

## REVIEW

## Ethics support in clinical practice

A R Watson

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Ethical considerations have long been a part of clinical decision making. However, just as doctors and healthcare professionals are being increasingly challenged about the evidence base for their practice, there is increasing focus on the ethical dimension of clinical care.<sup>1</sup>

It may seem simple to apply principles such as those of Beauchamp and Childress<sup>2</sup> (respect for patient autonomy, beneficence, non-maleficence, and justice) to analyse the ethical dimension of clinical problems, but there is increasing pressure for ethical reasoning to be more transparent for patients, families, and society. This is due in part to:

- The general shift from paternalism (knowing what is the best for the patient) to a greater respect for patient autonomy (do nothing to me without my consent). There is increasing recognition that children of all ages should receive age appropriate information and that the individual child's competency be assessed
- High profile clinical incidents in the UK such as the report of the Bristol (heart) and Alder Hey (organ retention) enquiries have increased the media and public scrutiny of the activity of health professionals and hospital management staff who need to be able to justify practice in ethical, as well as clinical, terms<sup>3</sup>
- Advances in intensive and critical care, organ transplantation, and reproductive technologies have created new ethical dilemmas in both maintaining and creating life.

There have also been a number of significant developments in the law relating to ethical issues in medicine. These have included the Children Act, the Human Fertilisation and Embryology Act, the Human Rights Act (1998), and others in the pipeline such as the Human Tissue and Mental Capacity Bills.

Guidelines have been produced by the General Medical Council, British Medical Association, and Department of Health on issues such as confidentiality, withholding and withdrawing life prolonging treatment, and consent.<sup>4–7</sup> The Royal College of Paediatrics and Child Health publication on withholding or withdrawing life sustaining treatment in children has been recently revised.<sup>8</sup> Legal advice and guidelines have further increased the pressure on clinicians to not only “do the right thing” but also to do this to avoid medico-legal consequences.

However, even current guidelines on withholding and withdrawing life prolonging

treatment are being challenged in the courts.<sup>9</sup> The UK media has recently been dominated by High Court cases involving a profoundly brain damaged 11 month old baby, and another with Edward's syndrome, where the parents disagreed with the clinical opinion that further invasive treatments, such as ventilation, were not in the children's best interests.<sup>10</sup>

The purpose of this review is to briefly examine the sources of ethical advice available to clinicians and the increasing role of clinical ethics committees in providing ethics support and advice.

### SOURCES OF ETHICS SUPPORT

Traditionally, clinicians have sought support from colleagues and senior members of the profession in a “seek the wisdom of others” manner. Since modern medicine is largely practised in a multiprofessional setting, decisions are often arrived at after discussion at team meetings or conferences.

However, although clinical ethics now features on the medical school curriculum a recent large survey of specialist registrars (in predominantly adult specialties) found that one third reported no training in clinical ethics and the majority felt they lacked the skills to address ethical issues arising in clinical practice.<sup>11</sup> When 52 new house officers were asked to rate their overall knowledge of clinical ethics on a five point scale (poor–excellent), their score was 2.6 (SD 0.68) which was similar to the 2.5 (SD 0.8) rating for confidence in addressing ethical issues.<sup>12</sup>

Since these junior doctors will become the clinical leaders of tomorrow, this apparent lack of training, along with reduced clinical exposure due to the European Working time directive and loss of the “firm” structure, may well lead to increased requirements for clinical ethics support.

### CAN ADVICE BE PROVIDED BY A CLINICAL ETHICIST?

Although there are many university based academics working on ethics issues, very few are directly involved with clinical practice outside of involvement with clinical ethics committees. The clinical ethicist at the Oxford Radcliffe Hospitals Trust has an educational and supportive role as well as providing some input into cases and the development of policies.<sup>13</sup>

Interestingly, the specialist registrar survey conducted by the Royal College of Physicians showed that 23% of responders were in favour of clinical ethics support from an *individual* with a specialist interest in ethics. This suggests that there may be an increasing role for a clinician with a particular interest in medical ethics

Correspondence to:  
Dr A R Watson, Children &  
Young People's Kidney  
Unit, Nottingham City  
Hospital NHS Trust,  
Hucknall Road,  
Nottingham NG5 1PB, UK;  
jhayes1@ncht.trent.nhs.uk

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playing a lead role within the hospital or group of hospitals as part of their official job description. This has already been recognised by a recent appointment at one major paediatric teaching hospital. The role in other trusts may be provided on an unofficial level by the chairman of the clinical ethics committee.

### EXTERNAL SOURCES OF ADVICE

- The British Medical Association Ethics Unit responds to an increasing volume of ethical/legal queries per year both directly and via the website ([www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)). Its book *Medical ethics today* was printed in 2004 and is twice the size of the first volume published in 1993.<sup>14</sup> It is interesting to note that in response to a high volume of demand, guidance notes have been produced on child protection, treating unaccompanied minors, and consent rights and choices in health care for children and young people.
- The Medical Defence Union advises on a range of issues which reflect the greater ethical and legal complexity in the day-to-day clinical work of doctors. Advice on legal aspects can be provided by the hospital legal department, but many clinical dilemmas are not “black and white” and uncertainty requires debate.
- Most Royal Colleges have an ethics advisory group which is responsible for advice and policies and arranging forums for discussion such as at the Royal College of Paediatrics and Child Health annual meeting. Withdrawal of life sustaining treatment in appropriate circumstances is not seen by the courts as active killing, and guidelines are helpful.<sup>8 15</sup> However, the debate about euthanasia continues, with considerable variations in practice in neonatal intensive care units throughout Europe.<sup>16</sup>
- The General Medical Council of the UK has also produced guidance on withholding and withdrawing treatment in patients. However, this guidance has recently been challenged by the Burke judgement, and clinicians may have to resort to the courts for decisions about withholding or withdrawing treatment when it has not been achieved by consensus between health professionals and any person with a reasonable claim to an interest in the patient’s welfare.<sup>9</sup>
- The Nuffield Council of Bioethics has recently set up a working party to examine issues around prolonging life in fetuses and newborn babies.

### CLINICAL ETHICS COMMITTEES

The development of clinical ethics committees (CECs) in the United States was largely driven by the courts, following the Karen Ann Quinlan case and by a major President’s commission, so that by 1987, 60% of all American hospitals either had a CEC or a form of clinical consultation service.<sup>17-19</sup> In 1992 the Joint Committee on the Accreditation of Healthcare Organisations has made it a mandatory requirement for accreditation that hospitals have in place a mechanism for addressing ethical issues on patient care.<sup>20</sup> Although there is almost universal provision for ethics consultation in American hospitals, there is much less provision in Europe where there is often a mixing of clinical and research ethics functions.<sup>21</sup>

Clinical ethics committees began to emerge in the UK in the 1990s, driven by clinical need rather than the top down approach in the USA.<sup>22-25</sup> In 2000 a survey funded by the Nuffield Trust and carried out by the Ethox Centre in Oxford identified 20 NHS Trusts with formally established CECs.<sup>21</sup> By July 2004 that number had grown to 68 (four in children’s hospitals) and a National UK Clinical Ethics Network had

been established, providing web based links and information ([www.ethics-network.org.uk](http://www.ethics-network.org.uk)). The original survey for the Nuffield Report showed significant variation in the way that ethics support was provided in hospital trusts. Some had a formal CEC and others a less formal clinical ethics forum or discussion group independent of the Trust management structure. The report also focused largely on secondary care institutions and did not include primary care where ethical dilemmas are just as likely to arise.

### WHAT FUNCTIONS DO CLINICAL ETHICS COMMITTEES PERFORM?

CECs have a PEP role: Policy and guidelines, Education, and Patient consultation:

- Policy and guidelines: a CEC can provide ethics input into policies being initiated by the Trust or externally by the Department of Health, such as Do Not Resuscitate policies. The experience of case discussions at the CEC can suggest the development of policies and guidelines from an ethical dimension, for example, Advance Directives. It may also be appropriate to review existing policies from an ethical perspective, for example, Disposal of Foetal Remains or Consent to Treatment.
- Education: the indications are that doctors and members of the multiprofessional team would like further education or training in clinical ethics. This can be done by members of the CEC being present at formal medical Grand Rounds, organising specific Grand Rounds or an open ethics forum on ethical issues, or by providing support to particular groups with high ethical demands, for example, genetics, intensive care, neonatal care. Publication of minutes from the CEC on the hospital intranet site can also provide a teaching resource as well as reminding staff of current guidelines with ethics booklets and staff induction material. Time and enthusiasm are the major constraints for this “non-paid” work.
- Patient consultation: clinicians may be suspicious that a CEC will be involved in proxy decision making relating to their clinical activity. However, CECs see themselves as a multidisciplinary forum for discussion of ethical issues involved in difficult cases in a way that is advisory and supportive, rather than directive. Most cases are brought to the CEC by the clinician in the “cold light of dawn” to reflect on the ethical issues and course of action (box 1).

However, some CECs offer a *rapid response service* to deal with acute ethical dilemmas. Such advice may be provided by the chairperson and/or a quorate of members. Anecdotally the CEC chairperson or deputy often provides telephone or corridor consultation about patient problems with the suggestion that at a later date the case may be brought to the CEC for fuller discussion. Potentially, the CEC chairperson could assume the role of a “clinical ethicist” in the hospital setting, but this brings with it issues of training, responsibility, and time constraints.

CECs have an increasing role in organisational ethics since distributive justice is one of the key ethical principles. Since no health system in the world has unlimited monies it is inevitable that resource allocation issues, guidelines on eligibility for treatment, and the management of waiting lists have their own clinical and ethical dilemmas. CECs usually have a significant representation of members from outside the hospital and medical profession who can provide a very useful perspective for clinical staff who wish to debate these issues. Committee members should represent the values and principles that define the hospital as a humanitarian community and ensure it remains aware of its moral rather than commercial responsibilities.

### Box 1: Selected "paediatric" issues discussed at Ethics of Clinical Practice Committee, Nottingham

- Withdrawal of treatment in neonate with family opposition
- Ethical disposal of fetal remains
- Parental pressure for children to have operations
- Ethical dilemma in a neonate with megacystis, megacolon
- Can children and young people consent to be tested for adult onset genetic disorders?
- Preimplantation genetic diagnosis
- Ethical and research dilemmas for fertility preservation for children treated for cancer
- Two antenatal dilemmas
- Testing of an infant of a patient with adult onset muscular dystrophy
- The use of an unlicensed drug in a young child
- Withholding of renal replacement therapy in a handicapped child
- Paediatric cochlear implant programme
- An ethical dilemma for proposed new treatment in a child
- Extent of resuscitation for hydrancephalic infant

### FORMATION OF A CLINICAL ETHICS COMMITTEE

There is no formally agreed prescription and a practical guide has recently been produced.<sup>26</sup> CEC membership may vary from 6 to 26 members.<sup>26</sup> The Ethics of Clinical Practice Committee in Nottingham started with 10 members in 1994,<sup>25</sup> but increased its size in 1999 to 24, to represent two major hospital trusts and primary care. Its current composition of 20 members is shown in table 1. An average of 12 members attend each meeting.

The "learning curve" experience of CECs to date would suggest that for the committee to be successful it requires:

- A chairman who is keen and enthusiastic. The chairman does not have to be a clinician, but a clinical lead does help to allay after clinicians anxieties that this is not yet another management committee threatening professional autonomy. A clinician is also likely to cajole medical staff into bringing their ethical dilemmas for reflection to the committee.
- Attempts should be made to balance the membership of the committee between clinical and non-clinical members. A legal representative or access to legal advice

### Box 2: Ethical decision-making; guidelines for practice

- Always act in the child's best interest
- Assemble all the available evidence
- Discuss the issues with all relevant family members
- Check out second-hand or hearsay information
- Respect the opinions of everyone on the team
- Seek the wisdom of others
- Do not be afraid to ask for second opinions
- Attempt a consensus whenever possible
- Consider consulting a clinical ethics committee if lack of consensus

is essential. The selection of "lay members" has been approached by some committees by local advertising and interview. Competencies, requisite skills, knowledge, and attitudes to be a member of a CEC are only now being addressed.<sup>27</sup> Members should be committed to serving on the CEC for at least 2–3 years in order to build up the committee expertise and "ethical memory".

- Education and training of committee members should be considered. At least some committee members who are recruited or volunteer should have graduate degrees or training in ethics, and other members who are interested should avail themselves of the training workshops, meetings and courses ([www.ethics-network.org.uk](http://www.ethics-network.org.uk)).
- The standing of the CEC within the Trust structure needs to be clarified so that the CEC is not seen as another tool of management but retains a high degree of independence. The CEC should be accessible to all healthcare professionals.
- Funding and administration are key issues to the success of the CEC. At present, CEC membership is unpaid work and meetings are usually monthly for 1½–2 hours with additional preparation and training time. It is essential that adequate secretarial time is available and reimbursed, as well as monies being available for the education of committee members.
- The CEC needs to be sensitive to, and aware of, a local population's beliefs, languages, and practices. This may be achieved by representation from ethnic groups on the CEC or by inviting representatives from other groups when a relevant issue is being discussed. Most CECs have a representative from the chaplaincy or "multifaith" centre with access to the appropriate faith representative if a particular issue arises.

**Table 1** Present composition of the Nottingham Ethics of Clinical Practice Committee

Hospital based	Community based
Consultant Geriatrician (Chairman)	Professor of Sociology
Consultant Paediatric Nephrologist	General Practitioner
Consultant Urology	General Practitioner (retired)
Consultant Intensivist	Director of Public Health, Primary Care Trust
Consultant in Clinical Genetics	Head of Clinical Governance, Primary Care Trust
Consultant Respiratory Physician	Solicitor
Matron, Children's Medicine	Two members of Nottingham Community Health Council
Nurse Consultant, Renal Unit	Psychologist, Learning Disability Service
Lecturer (Honorary SpR) in Healthcare of the Elderly	
Hospital Chaplain (Multifaith Centre)	
Resuscitation Officer (Nurse)	

- Trusts have indemnified CEC members for their work on the committee. The legal standing of CECs has not been clarified, but since the advice given is supportive and discussive rather than directive, it still remains the clinician's responsibility to act appropriately with or without the CEC's discussion being recorded in the patient's notes.
- Many committees are now experiencing patients/carers wishing to put their own case before the committee. This development respects patient autonomy, and in paediatrics the duty of parents to act in the best interests of the child by seeking extra advice outside the immediate healthcare team. It could be seen as an important opportunity to achieve consensus viewpoint when doctors and carers are in disagreement about the best interests of a patient (box 2).<sup>28</sup>
- Discussion of such cases enables the clinical team to "think outside the box" of their own clinical situation and may provide a route for conciliation and mediation which may be beneficial to all parties involved in the ethical dilemma as well as avoiding the need for recourse to costly court procedures.

Competing interests: ARW is Chair of the UK Clinical Ethics Network Committee

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