HUMAN VALUES

Values, Ethics and the Law—Issues for Practice and Education

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ABSTRACT  For many years, thoughtful medical practitioners have concerned themselves with the place of health services and medicine in their social setting. They have recognized that there are genuine moral dilemmas which are peculiarly modern or postmodern. As the potential to treat has gathered momentum, so has the cost of health services. These two forces have now collided. The resultant damage is far from finished, and the full extent remains to be assessed. It is clear that medicine will never be as it was, and that it will need to be re-thought in radical ways. To do that, we will need to know what societies expect from their health services, what goods they value as primary, what priorities they may assign to competing goods, like health and education, and what level of taxation they will endure to secure these goods. However, who will think about these matters, and who will create the opportunities for intelligent people to cross disciplinary barriers to talk about them? This paper represents one small attempt to enter this domain.

The Centre for Values, Ethics and the Law in Medicine

The Centre was opened within the University of Sydney’s Department of Surgery in May 1995. In November 1996, the University of Sydney awarded the Certificate of Official Status as a University Centre during the opening ceremony of a seminar on equity and rationing in health. The Centre consists of a core group of people drawn from a number of professions and academic backgrounds. Clinical medicine, community medicine, health economics, sociology, education.

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philosophy, sociology, ethics, law and anthropology are all represented. Some members come from the campus of the University of Sydney, others from outside. All have particular interests in the value-laden fields of medical ethics, bioethics and health law.

The Centre has three major roles. It is a place for the referral of difficult bioethical problems, outside the scope of institutional ethics committees; it provides resources for research; and it has an educational function.

**Bioethical Consultation**

In its role as a bioethical consultative group, it receives matters that are referred from hospitals and Area Health Services, the University of Sydney and its Faculty of Medicine, the learned Colleges and various other bodies faced with bioethical problems. The Centre has provided advice on such matters as reproductive medicine, euthanasia, the committee structures for dealing with ethics in new clinical schools, the ethical issues involving medical students with incurable infectious diseases and the ethics of epidemiological studies. We have devised a set of structures for examining ethical issues, which encourages the core membership to examine problems from many directions, and to employ what Hannah Arendt called ‘representative thinking’ (Arendt, 1961). We have been especially concerned to expand ethical consideration beyond the familiar, but limiting, confines of principle-based ethics. Our advice is always offered with the proviso that it is seen neither as a prescription for policy nor as a means to shift responsibility. We stress strongly that ethical advice explicates moral issues. It does not determine policy, and it does not remove responsibility from those who referred the problem in the first place. Although we try to consider the legal implications of each matter, we stress also that ethical clearance is not legal absolution, and that there are sharp distinctions to be drawn between ethics and the law. Indeed, the existence of a law may actually create ethical problems when the law runs counter to the ethical commitments of health workers. Euthanasia and rationing are two areas where this conflict can be particularly difficult.

**Research Roles**

The Centre provides ethical advice about research protocols. It may advise a research group, for example, which proposes to carry out an epidemiological study, in which diagnostic data may be uncovered that should be protected by anonymity, but which is of profound importance for the lives of those affected. Once again, we provide an ethical analysis, but do not attempt to write the research applications. Our opinion does not absolve the research group from its responsibilities.
We also conduct our own research, which is broadly based, and not confined to purely ethical or ethico-legal matters. We certainly contribute to questions of informed consent (Little & Leeder, 1996), autonomy (Little, 1993), euthanasia (Little, 1995a, 1995b) and equity and justice, but we reserve a major commitment to even more basic issues. Each month, we meet for discussion of a nominated research topic. The person who nominated the topic prepares a paper which defines the issue and includes a reading list. At the meeting, the same person chairs the group, speaks to his or her paper, which is then discussed. These meetings last for about 90 minutes. We have discussed such issues as the influence of money in the agency relationship, and the ethics of epidemiological research.

The presence of the word ‘Values’ in our rather long title is seen to be particularly important. While ethics is based on values, there are matters beyond the conventional scope of ethics which also depend on values. Take, for example, the subject of medical treatment outcomes. Outcomes research is in vogue in some circles at the moment, and there have been moves to judge ‘best practice’ and ‘cost–benefit’ in terms of outcomes. The problems are enormous. Who judges whether an outcome is ‘good’ or ‘bad’? Clinicians have long recognized that there are patients with (medically judged) bad outcomes who are grateful for their care and accept the outcome. Equally, they recognize that there are many whose (medically judged) outcomes are excellent, but who feel angry and disappointed with their care and their health status. The families and friends of patients often feel that (medically judged) good medical care has been very bad, and they write complaints which are seen to be unjust. What values determine these responses? Are we right to consider groups of patients with a particular disease, like colorectal cancer, as sufficiently homogeneous to be thought of as a ‘community’, linked by similar narratives of illness, or are there subgroups with special narratives that might determine radically different perceptions of good or bad outcome? Should we consider perceptions of the treatment process as part of the outcome, as many patients and their families do? These kinds of questions are the basis of some of the major projects which the Centre is formulating and taking as its research brief.

Teaching

We recognize a major responsibility to teach. We contribute to the new Graduate Medical Programme at the University of Sydney by providing much of the material for lectures and tutorials and by contributing to the ethical components of the problem-based learning which is the mainstay of the new programme. We wish to see the ethical programme interwoven with the science and clinical content in such a way that it is simply accepted as an intrinsic part of the learning process. Our teaching extends widely into the graduate and postgraduate phases of medical education. Our members regularly contribute to panels,
seminars and workshops which concern values, ethics and the ethical–legal interface. One of our major commitments is to the NSW State Cancer Council. We are helping to formulate the content of their teaching programmes for health care professionals involved in the care of patients with cancer, and we participate in their seminars and workshops on communication and ethics. We also provide contacts for media people seeking ethical and moral comment on issues like rationing of services, euthanasia, poverty and health, gene-technology and the introduction of new technology.

Distinctive Features of the Centre

This very bald statement of what we do does relatively little to distinguish us from many other similar groups with bioethical interests and responsibilities. We think that there are some distinctive features:

1. Our multidisciplinary core group, and its devotion to ‘representative thinking’.
2. Our insistence on the importance of theory.
3. Our anchoring in the practical world of policy in health and law.
4. Our educational commitment.

For a variety of reasons, we have chosen to locate ourselves firmly within a university, even though we have recruited people from outside the academic world. Despite the plight of universities world-wide and their crises of identification which accompany the financial stringencies they experience, universities continue to offer something distinctive to groups with intellectual needs (Minogue, 1973). Governments support the concept of universities, but want them to become more like businesses. This may be good in some respects, but it is very dangerous in others. Universities are criticized by both government and business for being ‘unfocused’ in their activities and ‘inefficient’ in their managerial practices. These criticisms may be accurate, and there is undoubtedly much that can be done to ensure that universities make better use of their money. However, there is an important sense in which these strictures reveal a dangerous ignorance of the telos of the University as an institution. Semantically, the Universe part of the word reminds us of the scope of the University’s interest. Some universities proclaim themselves as having a narrower focus, such as business or religious studies. But the University, whether ancient or modern, stands or falls by the breadth of its studies. Institutes of Technology are focused, productive and attract many of the best minds to study, do research and teach, but they are not universities.

Universities, therefore, justify their existence by their breadth, and that intellectual pluralism is their strength, though it is their weakness in the eyes of those who have vested interests in focus, efficiency, productivity and economically measurable output. The problem in setting up a Centre of our kind outside
the University comes from just these vested interests. Direct subsidy by Government, business, professional bodies, political parties or religious groups immediately identifies a possible influence, and immediately deters the support of at least some who feel, rightly or wrongly, that such opinion and advice must be tainted.

Universities continue to provide the richest grounds for exchange of information, experience, knowledge and wisdom. It is never easy to assemble experts, but it is far easier to do so within a university than it is outside. The network of expertise that connect experienced academics to the best source of advice on almost any matter is truly remarkable. An interdisciplinary group meeting within a university can tap a breadth and depth of opinion which is unrivalled.

Further, universities function as educational bodies. If there is an obligation, a need or a desire to teach in the field of an endeavour, the university offers the chance to do so at all levels of education.

Values, Ethics and Medical Education

Why emphasize values and ethics in medical education? Surely, doctors are sufficiently aware of their ethical obligations, and the problems that medicine faces are to be fixed by promoting evidence-based medicine. These two claims can be dealt with together, but it is best to move back a step before we do so.

Medicine is in serious trouble in the late twentieth century. Its achievements have been spectacular, and the average expectation of life at birth has been prolonged by 27 years in Western countries since the start of the twentieth century. Yet complaints and Complaints Departments proliferate, litigation against doctors continues to increase, defensive medicine has become a reality in many countries, and politicians and bureaucrats increasingly assume control of health services. There are many causes for these problems, but it is worth while to single out a few.

Science has driven the advances in medicine in this century as nothing else has. Western societies are devoted to science, and doctors proudly practise "scientific medicine". But few stop to question what this means. Vast sums of money are committed to scientific research in medicine, yet there is little cost–benefit data available to certify that the money has been well spent. Scientific research of this kind is generally 'objective', parametric, controlled, reductionist and depersonalized. A good outcome for a funded project is a set of results confirming a hypothesis that some part of a bodily system works in a particular way, or responds in a particular way to a particular intervention. However, this is not what justifies the massive expenditure on health. Medicine justifies its existence by the widespread acceptance that there is something special about individual human life, its experience, its quantity and quality. No matter how orientated we may be towards concepts of community and public health, the justification for effort and expenditure in relation to health is this
valuation of individual human life. The concept of making a community of people better or happier has no meaning without this underlying acceptance that ‘better’ and ‘happier’ have individual referents. A community is not happier if none of its individuals are happier.

Medicine and the whole endeavour for health, therefore, derive their telos from this basic value judgement. Even if we follow Singer (1994), and agree to reject the specific moral superiority of being human, we cannot evade the truth that human life is our yardstick within medicine, and that human life is at least as importantly described by its qualities as by its quantities. It is for this reason that science and evidence-based medicine alone cannot supply what it is that our patients find wanting in modern medical practice. Where personal illness and suffering are concerned, we are often at a loss. Our science in clinical medicine is not deterministic, but probabilistic. The best evidence may tell me that this patient with apparently resectable liver secondaries has a 25% chance of cure by surgery. Yet the most sophisticated tests, the most rigorous of meta-analyses will not tell me whether this patient will be among the 25 who live or the 75 who die. Dealing with this quandary, which is at the root of so much of the dissatisfaction with modern medicine, is a problem for our values and our ethics, rather than our science (Little, 1995b). Expertise is good to have and to employ in the service of others. But expertise by itself is not enough. A skilled doctor may choose to dedicate his life to the service of others, but he can also become an advisor to the torture unit of the secret police. His expertise in understanding pain may be based on long study and careful, trained observation. Without morality, expertise offers no guarantee of the way in which it will be employed. Ethics and morality define professional practice just as strongly as expertise.

We have come a long way in our acceptance of ethics in medical practice and education. As a student in the 1950s, I learnt that medical ethics were much the same as medical etiquette, and that the observance of ethical standards would keep me in good standing with my colleagues and keep me out of trouble with the law. The upsurge of interest in medical ethics that followed the Nuremberg trials of the 1940s and episodes like the Willowbrook trial (of deliberate infection of handicapped children with hepatitis) or the Tuskegee study (of untreated syphilis among black men) led to the ethical movement in medicine. Principle-based ethics has dominated ethical thinking in medicine, and has done much to help medical practitioners to think in ethical terms (Béauchamp & Childress, 1989). Unfortunately, the original formulation as principles has drifted into a modern formulation as precepts, and there are many who think that if they remember beneficence, non-maleficence, autonomy and justice like a mantra, they ‘know ethics’ and can stay out of trouble. It is this unfortunate attitude that leads some to say that the ethical movement is over, and that new ethics have been simply incorporated into contemporary practice. This is, alas, untrue on every front. Ethics still have too little presence in medical thinking, and the rapidity of advance of medical technology has far outstripped the four principles, helpful though they are in many ways. If we are to decide justly,
prudently, beneficently and courageously about the ethical implications of the human genome project, we will need to be cognisant of many values, and we will need to think in many different ways. The medical model is a great and beneficent one, but it does not have all the answers, even to the problems which it creates, still less to those it is about to create. While we recognize that our Centre will never resolve these issues, we believe that it does something worthwhile by providing a meeting place for minds from many disciplines, a forum for informed discussion, a resource for values-based research and a milieu for education and educational development. We hope to be a small part of a growing movement in many countries.

Notes

1. Postmodernism refers to the contemporary intellectual movement which denies the validity of universal principles and embraces the *avant garde*. It takes the view that individual response to anything, be it an aesthetic event, a work of art, or literature or a political event, can only be validated within the individual. Postmodernism denies that there are essentials, principles or rules which make certain acts or creations better than others.
2. This refers to the imbalance of power in virtually any professional relationship, where individuals deliberately entrust their affairs to another individual.

References


