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## Challenging Case

# Carlos: A 12-year-old Boy Discovers His Mother is HIV Positive

**CASE.** Carlos is a 12-year old Latino male who lives with his parents and his 5-year old sister. Carlos' mother is HIV positive. He was one year of age when his brother died of AIDS at the age of 3 years. Carlos' mother, who was severely depressed after his brother's death and continues to have episodes of depression, never informed Carlos about her HIV status. Carlos is HIV negative as determined by negative tests at birth and 18 months of age.

Carlos developed numerous behavior problems in the past year. He was referred to the Children's Art Therapy Group sponsored by the University of California San Diego (UCSD) Mother, Child and Adolescent Program. The group is attended by HIV infected and affected children. Carlos did not understand why he was attending the group and asked his mother who was HIV positive. The mother eventually disclosed to Carlos that she was HIV positive. Subsequently, he was quiet, withdrawn and expressed anger in the art therapy group. His teacher, who was concerned about ADHD behaviors and academic underachievement in the past, reported that inattentiveness, poor concentration and forgetfulness were increasing in the classroom and his grades were falling.

Carlos was referred to his pediatrician for an evaluation for ADHD. During the initial primary care appointment, a pediatric resident made a significant and positive impression on Carlos. The resident detected an underlying anger, and Carlos started to talk about himself and his family. The pediatric resident diagnosed ADHD, initiated medication, recommended classroom accommodations, and made a referral for individual therapy. Carlos continued to see the resident during monthly visits for monitoring ADHD treatment while encouraging Carlos to talk about home life, school and friendships. *J Dev Behav Pediatr 27:51–54, 2006.*
Index terms: *HIV, ADHD, disclosure, chronic illness.*

**Susan Okuno, M.S.W, L.C.S.W.**

HIV carries with it a terrible stigma, particularly for children and more so in the Latino community. The delay in disclosing HIV to the family is prolonged with the Latino families we see in the UCSD Mother, Child and Adolescent Program. The communication in Carlos' family was closed; the mother was unable to discuss HIV with Carlos and did not give Carlos opportunities to talk about his feelings. The Children's Art Therapy Group was the first chance that Carlos had to acknowledge this unspoken ''secret'' in the family. (Figures 1 and 2) In the beginning, Carlos did not like attending the group because it was a place where HIV was discussed, but the friendships he made in the group secured his attendance.

When Carlos learned that his mother was HIV positive, he became quite fearful that something would happen to her. He worried incessantly, his schoolwork suffered, and his attention problems worsened. Consequently, he did poorly in school, which contributed to his low self-esteem and withdrawn behavior. Carlos was angry. He was angry about his mother's HIV infection, and he was scared about losing her. He had few outlets to express his emotions.

Family studies on chronic illness in a parent show a strong correlation with behavioral and school problems, depression, anxiety and low self-esteem in the children. Maternal depression has been associated with problematic psychosocial outcomes during childhood and adolescents. In a study of 5,000 youth, the highest rate of depression was found in Mexican-American youth.[1] A recurrent theme of negative coping behaviors has been found in adolescents with an HIV positive family member identified.[2] The uncertainty, stigma, and secrecy experienced by HIV affected children compound the developmental process and affect emotional health and coping.[3]

The pediatric resident, who saw Carlos in his clinic, was a young male, and he was supportive and recognized that Carlos was in crisis and open to intervention. The resident's intervention gave Carlos concrete tasks for him to do that bolstered his self-esteem and sense of importance for the family. Task assignment as a technique in crisis intervention places control back with the person and in effect, relieves the crisis. The resident told Carlos that he needed to help his mom, do his homework, help in the house, be a responsible male figure. The resident was interested and engaged with Carlos who responded to the positive attention with increased self-esteem. Carlos improved his school performance, while ADHD behaviors decreased. The resident introduced the need for counseling/therapy and Carlos was receptive.

**FIGURE 1.** The face represents "a person with the virus (black) and a person without the virus (white). It doesn't matter if you have HIV. Inside the person is the same."

As seen in this case, pediatricians have the opportunity to assess the needs of HIV affected children, or children dealing with the loss or illness of their parent, and then to make the appropriate mental health referral. These children have overwhelming psychological issues and risks to their development that are often overlooked.

Carlos has multiple issues that will require intervention beyond the primary care setting. He will need to learn to live with uncertainty, stigma and secrecy related to his mother's HIV status. Carlos has been referred for therapy and the challenge is to find someone with whom Carlos feels ''safe'' to discuss difficult topics.

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## RECOMMENDED READING

The Uninfected Children of HIV-Seropositive Parents, HIV & Psychiatry: A Training and Resource Manual. Found at www.cpa-apc.org/publications/HIV/children.pdf

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## Mary Jane Rotheram-Borus, Ph.D.

Carlos, an early adolescent whose mother is living with HIV, demonstrates a common pattern of anger and adjustment problems at school when his mother disclosed her HIV infection. Carlos' adjustment problems persist for a considerable period and he is eventually diagnosed with Attention Deficit/Hyperactivity Disorder.

Carlos' experience is normative in many dimensions. He did not learn of his mother's HIV infection early, but she did disclose her diagnosis when he entered adolescence. Only 25% of young children know about their parent's HIV, while 75% of adolescents are told about the HIV infection.[1] Carlos' mother did not make an independent decision to disclose to her son. While he attended an HIV-related event, disclosure was triggered by interacting with peers coping with parental HIV. After a single disclosure, it is not clear whether his mother was prepared to discuss his reaction to her HIV status.

When parents disclose their serostatus, their children's adjustment decreases for about 3 years[1] and most parents stop talking about HIV within a year of learning their serostatus. With no one to discuss the meaning of his mother's illness, Carlos' behavior deteriorated. His adjustment problems included withdrawal from activities, decreased attention span, and diminished school performance. Compounding the problem, Carlos' mother was depressed for an extended period of time during his early years, which occurs in 80% of parents living with HIV. His mother's depression increases the likelihood that Carlos

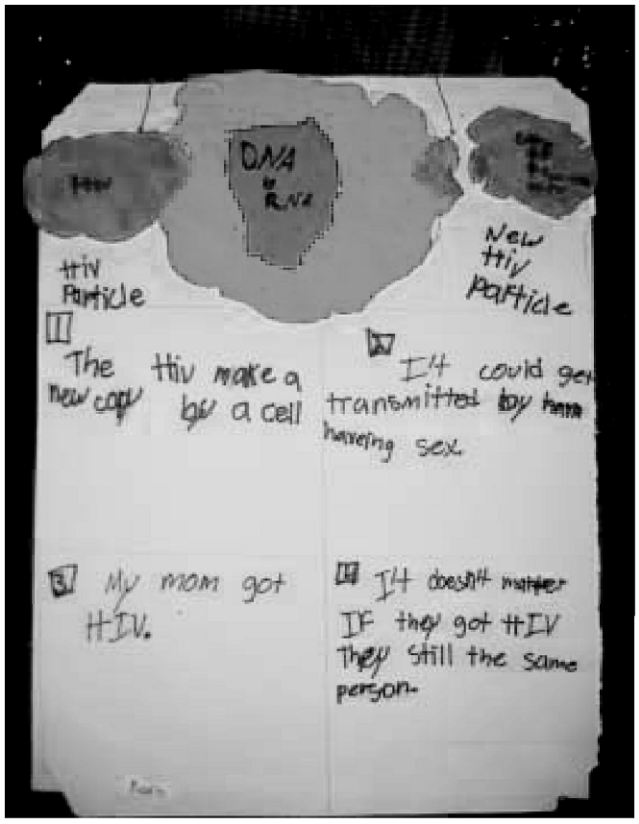


**FIGURE 2.** (See commentary by art therapist, Emily McCuthan)

will be depressed,[2] again similar to other children of parents living with HIV.

Both Carlos' experiences regarding disclosure and his reaction to his mother's HIV are common, as are the clinical treatments offered to Carlos. Healthcare clinics in the United States are organized to treat an individual's illness, not the family affected by a chronic disease. For a few diseases, we have recognized the importance of the family and developed family-based treatments—primarily for cancer, substance abuse, and mental illness. HIV is also a family disease,[3] yet treatment for HIV is not family-based. Clinicians do not anticipate that the children in families coping with HIV will face challenges of stigma, isolation, depression, and anxiety. About half of children in families with parental HIV will develop a psychiatric disorder.[4] When symptoms emerge, as in Carlos' case, the child is seen as maladjusted and receives an individual diagnoses, rather than being recognized as coping in a normative manner in a family facing a terminal illness.

Clinicians often treat with individual counseling because of inexperience with HIV-affected families and because there are few options. HIV is not a highly prevalent disease in the United States, so there are at best a few HIV-affected children in any one clinic. With more common diseases, it is easier to form multi-family groups to address shared concerns, challenges, and solutions to coping with illness. There are evidence-based interventions for families living with HIV.[5–7] When parents with HIV and their children receive small group training in coping with parental illness and forming new life goals, both benefit for about 6 years. Grandchildren are also better adjusted when a family intervention approach is delivered.[8] Carlos would likely benefit from a group intervention or even from support groups with peers whose parents are living with cancer, alcoholism, or mental illness.

Clinicians are challenged to recognize the interconnectedness of parental and child challenges in coping with parental illness. It is critical that children's stressors be anticipated and prevented before they emerge, as problems are far easier to address before they become routine. In particular, clinicians can help parents disclose their own illness in a manner that considers the children's (not the parent's) needs and to proactively anticipate stressful and potentially stigmatizing situations that their children will encounter.

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### Emily McCutchan

The mask (Figure 1) and the HIV collage project (Figure 2) suited Carlos's level of cognitive development which is more concrete than abstract. His words about the mask and the HIV story formed as his hands smoothed the plaster and molded the clay.

In the HIV collage storyboard project Carlos wrote a story of HIV transmission and made models of the virus. This project allowed Carlos to control the unseen enemy, HIV, which might kill his mother. He made HIV real and told the secrets of how it gets in and makes someone sick. For him there is power in the truth. He sees his mother as good and not defeated by the bad disease.

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### Chad Newell, M.D.

Although the patient was scheduled for an appointment to assess ADHD, I was informed about his mother's HIV positive status prior to the visit. I was also aware that this information was new and troubling to this patient. When I entered the room, Carlos was quiet; he avoided eye contact and had a restricted body posture. These initial observations informed me that a cautious approach should be used. In addition, although ADHD was the chief complaint, I decided that we should spend time talking about his behaviors in the art class and in school.

I explained HIV in terms accessible to an early adolescent, the general care of those with the disease, the importance of testing and disclosing of HIV status. Initially, Carlos refused referral to a counselor to help him deal with his mother's HIV disclosure.

I continued to be patient and tried to understand his resistance. I discussed with him his future plans – goals (for school, job and family), places he wanted to see, and things he wanted to do. I urged Carlos to think about what was best for him and arranged for close follow-up. When I returned after presenting the history and assessment to my attending, Carlos decided to follow-up with a counselor.

As a resident, this experience impressed upon me the importance of the encounter as an isolated opportunity that may never present itself again. There can be no reliance on the next visit. Patience and persistence need to be equally utilized to help our patients.

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There are two aspects of this case that are particularly instructive for primary care pediatricians: the challenge of a significant chronic illness in a close family member and discovering strategies to use the information to benefit the children; and the many ways ADHD can be interwoven into our assessments.

Other ''challenging cases'' published in this *Journal* highlight the significance of knowledge about a family beyond a superficial family history of medical illnesses.[1] It is especially useful during an assessment of complex behavioral problems. I have found the following areas of family history to be informative during a variety of different clinical encounters: parents' memories of their childhood, their experiences in school, their early friendships, and dreams for their child's future. The make-up of the household (who are the child caretakers?), an update on marital status, and recent or chronic illnesses are also important data. It is a reminder that ''the family is the patient.[2,3]

Growing up in a home with a mother who suffers from recurrent episodes of depression is a psychological burden and risk as pointed out in the commentaries. A parent with a major depression increases the risk for depression in children and adolescents. In addition, the relationship between Carlos and his mother was likely affected by the secret she kept for so many years, a secret associated with the HIV related death of his brother when Carlos was an infant. Her guilt and grief likely contributed to her inability to disclose her HIV diagnosis to her son. This case of delayed disclosure is probably not unique. With improved pharmacological therapies and supportive care systems in developed countries, HIV/AIDS has become a chronic illness with more parents living longer lives. These changing disease demographics are in contrast to the estimated 15 million children worldwide who have lost at least one parent to AIDS; fewer than 10% HIV positive women get treatment.

Core features of ADHD—hyperactivity, impulsivity and inattentiveness—can be seen in many conditions other that ADHD. Biological, psychiatric and environmental conditions may be associated with one or all of the core ADHD behaviors.[4] They represent a common behavioral pathway for many disorders and environmental conditions. Carlos had symptoms of ADHD in school prior to the disclosure of HIV; the behaviors exacerbated with increasing poor academic performance following the disclosure. An elaboration of his ''numerous behavior problems'' during the year preceding his knowledge of his mother's HIV status will provided insight into his psychological state prior to the disclosure. In consideration of his mother's history of depression, a comprehensive interview with Carlos is necessary to evaluate mental health conditions. In addition, maternal HIV is associated with substance abuse. A history of fetal alcohol exposure (as well as other substances) is important in addition to looking for evidence of somatic features of fetal alcohol syndrome on physical examination. With these considerations, it would have been reasonable to delay the treatment for ADHD until a more comprehensive psychosocial assessment was completed.

The pediatric resident did the right thing when he recognized that he had an opportunity to talk to Carlos about his current feelings and future plans as a way to prepare him for a referral to a mental health counselor. As important, he arranged to continue monthly appointments with Carlos to maintain continuity, monitor ADHD treatment and provide supportive care.

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