



# Family-Centered Care Across the Border: A Postmortem Reflection

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AS SHE CELEBRATED her fifteenth birthday, Selena (names and various identifying details have been changed to protect the patient's and family's identity) had many reasons to be thankful. After a grueling 8 months, her acute myeloid leukemia (AML) had been treated into remission, and she had just reached 2 months off treatment. Although she was excited to be done with chemotherapy, she was just as thrilled to be reunited with her mother back in Mexico. Although initially diagnosed with AML in Mexico, she was treated at a hospital near an aunt and uncle in Texas, where Selena was born. She spoke regularly with her mother via video phone calls during her treatment, but that was no replacement for being able to hug her and talk face-to-face once again.

Initially she felt great, enjoying the reunion with her mother. But, over the course of a few weeks, she again started feeling unwell, and the symptoms were all too familiar. Concerned that her leukemia had relapsed, she tried to travel back to the hospital near her aunt and uncle in Texas. Her family struggled to arrange transportation, so she instead presented to a local hospital in Mexico, where a peripheral smear again showed blasts. She was admitted for further management—chemotherapy, antibiotics, blood product transfusions—but when it became apparent that her family would not be able to pay for the hospitalization, she was discharged in the midst of her treatments.

Selena's mother ultimately arranged for Selena and her 21-year-old sister, Mayra, to travel back to her primary oncologist in the United States. However, after crossing the border, Selena had a syncopal episode, forcing them to detour to a closer hospital rather than risk her decompensating en route. At that hospital, the physicians found her to be in compensated shock with pancytopenia and acute kidney injury. She was admitted to the pediatric intensive care unit (PICU), where she was intubated. Although she initially improved and was extubated, she subsequently developed an invasive fungal infection.

Due to the extent of her disease, she was transferred to our institution in Houston for further evaluation and treatment.

Although Selena was initially admitted to the oncology acute care floor, she quickly decompensated and was transferred to the PICU. In the PICU, we immediately intubated and sedated her and started vasoactive drips for uncompensated shock. Throughout the initial resuscitation, her sister sat tearfully alone at bedside. With the assistance of our chaplain and social worker, we began our efforts to get to know Selena and her complex medical history.

As conversations with Mayra filled in many information gaps regarding Selena's treatment since diagnosis, we also began to unfold the social situation. We discovered that Mayra had joint guardianship with her aunt for Selena; she had temporarily moved to Texas to be with Selena during her initial treatment. Their father had passed when the girls were young, and their mother had never remarried. Although they technically grew up in a single-parent household, Mayra spoke fondly of the myriad adults—mostly aunts and uncles—who helped raise them in Mexico. The aunt and uncle with whom they lived during treatment would travel to Houston in the next few days. A second aunt now lived in the Houston area, and Mayra had been speaking with her since coming to the hospital.

As we inquired about their mother's absence, Mayra expressed concern that crossing the border may not be straightforward. Before their father's death, he had fled to Mexico after being on house arrest in Houston. Selena's mother was accused of aiding his escape. Unable to provide the police with substantive information about her husband's whereabouts, she agreed to voluntary deportation rather than face lengthy court proceedings and costly lawyer fees. Although their mother maintained her innocence, it was clear these circumstances would likely interfere with her ability to be at Selena's side once again; she initially sent Mayra in her place.

During the first 24 hours under our care, Selena's clinical status continued to deteriorate. We involved our palliative care team in her care. During a multidisciplinary meeting, we explained to Mayra that, given the extent of Selena's disease and her multiorgan dysfunction, we felt there was little more we would be able to do to provide therapeutic care. Selena's chances of surviving the hospitalization were slim.

Meanwhile, their mother continued her attempts to travel across the border from their home in Mexico. She had a letter that was provided by Selena's doctors before her transfer to Houston, explaining Selena's critical state. After a 4-hour bus ride, she arrived at a border crossing about 500 miles from Houston, attempting to enter the United States for the first time since leaving voluntarily 10 years ago. She explained the situation to the border patrol agents and provided them with the letter, tearfully begging for the opportunity to see her daughter one last time. The agents took her fingerprints, letter, and necessary forms, and told her that she should have an answer within 24 hours. She left the border station to find a hotel, hopeful that her request would be granted.

Unfortunately, when she returned to the border the next day, our fears were confirmed: she would not be granted access to the United States to be with Selena in her final days. We conversed daily with Selena's mom while she continued her efforts to cross the border and be reunited with her daughter. She joined in phone conversations with our team of providers: critical care, oncology, infectious disease, and palliative care. And while she could see Selena over video calls, she tearfully expressed her wishes to be present.

The amount of medical support Selena required continued to increase, and it became clear that she was dying. Although Mayra had legal decision-making power, our palliative care and oncology colleagues agreed that it would be best not to burden her with such decisions alone at bedside. After her mom's first failed crossing attempt, a resident on our team called border control and explained to the Customs and Border Protection officer the gravity of the situation; however, her mother's second attempt also was unsuccessful. Next, we faxed a letter to supervisors at border control pleading with them to let her mother across to assist in medical decision-making; she was turned away

a third time. At this point, a local holiday closed the border checkpoint to any crossing for 4 days.

After extensive discussions with our multidisciplinary team, the chaplain, and her mother over the phone, Selena's sister made the brave and noble decision for a compassionate extubation. We were able to continue life-sustaining measures long enough for her aunt and uncle, with whom she lived during her initial AML treatment, to arrive at bedside. That night, with her mother on the other side of the border, Selena died under our care. She quietly passed, surrounded by her sister, sparse family members, nurses who had cared for her previously, and our medical team.

Although we coordinated video conferencing for her mother to speak with family members and look at her daughter one last time, the lack of her physical presence continues to weigh heavily on our hearts. When patients pass, we second-guess many of the decisions made leading up to death, whether to improve our own practice or to reassure ourselves that we did everything we could. In this case, our postmortem reflection extends well beyond the choice of antimicrobials or vasoactive drips. We ask ourselves whether we did everything we could to support the entire family through these times.

Six months after Selena's last days, many questions remain unanswered. The final entry in her medical record is an attempted bereavement phone call from our palliative care team to Mayra, unanswered and unreturned. Did she move back to Mexico, and thus is simply unreachable at her previous number? After serving as her sister's caregiver through cancer treatment, and death, is her grief too much to bear, unable to engage in conversations with the medical team? Does she feel guilty for agreeing to bring her sister to the United States for treatment, knowing that her mother was then unable to join Selena in her final days?

As we continue to move forward in our own grieving process, we are disheartened that, despite advocating for Selena and her family the best we knew how, we were unable to bridge the border divide. Although the physical presence of her mother likely would have had no effect on Selena's outcome, there were undoubtedly effects on the family. We can easily reassure ourselves that there were too many factors beyond our reach, but the fact remains that this vulnerable teenage girl died under our care, with her mother 500 miles away.