

The Bedrock of Health Care

~ what patient centred care means to me ~

We are all just walking each other home.

– *Ram Dass*

All my stories dance on the edges of patient centred care. I fear that patient centred care is a term used so often that it has become meaningless jargon. The phrase is slapped on hospital strategies at an alarming rate. I contend that you can't say you are patient centred until patients say you are patient centred.

Patient centred care has birthed other phrases like patient experience and patient engagement. Now my head is swimming with all these corporate terms.

I'd say that my experiences in health care are stories that illustrate the foundational elements of patient centred care: respect, dignity, information sharing and collaboration.

These foundations can apply to any relationship in health care. To be healthy in the health care system, we all need these elements – patients, families, staff and physicians.

Respect is what underpins all relationships. Trust is built on a

bedrock of respect. But respect is such a vague term. What does respect look like in a health care setting?

This is what respect looks like to me as a patient: respect is knocking at the door before entering. It is asking, “Is this a good time to come in?” It is introducing yourself, along with your role and what you are there to do. It is engaging in chitchat to get to know each as human beings, not just as patients and professionals. It is slowing down and even sitting down if you can. It is not appearing rushed if you are rushed. It is making eye contact. It is smiling.

It is asking the patient what they like to be called. It is not calling a mom Mom or a child Buddy. It is using proper names.

It is pausing for an answer after you ask a question. It is not interrupting. It is saying, “What questions do you have?”, and then waiting, instead of the often-rushed “Do you have any questions?”, asked as you are heading out the door. Respect helps us build trust and we cannot have a healthy relationship with someone we don’t trust.

My old friend dignity is mostly about privacy. This means allowing our bodies as much dignity as possible. This means minimizing the flapping patient gowns – the paper gowns are the worst. It also means at least offering a gown so we don’t experience undue nudity. Covering someone up as you examine them. Finding a private room to have conversations. Not speaking about patients at reception, in elevators or other public places.

Information sharing is much more than handing a patient a pamphlet. When I waited for my cancer surgery, many people gave me pamphlets. I politely accepted them and shoved them in a file folder when I got home. I did not read a single pamphlet.

Just because you give someone a pamphlet doesn’t mean you’ve shared information with them.

Health literacy is the responsibility of health professionals, not patients. If people have low health literacy, it just means the profession-

als have not explained things in a way that people can understand. This includes offering information that has been translated for language and culture – which so rarely happens in health care. Almost all the patient education materials are in English, not in plain language or with accessible graphic design, and created with the assumption that people can read. That leaves many people behind in the dust.

Collaboration is the final cornerstone of good health care. This is the most challenging part of the equation because health care is rife with power imbalances. It is impossible to collaborate if you have no power. In order for patients to acquire power, health care has to give up some of its own power.

In my experience, authentic collaboration is rare. People and systems are reluctant to hand over any power. I'll illustrate this point with a story.

Once my son went to the audiologist to get his hearing tested. The appointment started off well, with me smiling and extending my hand so the audiologist could shake it. But then I made a crucial mistake: I started asking questions. We had waited months for the appointment and I had many questions. First, I asked about why there weren't sound systems installed in the schools, musing that a sound system would benefit my son.

"You don't have to tell me what a sound system is," the audiologist snapped, asserting her power as an expert over me.

I took a deep breath and said to her, "Can you please speak to me more respectfully?"

The appointment went downhill from there. I did not do my job to be a compliant mother. I was not being a good caregiver. Good caregivers are expected to be quiet and passive.

In response, she directed Aaron into the soundproof room where they did the hearing testing and slammed the door behind them, leaving me sitting alone in the little wait area. I didn't know where

they went, how long they would be, or what she was doing with my son. She walked in and out of the booth a few times, not acknowledging me at all as she adjusted levels for Aaron during his hearing test. I clearly had been a bad caregiver, and she made sure to punish me for that.

Now I sat back watching this whole experience unfold. I knew that Aaron was fine – although she spoke to him as if he was dumb as a post and about two years old, not 13. But she wasn't mean to him. I tried to focus on Aaron's experience instead and thought about the impression I made with her.

A mom comes in (me) and has a lot of questions about her son's hearing. Damn it, she's the expert, not this mom, so she needs to assert her power over me to put me in my place. It worked. Taking my son from me, not telling me what was happening, I felt shamed and small. She had won. From her perspective, I had questioned her expertise by asking questions. I'll admit I could have shown more reverence towards her. But I also believe strongly that it is okay for patients and families to ask questions.

Partnerships are built between two people who trust one another and acknowledge each other's expertise. Liking each other helps too, but liking each other isn't mandatory.

In this case, I was the expert in being my son's mom, and the audiologist was an expert in audiology. We should have come together because of what we had in common: concern for Aaron's hearing. We both became all prickly with each other, so there was no chance for collaboration.

Respect, dignity, information sharing and collaboration. It is pure magic when this happens in a health care encounter. Reflecting back on our son's first appointment with Dr. Darwish, his pediatrician, I know that every single moment can have these elements, so I know it can be done. When there's a will, there's a way.