

An ethicist's journey as a patient: are we sliding down the slippery slope to sloppy healthcare?

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ABSTRACT

People who are sick are often the most vulnerable in society. They frequently rely on caring and competent healthcare professionals and should and do have expectations of a safe and caring environment. In a recent unexpected adventure through the healthcare system, the organisation, professionalism, caring and compassion associated with healthcare provision were in very short supply. A lack of basic dignity and humanity were among the most concerning deficits. Any form of dehumanisation of the national health service that leads to unsafe, undignified and degrading treatment not only infringes patients' and clients' human rights but should not be acceptable or excused as a by-product of economic pressures.

Most people are aware of the major issues facing us all in the most constrained budget in the NHS's history. The likely outcomes include increased waiting lists, restricted access to community care, bed closures, and job losses. Does this equate de facto to a decline in professionalism and quality care? In August 2010, with systems under severe pressure and changes afoot, I became ill and it was the start of an eye-opening journey into a universal healthcare system that I did not recognise; where respect for patient dignity, patient safety, professionalism and basic humanity were in extremely short supply. As a huge fan of the NHS, I write this with some sense of trepidation, as I am all too aware of the love of and loyalty many of us have to this wonderful institution. I share my story in the hope it will resonate with patients and healthcare providers who read it.

In October 2010, I attended a consultant neurologist presenting with numb toes, fingers and face and a myriad of other symptoms including brain fog and joint pains. Two neurologists examined me thoroughly and they both informed me together

that they thought I had a somewhat rare disorder called a 'syringomyelia', a cyst-like tumour in my spine or brain. If it was as they suspected, they informed me that the damage could not be reversed. However, because the symptoms had remained unchanged over the 9 weeks that I had waited to see the neurologist, I was considered non-urgent.

Being categorised 'non-urgent' meant that I would have to wait 4–6 months for an MRI scan to confirm the diagnosis. In a panic, I asked if there was a way to undergo the MRI scan sooner by paying privately. I was told that if I had £700 'to throw at it', then yes. On departure, I was told that no matter what I decided, it was imperative that I contact them immediately if any of my symptoms changed. Ironically, I had arrived that day convinced I had a simple trapped nerve, and was leaving the hospital completely bewildered, feeling like a ticking time bomb that no one felt compelled to dismantle. As a 41-year-old, otherwise fit and sane mother of three, I thought it crucial to have a clear diagnosis as soon as possible. Three days later, after prompt referral and payment, I had the MRI scan.

It was not a tumour. The neurologist decided in November (a month after my initial consultation) that I probably had an inflamed spinal cord, perhaps even a form of multiple sclerosis that does not show up on MRI scans. In line with that hypothesis, I was prescribed a 500 mg, 5-day oral dose of methylprednisone to take the numbness away. Two days after completing the course, I was admitted to the hospital in what they said was a steroid psychosis.

I gathered that a steroid psychosis was not acutely worrying; although my doctor said it was rare. He also said there were 'people who would have paid big money' for this sort of delirium. For me, it was extremely worrying.

Far from being psychotic in any real or imagined sense of the word, I was merely experiencing visual disturbances. Many people appeared to me to be wearing shimmering gold lamé clothing. Buildings also had a radiant golden glow. I felt extremely unwell in every way, with all of my previous symptoms multiplied in intensity and number. So I was delighted to hear the A&E doctor (with his glistening-gold stethoscope) say he was admitting me since there had not yet been a firm diagnosis and perhaps admission to a general ward might be useful in finding one.

At 01:00, still in the A&E department, I rang the bell to get some pain relief as I had not received anything since 18:00 for my unyielding headache. After 20 min of the bell's incessant ringing, the nurse finally arrived. I was clearly distressed and asked her for headache tablets. She screamed at me, "You'll have to wait. You are not a priority." She turned the bell off abruptly and left the room. All that glitters is not gold. I was alone, felt vulnerable and helpless, and wanted desperately to walk out but was too unwell to do so.

By 14:00 the next day, now on an 'admissions ward' and still having not been evaluated by neurology, I was collected by an auxiliary and brought to my neurologist's outpatient clinic. I was wheeled into the packed waiting room, facing into the fully dressed crowd of 25 people in my pyjamas, sick, sweating and crying openly (but quietly) for 1 h and 40 min. During that period, many doctors and nurses passed me. I told a nurse I was feeling humiliated and asked her twice to be brought back to my bed on the ward. She told me not to worry (about the humiliation) and denied my request because "the doctor had to see me". I even began to feel sorry for the other patients having to witness my distress, as it must have been disconcerting. On seeing the neurologist, I hesitatingly but in sheer desperation said "I have so many more symptoms since taking the steroids and everything is now 10 times worse. You said the steroids would take the numbness away. Are you sure you've got the right diagnosis?" I could not believe the words came out of my mouth, but I did not flinch. A mere mortal questioning a neurologist at the top of his game—perhaps it explains his insistence on prescribing me a short course of Seroquel? Just as it had left my lips, I considered apologising profusely for my lack of faith when he confidently replied "Yes, I am sure. It's an inflammation of your spinal cord." After this very brief and frankly non-informative and non-inspirational consultation with my neurologist, I was brought back to the ward.

Sadly, during the entire two and a half days on that ward, there were too few nursing staff and unsafe, inadequate nursing care. Patients were literally taking care of each other on the ward. We all took turns tending to one female patient who had what appeared to be

dementia. This patient was afforded very little dignity or respect. Her care seemed very much in line with a recent, damning report from the Commission for Quality Care that found 3 out of 12 hospitals in England were treating elderly people appallingly with complete disregard for their human dignity.¹ On the whole, the nurses were task focused at the expense of patient-centred care; perhaps as a consequence of understaffing.

I was eventually discharged from the hospital and I actually felt bad leaving our patient with dementia behind on the ward. Other than the 5 min with the neurologist, I received little, if any, medical care on the ward. At no time was there an inkling that anyone was trying to diagnose what was wrong with me. Indeed, the label on my chart of steroid 'psychosis' may have provoked this situation. Perhaps when some healthcare professionals think (through this labelling) a patient is mentally incapacitated, they assume the patient will not know that they are being neglected.

There were so many problems along the way, for example, loud, uncaring, unhelpful and unprofessional ward and nursing staff 24/7. They were also other serious system failures, including initial blood tests being delayed in the hospital in an outbox for 2 weeks before sending them off to the UK lab because there was a staff member off on holiday; failure to provide information on possible side effects, including steroid psychosis, when prescribing the steroids; secretarial staff's failure to log or reply when promised to an urgent telephone call during which the question was asked as to whether what I was experiencing (in hindsight, the 'psychosis') was a side effect—this failure led me to believe there was nothing to be overly concerned about, even though there was a real risk to others, notably, when I nearly knocked down two pedestrians while driving in this condition; and the post-discharge lumbar puncture appointment being delayed for 4 months because of a consultant's dictaphone blunder. As an ethicist, lawyer, medical educator, former scientist, non-executive director on the board that commissions services, a patient, and a human being, I felt overrun with worries that stemmed from each role. Because of the patient safety issue in particular, I felt compelled to make an official complaint. After much bother, a very helpful apology was issued and it was admitted that much of the care I received was well below the appropriate standard of care and assurances were made that positive changes had been and were continuing to be made relating to patient safety, human dignity, human rights and professionalism. Indeed, the Trust in question appointed not one but three additional entry level nurses to the ward in question.

My family in America were alerted to the situation when I was initially admitted to the hospital. Upon

hearing the symptoms I had not shared with them until this point, my sister, who is a GP (family physician) in the USA, contacted my GP to say she felt, based on my symptoms, that this could be Lyme disease or some other rickettsial disease. I was immediately treated for neurological Lyme disease with doxycycline for 4 weeks initially with great success. My symptoms returned and I was given a further 6-week course. I am currently symptom free aside from residual facial numbness. However, as Lyme disease is somewhat rare in the UK compared with parts of America (where I would have contracted it through a tick bite) and advanced neurological Lyme disease is even more uncommon, this made the situation even more difficult. The diagnostic complexity was problematic because the test results were seronegative. In fact, every blood test for every disease and deficiency known to man was negative. When the results of the much delayed lumbar puncture all returned negative, my new neurologist said he now felt more satisfied with Lyme disease as the possible culprit and advised me to go back on doxycycline should the symptoms return.

Leaving the medicine to one side, it is interesting that although some of the issues of care highlighted require added resources, others can be solved through attitudinal and cultural change. First, many would agree that the proposition of waiting 4–6 months for an MRI scan to confirm a potentially serious condition is unsatisfactory and unsafe. It could also lead to mental health decline and impact on family and work. Waiting times for diagnostic testing should be given greater priority by clinicians and commissioners of services and those developing pathways of care should keep this in mind when defining 'non-urgent'. Second, creating working conditions where staffing levels are too low to cope with patients' basic needs is unsafe, unacceptable, dangerous for patients and staff and further threatens infringements of staff and patients' human rights. Third, human dignity and respect for patients should be reinforced and placed at the heart of all healthcare; degrading and humiliating treatment as well as verbal abuse of patients should carry meaningful consequences. Yet, there appears to be very little ramification for such inappropriate behaviour. A relatively recent pilot programme in England 'Human Rights in Healthcare—a Framework for Local Action' trained healthcare professionals to adopt a human-rights-based approach to healthcare.² Evidence suggests that it has started to make a difference in the five pilot Trusts and that there has been substantial positive change to the provision of care.³ Maybe rolling this programme out across the UK could encourage positive changes in attitudes and culture. Fourth, complaints are often answered by either

insincere or worthless investigations, accompanied by defensive behaviour leading to missed opportunities to learn lessons and make improvements. This occurs even when guidance⁴ has recommended truth telling and openness and when legal statute now compels trusts to approach a breach in a duty of care by providing an offer of compensation, explanation, apology and report of action to prevent similar occurrences.⁵ Finally, clinical leadership is integral to a good healthcare service, but currently is sorely lacking. Perhaps investing in and empowering interested doctors and nurses through management training and structures should be part of any major reform.⁶ Additionally, identifying and implementing a meaningful way to foster better working relationships between non-clinical management staff and clinicians should be a priority.

I know I am not alone in my belief in the power and worth of a great universal healthcare system nor am I alone in my newfound lack of confidence in the dysfunctional system I experienced.⁷ A civilised society expects their basic human dignity to be respected regardless of the economic pressures a system faces. A lack of professionalism, common sense and patient care cannot be explained away opportunistically by pressures on systems and teams. The slippery slope to sloppiness in healthcare provision cannot be tolerated or justified as a consequence of cost cutting and budget constraints. We need to remember and restore the values that the NHS was built on. By listening, being courageous enough to make tough decisions and putting human rights at the heart of healthcare provision, the government along with healthcare professionals can surely restore a safe, equitable and effective health service, free at the point of delivery, with patient dignity and respect at its heart.⁸

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