

## **BEING HIV POSITIVE: A LOVE STORY**

One of the very unique aspects of being a physician, specializing in fertility is the fact that we usually only deal with healthy patients. Women with major medical problems rarely try to conceive and, even less frequently, will go through the effort of pursuing fertility treatment.

Exceptions, however, occur and this is the story of one of the more extraordinary ones.

Tara and Holden seemed like your average African-American couple when they came through the door of my consultation room in New York City. She was 36 and he was 42 years old. Tara had no children, while Holden had three from previous relationships. They were married for 18 months but had been together for over five years. Tara was known to have severely diseased fallopian tubes and they, therefore, had come to pursue in vitro fertilization (IVF).

Their infertility history was not that different from hundreds of others, except that – both Tara and Holden, were HIV-positive.

In every infertility practice, alarm whistles and lights go off, whenever a patient with a contagious disease shows up. Hepatitis is bad enough! But HIV?!

Many IVF programs will simply not accept HIV-positive patients with the explanation that their laboratories are not properly set up to prevent the possible contamination of other patients' embryos. This is, of course, just an excuse since standard IVF laboratory guidelines mandate that human specimens, at all times, be handled with appropriate infectious disease precautions. In lay terms this means that all sperm, eggs and embryos should be treated as if they had come from a hepatitis or HIV-infected person.

Paradoxically, most IVF programs that do not accept HIV-positive patients will accept hepatitis - infected couples, despite the fact that the hepatitis virus is significantly more infectious and, therefore, an easier vector of contamination, than the HIV-virus.

The courts, including the U.S. Supreme Court, have repeatedly opined that a health care provider's refusal to provide service to an HIV-infected patient, because of the individual's HIV-status, is discriminatory, and many professional organizations have followed suit in their published guidelines. Nevertheless, offering fertility services to HIV-positive patients appears to represent a different cost-benefit calculation than providing life saving surgery or even dental care. Dental care, in fact, was the circumstance that led to the Supreme Court's decision that the refusal to provide care to HIV-positive individuals was discrimination under the Americans for Disability Act.

In helping HIV-positive patients to conceive, we are not only supporting their own personal needs and wishes but also assume responsibility for their offspring, conceived as a consequence of our treatments. If a mother is HIV-positive, her child carries a significant risk of being born HIV-infected. Modern treatment of pregnant women has decreased this risk remarkably but has not eliminated it. Is it ethical to help establish a pregnancy and then see a HIV-infected child born as a consequence of our medical treatment?

Furthermore, is it ethical to help bring children into this world who's parents are afflicted by a deadly disease which, most likely, will lead to their premature death, maybe, while the children are still little? Are we, therefore, simply helping to create orphans?

There is, of course, no simple answer to any of these questions, though, as the courts have stated, the right to reproduction is a basic activity of life which cannot be withheld from mentally competent individuals who wish to have children.

I had seen a considerable number of HIV-positive men and women in my practice. But never before had I encountered a couple where both partners were infected. Paradoxically, this unique situation simplified some of the more complex issues which we have to face when only one partner is HIV-positive. Though, in many other aspects, we would have to break new ground.

It is not uncommon to see couples where the male is infected and the female is not. In such a circumstance, receiving infertility treatment, either through inseminations or through IVF, with the use of the infected partners semen, of course, creates a risk of infection for the wife. Studies have shown that this risk is relatively low with inseminations and almost completely absent with IVF. However, can or should even the smallest risk be taken in such a situation, creating the possibility that the act which will lead a woman towards motherhood, potentially also may lead her into death.

Is such treatment ethical when alternatives exist? There is, of course, semen donation as an absolutely safe alternative. It, however, obviously, does not allow for the male partner's genetic paternity. I still remember my first such case in Chicago in the late 80's. In those days, nothing was known about the fact that the degrees of risk to get infected, was depending on viral load, an acronym for how much virus was circulating in blood and/or semen. No studies had been performed to assess risk at all and, consequently, nobody was willing to work with HIV-infected semen. Using the semen of a HIV-infected male was, therefore, never an option. My first couple, consequently, chose to use the semen of the husband's brother to at least partially reflect the husband's gene pool in their offspring.

Such options exist, as do thousands of very carefully screened donor semen samples, frozen in respectable sperm banks all over the country. Since semen, in contrast to eggs, can be reliably frozen, recipient couples have considerable choice in selecting a suitable sperm donor. Considering this fact, is it ethical to use the potentially unsafe semen of the partner?

I have also seen couples where the female was infected and her partner was not. In many ways, this represents ethically the easiest case scenario: Fertility treatment will in such a circumstance, never create a new risk of infection for the uninfected partner. Moreover, especially if the relationship between the partners is stable, one has at least assurance that one parent will survive and be able to raise the child.

But this is, of course, not the case when both partners are HIV-positive.

As I now was listening to Tara's and Holden's detailed medical history, I learned that I had met Tara, in fact, once before. Approximately three years earlier, before they had gotten married, Tara had come to see me at our New York office for a single, brief consultation. At that time, she was unemployed and did not want to pursue IVF since she did not have insurance coverage, nor could she afford it on her own. While I had no specific recollection of meeting her, my notes reminded me of my recommendations and of the discussions we had about alternative treatments.

Amongst different options, we discussed the possibility of recannalising her obstructed tubes with a transvaginal catheter procedure. This represented a very successful treatment option for carefully selected women. My notes reflected, however, that I did not feel Tara was a good candidate for the procedure and that I had advised against such an approach. The chart also reflected the fact Tara was HIV-positive but not that her partner was positive as well.

Tara apparently had gotten infected from contaminated needles when she was a drug user. When I saw her for the first time, she claimed to have been drug-free for over two years and was being followed for her HIV-status by an excellent academic medical center in upper Manhattan. By coincidence, that same medical center was at that time also conducting a research study, involving HIV-infected males who wanted to pursue IVF. I thought they might be willing to consider Tara for their IVF program and, thus, recommended her to contact the program chairman.

I never heard from Tara again, at least I thought so – now sitting across from her and Holden. As we were reviewing their past medical histories, I was, however, in for another surprise: Tara had taken me up on my referral suggestion and had contacted the Manhattan medical center shortly after our initial encounter. While she was invited for consultation, she then was told that she did not qualify for the program because both partners were HIV-positive. Had only Holden been affected, they would have been eligible and would have gotten an IVF cycle free of charge. Since Tara was positive as well, she was told that “they were not set up to deal with their problems as a couple” and she was not given access to the program.

Tara had been “on every hard drug you can imagine,” as she used to tell me repeatedly, until in her fifth or sixth rehab program she had met Holden.

Holden, in turn, had a very different history. He had been a New York City cop who one day discovered that he had joined the other side. His second marriage had failed. There were two wives to support, three children, and never enough money, or time for closeness. One day it was just so much easier to throw everything away. No more responsibilities, no more stressful work, just the good feeling of cocaine and heroine.

When Holden met Tara, it was after overdosing a number of times, sometimes accidentally, sometimes on purpose. He resented waking up in those same emergency rooms where everybody used to know him as a cop, when he “used to make fun of all those homeless derelicts who had nowhere else to go.” Now he was a homeless derelict, himself, and, maybe, even a little bit more so, because he basically knew better. Many of the others, he knew, were mentally ill. He wasn’t!

He knew exactly where and when he contracted the HIV virus and, while, maybe, he didn’t do it on purpose, he truly didn’t mind. Life had ended a long time ago, and “a little bit of HIV did not make much of a difference anymore.”

It was one of the emergency room docs who knew him from his days as one of New York's Finest, who finally convinced him to be admitted for an in-hospital detox program. As Holden explained this part of his history, "I would never have agreed, had I not been so scared out of my mind when Dr. Luther grabbed me and insisted that I admit myself for rehab." He went on to say, "I lived on the street, had no friends, no family, no food, no drinks and no money to buy drugs. I was ready to steal but I was not ready to kill somebody to get high. So what was there left to do? I checked myself in."

Dr. Luther probably saved Holden's life. While in the hospital for detoxification, he for the first time started receiving comprehensive medical care for his HIV infection. He was started on protease inhibitors, "his new cocktail" as he called it and showed a dramatic response in viral load. After only a few months of treatment, his HIV virus became practically undetectable in peripheral blood. Its "Magic (Johnson) and me," Holden started to boast, "we will outlive you all!"

Social services arranged foundation-supported housing for Holden, once he was discharged from the hospital. It was just a small room, with the toilet down the hall, but it was the first roof over his head in years and, more importantly, it was "his." Social services also had linked him up with an outpatient drug detox program, where he continued to attend services two to three times a week and where, on what probably ended up to be the most important day of his life, he met Tara.

Shortly after meeting Tara, he applied for his first job in many years as a security guard on a construction site. He was actually amazed when he was hired and, as he told me, "will never forget when I picked up my first paycheck." Holden continued working for the construction company and, by the time I met him for the first time in consultation, had become the assistant director of security, responsible for close to 20 men and women. He made a good living and was even able to send some money monthly to his two prior wives in support of his children. He saw his children regularly and noted to me "how amazingly and quickly they had grown up," while he, as he repeatedly stated, "had temporarily checked out from their world."

Tara had come into rehab through a much more circuitous route. She was first introduced to drugs at the tender age of 12, when an older half-sister gave her a joint to smoke. By age 14, she had experienced it all, and by age 15 she had abandoned school, left her mom's house and had moved in with a part-time drug dealer, part-time aspiring musician, 14 years her senior.

Photographs she showed me from that period demonstrate a precocious teenager who looked much older than her age, with the very obvious life experience of a woman. Those pictures show her in revealing dresses and skin-tight pants and T-shirts. Despite her young age, she was obviously aware of her mature sexuality and had no hesitancy in flouting it.

The relationship barely lasted two years. As soon as her partner encountered modest success as a musician, Tara was “dumped,” as she described it to me. “One day he came home and told me to get out of the apartment, right then and there. He grabbed all my clothes, threw them into a heap on the floor and told me to be out of there within five minutes.”

Within five minutes, Tara found herself on the street without a roof over her head, without money and without friends since “all of our friends had been his and nobody wanted to deal with me once he had kicked me out,” she explained.

“Drugs had never been a problem during the relationship,” she told me, “because V. was always dealing, even when he started getting gigs on a more regular basis. We, therefore, always had all the stuff I needed around the house and I never had to worry about where to get the next high from.”

This changed, however, abruptly once Tara was on her own. “Suddenly I had no home, no money, no drugs to get high and no money to buy drugs to get high,” she continued, “and I was barely 18 years old.”

The next 13 years were, more or less, a large blur for Tara. She remembered certain episodes during that time period in very much detail and had absolutely no recollection about others. I was never able to determine for certain whether she, in fact, had amnesic periods in her memory or simply did not wish to remember and/or discuss the most painful episodes in her life.

What became obvious, however, even from those memories she was still able and willing to communicate, was that those years had to have been hell. It did not take very long after leaving V's house, before Tara was supporting herself through prostitution. "It was the only way to make enough dough to pay for a roof over my head and for my highs," she explained. Over the ensuing 13 years, Tara went in and out of prostitution, was arrested innumerable times and entered drug rehab programs, mostly involuntarily and mandated by the courts, at least half a dozen times.

At some point, Tara did not recall when exactly, she was found to be HIV-positive. She didn't know whether she had acquired the virus through prostitution or drug use. And she didn't care! Even though she was counseled about the risk of transmitting the disease to others, she continued on the street and continued to share needles. "God only knows how many people I infected," she told me one day with obvious trepidation in her voice. "I wish I had done this differently, believe me, I wish I had had a different life."

Her life did start turning around with her last arrest. She was booked for possession of a controlled substance and prostitution, after cops raided a dingy hotel where Tara used to pursue her trade. Because she was a repeat offender and because the judge felt that she had seen her one time too often, Tara was sent to jail for six months. In jail, Tara for the first time went through an uninterrupted detoxification process. Even though drugs were available inside the jail, she did not relapse. She credited her ability to withstand all temptations to her newly found faith.

A catholic priest had befriended her in prison, she told me. "God, through him,

helped me turn my life around.” After serving four months in jail, Tara was discharged early because of good behavior. She first was placed into a halfway house, where her freedom to come and go was still strictly supervised. Regular drug checks were one condition of her probation. Catholic charities hired her as a receptionist and paid her tuition to obtain a high school diploma.

“The day I received my high school diploma, at age 34, was the proudest day of my life,” she told me on many occasions.

Her job came with comprehensive health care benefits, which allowed her to pursue appropriate treatment for her HIV-status. She, too, was placed on protease inhibitors and responded magnificently by reducing her viral load levels to an undetectable range. When her physicians declared her virus-free, Tara, decided to go on to the next step in her life and have a baby. This was when she came to see me. At that point, Holden had already become her “social partner,” as she called it.

As different as their histories were, the similarities were only too obvious. Here were two individuals who had been eaten up and spit out by their respective worlds. They had fallen as low as one could fall and had miraculously survived against all odds. Yes, they were HIV-positive, but so what? They were taking their medication, even if the side effects, at times, were difficult to tolerate. They both were holding jobs of responsibility, they were earning good money, they had a roof over their head, actually a nice house in West Harlem on 139<sup>th</sup> Street, their health was stable, they had been off drugs for years and they even had a little money saved.

Why not have a child now?

After being rejected from entry into the program at the Manhattan medical center, Tara was desperate. At that point she did not yet have any savings, her insurance would not cover IVF, and Holden was also not yet in a position to help her. She decided to be resourceful on her own and, through the Internet, researched the treatment of tubal

disease. In doing so, she came across a number of research papers on the recanalisation of obstructed fallopian tubes, using transvaginally applied catheters. Many of these papers were, in fact, written by me and one of my Chicago colleagues, Dr. Vishvanath Karande. Since she knew that I had recommended against such a procedure, she was hesitant to call me once again. Instead, she decided to make, unbeknownst to me, an appointment with my colleague, Dr. Karande, in Chicago. He tried his best but, as I had suspected, her fallopian tubes turned out to be too damaged for repair. She needed IVF.

Shortly after this failed procedure, Tara and Holden got married. They asked their friends to refrain from buying any gifts and requested, instead, contributions to what they called their “baby fund.” This was a separate bank account into which they started to deposit every extra dollar they could afford to save up to be able to afford an IVF cycle.

By the time they came to see me a second time, they had saved more than enough to start infertility treatment. I will never forget Tara’s jubilant face when she finished telling me the details of their story and pulled out of her bag a savings book from her local bank to make that point. “Here is my baby,” she said, pointing the book at me, and it was obvious that she meant it!

Because we never before had treated a couple where both partners were HIV-positive, I decided to take the case for discussion and approval to our Weekly Conference. Once a week, we get all of our physicians from the Chicago and New York offices, and all of our senior nursing and embryology staffs on a conference call, where unusual cases, complications and adverse outcomes are discussed. When I presented the case, there was obvious concern, primarily with their respective health statuses and in regards to life expectancy. We, therefore, decided that, before we would take them into an IVF cycle, they had to meet a number of additional conditions: We required a letter from their respective infectious disease physicians, confirming their low viral loads, and specifically stating that they saw no medical reasons why they should not pursue pregnancy. We also required that both undergo psychological screening, followed by a

letter confirming the good state of their mental health, and we requested that Tara undergo a general physical examination by an internist to verify that she was in good enough physical shape to go through pregnancy. Finally, we insisted on them together seeing a perinatologist (a high risk obstetrician) to, once more, receive a detailed explanation what the risks to their offspring could be.

I had also discussed with them very openly my concerns about their life expectancy and who would bring up their child under a worst case scenario. Tara had assured me that both her mother and her sister were ready and willing to step in at any time. We, therefore, now requested letters from them confirming this fact.

It took approximately six weeks before Tara and Holden had met all these additional requirements. I was, in fact, amazed how quickly they had succeeded in making all the necessary appointments.

Shortly thereafter Tara was in a first IVF cycle. She did not conceive and we, therefore, decided to perform a laparoscopy to clip her fallopian tubes before transferring some of the cryopreserved embryos we had in storage from her cycle. So called hydrosalpinges, fallopian tubes filled with fluid, have been known to, at times, affect pregnancy rates adversely in IVF cycles. The theory is that this fluid may flow backwards into the uterine cavity and negatively impact on the endometrial lining or the embryos themselves. By disconnecting fallopian tubes from the uterus, such backflow is prevented. Two months after Tara had her tubes clipped, we transferred three of her frozen embryos, of course, after they were thawed. This time we were lucky and Tara was pregnant with - twins.

We followed her pregnancy till approximately eight weeks, when after a last ultrasound examination confirmed normal growth for both fetuses, we discharged her into prenatal care to a high-risk obstetrical service. The sign-out consultation was one of the most emotional and joyous occasions I can remember in my medical career. Tara and Holden brought an enormous bouquet of flowers “for all of you wonderful people who

helped us when nobody else was willing to do so.” There were tears of happiness on both sides of the relationship. Not only had I grown very fond of this remarkable couple, our staff had as well!

“Bring the babies by or, at least, send us pictures,” were my last words to them, as they left our office for the last time in their pregnancy. “And don’t forget about their brothers and sisters in our freezer,” I added, since they still had four embryos cryopreserved with us. Both of them smiled in response as they walked out the door.

Once patients are discharged into obstetrical care, I rarely hear from them before delivery. It is even rarer to hear from their obstetricians. I was, therefore, somewhat concerned when, approximately three months later, our receptionist told me that Tara’s perinatologist was on the line, wanting to talk to me about Tara.

Bracing myself for bad news, I, nevertheless, did not expect what followed.

As an obstetrician I was perfectly aware of the fact that complications can arise in every pregnancy. Tara was now 37 years old and carried a twin pregnancy. The older the maternal age, the higher the chance of complications. Twin pregnancies were more risky than singletons. “Maybe, she lost one of the twins,” I thought to myself. “Or, maybe, there was a complication with the amniocentesis,” which, because of her age, I was sure, Tara had undergone.

These and other thoughts went through my mind as I rushed towards a telephone. The somber voice of the perinatologist, whom I knew well, only further enhanced my anxiety. “I unfortunately have bad news in regards to Tara,” he started out saying. “Everything went well with the pregnancy. She had a normal amniocentesis, - a boy and a girl - and we all were very optimistic,” he continued. “Approximately, 10 days ago, Tara developed pneumocystis carinii pneumonia and now has full blown AIDS.”

I was in shock! Here, I had feared obstetrical complications but, never in a

million years, had it entered my mind that there might be a problem in regards to her HIV-status.

“Her cell counts are down to nothing and our infectious disease people don’t know whether she’ll make it,” he continued. “Tara wants to talk to you because we have suggested to her that she have the pregnancy terminated. We don’t believe the pregnancy makes her AIDS worse but it makes it more difficult to treat her, since we have to be concerned about medication effects on the babies. Tara is not willing to have an abortion unless you tell her so!”

This was, of course, not a discussion to be had over the telephone. I got my coat and raced out of the office, leaving a packed waiting room behind. Our office was only a short cab ride away from the Upper East Side hospital where Tara was hospitalized. Less than 15 minutes after I first had received the news, I sat at Tara’s bedside.

We fertility specialists have only one goal in our professional lives, to help establish pregnancies that lead to healthy deliveries. Most of us do not oppose abortions and I, for one, of course, fully support a woman’s right to choose. At the same time, the termination of a pregnancy, especially if conceived after fertility treatment, is the antithesis to what we do.

And, yet, here I was trying to convince Tara to have her twin pregnancy terminated. I suggested to her that having the children and not being alive shortly thereafter, was in nobody’s best interest. After all, she still had four embryos cryopreserved. Didn’t it make much more sense to get better and then, maybe, try again?

Holden needed no convincing. Sitting next to Tara’s head and holding her hand, it was obvious that he had made this argument before, many times over.

Tara just laid there, eyes mostly closed, breathing with obvious difficulty despite an oxygen tube in her nose. Small sweat beads formed on her forehead, reflective of her

high temperature.

“I can’t do it, doc,” she said with obvious strain. “Those are our babies. I have waited for them all my life. I can’t do it.”

Tara died three days later. Her twins were too immature to have a survival chance and were, therefore, not delivered. I saw Holden for the last time at Tara’s funeral. Their embryos are still in storage with us. We have been unable to locate Holden ever since. I hope he is well!