



Reflective practice

Deformed knowledge[☆]Ora P. Kalfa^{*}

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“You are so deformed. Your only option is surgery”. These were the words that greeted me from one of the top spinal specialists as I walked into his office for a much long awaited consultation. He saw, assessed, diagnosed, and sentenced me within a split second. The above statement and the encounter that followed shattered me. In one surreal and clearly unbelievable experience I flashed back to numerous experiences that occurred in my 29 years in the medical system where the same message was given, just with more subtlety and finesse. This encounter reminded me how vulnerable patients are and thus, how critical it is for us to be informed and empowered when encountering the medical world. It also highlighted the necessity of open dialogue, mutual respect, and bi-directional trust between two very different and powerful sources of knowledge about the body; the patient and the healthcare provider. I know that it is because of medicine that I survived. But I also now know, after years of intense self-learning and trial and error, that it is because of my own self that I live. In this piece I hope to use my critical analysis and reflexivity to highlight a critical issue within medical encounters.

Medicine and medical professionals are significant and powerful sources of knowledge about my body, knowledge that I am often not privy to. I have learned, however, that I too am the bearer of intimate knowledge about my body, knowledge based on my own experiences that no medical professional can possess; this is knowledge that can contribute a great deal to my health and

healthcare. No one else lives in my body or knows its pain, emotions, struggles, experiences, and expanses. No one knows how each of these and all of their individual and combined histories affect me. No one else lives with the short and long-term consequences of health choices and decision-making. However, in a medical system that often prides itself as being the sole legitimate power over my body and mind, there is almost no space for self-awareness, self-knowledge, and self-trust; there is no space for me. I have come to understand that one of the most difficult aspects of living with my body, which is a corporeality of chronic pain that requires ongoing intensive treatments, is learning to develop and trust in myself and my body's intimate knowledge and experience. Such concepts are extremely difficult and frightening, particularly for people like me, a patient who is vulnerable and living with a body in a precarious position that is subject to the medical system, often for survival. Because of such incongruence in experiences, a power struggle often results between these two sources of knowledge, impeding both personal and professional goals. How can this tension and disconnect between intimate knowledge and professional knowledge be reconciled? Can any progress be made without synergy between the two and trust in both? I do not have the answers, but I am constantly struggling to create my own balance between the two; my health and my future depend on it.

I have always had to trust in medicine and medical professionals, from the day I was born my life depended on it. It is a trust that seemed inherent, natural, and unchallengeable, a blind faith in an external and infallible source that appeared to know me better than I knew myself. It was dogma about the site of knowledge and power that passed through me from my parents who in their own vulnerability and desire to do right, had to grab hold of. It is a faith that demands the giving over of my body and being without question. It meant accessing and relying on *their* knowledge and accepting *their* assessments, skills, recommendations, and procedures for my health. Such faith entailed following *their* advice and subjugating myself to tests, procedures, experiments, and surgeries. This system and its professional missionaries saved my life. In most areas I was not knowledgeable and had to rely on their professional knowledge, tools, assessment and skills. There is a calmness and freedom in this blind faith that is often born out of necessity. This faith that is systemically encouraged had allowed me to give myself over and absolve myself of responsibility.

My faith in the medical system was the easy part. The resulting challenge is that I was taught not to trust myself when it came to my health or medical care. Great stigma accompanied my attempt

[☆] For more information on the Reflective Practice section please see: Hatem D, Rider EA. Sharing stories: narrative medicine in an evidence-based world. *Patient Education and Counseling* 2004;54:251–253.

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to rely on myself and therefore for a most of my life I disconnected and shut down completely; I had great difficulty in connecting and feeling, my body was not mine to experience. “You do not know what you are talking about” and “trust in the doctors” are messages I was told directly and indirectly. “Do what the doctors say as they know best” is what I grew up knowing. Such sentiments created and reflected the belief that there is only one legitimate source of knowledge about medicine, healing, and body, and that this source is unquestionably that of the modern medical system.

I want to discuss and critically analyze a recent medical encounter that highlights the dissonance between and importance of different types and sources of knowledge. It is my story of one encounter with one doctor, but it is a story I am sharing because I know that while it is bold and extreme, it reflects elements that are prevalent in many encounters and difficulties with the body, the self, and the medical system.

I had been waiting eight months for an appointment with a top spinal surgeon. I was looking for follow up care for my congenital scoliosis which consists of two spinal curves, naturally fused vertebrae, hemivertebrae, and kippel feil syndrome. I am 19 years post spinal fusion and tethered cord repair. I have had 14 years of bracing including Boston and Milwaukee braces. I live in chronic pain. It was our first and only meeting. I walked into his office for my appointment. He was sitting at his desk as he took his first look at me. Surprise surfaced on his face, and he exclaimed in shock,

“You are really deformed. Wow. So deformed. You are very crooked. You need to have surgery”.

I am shocked. I did not expect such a greeting. I do not know what to do with it.

I know I am crooked, thank you for your insight. I have been crooked since the day I was born. Deformed? Is that your professional assessment of my body? All of this runs through my head but I say only,

“Hi, I appreciate your assessment but I have had surgery on my spine already”.

“No, you haven’t”, he **replies** automatically.

“Yes I did!! I remember it clearly and experience the affects of it every day of my life”, I retort sarcastically.

“No you did not but fine”, the doctor **answers**. “How can I help you?”

I **realize** immediately that the meeting **is** useless and that there is nothing he could offer me. Despite his blatant rudeness to me and my body, it **is** clear that he **has not** read my very thick medical chart which details extensive medical experiences and decisions, he **has** not examined my X-rays or MRI’s, and he **has** certainly not consulted with me for even 2 min before deciding to send me to the operating room. He completely **discounts** my personal knowledge of my body and its history, displaying only disrespect and arrogance. Even though I **realize** all of this, I had to go along with the absurdity presented, it had to be a joke I thought.

“I want to get a professional assessment of the one centimeter shoe lift I was advised to wear in my right shoe to compensate for the tilt in my hips. I have been wearing the shoe lift for a couple of years, but because of issues that have recently developed such as a herniated disc, I want to make sure that the

shoe is not causing damage to my lower spine by disrupting my skeletal structure”.

I **recognize** my limitations and was seeking out expertise that I expected would be based on accumulated medical knowledge and tools.

At this point I expected him to make use of his professional knowledge and examine the comparative X-rays I had taken the week before – ones that showed my spine with and without the shoe lift. I expected wrong.

He **looks** at me and **states** conclusively,

“You do not have a tilted hips. Whoever told you that was speaking nonsense”.

His disbelief and distrust was confusing. I had made an appointment with him as a vulnerable patient seeking support. I thought I was coming to collaborate, to piece together my knowledge with his, and together to gain a greater understanding of my body that could lead to its gradual healing. Despite his status as a top professional in his field, he dismissed the facts and conditions of my medical history, as though I nothing more than an ignorant child looking for attention.

“Yes, I do have a tilt. You do not have to believe me but please look at the X-rays so you can measure the difference.”

“Fine”, he **answers** begrudgingly and opened the screen to view the X-rays.

He **takes** one cursory look, and, without checking whether it was the X-ray with the shoe lift on or off and without measuring my spine or hips, **states** conclusively,

“Your hips are straight. I do not know what you are talking about”.

Instead of using any of the existing extensive protocol and measurement tools, he **measures** this apparent lack of obliquity all with the good graces of his razor sharp eyesight. No need for rulers. And no, my hips are not straight. Most of my weekly physical therapy treatments are aimed at addressing this unevenness and the effect it has on my posture, pain, balance, and strength.

After making this statement he **turns** to me and for the first time **consults** with me,

“How do you feel with the shoe lift? Better or worse?”

“Better”, I replied.

“Then continue wearing it”, he told me.

“But I do not really care about how I feel at this moment”.

I am subjugating myself to him for what may have seemed to him trivial but what was in fact a very critical decision that would affect my health in the long term. I have learned the hard way that temporary ‘good feelings’ can often result in long term consequences such as pain and deterioration.

“I am coming to get your professional advice on my skeletal structure and your assessment of the affect the shoe lift is having in the present and future. How I feel at this moment is not relevant”.

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