At the coalface – medical ethics in practice

Autonomy: the need for limits

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Abstract

This essay addresses the issue of the autonomy of the National Health Service (NHS) patient in the UK. It is argued, with reference to clinical examples, that some patients abuse their rights to medical care to the detriment of other patients and the service providers. A case is made for limiting the rights of patients in order to improve the service for all who use it. A range of mechanisms are considered with a discussion of the issues raised by each solution in turn.

"Moral decisions must be made in the real world of scientific and economic facts".¹

This essay contains illustrations from general practice that demonstrate that individuals exercising their right to autonomy are creating a crisis within the National Health Service by disproportionate use of limited resources. This crisis could be addressed by a radical redistribution of resources or limitation of the rights of autonomous individuals to use scarce resources, especially in circumstances where these rights cause harm to the providers of the service or other users with the same rights.

The UK economy is in relative decline. The nations of the Pacific basin now lead the world in terms of economic growth. This country on the other hand is recovering, some would say still suffering, from the worst recession since the thirties.² Unemployment is at a peak. Poverty is increasing and the gap between the rich and the poor is growing. The National Health Service is subject to the reality that resources are limited, thus the provision of general practitioners (GPs) funded from state resources is limited.

The scientific facts are that it is precisely in these circumstances that physical and mental illness thrives.³ The demand for consultations with general practitioners is rising.⁴ There is no incentive for this demand to decrease and every incentive for it to increase. General practitioners provide support for

an ailing, aging population struggling to cope with unemployment, unhealthy responses to stress and rising chronic illness. And all of this demand is fuelled by the patients' charter which enshrines the most widely abused right of the National Health Service patient: "To receive emergency medical care at any time, through your General Practitioner".⁵

In this context consider the following dilemma based on my real clinical experiences but with details changed so as to ensure confidentiality. The case may sound, and is, extreme but it illustrates a real problem. You are working as a general practitioner in a deprived, isolated rural area with twenty five per cent unemployment. Your patients consult at twice the national average. There are four GPs in your practice, which covers 20 square miles. You and your partners take it in turn to provide out-of-hours cover for your patients. There is no hope of a cooperative or deputising service to cover the practice out of hours. You work fifty miles from the nearest District General Hospital. At one am about once a month an alcoholic patient presents himself at the casualty department of your cottage hospital. He tells the staff nurse that he has taken an overdose of paracetamol tablets or displays several deep self-inflicted gashes on his arms. He claims to be depressed. You are duly summoned to attend but the patient refuses to receive any treatment or absconds on seeing your car approaching. He often returns a couple of hours later seeking treatment and wishing to discuss his problems with a doctor. The local ambulance crew refuse to take the patient to hospital unaccompanied as the patient attempted to jump out of a moving vehicle one night and then complained that he had been forcibly restrained against his wishes. He is not always drunk when he comes and is discovered not to have taken an overdose when blood tests are done to confirm his story. However, on at least one occasion he required admission to intensive care after a serious attempt to take his own life. You have already referred the case to the local psychiatrist who seems impotent to act when the patient defaults from clinic attendance or refuses to open the door to the community psychiatric nurse. Twice you have admitted the patient to hospital under the Mental Health Act but on each occasion he has successfully appealed against detention the following

Key words

Autonomy; general practice; rights.

day. You have been cautioned against the use of emergency powers in what appears to be an inappropriate case. His sister telephones you regularly to express concern about her brother but cannot offer any material assistance. The local social work department are reluctant to get involved, especially at one am and even more so if the patient appears to be under the influence of alcohol. Besides which the duty social workers would have to travel thirty miles to come to your aid, a journey which takes at least an hour. The police cannot be summoned because the patient has not broken any law and seems perfectly polite even when drunk.

You must attend to such a patient in the middle of the night, often spending considerable time dealing with the crisis and then work the following day, exercising due care and attention in your dealings with other patients. Whilst such a patient causes nuisance and disruption, others who are exercising their rights can do the same, albeit to a lesser extent. These include:

1. Those who repeatedly fail to attend for their appointments.
2. Those who regularly demand home visits for their own convenience when a surgery attendance is more appropriate.
3. Those who are rude and abusive.
4. Those who vindictively make false accusations and spurious complaints to the Family Health Service Authority.

Patients committing deliberate self harm are exercising their right to autonomy as defined by Lord Donaldson: "This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even nonexistent".⁶ However, the consequences of this behaviour when it results in the abuse of carers in the manner described above might be a factor in the growing recruitment crisis in primary care, especially in deprived areas where one might hope the most skilled and dedicated doctors would practise.⁷ Furthermore there is mounting concern about the phenomenon of burnout among general practitioners, regardless of the length of service in the profession.⁸

At this point it may be worth exploring in a little more detail the impact of the dilemma outlined above. The main impact is likely to be on the doctor and the patients he/she must treat the day after attending to such "emergencies". It has long been established that doctors have a higher than average risk of death from suicide, cirrhosis, and accidents and a high incidence of psychiatric admissions. I do not mean to imply that this is the direct result of having to attend to patients whose behaviour is unacceptable. The precise contribution of this dilemma to GP morbidity is difficult to tease out among the many other sources of discontent for the

profession. Those often listed in surveys include: fear of assault, fear of complaints, 24-hour responsibility, increasing administrative burdens, unreasonable patients' expectations and constant interruptions at home and work.⁹ However, occasionally doctors or their spouses have the courage to publish their feelings on the matter as this GP's wife did recently: "How can I begin to describe the life of an overworked and stressed GP's wife during a weekend when he is on-call. ... Should I tell you about the patients who injure themselves, wait 12 hours to seek medical advice and want it within 20 minutes? Can I interest the BMA in the fact that not only junior doctors work ludicrous hours but also middle-aged family doctors?"¹⁰

Marital disharmony

It is now acknowledged that GPs rank on-call as the main cause of stress in their lives. The price of a commitment to these duties is often marital disharmony, substance abuse or depression. Such doctors cannot be effective healers or carers. There is some evidence that the quality of patient care is affected by increased stress and lowered job satisfaction. Tired demoralised doctors are more likely to prescribe inappropriately, to adopt a less than helpful attitude and to "depersonalise" their patients.¹¹ Those most likely to suffer are those who see the doctor at his lowest ebb even if their need is genuine and appropriately presented. This idea gains some credibility in the light of a survey in 1992 involving 740 GPs, in which working the day after a night on-call ranked as the third most stressful experience in GP life.¹² Clearly therefore the adverse impact of this small subset of patients who abuse the service is felt by both the carer and his or her patients.

I will now consider alternative approaches to such demanding patients and raise at least some of the ethical questions posed in each case.

1. *Such patients should be excluded from care in the NHS.* In practice who would decide to withdraw care, when and for how long? How would the ban be enforced? Ethically this is virtually an indefensible stance. It involves discrimination against patients based on a judgment that the patients' demands were unreasonable. At worst the discrimination might extend to people from different cultural and social backgrounds, thus depriving more people of care and challenging a fundamental principle of medical ethics: "You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, sex, sexuality, age, social status, or perceived economic worth to prejudice the treatment you give or arrange".¹³ Of course in a purely private health care market those who cannot or will not pay automatically exclude themselves from care before they reach the consulting room. However, at present NHS GPs may exclude patients from their personal lists without offering any justification. There has

been concern that some fundholders might do so for reasons other than a breakdown in the doctor-patient relationship.¹⁴ These concerns may jeopardise this right in the future and create further discomfort for embattled GPs struggling to cope with unreasonably demanding patients. Most doctors do not accept that the right in law to walk away from a patient who deliberately self harms and is not mentally ill, as defined by the Mental Health Act, is helpful, because there is a greater duty, which is the duty to care and most GPs will spend time trying to persuade such a patient to reconsider, even if it is at the expense of a few hours of sleep.¹⁵

2. *Those who commit deliberate self harm in the community should be referred directly to the psychiatric services as part of their commitment to community care, without the need to involve a general practitioner.* Whilst this might appear to be a neat solution it poses several problems. Not all of those who commit self harm create a crisis and not everyone who engenders a crisis commits self injury. Many neurotics with intractable, or unexplained pain, physical or psychological, seek assistance out of hours with monotonous regularity. Therefore this solution does nothing to solve the fundamental problem, merely burdening another sector of the service with the care of a specific subset of the population. Besides, there is an ethical argument about whether allocating more resources to the psychiatric services for the care of a minority group is an equitable or cost-effective use of scarce resources.

3. *Remove the responsibility for out-of-hours care from the contracts of primary care physicians.* This will require either an admission that the state cannot afford 24-hour primary care or willingness on the part of the state to take responsibility for organising a service other than what is available between office hours. It may require the profession to concede that continuity of care is no longer possible. Clearly, if we were to pursue any of these options a major re-allocation of resources would follow. Either GPs would be paid less or the money to provide this service would have to come from elsewhere in the NHS, with an attendant debate about the opportunity cost of such re-allocation. The current government initiative, which offers an investment of forty five million pounds to help GPs to share the burden of out-of-hours care, may not help to address the dilemma posed in this essay. It is simply not possible to share the burden of out-of-hours work in every corner of this island because of geographical considerations and because practitioners fail to agree on how such cooperatives should operate. A further ethical debate might be kindled by the death of a patient from a treatable cause because of delay in getting medical attention from an over-stretched cooperative doctor.

4. *Introduce further legal powers, backed by punitive measures, to deal with patients who are demonstrated to "abuse" the practitioner.* Notably, India recently introduced legislation to penalise "consumers" who

file false or frivolous complaints against doctors.¹⁶ This attempts to give some weight to the "rights" of the practitioner. This solution retains the status quo in terms of resource allocation but increases the burden on the judiciary to make tricky judgments about what constitutes "abuse" of a practitioner. I suspect that the courts would be choked by an influx of claim and counter-claim. Confidentiality would be undermined as doctors revealed details about what took place in the consulting room. Such disclosures would serve the needs of the abused practitioner for retribution. Many would find this morally repugnant: "The right to autonomy includes the right to privacy"¹⁷ However, such a change in the law might signal society's willingness to allow doctors to seek punishment of individuals who compromise their ability to function effectively. This is consistent with the so called utilitarian philosophy. It would then be up to the courts to define what constitutes "abuse" in the way that Gillick competent has been defined in recent judgments.¹⁸ The weight of this responsibility cannot be over-estimated, the doctor-patient relationship may be undermined by the threat of disclosure from the confidant if he or she chooses to pursue an action under this new legislation.

In the prevailing economic climate society has a moral imperative to deal with this issue and on the solution will depend the future of the NHS.

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News and notes

The British Society for Ethical Theory

A new British Society for Ethical Theory was inaugurated at a conference at Keele on 28th March this year. Originally called the British Society for Metaethics, the society arose as an electronic mailing list organised by David McNaughton from Keele with around 50 members. The society will seek to promote ethical theory in Britain and to foster contact among members of the ethics research community, primarily in the first instance by organising conferences, at least

annually.

The society also aims more generally to promote the exchange of information, drafts of papers, reviews, etc by both electronic and conventional means.

Further information and membership application forms may be obtained from the Secretary, Dr James Lenman, Department of Philosophy, Furness College, Lancaster University, Lancaster LA1 4YG; email: j.lenman@lancaster.ac.uk.

News and notes

College for children's health founded

The College of Paediatrics and Child Health (CPCCH) was created earlier this year with the granting of a royal charter to the former British Paediatric Association. The CPCCH is the thirteenth medical royal college in the UK, but the first to be concerned specifically with the needs of Britain's children.

As the academic body for paediatric medicine and child health, the CPCCH takes over the three Royal Colleges of Physicians' statutory responsibilities in

relation to the training of hospital and community-based paediatricians. The objects of the CPCCH are: 1 To advance the art and science of paediatrics; 2 To raise the standards of medical care provided to children; 3 To educate and examine those concerned with the health of children, and 4 To advance the education of the public (and in particular medical practitioners) in child health.

For more information please contact James Kempton, telephone 0171 486 6151.

News and notes

Fellowship in Clinical Bioethics

The Department of Bioethics at the Cleveland Clinic Foundation invites applications for a one-year bioethics fellowship residency, beginning July 1st 1997. The programme has an interdisciplinary focus and includes academic, clinical and research bioethics components. Each fellowship is tailored to meet individual strengths, needs and interests. Concentrations in medical subspecialties (for example, geriatrics, infectious diseases) are

available. Stipend and health care benefits are provided. Completed applications must be received by January 15th.

For information contact: Martin L Smith, STD Department of Bioethics, P-31 Cleveland Clinic Foundation, 9500 Euclid Avenue, Cleveland, Ohio 44195, (216) 444-8720. e-mail address: smith@cesmtp.ccf.org.