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LESSONS FROM A SYMPOSIUM ON ETHICAL AND ECONOMIC CONFLICTS IN A CHANGING HEALTH SERVICE HELD IN THE COLLEGE ON 1 FEBRUARY 1996*

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Patients today have many expectations from the National Health Service, which those who work in it at the individual level, and Health Boards and authorities at the population level strive to meet. Economic and political pressures continue to raise ethical dilemmas about the rights of patients, the role of care in the community, general practitioner fundholding and the functioning of NHS Trusts.

Expectations of the modern patient

Patients have many assumptions about the NHS. These include access to teatment free at the point of delivery, optimal care from the cradle to the grave, effective treatment by skilled professionals and access to a doctor at any time. Such assumptions do not necessarily equate with rights but increasingly patients are perceiving them as their rights. This was reinforced by the Patients' Charter which listed what a patient could expect from the NHS, but not necessarily as a right.

Patients expect to be kept accurately and regularly informed on a wide range of subjects from the possible adverse effects of treatments to which of their local NHS Trusts has the best performance. Delivery of information remains limited and is still lacking in some areas of clinical practice and, even when information is available to clinicians, this is often not shared with or made readily available to patients; for example pharmacists may be more knowledgeable about the adverse effects of drugs.

Responsibility for health should be shared between the patient and the doctor. Patients and their carers should be provided with information on all stages of their care, allowing them to make informed choices. Individual clinicians, NHS Trusts and health boards. These should be accountable to patients who, in return for being informed, should take responsibility for decisions, which are often difficult, about their care.

Meeting patients' expectations

Expectations can be divided into those of individual patients and those of populations. Expectations of individuals have implications for professional staff and their teams in primary, secondary and community care; expectations of populations, the potential health service users, often with long term needs, have implications for NHS purchasers. To meet their patients' expectations doctors require the following attributes: competence, communication, confidentiality, consent, compassion, courtesy, commitment, confidence, coping and the ability to form community links.[1] It is not to be expected that every member of every clinical team meets these requirements every hour of every day, and patients should be encouraged to rely on each of the members of a team. Progress has

*A list of speakers and the titles of their papers presented at this symposium is recorded in *Proceedings* vol 26 p. 347.

been made to improve the responsiveness of health professionals to patients' expectations; the health service continues to strive to achieve these standards through, for example Project 2000 and the new medical curriculum.

Interactions with health professionals in making decisions range from medical paternalism to patient autonomy. Rightly medical paternalism is now being questioned, yet patients do not want full autonomy but rather shared responsibility, dependent on open information. For most patients participation with their doctor can be achieved leading to shared decisions. The move, however, towards greater patient involvement allows the tiny proportion of very demanding patients to make unreasonable demands.

From the population perspective, the purchaser has to consider the ethical concepts of beneficence, justice and respect and so weigh up benefits against harm to individuals and to the wider community. The criteria used to assess health services differ between patients and health professionals[2] and between the healthy and unhealthy patients.[3] Therefore, to make choices regarding health services, each group of interested parties should be consulted and listened to.

There needs to be an open dialogue and mutual understanding between patients and professionals with information shared openly. Reasonable patient expectations of competent and understanding professionals should result in high quality services but as resources are always limited, the limits to what is possible should be laid down at a regional or national level and not left up to individual doctors.

Economic and political pressures (rationing)

Trade-offs between equity of access, choice, costs and comprehensiveness occur within all health services, and increasing social and economic pressures make rationing inevitable. The moral choices required to ration health services have been described by some as being too brutal for society to contemplate.

One approach to rationing is to withdraw ineffective services and to base decisions on research based information. The NHS Research and Development Strategy and the trend towards 'evidence based medicine' encapsulates this. Many centres throughout the UK were set up to approach this, but doubts exist as to whether clinical practice is being actually affected by such evidence and that research may not actually be put into development. For care of an individual patient, evidence based medicine may be hard to put into practice. Many complex factors (health, social, individual preference) interact when a decision is made regarding a specific patient. Evidence based medicine may engage the scientific aspects of medicine, but forget its art and craft and so ignore the quality of a patient's life. For example, a treatment may be effective clinically, but result in a poor quality of life. Politicians support evidence based medicine, because it takes from them the pressures of making decisions and places these on the shoulders of scientists and health professionals. Political and ethical tension thus exist between evidence based medicine fulfilling the greatest good for the greatest number and what individual doctors believe is best for individual patients.

Patients could be described as having rights to health care according to need, at any time, regardless of the ability to pay (substantive rights) and also the right to be registered with a GP (procedural rights). The Patients' Charter includes these, but is not legally binding. As consumerism increases it produces the dilemma of the rights of the individual versus the rights of society, with the

rights of the patient challenging the collectivism of the NHS. Individual rights should not be a substitute for collective decision making; patients, professionals and managers should work together and be inter-accountable. Patient participation in decision making, from the level of consultation through to the level of forming strategies and setting up contracts, should be encouraged rather than patients' rights.

Fundholding—ethical aspects

Fundholding, introduced in 1989 as part of the NHS reforms, has created a fundamental ethical dilemma for general practitioners who, as providers, are advocates for individual patients and yet, as purchasers, have a responsibility to the whole population. It is questionable whether these two roles are compatible. Rationing is exposed by fundholding—a GP may feel it is best to withhold treatment from one patient for the benefit of all their patients.

Two ethical concepts—deontology (the duties and rights of the individual) and utilitarianism (greatest good for the greatest number)—can be used to describe this dilemma further. Before NHS reforms, allocation of resources to general practitioners was utilitarian; while after NHS reforms, it is seen as deontological, because each patient is meant to have a choice in their treatment. However, some fundholders work in an explicitly utilitarian fashion after all possible savings have been made.

Fundholding raises other ethical dilemmas. 'Fast tracking' of fundholding patients into secondary care ahead of non-fundholding patients is not considered ethical but whether this actually occurs, requires further research. Fundholders are allowed to buy services for their patients, which are otherwise rationed by the traditional NHS, for example some plastic surgery. Fundholding encourages discrimination against 'expensive' patients. Personal profits may be increased indirectly through fundholding, for example by extending practice premises and this is contentious. It is suggested that fundholding may result in increased litigation and thereby increase the stress of general practitioners. In spite of these ethical dilemmas, the benefit of fundholding may spread to non-fundholding patients, for example by reduced in-patient stays.

NHS Trusts—ethical dilemmas

Many ethical dilemmas are faced by those working in NHS Trusts. Rationing is one, which needs to be explicit and requires clinicians to be involved in decisions at the Trust level. Management has to balance teamwork with production, and it is often difficult to carry out a task in hand and keep both employees and patients contented. Confidentiality is an important issue; voicing of complaints should be encouraged, but confidentiality maintained. Openness is essential, for example, at board meetings, but there should be opportunities for discussing confidential issues at closed meetings. The competitive market introduces the dilemma of balance between a managed and a freely competitive market. Trusts do not want either to turn away business or to be unethical by only treating fundholding patients. In addition, contracting is a complex process in which the role of the clinician is undecided; doctors are often blamed for overspending, although often they do not have responsibility for the budget.

Funding of community care—who should be responsible?

The media in the UK have portrayed an image of the elderly as a problem. They

have been increasing disproportionately and in the last few years the increase has been more gradual. The question still remains of whether the welfare state can afford to care for all the elderly. Today, only a minority of the elderly live permanently in residential or hospital accommodation, while the majority live on their own and are independent. Therefore, this is not an intractable question, but a political question of how much the government is willing to fund community care. If community care is underfunded, a crisis is produced which then extends to the hospital sector; insufficient support in the community is followed by people referred to secondary care. The interdependency of community and secondary care needs to be clarified and interlocking, rather than isolated budgets developed. In addition to users, carers should not be forgotten. It is estimated that if carers were paid at the local authority pay rate, they would cost millions of pounds, and if carers withdrew their support community care would collapse. The contributions by carers should be recognised and they must be supported in their work.

We are all part of a community. Community care is not a political football and needs consensus politics and long term planning. Decisions are needed as to how the money is raised, who should raise it and how it should be spent. Maybe it is time to look for examples from abroad, for example Germany's system of social insurance.