Secrets & Lies

Telling kids they have HIV is a parent's worst nightmare.

February 1, 1999 By Steve Friess

Nina Buffa had Lyme disease. That was why she went to the doctor so often for blood tests. Why she took antibiotics with every lunch. Why she was forced by her mother to drink bizarre cabbage-and-grapefruit-juice cocktails every morning.

Or so Nina believed -- even as she watched her baby sister and then her mother succumb to AIDS. On her deathbed, Nina's mom insisted to her 12-year-old daughter, "You're the lucky one in the family."

Nina, now 15, never questioned the lie set forth by her mother and perpetuated by relatives, family friends and even doctors in her rural Howell, New Jersey community. "It turns out I had HIV from birth, but she was my mom, so I never second-guessed her," Nina says, laughing bitterly.

Her mother always claimed that the elaborate deception was an act of protection, an attempt to shelter Nina from the perceived hardships of being HIV positive and to avoid the dreaded moment when Nina might blame her. And yet, far from protecting Nina, the lie endangered the girl, keeping her from any prescribed anti-HIV treatments or advice on healthy living. Instead, as Nina's mother fed her antibiotics and weird drinks, the child's CD4-cell count tumbled to 14 by the time she was 12.

Nina discovered the truth six months after her mother's death, when she was diagnosed with tuberculosis. It was her first HIV-related symptom, and the family friends who became her guardians instructed a doctor to tell her the truth. The news enraged Nina -- she remembers racing through the halls of the doctor's office and screaming at her guardians in the waiting room. Even now, three years later, Nina recalls a sharp sense of betrayal: "Think of all the stupid stuff I could have avoided if they had told me! How many times did I fall down and bleed and have someone help me who wasn't wearing any protection? Why didn't they tell me?"

It's a question with complex answers, and Nina's experience, while extreme, is by no means unique. Hundreds, if not thousands, of children are thought to be in the dark about their HIV positive status or that of the adults who care for them. As in Nina's case, the secrecy can wreak havoc on kids' bodies and minds. "It makes it difficult to provide good care," says Jerry Cade, MD, an HIV specialist in Las Vegas and a member of the Presidential Advisory Council on HIV/AIDS. "Maybe years ago there wasn't much faith in treatment, but now we can keep children healthy for

years. If they don't know, it can cause real problems for them and for their doctors."

Lori Wiener, PhD, coordinator of the Pediatric HIV Psychosocial Support Program at the National Institutes of Health (NIH), calls the decision of whether to disclose a child's HIV status "the greatest struggle that a parent can have. Not only are they disclosing a life-threatening disease, but that one disclosure often leads to another."

The dilemma burns up computer screens day after day on an America Online chatroom for parents called "Positive Living." There, a whole range of disclosure questions arise, be it how to tell a child she is HIV positive or how to explain that a parent has AIDS. Sheltered in anonymity, chat-group parents like Gina of Hartford, Connecticut, express their anxiety at the prospect of addressing the matter with their kids. Gina got HIV through sex with a bisexual boyfriend, and passed it on at birth to her daughter, now 7. "Talking about gay sex with a young child is not appropriate, but that's what I may have to do," she keystrokes one night. "I think it may just be easier not to bother, to make something up until she's older."

Psychologist Nancy Heilman, PhD, who worked with Wiener for three years at NIH, estimates that at least 25 percent of the children and adolescents with HIV at the NIH clinic don't know their diagnosis. No researcher has determined how many of the nation's more than 8,000 children with HIV are unaware of their status, but Heilman believes that the figure is likely higher than her NIH experience suggests. At NIH, she says, patients are generally more aware and ask more questions amid its AIDS-friendly atmosphere.

Still, no expert could identify a pattern that makes disclosure more likely -- whether families live in rural areas like Nina's, isolated from services, or in cities, where black children comprise more than half of the nation's pediatric AIDS cases. "I'd say about a third of the time, families actively struggle with this," says Donna Futterman, MD, of Montefiore Medical Center's Adolescent AIDS Program in New York City. "Rich or poor, black or white, I doubt it's easy for anyone."

Jodie Moss lives far away from the world of NIH, in a working-class suburb of a city in the Southwest she doesn't want named. As I speak to her, she rests her head against the windowpane in her den, glancing out with a bittersweet smile at the backyard antics of her 7-year-old son, Matthew. The boy, breaking in his new Louisville Slugger, just cracked a curveball over his father's head and is rounding the makeshift bases with flailing, celebratory arms.

"He's so normal, living such a happy life," Moss says, turning away and sipping from a steaming mug ringed with red letters that spell out World's No. 1 Mom. "Even though I know it's important to tell him," she says in a whisper, "I just can't bring myself to take that away from him. I don't know how I would explain it."

Moss knows there will be plenty to explain later on, a prospect that terrifies her. One day, she'll have to tell Matthew that he has HIV, that this status carries with it a social stigma and that there's no cure. Even worse to Moss, though, is her conviction that she'll have to tell her child why.

"Can you imagine having to tell your kid that he's got this damn disease and that you gave it to

him?" she asks. "I love that boy more than anything else on earth, and I have to sit him down someday and say, 'Matthew, you're gonna be this much away from dead your whole life, and it's all because your momma was high and horny.' Boy, is he gonna love me or what?"

Matthew, for his part, is oblivious. The chunky, freckled boy with his mother's curly, tomato-red hair storms through the den and heads for the kitchen followed by a tail-wagging white Siberian husky named Drake. He summons Mom to serve up a glass of iced tea and asks whether she saw his last hit, the one his father is still fishing out of the bushes. Moss looks at the cactus-shaped clock and, realizing it's time for Matthew's "vitamins," lays down his doses of ddI, 3TC and Crixivan next to a plate of Nilla wafers. To Matthew, who has no siblings, gobbling down the meds are as typical a part of life as his regular doctors' visits and blood tests.

Moss and her husband, Paul, are paralyzed by a lack of easy options. They want to tell their son the truth, but they can't be sure how much he would understand. They fear that he'll blame his mom, and this fear has created a strain that shows in the premature crow's feet that bunch around Jodie's eyes.

While little research has been done on the problem, Wiener and Heilman have compiled data that suggest the rejection, hopelessness and confusion that parents fear rarely materialize. Their study of 99 parent-child pairs shows that most children who later found out their status said they wished they had known immediately. But parents tend to wait at least two years after diagnosis to disclose it. In a 1996 paper on the study published in the journal *Pediatric AIDS and HIV Infection,* Wiener and Heilman conclude, "Most parents and children did not regret or feel damaged by the decision to disclose."

That's common sense to parents who have disclosed from the start, like Pat Broadbent of Las Vegas. Her 14-year-old daughter, Hydeia, understood her diagnosis so well that she was caught by a TV camera at age 6 explaining what HIV is to a playmate (see "She's Come a Long Way From Baby," *POZ*, October 1997). She's even contributed to *Be a Friend: Children Who Live With HIV Speak,* a compilation of writing and art by children ages 5 to 15 that Wiener says some parents use to help kids comprehend.

Pat Broadbent says she can't imagine having hidden this information from Hydeia as the child bounced between hospital visits and treatment protocols. "You want your child to participate in her own care, and you can't do that unless she knows," says Broadbent, who suggests that she may have felt less burdened by disclosure since Hydeia was adopted. "It was never a secret, anything to be ashamed of. It just always *was.*"

Most experts believe kids with HIV already sense the truth but take their parents' silence as a message that they should be ashamed or worried. "I am of the philosophy that kids can face scary things more easily if they can name and understand them," Futterman says. "It's very obvious when there's something people aren't talking about. That makes it much more frightening and teaches that there's something so big and terrible in their lives that they can't even talk about it."

And Wiener says full disclosure isn't always necessary right away. "For certain children, saying,

’We’re taking vitamins to stay healthy and strong’ may be all that child needs to know,” she says. “You only have to give enough information to help the child understand his or her day-to-day experiences. You can add to that later.”

More important is opening the communication lines, because parents otherwise risk losing the trust of their children. “When a parent lies to a child or doesn’t give any information, the child may come back later and say, ’What else haven’t you told me?’” Wiener says. “I’m not concerned that the child knows it’s HIV and HIV leads to AIDS and the whole virology. But I’m concerned about the best health of the parent-child relationship.”

Keeping quiet is a gamble Shelley Harrington-Buster of Gulfport, Florida, is happy she didn’t take for long. Harrington-Buster withheld her son’s diagnosis until he was 7, but found it impossible not to let Ricky know as his father lay dying from AIDS in 1988. Says Harrington-Buster, who is also HIV positive, “We kept it from him because I simply did not know how to tell him. I didn’t want him thinking he was going to die. Then one day he says to me, ’Mom, I have AIDS, don’t I?’ I was wigged out.”

Yet in keeping with Wiener’s observations, young Ricky didn’t want to know as much as his mother thought he might. “He just wanted some simple answers,” Harrington-Buster recalls. “I told him that yes, he had this disease, that Mom and Dad had the disease, and [his now-deceased adopted sister] Autumn had the disease, but his [11-year-old] brother did not. And I said we were going to take a lot of medicine to make us feel better.”

From then on, Ricky, now 17, demanded he be kept abreast of his situation. “I was brought up like an adult, always knowing,” he says. “I was definitely interested and wanted to know more about it. I was there for every conversation. But no, I never blamed anybody because there’s no reason to. That wouldn’t help anything.”

Many doctors encourage parents to disclose to HIV positive children, but they can’t always force it. Heilman remembers one case at NIH in which a 15-year-old girl had been HIV positive her whole life and the mother refused to tell her. In protest, some physicians refused to treat the child. “We all tried to address it, but she just knew it would devastate the daughter,” says Heilman. “The mother accompanied the girl everywhere, and no one was allowed to see the girl alone.” In some states, laws would have forced that mother to disclose. In Washington, for example, where Heilman now practices, 14 is the age at which a child must consent to any medical procedures.

Wiener and Heilman say new AIDS treatments and increased societal acceptance of people with HIV should relieve parents of some of their fears. A mother now has reason to believe that her child might not die from HIV and could experience a relatively healthy childhood, they say. These changes could make disclosure issues less grave.

But Sylvia York of St. Louis remains unconvinced. York has a 2-year-old son with HIV, and even as she assumes she’ll tell him when she thinks he can understand it, she fears damaging his outlook on the future. “I don’t care how many drugs there are and how many made-for-TV movies they make,” York says. “We’re talking about the life and death of a child here. How could that ever be

an easy thing?”

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/Secrets-Lies-1461-4687