A personal experience of care and the lack of it

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I have been unfortunate enough to have a month long stay in hospital and as my trade is infection prevention and control at a large acute teaching hospital, I thought I would take the opportunity to share with others, my observations and experiences.

What I hope to gain from writing this is to provide a wake up call to infection prevention professionals to show that for all the falling meticillin resistant *Staphylococcus aureus* (MRSA) bacteraemias and *Clostridium difficile* infections, the Francis report is not an aberration – it's how it is in some of our hospitals.

In the early hours of one night in January this year, I woke with severe abdominal pain. I attended my GP surgery the same morning where I was given a volterol injection and informed that it was likely to be a viral infection. By lunchtime the pain was unbearable, I had started vomiting and I was sweating profusely. My husband took me back to the GP surgery where a 999 ambulance was immediately called. I was cannulated after a cursory swipe with an alcohol swab, given morphine by the paramedics and rushed to my local A&E department.

After an abdominal x ray, I was transferred to a surgical assessment unit where I remained (in agony) until the following morning. After a morning review by a consultant surgeon, I was sent for a CT scan. While in the CT scan room, the cap off my cannula fell on the floor and I managed to stop the staff member reattaching it. Despite my vulnerable predicament, I was determined to do all I could to stop myself getting any infection.

The CT scan showed an ischaemic small bowel caused by a Meckel's diverticulum becoming wrapped around and cutting off the blood supply to the rest of my gut. I was immediately consented for a bowel resection. I attended theatre that afternoon, where I underwent an ileocaecectomy. I returned to the ward some six hours later complete with epidural, intravenous infusions, oxygen, bladder catheter and nasogastric tube.

The first day post op, I was seen by a registrar who took off the abdominal dressing to look at the wound, then put the bed covers back over the unprotected wound. I asked the nurses to redress the wound, which was done several hours later by simply applying a new dressing, there was no evidence of hand hygiene; the wound was not cleansed.

On day 3, I sat out of bed and the epidural began leaking down my back. It was early evening and I returned to bed with assistance whilst awaiting the anesthetist to review it. He said it looked dry and was reluctant to remove it unless it was definitely leaking. He therefore asked the nurses to change the dressing so he could properly assess it later on. He left two dressings for the nurses to apply. For this to be done, I had to grab the cot sides and pull myself forward; this was difficult because I was in a lot of pain with a very swollen abdomen.

The nurse removed the old dressing but then did not know how to apply the new one, as she had never used one before. She then called a colleague. It was becoming increasingly difficult for me to hold myself forward, so she asked me to just lie back. I had no dressing at all covering the epidural site and so I refused, as I am fully aware of the serious effects an epidural site infection or cannula migration could have. After some time, she applied a clear dressing just for protection and the epidural was removed shortly afterwards as it was leaking.

After the first couple of days I was very much left to my own devices with regard to hygiene needs. I therefore looked after my own urinary catheter. I know that the focus these days is to remove as soon as possible, but I have to admit I was rather fond of it, as it saved me the physical effort and pain of traipsing to the bathroom every few hours. It was a real effort because I was still in a lot of pain, and I was attached both sides to intravenous (IV) infusions which were disconnected every day so that my night clothes could be changed. I eventually requested removal of the urinary catheter after two weeks as the constant leakage of pus from my abdominal wound was posing a risk of infection tracking elsewhere. Although I missed the convenience of the urinary catheter, it was one less thing to worry about once it came out.

I required multiple IV medications and infusions for the majority of my stay and despite having very poor venous access, I was never offered an alternative type of line. In total I endured 14 peripheral cannulas, each requiring two or three attempts. I also required regular blood tests, which again required two to three attempts. This means I was stabbed around 40 times and became quite needle phobic in the end.

On one occasion when I was using patient controlled analgesia (PCA) for pain relief, my cannula needed re-siting due to phlebitis and one of the healthcare assistants (assistant practitioner) was asked to do it. Some hours later, she came to do it and informed me she would be taking bloods from the newly inserted cannula. Unfortunately the tourniquet was left on for some considerable time, which meant the blood would not be suitable for processing. When I informed her of this, she simply walked out of the room, leaving the tourniquet on. I released it and she came back in the room and without speaking, reapplied the tourniquet and went to insert a cannula. I stopped her as she punctured the skin, as she had not cleaned the skin with any antiseptic. She proceeded to walk out of the room again. When she returned with another cannula, she proceeded to wipe the skin and insert a cannula without attempting to make sure it was in or even near a vein. She did not assess flashback, did not flush, she just applied a dressing and walked out. In my eyes this was one of the lowest points of my experience. I felt unsafe and frightened and asked my mum to find out who the matron was and to ring her in the morning to say that care

was unsafe on this ward. My mum was horrified and still refers to this person as the evil nurse. I soon changed my mind about complaining, as I was frightened the care would be even worse if I made a fuss.

Ironically a matron came to see me the following day and I recounted a number of issues mentioned above and she took this away. From then on, the staff always made sure I had my buzzer and encouraged me to use it as necessary. My buzzer was always answered promptly after this.

Intravenous care was variable, with several nurses not cleaning the needle free port prior to attaching a giving set. Not all nurses flushed the cannula when disconnecting and it was always blocked when it was reconnected. The cannula was flushed with force using the hub, a practice I would not advocate. Dressings were on occasions applied poorly leading to the exposure of the insertion site, particularly by medical staff. On one occasion, a new extension set was attached to my cannula without being flushed, i.e. full of air. I told the nurse that she couldn't flush it once it was attached, as it would push air into my vein. She said they always did it like that but she left the room and returned with a pre flushed extension set and swapped it for the unflushed one.

I was incredibly sick for most of my stay of a month and required IV fluids for the majority of that stay. I was unable to have any nutrition orally for 15 days. I had profuse diarrhoea for the majority of my stay and still have now. At no point was I offered total parenteral nutrition, and I regularly requested that this be considered. The consultant said that with my track record for things not going according to plan, I would end up with a pneumothorax so he wasn't going down that road.

After a few days and no signs of improvement in symptoms of pain and nausea and vomiting, I was sent for another CT scan. I was taken down to the department in a wheelchair by a porter accompanied by my husband. I had not really sat up for long periods prior to this and was still nauseous with frequent loose stools. I had the scan with contrast and afterwards felt quite ill while still in the radiology department. My husband wheeled me into a tiny toilet cubicle where I had profuse diarrhoea while vomiting in the handwash sink. I was sweating and in severe pain. We could not wait for the porters to take us back to the ward so my husband dashed back to the ward with me and put me back to bed. I still feel guilty about this but feel we should have been accompanied or at least provided with vomit bowls for the transfer. I was diagnosed with an ileus and I also had a collection of pus in my abdomen.

My abdomen remained very distended and around 10 days after the surgery a large exudate appeared through the clips. The nurse removed a clip to allow it to drain and when she did, a huge amount of stinking pus came out of my wound. I had to wear a bag to contain the drainage and when the clips were all removed, the wound opened up and had to be packed initially twice a day, reducing to once a day for a further three months. It finally closed after four months but has left an unsightly scar and disfigured my abdomen.

Both hospital and community staff were consistent with their dressing changes with regard to aseptic non touch technique (ANTT), but one episode involving the consultant still haunts me. On the third week of my stay in hospital, he came to review me with a number of his team and the nurse in charge. He had non-sterile gloves on and proceeded to put his hands inside my abdominal wound and start

pulling at something. I had no pain relief prior to this (other than a fentanyl patch) and at no point did he explain what he was doing. It was a horrific experience that made me cry. He asked for some scissors and then began snipping at something inside my abdomen. By this point I was begging him to stop. He carried on until he had cut out a long internal stitch which he said wasn't doing anything except hampering the healing process. He told me he had to be cruel to be kind. I was incensed and extremely traumatised. I tried reporting my concerns to the nurse in charge but was told it didn't matter as it was a dirty wound anyway and the gloves were clean. I therefore reported it to the matron, who by this time visited me almost daily to assess my progress and support me in any way she could. She asked the nurse to complete an incident report and later told me she had raised it with the consultant and told him to stop frightening her patients. I asked if he thought he was wrong but she shrugged and said you know what he's like. He never came to see me again after this incident.

Throughout my stay in hospital and later whilst receiving community care, hand hygiene was mostly excellent and with consistency in ANTT, it seems that some of the key messages are now embedded within daily healthcare practices, but, although some of the nurses were very nice, only a handful seemed to genuinely care. This leads me to suspect that such improvements in practices are simply performed as rituals without the desire to genuinely protect patients, or maybe they were keen to ensure I had no further cause for complaint.

I was extremely grateful for the single room as I lost all my dignity with the advent of the diarrhoea, which is still a problem. It also meant my family could stay with me and they actually supported me with personal needs. Some of the care and treatment I received left a lot to be desired and I feel let down by my profession. I was terrified for the month I was in hospital because of the complications I suffered, the treatment and care I received and the lack of continuity and communication between professionals and professions. I felt desperately ill, yet I felt I had to scrutinise all that was happening to me in order to make sure I was given the best possible chance of recovery. On reflection I was not in a fit state to do this but I thought there was no one else on my side.

You may wonder why someone such as myself did not shout louder about the standards of care and treatment but until you have been in this vulnerable situation yourself it is difficult to appreciate just how frightening it is. There are no words to describe it, but I felt weak, desperately ill and became apathetic. I did not want to alienate the staff, but above all I just wanted to feel better and go home.

So this was my experience. I needed to write it down to speak to my co-professionals and say that whatever we think we have achieved, whatever data we can point to show progress, we have not and do not provide the basic care that is required to demonstrate humanity. I cannot tell what was and was not done right in theatre. I bear witness to just what was done and not done to me in the name of care and infection prevention and control. My personal Francis report suggests that professions do not know, or do not practise, how safely to care for people. Distressingly, at times this fact seems insignificant to those who deliver "care" (sic). Consequently, in light of the main Francis report and this personal one, I make a call to arms – let us re-design care back to our NHS. Let us make it clear what is and is not acceptable and let everyone know we will only accept humanist, proficient, and safe patient-centred care.