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The Role of Clinical Ethics Committees

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Since the mid 1990s, more than 70 Clinical Ethics Committees have been established in hospitals and other healthcare settings across the UK. University courses in Medical Ethics are thriving, as is the Royal Society of Medicine's three-year-old journal, *Clinical Ethics*, which has attempted to replicate the proceedings of CECs within its pages.¹ The popular press and broadcasters now examine philosophical dilemmas more often than ever; and as budgets bite, the ethics behind providing and rationing medical resources are at the heart of politics too. Within this climate, CECs exist for several purposes. They discuss current cases that are worrying medical staff; they review past cases with troubling outcomes, or successful interventions where the clinician concerned feels uneasy about a procedure used, or a priority given; they may address systemic matters, where hospital procedures leave staff or patients morally uncomfortable; and they may adopt a training role, aiming to produce "better" clinicians, capable of recognising, analysing and addressing such situations themselves.

The role of Britain's CECs deserves examination by any other medical system, such as Poland's, where such bodies are almost unknown. Would CECs be worthwhile for them? A recent article by Daniel K Sokol in *The British Medical Journal* would be enough to put anyone off.² Sokol insists that, in his experience and opinion, CECs are of limited use. Though some of his criticisms resonate with my own experience, his essential defeatism about the role of CECs seems to me to be a regrettable application of the particular to the general: CECs need not be as ineffective, intimidating and undynamic as those on which he has served, or of the 30 (fewer than half) which took the time to fill in his questionnaire. CECs can, as in the case of the Great Ormond Street body on which I sit, play an important part in maintaining the good practice of professionals, and improving the experience of patients; and (as the experience at Great Ormond Street shows) they are already forming a springboard for the establishment of the more extensive and flexible ethical services Sokol advocates.

¹ Draper et al. [2006-2007].

² Sokol [2009].

So what makes a “good” CEC? Like any other body, everything depends on the membership, and in particular the chairmanship. In the current economic climate it is hard to imagine any institution paying the members of its CEC, so we are talking about volunteers. That brings both advantages and disadvantages: only enthusiasts need, or will, apply; but there is a risk of attracting people who are attending for their own entertainment, because they enjoy meetings, or to acquire an extra line on their *curriculum vitae*. As Sokol warns, there is a danger that the social make up and philosophical outlook of the group will reinforce themselves if new appointments are made by friends passing on the word to each other. But that need not be the case. The existence of the committee can (and should) be advertised, and a deliberate effort made to achieve a range of backgrounds around the table. Lawyers, religious representatives, teachers, social workers, administrators from within the host institution and medical people (in particular General Practitioners) from outside, should all be included, alongside professionals from all levels of the hospital’s own hierarchy. People trained in analytical thinking are invaluable. Several committee members at Great Ormond Street have formal qualifications in medical ethics, and the arrival of an academic philosopher has transformed the quality of debate, avoiding descent into the “unstructured free for all” that Sokol fears.

The lay members of a CEC should bring a range of experience and expertise from the non-medical world. The only limitation, and an inevitable problem, is that they are bound to be drawn from the pool of those with time to give. But that need not mean a bland haul of ageing middle-class “do-gooders”, though they are bound to be the easiest to find. One type must be guarded against: anyone giving up their time for free is bound to have some selfish motives – if only a need to feel good about themselves or to exercise unfamiliar mental muscles – but some may be attempting to make sense of, or get acknowledgement (or even retribution) for, a particular tragedy in their own lives. Such people unlikely to be suitable members of any CEC.³

Of course, it’s ridiculous to expect a handful of outsiders to represent the vast spectrum of attitudes and experiences of the population as a whole, but lay members have a key part to play in making the “insiders” behave: embarrassing them into abandoning their professional power-play and office politics for the duration of each meeting. Sokol writes as if that were an unrealistic dream, describing meetings as intimidating, particularly for junior staff. “I doubt that the average junior doctor or nurse would feel comfortable sitting at the end of our boardroom

³ Updale [2006].

table", he writes. That is more a reflection of the atmosphere of his own committee (which presumably lacks junior members) than a universal truth. It really isn't very hard to involve junior staff. Invite them in. Advertise for members and then welcome them. After all, junior doctors and nurses are likely to have had more actual, and recent, training in ethics (however brief) than their most senior colleagues; even if some of them find it hard to imagine implementing that training on the wards.

The lay members can help here, too. They need to be encouraged in one of their key roles: saying the "unsayable". A lay member can ask the apparently stupid question. Professionals might feel too shy, or proud, to seek an explanation of an acronym or other jargon, or to ask a colleague to account for an obvious gap in a case presentation. Outsiders can keep the language clear (for the benefit of everyone round the table) and focus the debate on the key points of the ethical argument, rather than matters of institutional convention and structure. It all comes down to good chairmanship. A CEC run by a bombastic careerist won't work. One which focuses on providing a civilized forum for wide-ranging discussion, with the aim of alleviating moral perplexity in the minds of the medic and the patient stands a chance of success. That is one reason why making CECs a statutory requirement for all hospitals is a bad idea. A co-opted committee, put in place by a reluctant management with an uninterested, untrained Chair is unlikely to achieve much.

Of course there is no point in having a committee at all unless people refer cases to it. While the ideal situation is for the committee to be well-publicised, and seen by anguished staff as a welcome resource, it may sometimes be necessary to solicit cases from colleagues in order to ensure that the committee is presented with a varied portfolio of issues, for the sake of the members' own development and education, as well as the resolution of the cases themselves. There is nothing wrong with using friendship connections to do that. The committee should meet sufficiently often (at least once a month) to be able to build up its expertise and to establish a reputation within its home institution. Regular meetings also allow for quick feedback from clinicians who have, or have not, taken the committee's advice.

There should be no restriction on who can refer something to the CEC. Often problems are perceived first, or most frequently, by people low down the chain of command. Again, good chairmanship is needed, in order tactfully to encourage those at the head of the chain to participate in the examination of the issue. It is best if as many as possible of the treating team attend the meeting, so that every perspective can be explored. Recriminations within the team must be avo-

ided by a clear focus on the ethical, rather than the personal, issues in play, especially at the start of the discussion.

Nevertheless, the solution to a problem may not have an obvious “ethical” base. Sometimes inadequacies in communication or organisation may be revealed. The word “ethics” in the title of the committee should not preclude grappling with such practical problems. Helping to resolve personality clashes, to repair dysfunctional systems, and to give a voice to every member of a team is the “ethical” thing to do. The committee must not close its mind to the possibility that ethical conundrums may be housed within familiar procedures and everyday events. The world of medical ethics is a prone to fashion as any other discipline. Some issues tickle the ethical spot more readily than others. It is easy to see why consent will always be a focus of ethical debate. Do Not Attempt to Resuscitate’ orders, xenotransplantation, and decisions about corrective surgery on intersex patients will always generate intriguing, and entertaining, discussions. But more humdrum areas need attention, too. Why should a decision about priorities on a transplant list necessarily be more worthy of discussion than the supply of translation facilities, or even appointments systems and cleaning routines? All those things may operate in such a way as to deny, impede, or undermine the appropriate treatment of patients, and are as capable of the inadvertent infliction of harm as the most glamorous new surgical procedure.⁴

To achieve the degree of relaxation and confidence necessary to make meetings work, it is essential that (within the constraints of good practice discussed below) each session should be as informal as possible. For this reason, some groups prefer to be labelled as a Clinical Ethics Forum, rather than as a committee. This does not mean that the discussion can be sloppy or undirected. There must be a framework and a focus: not least at the beginning of the entire process, when the ethical point at issue must be clearly identified and outlined to all present, so that the discussion does not degenerate into a technical assessment of clinical procedures. But, despite the need for rigour, people must feel free to speak out regardless of any potential professional backlash, and also to explore the extremes of a line of thought. It must be perfectly acceptable for any committee member, or visitor, to express apparently conflicting views as they grope towards a resolution of competing arguments. Almost all cases will find their way to the committee because there is no simple solution to the problems they involve. It would be mad to expect the committee to come up with a simple answer. Most often, any recom-

⁴ Updale [2008].

mendation will be a balance of “goods” and “harms”. Sometimes, even the “right” thing can only be recommended with a heavy heart.

The informality necessary to achieve a free-thinking dialogue can be in conflict with the increasing tendency to document everything, especially in an age when patients are becoming more litigious. If people can’t speak their minds and test out unfamiliar, controversial, or even apparently outrageous ideas, the committee has no purpose. So while record-keeping has been established (at least in the UK) as a legal necessity, the style and content of any minutes must be such as to preserve the practical working of the committee and to protect committee members from attack by people unfamiliar with the status and style of the meeting. I imagine that few would now argue, except in extraordinary circumstances, that patients, or their representatives, should not be informed that the CEC has discussed their case. But should they be permitted to read the minutes? Might they be invited to attend a meeting? Do they have a right to do so? These are questions a committee should ask itself frequently, and decide on a case-by-case basis. Should patients have equal rights to turn to the service for advice? After all, they often face enormous moral issues in deciding, for example, whether to consent to treatment or to its withdrawal. They live with those dilemmas 24 hours a day, and are more directly affected by them than anyone else. They are unlikely to have the benefit of even the cursory education in ethical matters now given at medical school. Why should they not be allowed to access the support on hand to the hospital’s staff? But what if the debate is about rationing? Should the competing demands of two patients to one set of facilities be argued out in front of them? Should they be allowed to see professionals groping towards a solution by “thinking the unthinkable”? Is there a risk that to do so might undermine their trust in their doctors, and make things worse for them; and, if so, who decides? These questions go right to the heart of the issue of what CECs are for. Are they a resource for the hospital and its staff, or part of an overall “Ethics Service” that is on offer to patients too?

And if the committee makes a recommendation, should it be binding? Given the ramshackle nature of the means by which membership is determined at present, and the lottery of who actually turns up to each meeting, it is hard to see why they should be. This must not be seen as a weakness. The institutional “weirdness” of CECs is in fact part of their strength. To formalise them further could have two dangerous consequences: it might lead to them being used as a cover by timid managements unwilling to grapple with difficult policy matters; and it might drive away hands-on professionals in genuine need of advice, but reluctant to be seen seeking it. A casual, amateur, “corridor consultation” might

result, with clinicians taking advice from colleagues known to have ethical expertise. There is nothing wrong with that, of course, but it would be a shame to deny the advice-seeker and the advice-giver the benefit of several other points of view because the system had become too bureaucratic. Another danger of over-formalisation is that the CEC might be used by some clinicians as a bogus “second opinion”: a body to which bucks can be passed, and whose judgements can be used as a substitute for proper professional decision-making by the clinician with overall responsibility for a patient. There is enough momentum behind the tendency to infantilise medical professionals (by undermining their freedom to make decisions) without throwing an extra lifeline to the cowardly.

So the service must not be statutory or over bureaucratized, but it must be orderly, and properly administered. Too many British CECs are run without the practical back-up necessary to supply members with background reading, let alone the minimum requirements for organising and recording meetings. Potential applicants for the CEC’s assistance need a clear and helpful first port of call. If an ethics service is to function properly, it should be adaptable to the unpredictability of medical life. Several CECs strive to provide rapid responses when a decision about “right” and “wrong” is needed in an emergency. The Rapid Response Service can be an important contribution to achieving peace of mind for professionals and patients at a time of crisis, and the benefit can live on after the event. For a Rapid Response Service to work, a small but balanced group of CEC members (neither all professional nor all lay, possibly not all of one gender or religious or cultural background) needs to be gathered at speed. Unless the goodwill of volunteer committee Chairs and members is to be strained to the limit, that cannot be done without office help. Neither can the efficient documentation of the committee’s activities. CECs need an archive so that they can revisit discussions, spot patterns, follow up cases, and assess the utility of the service they provide, even if quantifying their value is fraught with difficulty. They need to be able to publicise their service too. CECs need the status within the institution, and the office time, to enable those tasks to be performed.

Sometimes, practical systemic malfunctions, or even malpractice, will be highlighted during the discussion of an ethical problem. It is not just the CEC’s right, but its duty, to inform the management about these, and to take a positive role in seeking, or even suggesting, institutional remedies. That is unlikely to happen unless the CEC has the ear of people high up in the management structure. Someone, preferably the Chair, should be formally in dialogue with people who can make things happen. That is impossible if everyone on the CEC is working full-time in another job, with no administrative back-up. There is a delicate bal-

ance to be struck here: preserving the essential informality of the committee's atmosphere and proceedings, while giving the committee a formal place in the life of the institution. Bureaucrats like structures; they will tend to demand ever more formal routines and paperwork. That tendency has to be fought, and the bureaucrats "educated" in the advantages to the institution of maintaining the more managerially "dangerous" aspects of the CEC's functions.

So a CEC is not a cost-free option for a hospital, or at least it should not be. For it to deliver successfully, it should be part of a wider Ethics Service, capable of responding to the requirements of the institution as and when they arise, and of promoting the consciousness of ethical issues within that institution. Although most CECs in the UK are able to function only because of massive good will and voluntary out-of-hours work by their members, that situation cannot go on forever. It should be avoided in countries where CECs are being introduced for the first time. Creating them will take courage, imagination, and the willingness to cut across all sorts of well-established working practices and hierarchies. Huge problems will remain for even a well-functioning CEC. Perhaps the biggest perennial challenge is how to embrace those colleagues who desperately need "ethical" input into their decision-making, but do not perceive that need (or even fail to see that they are making decisions at all). There is always a risk that the clinicians who refer cases to the CEC are in fact the "good guys" who, because they recognise their dilemmas, are least in need of help. But even so, the pay-off can be great. A good CEC will give professionals the confidence to make difficult ethical decisions for themselves, and to pass on the habit of philosophical thought to their junior colleagues. It will enable clinicians to explain to patients and their families how and why decisions have been reached, and to embrace them into the decision-making process. It will not pretend to have all the answers, nor that it gets all its answers right. It will not, and cannot, prevent problems from arising again; but it should, over time, develop an expertise in dealing with them when they do. It will ensure that ethical issues are properly and methodically addressed, and that, whatever the outcome, everyone involved can sleep more peacefully, knowing that they have done their best.

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