

The Cortez Family

Paula is a 43-year-old HIV-positive Latina woman originally from Colombia. She is bilingual, fluent in both Spanish and English. Paula lives alone in an apartment in Queens, NY. She is divorced and has one son, Miguel, who is 20 years old. Paula maintains a relationship with her son and her ex-husband, David (46). Paula raised Miguel until he was 8 years old, at which time she was forced to relinquish custody due to her medical condition. Paula is severely socially isolated as she has limited contact with her family in Colombia and lacks a peer network of any kind in her neighborhood. Paula identifies as Catholic, but she does not consider religion to

be a big part of her life.

Paula came from a moderately well-to-do family. She reports suffering physical and emotional abuse at the hands of both her parents, who are alive and reside in Colombia with Paula's two siblings. Paula completed high school in Colombia, but ran away when she was 17 years old because she could no longer tolerate the abuse at home. Paula became an intravenous drug user (IVDU), particularly of cocaine and heroin. David, who was originally from New York City, was one of Paula's "drug buddies." The two eloped, and Paula followed David to the United States. Paula continued to use drugs in the United States for several years; however, she stopped when she got pregnant with Miguel. David continued to use drugs, which led to the failure of their marriage.

Once she stopped using drugs, Paula attended the Fashion Institute of Technology (FIT) in New York City. Upon completing her BA, Paula worked for a clothing designer, but realized her true passion was painting. She has a collection of more than 100 drawings and paintings, many of which track the course of her personal and emotional journey. Paula held a full-time job for a number of years before her health prevented her from working. She is now unemployed and receives Supplemental Security Insurance (SSI) and Medicaid.

Paula was diagnosed with bipolar disorder. She experiences rapid cycles of mania and depression when not properly medicated, and she also has a tendency toward paranoia. Paula has a history of not complying with her psychiatric medication treatment because she does not like the way it makes her feel. She often discontinues it without telling her psychiatrist. Paula has had multiple psychiatric hospitalizations but has remained out of the hospital for at least five years. Paula accepts her bipolar diagnosis, but demonstrates limited insight into the relationship between her symptoms and her medication.

Paula was diagnosed HIV positive in 1987. Paula acquired AIDS several years later when she was diagnosed with a severe brain infection and a T-cell count less than 200. Paula's brain infection left her completely paralyzed on the right side. She lost function of her right arm and hand, as well as the ability to walk. After a long stay in an acute care hospital in New York City, Paula was transferred to a skilled nursing facility (SNF) where she thought she would die. It is at this time that Paula gave up custody of her son. However, Paula's condition improved gradually. After being in the SNF for more than a year, Paula regained the ability to walk, although she does so with a severe limp. She also regained some function in her right arm. Her right hand (her dominant hand) remains semiparalyzed and limp. Over the course of several years, Paula taught herself to paint with her left hand and was able to return to her beloved art. In 1996, when highly active antiretroviral therapy (HAART) became available, Paula began treatment. She responded well to HAART and her HIV/AIDS was well controlled.

In addition to her HIV/AIDS disease, Paula is diagnosed with hepatitis C (Hep C). While this condition was controlled, it has reached a point where Paula's doctor is recommending she begin treatment. Paula also has significant circulatory problems, which cause her severe pain in her lower extremities. She uses prescribed narcotic pain medication to control her symptoms. Paula's circulatory problems have also led to chronic ulcers on her feet that will not heal. Treatment for her foot ulcers demands frequent visits to a wound care clinic. Paula's pain paired with the foot ulcers make it difficult for her to ambulate and leave her home. As with her psychiatric medication, Paula has a tendency not to comply with her medical treatment. She often disregards instructions from her doctors and resorts to holistic treatments like treating her ulcers with chamomile tea. Working with Paula can be very frustrating because she is often doing very well medically and psychiatrically. Then, out of the blue, she stops her treatment and deteriorates quickly.

I met Paula as a social worker employed at an outpatient comprehensive care clinic located in an acute care hospital in New York City. The clinic functions as an interdisciplinary operation and follows a continuity of care model. As a result, clinic patients are followed by their physician and social worker on an outpatient basis and on an inpatient basis when admitted to the hospital. Thus, social workers interact not only with doctors from the clinic, but also with doctors from all services throughout the hospital.

SESSIONS: CASE HISTORIES • THE CORTEZ FAMILY

After working with Paula for almost six months, she called to inform me that she was pregnant. Her news was shocking because she did not have a boyfriend and never spoke of dating.

Paula explained that she met a man at a flower shop, they spoke several times, he visited her at her apartment, and they had sex. Paula thought

he was a "stand up guy," but recently everything had changed. Paula began to suspect that he was using drugs because he had started to

The Cortez Family David Cortez: father, 46

Paula Cortez: mother, 43 Miguel Cortez: son, 20

become controlling and demanding. He showed up at her apartment at all times of the night demanding to be let

in. He called her relentlessly, and when she did not pick up the phone, he left her mean and threatening messages. Paula was fearful for her safety.

Given Paula's complex medical profile and her psychiatric diagnosis, her doctor, psychiatrist, and I were concerned about Paula maintaining the pregnancy. We not only feared for Paula's and the baby's health, but also for how Paula would manage caring for a baby. Paula also struggled with what she should do about her pregnancy. She seriously considered having an abortion. However, her Catholic roots paired with seeing an ultrasound of the baby reinforced her desire to go through with the pregnancy.

The primary focus of treatment quickly became dealing with Paula's relationship with the baby's father. During sessions with her psychiatrist and me, Paula reported feeling fearful for her safety. The father's relentless phone calls and voicemails rattled Paula. She became scared, slept poorly, and her paranoia increased significantly. During a particular session, Paula reported that she had started smoking to cope with the stress she was feeling. She also stated that she had stopped her psychiatric medication and was not always taking her HAART. When we explored the dangers of Paula's actions, both to herself and the baby, she indicated that she knew what she was doing was harmful but she did not care. After completing a suicide assessment, I was convinced that Paula was decompen

sating quickly and at risk of harming herself and/or her baby. I consulted with her psychiatrist, and Paula was involuntarily admitted to the psychiatric unit of the hospital. Paula was extremely angry at me for the admission. She blamed me for "locking her up" and not helping her. Paula remained on the unit for 2 weeks. During this stay she restarted her medications and was stabilized. I tried to visit Paula on the unit, but the first two times I showed up she refused to see me. Eventually, Paula did agree to see me. She was still angry, but she was able to see that I had acted with her best interest in mind, and we were able to repair our relationship. As Paula prepared for discharge, she spoke more about the father and the stress that had driven her to the admission in the first place. Paula agreed that despite her fears she had to do something about the situation. I helped Paula develop a safety plan, educated her about filing for a restraining order, and referred her to the AIDS Law Project, a not-for-profit organization that helps individuals with HIV handle legal issues. With my support and that of her lawyer, Paula filed a police report and successfully got the restraining order. Once the order was served, the phone calls and visits stopped, and Paula regained a sense of control over her life.

From a medical perspective, Paula's pregnancy was considered "high risk" due to her complicated medical situation. Throughout her pregnancy, Paula remained on HAART, pain, and psychiatric medication, and treatment for her Hep C was postponed. During the pregnancy the ulcers on Paula's feet worsened and she developed a severe bone infection, osteomyelitis, in two of her toes. Without treatment the infection was extremely dangerous to both Paula and her baby. Paula was admitted to a medical unit in the hospital where she started a 2-week course of intra venous (IV) antibiotics. Unfortunately, the antibiotics did not work, and Paula had to have portions of two of her toes amputated with limited anesthesia due to the pregnancy, extending her hospital stay to nearly a month.

The condition of Paula's feet heightened my concern and the treatment team's concerns about Paula's ability to care for her baby. There were multiple factors to consider. In the immediate term, Paula was barely able to walk and was therefore unable to do anything to prepare for the baby's arrival (e.g., gather supplies, take parenting class, etc.). In the medium term, we needed to address how Paula was going to care for the baby day-to-day, and we needed to think about how she would care for the baby at home given her physical limitations (i.e., limited ability to ambulate and limited use of her right hand) and her current medical status. In addition, we had to consider what she would do with the baby if she required another hospitalization. In the long term, we needed to think about permanency planning for the baby or for what would happen to the baby if Paula died. While Paula recognized the importance of all of these issues, her anxiety level was much lower than mine and that of her treatment team. Perhaps she did not see the whole picture as we did, or perhaps she was in denial. She repeatedly told me, "I know, I know. I'm just going to do it. I raised my son and I am going to take care of this baby too." We really did not have an answer for her limited emotional response, we just needed to meet her where she was and move on. One of the things that amazed me most about Paula was that she had a great ability to rally people around her. Nurses, doctors, social workers: we all wanted to help her even when she tried to push us away.

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While Paula was in the hospital unit, we were able to talk about the baby's care and permanency planning. Through more and more evident. Paula had not told her these discussions, Paula's social isolation became parents in Colombia that she was having a baby. She

feared their disapproval and she stated, "I can't stand to hear my mother's negativity." Miguel and David were aware of the pregnancy, but they each had their own lives. David was remarried with children, and Miguel was working and in school full-time. The idea of burdening him with her needs was something Paula would not consider. There was no one else in Paula's life. Therefore, we were forced to look at options outside of Paula's limited social network. After a month in the hospital, Paula went home with a surgical boot, instructions to limit bearing weight on her foot, and a list of referrals from me. Paula and I agreed to check in every other day by telephone. My intention was to monitor how she was feeling, as well as her progress with the referrals I had given her. I also wanted to provide her with support and encouragement that she was not getting from anywhere else. On many occasions, I hung up the phone frustrated with Paula because of her procrastination and lack of follow-through. But ultimately she completed what she needed to

Key to Acronyms
AIDS: Acquired

Immunodeficiency
Syndrome

HAART: Highly Active
Antiretroviral Therapy

HIV: Human
Immunodeficiency Virus

IVDU: Intravenous Drug User

SNF: Skilled Nursing Facility

SSI: Supplemental

Security Insurance

WIC: Supplemental Nutrition Program for Women,
Infants, and Children

for the baby's arrival. Paula successfully applied for WIC, the federal Supplemental Nutrition Program for Women, Infants, and Children, and was also able to secure a crib and other baby essentials.

Paula delivered a healthy baby girl. The baby was born HIV negative and received the appropriate HAART treatment after birth. The baby spent a week in the neonatal intensive care unit, as she had to detox from the effects of the pain medication Paula took throughout her pregnancy. Given Paula's low income, health, and Medicaid status, Paula was able to apply for and receive 24/7 in-home child care assistance through New York's public assistance program. Depending on Paula's health and her need for help, this arrangement can be modified as deemed appropriate. Miguel did take a part in caring for his half sister, but his assistance was limited. Ultimately, Paula completed the appropriate permanency planning paperwork with the assistance of the organization The Family Center. She named Miguel the baby's guardian should something happen to her.