

What A Patient Centered System Could Be

I picked up my 85-year old mother from her Adult Family Home in the North end of Seattle at 9 AM to take her to her 10 AM interview with a new health care system. I changed health systems after her Adult Family Home raised its rates by \$500 a month and reduced staff and services. I enrolled her in a senior care program that would have responsibility for her health care, adult day care, and housing.

I have been writing on health care policy for 30 years and nothing prepared me for this experience. This is how a good health system could work.

The First Encounter

When I picked up my mother, she was loopy from the anti-anxiety medications we gave her to ease her move. She had Alzheimer's disease and we were trying to make the move the least disturbing as possible for her. I realized after I got her into the car, however, that because of the medications she was too dazed to understand how to get up and out of the car. I also realized I could not lift her out.

I arrived at Providence Elder Place at 10 AM, just as all the vans with the adult day care patients were arriving. I parked right under the 'No Parking' sign at the front door because I needed help. As I got out of the car, and went to my mother's side to help her out, a very large man came out the front door. I was in full fight mode ready to insist that someone help me—when he said, "Stay right there. Don't move. We'll get a wheelchair for you right away." I stared at him incredulous, thinking, "What? No fighting to get what she needs? They are helping me instead."

The Team

For the next two hours we met with her new doctor, her nurse, her social worker and an occupational nurse who helped with her cracked collarbone from a recent fall. We talked not only about her health history, which I had to give because my mother could no longer communicate because of two massive strokes and the onset of Alzheimer's. Not only did they want her health history, they also wanted to know who she was, what she liked, and what her personal interests were.

After these interviews, the social worker took me aside and asked how I was doing. At which point I burst into tears. I told her I was fine until people sympathized with me.

By the end of those two hours, they had arranged for my mother to sit with a Japanese woman at lunch, since my mother's major love was Japan and we had lived there. They created an activity plan to care for her the rest of the day and provided her transportation with a caregiver to her new Adult Family Home. This enabled me to take care of moving and arranging mom's things during the day. By the time she got to her new home, we had the room with her things so it would be as familiar to her as possible.

The nurse came to me after all these arrangements were made, told me what they would do, and said I could go now, because she knew I had a lot to do with the move the rest of the day. Then she added: “I heard that you are fine as long as no one sympathizes with you. Is that true?” I said yes. “Then get out of here,” she said. I left amazed that one member of the team had taken the time to tell something important to my well begin to another member of the care team.

The Transition and Services

Mom eased into the home right away. The home was immaculate and managed by an Indian family that lived upstairs. Children and grandchildren were in and out, so the home did not have the senior “warehouse” feel to it so many places do. Their home was clean, safe, and filled with the warmth and liveliness of an extended family.

I would get calls once a month from the social worker or the nurse who visited my mother periodically. Not only were they making sure things were well with my mother, they wanted to make sure things were well with me also. When I visited with my mother I was always included in the meals. Paula and her family also prepared wonderful group dinners at Christmas and Thanksgiving for the clients, other caregivers, and the families.

My Mother’s Passing

Then one Thursday in February, mom’s social worker called, saying that mom had stopped eating on Monday, stopped drinking on Tuesday, the doctor had seen her on Wednesday and there was nothing clinically wrong with her. It was not uncommon, she said, for patients with dementia to just ‘shut down.’ She said the nurse and the doctor would also call me.

The doctor called and told me what medications they were giving her and why. He explained that this “shutting down” was relatively common in dementia patients. Sometimes they just stopped drinking and eating. We had earlier discussed that we would take no extraordinary measures if my had a heart attack or stroke, so we decided to let my mother pass in comfort.

Then the nurse called and said she had already talked with Paula, who said it was fine for mom to remain there at the home and die there in peace, rather than be transferred. The social worker called and told me she had talked with the pastor to see if he could see my mother on Friday; and she had called a hospice nurse and arranged for me to meet her at the home on Friday morning. She faxed me some papers so I could arrange for mom to be cremated, per her wishes, and gave me the number of the funeral home that I needed to use.

On Friday morning, Paula and her son and I met with mom’s nurse and the hospice nurse. We went over everything we needed to do—and what we must not do. I was able to stay with my mom for awhile. She was unconscious and had very shallow breaths. I left to take care of payroll at the office. When I returned at 5 PM, the minister had just arrived and was with my mom. He left about 6. I was with her from then until she died at 9 pm. Paula and Manpal, her son, were with us as well. The three of us held her and talked to her and prayed as she peacefully slipped away.

We cried and hugged and grieved together, remembering my mom. We called the hospice nurse about 11 and within an hour, the people from the funeral home arrived.

Dignity and Respect

That is what health care should be and could be. My mother was taken care of clinically and personally. She was treated with dignity and respect. I was taken care of and treated with dignity and respect. In those last two days, all our clinical and non-clinical needs were met. We were given effective, efficient, respectful, helpful, and compassionate care.

As opposed to my son's death in a major urban trauma center, when the first words to me were, "Whose health plan is he on?" (He was a minor at age 13). And, the doctor meeting me for the first time saying, "How many children do you have?" No one told me what to expect beyond "brain-stem level activity." Does that mean coma and hope or does that mean chronic vegetative state or die in a few hours/days? No one wanted to face me with the news that my son was fatally injured. I know no one wants to give a family member that fatal news, but not delivering it will not change the outcome.

These two very different deaths I think illuminate what a health care system could look like, if the patient were the center of care—if our health and well-being were the goal of a health system. Circumstances were the same for my son and my mother. Neither would return to health and well being. With my son, his father and I were left to wait, with forms to sign, and countless arrangements to make. My mother and I were tucked into a system that took care of us and saw that our needs were met so we could have the time and peace to say goodbye.

This is how a health care system could work. The front-end investment of time with the care team meant that we knew each other, trusted each other, and respected each other. They assumed responsibility for her care needs, certifying the Adult Family Home, and coordinated non-care needs, such as transportation and the end-of-life needs. They knew us and took care of us. We were not left alone to fend for ourselves at a time when we were most afraid and vulnerable.

We can have a compassionate and caring health care system. It could be that simple. We must tell our policy makers what is important to us, so we can have the system we deserve, not the one we have defaulted into.

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