

An Insider's Experience of the Healthcare System

Health professionals are trained to be attentive to patient needs and to continually re-evaluate and process both physical and verbal cues in order to provide the best treatment possible. In spite of this, the system continues to produce adverse outcomes. The following is one young man's reflections on such an experience.

Almost two years ago I started to experience regular headaches. I have a high tolerance to pain and this was a new experience, so at the urging of my mother (a nurse of 30 years) I agreed to seek a medical opinion.

The doctor assumed that I was experiencing migraine and prescribed various medications that dulled the pain. After a period of time, I once again sought the counsel of my mother as the painkillers were no longer alleviating the headaches.

This resulted in another GP visit, where I requested investigation by a neurosurgeon. The referral took many weeks - as is common because specialists have long waiting lists. After finally being seen, the doctor ordered an MRI of my brain.

At this point, I realised that many presumptions are made within the system. This service was provided by a private provider and resulted in a bill that I had no capacity to pay.

Lesson 1: State constantly that you are broke when seeking treatment and hope that this does not result in further disadvantage!

A few days after the MRI I was advised by the neurologist that I had not one, but two brain aneurisms. Knowing I was a walking time bomb, I left my appointment highly anxious but without any emotional support or referral for support provided by my specialist. In fact, my specialist pretty much informed me in the same sentence as my diagnosis that he was going on holidays and would make an appointment with another neurosurgeon to coordinate further treatment.

This advice left me feeling that things could not be that bad. Being a bloke, I felt that if the neurosurgeon could go on holidays then he was not too concerned. In contrast, my mother and sister (also a nurse) were deeply concerned and sought information about the size of the aneurisms; where they were located; would I need brain surgery? All questions to which I had no answers!

Lesson 2: Don't assume that you will automatically be provided with pertinent information on the gravity of your illness!

The doctor left for his holiday without referring me to another neurosurgeon as promised. I had no information, and to get a referral to another neurosurgeon through the GP would take weeks again. Did I have weeks?

At my family's insistence, I obtained a copy of the MRI from the clinic where it was performed. My mother looked at the MRI on her computer and identified one aneurysm of seven millimetres on the right hemisphere of my brain (the second aneurysm was a 'fusiform'). There appeared few options, so my sister and I went and sat in accident and emergency, as this was the only way we were going to get a doctor to officially interpret the scan and, hopefully, initiate appropriate treatment.

The emergency triage nurse was horrified at my experience, as was the registrar who viewed the MRI and immediately called the neurosurgeon to make an appointment for me to have brain surgery. I was lucky that in this instance the aneurysm was stable, but it was on a large artery and I was operated on within three months of the trip to the ED.

Lesson 3: You can ask for copies of information that others hold about your health

Fourteen months later I was happy with life. I was being medicated effectively for bipolar disorder that followed my brain surgery, and I had commenced a new apprenticeship.

However, one day while at the beach I felt lumps under my armpit. Initially I ignored the lumps, but they did not go away. Once again, I consulted the nursing expertise available to me as I didn't know if simple lumps could be anything serious. Once again, this resulted in a suggestion that I get the symptoms checked out by a GP.

So I visited a GP at my local Community Health Centre and was advised "not to worry; boys get lumps". I remember the shocked look on my mother's face when I recounted the tale: "Boys don't just get lumps - get a second opinion," she said. So I found another bulk billing GP in the area that I had just moved to, but the second GP was not concerned either. I do not have a regular GP, and in both instances it was the first time that I had seen either of these doctors.



By now I was starting to tire easily but still thought that my mother's concern that it was possibly cancer was just the utterance of an overly-concerned parent. This perception was reinforced in my mind because I had the word of two GPs that there was nothing to be concerned about.

I recall my mother saying she felt as if she was going crazy; perhaps it was her many years of experience as an oncology nurse, or maybe just a mother's intuition. My mother made another appointment for me (this time with her doctor) that I reluctantly attended. This doctor immediately sent me for a CT scan that revealed seven tumours in my lungs. Neither of the previous GP visits had resulted in any referral for tests.

Lesson 4: Don't be made to feel that 'a' doctor knows more about your body than you do, particularly if they assume that without evidence

I mistakenly assumed that seven lumps in a 23 year old's lung would make people want to investigate the cause with some haste. Unfortunately, what followed was a month of waiting. To get an appointment was like running the gauntlet. No professional support for my emotional state was offered during this time. The doctors' receptionists guarded them from my reality, and they showed not a hint of compassion or sympathy for my predicament.

When I finally got an appointment I waited for hours, only to be told that my name was not on the doctor's list and to go elsewhere. In her distress, my mother cornered a doctor in the oncology clinic - who was on a day off and had just come in to grab her diary. She pleaded with her to just look at my scans to help me figure out how serious this really was. The doctor demonstrated empathy for my plight, and read the CT results.

It was serious, probably lymphoma, and would need a PET scan to identify if there were any more tumours. My anguish didn't end there. More time spent in waiting rooms, waiting hours for appointments organised with doctors that didn't even know I had an appointment. I spent three consecutive days fasting for a potential node biopsy, but because the theatre was overbooked each time I returned home, nodes intact.

I have been treated by people who have made it clear they don't really care about anything other than what time lunch is. And I have even experienced a doctor complaining about his sore back as I sat receiving chemotherapy for my Hodgkin's lymphoma.

I must say in this journey there have been some wonderful, compassionate people, but the lack of insight and 'production line' ethic demonstrated by others also resonates.

It makes me concerned that if my mother had not been such an advocate for me, that I may have died from the brain aneurysms before suffering the Hodgkin's, or that I may have never had the Hodgkin's disease diagnosed in time to receive the appropriate treatment. I also wonder if I have been treated differently because I suffer from bipolar illness.

I am not yet in the clear, but the last PET scan did provide me with a sense of a future. I pity the people who place their trust wholeheartedly in our healthcare system, because there is a fairly high chance that they will slip through one of the many cracks.

Informed Consent

Ensuring clients actively participate in decision-making is integral to people centred care. Client and carer involvement in decision-making is not only a legal entitlement but an activity underpinned by strong ethical principles.

The VHA's Clinical Governance in Community Health Project recently examined the issues surrounding informed consent and interventions in the community health sector.

Informed consent requires the voluntary agreement of a client/carer to a proposed intervention and any agreement must be based on the client having sufficient information about the intended procedure. Failure to obtain informed consent for an intervention is an issue identified in complaints to both insurance companies and the Victorian Health Services Commissioner.

The law protects clients by allowing claims of trespass and negligence to be made against professionals who either fail to obtain a valid consent or fail to provide adequate information for a client to base their decision for intervention. However, consideration of the ethics rather than the law related to consent may be more helpful for understanding and implementing informed consent for intervention processes in health services.

The main ethical principle serving as the basis for informed consent is that of autonomy. The principle of autonomy highlights that competent adults have the right to decide what is done to them. When the principle of autonomy is used as the basis for informed consent, consent is required because it promotes clients' right to self-determination. Consent therefore applies to a wide range of interventions, including those considered low risk or not harmful.

Research shows that health care professionals' interpretation of the ethical obligation to obtain informed consent is often underpinned by an overriding motivation to obtain a beneficial outcome for the patient (the principle of beneficence), rather than by a primary concern for respecting patient autonomy.¹

These principles clash when a client decision may not produce, in the service provider's opinion, the best outcome for the client. For example, a dental service may try to preserve a client's natural teeth and the client may prefer extraction.

Recognition is needed that the service provider's and the client's goals may not coincide even after a full explanation of the benefits and risks. To assist health services navigate the ethical and legal issues on informed consent, the project has developed a discussion paper and suggested procedures for obtaining informed consent.

In a related area, the VHA has also developed clinical indicators for care planning. These care planning indicators provide tools to monitor whether the goals of care have been agreed to and signed off by the client. Care planning that actively involves the client is yet another process that can be put in place by health services to promote people centred approaches to healthcare.

The informed consent and clinical indicator papers can be found under the Clinical Governance Resources section of the VHA website, at www.vha.org.au.

¹ Delaney, C., M. 2007 *In private practice, informed consent is interpreted as providing explanations rather than offering choices: a qualitative study.* Australian Journal of Physiotherapy 2007 Vol. 53