NICE news in the annals

The age of consent

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It used to be so much easier. Doctor knew best, gave his or her advice, recommended an operation and patients did what they were told. I exaggerate, of course – but only slightly.

Back in the distant past when I was a junior doctor, ‘consenting’ became a verb, as in ‘Have you consented Mrs Jones?’ In those days, the medical dictionary was full of words like ‘pop’ – as in ‘Pop up on the couch and we’ll have a look’ or ‘I can soon pop that lump out for you’. Informed consent felt about as meaningful as the consent most of us give these days prior to the installation of software updates on our computers. Detailed discussion all too often seemed rather thin on the ground.

It wasn’t inevitably like that, however. There were surgeons who really did want to explain in detail what they intended to do. When my son was about five years old, he needed an operation. We went to see a consultant surgeon at a local teaching hospital and, probably because I was a doctor, this eminent specialist started to run through the options.

‘Well,’ he said, ‘I could do Von Recklingstat’s procedure [you will appreciate that I can’t remember the details at all – these are fictitious], which has a 78% success rate and the following possible side effects...’, which he terrifyingly enumerated. ‘Or,’ he went on, ‘there is the Weneger technique, which...’ And before he could go on, I stopped him. ‘Bob,’ I said, ‘I’ve only got two questions. Are you the best and is he going to be alright?’ Bob said ‘yes and yes’ and that was that. I was absolutely clear that I couldn’t cope with any more information.

But that was then. This is now. The information explosion has had a profound effect on all our lives. The power has shifted. For centuries, the medical profession held all the knowledge and patients came to us as supplicants. There was a real power differential and everyone knew it.

Indeed, there is also an interesting analogy here with religion. Prior to the reformation, priests held all the power and had access to the knowledge, to the scriptures – which were in Latin. As one writer has said, an educated priesthood was seen as essential to explain the meaning of the Bible to ordinary people, who could not be trusted to interpret it for themselves.¹ Then the Bible was translated into English, and the relationship between clergy and laity changed dramatically.

Knowledge was power. Now that all the knowledge in the world (including NICE guidelines and the whole of NICE Evidence Search web portal) is available to anyone with access to a computer or smartphone, the medical profession can no longer be the only source of knowledge. Patients question more, expect more, challenge more. Whose body is it, anyway?

These are not straightforward issues. It is hard enough to make difficult personal choices at the best of times. When someone is frightened and alarmed, the desire for someone else, someone expert, to take over can be overwhelming. In transactional analysis terms, such people are seeking a ‘parent/child’ relationship with their doctor. However, for most medical decisions, especially related to long-term problems, the relationship is far healthier if it is ‘adult/adult’ and I suspect one of the true skills of an empathetic doctor is to know which is the appropriate model for which patient.

However, this issue raises important and complex questions. Does patient autonomy mean that patients might have the right *not* to have information or to have to make decisions? How do we know when this is appropriate, and when it is patronising, paternalistic and unacceptable?

What I remain certain of is that trust (the ability to absolutely trust another human being) is a profoundly important human characteristic. People who are sick and terrified need to be able to trust their doctor (or their surgeon), and despite all that the media may have thrown at the medical profession over the past few years, trust levels in doctors remain remarkably high. In 2014 Ipsos MORI’s annual study of trust in different professions, showed that 90% of the population answered ‘yes’ when asked if they would generally expect doctors to tell the truth.²

Nevertheless, we need to remember that this trust is not an automatic right, particularly in these days when trust in almost every other aspect of public life has dissipated like morning mist. Remember the television programme *Dad’s Army*? Arthur Lowe’s character was a banker, chosen as a symbol of stable and trustable security. The programmes were only made a few decades ago but today the word ‘banker’ is almost used as a term of abuse. The medical profession has to ensure that it doesn’t find itself in the same position.

The whole paradigm of healthcare is gradually shifting, an issue that we are increasingly aware of at NICE. The rising incidence of multimorbidity means that single disease approaches are becoming much less appropriate, even to the extent of making it harder to define what a quality outcome is for an individual. How do you define or determine 'good care' when looking after a patient with six or seven long-term conditions? Perhaps only one person knows and that is the patient.

However, as researchers like Al Mulley and colleagues from the King's Fund have explained in an excellent paper that when patients are well informed, they make different choices about their treatment.³ Critically, they showed that what patients want is often very different from what their doctors think they want (for instance, in such situations as the surgical management of breast cancer). They term this a preference misdiagnosis and say that it can potentially be as important as a medical misdiagnosis. This matters to the healthcare system as much as it does to the individual; offering care that people would not want if they really understood the options, outcomes and evidence is hardly ideal practice – medically, surgically or fiscally.

At NICE, although we have been committed since our formation to taking patient and carer views into account in all our work, we have been exploring the potential of increased levels of genuine shared decision making. If you aren't convinced, ponder this: There are major differences between what doctors advise for patients and what doctors choose for themselves when they become patients, suggesting that doctors struggle to see medicine from a patient's perspective until they become patients themselves.⁴ There is so much more to consent than a signature.

References

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