Chapter 18
Patients and Surgical Education: Rethinking Learning, Practice and Patient Engagement

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Overview Patient involvement offers many opportunities for surgical education. This chapter presents ideas and examples to stimulate new ways of designing educational experiences. Patient involvement in medical education is presented as more than storytelling; it is how patients can be active teachers, curriculum developers and assessors. Involving patients may change surgical education and even surgical practice. In particular, patient involvement may shift (1) where the lesson starts and ends, (2) who decides what 'good' looks like, (3) what skills need to be learnt, (4) the role of the patient and (5) how to provide a good surgical service.

I learn so much from my patients is a common aphorism in medical education. However, patients can contribute more to surgical education than an opportunity for practice and/or being a role model of fortitude. This potential for patient involvement is mostly unexplored. There is relatively little literature with respect to patient engagement in surgical *practice* and even less literature describing patient involvement in surgical *education*. This presents an opportunity as other areas such as interprofessional education or chronic care education have a longer history of patient involvement [1], and surgical education can build on this work. Moreover, by thinking about surgical education differently, surgical practice itself can be rethought.

Sadly, Dr Rosamund Snow passed away in early 2017. Please take a moment to read her obituary in the British Medical Journal (BMJ 2017;346:j850). Rosamund was a compelling thinker, a fierce advocate and a delightful colleague. We shall miss her.

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D. Nestel et al. (eds.), *Advancing Surgical Education*, Innovation and Change
in Professional Education 17, https://doi.org/10.1007/978-981-13-3128-2_18

The 2016 ‘Vancouver statement’ regarding the ‘patient’s voice in health and social care professional education’ outlines a consensus view of current endeavours in this field [2]. According to this statement, the value of the patient voice is seen as being on the ‘fringes’, and while studies are increasing, patient participation in health professional education has not been studied in a way which demonstrates the impact or lack thereof on longer-term patient outcomes. However, programmes that promote patient participation in education have shown positive benefits for undergraduate students. To give a specific example, Ruitenberg and Towle [3] describe, through detailed qualitative analysis, the value of an inter-professional student group being mentored by a person with a chronic health condition. Studies indicate benefits to patients, such as a more ‘positive sense of self’ [4] and the reward of making a valued contribution [5]. They also suggest potential harms that can come to patients, if the approaches taken are not carefully considered, such as the negative emotions associated with vulnerability [5]. Finally, there is a distinct deficit in literature regarding patient involvement in advanced training programmes, which is where much of surgical education takes place. Nestel and Bentley [6] describe the contribution of real patient input into designing hybrid simulated patient scenarios for surgical trainees, but there appear to be few other examples.

This chapter presents ideas and examples to stimulate change. We describe what we mean by ‘patient involvement’ and then suggest how patient partnerships in surgical education have the potential to transform learning. We provide concrete ways of thinking about how this might be done, drawing from practical examples from outside surgery. Finally, we suggest how patient collaboration in surgical education may change surgical practice itself.

18.1 Thinking About ‘Patient Involvement’

The phrase ‘patient involvement’ can mean very different things to people, depending on their background, location, and the way they think about the role of patients and clinicians. There are often semantic issues, such as who is a ‘patient’ and what constitutes a ‘lay’ perspective [7]. In general, there are a number of frameworks based on the 1969 ladder of citizen participation [8]. These map to stages of patient involvement from none to collaboration arrangements where the power differential between clinician and patient are flattened or reversed. These frameworks are cited in the patient involvement medical education literature [7] and are increasingly part of health service delivery. For example, patient involvement in developing patient safety is noted as aspirational from a report in the National Health Service in England [9]. We present the following, more informal, spectrum of possible responses from healthcare professionals.

Stage 1: I don’t know what patient involvement is

For some, patients are seen as either recipients of care or participants in research. In this case, ‘involvement’ or ‘engagement’ may be interpreted as ‘patient understanding’ where clinicians try to increase a population’s health literacy.

In these cases, information tends to flow from clinician to patient as outlined in Mulsow et al.'s 2012 study of surgical patient consent [10]. This is not what we mean by involvement; when patients are fully involved in education, the patient actively teaches the clinician (as described in Stage 5).

Stage 2: 'I don't see how patients would have anything to contribute'

Healthcare professionals listen to patients' histories and symptoms with a view to making decisions (or shared decisions) about an individual's care. In this worldview, the clinician is the expert, and the patient only interprets this expertise in the light of his or her own preferences. The next step is for the clinician to appreciate how much they can learn from patient's practical insights about their own bodies and contexts as well as biomedical knowledge, which in some instances is considerable, for example, after years of disease self-management.

Stage 3: 'I can see how patients might contribute to learning, but it wouldn't be appropriate to ask them – and who would I ask?'

Ethical concerns and worries over 'representativeness' tend to dominate this stage of patient involvement, alongside fears that patients asked to teach have an 'axe to grind' and will damage the learning experience. Certainly, a patient in receipt of care should not be made to feel that that care is dependent on agreeing to teach or help with education; but in general, the ethics of working with patients (including issues of payment) is the same as the ethics of working with anyone else.

Representativeness is another thorny issue perhaps left over from thinking of patients as research participants. No patient can represent others, but nor do they need to, any more than any one medical educator is expected to represent all doctors. Similarly, any teacher can have an 'axe to grind'; teacher training can help turn that passion into useful learning outcomes to pass on to the next generation.

Stage 4: 'Storytelling is a great way to learn. I can get patients to tell the story of their experience'

Often, the first step in patient involvement is to get a layperson to describe their disease or offer the life context around a biomedical issue. Such patient stories can be very powerful and useful ways of providing information. However, the impact of patient stories can be limited if the rest of the curriculum, and crucially, assessment, do not offer other opportunities for patient involvement. Emotional resonance and patient perspectives are very valuable; however, patients can and do contribute significantly more to medical and surgical education.

Stage 5: 'Patients can work alongside me to design, deliver and assess education'

In this chapter, when we discuss patient involvement, we are referring to the idea that patients can be active teachers, curriculum setters and assessors. In this way, patients may actively contribute to, and possibly *change*, surgical education. In the next section, we outline some substantive ways by which patients can contribute to surgical education – and surgical practice. We offer examples, most drawn from outside of surgery, to provide concrete illustrations of the possibilities or issues at hand.

18.2 How Patients Can Change Education and Practice

The fundamental point about working with patients is that their contributions will necessarily be different from the clinicians. Patient involvement may alter the clinicians', educators' and organisation's concept of surgical education and surgical practice. In particular, patients may change thinking about:

1. Where the lesson starts and ends
2. Who decides what 'good' looks like
3. What skills need to be learnt
4. The role of the patient
5. How to provide a good surgical service

18.2.1 Where the Lesson Starts and Ends

Whenever a set of skills is taught or a particular scenario chosen as a teaching medium, a decision is made about where to start and end, and what counts as the point where learning begins. For example, in simulation environments, learners may enter a room where a mannikin is already prepped and 'unconscious' or where a part task trainer is laid out for a specific skill to be tested. When patients are asked to define the scope of learning, however, they may start earlier and end later; they may focus on how preparation for surgery can change their experience and recovery, and how surgical decisions can impact on their later quality of life. This also means that the life experience of the patient, prior to the treatment at hand, may be more salient in a particular lesson. For example, patients with co-morbidities are likely to provide valuable information on what they need to know to self-manage safely, and what they will need from healthcare professionals while in hospital [11].

We suggest that to concentrate on teaching one part of a surgical pathway is the equivalent of learning to fly a plane without knowing how take off or land; it will work in a simulator, but great damage can be done if the pilot isn't prepared for a real-life journey. For an example of how patient-led lessons can vary, see Box 18.1.

Box 18.1: Real-Life Skills: Surgery Derailed

People with insulin-dependent diabetes designed and implemented a simulation scenario based on their own experiences. In this scenario, a young man who had lived with type 1 diabetes for 20 years presents to an emergency department with a serious fracture requiring surgery. The actor was trained by patient tutors with type 1 diabetes, who also guided him via in-ear communication during the simulation.

(continued)

Box 18.1 (continued)

During the scenario, the patient experiences hypoglycaemia and asks to have his bag passed to him so he can self-treat with lucozade. In repeated runs of the simulation, different groups of candidates (junior doctors or final year medical students), aware that he should ideally be kept nil by mouth, refuse to comply with the patient's request. Due to hypoglycaemia, the patient becomes angry and aggressive when asked to test his blood glucose or consider a glucose drip. The scenario usually ends with him untreated and unconscious.

Patients with type 1 diabetes helped debrief the candidates about the issues they had most struggled with. This included the fact that – however much they wished to manage this patient according to textbooks – the optimum solution was to respect the patient's own expertise and allow him to self-treat by simply handing him his bag.

Candidates were asked to consider the following: after 20 years with type 1 diabetes, the patient probably would have self-treated several thousand mild hypoglycaemic episodes already, with skills developed since childhood. He would be extremely familiar with his personal 'hypo' symptoms, so a blood test would be less crucial than it might seem to a clinician, and it would seem pointless to an already angry patient to have a test when symptoms were very clear to him. Hypoglycaemia reactions are enormously varied, and medical textbooks barely touch on the range of responses; those who respond to hypoglycaemia with aggression may actually do physical harm to those they feel threatened by, so pragmatism is vital. Finally, any patient who was left to slip into coma due to a delay in treatment is unlikely to be accepted for immediate surgery in any case – and far more likely to sue.

18.2.2 Who Decides What 'Good' Looks Like

Traditionally, senior doctors or medical practitioners who are academics decide what the next generation is assessed on and to what standards. This is based on their own experience, learning and observations. This gives only a partial picture. While an experienced doctor is well placed to check things like technical ability and biomedical knowledge, it is much harder to argue for a medical practitioner's ability to assess patient-centred care, appropriate communication skills or patient comfort. Increasingly, patients are voicing concerns about what 'good' looks like in these areas [12]. In medical schools where patients are involved in assessment, changes have been made to both communication and practical skills requirements for students. See Box 18.2 for an example.

Box 18.2: Assessment by Patients

At many medical schools in the UK and USA, undergraduate students are taught how to perform vaginal exam by laywomen who use their own bodies to teach [13]. At the University of Oxford, these women, known as Clinical Teaching Associates (CTAs), worked with gynaecological surgeons to co-produce the students' final exam; the CTAs themselves act as assessors. Students are required to insert a speculum into their examiner, who will give them a mark based not only on communication skills but also on the technical skills that make the experience comfortable and safe. In the process, CTAs have changed the standards for consent. Students must not only ensure that the woman is happy for them to begin, they are also required to tell her that they will stop at any time if she becomes uncomfortable or upset – thus empowering the patient and restoring agency and dignity during what can be a very difficult procedure for many women. Prior to the introduction of this exam, students were tested on a plastic pelvic model with no pubic hair or realistic vulva (consent presumed), and a clinical examiner decided from external observation whether the student had performed the task adequately. The patient-led exam is, obviously, a more appropriate test of the skills these young doctors will need in practice.

18.2.3 What Skills Need to Be Learnt

A patient does not necessarily distinguish between technical and so-called 'non-technical' skills; moreover, they may not actually be independent of each other in practice [14]. Although communication and 'soft' skills are taught more than they used to be, they are still often part of a separate curriculum, perhaps involving role-playing actors who have no experience of the conditions or situations they are simulating. Practising on a silent mannikin or part task trainer can reinforce this skill split. A student or trainee may be able to perform a technical task such as suturing perfectly as long as she or he doesn't have to talk. Managing this kind of situation takes practice, and yet traditional medical education rarely supports students to acquire these skills. In patient-led scenarios, candidates may be explicitly asked to work on this task-combining, and learn how to negotiate situations where it is more difficult to respond to patients [15]. We provide an example of such a scenario in Box 18.3.

Box 18.3: 'She Asked the Questions in the Wrong Order!'

In one patient-designed emergency room simulation, candidates were asked to manage a drip and ongoing treatment while the patient herself (a mannikin voiced by a woman who had experienced the situation in real life) regained consciousness and asked questions about what was going on. Students who were very good at explaining a diagnosis in lay language when that was all they were required to do struggled when the patient asked questions in what they felt was 'the wrong order', while they were also trying to monitor vital signs. In particular, they found it hard to answer the question the patient had herself asked at diagnosis: 'will I be normal?' The patients who helped to design these scenarios all reported the enormous impact of doctors' responses to them at diagnosis, including difficult silences or doctors avoiding questions (even if those silences were due to the doctor trying to do something else of practical value).

18.2.4 The Role of the Patient

If asked, patients may choose learning outcomes that have a very practical emphasis and real impact on long-term health. Patients coming out of surgery and returning to self-management are part of the healthcare team and require a handover just as useful and practical as those clinicians are taught to make to their colleagues. Learning how to do such a handover can make the difference between a patient being able to care for themselves and a patient being readmitted or requiring out-of-hours advice in an already hard-pressed healthcare service. This is particularly pertinent to patients who are self-managing chronic conditions, an increasing part of all medical work as the population lives longer and acute diseases become more curable.

Again, using an undergraduate example, Box 18.4 illustrates how patient design of learning can fundamentally shift teaching.

Box 18.4: Miscarriage Management

In the University of Oxford, women who have experienced miscarriage have designed teaching and assessment alongside clinicians. While the doctors' version of assessment involved a role play with an actress and focussed on communication skills and 'breaking bad news', the patient tutors set a different range of learning outcomes. These included students' ability to give the miscarrying woman enough information and empowerment to handle the subsequent few days safely: discussion of home pain relief, advice on how to tell what was 'normal' in terms of bleeding and pain after natural and/or surgical miscarriage, when to call emergency services and whether the process meant that the woman would actually see her foetus.

18.2.5 How to Provide a Good Surgical Service

Patients' role in surgical education is not restricted to training junior surgeons. Patients have relevance for how surgeons understand their role in the overall surgical service. The effect of patient involvement may go beyond focusing on the surgeon's 'soft skills' critical to functional and safe relationship with patients. What matters to patients are not just the safety of the surgery, the quality of surgical treatment and surgical outcomes and the experience of their relationship with their surgeon. What matters also to patients is the impact of the surgical service as a whole on their bio-physiological, psychological and social well-being. To return to the metaphor of the surgeon as a pilot in charge of the entire surgical journey, the surgeon-pilot is skilled not just in flying the plane but also in taking off and landing. That is, a surgeon should ensure the patient is prepared for the surgery and equipped to manage its aftermath. But from a patient perspective 'taking off' and 'landing' refer not merely to ensuring the patient has the necessary information before and after the surgery. These metaphors also refer to the treating surgeon's awareness about what happens with the patient along the entire treatment journey.

Consider Box 18.5 for an insight into the kinds of things this patient (a nurse herself) would see as central to how surgeons are educated.

Box 18.5: A Patient's Experience of Fragmented and Inadequate Surgical Care

A 68-year-old patient with a background in nursing was admitted to the emergency department with severe abdominal pain. She had surgery and then spent 5 days in the intensive care unit before transferring to a ward. While on the ward, she developed a bedsore and an infection in the wound site. Then on discharge, her treatment plan did not include follow-up by a community nurse, and the patient had to look after this infection herself. She was given no information about how to dress the wound but managed to look after the wound herself, with difficulty. She was very angry about this and wrote a letter of complaint to the hospital. The hospital responded that she was not entitled to community nursing. At her follow-up appointment with the surgeon, medical students were present, and she explained that she felt that she did not have the opportunity to raise the concerns she had about her care. A few weeks later, she developed pain on her side which became severe and continued for 1 year undiagnosed until her GP discovered a hernia. The pain was so severe that the patient felt suicidal at times because she could not function in her everyday life. Her experience of her original surgeon was such that she refused to go back to him and so was referred to another surgeon who found an incisional hernia, a complication of the first surgery. The patient then

Box 18.5 (continued)

underwent a second operation to repair the hernia. Judging from the attitude of her second surgeon, she believes that the first surgeon is still unaware of this complication. The patient feels very angry about both her surgical care and nursing care. She has been given no opportunity to provide any feedback to the hospital or clinicians. She knows there has been no incident report made about the complication of the first surgery. She has not had a meeting granted with the hospital, denying her an explanation about what happened and an apology for what happened. She still has some days when she suffers severe pain.

Were the first surgeon to have practised the ‘soft skills’ discussed above, some of the problems described in this example might have been avoided. However, what is at issue here too is how the surgeon relates to and identifies with the service she or he provides. In saying this, we do not underestimate the incentives and constraints that bear on how surgeons practise and that perversely tend to limit the control that surgeons have over how their service is run, such as throughput targets, long theatre hours, inter-professional competition for theatre access, specialty control over what happens to surgery patients in intensive care and so forth. These social and environmental factors are far from immaterial to patients, their surgical care and their experiences of this treatment and its outcomes. However, patients are not given the opportunity to engage with any of these aspects of their treatment. These matters may be of great interest to patients who are open to becoming involved in surgical education. Specifically, if were patients like the nurse in the example above were given the opportunity, they might educate surgeons about two overarching issues: surgical service design, and surgeon identity. These are discussed each in turn.

The patient’s contribution to *surgical service design* may highlight the importance of balancing official targets and service-internal pressures against continuity and consistency of surgical care for the patient, patient safety, transparency about surgical outcomes (including complications and incidents, and national policy mandating incident disclosure and the ‘duty of candour’). These issues pertain not just to how surgeons *and the surgical team* communicate with their patients; they pertain also to how clinical teams structure, coordinate and organise their care processes for individual patients from the moment they enter the service to when (and how) their care is transferred on to primary and/or community care. From the patient’s perspective, surgery encompasses clinical, interpersonal *and* organisational skills.

It is important to acknowledge that these service issues bear significantly on *surgeons’ identity*. The relevance for surgeons’ identity becomes apparent when we acknowledge that, for patients, surgical authority must encompass a surgeon’s *personal* sense of responsibility for the organisational, managerial and temporal dimensions of their service. As this entire chapter highlights, the notion of 'surgery' does not apply merely to what happens shortly before, during and shortly after the operating theatre. Critically, for patients, the concept of surgery applies to the entire care experience and ultimate outcomes of the patient's treatment. This in turn broadens 'being a surgeon' from the role of the technician who negotiates an incision on a patient to the role of the professional who has responsibility for how patients journey through the whole trajectory of surgical care. This includes tracking, investigating and learning about mishaps that occur during patients' care. This may require negotiating information provision and activities with the surgical team as well as previous and future care providers.

Put together, the educational contributions that the nurse patient in the example above might want to make foreground the surgeon's responsibility for ensuring their service is safe and for making the patient feel safe. This underlines the notion that the surgeon's overall role and attendant skills are far from mostly 'hard' complemented with some that are 'soft'. The contemporary surgeon's skills are *multivariate*. These multivariate skills correspond to *all* the surgery treatment values that matter to patients and that play a role in their healing. As noted above, these skills include informing patients about what will happen and what has happened, understanding and acting on patients' preferences, organising patients' care as it traverses surgery and any other domains such as intensive care and the hospital ward and taming the constraints and pressures that are inherent in day-to-day hospital work such that patients remain safe and their outcomes are optimal. Engaging with patients at every step of the educational journey, from university student to trainee to senior practice, is critical to shifting the notions of surgeon identity, surgery care and surgical professionalism.

18.3 Conclusions

Surgical education has, to date, not engaged with patient involvement in any significant sense. However, the world of education and practice is shifting. Patients are increasingly contributing to the shape of medical education as well as medical practice. This offers huge opportunities for surgical education and surgery as a craft group. If patients are involved, surgical education and practice will inevitably change. In this brave new world, there is a tremendous opportunity to work with patients in designing surgical education and by extension, surgical service. It may be that despite the fears, patients will have better outcomes and be more satisfied with their treatment, if they are included in shaping surgical training and service rather than being the grateful or long-suffering recipient of care.

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