

What and who are clinical ethics committees for?

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Sheila A M McLean

As support for clinical ethics committees in the UK grows, care must be taken to define their function, membership and method of working and the status of their decisions.

The modern practice of medicine raises a plethora of complex issues—medical, ethical and legal. Doctors and other healthcare professionals increasingly must try to resolve these and may sometimes have to do so in the face of contrary opinion expressed by patients and/or their surrogates. While clearly qualified in the medical arena, and although there is now more ethics teaching in the medical curriculum, healthcare professionals are seldom qualified to adjudicate on ethical or legal matters, or even, perhaps, to recognise them when they arise. Yet, as Doyal says, “clinical life must go on and moral and legal indeterminacy within medicine cries out for practical resolution.”¹ Meanwhile, the expectations of patients and their families—and, indeed, of wider society—are that decisions about patient care, resources and therapeutic regimes should be soundly based on appropriate ethico-legal, as well as scientific, principle.

Recognition of these additional burdens on healthcare professionals has generated some interest in the provision of ethics consultation. In the USA (and elsewhere) this has been undertaken by a variety of tribunals and individuals. Hospital ethics committees and ethics consultants feature in many US hospitals and perform a variety of roles. In Europe, a number of countries have also established clinical ethics committees (CECs) and they are becoming more common in the UK—primarily in England and Wales for the moment. Whereas, however, “[i]n North America, CECs have ... become an integral part of the organisational infrastructure of hospitals ...”,¹ in the United Kingdom they remain essentially ad hoc bodies, generated for a variety of reasons and with different goals, structures, membership, methods of working and functions. The initial impetus for the formation of these committees has been described as deriving from a range of interests. Slowther and Hope describe their development in this way:

variety of local reasons. Some were an institutional response to one or two problem cases. Others developed because a few clinicians were particularly concerned with, and interested in, the ethical aspects of clinical practice.²

They believe that CECs “can change clinical practice through policy development and case consultation, and indirectly through education and raising awareness of ethical issues throughout the trust.” They also, however, note that “evaluation is needed to determine whether these committees are influencing clinical practice ...” In January 2001, “a meeting of committee representatives ... led to the development of the UK Clinical Ethics Network ...”,³ which aims to

... promote the development of clinical ethics support in the United Kingdom, to encourage a high level of ethical debate in clinical practice, and to facilitate sharing of best practice between clinical ethics committees.

Certainly, there was reason to believe that clinical ethics support might be welcomed, by at least some healthcare professionals. Following a survey, Slowther and colleagues found that “many senior clinicians, as well as trust and health authority chief executives, believe that some form of ethics support service is desirable.”⁴ Presumably, this support reflects recognition of the fact that healthcare professionals seldom have the training or skills required to make complex ethical decisions. Similar findings emerged from an international survey of doctors in Italy, Norway, Sweden and the UK, where the extent of self-reported ethical awareness was as follows:

medical school. Just over half (53.8%) were somewhat confident of their knowledge of ethics. Only a minority (17.6%) reported having access to ethics consultation in individual cases and only 13% had ever used such services.⁵

As these results are based on professionals’ own assessment of their ethics skills, they are somewhat suspect, of course. Perhaps more interestingly, however, only a small percentage of those who responded admitted that they had used ethics services when they were available. The reasons for this are, of course, open to discussion. For example, professionals may resent third parties “muscling in” on an area which has hitherto been their primary domain, or they may not have been aware of the existence of the services or they may have failed to recognise that a problem actually was ethical. Funded by the Wellcome Trust’s Biomedical Ethics Committee,¹ we are currently analysing the function of clinical ethics committees in the United Kingdom.

We are also seeking to identify in one pilot area (Highland) and one established committee (Grampian) to what extent such committees are used by healthcare professionals and in what ways. To this extent we have sought to rise to the challenge posed by Slowther and colleagues in 2001, when they wrote:

Several of the CECs in the UK are not yet clear about their exact role in the institution and there are concerns about how effective the committees are ... It is therefore important that any services have clearly stated objectives, and that there is a rigorous evaluation of both process and outcome during their development.⁴

WHAT ARE CLINICAL ETHICS COMMITTEES FOR?

In the USA, where such committees are more common, Hurst and colleagues identified the main reasons for doctors to seek ethics consultations as follows:

- to obtain needed help in deciding what to do
- to identify a practical way of doing what had already been decided should be done
- to implement a practical solution
- to obtain reassurance that the correct decision was being made

¹With additional funding from NHS Grampian.

The first clinical ethics committees in the United Kingdom developed for a

A third of respondents (35.6%) reported having ethics courses in

- better to face people who might otherwise think that the decision was inappropriate
- to seek consensus.⁶

Not all of these considerations can be described as truly “ethical”; indeed, arguably none of them is. If experience in the USA is anything to go by, then one might be inclined to agree with Annas’ critique of them, namely, that they are essentially vehicles for dispute resolution rather than “ethics” committees *in se*.⁷ Annas considers that these committees have “grown from an anomalous entity to provide ethical comfort to a few, to an almost standard entity to provide ethical cover for many”. He also—and importantly—notes that dispute resolution requires attention to due process, resulting in the committee becoming a “mini court ... and both its procedures and the substantive rules it applies are likely (and appropriately) to be much more legal in nature than ethical.”

This is an extremely important point, and one which seems to have been given little attention by those whose proclaimed mission is to expand the system of clinical ethics committees in the UK. A committee must be willing and able to adhere to legal constraints and considerations if it is to function well—indeed, arguably if it is to function at all. Thus, considerable focus must be on what might be called rules of procedure and establishment (which have been dictated by law in some countries, such as Belgium⁸). It is plausible that many of the issues brought to ethics committees are essentially practical or legal rather than “ethical”. Yet questions about the law are arguably ill-suited to ethics consultation, and a considerable debate has been generated in the USA about whether or not committees should contain lawyers or might even end up usurping the role traditionally occupied by courts of law. Annas, for example, has said:

Setting up an additional bureaucratic entity called an ethics committee to make legal pronouncements can only make medicine more legalistic and impersonal. Moreover, encouraging a group of lay people to attempt to practice law makes no more sense than encouraging a group of lawyers to attempt to perform surgery ... Good ethics committees begin where the law ends.⁷

Interestingly, however, some US courts seem to have been sanguine about the possibility of ethics committees performing a legal function. For example, in *Re Quinlan*,⁹ which involved reaching a

decision about removing life-sustaining treatment from a young woman in a persistent (now permanent) vegetative state, one judge said:

Upon the concurrence of the guardian and family of Karen [Quinlan], should the responsible attending physicians conclude that there is no reasonable possibility of Karen’s ever emerging from her present comatose condition to a cognitive, sapient state and that her life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital “Ethics Committee” or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen’s ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefore, on the part of any participant, whether guardian, physician, hospital or others. (p 671)

This is a remarkable statement: it passes responsibility for deciding about the end of a young woman’s life to a committee whose constitution, membership and expertise are unknown, and the judge was also prepared to absolve anyone of any legal liability for that decision. Annas has, in my view correctly, described this as “dangerous and inappropriate”,¹⁰ and indeed in a subsequent case, it was said that:

[Q]uestions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this idea is our responsibility ... and not to be entrusted to any other group purporting to represent the “morality and conscience of our society”, no matter how highly motivated or impressively constituted.¹¹

Nonetheless, in other cases, courts have voiced considerable support for such committees. For example, in *Re Conservatorship of Torres*,¹² which involved the decision to remove a ventilator from a 57-year-old comatose man, three ethics committee reports agreed with the decision to stop treatment, and the court said that “these committees are uniquely suited to provide guidance to physicians, families and guardians when ethical

dilemmas arise” (p 336, n 2). In *Re AC*,¹³ in which a terminally ill, pregnant young woman eventually found herself subjected to a non-consensual caesarean section, Terry, J. said (p 1237, n2):

We observe ... that it would be far better if judges were not called to patients’ bedsides and required to make quick decisions on issues of life and death. Because judgment in such a case involves complex medical and ethical issues as well as the application of legal principles, we would urge the establishment—through legislation or otherwise—of another tribunal to make these decisions, with limited opportunity for judicial review.

Lest one underestimate the gravity of the kinds of cases brought to the clinical ethics committees in the UK, it is reported that the most common issues raised with UK clinical ethics committees are “withholding and withdrawing treatment, consent and DNR [do not resuscitate] orders.”¹⁴ Interestingly, in response to the question “which area of clinical practice do you find creates the greatest ethical difficulties for your Committee,” the areas identified tended to be those that are not dealt with frequently by committees—genetic testing, assisted reproduction, accident and emergency, intensive care and National Health Service targets.¹⁴

These are obviously important, complex and sensitive matters, requiring considerable skill levels, yet to date there is no accurate way of knowing that such skills are actually represented on existing committees. Despite the lack of evaluation of clinical ethics committees, even the Royal College of Physicians has jumped on the bandwagon, noting that there is, and will continue to be, a need for “formal ethics support which is both timely and informed.”¹⁵ This, the College says, will in most cases be carried out by local clinical ethics committees. However, the College also notes (p 37, R6) that:

In the absence of adequate, prospective studies and retrospective surveys of benefit, these recommendations regarding CECs should be regarded as provisional and subject to review in the light of further experience.

WHO ARE CLINICAL ETHICS COMMITTEES FOR?

Additional issues raised by the development of clinical ethics committees concern who actually is to benefit (if benefit there is) from their deliberations. It might

have been anticipated that the primary beneficiaries of ethics consultation would be patients. After all, the purpose of all medical decisions is surely to provide the best service available in the interests of patients, and, while ethical decisions are not strictly medical, they are taken within the context of healthcare provision. However, there is evidence from the US experience that all too often such discussions seem to be primarily for the benefit of the healthcare professionals themselves. This is not to say, of course, that there is no value in this, or that the two are mutually exclusive, but rather to expose the potential limitations of ethics consultation. In addition, as we will see, the question of for whom these committees exist will have an impact on the important issue of process.

A prominent critic of what might be called the clinical-led rather than patient-led model of ethics committees is Susan Wolf. She claims that “apart from whatever legal obligations a given committee may have to accord due process, committees do not honor the values underpinning due process when they engage in case review. There is no indication that committees reliably alert patients to their existence and the ground rules for case review, give notice of impending review of the patient’s case, or provide patients with adequate tools for direct participation in the process” (Wolf, p 84).¹⁶

In the UK, where the development of CECs has been welcomed (admittedly cautiously) by austere bodies such as the Royal College of Physicians,¹⁵ the role of these committees has been described as being “the provision of support and advice to health professionals and patients on ethical issues arising from clinical practice or patient care” (Slowther and Johnston, p 950).³ The Royal College of Physicians concluded (p 37, R1) ¹⁵ that “[t]his can no longer be left to chance or allowed to depend on the enthusiasm of individuals.” Finally, the College proposes (p 40, R21) that

If CECs are to be effective they must provide, and be seen to provide, support to health professionals dealing with difficult ethical issues, as well as others affected by such cases. In practice this will usually mean making it clear at the outset that their role is to provide a multidisciplinary forum for the discussion of issues, and thereby to support the decision-making of health professionals.

Having said that, however, the College also sees some potential role for patients, recommending (p 40, R25) as follows:

The input of patients, and awareness of the patient’s values, will need to be at the heart of the resolution of an ethical issue. Some committees may come to the conclusion that there are circumstances in which it is appropriate for a case to be referred by a patient, or for a patient to be present to participate in the discussion. CECs will need to take these factors into account in the development of their referral procedure.

With respect, it is difficult to see how patients’ values can be at the heart of decisions if they are presumed rather than directly canvassed. This would seem to *require* patient involvement as an obligation, rather than an occasional event. What the preceding section seems to suggest is that there is uncertainty as to the role that CECs should play in respect of healthcare professionals and patients. This question has generated considerable interest in the USA, where one of the fundamental questions about how they function and what their purpose is has been “the appropriate degree of access to and participation in hospital ethics committees ... by patients and their families.”¹⁷ This, it is argued, comes about because of “the basic ambiguity in and uncertainty about the function and process of case review itself”.

Indeed, it may be too simplistic to presume that ethics committees can perform a function for healthcare professionals as well as patients. As Wolf has said, they have to “serve two sets of masters” (p 820).¹⁸ On the one hand, they must have regard to the interests and needs of their colleagues, while on the other “they also may claim to serve the patient by attending to her needs and interests.” Thus, she concludes that

... the committee may be laboring under the delusion that serving care givers is serving patients, that their interests are identical. Thus the committee actually may not serve patients, but serve caregivers instead. Yet the patient may not realise that, and may rely on assurances that the committee serves her interests. (p 822)

This potential confusion of roles is of considerable importance. It cannot be presumed that the interests of medical professionals and patients will inevitably be the same, nor that the route to an ethical decision is the same from either perspective. Committees in the UK have developed without, it appears, much attention being paid to this most

fundamental of questions, yet surely an answer is needed? While Wolf¹⁸ may exaggerate in calling such committees a “battleground”, she is surely right to draw attention to the possibility that “the setup is guaranteed to activate whatever ambivalence or hostility committee members feel toward patients’ rights and authority.”

Whatever function these committees believe themselves to play—and this varies between committees⁴—they undoubtedly will have an impact on patients. Very often, this can be a serious impact, as the kinds of cases brought to ethics committees are likely to be the most difficult and may even involve life-and-death decisions. Therefore, it is indisputable that in those countries where they are well developed, “ethics committees now wield sufficient influence over the fate of real patients.”¹⁶ That being so, it is not unreasonable to assume that they should be accountable and transparent in their decision-making, that they should attend to appropriate process and that they should be grounded in appropriate expertise. This is particularly so when they provide case consultation. Wolf argues that “when a committee is asked to review (or consult in) an ongoing case, and so has the potential to exert significant influence over treatment decisions, ... patient involvement and due process are required.”¹⁶ Hendrick even suggests that there may be a role for lawyers in ensuring that there is no confusion “about whom they are advising and in respect of what ...”.¹⁹

CONCLUSION

As we have seen, there seems to be considerable personal and institutional support in the UK for the development of clinical ethics committees, similar to that which existed in the USA as these committees were developing. It would be naïve to assume that this support will not similarly be translated into considerable weight being accorded to their conclusions. Before this occurs, agreement on function, membership, method of working and the status of their decisions is absolutely vital. If they are only to be a talking shop for healthcare professionals, there is probably little chance of harm resulting from their deliberations, although if their deliberations are taken seriously, this of course could change. If they attempt to venture into matters which have a legal component, they run the risk of significant error. Wolf argues that:

Ethics committees should remain advisory. They have no warrant for pre-empting the decisional authority of

patients or their surrogates. Ethics committees also should not substitute for courts. Committees have neither the personnel nor expertise to adjudicate legal claims. Indeed, committees vary enormously in quality, are bound by no commonly accepted rules of reasoning or system of precedent, and in any case lack the necessary independence of a court.¹⁶

Yet, as the US experience suggests, even if their deliberations are only given advisory status, the authority given to them, or gathered by them, can come to overtake concerns about the actual or likely quality of their advice. The industry of ethics committees is in its relatively early days in the UK, and there is much that can be learnt from the experience of the USA in particular. Although it is, of course, by no means certain that the UK will go down the same path that has been followed there, it would be surprising if the same questions did not need to be addressed.

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