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The development and function of Clinical Ethics Committees (CECs) in the United Kingdom

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Introduction

The expansion of the technological capabilities of modern medicine has been accompanied by the growth of medical ethics as a practical and academic discipline. The reasons for this analysis and debate on what *should* be done as opposed to *implementation* of what is technically possible are clear. Development of new techniques, e.g. assisted reproduction procedures, organ transplantation and improved life support systems offer treatment opportunities but stimulate ethical debate about their application. There are concerns about the appropriate allocation of resources especially in the face of clear inequalities in global health care distribution.

There is also increasing recognition of patients' rights and of the patient's subjective experience of the health care journey: It is accepted that there is a greater need to involve patients as partners in their own health care. In consequence there have been demands for greater candour, transparency and accountability in clinical decision making and that the latter should be based on sound ethical principles.

In the UK there have been widespread public concerns about ethical aspects of medical practice raised by such events as the mortality following paediatric cardiac surgery in Bristol, and the retention of organs from dead children without consent in Liverpool. Government commissioned reports have drawn attention to individual and institutional deficiencies, which have significant ethical and cultural as well as technical connotations. In paediatrics the UK's Children's National Service Framework has focussed attention on the healthcare needs of children, and how their voices may be heard more widely about issues that concern them.

It is hardly surprising that many professionals frequently encounter ethical perplexity or dilemmas despite a plethora of guidelines, recommendations and regulations from professional, regulatory and government bodies. Surveys in the UK have confirmed the frequency with which professionals experience ethical dilemmas and their nature, have examined the mechanisms for dealing with them and have explored the need for education and training.¹

¹ Larcher et al. [1997]; Slowther et al. [2001].

These surveys have formally identified a need, arising from clinicians and others directly involved in patient care, for clinical ethics consultation and support that is both practical and intellectually rigorous.² Such support may be provided by individuals, small groups or even specialist departments of ethics. Clinicians appear to favour a committee approach and have preference for clinically trained ethicists. However, there are relatively few individuals in the UK who provide stand alone ethical support or consultation services. It is possible to argue that such an individualised approach might introduce potential for bias and unduly narrow perspectives in complex ethical situations. Equally there are few, if any, departments of clinical ethics that have been established to serve these essentially clinical needs in the sense that is understood in US hospitals. In some centres academics working in an attached or affiliated university department may provide a clinical ethics service, but alongside their major responsibilities in undergraduate teaching and academic research.

In the UK the most frequent mechanism for providing ethical support has been by Clinical Ethics Committees (CECs), which have arisen mostly in response to local need and interest.³ UK CECs have supportive, educational and consultative functions that are advisory rather than prescriptive or quasi judicial.⁴ Although CECs were first described in the UK in the mid 1990s numbers have increased from 20 in 2000 to a current 85 registered CECs. In 2001 the UK Clinical Ethics Network (UKCEN) was formed to provide CECs with support and advice and to enable them to pool their expertise.⁵

This UK experience contrasts to the “top down” approach to the provision of ethics consultations and support in the USA where health care ethics committees have been in existence for over 30 years. Their development has been driven by recommendations of Courts,⁶ government advisory bodies and hospital accreditation requirements.⁷

The role of avoiding litigation, a feature of American committees⁸ has not yet been one of UK committees.

² Slowther et al. [2001]; Ethics in Practice [2005].

³ Slowther et al. [2001].

⁴ Larcher [1999].

⁵ Slowther et al. [2004a].

⁶ *Re Quinlan* [1976].

⁷ JCAHCO [1996].

⁸ Weiden [1987].

Establishment, composition, management, and accountability of UK CECs

Some groups have tried to avoid the bureaucratic connotations of “committee”, by emphasising that they provide a forum for considered, informed, and reflective discussion that might exist outside formal clinical governance structures. It is not clear whether this situation can be maintained if CECs come to have a more formal role in hospital or institutional practice. Whatever their title, it is important that groups providing ethics support or consultation maintain a confidential, independent advisory, supportive, and non-prescriptive role that permits free discussion of the issues involved. In 2004 practical guidance on the structure, composition and function for both established and developing CECs was published.⁹

This practical guidance strongly recommended that the functions of the group are clearly defined and for this it is necessary to have terms of reference that outline:

- a) the aims of the ethical support to be provided, e.g. education, policy development, case analysis,
- b) the model of ethical support that is to be used, e.g. full clinical ethics committee (CEC), small group, use of ethicists,
- c) the objectives of the group or the support to be provided, e.g. advice, discussion rather than proscription,
- d) the functions and scope of the support provided,
- e) selection criteria for the committee or group members and terms of membership, including the process for review,
- f) the process by which cases and issues are to be referred and recorded,
- g) the mechanism for dissemination of any outcomes reached.

In the UK there is no obligation, statutory or otherwise, to request clinical ethics consultation by a CEC and there is no obligation to follow its recommendations, although evidence suggests that those who seek advice would be likely to take it. Although some committees are accountable to the management bodies of the hospitals or institutions in which they work, their independence is important for their own integrity and in gaining confidence of clinicians.

Administrative support is essential for proper record keeping that accords with the CEC'S terms of reference and should be adequately funded. Indeed the whole question as to *how* ethics support is to be funded needs to be clearly addressed at the outset so as to avoid future problems.

Although some ethics support may be delivered by individuals both the size and composition of CECs or groups depends on their intended functions. Acute

⁹ Slowther et al. [2004b].

review of cases may best be accomplished by small groups¹⁰ but for more complex issues a larger membership may be desirable. Members of UK CECs are typically drawn from a wide variety of disciplines but membership should include representatives of the institution the CEC serves as well as a wider representation of the community in which it sits. Membership is likely to include physicians, surgeons, nursing staff, representatives from psycho-social services, chaplaincy and from patient advocacy and liaison services: there should be a significant lay membership. The latter's contribution is especially valuable because of differing perspectives and experience that such members bring to case discussions.¹¹ Lack of detailed scientific knowledge amongst lay personnel is not a barrier provided that other members of the group and those who present to it have appropriate communication skills. Most UK committees now include lawyers or have contact with, or access to, academic or other legal opinion to provide appropriate expertise. The selection of chairman and vice chairman is important and needs to be formally set out as does the means by which members are recruited and selected (see later).

As well as having proper terms of reference CECs might be expected to act in a reasonable fashion with due care (see legal duties) and show accountability by publishing an annual report.

Functions of UK CECs

a) Contribution to the generation of guidelines for good ethical practice

An important function for some UK CECs has been the provision of ethical input into hospital or NHS trust policy and guidelines that involve clinical practice. These may include:

- a) the development of local ethical guidelines that are based on or compatible with national or professional guidance,
- b) providing an ethical input to other policies and procedures developed by other groups within the organisation,
- c) commenting on and qualifying existing national policies and guidelines with especial reference to local need.

Many UK groups have used smaller working groups that also co-opt relevant expertise before submitting a draft policy to the whole group. Some institutional ethical guidelines have used similar construction techniques with the institutional ethics committees having overall responsibility.¹² Constructing such gu-

¹⁰ Thornton, Lillford [1995].

¹¹ Updale [2000].

¹² RCPCH [1997, 2007].

idelines and policies requires collaboration- to prevent misunderstanding of roles and duplication of work-, communication, and inter-professional respect. Implementation requires individuals to have a clear understanding of their roles and responsibilities, and sense of co-ownership. Some have criticised ethical guidance or policies because they may threaten clinical freedom, are too detailed, or strike the wrong balance between ethics and law. Guidelines that are developed in response to a particular clinical problem are more likely to be accepted and used.

In the UK it is usual practice for guidelines and policies are submitted to relevant hospital clinical and administrative groups for ratification. Most CECs do not rewrite national guidelines but may modify them where necessary to accommodate local needs. All ethical guidelines or policies must comply with current UK law.

b) Facilitating ethics education for health care professionals

The educational function of CECs is directed at raising awareness of ethical issues and in supporting professionals in making difficult decisions and to provide them with the formal competencies to do so. In the UK there may still be disparity between the training in ethics and law that doctors and nurses receive; neither is there clear consensus on how ethics and law should be taught to post-graduates. Educational needs may be identified by informal or formal surveys of professionals or from direct requests for defined pieces of work.

Ethics may be embedded in the culture of an institution by providing educational materials for new staff at induction. Case analysis based education may be opportunistic rather than structured, but formal teaching programmes based on core curricula can be developed. These may include seminars, lectures, tutorials and workshops, together with contributions to postgraduate meetings and teaching courses. Biannual study days in ethics on diverse topics: (consent, end of life care and decision making transplantation, children's rights, and adolescent medicine) have also proved popular. There is considerable future potential for innovative teaching activities, especially in the area of continuing education and involvement of patients in the process.

c) Confidential, multidisciplinary analysis and discussion of cases and topics

A primary function of many CECs (both in the UK and the US) is case review that may include elements of discussion, analysis, and the provision of an ethical opinion as to the "right" course of action. Requests for ethical review may occur in response to issues raised by a specific case which has been resolved but over which doubts remain (retrospective analysis). Similar requests for review may also arise in current cases before critical decisions, such as withholding or

withdrawing life sustaining treatment, are made (prospective analysis or acute cases). Both forms of analysis or review satisfy requests for guidance, may help prevent or resolve disputes within multidisciplinary teams, and separate ethical from technical or scientific issues.

However it has been argued that the prospective approach may: fail to adequately respect the autonomy of clinicians to make the best decisions they can for their patients; erode doctor-patient relationships; risk undermining patients' interests in favour of those of the staff or the hospital; enhance rather than prevent inter-professional dissent and increase bureaucracy and reduce time available for patient care.¹³ Dealing with acute or current cases also requires a mechanism for dealing with urgent requests including those that occur out of hours.¹⁴ Some UK CECs have developed mechanisms for providing rapid responses for such requests by small groups with relevant expertise.

These criticisms and concerns can be overcome by newly formed CECs concentrating, initially at least, on retrospective case analysis, because it is less threatening and intrusive. Indeed retrospective review of topics, by emphasising confidentiality, asking that teams rather than individuals attend to discuss issues, and underlining the voluntary nature of both consultation and following recommendations, may have the effect of allaying professionals' fears and establishing their trust in the CEC.

Many UK CECs have performed retrospective case reviews involving a wide range of cases and topics. The latter include: withholding or withdrawing treatment decisions; refusal of procedures; determination of best interests; conflicts over information that staff or parents thought a patient ought to receive; management of potentially harmful behaviours in patients; DNR orders; treatment without consent, when management of children in referring hospitals fell short of established good practice; prescription of experimental or innovative treatment; resource allocation. Discussion of such cases enables CECs to develop and evolve their competencies to deal with prospective cases.

A year's experience at our institution (Great Ormond Street Hospital for Children London) provides some illustration of the case mix that UK groups may see.¹⁵ We identified 49 cases (29 active, 20 retrospective) from a wide range of specialities over a 12 month period. All case discussions involved multidisciplinary

¹³ Gillon [1997].

¹⁴ Sokol [2009].

¹⁵ Larcher, Mulvaney [2007].

teams, or small groups with the full CEC providing additional input in 12 cases. The ethical issues arising in the acute and retrospective cases were similar.

Important outcomes of the 20 retrospective discussions were to limit or withhold future life sustaining treatments (LST) or change goals of care in 12.

Discussions in 29 active cases resulted in decisions to withhold or withdraw LST in 4, to limit its use in 10, or to continue or escalate active treatment in 15.

Most cases involved a substantial number of secondary ethical issues of which communication difficulties, consent, exposure of the institution to risk and resource allocation were the most frequent. Records of such case discussions provide a formal record of precedents and a teaching resource, as most case discussions include an educational component. Detailed ethical debriefings on particularly difficult cases were an increasing feature; numerous informal discussions were held. Consideration of some cases has led to the production of policy documents on management e.g. the use of home total parenteral nutrition in children and the use of compassionate or innovative treatment.¹⁶ Both sets of guidance may be used to provide an ethical framework for the discussion of acute cases.

It seems that retrospective case consultation may lead to the development of an acute more responsive ethics service that can respond to both urgent and routine clinical demands. We do feel that it is important to determine what level of consultation is required and what its role might be. It is possible to consider a request for ethics consultation much in the same way as any other request for a specialist opinion. In this type of consultation the role of the ethicist or ethics committee is to contribute to the multidisciplinary assessment of a patient. In these circumstances the role of ethics is to broaden perspectives of those involved, to question moral assumptions or values of the parties and to provide clarity in separating facts from values. In this consultation model the role of ethics is primarily to analyse question and inform rather than to resolve. In what might be termed a pure ethics consultation the focus is on analysing the ethical dilemma and suggesting a solution to it that satisfies the requirements of sound ethical decision making in terms of consistency transparency, inclusivity, accountability and reasonableness. It is vital that those who request ethical input know what kind of consultation they require and the differences between them.

However some commentators have felt that a committee based approach is “ill suited” and “too clumsy” to provide adequate ethics support. Sokol has argued that UK CECs are under used, under trained and insufficiently rapid in their

¹⁶ Bierley, Larcher [2008].

responses to acute ethical dilemmas.¹⁷ He contrasts this to the situation in the US where trained ethicists provide individual case consultation in bioethics centres but it is not clear that the latter is indeed the case in the US as a whole.

A more serious concern for some is the legal status of CECs and of the opinions they provide. In contrast to UK Research Ethics Committees, there is no formal legal or regulatory governance framework for UK CECs, nor any defined educational requirements or specification of core competencies for their members.¹⁸ It is therefore unsurprising that critics of CECs have questioned their legitimacy as bodies of ethical expertise, their function and purpose, and the extent to which governance and regulation should apply if their role is to be extended.¹⁹

In particular there are concerns that UK Committees may follow their US counterparts and pay insufficient attention to questions of formal justice and due process.²⁰

Whilst some of these criticisms with respect to composition and function have been addressed by the UK Clinical Ethics Network guidance²¹ it seems appropriate to consider the relationship between ethics and law as it has evolved in the UK and the impact that this has on the function of CECs.

The Legal Status of Clinical Ethics Committees (CECs) in the UK

a) Law and Ethics and the role of lawyers in CECs²²

Both ethics and law are normative disciplines in that they distinguish between acceptable and unacceptable behaviours, reflect public opinion and current mores. Law is concerned with minimal standards that must be fulfilled and imposes penalties if they are not. In contrast ethics is aspirational, concerned with universal goals and carries no penalties if they are not achieved. Behaviour that is unethical e.g. lying is not necessarily illegal but of course may be so, whilst concern about bioethical issues may amount to a coded request for legislation. But legal intervention, though sometimes helpful, can translate ethical problems into legal problems and inhibit moral debate. As a result a Court's moral judgements might be perceived as moral standards of the jurisdiction in which they are

¹⁷ Sokol [2009].

¹⁸ Campbell [2001].

¹⁹ Williamson [2007].

²⁰ Wolf [1992]; McLean [2001].

²¹ Slowther et al. [2004b].

²² Larcher et al. [2009].

founded. Overemphasis on legal procedure in ethical debate may also result in moral reasoning being reduced to rule following and debates about what is moral become debates about what is legal. However in many contentious issues e.g. the withholding or withdrawing of life limiting treatment, allocation of scarce resources, it is clear that far more the legality or otherwise of actions are concerned. Using the law in ethics discussions may lead to a focus on second guessing how a Court might decide an issue rather than concentrating on the ethical principles involved.

The role of lawyers in CECs in the UK depends upon the function of the committee. For CECs with a primarily educational function the lawyer's role is in explaining the law as it applies to specific aspects of clinical practice e.g. consent, confidentiality and negligence. If the CEC's function is the formulation of policy then the lawyer's role may be to scrutinise policies for clarity, lack of ambiguity and to check their compatibility with existing statute or case law.

The lawyer's role in case review is less clear but depends upon the type of analysis and the procedures used. In some relatively rare instances ascertainment involving active or acute cases the review process might be regarded as a potential substitute for the courts. It is this aspect of case review that has produced most criticism by legal commentators and has led to calls for attention to procedural and governance matters. The latter might include specifying who may bring cases, who attends committees, what the process of decision making entails and who represents/advocates the rights of patients.. In some instances committees discuss cases and provide specialist ethical expertise rather than make formal decisions. This is more likely to occur when cases are analysed retrospectively and here the lawyer's role may be in defining the relationship between law and ethics and advising on the legal aspects of the options discussed. Where the functions of the CEC are more analytical or where the intention is more educational, the role of lawyers is to provide legal clarity or a more academic account of the law.

b) CECs and UK law

Despite their increasing numbers, the legal status of CECs in the UK remains unclear.

- 1) There is no statutory obligation for Trusts or UK institutions to establish CECs, or for clinicians and others to seek their advice. Trusts are not obliged to use CECs for any of the various other functions they fulfil. In the UK, any authority a CEC has is informal and extra-legal.
- 2) Although the roles of CECs vary, their functions of case review, consultation, counselling and discussion are advisory rather than prescriptive. Their educational activities do not exist within a specific legal framework and

some are incidental to their work of case review. Policies which they produce or review are usually subject to ratification by appropriate Trust management systems.

- 3) CECs cannot advocate or sanction illegal actions. It therefore seems wise for them to have access to legal advice which may be necessary for other functions, e.g. education, policy drafting (see above).
- 4) Records of CEC discussions of individual cases may be considered in law to form part of the patient record and will therefore need to satisfy the same criteria that the Common Law demands for such records.
- 5) The legal duties and responsibilities of CECs await definition, but presumably should be seen in terms of the varying functions of CECs.
- 6) The responsibility for carrying out such duties rests upon individual members rather than the CEC per se. The clearest potential for legal responsibility occurs when CECs give advice concerning management of particular patients, rather than comment on principle. It is growing practice for Trusts to indemnify CEC members against actions for negligence in which a patient could argue that there was a failure by the CEC to act with due care and in consequence s/he suffered injury.

c) CECs and Negligence

One potential hazard for CECs is to the extent to which they might be regarded as negligent in exercising their duty of care in ethical decision making. In practice this may only arise if patients are able to approach CECs for advice and this is rarely a function of UK CECs. In order to fulfil their duty of care with regard to ethical decision-making, CECs should give a proper and detailed consideration of the relevant medical facts, the risks and benefits of what is proposed and social, cultural, emotional factors relevant to the patient and their family. They should be aware of the skill and expertise of those seeking advice and the facilities they possess and of the need to obtain valid consent and respect confidentiality. They should be able to provide a reasoned analysis of the patients best interests and be aware of their rights whether supported by legislation or not.

To make a successful claim in negligence the patient would need to show that: s/he was owed a duty of care, there was a breach of that duty, and as a consequence they suffered a harm. However it could be argued that in the UK the duty of care owed by the CEC is currently to the clinician seeking advice, not the patient. It is unclear what the law would require of a committee member, but it seems likely that the standard would be that of a "reasonable" member of a CEC. Given that the function of CECs varies this standard may be hard to define but for case analysis it could include the duties listed above. The core competencies nec-

essary to undertake them have recently been set out by UKCEN (see below). Similar constraints may apply to other CEC functions.

d) CECs and Judicial Review

As McLean and others have indicated CECs may have some other collective and procedural duties and failure to observe them could lead to their decisions being examined by judicial review.²³ These scenarios might include:

- 1) a failure to act within the terms of reference which established the CEC,
- 2) improper constitution of the CEC, e.g. with respect to selection of members,
- 3) a failure have proper working procedures/standing orders,
- 4) a failure to demonstrate proper, accountable and reasonable actions.

Although no such actions have been taken against CECs thus far, this may not always be the case. As the number of CECs increases and their role in case discussion/review attains higher profile the potential for requests for review of their advice may be expected to increase. Courts may either accept or reject the CECs analysis but at least some clarification of their legal status may result.

The need for core competencies for clinical ethics support

It is clear that if CECs are to develop further in the UK they will need to demonstrate evidence that they are appropriately constituted and have the required competencies to provide ethics support to health professionals and that they show a reasonable standard of care in so doing. Following the recommendations of the Royal College of Physicians' Report in 2005, the UKCEN steering committee has produced a statement of core competencies²⁴ that is broadly similar in principle to that produced by the USA's Bioethics and the Humanities (ASBH) group.²⁵ The approach to ethics consultation as practiced by many UK CECs and recommended by ASBH seeks to include the patient (or their appropriate representative in the case of incompetent patients) in the decision making process. This approach addresses some of the procedural and "due process" criticisms. It involves the identification and analysis of ethical issues with a view to achieving consensus over what action might be taken. Whilst this approach may not be appropriate for all societal contexts it does identify the key tasks involved in providing ethics support in individual cases.

²³ Williamson [2007]; McLean [2001].

²⁴ Larcher et al. [2009].

²⁵ Aulisio et al. [2000].

These key tasks involve:

- gathering relevant data,
- clarifying relevant concepts, e.g. consent, confidentiality, best interests, autonomy, justice,
- identifying and clarifying personal moral and other values of those involved in the decision-making process,
- clarifying relevant normative issues, e.g. societal values, law, policy,
- assisting in the identification of a range of morally acceptable options.

To carry out these tasks effectively requires certain *competencies*. Although these competencies are primarily those necessary for case consultation, they are also relevant for other documented functions of CECs in the UK e.g. education, policy making.

Competencies relevant to the provision of clinical ethics support

The necessary core competencies to undertake clinical ethics support are “collective” in their application to a particular committee or group. It would be unrealistic to expect that each member of a committee should possess them all. But a potential strength of the committee approach is the complementary and cumulative experience and expertise that individual members bring to the group. Individual CECs will have differing functions or a differing balance between functions. The core competencies necessary to fulfil them require different levels of skill and knowledge depending on what is to be done. The American Society for Bioethics and Humanities classified the competencies required for ethics case consultation as either basic or advanced, defining these in functional rather than absolute terms. A basic level of skill or knowledge is that which would be required for the resolution or discussion of a common and straightforward case whilst an advanced level of skill or knowledge is that necessary to achieve similar objectives in more complex cases. The mixed clinical and lay membership of UK CECs provides a wide range of skills and knowledge, and in the initial development of a CEC it would be acceptable for the specified competencies to be present in the committee as a whole (with different members possessing different relevant skills and knowledge). In time this would move to all members having at least basic competencies whilst those leading discussions would need advanced levels. In addition, if specific knowledge or skills are necessary in a particular case the committee should be able to access this expertise externally to supplement the discussion, just as clinicians are able to obtain specialist or second opinions in challenging cases. Examples might include consulting a specialist in a particular clinical field or an expert in data protection or public health policy.

Retrospective case analysis is more reflective and does not usually require an urgent assembly of individuals with advanced skills and knowledge. In acute case consultations, involving a small number of committee members or an individual ethicist, it is particularly important that *one* of the members involved should have experience with complex clinical situations and the ethical dimensions of such cases.

a) Skills

The skills required of members of CECs can be described as ethical assessment skills, operational skills and inter-personal skills.

Ethical assessment skills include the ability to: identify and discuss the nature of the moral conflict and the need for consultation; elicit and understand the moral beliefs and values of all concerned; analyse moral uncertainty and conflict; explain the ethical dimension of a case to those involved and to formulate and justify morally acceptable solutions.

Operational and procedural skills include facilitation of case consultations and meeting and the ability to negotiate and mediate conflict resolution in situations of emotional distress.

Interpersonal skills include communication and advocacy skills; the latter enable articulation of the views of those who find it difficult to express themselves. It is important that individual members are non-judgemental in their approach and are aware of the imbalances in power that can exist between patients and professionals and between professionals themselves.

These skills are necessary for the facilitation of the resolution of “real life” moral dilemmas rather than the abstract discussion of the theoretical issues. Explicitly, operational and procedural skills may satisfy the requirements of due process. Those who undertake individual case reviews need to possess all the above skills at an appropriate – often advanced-level.

b) Knowledge

The knowledge required by a clinical ethics committee can be wide ranging and hence it may be impossible for any individual to cover all that is involved.

It is important that CECs have:

- 1) basic concepts of ethical theory and principle, and the application and practice of moral reasoning with at least one member having “advanced” levels of knowledge,
- 2) knowledge of the position of the CEC in the institution’s framework and its link to clinical and legal governance,
- 3) relevant knowledge of clinical terms and disease processes (see below),

- 4) cultural context of patient and staff population and of local community,
- 5) relevant local or national professional codes of ethics,
- 6) relevant health care and statute law, including UK human rights legislation,
- 7) local/national government policy, e.g. national guidelines on funding of treatments.

Advanced knowledge in specific areas such as health care law, organisational structure, and cultural context can be provided by recruitment of appropriate individuals to the committee. Understanding of clinical terms and disease processes needs to be conveyed by clinical input with appropriate but detailed explanations for lay members. Advanced clinical knowledge in specific cases can be acquired by the CEC co-opting relevant expertise.

In addition the UKCEN recognised the need for individual members of groups providing ethics support to acquire and nurture certain personal characteristics. To a large extent these are virtues that can be regarded as important for other aspects of life, rather than pre-requisites for ethical reasoning. However, they may enable core skills and knowledge to be acquired, applied and developed appropriately. The possession of tolerance, patience, compassion and honesty, enables members of CECs to recognise: disparate views that are held in difficult situations; their own personal limitations and the need for development of relationships based on trust and respect; the power imbalances that exist between individuals and how to address them. They also permit the voices of weak and vulnerable to be heard and permit a channel for their expression. Humility and self awareness remind individuals not to go beyond their level of competency and/or to acknowledge conflicts between their own personal moral views and how these may play a part in the consultation process. Possession of courage and integrity allow the pursuit of ethically relevant options when it might be convenient to do otherwise.

The UKCEN document also suggests how competencies may be assessed, maintained and acquired. Deciding whether individuals or committees collectively possess the relevant competencies and the extent to which they do so is not easy especially when committees in the UK are mainly composed of unpaid but interested enthusiastic and committed volunteers. In the US it has been suggested that those responsible for educational programmes in ethics should ensure that competencies are taught and educational objectives achieved. In the UK the informal voluntary nature of CECs has meant that many members might be unable – or not be funded – to attend formal educational programmes. However there is a pressing need to demonstrate a basic level of competency if UK CECs are to be recognised as having an important and useful role. Thus the level of competency

of existing and potential new members of established committees could be assessed by the completion of an application or registration form that records the following: personal and professional details; relevant publications or presentations; a stated commitment to develop competencies; details of training in clinical ethics undertaken and/or a willingness to participate in training an example of personal response to an ethical dilemma. There should be both references and a brief structured interview for prospective new members. These are similar criteria to those used to recruit members of UK Research Ethics Committees.

Although competencies may be acquired by exposure to practical ethical dilemmas teaching and training are necessary to acquire basic competencies. This is analogous to the mandatory requirement for members of UK Research Ethics Committees to undergo basic training in ethical theory and analysis under national governance arrangements. Maintenance of competencies can be assessed by similar techniques to those used in assessing continuing professional development e.g. keeping an individual or collective portfolio/record of relevant educational activities undertaken and participation in CEC functions. Regular attendance and evidence of engagement with educational activities should be a requirement of membership and monitored on a regular basis.

Conclusions

In the UK Clinical Ethics Committees have developed as a practical means of providing clinical ethics support, mainly in response to requests from health-care professionals rather than patients. To some extent they can be seen as an evolutionary step towards the introduction of more formal clinical ethics support services such as those developed in other places, e.g. USA. Increasingly CECs work together with or alongside bio-ethicists to achieve this purpose, but the nature of UK clinical practice means that, at least in the short term, such services probably will be mainly delivered by clinicians with ethical expertise rather than philosophers. This is not to say that the rigorous academic input that the latter provide is not welcome or necessary for future academic research in bioethics.

Of all the functions served by UK ethics committees that of acute case review has proved the most controversial as it is likely to involve some cases where disputes arise between parties that might otherwise require resolution by Courts. UK CECs have not been constituted or formed with the intention of circumventing or usurping the role of courts. Nevertheless there have been concerns that the ethical review process, as delivered by enthusiastic volunteers does not meet the legal requirements of fairness or due process and does not take proper accounts of human rights. The establishment of a UK Clinical Ethics network as a registered

charity with specific educational and supportive objectives has enabled the provision of advice on the establishment and composition of CECs and on their terms of reference. More recently the UKCEN has defined the core competencies necessary to provide clinical ethics support and has outlined a mechanism for their assessment, maintenance and acquisition. These proposals together with previous advice should enable UK CECs to establish standard operating procedures that can be subject to audit and that are consistent with principles of ethical governance. This should enable ethics and law to work together in a common purpose.

References

- Aulisio et al. [2000] – M.P. Aulisio, R.M. Arnold, S.J. Youngner, *Health care ethics consultation: nature, goals, and competencies. A position paper from the Society for Health and Human Values-Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation*, “Annals of Internal Medicine” 133 (1) 2000: 59-69.
- Brierley, Larcher [2009] – J. Brierley, V. Larcher, *Compassionate and innovative treatments in children: A proposal for an ethical framework*, “Archives of Disease Childhood”. Published Online First: 19 May 2009, doi:10.1136/adc.2008.155317.
- Campbell [2001] – A.V. Campbell, *Clinical governance – watchword or buzzword?*, “Journal Medical Ethics” 27, 2001 (suppl 1): 854-856.
- Ethics in Practice [2005] – *Ethics in Practice. Background and recommendations for enhanced support*, “Royal College of Physicians” London, June 2005. www.rcplondon.ac.uk
- Gillon [1997] – R. Gillon, *Clinical Ethics Committees: pros and cons*, “Journal of Medical Ethics” 23, 1997: 203-204.
- Hendrick [2001] – J. Hendrick, *Legal aspects of clinical ethics committees*, “Journal of Medical Ethics” 27, 2001 (suppl. 1): i50-i53.
- JCAHO [1996] – Joint Commission for Accreditation of Health Care Organisations, “Comprehensive Manual for Hospitals”, Chicago, 1996: 95-97.
- Larcher [1999] – V.F. Larcher, *The Role of Clinical Ethics Committees in Paediatric Practice*, “Archives of Disease Childhood” 81, 1999: 104-106.
- Larcher et al [1997] – V.F. Larcher, B. Lask, J.M. McCarthy, *Paediatrics at the cutting edge do we need clinical ethics committees?*, “Journal of Medical Ethics” 23, 1997: 245-247.
- Larcher et al. [2009] – V. Larcher, A. Slowther, A. Watson, *Core competencies for Clinical Ethics Committees*, Clinical Medicine 2009. In press.
- Larcher, Mulvaney [2007] – V. Larcher, R. Mulvaney, *Can provision of clinical ethics support be justified? A year's experience at a children's hospital*, “Archives of Disease Childhood” 92, 2007 (suppl. 1): A36.
- McLean [2007] – S.A.M. McLean, *Who and what are clinical ethics committees for?*, “Journal of Medical Ethics” 33, 2007: 497-500.

- RCPCH [1997, 2004] – *Withholding or Withdrawing Life Sustaining Treatment in Children A framework for practice*, Royal College of Paediatrics and Child Health, London 1997, 2004.
- Re Quinlan [1976] – In Re Quinlan, NJ 1976, 355 A2d 647.
- Slowther et al. [2001] – A. Slowther, C. Bunch, B. Woolnough, T. Hope, *Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK*, “Journal of Medical Ethics” 27, 2001 (suppl 1): i2-i8.
- Slowther et al. [2004a] – A. Slowther, C. Johnston, J. Goodall, T. Hope, *Development of a national clinical ethics network*, “BMJ” 328, 2004: 950-952.
- Slowther et al. [2004b] – A. Slowther, C. Johnston, J. Goodall, T. Hope, *A practical guide for clinical ethics support*, The Ethox Foundation, Oxford, 2004.
www.ethics-network.org.uk/reading/Guide/Guide.htm
- Sokol [2009] – D. Sokol, *The unpalatable truth about ethics committees*, “BMJ” 339, 2009: b4179.
- Thornton, Lillford [1995] – J. Thornton, R. Lillford, *Clinical ethics committees*, “BMJ” 311, 1995: 667-669.
- Updale [2000] – E. Updale, *The challenge of lay membership of clinical ethics committees*, “Clinical Ethics” 1 (1), 2000: 60-62.
- Weiden [1987] – P. Weiden, *Ethics by committee*, “The New England Journal of Medicine” 317, 1987: 14-18.
- Williamson et al. [2007] – L. Williamson, S. McLean, J. Connell, *Clinical ethics committees in the United Kingdom: towards evaluation*, “Medical Law International” 8 (3), 2007: 221-228.
- Wolf [1992] – S.M. Wolf, *Due process in ethics committee case review*, “HEC Forum” 4, 1992: 83-96.