A Personal Look at Therapy and Loss in the Early Days of AIDS

A psychotherapist recalls her first client with AIDS in the years before effective treatment.

August 12, 2016 By Julie List

Editor's note: The first HIV meds debuted in 1987 but were unsuccessful in stopping the virus. All that changed in 1996 with the addition of a new class of antiretrovirals called protease inhibitors.

This year, POZ celebrates the 20th anniversary of effective HIV treatment. As we mark the lifesaving advancements of the past two decades, we also want to remember those who are no longer with us—and those often-unsung heroes who have provided care throughout the epidemic. In her powerful story "River Angel," Julie List, a licensed clinical social worker, looks back at the psychotherapy she provided for David, her first patient with AIDS.

River Angel: Therapy and Loss in the Early Days of AIDS

By Julie List, LCSW

It's been 20 years since David Silverman* washed down a bottle of valium with a fifth of vodka, left his wallet and keys on his kitchen table and jumped into the Hudson River. David wrote one suicide note, and it was addressed to me. He attached a postcard to the note: two embracing angels in Caravaggio's "The Seven Acts of Mercy."

David was my patient at a Manhattan outpatient mental health clinic linked to GMHC for nearly two years before his disappearance. This act was what he would have called his "rational suicide," although the resulting loss for his family, friends, doctors and me was as deep as any other. As a gay man with AIDS in 1995, prior to the availability of protease inhibitors, David believed that the deterioration of his body and mind was his inevitable future, and he couldn't bear the thought of wasting away, in pain and alone.

When I first met him in 1994, I was a psychiatric social worker with less than a decade of experience doing psychotherapy. I had primarily practiced family therapy with a physically healthy population of mostly straight clients. Not only was David one of my first openly gay clients, but he was also the first to be quite ill with AIDS.

David was a 43-year-old white, non-practicing Jewish artist and writer, in recovery for five years from alcoholism. He had been diagnosed with AIDS less than a year before. His longtime lover,

Joey, had died of AIDS-related illness six years earlier. David's current on-again, off-again lover, Kevin (who lived with another man in a long term relationship), also had AIDS but was not as ill as David. David reported to me that all of his friends had AIDS.

When he came to us, David had a T-cell count of 3. That was our marker in those days; we geared ourselves for the proximity of death by the dwindling number of T cells. We quickly learned that our patients' T-cell counts could rise and fall over a long period of time and that the viral load was a better predictor of their longevity.

David's doctor told him this would be the last year of his life. I was stunned at the bluntness of that statement. David's primary search would now be for love.

David was an attractive man with dark eyes and hair, tall and slender, emanating intelligence and vulnerability. He was losing weight rapidly. He always wore boots, claiming it made it easier for him to walk with the KS lesions on the bottoms of his feet. Rolling up his pant leg, he showed me angry dark-purple lesions on his calf. He also had a few on his nose that embarrassed him. He periodically received radiation treatments to burn them off his face.

David was immediately matched with our staff psychiatrist, the late Dr. Eugene Glynn. Dr. Glynn was a brilliant, older gay psychiatrist who came of age in his field when being gay was treated as a mental disorder. Underneath his gruff demeanor, he was loving and tender. He treated hundreds of sick and dying young men throughout the worst of the AIDS epidemic. He also taught our community of social workers and psychologists about the medical and psychic traumas of the disease—obviously for the patients, but also about the impact it might have on us, as mental health professionals living and working in the eye of this storm.

Dr. Glynn and I were partners in working with David, who was struggling with acute anxiety since his diagnosis. Dr. Glynn prescribed him 5 milligrams of Valium daily. Given the sad predictability of the foreshortened life span of these very ill patients, there was less concern about the habit-forming nature of this medication. Normally, we would not have given Valium to an alcoholic in recovery.

As the year progressed, David became more depressed, prompting Dr. Glynn to add 20 milligrams of Prozac to the daily medication regimen. David told both Dr. Glynn and me that if he started to get sicker without any hope of improvement, he would consider taking his own life while he still had control over his destiny. At this time, there was no hope for a cure, just the certainty of a painful withering away. According to Dr. Glynn, many of his patients had similar plans but became too sick too quickly to take action. It was a controversial topic for us, given our mission to help people to stay alive at all costs.

6/29/94 Progress Note

David reports his health is improving (T cells 6), although his KS lesions are increasing. Reports AIDS represents “the cruelty of Nature.”

As psychotherapists working in the late 1980s and continuing throughout the mid-1990s, we, like our patients, had to come to terms with the fact that there was no foolproof medication regimen to prolong the lives of those we had come to care about. We had to learn to provide therapy to a generation of mostly gay young men whose friends and lovers were dying in droves. The high number of death notices of young men had not been this significant in America since the losses from the 1919 influenza outbreak.

At first, I wasn’t sure I was up to the task of doing psychotherapy with a man dying of AIDS. I had no special training for this, other than the courses Dr. Glynn had been giving us. Although there was literature on working with physically ill patients, nothing of this magnitude had ever occurred with such virulent insistence, decimating the young. I was treating him the only way I knew, not allowing for the possibility that he would die on me. I tried to connect to him as a man living through massive losses, focusing on who he was before the disease and what his passions were.

7/8/94 Progress Note

David is relieved, because his CMV test was negative. Feels he has gotten a reprieve. Gives me herbs he grew in his garden.

David had never come out as a gay man to his parents or to his sister. Although he had lived with Joey for many years, he told his family Joey was his close friend and roommate. Even when Joey died in the late 80s, there was no discussion of AIDS or of being gay. We explored how to tell his parents that he was sick and then to reveal to them that he was gay. He was ambivalent and admitted he wanted to punish them by “keeping them in the dark.”

Instead of telling his family, he decided to confide in the rabbi—who happened to be gay—in the town where his parents lived so that once David died, the rabbi could help the family deal with the many facets of the complicated loss.

David’s main source of joy and support came from his best friend and sometimes lover, Kevin. Kevin was starting to pull away, however, dedicating himself to his live-in partner, his career and his own health. David was no longer sexually active, leading to a deep sense of alienation.

12/8/94: Progress Note

David feels depressed, lonely, yearning for physical affection, especially from Kevin. Feels he is “rotten fruit” and that no one would want him. Never imagined he would have AIDS and be alone.

Our relationship seemed unusually close—and different—given that I was his therapist. I was drawn to his mind and his heart. I wanted to protect him from further decay and humiliation. Sometimes he came in excitedly, reporting about a party he had attended at Friends In Deed. He balanced his need for human, sexual connection with a haunted feeling of tiptoeing through a graveyard, fearing that he would soon be among the dead.

David's doctor told him this would be the last year of his life. I was stunned at the bluntness of that statement. David's primary search would now be for love. He admitted that he was actually deeply in love with Kevin, and the rejection was a deep injury, a fresh death. For Christmas, he gave me a candle and a postcard of an angel, a beatific creature with no defined gender. On the back, he wrote, "Happy whatever, but mostly, thanks. D."

> 1/20/95: Progress Note
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> David is experiencing pain from his KS lesions on the bottom of his foot and leg. Worries that he has begun a gradual decline. Wonders if he could possibly meet anyone else to love at this late stage. Feels lonely, wants companionship.

> 1/26/95: Progress Note
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> Has gotten all of his legal and financial documents in order, in case he dies suddenly.

A month after this session, David drank some vodka and took an unknown quantity of Valium, unbeknownst to Dr. Glynn and me, in what we later discovered was a "dry run" for his eventual suicide. Dr. Glynn evaluated him and assessed that David was not an immediate suicide risk. He increased David's dosage of Prozac. We all discussed that for an alcoholic in recovery to drink represented a loss of faith. Perhaps as he was already succumbing to one disease, he no longer saw any reason in fighting another. He still had the will to live but acknowledged how surreal it was to live with the specter of death beside him. He felt it as a presence.

Over the course of our work together, David's doctors told him that he could have gone blind if he had gotten CMV, that his KS was worsening and, at one point, that he might have had lymphoma and that his stomach lining was thickening. His T cells remained low; his viral load increased. He was officially drinking again. He admitted he wanted me and others to take notice; he wanted to provoke his friends to worry about him and maybe attract Kevin back to his side. He adamantly refused to go to AA meetings. Then, one of David's primary HIV doctors, a woman, suffered a nervous breakdown and took a leave of absence.

In September 1995, after a short reprieve in the Hamptons over the summer, David returned quite hopeless. His distress intensified as his bouts of diarrhea increased. He assumed he was on his final decline. Looking back, I see that I still could not fathom losing him. I saw my role as his lifeline, and as he drifted further and further out to sea, I tried to keep him tied to me, to us, to our world.

> 9/15/95: Progress Note

> David has a KS lesion on his penis and feels no one will ever want him. He's angry about this disease, doesn't know if he can accept it.

At this point, in spite of our attempts to keep him connected, David pulled away from Dr. Glynn and me. I encouraged him to keep going to GMHC and to Friends In Deed, where he had often found solace, but he insisted his diarrhea prevented him from going.

> 9/29/95: Progress Note
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> Is still pining for Kevin. Hates being alone and sick. He says he is "rotting." Feels detached from his own life, frightened of the future. His symptoms also include fever and chills, and he is having a hard time concentrating or working.

I tried again to get him a Buddy from GMHC, but he refused. His worries about finances intensified, and he feared he might need to leave his apartment or get a roommate, stating, "I never expected to live this long." In what ended up being our final session, David expressed a feeling of desolation about his medical condition but denied suicidal thinking. He reported staying in bed the day before and not taking his medication. He achingly described that he was in mourning for his lover, Joey, and he was fearful of getting sicker.

Two weeks later, David was gone. Kevin left me many messages on my office voicemail, as did a detective from the 6th precinct. David was missing, his wallet and keys were on his kitchen table, and there was a suicide note addressed to me. I don't remember who called to read me the content of the note:

> "Julie, please try not to feel bad about this. You've done nothing but help me.
>
> Thank you forever, D."

I took the blow hard, a punch to the gut. Later, on the phone, Kevin said David had gone into the Hudson River, that his rational suicide plan had always been to kill himself before his living body and mind decomposed. Kevin knew that David's plan was to mix Valium with vodka and then drown himself. Nonetheless, Kevin was enraged. He couldn't believe that David had given up before the disease took him. Kevin was heartbroken.

I connected to the bravery that David had shown while dealing not only with his own physical deterioration but also with the horrors of an epidemic that had been killing his friends and lovers since 1981.

It was a Saturday. I was home that day. David, gone—it was a shocking absence. Although I normally shed tears easily, none came. I started fixating on the idea of David's body at the bottom of the Hudson River. Then the terror set in. Gentle, talented and frightened David was being tossed over sharp rocks, rolling over and over in polluted waters, his body battered and cold. His dreams of a late, last love dashed, knowing he was dying, he made a calm decision to take control of his demise. I couldn't stop obsessing about David in the freezing waters. After accompanying him on his journey for the previous two years, I was rattled deeply by his sudden disappearance and the note to me. I didn't know how to make peace with this. I reached out to the chief psychiatrist of our agency at the time, a trauma expert and someone I had known for several years. When he asked how I was holding up, I finally became tearful. I told him about my intrusive thoughts of David being enveloped in the freezing grip of the dark water, about the man who had suffered such pain and solitude as the disease wiped out his generation and was about to carry him into the vortex. I kept imagining him under tons of heavy water and the thoughts would not stop. "Julie," the doctor said in the gentlest voice possible, "that is not David in the water. That is just the shell that housed his spirit. David is free. David is not there at all."

Those simple words released me. I could then feel the strong connection I had had to David and to the bravery that he had shown while dealing not only with his own physical deterioration but also with the horrors of an epidemic that had been killing his friends and lovers since 1981. The sadness I felt was not only that we hadn't been able to help him to stay alive, but also the hopelessness about losing all the young men, women and children who had been dying for more than 15 years.

In the following days, I spoke to David's parents, who were truly devastated. They called me in great distress, having to make sense not only of the suicide, but also that their son was gay and had AIDS. They were trying to understand the enormity of this loss and wanted answers that nobody had. I was not at liberty to tell them about David's dilemma. Kevin came to my office to meet with me. He gave me the suicide note and the postcard. We cried together and embraced when he left.

Sometime later I was told they found David's body. It was no longer under the waters of the Hudson River. My colleagues were kind and empathetic. Some whispered, "It's her first suicide," and it was. Dr. Glynn and I spoke at length about David. Dr. Glynn had lost many patients in his long career, most to natural causes, some to suicide, and some of the men with AIDS had chosen to die the way David had. He understood they had no other way to fight the vicious progression of the disease. At the time, I believed Dr. Glynn had supported David's decision and that of the others who had found themselves with no alternative. He was not shocked, nor did he feel we had done anything wrong. He believed it was a rational choice. And we grieved together.

In time, the void was replaced by a sharp missing of my visits with David. I accepted his utter necessity for love. In some ways, I wondered if he had died more from loneliness than from AIDS itself. Given that the only note he left was for me, I wondered what my role had been for him. Perhaps leaving me the note had been a gift. He didn't want me to feel responsible or guilty or that I had failed him. A generous act. Leaving the note also kept me tied to him forever, as one

can see by the fact that I have kept all his session notes, the angel postcard, the suicide note and the postcard of Caravaggio's "Seven Acts of Mercy." What I felt toward him was akin to love. I have kept David with me every day for these 20 years, and this is my way of bearing witness to his brave struggle and the battles his compatriots fought against a merciless enemy.

There is an even crueler irony to the timing of David's premature death. In the middle of 1995, an experimental class of drugs was starting to become available to certain patients with advanced AIDS. By 1996, the protease inhibitors were shown to have extended the lives of some of the very ill. Although the cost was astronomically high at first, more than $15,000 a year per person, the benefits were so great that people began living with AIDS. By 1997, the domestic AIDS death rate had dropped by 47 percent. Could David still be alive today if he had waited for the medication cocktail no one knew was imminent? We'll never know, nor will we know whether he would have died on his own instead of taking his own life.

*Names of patients and friends have been changed in this article.

Julie ListCourtesy of Julie List

Julie List is the director of a Caregiver Support Center at Montefiore Medical Center in the Bronx. An earlier version of this piece appeared in Mental Health News (now titled Behavioral Health News), mhnews.org, summer 2012.

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