

Medicine of the Person

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What factors mitigate against shared decision-making in acute inpatient hospital care?

I am going to tell you two stories, which I will use to illustrate the complexities and dilemmas of shared-decision making in acute care.

A 53 year old man who worked in a photography shop developed chest pains whilst taking some family portraits. Apart from being a smoker he was otherwise healthy. He was married with two teenage children. He called the Emergency Services and during the journey to hospital the paramedics recorded an ECG and diagnosed an acute anterior myocardial infarction. In the emergency room he was treated with morphine, had a chest x-ray and was transferred to the coronary care unit. A coronary angiogram was performed and percutaneous coronary stents were placed. His ejection fraction was well maintained and he was soon discharged home. He stopped smoking and decided to have more leisure time, playing golf. A few months later on the golf course he felt unwell and was again rushed to the emergency room. Fearing another myocardial infarction the doctors treated him with anticoagulants and transferred him to the acute medical unit. It was soon apparent that he had felt unwell because of an acute gastro-intestinal haemorrhage, made far worse by the anticoagulants. He needed a major transfusion and a therapeutic endoscopic intervention. My first contact with the patient was when I reviewed him the morning after the second admission. I had to inform him that he had been mistakenly treated for a myocardial infarction, making his internal bleeding far worse. I also had to tell him that his new chest X ray showed an inoperable lung cancer, and that a few months ago an early lung cancer had been seen on his first chest x-ray. The x-ray had been reported by a radiologist, but the report had never been read by another clinician. He made a good recovery from the gastro-intestinal bleeding. He had some palliative chemotherapy. He sued the hospital, not out of malice, but to secure an income for his wife and children. He wanted to help me make a video to use to teach staff the importance of looking for results of tests, but our organisation would not allow us to work together during a legal action against the organisation. An out of court settlement was made and he has subsequently died. This man's care went badly wrong during two acute life threatening events, a myocardial infarction and a gastro-intestinal haemorrhage, and he died of what had been a potentially treatable lung cancer. Did he have any possibility of shared-decision making during these episodes? Is there any way he could have been enabled to challenge his doctors over whether they were certain about his diagnosis and had everything been done?

A 60y old woman developed a right parietal high grade cerebral glioma. She had to give up work, and had a number of operations on the tumour. The tumour continued to grow herniating out through her skull at the site of her craniotomy. The wound site became infected down to the skull. She came under my care during a planned prolonged period of intravenous antibiotics prior to some palliative radiotherapy. Despite extensive clinical notes, I could find no record of her work, home life or family. The notes said she did not want to discuss prognosis. When I talked with her I found out she was a widow, but had several children and grandchildren in a close family. She had to give up her work as a travel adviser, and told me she was very sad that she would never get well enough to visit Vietnam, which was her life's ambition. We chatted about how my wife wants to go to Vietnam and she told me to take her, unless some misfortune befalls us. The next day she said she was worried she was dying and might not live to Christmas. We had an emotional conversation exploring that this was probably true and what she might hope for in those weeks. She wanted to go home, but her left side was becoming weaker and weaker. The next day, a Wednesday, she asked if she could have a day out on Sunday to travel 130 kilometres with her family to see Father Christmas at a theme park. I could imagine all sorts of problems. Maybe she would have a fit? Maybe she would die? Maybe the family wouldn't be able to help her to the toilet? She and the family seemed to have anticipated everything. I suggested she had a urinary catheter for the day, so she did not need to go to a public toilet. I was so apprehensive that Sunday, but on Monday she was so happy. She had a beautiful family picture, which moved me to tears. She thanked me for the idea of the catheter. She accepted my recommendation that the antibiotics be stopped and that our palliative care team helped her to get home. She was at home for Christmas, and at the end of January moved to our local hospice, where she died peacefully in February. Somehow during that admission she had decided to open up about her prognosis, we had shared a nerve wracking decision about a day out, we had shared a decision about end of life care, and she got her wishes. Both of these patients died, one death feels terrible, the other almost fulfilling. In one there was no shared decision making, in the other there was, but did the amount of shared decisions making really have a major influence on the outcomes?

In acute care, as shown in the first case, we have to move faster than the disease process progresses. Unless the cardiologist can perform a therapeutic intervention soon after the onset of symptoms in a myocardial infarction, there will be substantial damage to the myocardium. The patient would then develop cardiac failure with lassitude and breathlessness. The extent of shared decision making is only that the patient believed he might have a serious health problem, called for help and decided to trust the paramedics, doctors in the emergency room, the cardiologist and the organisation to do everything they could to salvage his heart and maintain his health. At some point he probably signed a consent form for the coronary angiogram, probably on the recommendation of the cardiologist "If I was in your shoes, I would have an angiogram and stent as soon as possible." After recovery the patient was given advice to stop smoking and to take regular medications to protect his heart. He did both of these. I regard this as sensible behaviour. He put his trust in the professionalism of the staff caring for him. The paramedics, A+E nurses and doctors and the cardiologist have all been through years of accredited training and passed professional exams. The staff has been subject to regular appraisal, audit and

professional development. Society has put in place many processes and measures to ensure that it is a wise shared, but not formally expressed, decision to trust the professionals in a rapidly evolving life threatening clinical condition. The possibility for some shared decision making would have been at the time of discharge from hospital. Knowing how busy we are in our hospital and the pressure to discharge patients as soon as possible, I doubt that there was any discussion about the value of stopping smoking and the cardio-protective medications. Who knows if a discussion about the indisputable value of stopping smoking might have prompted him to ask if his chest x-ray was OK? The value of taking cardio-protective medications may seem indisputable to a cardiologist, but were the pros and cons discussed and the statistics interpreted in a way he could understand? Again unpressured time to explore this could have resulted in a shared decision with better understanding than only "I will take the medications, because my cardiologist told me to". The patient decided to trust that the organisation had robust processes to highlight any Red Flag (unexpected serious) findings on x-ray, and here, sadly, his trust was misplaced. The only ways I could see that in the future we could avoid this would be firstly better order communications systems within the hospital and possibly giving patients copies of all their results as well as a discharge summary. The patient could then decide whether to ask about the importance of the results. We don't expect patients to challenge us "Just checking Doctor, are you sure you have covered everything about my care? Have you looked at all my results? Have you checked my medication lists?" In his second admission, again he was unable to be involved in shared decision making because of the immediacy of the clinical situation. Again we do not expect patients in the emergency room to challenge us in Jerome Groopman style. Groopman wrote the book "How Doctors Think" to provide patients with incisive questions to ask of their Physicians "How sure are you of the diagnosis? Could it be two diagnoses? Could it be something else? What if you are wrong, could the treatment harm me?" Or in this man's case "Last time I had terrible chest pains, this time I have had none, could it be something else making me feel ill?" Maybe as part of the trust patients put in us, we need to have a set of such questions we ask of ourselves on behalf of the patient?

After the second admission, I felt I offered him the possibility of deciding what to do about the medical errors. This was before Duty of Candour became so prominent. I felt I could not hide from him the missed chest x-ray report, nor the mistaken administration of anticoagulants. I saw it as part of the professional relationship of trust to admit that our side of the relationship had failed him. I believe those conversations resulted in his not bitter action against our organisation, and his willingness to volunteer to be in a video, which was blocked by our organisation. I met him twice during his palliative chemotherapy and he always spoke to me with kindness and respect, giving me sympathy for what I was feeling. When patients are in acute clinical situations we must strive to know the person, talk with him as an equal human being, and strive to offer unhurried time for conversations. We need to learn how to ask ourselves the challenging Groopman type questions to keep our patients safe. Our organisations must be organised to provide water tight processes to protect patient safety and reward the trust that patients put in us to provide correct care.

The case of the travel adviser who died of her brain tumour after the family day out with Father Christmas, illustrates what can be achieved in an acute setting, when shared decision making is encouraged and the situation is not truly acute. When I reflected on her

case, what fascinated me was the way the conversations and decision making opened up. My opening topic of conversation with each patient on the ward after “Hello, Mrs Jones, how are you today?” is always to ask “What is (or was) your work? What are your interests?” or “What do you enjoy doing?” before moving on to the clinical assessment. Often this opens up into a brief conversation such as the one about travel to Vietnam. At that first conversation I did not know her prognosis because most of her care had been at another hospital, and I did not have the notes. I was not trying to direct a conversation towards prognosis, treatments, or hopes for the future. The next day for the first time in her complicated illness she started to ask about prognosis. What I believe had happened is that because of my interest in her, she had recognised me as someone she could trust, someone who saw her as an adult, as a parent and as a grandparent. Sometimes on ward rounds and I clinics I think the only thing I add is to build that small bit of human connection. In the last year I met a patient utterly miserable with a horrible pelvic tumour, who had five volumes of notes, without a mention of her work or interests. She was a musician who composed and played piano music. Suddenly she was no longer a doubly incontinent lady ground down by pain; she was smiling and talking with animation. I believe if we really want to encourage shared decision making the starting point has to be working to find out the Who of the Person, before we start recognising the person as only a patient with a disease label, or even worse just a disease label. For my patient with the brain tumour everything progressed unplanned, a tangential human interest unlocked her from being mute about her condition. I felt very apprehensive about the shared decision to agree to her day out from the hospital. I thought other clinicians might criticise me for a day without her antibiotics, management might not allow the day release and discharge her and lose her bed place. She might have a convulsion and be admitted to another hospital. Shared decision making can make me feel uneasy!

The easy option would be to have said: “No, too risky”. I am so pleased I did not take that option and saw the happiness of that dying lady.

I will go back to the point about labelling patients as a disease. I believe if we don't make that small connection with the person, who is becoming a patient, we start on the slippery path to disease centred care. Our societies make much of Person Centred Care or the less valuable phrase Patient Centred Care, which already frames the person as a patient. Yet what we seem to end up practising is disease centred care, or pathway care, or guidelines care. The first patient got perfect acute myocardial infarction pathway and guidelines care. No one stopped for a few moments to think “He is young, has developed one smoking related disease, I wonder if he might have COPD as well?” and reviewed his chest X ray. He was labelled “Myocardial Infarction” not even “Smoking related myocardial infarction” and certainly not as “The professional photographer, married with 2 children, who smokes and has had a myocardial infarction.”

This looked to have been even more the case in the travel adviser lady who died of a brain tumour. It looked to me as if her brain tumour had been treated with repeated resections, and her wound infection had been treated with antibiotics. She was the woman with a big nasty brain tumour. It looked as if no one had tried to approach with her whether she wanted this “treatment”, which at best was palliative and at worst entirely futile. Did she want months of the last year of her life in hospital, or a hands off approach at home

supported by a caring team of professionals? I suspect in her case the doctors used the acute care model of “We know what is best, the patient trusts us, we will go ahead with treatments.” I am sure the doctors involved will think that they went through shared-decision making, and that the signed consent form was proof of that. Often doctors do not realise the power we have to sway decisions. An oncologist enthusiastic for palliative chemotherapy will easily persuade the patient to accept the treatment. Had the patient encountered a palliative care consultant eager to keep patients away from hospital, the patient would easily be persuaded to opt for hands off palliative care. I need to know this about myself, am I an interventionist or not? Sometimes a shared decision with a patient will be a decision to ask for a second opinion on treatments and prognosis. A disease label may mean we as doctors feel forced into certain treatments, for fear of not doing the right thing for the disease. What is right for the disease may not be right for the person patient.

There are other factors in the hospital setting that mitigate against shared decision, which I shall briefly discuss.

Most often in the United Kingdom consultations take place at the bedside. Commonly the bed is in a bay of 4 or 6 patients. There is often little space around the bed and the doctors and nurse may be forced to stand over the patient. This puts the patient in an inferior position physically and psychologically with the additional problem of being surrounded by a crowd of professionals. This can make it difficult for the patient even to talk, let alone be truly involved in shared decision making. The ward environment is also often noisy and distracting. Many elderly patients have problems with deafness and impaired vision, again making simple communication difficult. Delirium or dementia can also affect a person’s capacity to make decisions. Usually doctors are in a hurry to complete rounds and often have inadequate time to talk with and listen attentively to patients. I hope that the nurses in our team will have time to talk in more depth with patients and relatives, but sadly they seem as busy as us, with little time to talk and listen. Further it is now rare for a nurse to be present during my rounds to speak up on behalf of the patient. A relative could often speak on behalf of a patient, but still in the UK we seem to discourage relatives or close friends from being present on the ward during consultations.

Patients are excluded from many meetings in which important decisions about their care are made, which seems at odds with our stated intention to provide Person or Patient Centred care. For example patients are never invited to our ward multi-disciplinary team meetings at which discharge arrangements are decided. Nor are patients ever invited or expected to attend cancer multi-disciplinary team meetings where decisions about treatment are made. I assume a patient’s decision about whether to take up palliative chemotherapy would be an important and very personal decision, yet the person patient is not at the meeting to voice her thinking!

Some of these problems could be alleviated if the patient had a well thought through Advance Care Plan, which was brought into hospital with them. Although uncommon, more patients are doing this, so that we can know what for example their hopes were for end of life care.

Shared decision making is importantly constrained during an acute admission to hospital partly because of the need to act swiftly to deliver effective treatments before the diseases progress and partly because of the physical, psychological and emotional environment of acute wards.

I believe we should still strive to take every opportunity to enable patients to speak up and express their thinking. A simple way to do this is to show interest in the person from the first consultation. Nearly always my opening questions after social introductions are to find out something about the person. Usually I ask about current or past occupation, interests outside of work, or who is at home. This shows I am interested in the person before the disease, and seems to allow patients to open up more, so that I can know a little of the person. I showed the value of this in the story of the lady with the brain tumour. I believe this simple step increases the patient's confidence and trust in the Doctor, allowing the patient to be more confident to express more emotive questions and thoughts.

In Kungälv, near Gothenburg, in Sweden, I saw a new model of ward rounds. Dr Valdemar Erling and his team have created ward round rooms. The patient comes to the room, where she sits at the same level as the care team. The privacy of the room is well protected and the conversations that I observed were much more equal than when doctors and nurses tower over the patient in bed. At least three quarters of the patients on the ward were able to get to the room for this more private consultation, which must improve the possibility of shared decision making.

In Atlanta Georgia in the United States, Dr Jason Klein and his team have developed a new ward rounds process called Structured Interdisciplinary Bedside Reviews, which look to me like a mobile multi-disciplinary meeting with the patient literally at the centre of care. Again the videos of this make it look more like a process in which the patient at least has a voice in the decisions about hospital care.

The Royal College of Physicians on London has set up a project called The Future Hospital. I believe that the design, staffing and processes of care of the hospitals of the future should be developed to optimise every opportunity for shared decision making, because right now shared decision making in acute hospitals is more of a myth than a reality.

Thank you