

Leading Article**Medical ethics, Paediatrics and the Paediatrician**T L Chambers¹*Journal of the Ceylon College of Physicians, 1993, 26, 5-9*

Drawing on the views of the late Sir James Spence, one of the most distinguished British paediatricians, this lecture will review the general duties of physicians and then focus on their obligations to patients. These are autonomy; beneficence and non-maleficence; truth telling; justice; with reference to paediatric practice. Then follows a brief discussion of four ethically controversial topics relating to children: euthanasia, consent, resource allocation and research. The functions of ethics committees and ethicists will be reviewed and suggestions made as to how the medical profession should meet the challenges for its further external regulation that some groups propose.

Sir James Spence lived from 1892 to 1954 and was the outstanding physician-paediatrician of his generation: In the *British Medical Journal* his obituary starts: "Paediatrics has lost a leading figure and the nation a wise counsellor....." In his honour the British Paediatric Association named its highest and most prestigious award the James Spence medal. Like most really great men Spence did not confine his reflections or writings to his specialty but roved much wider. He was particularly interested in the practice of medicine and his conclusion about it was this:

"The real work of a doctor is not an affair of health centres or public clinics or operating theatres or laboratories or hospital beds. Techniques have their place in medicine but they are not medicine. The essential unit of medical practice is the occasion when, in the intimacy of the consulting room or sick room, a person who is ill, or believes himself to be ill, seeks the advice of a doctor whom he trusts. This is a consultation, and all else in the practice of medicine derives from it."

Spence was writing most movingly about the doctor-patient relationship which is one of the most profound in human affairs. The most important point I wish to make about medical ethics is that it should enhance rather than challenge that relationship.

Duties of physicians

I would argue that physicians and paediatricians have three main ethical duties: to their patients, their colleagues and to themselves.

To their patients

The doctor's responsibility to their patients and relatives concerns the accurate diagnosis, treatment and prognosis of the condition about which they are being consulted which may range from the most minor upper respiratory infection to a life threatening condition such as cancer. Implied in this is that the doctor will ensure that the consultation is not hurried and that the patient or relatives have full information about the condition and that the consultation should leave them feeling that their questions have been answered adequately and that they have confidence in the physician answering them. In modern terms the doctor should have good communication skills. However I would put such skills alongside, but not more important than, accurate diagnosis. This can be a challenge in children where one is always trying to spare the child unpleasantness by performing the least number of investigations. However we do no service to a child by undue hesitation and an incorrect diagnosis. Paediatricians are the medical specialist of the child and the quality of their medical work is as important as the way in which results of it are communicated.

Paediatricians owe a duty to their patients over the question of referral. We all relish the challenge of managing an unusual or difficult case and can feel threatened or angry if parents challenge our ability and ask, say, for a referral to a paediatric sub-specialist. We must, however, remember that it is the patient whose interests should come first and that we must recognise our limitations. I realise that this presents a challenge to the general paediatrician who may feel that all he has left to deal

1 *Consultant Paediatrician, Bristol; Clinical Lecturer, University of Bristol, UK.*

with is child protection, long term handicap and the worried well. In some parts of the United Kingdom this difficulty is resolved by a system of shared care between specialist paediatrician and his general paediatrician colleague.

To their colleagues

Paediatricians have a duty of loyalty both individually and collectively to their medical colleagues to practice to high standards so that the reputation of the specialty and the profession is unimpaired and to be judicious about commenting, particularly adversely, on another paediatrician's practice.

To their families and themselves

Paediatricians work very hard and at unsocial hours. Many of us would counsel our patients' families or colleagues against such behaviour out of respect for our family life and the individual paediatricians health. One would argue most forcefully that employing authorities should note this point and not exploit their medical labour whether trainee doctors or consultants.

Ethical treatment of patients

The principles underlying good ethical treatment of patients have been described as autonomy, beneficence, non-maleficence, truth and justice.

Autonomy

By this we mean that a competent patient should determine his or her future and in medical practice this may or may not involve taking the advice of a doctor whom he or she consults. In paediatrics many patients are not competent because of their young age and lack of understanding (although it is likely that we underestimate the age at which children can comprehend the subtleties of medical decision making — especially life or death ones). Almost invariably the parents are highly motivated and excellent proxies for the giving of consent but every paediatrician will have had to deal with the occasion when the exercise of parental autonomy on behalf of their child would probably act against its best interests and parental autonomy is overridden. One example is where the parents of a newborn baby with Down's syndrome might refuse consent for the life saving operation of relief of jejunal atresia. This would not be denied to a baby without Down's syndrome and if the parents refuse in the face of repeated discussion then the support of the Courts is usually obtained.

A further difficult question concerns when a child is judged mature enough to exercise autonomous judgement. In the United Kingdom the legal age of consent to medical treatment is said to be sixteen years but the courts have recognised that younger people may take autonomous and confidential decisions about their lives, provided the doctor that they consult judges them competent to do so.

Beneficence and non-maleficence

Here we are affirming that we should always treat patients with regard to their best interests and not practice in anyway that would harm them. Although we may reflect on whether a third party such as a parent or doctor can be the judge of the best interests of the individual (even an incompetent one such as a newborn baby) for most of paediatric practice we assume that the parents and physician will agree on what the child's best interests are and pursue them. This view has been challenged, especially by older handicapped people who suggest that when paediatricians and parents agree that medical treatment be discontinued or altered because of the low quality of life expected for the child it is difficult to be sure that their own interests are truly separate from those of the child who might well prefer to be alive despite profound disability.

Truth

It is an axiom of good paediatric practice to take parents into the physician's confidence and be frank about what one is doing and what one is trying to achieve. The truth may be complex and difficult to absorb by anxious and defensive parents and the doctors duty is to develop a measured consultation perhaps over several days so that the parents are given a truthful account of the child's condition and management at a rate which allows them to understand, reflect upon and discuss each detail.

Justice

This principle means that we should not deny treatment to children on purely arbitrary grounds — that their parents come from a low social-economic group, a certain ethnic background and so forth. Furthermore once treatment is developed and moves from the experimental into clinical practice then it should be available to all patients in the population. This is particularly sensitive because it raised important questions about resource allocation and the means by which those allocations are made. Furthermore satisfying this principle of justice may offend other ethical principles in other patients — such as

beneficence. Giving a single child an expensive treatment might harm the interests of many other children who have conditions amenable to cheaper treatment.

Difficult ethical questions for paediatricians

I will consider four: euthanasia, consent, resource allocation and research.

Euthanasia

Strictly speaking this means a gentle, easy death and none of us would wish to deny this to our loved ones nor ourselves. However in popular understanding it has come to mean the deliberate medical killing of patients. Some would see this as a rather narrow definition and would include within it withdrawal of medical treatment in the case of a hopeless prognosis; the decision not to start medical treatment in the face of a hopeless prognosis or the use of symptom relieving measures which risk shortening life. These questions have been discussed in much more detail in the British Medical Association working party publication *Euthanasia*. In general the medical profession would regard the medical killing of patients as unethical and in the UK it is illegal — as is aiding and abetting of suicide. However the profession has to face a generous measure of popular support (judged by the results of opinion polls) for euthanasia or mercy killing. Whether the questions have been framed in such a way (or whether public education is sufficiently sophisticated) to make those polled realise the implications of their decision I do not know. However despite the continuing opposition of the medical establishment and the churches in Britain I do not think it long before the question receives further consideration. Although it could be argued that the performance of euthanasia is the ultimate recognition of the patient's autonomy it is currently felt that the autonomy of the medical profession and society overrides the wishes of the individual and that the profession and society would be demeaned if it became a legal way of death. I am, of course, aware that euthanasia is undertaken in Holland but also sceptical about how widely practices which are acceptable to one nation are to others.

Few paediatricians would regard (as unethical in children) the withdrawal of medical treatment or a decision not to start it because of its futility and in the face of a fatal prognosis. Of course this would only happen after detailed discussion with parents and child and with consent of all concerned. The use of symptom relieving

measures, particularly to alleviate pain, is humane medical practice and those practising terminal care in children have developed quite sophisticated means of symptomatic management of that most important phase of a child's life, its dying and death.

Consent

It has been said that all medical ethics boils down to questions of consent and the degree to which this, can be or will ever be informed. With a better educated public having high expectations it is understandable that physicians caring for children can expect a greater degree of scrutiny and questioning by parents than was the case twenty years ago. This is to be welcomed but it carries a penalty for the parents in that they have to now share in medical uncertainty which was not communicated in the "bad old days". Occasionally this may limit autonomy and undermine best interests as, for example, when parents become fearful about extremely rare side effects of a drug or operation and deny them to the child to whom they would undoubtedly be of benefit. I have no ready solution to this other than recommended by Spence — good doctor/patient relationships and honesty. All of us have met circumstances where the parents' right to give or withhold consent has been overridden — for instances of cases of emergency blood transfusion for children whose parents' beliefs prohibit such measures. The wise paediatrician always tries to keep the parents on their side, using nursing, social work, family doctor and clerical colleagues. If all else fails then in an emergency the responsibility is his or hers and it is likely that the Courts would support measures taken in an emergency to save life. Where events are less pressing then the guidance of the courts should be sought to judge between the various competing interests. It is a paediatricians' ethical duty in these circumstances to provide accurate and dispassionate evidence to help the court, however emotional he or she may feel in the case.

Recent developments have raised new questions concerning the ethics of consent. I have in mind treatments like growth hormone for short normal children. The treatment is expensive, demanding (daily or nearly-daily injections) and the long term side effects unknown. Short stature is not a life limiting condition. However members of society who are short have written and spoken eloquently about their disability and would probably regard it as further the best interests of a short child for it to receive growth promoting therapy — described by sceptics as cosmetic medicine. Questions of the child's consent are

not always raised and, even if so how informed and unfettered the consent of, say, a short ten year old boy might be. This is one of the conditions where in the United Kingdom a strong self-help patients group has emerged championing the cause of identifying and treating poor growth and short stature and there are many others. These lay groups represent a new constituency in the medical establishment. In earlier times medical progress and resources required it was dictated by the weight of medical (and particularly consultant medical) opinions. Not only have other medical groups (nurses, psychologists, social workers) claimed a voice in what would be regarded as traditional medical decision-making but the patient's voice is now heard louder. How much weight the collective patient voice, articulated by a single pressure group, should be given is one of the unanswered ethical questions of the 1990s. There is no doubt that some pressure groups are far more effective and eloquent than others but does this reflect the relative strength of their cases? These are particularly important questions when resources are limited.

Resource allocation

Although, thankfully, much of the treatment of children is relatively cheap requiring only a skilled and sympathetic doctor, there are rare children who have major illness requiring expensive treatment. I have in mind such medications such as surfactant therapy, erythropoietin, human growth hormone and anti-cancer agents. There are also the expensive technologies such as intensive care of the newborn and other child, including such techniques as extra-corporal membrane oxygenation and the organ replacement therapies. As I have hinted earlier the group that decides on priorities is much wider than hitherto and is not confined to the medical consultant. Society is demanding to have its voice heard either directly as a consumer or patient or indirectly through politicians, health service managers and medical insurance companies. However the individual doctor's responsibility is to his individual patient to obtain the best possible treatment hence enhancing the patients autonomy and acting in his best interests. If those interests are overridden because of shortage of resources then it is the doctor's duty to press as hard as he can to obtain them and if fails to be frank with the patient and relatives about why the best treatment is not being given. Patients in the past were denied scarce medical treatment but were not told so: rather it was suggested that their illness made such treatments unsuitable.

Research in paediatrics

Major questions of autonomy, beneficence and consent arise in trying to balance the absolute view that children should not be the subject of medical research (because nothing should be done to a child who cannot consent to interventions which are not in its interests) with the utilitarian view which is that no progress will be made in paediatrics without good scientific research and that the individual child and its parents owe society the obligation of participating in the advancement of knowledge. Practical paediatric scientists chose a path between two extremes, the first of which recognises the claims of a child not to be taken advantage of or have its interests hurt and the second which is the dubious ethics of allowing children to be treated by methods that have not been adequately researched. Research in children has been addressed by research committees and professional associations — in the United Kingdom the British Paediatric Association. In general therapeutic research is acceptable, with the consent of child and parents — indeed some would argue that for rare conditions it is unethical for a child to be treated out with a research protocol.

Non-therapeutic research should be limited to minimally invasive procedures such as blood taking.

Understanding and consent remains a major challenge: in undertaking research with the newly born does one try and obtain consent from parents adjusting to their new status and to perhaps the birth of a sick baby or does one obtain blanket consent during the antenatal period? Paediatrician researchers on large populations are likely to have to take consumer/parents/childs views into consideration, when for example, undertaking experimental screening programmes when only half the population is screened for a certain condition, such as for cystic fibrosis. The general public has not always welcomed the news that it has involuntarily been the subject of a clinical trial — I have in mind the reactions to trials of treatment of breast cancer — and it is likely that some means will have to be found of sampling public opinion before such trials are undertaken. This raises the inevitable questions about how representative that public opinion is and whether the familiar so called paternalism of the doctor has been substituted with the paternalism of a committee.

Ethics Committees and Ethicists

"The custom of physicians making decisions about life and death in private with relatives is becoming an anachronism"

"Hospital ethics committees are increasingly becoming a part of decision making involving life support in critical ill patients"

These two quotations appeared in an edition of the *Journal of the American Medical Association* in 1985. In the United Kingdom paediatricians would, along with colleagues in other specialties, reserve the responsibility and privilege of decision making about extremely difficult and delicate matters between those who share the ultimate responsibilities — the patient or relatives and the physician. However the circumstances often involve care from many other professions and the wise paediatrician will satisfy himself that all their colleagues feel that they have made a contribution. Again I am thinking about the nurses, social worker, chaplain attending a neonatal intensive care unit. However this consultative opinion-forming exercise — which should avoid becoming a cosy and collusive conspiracy against the child and/or parent — is a long way from formal committees and most paediatricians would resist their development. Research ethics committees appear to play a useful part in decision making in that limited field — although critics have expressed their reservations about them — and in the United Kingdom there seems no strong case for widening their brief to look at ethical aspects of medical practice. Some countries have formed national bioethics committees to examine medical developments, both in technology and practice such as in reproductive medicine. However their performance is variable and although they may appear to be widening the social base of medical decision-making it may again be substitution of paternalism with the distinct disadvantage that a committee is not bound by the same ethical rubric as the individual physician. A national research ethics committee does seem an attractive proposition particularly for multi-centre projects which may falter on the whims of individual local committees.

In 1965 another British medical hero, Sir Theodore Fox, formerly editor of the *Lancet* wrote:

"Do we then need some kind of specialist to advise on these difficult decisions — a specialist

perhaps with such mental degree in moral philosophy? Heaven forbid!"

Ethics should not be seen as a medical specialty in its own right. It is part of warp and weft of all medical practice including individual patients and populations and curative, preventive and even complimentary medicine. Some doctors may read more deeply in the subject and their interest in it becomes known to their colleagues who may consult them about certain difficult problems. This informal process is part of the healthy medical tradition. I side with Fox in resisting any further specialist differentiation and personal claims to be a medical ethicist should be examined with care. Furthermore I think that doctors should play a major part in the teaching of medical ethics to undergraduates; contributions from philosophers and lawyers are welcome, particularly giving the theoretical background. However the interweaving of ethical considerations of the very many medical problems that confront students is for the profession, and more importantly, for the clinician in charge of the case to discuss. Medical students have complained that their teaching in ethics is lacking; others have suggested that this is because such students lack the sophistication to recognise the ethical dimension in any medical consultation.

Conclusion

This brings us back to Sir James Spence, the medical consultation and the doctor/patient relationship. In every such encounter there is an ethical component — usually trivial and dealt with by reflex action and that is the point which we need to impress on our medical students. For paediatricians there is a wider aspect because of their practice not only with children but with their parents. Usually the interests of child and family will coincide but not always and in these circumstances the paediatrician must remember that he is the child's physician. When the going is tough he must always remember to practice according to the motto of that most famous Hospital for Sick Children, Great Ormond Street, London — "The Child First and Always."