

Health care reform and the fragile physician-patient relationship: Medical Horror in a US Territory

By Christopher Guadagnino, Ph.D.
Freelance health policy writer

There's plenty of partisanship, misunderstanding, and name-calling in our current national debate on health care reform. Legislative health reform proposals are lengthy and complex, and many people are understandably concerned about the way that fine print may gain the force of governmental authority over some of the most personal details of their lives.

Health care is unique among other types of social reform. It may be easy to accept -- and perhaps even welcome -- expanded government regulation of safe food and drugs, or fair housing, or environmental protection. Most would agree that no American should go without medical care and treatment when they are sick or injured, but many of us question how the consequences of reform -- intentionally or not -- will compromise our authority to make our own personal health care decisions.

Socialized medicine? "Willful misrepresentation!"

Government rationing of health care? "Outrageous myth!"

Death panels deciding what life-saving treatments will be withheld from the elderly? "Fabrications, ludicrous ideas, and outright distortions!"

Fiery rhetoric, to be sure. But it is hard to know how much control we might lose over our choice of doctors or treatments when many of our elected officials want to control key business practices of our health insurance companies, or want to see that government-run companies with federal financial backing and clout compete in the private health insurance market, or want to empower panels of experts to make treatment and coverage recommendations based on efficiency calculations.

Many are left wondering whether they will still be able to get the medical care they want and need if legislators decide to greatly expand government's authority over how our care is paid for. Perhaps a more frightening prospect than ratcheted-up rationing of medical care is the unintended consequences that expanded government authority may have on our personal relationship with our doctor. We are in trouble if doctors believe (justifiably or not) that their allegiance to our personal health care needs takes a back seat to their accountability to government mandates.

That seemingly far-fetched scenario happened about a year ago to Megan and her family while on vacation in Puerto Rico, a U.S. territory whose health care system is much like our own: health care services are provided mainly by the private sector, and the government finances health care for the indigent (a very large segment of the population). The physician-patient relationship in Puerto Rico is already severely eroded, according to a special Health Reform Evaluation Commission appointed a few years ago by the island's governor. Whether real or perceived, governmental pressure on the doctor-patient relationship can lead to disturbing consequences.

Megan, a mother from Pennsylvania, describes her terrifying experience at a hospital in Puerto Rico with her young son Luke, and she offers it as a cautionary tale for those who might embrace too hastily more government authority in personal health care decision making. She not only was denied choice of care for her little boy; she was denied *parental rights*. The incident is worth recounting in her own words.

"We went to Puerto Rico with some of my in-laws. Within our group was my sister-in-law, Maria, who is a primary care physician. On our second day there my 13-month-old son Luke had a seizure on the beach for about 40 seconds. Fortunately, we were able to get him under a cool shower to stop the seizure. With the help of

security and some others around the beach, Maria and I were off to a nearby hospital to have Luke evaluated and treated.

"Once we were seen by the triage nurse, we learned that Luke had a 103.1 fever. They immediately administered an acetaminophen suppository to reduce the fever. Once we were seen by the ER doctor, he checked Luke's ears and throat for infection. He saw some redness and thought it could be the cause. Later we were seen by the pediatrician on ER staff. Thankfully, Luke was happy and playful, although his fever would not go down. He was given acetaminophen around the clock to reduce his fever, but to no avail -- his fever never went below 102.6. One of the doctors ordered chest x-rays and blood work. Eventually four rounds of blood work and all labs were negative except for C-Reactive Protein (CRP), which not surprisingly, showed positive for inflammation.

"Maria had requested that Luke be given ibuprofen since the acetaminophen had not been effective. The pediatrician told us it was contraindicated, explaining that Luke may have "viral syndrome" which could impact platelets and cause bleeding. Maria stated that this type of treatment is common practice in the U.S. and that, if our goal was to reduce Luke's fever and prevent another seizure, then the benefits outweighed the (minimal) risk. The pediatrician said that although Luke's white blood count was normal (indicating no bacterial infection) we could not be sure it was not meningitis, so her workup was to rule out meningitis. She told me that we had to get the fever down, that she would like to do a CT scan of his brain, and at the very least she would like to observe him for many hours or admit him to the hospital. If he was admitted, she would plan to keep him for at least two days. I could not believe this was happening. She then decided that Luke needed a dose of intravenous Rocephin -- a big gun antibiotic, something he would only need if we knew it was a bacterial infection, primarily meningitis.

"At this point Maria called a friend in the U.S. who happened to be a pediatrician, as well as Luke's own pediatrician. At this point it was 9:00 pm on Mother's Day and I was asking for the help of all of these wonderful mothers! Both pediatricians validated Maria's opinion. Luke's lab results were negative and he looked and seemed like himself to me, even playing peek-a-boo in the ER. Only the fever persisted, which we felt confident would be reduced once we left the hospital and gave him the ibuprofen that Maria had in her hotel room. We did not want to go ahead with the CT scan. Luke would have to be sedated for this, and neither I nor Maria felt this was a necessary risk.

"Once we were given verbal confirmation of our decision by two physicians -- including Luke's own pediatrician, we asked the ER pediatrician treating Luke to allow me to sign an AMA release form and take Luke home. The pediatrician told me I could not sign him out '*because he belonged to the government now.*' She went on to explain that her own license was on the line, and that she '*answers only to the government, not to parents.*' Maria and I were completely shocked to hear her say this.

"We realized that we had to get Luke's fever down on our own to get him out of this hospital, since their next strategy was for us to put Luke in a cold bath for 30 minutes. They made us do this ourselves in a sink in another patient's exam room in the ER. We watched Luke shiver and cry for the first time we'd been there.

"When I asked them what would happen if I just left with Luke, they said they would call the police, since it was against the law. We could not believe this could possibly be happening in a U.S. territory. I kept thinking maybe I misunderstood, and that they could not be telling me this. They had a uniformed security guard posted in the ER. I told them that I felt like a prisoner, and they said, "*yes, you are.*"

"Maria brilliantly suggested that we call the hotel and have my husband sneak ibuprofen into the hospital. He successfully arrived at 12:45 am and we administered the ibuprofen to Luke, unbeknownst to the hospital staff. Within an hour Luke's fever broke. We talked to the staff about leaving with Luke, and they said no, only the pediatrician can discharge Luke, and she went home for the night. They said she was not answering the phone,

that her husband was sleeping, that no pediatrician was on call, that the ER doctors could not discharge us, and that we would have to wait until 7:00 in the morning when the pediatrician returned.

"In the middle of the night an ER doctor came in to say that, based on the CRP results having been positive, the pediatrician had called in a second dose of Rocephin for Luke from her home (but did not come in to see Luke until morning). This is another error, since CRP is not an indicator of meningitis, but a marker of inflammation, and in no way is a reason to give another dose of Rocephin. So, Luke ended up getting two doses of a big-gun antibiotic for no reason, and he had never received antibiotics before.

"We continued to wait in the ER until morning for the pediatrician to return to evaluate and (hopefully) discharge Luke. At this time there was no treatment for Luke. He had no fever, he was not receiving any fluids and not receiving any medications, so there was no reason for us to be there. We sat there until 8:00 am as prisoners. It wasn't until 8 o'clock that we even received food and water for Luke (applesauce and milk) after 22 hours -- and only after I had insisted upon it. Luke had nothing to eat or drink in over 14 hours except for my failed attempts to nurse him because I was dehydrated myself, and had already weaned him to nursing at night only.

"It was my husband Patrick who finally freed us from our 'prison.' He had been watching our older son back in the hotel room during this whole ordeal. After meeting us in the ER, he went to find a hospital administrator. He informed them in no uncertain terms that, one way or another, he and our family were leaving. He let them know that Luke had a fever that was not being treated adequately, that when we tried to refuse treatment we could not leave the hospital, and that we were told we were prisoners and that Luke 'belonged to the government now.' After many conversations between the administrator and the pediatrician treating Luke, they presented us with the AMA release form to sign saying we refuse a CT scan and Lumbar puncture (for a spinal tap, which they wanted to perform). Suddenly, we were free and being driven back to our hotel in a cab.

"We had since learned that Luke had a febrile seizure due to a rapidly rising fever, and dehydration due to a common childhood virus called roseola. He broke out in a rash the day after we returned home. It turns out that I had a similar experience as a baby, and the condition can be genetic.

"I had spent 20 hours in a hospital fearing for my child's welfare. He was subjected to invasive tests and IV antibiotics against my wishes as I sat back and could do nothing to protect or advocate for him. Our ordeal ended without harm to our son, but I share this story to raise a red flag. If you travel to Puerto Rico with your family feeling that your rights are protected since it is part of the U.S., I am here to tell you otherwise. My gut instinct told me that Luke's workup was not right. Maria and I were aware of appropriate protocols for many illnesses, including a baby presenting with a high fever and a seizure, and the hospital staffs' conclusions did not make sense. My fear then evolved into terror when the pediatrician personally told me that I could not leave the hospital because *'he belongs to the government now.'*

"They evoked the government's supreme authority over Luke's health care as gospel. They ignored the opinions of two pediatricians we knew personally and spoke to on the phone (one of which was Luke's own doctor), as well as the evaluation of Maria, a doctor of family medicine, who knows Luke intimately and was going through this with us. We requested to release Luke (by signing an AMA release) to us and were denied repeatedly. When we asked, 'What would you do if we just left?' they posted security outside our ER curtained area.

"In hindsight, if I were to take my cynical glasses off, I'd like to believe that we all wanted Luke to get better. But even if we all had Luke's best interest at heart, my rights as a parent were blatantly trampled on. A hospital may not deny your right to sign a release and refuse treatment unless the patient's health would be in immediate peril, based on a definitive diagnosis (not merely symptoms like high fever and seizure). Testing had actually ruled out that Luke was in any immediate peril. The attending pediatrician believed she had governmental

authority to take away my parental rights and keep Luke under her care until she determined the cause of his fever.

"As an American, I truly value (and perhaps take for granted) my parental rights. After my experience I will never vote for anything that could jeopardize my rights to care for my children. When you allow the government to pay for your health care, you also may risk forfeiting your rights to make important personal decisions about that care."