

Patients and doctors: rights and responsibilities in the NHS (2)

Melissa Smith

ABSTRACT – Our society is very concerned with endowing and protecting people’s rights and the existence of a National Health Service in this country has allowed such concepts to be applied to medical care. It is not clear, however, whether the concept of rights helps either doctors or patients, and it may in fact be misleading or even damaging. A discussion of the suitability of rights ethics to the healthcare context is presented, particularly highlighting the problems of attributing positive rights. The way in which rights create corresponding duties and responsibilities, and the particular problems that this creates for our health service is also addressed. Finally, in the light of the ongoing changes in the doctor–patient relationship, the future balance of rights and responsibilities in healthcare and the impact this will have on clinical decision-making is discussed.

KEY WORDS: clinical decision, doctor–patient relationship, duty, ethics, negative rights, NHS, positive rights, responsibility, rights

The nature of the doctor–patient relationship is constantly changing and evolving. Both parties’ expectations of these interactions are subtly different from those they had ten years ago and radically different from those found back in 1948, when the NHS was founded.

This evolution, or perhaps revolution, has been underpinned by society’s increasing attachment to the ideas of liberal individualism. According to these principles, society must provide enough space for each individual to carve their own niche as they wish to, and to pursue their own projects without external interference. Whilst far from new, such ideas found particular resonance with a generation raised in Thatcher’s Britain and educated to think for themselves, rather than to accept received wisdom. The background of the welfare state, of which the NHS is a central part, protected such projects and further encouraged individual endeavour.

In medical ethics, this has been paralleled by the fall from grace of the paternalistic principles of beneficence and non-maleficence, and the apparently inexorable rise of autonomy as the ‘trump card’

in the ethical pack. As autonomy has become more and more important to us, we have found a new language with which to defend it, and talk of ‘rights’ to and within healthcare (inconceivable before the existence of the NHS) is increasingly commonplace. How well suited rights-based ethics are to a medical setting will be the subject of this discussion.

A key feature of rights ethics is that for every right that is created, a corresponding duty or responsibility arises, in this case for the healthcare provider. What problems does this pose in the healthcare context?

The subdivision of rights into negative rights (the right to *refuse* treatment and decline assistance, advice or information) and positive rights (the right to *demand* certain products, information and services) helps to highlight why some ‘rights’ are self-evident and less troubling (and onerous) to us than others.

Negative rights are clearly enshrined in our thinking and practice, and are, for the most part, treated exactly as we describe them – as an absolute right. For example, it is difficult to think of an instance when a competent patient’s right to refuse surgery or to decline to act as an organ donor, for example, could feasibly be overturned by a competing claim.

Positive ‘rights’, however, whilst often talked and written about, do not tend to bind us in the same way. For example, we might talk of a patient’s right to information about his or her diagnosis and treatment, and will on the whole endeavour to keep all our patients as informed and involved in their management plan as possible, but in practice we do not regard this right as binding. For example, if a patient of ours is diagnosed with cancer, we might consider it in their best interests not to be told until the diagnosis or extent of the disease is certain, or until their family are present to support them, or until they have recovered from a difficult post-operative period. Or even, and perhaps more controversially, not to tell them at all, perhaps due to concerns in the family, or the patient’s frailty. This illustrates how notions of positive rights can generate difficulties in medicine. For whilst on the surface such principles seem sound, they will from time to time conflict with other ethical considerations. When this occurs we find that we treat these ‘rights’ as *prima facie*, (ie binding only if

Melissa Smith MB
ChB MRCP(UK),
Specialist Registrar
in Gastroenterology
and G(I) Medicine,
Darent Valley
Hospital, Dartford,
Kent

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not equalled or outweighed by competing considerations), just like all other ethical principles, and the term 'right' has actually been misleading.

Positive rights will also conflict not just in principle but in daily practicalities, when the number of hours in the day will mean that not everything that one or other of our patients has a 'right' to, can be physically achieved. This is a reality that the use of the term 'right' rather denies. Again, the negative rights (to be free from unwanted interference) seem to be the easiest to establish and exercise in practice. It is much less clear what positive 'rights' truly exist.

When a positive duty is created by a proclaimed right, an additional complication arises, in that it is not always clear how such a right is to be enforced or implemented. This is particularly true in the current NHS structure where the doctor–patient relationship may be less prominent than the hospital– or practice–patient relationship. Who is responsible for upholding the patient's right to be informed, involved etc when at every interface with the NHS they meet a different member of an ever-changing and ever-growing team?

As mentioned above, the increasing importance attributed to rights ethics has naturally flowed from the rising importance of the individual in today's society. It is not clear, however, whether such considerations are well suited to the work of a communal/societal institution such as the NHS. For whilst on one level we do exist to protect individuals (the first duty of a doctor being to 'make the care of your patient your first concern'), we also have responsibilities outside this one doctor–patient encounter and are bound to consider the well-being of other members of the public, resource allocation, waiting lists etc before we spend all the tax-payers' money in securing the rights of the patient we happen to be treating. This restriction on resources and the communal nature of the NHS will certainly limit the positive rights that can be granted.

Another way in which discussion of rights is poorly suited to the medical environment is that such concepts are unnecessarily adversarial, and have legal overtones and implications, and as such they generate conflict and bad feeling. It has been suggested that discussing medical ethics and particularly the doctor–patient relationship within such a framework can undermine affection, sympathy, trust and caring. These properties once underpinned the doctor–patient interaction, and have long been considered to be therapeutic in their own right. The necessity for, and existence of, patients' rights suggests something amiss with the healthcare providers. For if they really had the patients' best interests at heart and in mind then why would they need to establish and insist on their rights?

However, rights are an increasingly integral part of our society and we all expect to be treated at an established minimum standard. Most people who come into contact with us as healthcare providers do so as frightened, inexperienced novices, both physically and emotionally vulnerable, and when seen from this perspective, talk of rights seems much more important and natural.

These individuals, who have, after all, been paying for the NHS their entire working life, need to know that they are safe and protected and that they do have recourse should there be any cause for concern. The rights of each individual are after all the cornerstone of our democracy, and by according rights to each other we reaffirm our worth and importance, something which can be particularly crucial to the sick, injured, elderly or infirm.

Current best practice sets the doctor and patient as partners in decision making. Both bring particular knowledge to the encounter. The physician holds technical knowledge, data and experience; the patient holds the knowledge of their own particular symptoms, the problems they are causing them, and contextual detail that make one therapeutic option more desirable in their situation than might at first be obvious to the treating physician. The contract drawn up by this partnership is not, however, equally binding on both parties. The physician has to honour all that he/she has undertaken to do, whilst the patient has no such responsibility. It is often after they have left the consultation that their real decisions are made. Are they really going to take the prescribed medication? Give up smoking? Turn up to their clinic appointments or investigations?

In the evolution of the doctor–patient relationship the momentum of change appears to be heading toward patient primacy in therapeutic decision-making. But where along this timeline will the responsibilities catch up with the rights? Perhaps we are reaching a time when this contract should become just that – the doctor and patient both signing up to an agreed action plan and each being held to it. How such a scheme could be implemented is, however, far from clear. It does seem important to understand, though, that rights and responsibilities go hand in hand and that as more power is gradually handed over to patients and their representatives (for whose benefit after all, the NHS exists), so we will have to somehow ensure that our healthcare resources continue to be used responsibly and equitably, and that those for whom the protection of rights was really necessary do not end up becoming more disenfranchised than they already are.

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