Involving patients in the education of health care professionals

Involvement of patients and carers in their health care has its roots in the ethical imperative of patient autonomy and informed choice. More recently it has been identified as an important component of patient safety. Governments have promoted user involvement in health service delivery, especially in the UK. In addition, the value of actively involving patients and the community in research has been identified. However, how do health care professionals learn how to work with patients and the public as partners in care and research? Where is the voice of the patient in the education of health care professionals?

All too often in the process of professionalization that takes place during the basic training of health care professionals, the voice of the patient becomes attenuated. Patients are most often used for learning as passive ‘clinical material’ or audiovisual aids. Learning often takes place in clinical settings, such as teaching hospitals, where patient autonomy is diminished. Students recognize the value of patients’ stories and expertise, yet there can be tension between their educational needs and the provision of patient-centred care.

A number of recent developments show that changes are underway. The value of patients taking a more active role as teachers has been recognized. Higher education institutes in the UK are being encouraged to involve patients as teachers and include them more in curriculum design and assessment. O’Keefe and Britten state that ‘lay participation in curriculum development is clearly on the horizon for medical schools’. However, current educational initiatives are varied, isolated and often ephemeral. There has been no forum to share good practice or articulate a coherent framework similar to the rationale for the involvement of patients and lay people in health services or in research. In the case of research, patient and lay involvement has become a requirement of many funding bodies.

‘Where’s the patient’s voice in health professional education’ was the first international conference to address this topic. Held in Vancouver in November 2005, it was attended by 240 delegates both from patient groups and from teachers, researchers and students from schools of physiotherapy, social work, nursing and medicine. The conference presentations described a wide range of innovative educational, research and community initiatives, including: patients on advisory groups helping to define curricula, lay people who give expert feedback to help students learn communication and other clinical skills more effectively, patients who contribute their experiential knowledge as teachers to help students understand the impact of illness and disability on people’s lives, patients who participate as partners in research projects and patients who work with health care professionals to improve services and stimulate in-service learning.

Many of the initiatives that were implemented as specific educational interventions originated from the personal experiences and convictions of one or two individuals. To be sustainable and to have more than a transitory impact, they need to be embedded in the culture of the institution. Some of the most complex and systemic models of patient involvement are happening in the UK where initiatives are being driven by government policy. Examples were given of attempts to involve patients in curriculum design and delivery for social work, medicine, nursing, occupational therapy and physiotherapy. However, coverage is patchy at present. They all faced similar challenges in how to translate government directives into meaningful partnerships at a local level.

Barriers to the involvement of patients in education range from lack of access to libraries and university buildings, and defensive attitudes of some health care professionals. Volunteer community networks can be fragile and unreliable; individual patients may be unable to participate consistently in educational programmes because of the nature of their illness. What patients want students to know may not be the same as what educators think is important. Health care professionals, who are committed to involving patients, may themselves be marginalized within their own institutions and lack the support and commitment of senior management. Resources are required to pay and train people for their roles as patient educators.

If the inclusion of patients as active participants in education is to be more than a passing fashion, evidence will be needed to demonstrate that there are benefits to be had for learners, professional educators and patients alike, and that there is a connection between these benefits and improved outcomes. Evaluation of the impact of patients as educators is scarce. The conference was an important first step in establishing genuine collaboration between learners, educators and patients.

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References
Surgeons may have introduced a new operative technique in African-American patients

Is it conceivable that during the phase of adopting the technically more exacting ‘off-pump’ method of performing coronary artery bypass grafting (CABG), New York surgeons practised on their black patients? That is the implication of the findings of Mukamel and colleagues.1

For those not familiar with the terminology, we will introduce it with its history. In the 1950s, a means of substituting the function of the heart and lungs by cardiopulmonary bypass (CPB) was successfully achieved. During CPB, the patient’s circulation is diverted through a machine called the pump oxygenator; this permitted the development of all heart surgery. Coronary artery bypass grafting, from the time of its introduction in the late 1960s and throughout its development and refinement over the next 20 years, was entirely dependent on the functional support provided by CPB, referred to as ‘the pump’. During that era, although occasionally a straightforward operation was performed without going on-pump, CPB was used as a routine and still is to support the systemic circulation, typically for 60–90 mm, while grafts of only 1–2 mm in diameter are attached to the coronary arteries. However, there is a price to be paid for use of the pump: CPB injures the brain,2 the blood3 and other organs, usually subtly but quite consistently. So there is an emphasis on reducing the time or doing as much as possible of the surgery without CPB. Coronary surgery completely off pump was first reported in 1990.4 Enthusiasts hoped that avoidance of CPB would reduce brain injury and other damaging effects, while sceptics thought there was a price to be paid in terms of surgical precision. A systematic review and meta-analysis of 41 randomized controlled trials including 3996 patients quantifies that trade-off (Figure 1).5 There is, for example, an absolute reduction of 10 strokes per 1000 operations but an increase by about the same number of patients having a further coronary intervention within a year, possibly due to more graft failures.5

Adoption of off-pump surgery was governed by factors other than research evidence. Once it was shown that off-pump surgery could be achieved at low risk, there was an expectation that CPB-related organ damage could be avoided. There was growing pressure on surgeons to adopt this technique, both from referring cardiologists and well-informed patients. How the pros and cons were weighted was a matter of rhetoric, rather than science. Technical prowess was probably a dominant factor in surgeons changing their practice, while market forces (in terms of referrals and patient choice) were significant external pressures. There can be no doubt that those who mastered off-pump surgery talked up its merits, but it is an interesting paradox that when ex-President Bill Clinton had a coronary operation in 2004, his surgeon, a publicised advocate for off-pump CABG, used a 73 min pump run.6 In general, a perception developed that capability to perform off-pump CABG had to be in a surgical team’s repertoire. This was particularly so as it became clear that there were too many surgeons in too many hospitals competing for a diminishing pool of patients.

If they were to compete successfully, how and when were surgeons to learn the very exacting surgical techniques and skills required to perform microsurgery off pump, on a beating heart? On which patients? Learning on inherently low-risk patients gave a much larger margin for error, but to not use the pump might have been more justifiable in higher risk patients who have more to gain from the avoidance of CPB. The latter argument could be seen as a patient-centred decision, while the former argument protects the surgeon.

In decisions made in the management of patients undergoing cardiac surgery, there are many factors at play, and they may be interrelated in complex ways. Health care databases are rich sources of information, and expert analysis of them provides important lessons, but great care must be used in extracting cause and effect inferences from retrospective data analysis. Treatment decisions take into account many factors about the patient and the particular circumstances, and only some of those are recorded on databases. In addition, there are ‘unknown unknowns’ which might have created systematic differences other than those due to known risk factors between groups.