

Paediatrics at the cutting edge: do we need clinical ethics committees?

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Abstract

Objectives – *To investigate the need for hospital clinical ethics committees by studying the frequency with which ethical dilemmas arose, the perceived adequacy of the process of their resolution, and the teaching and training of staff in medical ethics.*

Design – *Interviews with individuals and three multidisciplinary teams; questionnaire to randomly selected individuals.*

Setting – *Two major London children's hospitals.*

Results – *Ethical dilemmas arose frequently but were resolved in a relatively unstructured fashion. Ethical concerns included: the validity of consent for investigations and treatment; lack of children's involvement in consent; initiation of heroic or futile treatments; resource allocation. Staff expressed the need for a forum which would provide consultation on ethical issues, develop guidelines for good ethical practice, undertake teaching and training, and provide ethical reflection outside the acute clinical setting.*

Conclusion – *Multidisciplinary, accountable and audited clinical ethics committees with predominantly advisory, practice development and educational roles could provide a valuable contribution to UK clinical practice and perhaps in other countries that have not developed hospital clinical ethics committees.*

Introduction

Contemporary paediatric practice increasingly poses ethical dilemmas for all members of the multidisciplinary team, irrespective of their seniority. These include:

- (a) whether treatment should be started, discontinued or withheld^{1 2};
- (b) whether children can consent to or refuse treatment^{3 4};
- (c) the allocation of scarce resources⁵;
- (d) in what circumstances confidentiality should be breached.

Key words

Clinical ethics committees; paediatric practice.

The ethical permissibility of experimental investigations or treatment, for example covert video surveillance, multiple organ transplants and xenografting have also been the subject of controversy between professionals and the focus of media interest.⁶

Despite a growing interest in health care ethics in the UK, there is no clear view as to how individual provider units might attempt to resolve ethical dilemmas which they face. In the USA and elsewhere some units have established institutional or clinical ethics committees (CECs) whose function has mainly been to provide a forum for ethical debate, analysis and evaluation, for both topics and cases.⁷⁻⁹ Although over two-thirds of US paediatric units have CECs no purely child-focused CECs exist in the UK, despite the specialised problems posed by paediatric practice. The function of a UK ethics committee has recently been described¹⁰ but we are aware of no prospective studies which might indicate the need for CECs in the UK.

To address this question the Great Ormond Street Hospital for Children NHS Trust set up a working party, whose terms of reference were:

- (a) to determine the nature of ethical dilemmas and the frequency with which they arose;
- (b) to examine the nature and adequacy of methods for dealing with them;
- (c) to determine what teaching and training staff received;
- (d) to explore what relationships might exist with the established research ethics committee (REC).

This paper describes the methods adopted by the working party to obtain information, its findings and recommendations.

Methods

Information was obtained using three forms of investigation:

- 1) Discussions concerning the nature and frequency of ethical issues were held with a wide range of health care workers of all degrees of seniority.

Responses were used to determine the content of the questionnaire.

2) A questionnaire comprising 44 questions and opportunity for comment was administered to 60 randomly selected staff from all disciplines, irrespective of seniority. The stem of the question (see example) identified a particular issue and the four-part response (scored 1-4) gave information concerning the frequency with which such issues arose. Average scores of greater than two were felt to reflect ethical concerns.

3) Semi-structured interviews were held with members of multidisciplinary teams from three units (one general medical, one specialist medical and one surgical). The purpose of the interviews was to explore questions raised by the terms of reference of the working party.

Clinical ethics questionnaire – sample question

Stem

How often do you think that adequate information about proposed investigations is given to parents?

Response and Score

usually/often/occasionally/ rarely

1 2 3 4

Scores of >2 reflect ethical concerns.

Results

A – THE NATURE AND FREQUENCY OF ETHICAL DILEMMAS

1. General comments

We found that ethical dilemmas arose frequently in clinical practice, irrespective of the type of unit or its degree of specialisation. There was general interest in ethical issues and enthusiasm for the establishment of a forum for ethical debate, analysis and guidance. Preference was expressed for such a forum to be both multidisciplinary and non-hierarchical. Many expressed an interest in active participation and a wish for education in this area.

Specific concerns which arose during discussion were broadly those which emerged from response to the questionnaire (see below).

Some interviewees expressed concern that an ethics committee might impose a further bureaucratic level upon already difficult treatment decisions. Fears were expressed that clinical ethics committees might produce erosion of clinical freedom, undermining of the clinician's role, and an adverse effect on the doctor-patient relationship. There were also concerns at the extra time which might be involved if clinical ethics committee consultation was mandatory and the ensuing effect on service provision.

2. Response to the questionnaire

The overall response rate was 60%. Responses to 20

of 44 questions gave scores (>2) indicating ethical concerns, with three questions scoring >2.5. The specific concerns identified were:

(i) The adequacy of information given (especially concerning investigations and medical as opposed to surgical treatments) and the adequacy of both parents' and children's understanding of the nature and purpose of all types of investigations and treatment. Constraints of both time and space were felt to exert pressure on children and parents to consent, which raised questions about the truly voluntary nature of the consent. A number of respondents specifically commented on the difficulties of obtaining truly informed consent from ethnic minority families whose understanding of English was poor.

(ii) Lack of involvement of children in obtaining consent and the infrequency with which the child's views were expressed or considered in treatment decisions.

(iii) The initiation of treatments which were distressing, heroic, experimental or futile and their continuation even in the face of a poor prognosis. As a corollary, the tendency for families not to be offered, routinely and sensitively, terminal care as an alternative.

(iv) Some respondents felt that it was appropriate that psycho-social factors should determine whether or not treatment was given.

(v) The majority of those questioned would agree, if so requested by child or parent, to keep secret information which might otherwise alter the child's treatment.

(vi) Difficulties in deciding how competing claims for scarce resources might fairly be decided.

B – THE METHODS FOR DEALING WITH ETHICAL ISSUES AND THEIR PERCEIVED ADEQUACY

The main multidisciplinary forum for discussion of ethical issues and dilemmas was the unit or psycho-social meeting, although occasionally ethical aspects of particular cases were discussed at regular hospital clinical presentations (grand rounds). Such discussions were criticised as being *ad hoc*, unstructured and constrained by time. Individual members of multidisciplinary teams tended to discuss issues within their own discipline and often with their peers, rather than senior or juniors. There was a general view that this was unsatisfactory, since it left tensions within teams and issues unresolved. Many felt that more public discussions of ethical issues away from acute clinical settings was desirable and could be achieved by a forum which would also have consultative, educational and policy-generating functions.

A view was strongly expressed that such a body should not try to decide individual cases and should not erode or threaten clinical freedom or integrity. The forum should be open to all who sought its advice.

C – TEACHING AND TRAINING CONSIDERATIONS

Nursing staff had received formal regular training in the theory of health care ethics at pre- and post-diploma levels (post-registration students receive 30 hours' teaching per annum); ongoing ethics teaching and training was provided in professional development courses. Although doctors should now have received training in health care ethics as undergraduates, not all currently employed medical staff had done so. Arrangements for postgraduate medical training were restricted and unstructured compared with those for nurses. However, many clinically-based postgraduate courses which were available to medical staff did have an ethics component.

D – RELATIONSHIP WITH THE RESEARCH ETHICS COMMITTEE (REC)

Many respondents and interviewees drew a distinction between research into ethical issues involving the disciplines of moral philosophy and the law, and the ethical basis of research which was the proper concern of local research ethics committees (LRECs). It was acknowledged that in some areas, for example the introduction of experimental or innovative treatments, there could be overlap between the areas of interest of both clinical and research ethics committees. Members of many LRECs do receive proleptic training and it was felt that this was an appropriate model for any clinical ethics group. The composition of LRECs, which include medical, nursing and lay members, was thought to be appropriate for clinical ethics groups, but it was felt that there should also be social work, chaplaincy, and perhaps legal representation.

Discussion

We found that ethical dilemmas arose frequently in clinical practice irrespective of the degree of seniority or specialisation of the staff involved. It was perhaps not surprising that responses to almost half the questions in the questionnaire reflected ethical concerns and that the mechanism for addressing them was considered *ad hoc*, unstructured and neither multidisciplinary nor non-hierarchical. However, there was considerable interest in health care ethics as evidenced by support for an ethics forum. Four desirable functions were identified; (a) consultation, but not prescription, on ethical issues including those which were case-related; (b) participation in development of guidelines for good clinical practice (c) education and (d) reflection on ethical issues away from the acute clinical setting.

In the USA these functions have been fulfilled by clinical ethics committees (CECs),⁷⁻⁹ which have been an established feature for over a decade. The percentage of US hospitals having CECs rose from 3% in 1982 to over 50% by 1985.⁷ In contrast establishment of CECs in the UK and Europe has been slow¹⁰

though a number now exist or are in the process of formation. An initial important driving force behind the formation of US ethics committees was the need for a mechanism to help resolve difficult ethical issues in specific cases, for example, withdrawal of treatment for patients with persistent vegetative state.¹¹ This role was supported by the President's Commission¹² and is one in which the greatest experience has been accumulated, enabling the identification of both advantages and disadvantages of CECs.¹³⁻¹⁴

We need to examine whether this experience, as applied to the four functions our study identified, supports the need for an ethics committee and if so, how it might operate to maximise advantage and minimise disadvantage.

a – To offer consultation but not prescription on ethical issues

This function clearly includes identification and analysis of ethical issues arising in individual cases, as is the case in US committees⁹ and in a recently described UK one.¹⁰

The benefits claimed for this approach include:

- (i) satisfying the request of health care professionals and public for guidance on ethical matters and helping resolve disputes within the multidisciplinary team.
- (ii) ensuring the relevant information has been obtained, imparted and understood by decision-makers, hence facilitating communication between professionals and families.
- (iii) separating ethical from technical issues.
- (iv) providing support for both staff and families, especially by formally acknowledging the complexity of the ethical issues faced.
- (v) advising when it seems that legal intervention might be necessary to resolve a dispute or establish a new principle of law.

This approach would satisfy some of the concerns raised by our study – for example the adequacy of information given and its understanding in relation to treatment decisions. It would be also likely to facilitate delivery of health care sensitive to the needs of children and their families.

However, the US experience has identified important pitfalls associated with case consultation, which should be appreciated and avoided if CECs are to safeguard clients' freedom of choice and avoid seeking to impose solutions by a further bureaucratic process. Clinical ethics committees should avoid (i) reaching a consensus too readily, (ii) accepting secondhand or hearsay information and (iii) overlooking innovative ways of settling disputes by allowing sufficient time for information to be gathered and expertise to be sought.¹⁴ They need to consult widely, have few restrictions on access and be consultative rather than prescriptive.¹⁵

The obligation to consult a committee in specific cases, for example discontinuation of life-sustaining treatment, has been disputed. Some have advocated mandatory consultation but optional implementation and this is implicit in guidelines from both the American Medical Association¹³ and the President's Commission.¹² However, most CECs adopt an optional/optional policy in that consultation is voluntary and decisions are non-binding.⁷ The latter maximises the educational function of CECs and is likely to have most acceptance in the UK.

A view is emerging from US practice that the case consultation function of a CEC is best fulfilled by a small group of individuals who are able to devote sufficient time to confidential analysis and evaluation. Employment of either a specific ethical consultant (the "grand master" approach) or a large committee approach (the "grand round" approach) introduces potential for bias and narrow perspectives on complex ethical situations.⁹ Such experience as exists in the UK indicates that a purely case consultative committee might, at present, have very little active function.¹⁰

However, the functional requirements we have discussed are not unique to case review ethics and we might expect that a CEC, in fulfilling a prospective analytical function on wider issues, would call on whatever expertise might be appropriate in order to provide an informed, reasonable and justifiable opinion.

b – To participate in development of guidelines for good ethical practice

Retrospective review of decisions in cases that have aroused ethical controversy enables the appropriateness of those decisions to be reviewed, with the hope that future cases may be better handled. An important consequence of this "moral audit" is the contribution that CECs may make to the development of integrated standards and guidelines, directed at enhancing good ethical practice and improving patient care. These include specific hospital ethics guidelines and others in which there is a significant ethical impact. Examples include Do Not Resuscitate (DNR) orders and consent and withdrawal of treatment guidelines. We would argue that the US experience with case consultative committees suggests that policy development and evaluation may be the most important role of future CECs. Although one outcome is likely to be the reduction of future conflict and controversy there will also be educational consequences, which we now consider.

c – To educate health care professionals in health care ethics

In order to fulfil this function it is crucial that members of CECs are themselves trained in ethical and legal analysis in an analogous fashion to those of LRECs by :

- i) becoming more familiar with ethical principles, concepts and theories;
- ii) studying relevant cases, policies and legislation;
- iii) receiving specific training by individuals with appropriate expertise;
- iv) having access to relevant literature.

In this way a core group can be identified who are knowledgeable about medico-legal and ethical issues and are committed to developing their expertise. With increased specialisation in hospital medicine it could be argued that such a group contributes expertise which otherwise might not be available and in itself can institute teaching and training for other members of staff.

d – To permit reflection on ethical matters away from the acute clinic settings

To some extent this is a combination of all the above functions, but with the important proviso that time is available for information-gathering, a proper debate of the issues and reflection. Attention to these details should avoid the pitfalls described by US authors.^{13 14} It would be more important for such a group to be multidisciplinary so as to support the concept of multidisciplinary working and holistic care. With increasing concerns about the inhumane nature of some modern medicine¹⁶ this function would be of considerable value.

All four functions would potentially increase chances of arriving at decisions which are both rationally and ethically sound, and enhance both professional and patient autonomy in partnership, when facing difficult ethical decisions. Much indecision, guilt and frustration which arise in such circumstances could be alleviated, and the possibility of obtaining a truly informed consent – an area of concern in our study – increased.

We believe that potential pitfalls can be avoided by CECs having a clear sense of purpose as expressed in their terms of reference; by being consultative and not prescriptive, and by having a membership which is multidisciplinary and ethically and legally trained. However, they should not try to usurp the role of a court and their primary purpose should not therefore be case decision. In the UK, courts have given clear signals as to the cases with which they wish to be involved and the presence of a lawyer on the CEC for both education and advice would be helpful. Clinical ethics committees are innovative and therefore should be accountable, evaluated and audited.

At a local level few satisfactory alternatives for ethical debate, analysis and policy-making exist. Local research ethics committees have a different remit, are prescriptive and their workload does not permit a dual function. Unit or socio-psychological meetings are multidisciplinary but may fail to provide structure or education, and to avoid bias and

be accountable. Some larger centres do employ ethicists with specific knowledge and training in bioethics and health care law, but, though numbers are increasing there are relatively few such individuals in UK practice. Moreover, this approach may not avoid bias or permit a broad enough perspective on ethical issues.⁹

At a wider level it could be argued that both statute, for example the Children Act 1989 and common law, for example *re B*, *re C*, *re J*¹⁷⁻¹⁹ have a role in deciding such issues as withholding or withdrawing treatment, but the law has been generally reluctant to be involved in issues of public policy or morality. Rather its function has been, as Lee argues,²⁰ to provide for a minimum standard of behaviour. This cannot be the sole solution of moral problems. However, access to legal opinion would be necessary, if only to protect members of CECs from criminal prosecution or civil action. In the US some states have provided immunity from prosecution to members of statutory committees²¹ but the status of a UK committee would be far from clear.

Warnock has argued for a properly constituted national ethics committee, similar to the President's Commission, whose remit would be to examine a wide range of issues arising in both medical practice and research, in response to the public need for candour.²² Although such a group might well have some relationship with local CECs its role would surely be to examine larger issues for which there was no local consensus. An additional function of local CECs could therefore be to submit issues to a national committee. As yet, apart from institutions such as the Nuffield Council for Bioethics, we do not seem to have moved significantly toward the formation of a national group; perhaps establishing local CECs could give the process some impetus.

We would therefore advocate the formation of CECs, with the safeguards that we have outlined. Such groups need to be accountable and accessible; for case analysis at least, patients and proxies should have access. Recommendations made by committees should be the subject of review and audit to determine whether they adequately reflect current ethical and legal guidelines.

Comparison between committees having different modes of functioning would be valuable and instructive. We hope that this paper will stimulate debate on the nature and function of ethics committees in the UK, and indeed internationally.

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