

On Denial and its nightmares.*

Sobre la negación y sus pesadillas.

Nancy Gaviria¹.

Three days had passed since M had received a kidney transplant at a private health facility in the capital of his native country. We had decided to have it there because in the U.S., it would take at least five years to identify a donor. Physically, he looked terrible, his body totally edematous and bruised, tired, overwhelmed, pale, he had aged significantly in a few days. He had difficulty breathing, needed oxygen intermittently. It was a Monday, and as every day during his hospitalization, I spent almost all of the time with him. It was summertime, and there was no air conditioning in the room. The hospital was a massive sauna, and we sweated incredibly. We had to wear disposable masks, gowns, boots, and gloves. Each time we entered the room, the ritual was the same. My job was to comfort him, massage him, implement aroma therapy, and attempt different ways to calm him down. We tried to start a chat to pass the time, tried to organize our future, looking forward to returning home. Somehow, we still thought, hoped or wished that the transplanted kidney would work.

It was during those conversations in the first two or three days after the surgery that I started noticing subtle changes in M's thought processes. I could not say what it was exactly, but my husband was not the person I knew. From time to time, he asked out-of-context questions, but immediately came back to the thread of our conversation. Something was going on; something was telling me that things were wrong. It

was an intrusive feeling in our connection that worried me. Some friends told me "it is all because he is tired." I knew it was something else; it was not in vain that we had spent already 13 years together, day in and day out.

That Monday I left at 10 p.m. Four hours later, my husband called me to say that he was not feeling good, and that he thought he had psychiatric side effects of the steroids prescribed. Furthermore, he told me that the nurses did not understand what was going on. I rushed back to the hospital, and the changes I had noticed as subtle were now critically obvious. M was awake and very anxious, did not want to be alone, was talking about his symptoms and the medications he needed (making appropriate recommendations in this regard), and was reflecting loudly about what else should be done. He told me that he needed a sedative and requested several times that it be administered immediately. His physician (not a psychiatrist), told me that M was getting high doses of anxiolytics, but I insisted that he needed something stronger. Both, my husband and I, knew that what he needed was a neuroleptic. At around 6 a.m. Tuesday, with M getting worse by the minute, his thoughts were now overtly paranoid. He told me that the nurses and the physicians wanted to hurt him, so he asked me to take him home. He was, of course, on oxygen, full of catheters, drainages, etc. I desperately tried to tell him that as soon as he was off all the tubing, I would take him

** This text describes the observations and experiences of the author whose husband, a psychiatrist, underwent a kidney transplant outside the U.S., and had a hyperacute rejection immediately after the procedure.*

¹ Occupational Therapist, Weiss Memorial Hospital. Gero-Psychiatric Unit, Chicago, Illinois, USA.
Dirección electrónica: nancygaviria@comcast.net

home. He would calm down for a few minutes, but then the agitation would come back. Once, he tried to take the IVs off. The physician came back in. I told him that M needed an antipsychotic, but he did not listen. M became physically and verbally aggressive. I allowed him to release his aggressiveness and his panic on me. He pushed me hard. I came back to him. He hit me in the face; I came back to him. I tried to hold his hands, and explain to him what was going on. The doctor and the nurses tied him down to the bed, and requested more personnel to control him. I could not resist anymore. I left the room, totally overwhelmed, crying inconsolably. I went back to the room and begged the doctor to give him a more appropriate medication. He responded "I am giving it to him now," but I knew he wouldn't. I called a friend. When she heard me crying, the first thing she asked was "Has he died?"

The next days were a real nightmare. He was intubated and transferred to the ICU. He was conscious but agitated, unable to talk, looking at "thousands of bags with water" (IV solutions) hanging from the ceiling, yet somehow, all connected to him in some unexplainable manner. There was no calendar, not a clock around. I learned to read his eyes, and so we made some subtle pacts, without the nurses being aware. I untied one of his hands. I tapped his lips with little watery sponges. He would feel better for a minute.

Days later, when he was extubated and able to speak, he demanded explanations of "why I had abandoned him," even though I had spent practically all of the time by his side. He became angry seeing me talk with the physician: "Don't believe him," he told me, "be careful, I don't trust him." He berated me if I was not with him in the room at 8 a.m. sharp. Four days later, he was calmer as his physical condition had improved somewhat. He started to tell me that before coming back home, we would go on a vacation to the Caribbean. We talked of the blueness of the ocean, the peace in distant places, how good it would be "not to be connected to any unknown liquid solution." The most difficult time for me was having to leave him alone in his room at night. I felt that he would be in the hands of people that did not understand what was going through his mind. I knew that he would request water, and they would not give it to him. I knew that he wanted them to call me, and they would not do it. Just to let him know that I would be there even if he did not see me, I left a little teddy bear hanging by the window. He told me later that seeing it calmed him down.

His periods of improvement, however, were transient. I knew that although his thoughts and judgments were altered, his medical and professional knowledge was intact. Nevertheless, he still thought that the staff, particularly the main surgeon, wanted to hurt him. He had studied the nurses' schedules, knew their shifts very well, and therefore had set in his mind "the best moment to escape." I had to use a number of little tricks to allow him to continue elaborating on his plans while, at the same time, postponing the "great escape." M now knew I was on his side, and not part of the "plot to get rid of him." The nurses gave me the nickname of "diazepam" because as soon as I arrived to the room, M would calm down significantly. I kept massaging him, talking to him about beautiful places, and he would slowly fall asleep for a couple of hours during the day. I spent the next several days and nights by his side, he used to tell me that just seeing me near him gave him a sense of trust and safety.

It took still a few more days for me to be able to persuade the doctors that what he needed was a neuroleptic. When they finally did it, M called me one afternoon I had been able to go home for a while, to tell me that he was feeling "much better." He was calmer, and told me that he was able now to sleep and rest. We then requested his discharge. The doctors were at a loss, didn't know how to explain or what to do with the many complications that had occurred. They finally accepted, as we promised that he would stay at least two more weeks in the city. Two days later, however, we decided to return to the U.S. The doctors insisted in keeping him on dialysis in order to give the transplant kidney "more chances of survival." We did not agree.

The return flight was another harsh and seemingly endless experience. M's breathing was still extremely difficult. He had lost up to 25 pounds, was unable to walk, and had not truly rested for over two weeks. I even thought that he could die during the flight back, but I never felt guilty for bringing him back. By then, however, we both knew that the transplanted kidney was dead. We didn't talk about it though. It was the self-redeeming end of a collective denial and its nightmares. This was confirmed, as soon as M was admitted to a hospital in Chicago. The transplanted kidney was removed immediately.

The delirious and paranoid symptoms had dominated M's life for at least two weeks. He was no longer suspicious or paranoid, but his memory and attention were still fragile. His mood switched from outbursts of irritability to hypersensitivity, easy tearfulness in the

face of situations that would have not affected him before. We kept talking and gave ourselves mutual support. His sleep was normalized only six weeks after our return. On many nights before then, he woke up with nightmares, or I had to wake him up because he was sweating so much that he needed a change of pajamas. His body was in a continuous struggle searching for equilibrium. His mind had to let him remember and accept that he was already back home.

All of my professional experience had certainly not prepared me to face the experience of my own husband going through delirium and psychosis, dealing with medical personnel that did not exactly ascertain what was going on or what to do, perhaps overwhelmed by the responsibility of dealing with a prominent colleague going through a very difficult experience. The events of those two weeks have made me even much more aware of the fact that any medical team must deal not only with the physical or biological aspects of the patient's plight. Neglecting (perhaps due to the

pressures and needs of the acute medical management, perhaps as an act of denial) the many psychological and CNS-related reactions to the severe aggression of a major surgery, impoverishes the practice of a good medicine and is terribly unfair to the patient and his/her family alike. Every medical team should forget the dichotomous, artificial separation of body and psyche, mind and brain. We all tell ourselves that the human being is just one full, solid, valuable entity. Yet, on the field, we many times tend to forget the most precious and the most fragile component of that arbitrary dyad.

Chicago, November 2007.

Acknowledgements:

To Renato D. Alarcón, MD, MPH for his critical review of earlier versions of this manuscript. The author also acknowledges her husband's (Moisés Gaviria, MD) permission to publish this piece.