A Hospital Death
Challenging our assumptions about dying.
by Anne Hunsaker Hawkins

There are few phrases more chilling than a “hospital death.” Too often, death in this setting comes about despite aggressive—and sometimes futile—medical treatment. It is often seen as a result of medical failure. For me, a hospital death has seemed like something to be avoided at all costs, especially in the case of a child. But the death of a child I will call Tiffany—which took place in an ordinary room on the pediatric floor—contradicted this view and challenged my assumptions about the care of the dying.

Tiffany was nine years old when she died, though she looked at least two years younger. A tiny child, Tiffany had long, dark hair; a high-pitched voice; and a talent for eliciting the affection of everyone who encountered her. She was the sickest child in our clinic. She had survived various HIV-related illnesses, such as Pneumocystis carinii pneumonia, Mycobacterium avium-intracellulare, and severe pancreatitis. Her viral load was in the millions and her CD4 count in the single digits, meaning that she had a high level of the virus in her body as well as a severely compromised immune system. Hasty trips to the hospital’s emergency room for various sudden problems—some false alarms and some real ones—had become a monthly, sometimes bimonthly, event. Ironically, Tiffany’s half-sister Jenny, a chunky, blond-haired girl “with a mouth on her,” as their grandmother observed, was one of the healthiest of our patients, with an undetectable viral load and a robust CD4 count.

Tiffany, along with an older brother who is not infected, has lived with her maternal grandparents since the death of their mother, which happened when Tiffany was six months old. The man whose name appears on Tiffany’s birth certificate claims that he is not her father and has refused DNA testing. Tiffany’s grandmother, Thelma, is familiar to all of the clinic staff, having brought Tiffany for monthly medical appointments for the past six years. Thelma is a thin, peppery woman with glasses that make her eyes seem huge. She seems to live on Pepsi, drinking some fourteen to fifteen bottles a day. She is devoted to Tiffany. The logo that adorns Tiffany’s favorite shirt perfectly characterizes their relationship.

Anne Hunsaker Hawkins (ahh1@psu.edu) is professor of humanities and director of the Doctors Kienle Center for Humanistic Medicine at Penn State’s College of Medicine. She is the author of A Small Good Thing: Stories about Children with HIV and Those Who Care for Them (W.W. Norton, 2000). Both the book and this story are based on six years as a participant/observer in an academic medical center’s pediatric HIV clinic, where she helped families with a wide range of social services and facilitated social interactions between families and clinic staff. Some information in the story derives from a taped interview. Names of all persons have been changed.
“Don't mess with me, or my grandma will come after you!” It seems surprising that Tiffany is not spoiled but remains a sweet and loving child—reminiscent of those fragile, otherworldly, mortally ill children like Little Nell whom one finds in novels by Charles Dickens.

The story of Tiffany’s mother is both tragic and typical of many mothers of orphans in our clinic. Thelma told me about it one afternoon while I was visiting her home. She showed me a picture of Tiffany’s mother at about twelve years old: I was struck by the disparity between the happy, healthy-looking preteen in the picture and the young woman she would become just a few years later. Tiffany’s mom, Cindy, left home at seventeen, married, and had two children. With two infants, she left her husband for another man and was soon pregnant again. When she gave birth to her third child, she agreed to HIV antibody testing for herself and her baby. She learned that she was infected. Her baby also tested positive. But all babies of infected mothers are born with antibodies positive for HIV. A subsequent test, six months later, revealed that the baby was not infected. Cindy did not pursue treatment for her HIV, looked healthy, and told no one she was infected. She proceeded to have two more children by different fathers—first Jenny and then Tiffany (the two children in our clinic). Neither child was tested at birth. While Tiffany was still an infant, Cindy was badly injured in a car accident. She was taken to the hospital in a coma and never regained consciousness. When hospital staff learned about her HIV status, they arranged for all five of her children to be tested. Only two—Jenny and Tiffany—were found to have HIV.

When Cindy died, Thelma and her husband found themselves suddenly thrust back into the role of caregivers for young children. The story of grandparents who, while still mourning the death of their daughters, assume care of HIV-infected grandchildren is a common theme in the story of American AIDS. Like many such grandparent/caregivers, Thelma herself was not in good health, as evidenced by the deep raspy cough and high blood pressure probably brought on by years of chain-smoking. Unlike many “AIDS grandmothers,” she did have a husband to help with the care of Tiffany and her brother, although he had recently suffered a major heart attack.

Facing Death

I first met Tiffany and Thelma at our hospital’s pediatric HIV clinic when Tiffany was five years old. She had just begun attending school, which she loved, although her constant fatigue meant that she often spent much of the day napping in the nurse’s office. Tiffany didn’t really play like other chil-
children—she was always too tired. Her favorite toys were tape and bandages. Every time she came in for a medical appointment, she would take one of the clinic’s toy shopping carts and “go shopping” at the various nursing stations, filling it up with bandages, tape, swabs—whatever she could find. When not being examined, she would make one of us “be the patient,” which usually involved the elaborate bandaging of a wrist or arm.

At one point, Tiffany was hospitalized for *Pneumocystis carinii* pneumonia. Despite oxygen, her respiration continued to be labored, and her heart rate was extremely high. Dr. Sam Bennett, the hospital’s pediatric HIV specialist in charge of the children’s HIV/AIDS clinic, decided that it was time to talk with Thelma about end-of-life issues. He reminded her of the severity of Tiffany’s illness and remarked on the quality of life Tiffany had enjoyed for so long. He warned Thelma that during one of these hospitalizations—he couldn’t tell exactly which one—Tiffany just wouldn’t bounce back. Emphasizing that he didn’t know what the outcome would be this time, he advised her to put Tiffany on Do Not Resuscitate (DNR) status. Thelma remembers this conversation well: “He said that if she were put on a respirator, it would be hard on her and hard on me too, and if she were on a respirator and in a coma and all that, it would be even harder then to make the decision to take her off the machine [and let her die].”

Thelma agreed to make Tiffany DNR. But several weeks later when she told me about it, her ambivalence was clear: “When things got really bad and the nurse said she didn’t think Tiff would last through the night, I sat there beside her and kept saying, ‘Come on, Tiff, Grammy loves you…I can’t live without you, come on, come on.’ I walked the whole way around that hospital praying and praying to The Man, and then I just knew she was coming home.” Thelma was right, and Tiffany did go home. “I know the day’s coming that she’ll leave me,” Thelma said to me at their next clinic appointment. “I know it’s going to happen sometime. I’ll just have to face that when it comes. But I ain’t ready for that yet, and neither is she.”

At first, despite a very high viral load, chronic fatigue, and repeated trips to the ER, Tiffany did well. Her grandparents learned to accept the fact that she slept only for a few hours at a time, waking because her skin itched or because she had stomach pains or diarrhea. When she was wakeful, it was usually “Poppy,” her grandfather, who stayed up with her. Months before, a permanent feeding tube had been surgically inserted so that Tiffany would get the nutrition her body needed, as well as the many medications required. Now, because her appetite was so poor, Tiffany was allowed to eat whatever and whenever she wanted. Gradually, though, during these last few months, Thelma felt that at some level Tiffany became aware of her condition. Driving home from an ER visit, she told Thelma, “Grammy, I’m so tired of my life.” And a week later she asked, “Grammy, who’s going to die first—you or me?”
Choosing To Stay In The Hospital

In the spring Tiffany was hospitalized—for the last time—with symptoms of flat affect, lack of urine and bowel control, and other central nervous system problems. She was diagnosed with acute myelitis and central nervous system degeneration (encephalopathy) secondary to HIV disease. Dr. Bennett told Thelma that he thought this might be the end: There was no treatment that would reverse Tiffany’s present condition. He suggested that she take Tiffany home, and the clinic social worker would arrange for home hospice care. However, to everyone’s surprise, Thelma refused—perhaps remembering that Cindy, her daughter and Tiffany’s mother, had died in the same hospital not many years before.

Thelma remained adamant about Tiffany staying in the hospital. Given the child’s condition, Dr. Bennett surmised that her hospital stay would be fairly brief, and this turned out to be the case. Tiffany stayed in her room in the pediatric ward, and what began as treatment for AIDS encephalopathy soon turned into what used to be called, rather grimly, a “death watch.” But there was nothing grim about it. I visited several times over her four-day hospitalization, and whenever I came, Tiffany’s room was full of family. Deprived as an infant of her mother and father, Tiffany was now surrounded by aunts and uncles and cousins as well as the grandmother and grandfather who had become her parents. Hospital staff, especially the nurses, were frequent visitors, too. Stuffed animals brought by family, friends, and medical staff sat on the bed and on the room’s window ledges. The children played; the uncles and aunts talked among themselves or with the nurses. Thelma was anything but the mourning grandparent in need of consolation. Instead, she held court, warmly and graciously welcoming all visitors, helping others with their grief. Tiffany was sleeping whenever I was in the room, but according to Thelma she woke up several times and was able to “take in” the presence of those who loved her. Four days after being admitted, Tiffany died quietly in the night.

Afterward Thelma told us repeatedly how grateful she was for the help she received from us. But it has always been my feeling that we received much more than we gave. From Thelma herself we learned how death can be expected and endured—even if not wholly accepted. Moreover, for those four days medical staff were also welcomed as participants in the tacit ritual of observance that is a death watch. For those few days, in the midst of all the busy purposefulness of a hospital, Tiffany’s room became a place of quiet, a time out of time, where the prospect of inevitable human loss created human community and caring.
Reflections

Aside from the gift Thelma gave hospital staff in participating in this death watch, there are two further “lessons” that can be learned from Tiffany’s last days. The first has to do with the ever-present need for cost containment, and the fact that Tiffany could have spent her final days at home instead of occupying a hospital bed. One could argue that there are times when it is necessary to spend more than is medically necessary, to achieve a “good death.” Although I believe this to be true, it is not the point of this story. On the contrary, Tiffany’s care was cost-effective: Tiffany was hospitalized very late in the course of her illness and thus spent a very short time there—only four days—before her death. Moreover, this physician’s willingness to forgo aggressive treatment when treatment seemed futile reduced hospital expenses for her care. Many if not most patients hospitalized with end-stage AIDS occupy a bed in an intensive care unit. Tiffany, however, was kept in the pediatric ward, at a much lower cost than in the ICU.

The second lesson and the most important one for me is to remember that although paradigms and protocols are necessary in medicine as in ethics, these can always have exceptions. I still believe that it is better, if possible, for a person (especially a child) with a terminal illness to die at home, as the hospice philosophy suggests. But Tiffany and her grandmother have taught me that this is not always so. Tiffany’s story demonstrates the importance of always looking closely at the circumstances of the individual case, rather than allowing rules and assumptions and algorithms to determine our decisions.