for his behavior at home: no drinking, no smoking, no spending time with his friends in the streets, bedtime at 10:00 p.m. During our individual session after the family session, Manny seemed unusually agitated. He paced the floor, shaking his head and laughing.

“You seem upset about something,” I said. “Does it have to do with your overnight pass?”

“Yeah,” he replied. “All their damn rules. They never made any rules before. Now, since they been seein’ you, all of a sudden they want to come up with a bunch of rules about what I can and can’t do. That’s a bunch of bulls**t.”

“You’ve been living under stricter rules than that while you’ve been living here, so what’s the big deal?” I asked.

“Well, I expected rules here. But not at home. We never had rules at home, ever. It pisses me off.”

“Well, Manny,” I said, “your parents were using before. Now they’re clean, and they want to be good parents.”

Manny stopped pacing and sat down. He chuckled, then buried his face in his hands. His shoulders began heaving up and down, and I realized that he was sobbing.

“Why are you crying?” I asked.

“Because this is some kind of bad fu****g joke, man!” he yelled. “It’s like I ain’t ever had real parents my whole life, and now, I got real parents and they’re gonna die!”

Manny’s words suddenly crystallized and simplified the case for me. Manny had captured the essence of the problem in his realization that his long held wish for a “normal” family in which his parents took care of him was occurring too late to save his parents. It was difficult for him to risk engaging with them as parents while knowing that their illnesses were likely to worsen and that they were going to die. Manny and his parents were going through a developmental crisis. They all were trying to grow up, but death was interrupting the growth process for all of them.

Understanding the issues facing the Lopez family, our therapy found its focus. First, Manny’s parents needed a “nurturing alliance” (Mackey, 1996) with the therapist (me). The parents’ need for nurturing was obvious and profound. Mr. and Mrs. Lopez had both suffered abuse as children, and neither had developed a secure emotional attachment with their parents. Because both had become addicted to drugs in early adulthood, their adult development had been severely stunted. Emotionally, both of them were in many ways still in late adolescence. My job, as I saw it, was to facilitate the emotional growth of both parents and their child in the ever present shadow of Mr. Lopez’ impending death.

I realized that I couldn’t do this alone. It was necessary to identify and coordinate whatever support systems were available to Mr. and Mrs. Lopez—emotional, financial, and medical—to make my job easier. We needed to expand the family system.
The first step was to try to reinvolve as many of the Lopez’ extended family as I could. Mrs. Lopez’ parents agreed to meet me in their home. I listened patiently to their complaints about the Lopez’s lifestyle and their anger at Mr. Lopez for influencing Mrs. Lopez to become involved with drugs. They did express love for Manny noting that his troubles weren’t his fault. They vowed to do anything they could to help him. They agreed to work with Manny’s mother but were not willing to interact with Mr. Lopez, whom they couldn’t forgive.

Next, I contacted Mrs. Lopez’ older sister, who had custody of Manny’s older brother. She was somewhat less judgmental of Mr. and Mrs. Lopez, and expressed genuine concern about Manny. She agreed to help Manny, as well as Mr. and Mrs. Lopez, in any way she could, so long as Mr. and Mrs. Lopez remained drug-free.

Finally, I called Mr. Lopez’ younger brother, who had moved to another city. Unlike his older brothers, he had gone to college, and started his own business. Although he had “nothing to say” to Mr. Lopez, he wanted to help. He agreed to correspond via mail with Manny, and he offered to help Manny find a job if he graduated from high school.

In addition to connecting the Lopez’s with their extended family, I encouraged Mr. Lopez to begin attending weekly NA meetings. Although he was reluctant to go, he later said he enjoyed sharing his story with some of the younger addicts and wanted to return.

The second focus of treatment was to coordinate the various systems involved with the Lopez family. We started by discussing which services they needed and wanted, and which ones they did not. The Lopez family did not realize that they had a say in determining which, and how many “helpful” people would be involved in their lives. This conversation helped them develop a sense of agency; a family’s active commitment to, and involvement in their own care (McDaniel, Hepworth, & Doherty, 1992).

The Lopez family members, with the exception of Mr. Lopez, agreed that they wanted to work with no more than two physicians and one therapist. Mr. Lopez was adamant about wanting to continue to see three physicians, for reasons that soon became apparent. They also appreciated the biweekly visiting nurse services and transportation assistance. Although they didn’t feel they needed both the family’s social worker and Manny’s caseworker, they saw these as system requirements that they were obliged to accept. I contacted the various social service providers who agreed to visit them less often so long as they continued family therapy with me and each therapist received progress reports. I also worked with social services to improve their access to transportation.

I then (with the family’s signed release of information) contacted the three physicians involved with the case. One was the oncologist who had treated Mrs. Lopez, another was a general practitioner at the local neighborhood clinic, and the third was the physician at the local hospital who was treating Mr. Lopez for HIV/AIDS. In comparing notes with the three physicians, we discovered that each had been prescribing strong painkillers for both Mr. and Mrs. Lopez. It seems that, while Mr. Lopez had, indeed, stopped using heroin, he had transferred his addiction to legally prescribed painkillers.

When confronted with this information, Mr. Lopez admitted that he had been using not only his own prescriptions, but his wife’s as well, as she rarely had need for them anymore. That is why he didn’t want to reduce the number of doctors involved with the family’s medical care.

Both the clinic doctor and Mrs. Lopez’ physician agreed to transfer the primary responsibility for treatment of both Mr. and Mrs. Lopez to the physician at the Lopez’ local hospital. They agreed that only that doctor would write scripts for pain
medication as he deemed Mr. or Mrs. Lopez genuinely needed it. Having discovered this “family secret,” I was afraid that Mr. and Mrs. Lopez might be angry with me. However, Mrs. Lopez expressed relief, as she had felt guilt about being an accomplice to Mr. Lopez’ continuing addiction. Mr. Lopez, after grumbling at me for a couple of weeks, forgave me for “busting” him, and continued to attend his NA meetings.

Over the next year, family therapy focused on exploring the family’s experiences living in a gang culture, creating a family organizational structure, and helping the family cope with the parents’ illnesses. Mrs. Lopez’ sister participated in some sessions and brought Manny’s older brother, who had also become involved in gang activities. Manny’s older sister also agreed to attend sessions, “to get some things off my chest.” She was pregnant at the time, by a 20-year-old gang member.

When the family discussed their gang affiliation Mr. Lopez admitted that his old gang associates had shunned him since he was diagnosed with AIDS. He angrily described how they had done nothing for him or his wife; “I can’t even get a ride from them to the drugstore to pick up my medicine; not a one of them has called me and asked how I’m doing.” This was the first time his children had ever heard him utter a negative word about the gang.

As therapy progressed, Manny and his siblings began to voice their anger at their parents for their hurtful behavior in the past. Manny told of his rage whenever he recalled his father beating his mother. Manny’s older brother expressed his hurt and anger at his mother having “given up on me and giving me away” when he was young. Manny’s older sister told Mr. Lopez “you always made me feel like shit because I was a girl. I think the only thing you cared about was that I do what you told me to, and not get pregnant.” During these sessions, which took several months, Mr. and Mrs. Lopez needed help to resist the urge to verbally strike back at their children. We also worked to dispel the children’s unrealistic ideas of what “real” parents should be like. Manny, for instance, admitted that his idea of what “normal” families were like was based on the Bill Cosby Show.

Mr. and Mrs. Lopez were gradually able to accept responsibility for the pain they had caused their children. During the final session in this phase, during which both parents apologized to each child for letting drugs rule the family for so long, there was a sudden shift in the children’s affect. They began crying, and Manny’s older brother and sister cried almost uncontrollably. Mr. Lopez hugged his daughter as she cried, and Mrs. Lopez hugged Manny’s older brother, saying that she was so sorry that he had lived apart from her for so long. Finally, both parents and siblings wrapped their arms around Manny, and told him that they wanted him to “make something of yourself; Get out of this barrio and be somebody.”

The increased closeness and support of his family seemed to energize Mr. Lopez in his struggle against AIDS. He became meticulous about his diet, adopted a daily exercise regimen of walking around the block, and religiously took his medications. He prided himself on being able to attend family sessions at the residential facility without the aid of a cane or a walker. Despite his prognosis of only 1 year to live, he suffered only a gradual decrease in his white cell count in the first year and a half of Manny’s placement.

During the same year and a half, Manny continued to live in residential placement. He displayed a remarkable burst of intellectual and scholarly effort in school. To the amazement of his teachers, he completed the 8th, 9th, and 10th grade curricula in a year and a half. He was by then 16-years-old, and ready to enter his junior year in high school. His grades had been all A’s and B’s.
After this year and a half, Manny was discharged to home, with continuing home based family therapy weekly drug screening. He enrolled in his district's public high school, and signed up for a welding class along with his required courses.

Unfortunately, soon after Manny returned home, his father's health began to deteriorate. His bad days began to outnumber his good days. Mrs. Lopez struggled to care for him. She was becoming increasingly depressed, and Manny was beginning to shut down emotionally. Clearly, it was necessary to mobilize all the resources in the family system to deal with the stress of Mr. Lopez' worsening condition.

The extended family rallied. Manny's aunt agreed to let Manny's older brother come and live with the family. She also agreed to come to the Lopez home once per week to help. Manny's older sister agreed to stop by daily and help her mother with the housekeeping chores and to help her mother move her father around when he was too weak to walk.

Some of the in-home therapy focused on basic life skills for the boys. Because they had no experience doing either cooking or shopping (particularly on the family's small fixed income), I devoted several “sessions” to teaching them how to do those things. Interestingly, during these cooking lessons, Mrs. Lopez, and sometimes Mr. Lopez as well, would suddenly find the energy to come into the kitchen “to make sure the boys know how to season things the right way.”

As the family became more organized they were able to cope with the daily stresses of having a family member in the home dying of AIDS. Through these difficult times, Mr. and Mrs. Lopez continued to set limits on their two sons' behavior, including bedtimes and curfews. In addition, although the boys could have taken advantage of their parents' weakened condition to defy their rules, both boys, and Manny in particular, were compliant.

Manny and his family made it through his first 6 months at home admirably well. He finished his first semester in high school with passing grades in all his classes, and earned an A in his welding class. He also passed all of his weekly drug screens.

However, shortly after he began his second semester, Mr. Lopez began failing. There were still times, a day or two at most, when he was relatively strong and lucid. The Lopez family needed to take advantage of these times to begin to deal with his impending death. The family agreed they would ask Mr. Lopez to talk into a tape recorder and share with them, for posterity, the lessons he'd learned from life, the hopes and dreams he had for his children, as well as all the loving thoughts he had about them and Mrs. Lopez whenever he was physically able. Mr. Lopez said some of the nicest things he’d ever said to his family members while speaking into that tape recorder. He completed a 2-hour tape before he became too tired and weak to talk at all.

During the final weeks of his life he was in a local hospice for AIDS patients, and either Manny's aunt or Mrs. Lopez' parents would drive Mrs. Lopez and the children to visit him. He died the day after Manny finished his second semester.

About the same time Mr. Lopez passed away, my court-ordered aftercare with the family ended. Mrs. Lopez and Manny moved into her parents’ home. She took a part-time job at a nearby laundromat, and Manny started his senior year of high school. His older brother obtained his GED and had joined the Peace Corps. The last time I saw Manny, we visited his father’s gravesite. As we walked out of the graveyard, he rolled up his sleeve to show me his new tattoo that read, “I LOVE YOU DAD. R.I.P.”

CONCLUSION

The therapeutic approach to this multidimensional case, which transpired over a period of nearly 3 years, was founded on
the central idea that this was a family in which all members, parents, and children, needed nurturance. At the beginning of therapy, the therapist provided most of the nurturing, but the balance shifted to the family members over time. There were multiple key stages during therapy. First, therapy focused on overcoming the family’s isolation by involving more extended family members in the family’s struggle. Then, the family achieved a greater sense of agency by coordinating and reducing the outside systemic intrusions on the family’s life. As Mr. Lopez’s condition deteriorated, therapy helped the family organize to reduce the stress of a sick mother caring for a dying father, and to establish a functional parental hierarchy. Finally, at-home tasks helped the family cope with the anticipated loss of the father, and allowed him to leave a loving legacy of words for his family.

REFERENCES