Chapter 1

From Compliance to Concordance and Beyond:

Rhetoric, Reality and Qualitative Research

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ABSTRACT

This commentary begins with a brief overview of recent developments in healthcare policy and practice in the UK. Particular attention is paid to the demise of the concept (and practice) of compliance along with and rise of the concept (and practice) of concordance. Analysis suggests that despite considerable changes in the organisation and delivery of healthcare there remains a clear gap between rhetoric and reality. Drawing on insights from qualitative health research issues of identity, embodiment and self-care are explored and synthesised in a single descriptive framework. Neither compliance nor concordance alone adequately captures the reality of patient experiences in everyday life. The framework of understanding proposed here contextualises compliance and concordance and their corollaries within distinct horizons of expectation. For a truly user-driven healthcare it is not a question of either/or but both and more and asking, in reality, what can a body do?

PATIENT NARRATIVE: EPILEPSY AND ME

By Katherine Thomas

BACKGROUND

On my journey through life with epilepsy I have had many encounters with people who have tried to help. While most of these have had good intentions, their limited knowledge both of me as a *person* and the disease they wish to control (or even cure) has had far reaching consequences. What follows is a personal account of living with epilepsy - from my diagnosis as a teenager through to pregnancy and parenthood - and some of the people I have met along the way.

The sensation began in my chest, like someone was pouring cement into my lungs. My head and body pulled back and I lost my sight. I had no idea where I had fallen. The pain of my muscles spasming all over my body outweighed any sort of

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pain that from the fall. I was convinced that I was tearing the flesh off of my face but later realised that it was all of the small muscles in my face seizing at the same time. It felt like sharp nails pulling back the flesh. The noise in my ears was like a radio playing a high pitched static, loud then soft, loud then soft though I could still hear the panicked voices around me. Nothing has changed since my first *grand mal* seizure, but these days the voices around me are calmer: my husband telling me that everything is ok and I am safe.

Soon after, my parents took me to see a neurologist. We were told that it is not uncommon for teenagers to suffer from seizures and that they would stop. But once I had the first seizure the floodgates opened and I began to fit on a regular basis.

I grew up in Canada, and at that time MRI scans were not freely used. Instead I was given a CT scan and a few EEGs. They came to the conclusion that I had a scar on my brain, an abnormality from birth. I was never offered counselling or any support just lots of medication and left to get on with it. My life would never be the same again. I stopped going out with my friends and for a time refused to leave the house. Occasionally I even considered taking all of my medication at once. I was a terrified 15 year-old.

The neurologists mainly spoke to my parents and visits were brief. I was initially put on *Dilantin* but developed an allergic reaction to it on New Year's Eve. I was rushed to hospital, and the doctor on duty decided that it was best to stop the medication immediately and return to see the neurologist in five days, but in the intervening period I suffered multiple seizures which were followed by hospitalisation.

It took a long time to find the right medication for me with blood tests indicating that I would most likely suffer adversely to all of the commonly used anticonvulsants. Finally, *Sodium Valproate*, which was not widely used at the time, appeared to bring about the desired levels of control with relatively few side effects.

A couple of years after diagnosis I had an MRI scan which revealed that I had a benign inoperable brain tumour. Devastating news you might think but I actually have very little to say about this, simply because it has always been 'benign' and hidden from view – only briefly reappearing during 6 monthly check ups. Seizures, however, are quite discourteous, showing up without warning or appointment. My contorting, distorting bodily displays are performed for all who care, or dare, to look and reactions, like seizures themselves, are not always predictable.

Even family members, though well intentioned, can make matters worse. Looking back, perhaps they too should have been offered support. Everyone had their own way of dealing with the situation, but all were motivated by fear: fear of the unknown, fear of death, fear of losing control. My father reacted by trying to wrap me in cotton wool. He became aware of every 'danger' and made every situation 'safe', even if it isolated me from my friends. My older brother reacted by going against everything that my parents did. They would ask him to accompany me with when going out with my friends but as soon as we were on our own, he would make me do everything that a person without epilepsy would do. Every day he would tell me that 'anything could happen to anyone at any time'. He was right about that much. Tomorrow I could be hit by a car, nothing to do with my epilepsy. What is important is to live for each day.

My mother was different taking me to see numerous 'alternative' therapists. One told her to stop all my medications, pull me out of school for a year and give *his* recommended serums. An iridologist looked into my eyes and told my mother that there was something very serious wrong:

'You found the tumour!' my mother gasped.

'Yes, in her lower spine' he replied.

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