

Meria, May You Rest in Peace

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I don't think I will rest in peace. I will not go in peace until I have completed the arrangements for my son, Johnny. Tony's left it all up to me (Meria, July 23, 1993).ⁱ

Meria began telling me her story:

My husband, Tony, called me from the hospital where he had been for the past few days for tests. He had been tired all the time. You know, he slept all the time. He got up, went to work, came home, took a shower and he was out. There would be a lot of arguments you know. I'd say, "You never want to do anything. You're always tired. You're always sleepy. You're young, you shouldn't be like that." We just never ever thought -- even when we were going through all the tests, it never ever went through our minds, you know, is it this? You know, we didn't know none of the symptoms.

I recognized the symptoms as soon as her twenty-eight-year-old husband, Tony, opened the door. I had driven from early morning to their home on a summer day known weather-wise as a real scorcher. And in this dry, dusty, rural town the heat was intensified. You know you're in the country when there are no sidewalks, no stoplights, and the kids, dogs, and cats share the road without visible boundaries. I drove my white Volvo with extra caution.

I had never been to this town before. Had no reason. It was not near a University, or on the usual vacation trails. It was part of the vast Central Valley of California. Even if you drove from San Francisco to Los Angeles, you would have to go way out of your way to go through this town. I knew I looked out of place.

Meria was not expecting me for an hour so I had time for lunch. As I drove around, I realized my choices were limited. At a Mexican lunch counter in a strip mall, I ordered and sat at one of the two tables. My presence seemed to have a quieting effect on the conversations. I ate, and left having spoken only a few words, just enough to say, "One chicken enchilada, no beans or rice, and a coke, please." I was conscious that my speech made me stand out among the men laborers.

Tony and Meria's home was in a tract, in a neighborhood where the houses look alike except that some have more stuff in the yard than others. At their corner house there were few trees, no shade, no green lawns, and no flowerbeds. The house and yard were surrounded with a cyclone wire fence with a wire gate that was opened. Directly across the street was a large lot loaded with old buses and trailers surrounded by a cyclone wire fence. Facing the house and across the street on the left was the "New Hope Missionary BAPTIST CHURCH" that looked like a warehouse with three large crosses, the largest on the top of the roof, and the smaller ones on either side of the industrial strength metal handled double doors. It had patches of green on the large dirt front yard, and no cyclone wire fence. Walking from the car to the front door I began to perspire, and the dusty, hot, wind powdered the sweat to my skin.

Tony answered the door in his pajamas, thin flannel, long-sleeved ones, which seemed out of place in this heat. He acknowledged me with a, "Hello," but did not meet

my eyes. He backed away in a low bow. He spoke no words in response to my introduction. He didn't return to an erect position, but turned and shuffled, like a very old man, as he led me to Meria. We passed through a gloomy crowded living room where all the shades were drawn. There was a portable fan with a bowl of ice set in front of it. The set up reminded me of Mom's system of beating the heat, but I thought now, as I did as a kid, the room might be cooler, but the lack of sun took the life out of it. We continued down a short hall to the bedroom. I observed Tony as he returned to the sofa in the living room where he had been watching television. He was very thin, with grayish pale skin, obviously ill. Disease was draining the life out of this young man. I wanted to thank him for opening the door for me, for escorting me to Meria, but more than that I wanted to apologize for causing him exertion, for intruding into his home, for the disease. But I said nothing.

Meria, by contrast, was full of life. As I entered the bedroom, she was busy finishing up a phone call. She was instructing the doctor or nurse on the line: what medication she needed, how much, and when. She was in control in a pleasant, but insistent way. I had a few moments to observe.

She was propped up in bed on top of the covers, fully clothed. Her long, brown almost black, curly hair framed her explicitly beautiful face. Her dark features, wide mouth, and large, decisive eyes depicted her classic Mexican and Cuban mixed heritage. Her make-up was apparent but not overdone. She wore a white, short sleeve blouse with elastic at the sleeves and neckline. The large ruffles on the scooped neckline and sleeves accentuated her full bosom, and youthful figure. She wore red shorts, and had bare feet. Meria did not look sick. The only evidence of illness was the almost-hidden catheter in

her chest, which was at times exposed by the ruffles when she moved. It seemed obvious that her dress was chosen to accommodate her pride and her catheter.

The well-lit bedroom had orderliness about it, in spite of its crowdedness. The bed took up almost the entire room. It jutted up against the long sideboard whose sole function appeared to be to hold the oversized television set, which was on but without sound. There was a nightstand with the latest high tech telephone and a lamp. There was no place to sit down. Meria motioned for me to sit on the bed. I did so with some hesitation, but there was no other choice, not even floor space.

Of all the interviews I've done doing my research on disclosure with women with HIV/AIDS over the years, this is the first one I've conducted in a home. My usual style was to meet interviewees at the place they usually went to for medical or social services. I knew this interview was going to be different, but I was not prepared for the surprises that followed; that the haunting story would be housed within me, waiting to be released years later.

Meria greeted me with a bright, cheerful smile. She spoke quickly, looking me directly in the eye, and was interested in the interview process. She did not defer to me, nor was she in awe of research. She had a story and she wanted to tell it. I had come highly recommended by a person she trusted. It was very easy to put her at ease; I imagined she thought the same of me.

She was eager to start telling her story. I had to slow her down to do the preliminary informed consent and discuss her rights as a research participant. She listened and waited until I finished. She had no questions. However, she instructed me to

spell her name correctly, Meria with an "e" not the usual "a." She was funny about this. Preciseness about her name was essential, and not to be left to chance. I made a note.

Meria continued her story.

When we first got married, Tony was always tired. But it had increased, you know, the tiredness was just getting worse. He was tired but he would say, "Okay, let's go, we're going to either go out to dinner or a dance or I'll take you out." Any little thing, you know. I felt that he was so young, but why does he always want to be sleeping. And when we went to visit any relatives or whatever, as soon as we got there, he just sat on the couch and fell asleep. And that used to upset me, because I used to say, "You know we come to visit and you fall asleep." I just couldn't understand.

Tony went to the clinic just to have him have a physical and then he'd get some vitamins or something to increase his energy because we were getting ready to go on vacation. We were going to be camping for a week and then we would come back and maybe drive down South to visit his sister for three or four days and then come back home. But he says, "I have some sort of flu or something and I haven't taken care of it."

At first they thought it was some sort of cancer. I do not know. His father is a stepfather so, you know. We had just recently lost his grandfather, but biologically they're nothing to him, so there was no connection like saying, "Well it runs in the family." We don't know from his Dad's side of the family, his real father's side of the family. He's never met him. We haven't been able to find him.

We've tried to find him at the time to see what history maybe it ran in the family. On his Mom's side of the family as far as we knew there's no cancer.

It lead to where the nurse said, "Well okay, let me run some blood work. The nurse ran the test and she came into the room and she was just like -- her face -- she looked shocked. She said, "I'm not going to try to worry you, I don't want you to go off the hammer here, but you're walking around with no immune system. Your white count is extremely low and so is your red count. There is no explanation from what you have told me. I really don't know."

So then the doctor came in, she was a doctor, so she had got another doctor and they talked, and he came in and he says, "I want you to go..." I mean he goes, "I need to get you -- hospitalize you, you need some blood," and he says, "and we need to increase your white count and your red count."

So Tony was in the hospital for six days. About three days into the week they had run all the tests that they could think of, everything was negative. So, finally the doctor came in and says, "Well everything's negative. The only test I have not asked you if we could do is the HIV/AIDS test." And Tony like, "Oh, that's no problem." He goes, " I know for sure I don't have that." They took it and about four days later we got the results back.

When Tony called I was home with the baby, our son Johnny. He was about three and a half months old. I was already very paranoid about the baby, very, you know, any little sneeze, cough, I mean I would just go off, you know, run to the doctor or run to the emergency room. I was very terrified. I thought that he was not going to live past four months old, since the first one had died at four

months. I just – there was something in me that just, that, I was, I guess I was kind of over protective. Any little thing I would - - My Mom like, "Calm down. Don't do that to him. You know he's going to be fine. You have to think positive, you can't think negative." She's on and on and on. I was like, okay.

"I need you to come right now," Tony insisted over the phone.

"What is wrong? Can't you tell me on the phone?" I said. I was always worried about taking the baby out right after a bath.

"I can't tell you over the phone, get over here right now." And he hung up.

So I get the baby, I get in the car, and I drop him off at my aunt's house. I told my aunt, "I got to go to the hospital. I don't know what's wrong; Tony didn't want to tell me. He doesn't sound sick." It just didn't, it didn't click in my mind saying, ooh, and maybe he got the results back -- I didn't think of that.

My husband's first words when he was told that his AIDS test was positive, when he got me and sat me down and knelt down and he was trying to say something to me and he was just like, you know, he couldn't believe it. And I was like, "Well what? I just never ever thought of it. When he said, "I – my test came back positive."

As I stared at Meria, who showed no traces of tiredness, and as eager to tell the story as when she had started, I pictured the hospital disclosure scene as this young man, in a hospital gown, on his knees before his wife, struggling to say the unbelievable. Did Tony, as Thomas Hardy wrote in the 19th century novel, *A Group of Noble Dames*, “embrace her in a tearful and passionate manner, and say he wished to make a confession?” What brought me out of my imagination was Meria's response to Tony.

Um, I remember saying, "Do you want to run that by me slowly, and tell me this again. You are joking, right?"

He said "No."

I said, "Ok. Well, I guess we can handle it. There is nothing much we can do." I go, "We have to be strong. Let's get some literature on this. Let's get to know it."

Meria's description of her reaction to Tony telling her did not seem as authentic as the rest of her story surely was. I say this because I have heard so many women's stories of betrayal, rape, intentional transmission of HIV, injecting drug use and their response to learning they were HIV positive. Why was I being suspicious about this part of Meria's story? I know I had lost my innocence about AIDS transmission and relationships, but shame on me, I thought, for being doubtful and skeptical.

Given the general public consensus that only gay people or people who inject drugs get HIV/AIDS, Meria and Tony were left to figure out how Tony could have become infected. I only know what Meria's shared.

There was just no way my husband could have AIDS. Because he was not gay, you know, and he had never used drugs. I guess Tony got AIDS with somebody he dated, when he was in the Navy. I do not know much about it because I'd rather not know much about it.

One of Tony's very first thoughts was, "Oh, my God, I'm going to die and people are going to think I'm gay." And I reacted to that, I was very hurt, you know. I looked at him and I said, "Why would people think you're gay?" And he said, "Well, you know, doesn't this just happen to gay people?"

You know it hit me right away that it wasn't just a gay disease, a homosexual disease. His way of thinking was, "Well, gay people deserve it. They know what they're getting themselves into." It has changed a lot the way he used to think, and he has learned a lot. I -- well I should say, we both have learned a lot.

Then we had to go through the worst horror. Life again. Our son Johnny was also HIV positive. When I had my test done they said they were going to have to test him. I didn't care about me being positive, but I did care about the baby being positive.

Meria told me that they had just had their second baby two months before Tony tested positive for HIV. Then she said, *"We already lost a baby."*

Two years after their marriage, Tony and Maria had their first born, a baby boy. They named him Tony, after his father. He lived only four months. The obituary reported that graveside services were held, but no cause of death was reported.

Meria continued the story about Tony, their first baby's death.

I had to tell the doctor, "Okay, take my baby off the life support." The doctors told me, "He's just not going to make it. You're just prolonging it with the machine." So that was a very difficult decision to make. It's never ever easy to lose a child, and then I had a new baby.

During the interview the new baby, now twenty months old came toddling into the room ahead of his aunt, Meria's younger sister. The baby climbed onto the bed with some help. Meria and he were gleefully jabbering away. It was touching to see him hug his

Mama. He pointed to her catheter and touched it. He lost interest quickly and went to be with his aunt and father.

Meria explained:

I've always allowed him to see my catheter. You know, he was very curious. He's never pulled it. He grabbed it, he looked and you know he said, "That mama's owie. And I said, "Well, it's not an owie." He calls an owie as either a scratch or a cut or when he hurts himself, whatever. I said, "It's not really an owie." I go, "It's for mama's medicine, which are vitamins. But he can't say vitaminas, so he says memina. So I say, "This is for mommy's vitaminas."

When I asked Meria she told me the baby now lives with his grandparents, and calls his nineteen-year-old aunt, who lives with their parents, "Mama." She said, "Tony and I visit him four to five times a week."

Then getting back to her story about learning Tony's positive HIV status, she said, *I knew I had to have AIDS. I just didn't want to deal with it. There was a lot I felt – there was a lot that had gone on in my life. I thought, my God, what else, you know.*

The "What else" is not completely knowable. Two years after the interview I began working on the manuscript of Meria's story at Hedgebrook, a community of women writers on Whidbey Island in Langley, Washington. When I received my letter of acceptance for my residency on May 2, 1995, one of my early phone calls was to Meria. I anticipated interviewing her again, perhaps meeting her mother and possibly seeing the

baby again. Her phone had been disconnected. I immediately phoned Judy, the social worker and my original recruiter.

Meria died at age 25 on February 13, 1995. Tony died at age 28 on August 31, 1993, less than one month after my interview with Meria. I was told by Silvia, her attending nurse that Meria died a miserable, and long suffering death, filled with guilt, until a miracle, a healing of the soul, occurred in the hospital between Meria and a priest. I never learned what that was about. But it seemed that by some miracle, according the hospital nursing staff, Meria woke up the next morning and said, "I want to home. I am going home."

Before Tony passed away, they had a re-commitment service and celebration of their marriage. Tony was not well, but was there in a white tuxedo, sat in a chair, to weak to participated. Meria wore her white wedding dress. The lace was re-designed to cover her catheter tube. There was a ceremony, officiated by a deacon and also wife of the priest of the local Episcopal Church. Photographs were taken, and there was a dinner and dancing at the local lodge hall.

According to Silvia, the ceremony was like a first wedding. She told me, "I will always remember Meria as a bride." Even though Tony was too weak to dance, Meria was lively, and had everyone dancing to the music. The most touching event in this was Meria dancing with her son Johnny, then four years old, dressed in a white tuxedo. Everyone watched as they danced together, and there was not a dry eye in the house."

Meria moved in with her mother and stepfather after that. She endured terrible pain, and her whole life was centered on looking forward to Johnny coming home from Head Start school and sharing his school life and what ever drawings he had done. She

lived for Johnny. According to Silvia, Meria should have let go and died, but she didn't. She hung on, through the pain, to experience another day with Johnny. She also hung on to assist her family to get a new house. As long as she lived with her family there were disability benefit checks and her disability status, which helped her mother, stepfather, two sisters, a brother, and Johnny qualify for self-help housing. She died shortly after the family moved into the new house.

She wanted to die at home. Her mother had doubts that she could handle her daughter's death at home, but she honored Meria's wishes. Though she had been in and out of the hospital, on her final day Meria collapsed at home. Her mother, who was described as a small, short woman, somehow picked Meria up, put her in the car, and drove to the hospital. This was a difficult task since Meria had several open sores on her back. A Franciscan Friar had been called to visit another patient, but when Meria arrived, the staff diverted him to attend to her. The Friar spoke Spanish and told the family to say their good-byes, and make their peace. Marie's mother called her husband and daughters and told them to come, but to leave Johnny at home with his uncle.

Meria and her younger sister had had a falling out, about what I do not know. They had to clear it up. According to Silvia, Meria was able to say what she needed to her sister. And whatever the difficulty, Meria had decided that her mother and stepfather would have custody of Johnny, and not her sister.

What started out for Meria as a high school romance with Tony, ended in a tragedy. A young girl marries her high school sweetheart, and they are supposed to live happily ever after, or at least have some fun trying. And in the end, a disease assumed to be far from

their intended script killed Meria and Tony and the family they had created. Their son, Johnny alone survived. An unintentional menacing series of events where the medical experts were not yet assuming that HIV could be transmitted between heterosexual couples and monogamous married couples, lead to the end of their original family.

Tony does not intend to destroy himself, his wife, and their first-born son. It is not as if he set out to eliminate himself and his family. But while the experts were dazed, overwhelmed and confused by the new disease, and focused on certain risky behaviors attributed to gay men alone, Tony slipped by without recognition. Would this tragedy have been averted, or altered had he been diagnosed earlier?

All Tony's sorrow, along with Meria's forgiveness, could not eliminate his guilt. There was no penance great enough, long enough, difficult enough, frightening enough, that could eliminate the guilt and erase the truth. Meria was forgiving, and at the same time took on all the responsibilities of childcare, husband care, health care, guardianship care, financial care, and death care.

What went wrong? Not only did Meria exemplify the good girl script by saving herself for marriage, she also blamed herself while burying her first-born, and feared her husband would leave her. She thought she had taken their baby out too soon, or perhaps his hair was wet. Then her husband was diagnosed with AIDS, and she knew that meant she had it too. Only then did they realize that the first child's pneumonia was most probably due to AIDS, eventually confirmed by their physician. But Meria feared that her second son had it also. And initially he did. However, at age two, Johnny's HIV status reverted to negative. Meria buried her husband. And then she died, an exceptionally cruel death. Yes, it's a tragedy, but her son Johnny lives.

Meria, may you rest in peace. Your mother and family care for your son. Your story is told.

ⁱ The names have been changed to protect the privacy of all people in this essay.