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# An experience of practitioners navigating the role of patient/caregiver

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## Abstract

This journey involved one of us having (repeat) intraspinal surgery in a country far from home but of a similar culture and with the same first language. The carer travelled across the world to be present during the hospital stay. We kept a journal during our admission, and following discharge realised there were significant differences between how we had documented our experience and the record presented in the clinical notes. The particular examples we present illustrate the relationships, rules and issues that we navigated. We share our experience in the form of moments from our journal, some of them alongside information recorded in the clinical notes for the corresponding timeframe. This provides insights into differing narratives between the experiences of the patient/caregiver and practitioners. We recommend that individual practitioners and organisations consider the lived experience of patients and how they consciously engage with patients/carers to address the risk of 'othering'.

## Keywords

Patient experience, patient-centered care patient engagement, patient- and family- centered care, quality of care, communication

## Our experience

We are friends and colleagues, one a nurse and the other a doctor. We believe that experience informs our work as health practitioners. We are experienced in providing care to patients, in hospital and community settings and also work in health professional education in different university organisations. This background provides us with a wide basis from which to reflect on clinical care and practice, the factors that impact on it and recommend simple steps that could make a difference to patients.

We took care prior to the admission to have the carer/patient situation understood and formally documented in notes. Prior to hospitalisation we undertook to keep a journal for the purposes of personal reflection. The journal was completed by the caregiver during the hospital stay but often in conversation with the patient.

One of the first defining moments was our encounter with the shower on the morning of surgery. It was a slippery and mould-infested room directly off the main ward corridor, with a door that did not close. There were many unspoken rules - such as the fact the staff did not like patients using it because it tended to flood across the corridor. We scrambled to clean up the mess as the anaesthetist arrived to say we were due in theatre shortly. This was a difficult initiation but the majority of our experience took place following the surgery, the key

moments in our journey centred on relationships, rules and the management of pain.

## Moments navigating relationships

Navigating relationships took up a large amount of energy. Some of the staff were aware of our backgrounds as health professionals but we were careful to accept our roles as patient and carer and to assure staff we respected their roles. Despite this staff found our relationship an ongoing source of confusion and interest and seemed to interpret it according to their personal and cultural values, assumptions and beliefs. Generally within the clinical notes the staff referred to the carer as a 'friend' but we found that any suggestion we were actually blood relatives seemed to make it easier for them to engage with us.

We quickly learnt that our relationships with staff were critical and we went to considerable lengths to negotiate with them to get what we needed. An example of this is how during one busy morning shift we agreed to move beds to assist work on the ward but felt abandoned after the staff achieved their logistical goal. (Journal Entry A)

The most basic of tasks escalated into complex negotiations as language, attitudes, expectations and stress impacted on both parties. One example of this was negotiating the requirements for a bed bath. The carer wrote:

## Journal Entry A

Journal	Clinical notes
<p>[patient] and I negotiate with [nurse] that she will assist us to shower in exchange for using [patient]'s bed to put another patient on while they clean that patient's bed. All good and dandy, not hard, not fraught – everyone benefits, works in well with [patient]'s meds being on board. Only 2 hours later the nurses have left the room without any comment and so we remain here. The best part of the [medication] has worn off. (decide to manage showering etc ourselves). In preparation [patient] rings bell for [medication]. [nurse] returns “yes” – [patient] explains missed window of opportunity for showering etc and now would like to take [medication]. [nurse] leaves without uttering a word and [two male nurses] arrive- talk to one another, check [patient]'s ID, don't say a word to her or look at her, hand her a syringe, she asks a question about dose, they talk to one another and leave. [nurse] limping with a sore foot. They don't acknowledge or talk to [patient]. (took ourselves to the shower).</p>	<p>1425 assistance given with morning wash – [patient]'s friend helped. Neurologically stable GCS 15 BP is low patient states she is absolutely fine and she usually has low blood pressure, kept observed. 1355 patient controlled analgesia discontinued and at 1100 [patient] now on oral analgesia – oromorph hourly sevredol has been ordered from pharmacy. 1400 nursed in bed due to pain.</p>

“I bathed [patient]. I wanted to ask for help but when I went out it was one of the unhelpful ones. I asked for wash stuff and he said he thought I had already washed her, he'd been told I had. I had to keep saying I hadn't, I was waiting for wash stuff. It was like another bloody argument. I asked what should I use and he said patients usually bring their own stuff, I said [patient] had but should I use the wash basin to wash her??!! He gave me a basin and some disposable cotton wipes that were only marginally better than paper towels. We managed- probably did OK but it was a bit beyond me. There was no one I trusted to ask for help. So we made do. I am tired of ineffective and lying staff.”

## Moments navigating rules

There were many instances in which we wrestled with ‘rules’ which often created a sense of dissonance for us as we tried to understand what was expected. The overt rules banned flowers, regulated visitors and required that patients provide their own towels and other supplies. Our most defining experience of all was meeting the charge nurse on the first post-operative morning, the context for which was her belief that the ‘rule’ of the carer needing to have permission, granted by her to enter the ward outside of visiting hours, had been broken.

The sound of loud footsteps echoed through the ward and a nurse arrived at the bedside. She ignored the patient and told the carer ‘I am in charge of this ward and you have five

minutes to leave’. Following a brief exchange the carer and charge nurse retired to another area to talk. Our subsequent conversation and journal entry talk of how distressing this situation was, regret that it had happened, the personal challenges the charge nurse experienced and the apparent contradiction between her feelings and her behaviour. The carer wrote:

*She was annoyed I had come in without introducing myself to her. I apologised, said she had been talking to the Reg[istrar]. It went downhill from there. [Patient] pointed out she looked angry... in tears, not feeling safe. Safety and care being more than technical skill... She [charge nurse] said she needed to follow policy and pressure from management about visiting hours... I [carer] was an issue/risk in terms of infection control.... Turns out she [charge nurse] relates completely to [patient] and the position she is in – if she was where [patient] is, she would have her mother right beside her.*

The charge nurse explained she deliberately wore noisy shoes and for the rest of our stay we remained sensitised to this and wary of them coming through the ward. Their meaning was confirmed on a day the charge nurse was away, when another nurse we knew arrived wearing noisy shoes that we had not known her to wear before. We asked her about this and she explained that she was the acting charge nurse for the day and that she deliberately wore such shoes on those days.

One of the prevailing responses to questions was that there was ‘a policy’. This appeared in many contexts but

infection control was the most common. One example was when the catheter bag was full and we were told that the infection control policy required they all be emptied at 10pm (hours away), the following morning it had not been emptied. It felt to us that the notion of ‘policy’ was at times used by staff to defend their own preference rather than any formal organisational expectations – or rules.

### Moments managing pain

Another challenge for us was the management of pain and this encompassed issues with technology, medication and, again, relationships with staff. We experienced ongoing problems with managing pain including on the evening of admission when staff were very uncomfortable with administering the patient’s normal medication which was documented during the pre-admission process. Following surgery there was confusion about the use of intravenous and oral medication and moving from one opiate to another. Underlying all of this was a sense of mistrust – a suspicion that the opiates might be abused as the patient ‘overused’ the PCA and therefore needed to be warned of this and monitored. We experienced these frustrations amidst what we felt was a lack of understanding of delivering the medication through a pump as there were extended periods immediately post-operatively when the

pump was not working and also when the alarms went unattended. We felt that staff often focussed on the machinery and that some of them did so apparently in order to avoid looking at or engaging with us directly. Some examples of how we experienced this corresponding with how it was documented are: (Journal Entry B)

Our journal entries reference frustration with apparent lack of skills and knowledge and this escalated to anger when the pain became uncontrollable as a result. However, the staff documented the issues in relation to managing perceived risks and carrying out technical tasks. Some staff assisted us but they were often not those with the power to address specific issues.

### Our reflections and recommendations

The existence of multiple narratives of events raises questions about honesty – what really happened and what didn’t and who has the power to write the official story. By virtue of their humanness all practitioners experience patient-hood. However, complex and busy working environments and the need to manage emotional, physical and mental stress may increase the risk of practitioners constructing distinctions between themselves and patients.

### Journal Entry B

Journal	Clinical notes
<i>Today [nurse] couldn’t open PCA – took minutes to work out he couldn’t open PCA pump without a key! Took PCA off for minutes it then kinked again! They have no idea how to set a PCA. We waited for 25 minutes for alarm [PCA] to be answered.</i>	<i>PCA had run out, new prescription SHO happy to continue with PCA</i>
<i>[doctor] stated “can’t prescribe long acting (oxycodone) as then we will have nowhere to go”. (discussed misunderstanding of managing acute pain alongside chronic pain, details from preadmission etc)</i>	<p>Medical notes: 1740 [patient] aware of risk of using MST with PCA and has assured me that she would be careful... if PCA buzzed too often please stop PCA... review analgesia tomorrow.</p> <p>Nursing notes: 1900 [patient]’s friend [carer] expressed concern over [patient]’s analgesia. Apparently PCA ran out last night + [patient] in distress. MST due to being on PCA. Discussed with [registrar] who spoke with [patient] and [carer]. He has prescribed PCAs and has prescribed 10mg MST nocte. [patient] is aware she is not to overuse PCA and that if staff fear she is then PCA will be taken down with oromorph being used instead for breakthrough pain.</p>
<i>Negotiated at ward round to change to PO meds. [nurse] took PCA down immediately [patient] had had maybe 4mg morphine. No pain relief for &gt;90 mins we waited 25 mins for alarm to be answered. I lost the plot at [student nurse] who had come off break and seen alarm going. She wasn’t allocated to our area, And so we got meds. By this time [patient] was catatonic.</i>	<i>Analgesia as prescribed.</i>

### ***Reflecting on patient-hood***

We believe that consideration and analyses of lived experiences serve to remind us that we all constantly occupy multiple spaces as patients, carers and professionals while of course also being fundamentally human. There is a risk that within the context of busy and stressful work environments patients may be seen as less than individual human beings. Atul Gawande<sup>1</sup> alludes to the difference between wearing a uniform and a hospital gown as defining 'other'. Considering personal experiences of receiving care may help practitioners limit the tendency to think of patients as 'other'.

*We recommend that practitioners take the time to reflect on their experiences as patients in the hope that this will reduce the tendency to think of patients as 'other'.*

### ***Privileging the patient voice***

We understand the very real contextual issues hospital staff experience in terms of policy, physical environments, staffing levels and other resources. However, the power to construct patients and carers is wielded by all who document practice and interactions. The organisational, personal and practice challenge is to listen to, and privilege, patient voice in formal documentation but most importantly at an interpersonal level.

*We recommend that practitioners consider developing formats for documenting care that privileges patient voice, respectfully documenting their perspective and ensuring it has a place in care planning and delivery.*

### ***Deliberately focussing on power dynamics***

Our need to understand who had the power at any given point required constant attention. The staff's emphasis on achieving tasks meant that involvement and control, which we valued highly, received minimal attention. Our overwhelming sense was that we were controlled and managed by individuals who, regardless of the difficulties of their personal or work environments, made conscious decisions to respond to us in the ways that they did and then record our care in a manner that appeared to highlight their concerns and minimise ours.

*We recommend that clinical teams consider their philosophy of practice to recognise that at any moment in time the quality of care depends on decisions individuals make to engage with patients and those around them in ways that are appropriate and respectful to them.*

### ***In closing***

Any hospital experience involves interactions between practitioners and patients/carers and therefore the potential for different interpretations. However as practitioners we all have the power to choose how we interact with patients/carers and how we document the formal record of the clinical experience. As practitioners, educators and those living through this experience we

found it valuable to reflect on power dynamics.

Throughout our lives we all move between the roles of practitioner, patient and caregiver. Practitioners and organisations need to consider how they recognise patient voice and experiences as they deliver and document care.

### **References**

1. Gawande, A. *Being mortal: medicine and what matters in the end*. Metropolitan Books; New York, NY; 2014.