

## Patients are experts in their own field

*The interests of patients and healthcare professionals are intertwined*

The notion of being concerned with the interests of patients is not new. It is as old as medicine. What is new, or relatively new, is the question of how that concern is best dealt with. To put it another way, who is the best judge of a patient's interests? For almost the whole of the history of modern medicine, this question was not asked because the need to ask it was not recognised. A patient's interests were best judged by the patient's doctor. That was part of what a doctor did. Patients knew nothing of clinical matters. How could they be expected to decide what was good for them? Indeed, it was cruel to impose this burden on them.

Times have changed. A better educated population, exposed through a variety of media to the idea of choice and impressed by the language of rights, began to see themselves differently. They were no longer passive receivers of goods and services, grateful for whatever came their way, but consumers with choices who were entitled to expect good quality and to complain if they were not satisfied.

In relationships between professionals and clients, of which the patient-doctor relationship is one example, the accommodation of this change has not been easy. The consumer may be king in a supermarket, but not in a barrister's chambers, an accountant's office, or a clinic. The professional—let us concentrate on the doctor—is the one who knows. A patient's interests are safe in the doctor's hands. They would not be safe in the hands of the uninformed patient.

Of course, to arrive at such a conclusion demands the adoption of a very crude definition of knowledge. In fact, as all but the most recalcitrant now recognise, there are at least two bodies of knowledge that are relevant to the exchanges between doctor and patient—the doctor's and the patient's. Both are experts in their own fields—the doctor in clinical matters, and the patient in his or her experience, feelings, fears, hopes, and desires.

This is the context in which the question of who is the best judge of a patient's interests began to be canvassed as a question that should be asked and that required an answer. The emerging answer was that caring for a patient requires both parties to recognise and respect the other's area of expertise. The doctor knows what the operation on the ankle involves and what the likely physical consequences will be. The patient will know what it feels like to face the prospect of a limp or of never dancing or playing football again. Together they can pool their knowledge and choose the way forward. The language of partnership becomes the currency—not a swing of the pendulum from doctor

power to patient power but a relationship of interactive partnership.

To some, this development is wrong headed. It is the approach that appeals to that classic stereotype of the middle class—the assertive *Guardian* newspaper reader who is already well able to take care of himself or herself. It has no resonance, they say, with people who are vulnerable, disadvantaged, or excluded: indeed, it disempowers them by placing a burden of participation on them that they cannot bear. This sounds like the old argument, that patients cannot really know what is best for them, under a new guise. It suggests that only a certain section of the population needs to be actively involved in their health care because the rest have no view to express on what they want or hope for. Merely to say this is to recognise that it is as offensive as it is untenable. Disadvantaged people may need more time or more explanation, but they have their needs, their fears, their dreams, and their hopes like the rest of us. And like the rest of us, as citizens and as equals in their humanity, they have their claim to engage in their care.

My personal experience of hearing the stories of parents during the public inquiry into the deaths of children who underwent heart surgery at Bristol Royal Infirmary confirmed my view that good medical care must involve patients and carers as well as professionals. It also confirmed my view that, these days, most professionals do not seek to exclude patients. Rather, they genuinely, often mistakenly, believe that they are involving them, or they do not know how to do so, or they find the whole business too emotionally taxing. The lesson that we should draw from this is so simple that it is usually overlooked. We should not criticise nor blame professionals. Instead, we should help them through the barriers that prevent them seeing their patients as interactive partners. The place to start is at the beginning of professional education, but this process never ends.

How does this sit with the current growth industry of what is called “patient and public involvement” (with apologies to the English language: whoever dreamed up this title not only gave us another acronym to learn, PPI, but unwittingly turned the noun “patient” into an adjective)? Some of what is written under this banner purports to talk of patients' experience, but in fact describes what a patient experienced (that is, was exposed to) rather than what the patient experienced (that is, felt). In so doing, it continues to regard patients as passive recipients, albeit while using the smart new language. Other writing tends towards the strident

assertion of patients' rights, relegating professionals to the status of technicians, there to take orders. Neither of these polar positions advances the interests of patients or, equally important since their interests are intertwined, those of healthcare professionals. The "middle way," exemplified by the writing of Angela Coulter, is the only sensible way.

A mature culture will settle on sharing power and responsibility, on a subtle negotiation (not in a legalistic sense, but in the way we negotiate our way through life) between professional and patient as to what each wants

and what each can deliver. This is the culture which we should work towards—helping each other as we go.

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