

Personal Sketch

Role Strain: Illness in a Physician's Family

Howard D. Silverman, MD

Coping with a serious illness within a family can be a perilous process. This article describes such a process within a physician's family and focuses on the problems of communication and role strain. An innovative approach to the resolution of role strain, the design and performance of a family ceremony, is presented. Its effect on the family system is considered and the implications for similar situations discussed.

During the process of medical education, each of us develops a "Doctor-Self." This persona is functionally suited to professional activity, but its use in the home may result in difficulties. Here it may conflict with the "Father-Husband-Self" or "Mother-Wife-Self" roles, producing a phenomenon called role strain. This strain can seriously compromise relationships, as well as one's ability to function in all roles unless it is recognized and treated. A recent health crisis in my family demonstrated the importance of role strain and led to some methods to relieve it.

My wife began to suspect that our second child, Arielle, was not completely normal at two weeks of age. Attributing this concern to hormonal shifts, I was able effectively to deny the existence of any problem. As a family physician, I had reassured many parents about the normalcy of their children, and I viewed such parental concerns as an inevitable ingredient of parenting.

As Arielle grew, however, I began to have a growing sense of uneasiness that indeed she was not visually tracking as a child of her age normally would. Her eye movements displayed more nystagmus than other infants her age. My denial began to crumble, replaced by alternating hope and despair. It certainly is true that ignorance is bliss. I knew Arielle's differential diagnosis included brain tumors, global retardation disorders, and a host of irreparable obscure syndromes. Afraid of unleashing hysteria within our family, I developed an external attitude of "time will tell" while the fires raged inside.

When Arielle was eight weeks old, we had a family gathering to celebrate

Howard D. Silverman, MD, is assistant director, Family Practice Residency, Good Samaritan Regional Medical Center, Phoenix, AZ.

her arrival. My wife asked one of our friends, an ophthalmologist, for a hallway consultation. I was openly angry at such an unprofessional approach, yet secretly eager to hear his opinion. He diplomatically noted that he did not see any obvious problem, but suggested a more complete examination in his office the next week. It was at this point that my Doctor-Self and my Father-Husband-Self became divided. The former was visibly confident, reassuring, and detached. The latter was secretly fretful, fearful, and virtually without perspective.

The next few weeks resulted in a flurry of examinations, referrals, and more examinations. Each examiner came to the conclusion that nothing was structurally wrong, yet each felt a referral to another subspecialist was in order. Throughout, my external attitude remained philosophical. As my wife's suspicions and fears grew, I became more impatient and unwilling to offer the physicianly reassurance she seemed to need. I realize now that she was asking for communication and support rather than for my professional opinion. At the time, however, it seemed so much easier to hide the Father-Husband-Self behind the Doctor-Self and maintain the illusion of control and calm.

Finally, it was suggested that we obtain a cranial CT scan. I was opposed on the grounds of the radiation dose as well as the necessity for an IV. I also voiced the opinion that the results would not offer any option for correction anyway. Secretly, however, I was not sure I was prepared for the possibility of a malignancy. After considerable debate, I begrudgingly gave my approval and breathed a great sigh of relief as the radiologist read the scan: *Normal Cranial CT*. Arielle was given the diagnosis of congenital nystagmus, a condition with a relatively good visual prognosis.

My wife continued, however, to suspect something more was wrong. We decided to take Arielle to a physician who was recommended by the Foundation for Blind Children. He examined her and stated that he felt sure she did not have simple congenital nystagmus. Further workup was to include an electroretinogram (ERG), a test that might require general anesthesia. It was at this point that the tug of war between my wife and myself, as well as that between my two internal selves, reached its peak. I objected strongly to the possibility of a general anesthetic and accused my wife of putting our child through needless testing only to assuage her anxieties. I realize now that I also placed her in an impossible double bind. As a wife, she stood to lose her husband if a complication from the test occurred. But as a mother she knew instinctively that her child's condition had not been properly diagnosed. Luckily, we were able to arrange for the test to be performed without the need for general anesthesia. Hours after the test, the ophthalmologist phoned me to inform me that Arielle was definitely blind from a condition called Lebers Congenital Ameurosis. I will never forget the kindness and concern in his voice as he patiently answered the few questions I could think to ask. He gave me his home telephone number and urged us to call if we needed to. Having already activated the support network at the Foundation for Blind Children,

he asked me whether he should inform my wife. Without hesitation I told him that I preferred to tell her myself. Somehow, despite the shock of this news, I felt that I had turned the corner. As we talked on the phone, the grasp of the Doctor-Self fell away. It marked the end of that period of uncertainty and the beginning of a period of healing the rifts in myself and in my relationship with my wife.

Arielle is now 5 years old and thriving. Both of us harbor no regrets about the past. We realize that breaking down is a normal response to a stressor of this sort and precedes rebuilding and growth. We have moved forward together in our relationship, after much soul searching, talking, and hard work. We both have had to face some of our internal dragons. In doing so, we have been better able to see beyond our external behaviors to what was happening inside. Only dimly aware of this internal process at the time, we had become polarized by our external behaviors. As we talked, we realized that our internal process and suffering were almost identical. We discovered some methods that, in retrospect, greatly accelerated our rejoining. Furthermore, these methods proved to be of great value in relieving the role strain I was feeling.

After Arielle's diagnosis, we still found it difficult to talk directly about our pain and our fears and concerns for the future. This was a critical time, since it would have been easy to lose contact altogether, splitting up or, perhaps worse, living separate emotional lives. One day my wife noted that despite her acceptance of the diagnosis, her emotional suffering did not subside. I reflected that in my work with certain terminal patients at a hospice, I had witnessed the emotional healing potential of ceremonies. We began constructing a ceremony for ourselves with the object of healing our individual pain and our relationship. (It was never our intention, however, to affect Arielle's prognosis.) The purpose, then, was to let go of our pain so we could rejoin. More important, we felt it critical that we not transmit this pain to our child, either directly or indirectly. She was not aware that there was any problem, nor would she be unless we chose to define her specialness in that way.

We had no precedent, no examples to use as models. So we started to talk about the "obvious" aspects. Where should we hold it? Who should be there? As we talked about the construction of the ceremony, without knowing it, we began to reconstruct our relationship. We realized how important and similar our basic values were. We began to glimpse more of each other's inner selves, rather than concentrating on the external aspects, as we had in the past. We were able to approach even the most painful parts of our experience indirectly via the metaphor of building the ceremony. We were able to forgive and move on in a positive mode.

On the day of the ceremony, we both realized that the healing of our relationship and of our family had already occurred. Fifteen family members and close friends gathered in our home. I introduced and greeted all participants with cedar smoke, a custom we had learned from Native American friends and that we liked very much. We then shared some of our sorrows,

carefully making the distinction that these things were *our* sorrow, not our child's: her inability to see the visual splendors of nature, to see the faces of loved ones, potential limitations on her activities, being treated as "different" by others. Then we celebrated the positive: enhanced appreciation of nature through other senses, not being oriented toward appearance only, being continually challenged to push limits, showing others that being different need not be feared. We saw how our lives would be enhanced and appreciated in new and unexpected ways. We then allowed others to voice their pain and fears. I remember feeling sure that our family and friends probably thought we had "flipped out." Yet as we looked around the room, many were crying openly. Each spontaneously shared their pain—the double pain of our parents for us and for their grandchild, friends' fears about being comfortable around Arielle or having to explain her blindness to their children. We asked our friends to write down any fears that were too personal or difficult to voice out loud, throwing the crumpled scraps of paper into the fire. We closed with songs, united in one circle, one voice. The healing had come and continues—not just for us, but for and with our circle of family and friends. Arielle had fallen asleep halfway through the ceremony.

In retrospect, the content and form of the ceremony were arbitrary. There is no recipe to ensure success. A positive attitude and strength of heart turned out to be the critical ingredients. Such ceremonies can be custom made or borrowed in full or in part from an established religious or family tradition. Involving a circle of friends and family was also helpful.

The experience has helped me to grow as a physician and as a Father-Husband. Furthermore, it has shown me new ways to blend these two roles harmoniously, as exemplified by the ceremony. Conducting the ceremony required the simultaneous use of both the Doctor-Self and the Father-Husband-Self. In relieving my own role strain, I had the great fortune to experience an expansion in my definition of the Doctor-Self. Never before had I felt so much a "healer" as I did while conducting our ceremony.

My work style has also changed in a subtle way as a result of this experience. What some may consider old-fashioned, I now consider "ancient" and worth rediscovery. We must not forget the value to our patients of the commonly accepted ceremonies—the stethoscope, the white coat, the writing of prescriptions. I am more careful to take a patient's blood pressure myself or to listen to a patient's chest or heart, even if there is no medical indication for the procedure. I think we must also be more sensitive to the contribution ceremony can make for special situations, particularly when its construction and execution are carried out by the patient and family members.

This experience opened my eyes to the difficulties that we physicians face when we cope with illnesses within our own families. We are significantly at risk for role strain in such situations. Unless some way of balancing roles can be found, the physician is at risk for sacrificing one role for the other. This may lead to the breakdown of the family and may ultimately create the conditions for the physician's impairment.