Clinical Ethics Consultation in the United Kingdom

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Confronting and attempting to resolve ethical dilemmas are daily challenges in modern healthcare practice. Few clinicians can have escaped, or can avoid, this important aspect of their work, even if they do not always recognise what is an ethical, what a legal and what a purely clinical problem. Doctors and other healthcare professionals are seldom widely educated in ethics, and no matter the length of their experience, they are by no means guaranteed to have "ethical perspicacity".¹ This is an important consideration when evaluating the benefits, drawbacks and impact of clinical ethics consultation. It is also vital that the difference between ethics in general and *medical* ethics is carefully noted. While healthcare professionals might reasonably be assumed to be aware of the codes of ethics that govern their professions, and to be up to date with the guidelines issued by their professional associations (medical ethics), these address a microcosm of the ethical issues that can arise in sensitive cases where (general) ethics advice might be of greatest value. Ethical reflection requires a sophisticated awareness of the underpinning principles and values that pertain in specific circumstances and transcends the advice offered to healthcare professionals by their professional bodies.

Recognition of the complexities of the dilemmas that can confront healthcare professionals as medicine continues to expand its capacities, helping to create ever more sensitive and difficult issues, has led to enthusiasm in some quarters for the establishment of a forum that would provide advice and recommendations on how to proceed when these arise. Although these forums may have different names, and can take different forms, in the United Kingdom they are commonly – but not always – referred to as Clinical Ethics Committees (CECs). For ease this is the terminology that will be used throughout this discussion. The hope and expectation is that by establishing a body with a remit for ethical reflection and the provision of advice or recommendations, healthcare professionals will have access to a forum with the ability to undertake mature reflection on ethical questions and offer considered (and helpful) commentary on them. If clinical ethics committees are genuinely to offer "ethical" advice, then it seems obvious that they should be

¹ Sokol [2009].

capable of doing so. In other words, and without prejudging the value of clinical ethics committees, it is reasonable to require that they are fit for purpose – a question which will be returned to *infra*.

While nowhere near as commonplace as they are in other countries such as the United States, at present there are more than 70 Clinical Ethics Committees in the United Kingdom and this number may well continue to rise. CECs are not supported or mandated by statute in the United Kingdom, and no formal requirements exist for their constitution, membership or remit, although some support and training is offered by the Clinical Ethics Network which is organised by the ETHOX Centre at the University of Oxford.² Membership of the Clinical Ethics Network,³ which was established in 2001,⁴ is not mandatory, nor is it required that members of clinical ethics committees utilise such educational and supportive resources as are available. In the United Kingdom, there is no obligation (legal or professional) to consult CECs where they exist, nor is any conclusion reached by the CEC binding on anyone who does consult it. Membership is often at the discretion of the chairperson, can be fluid and no expertise in ethics is technically required.

Clinical Ethics Committees: The Main Issues

It has been suggested that the impetus for the creation of CECs came from healthcare professionals themselves, as they came to recognise that modern medical care generates a range of issues that go beyond the kind of expertise that is acquired in clinical education and practice.⁵ This recognition generated the perceived need to establish the early committees and continues to inform the creation of further CECs. While there are no formal roles defined for CECs, "most of them review hospital policies and provide advice on ethically problematic cases."⁶ There are a number of questions that arise about the role played by these committees, as well as reasons to interrogate their membership and authority. The most important of these will be considered in what follows.

² <u>http://www.ethox.org.uk</u> (accessed on 26/10/2009).

³ <u>http://www.ethics-network.org.uk/committees</u> (accessed on 26/10/2009).

⁴ For discussion, see Slowther et al. [2004].

⁵ Slowther et al. [2004]. The position in the United States appears to be similar; see: Hoffman [1991].

⁶ Sokol [2009].

Membership

In a recent study undertaken by the present author and her colleagues, the chairpersons of 75 UK CECs were invited to complete an extensive questionnaire; 33 of them responded. The survey included questions on membership, training, the amount of ethical and legal expertise represented on the committee, what kind of issues they had considered in the previous 12 months and the level of confidence they had in their ability to address such matters.⁷ In our analysis of the responses from CEC chairpersons, it emerged that the most frequently mentioned desirable skill was a basic knowledge of medical ethics, ethical principles, ethical frameworks, guidelines and debates (27%), followed by a basic knowledge of medical law and current legal debates (13%) and a knowledge of local and /or national health care service structure, governance, procedures and policies (13%). Moreover, 79% of chairpersons reported that someone on their CEC had a qualification in ethics and 76% agreed that such a person should be on the CEC. When asked if anyone on their committee had a qualification in law 94% of CEC chairpersons said "yes" and 76% felt that such a person was needed.

Although a number of CEC chairpersons reported themselves as being satisfied with the level of ethical (and legal) expertise available to them on the committee, it is not clear from the membership of committees in general why this level of confidence exists, given that the vast majority of members are trained in medicine rather than ethics (or law). To an extent, of course, it may well be that confidence is reasonably high because of nature of the work undertaken by CECs. Although the Clinical Ethics Network reports that matters such as consent, end of life issues and capacity have been considered by CECs, in fact few report dealing with actual "live" cases, and many prioritise educating healthcare professionals and assisting in shaping policy. While the former – the provision of advice on "real" cases – might require considerable ethical (and legal) expertise, the latter might reasonably be performed to a high level by those whose primary expertise is clinical or even administrative. Whether or not, however, the latter function requires the label of "ethics" to be associated with the committee is moot.

The question of membership and perceived expertise might also have an impact on the extent to which CECs are in fact utilised by healthcare professionals. As has been said, there is no obligation to take ethical issues to the committee and arguably the fact that a number of these committees appear to have a relatively

⁷ This research was funded by a grant from the Biomedical Ethics Committee of the Wellcome Trust – "Ethico-Legal Governance in Healthcare", Grant number 074466 (additional funding was generously provided by Grampian Health Board).

light workload of "live" cases suggests that many healthcare professionals do not use them. Duval concludes that:

The most common factors that triggered physicians' requests for ethics consultation were 1) wanting help resolving a conflict; 2) wanting assistance interacting with a difficult family, patient, or surrogate; 3) wanting help making a decision or planning care, and 4) emotional triggers. Logistical analysis indicates that physicians who are ethnically in the minority were more likely to ask for a consultation to deal with conflicts, while physicians who were trained in the United States and those from small communities were also moderately more inclined to call for consultations in response to emotionally charged situations.⁸

It might be concluded, therefore, that not every person who approached a CEC was in fact looking for advice on, or consideration of, a dilemma that was strictly speaking "ethical". Despite this, Hoffman has suggested that:

The motivation for establishing most....[US]... committees was internal – nurses, social workers, and physicians searching for a better way to think about and handle cases involving life-sustaining treatment, initiated the formation of the committees. *The stated purpose of the committees was to protect the interests of patients, especially those patients who could not speak for themselves.*⁹ [emphasis added]

While this may have been (and might remain) true in the United States, as we have seen it is not universally true and some reasons given for approaching ethics committees seem less "ethical" and more administrative, practical or professional.

This also raises the question of who uses CECs. Orlowski's research suggests that "doctors who use ethics consultation do so because they believe in shared decision making...",¹⁰ whereas those "who do not use ethics consultation tend to believe that it is their responsibility to resolve issues with patients and their families."¹¹ Perceptions of the role of the professional may well influence whether or not the taking of individual responsibility for managing disputes is seen as appropriate or desirable, as may self-belief. For example, Orlowski further discovered that some non-users of CECs "believe that they do not need help because

⁸ DuVal et al. [2001] p. i28.

⁹ Hoffman [1991] p. 747.

¹⁰ Orlowski [2006] p. 501.

¹¹ Orlowski [2006] p. 501.

they are already proficient in ethics."¹² Sokol also proposes that "[m]any doctors are unlikely to present their ethical concerns to a committee for fear of appearing foolish or ignorant. As junior doctors are notoriously loath to flag their ignorance, summoning the hospital's clinical ethics committee to evaluate a situation runs contrary to the prevalent ethos."¹³ The barriers to full utilisation of CECs may, then, be a combination of personal and professional.

In addition, whatever the reason for the attitudes of healthcare professionals to CECs, there is confusion as to the extent to which they are accessible to patents (and their representatives) and what role it is intended patients should play. By no means all of the chairpersons who responded to our questionnaire indicated that their committee would entertain a request for advice from patients, and this is not a problem that is confined to the United Kingdom's relatively embryonic system. While it might be expected that patients would be one important constituent, it would seem that their role is in fact more opaque. It as been said in the United Kingdom that "[c]linical ethics support can be described as the provision of support and advice to health professionals and patients on ethical issues arising from clinical practice or patient care"14 [emphasis added]. In the United States, "[t]he stated purpose of the committees was to protect the interests of patients, especially those patients who could not speak for themselves."15 Yet, where do patients actually feature except as perceived rebels against optimal medical recommendation or passive recipient of any clinical ethics advice given to, and accepted or rejected by, those caring for them? In the United States, Wolf has argued that "[t]here 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."16 While this problem may be endemic to the committees themselves, some of the respondents to our research suggested that it could also be the result of inadequate funding and administrative support. Whatever the reason, however, it is unfortunate that, even when the committee system is well-developed, it can still be said that "...the question of patient and family access to case review is complicated by the basic ambiguity in and uncertainty about the function and process of

¹² Orlowski [2006] p. 501.

¹³ Sokol [2005] p. 741.

¹⁴ Slowther et al. [2004] p. 950.

¹⁵ Hoffman [1991] p. 747.

¹⁶ Wolf [1992] p. 84.

case review itself."¹⁷ Since any advice or recommendations offered by ethics committees will, if accepted, be likely to have an effect on patients, it is surely unacceptable that their role in raising questions, or in deliberations, should be so uncertain.

Conformity with legal and human rights norms

Although CECs in the United Kingdom have no statutory basis, it was suggested earlier that it can reasonably be argued that they should be "fit for purpose", and it has already been argued that this requires a level of expertise in "doing ethics". Although at least one member with an ethical qualification (albeit unspecified) was reportedly on the vast majority of CECs in the UK that responded to our questionnaire, whether or not this amounts to adequate expertise can be questioned. Since healthcare professionals seldom have a qualification in, or even an in-depth knowledge of., ethics – yet they make up the majority of the membership of CECs – there must be room for doubt about the *ethical* quality of any advice offered. If sufficient ethical expertise is not available to the committee it is difficult to see how ethics could be properly taken account of; after all, ethics is not just common sense. It is an intellectual discipline requiring discrete skill and understanding.

Moreover, it is not just the internal quality of decision-making that is important; what might be called external ethicality is also of considerable significance. In other words, any decisions taken or advice offered - however competent - should also follow the requirements of legal process and, in the modern world, increasingly those of human rights norms if they are to be categorised as truly "ethical" decisions. This requires a degree of sophistication in practice, as it suggests that an "ethical" decision is one that not only gives informed consideration to the issue itself but also is reached in an "ethical" manner. The problem in part here is that in order for this latter to be achieved, attention to legal principles is also necessary. While our research suggested that most of the committees that responded have lawyers on them, they – like ethicists – are in a minority. Yet, like ethics, law is not simply a matter of the application of common sense and in particular utilising and interpreting its jurisprudential underpinnings require expertise and understanding. Two consequences potentially flow from this. First, if there is only one member (or at least a very small number) with legal training and knowledge on the committee, s/he will have to take responsibility for ensuring that adequate attention is paid by the CEC to concepts such as due process. While this may be

¹⁷ Agich, Youngner [1991] p. 18.

entirely within the skill base of the legal member, it also may result in their position becoming unduly influential. The ability to "do ethics" might be limited by the potential dominance of this person or persons. Second, and on the contrary, the relative paucity of legal representation might discourage or minimise attention to due process issues as minority voices can go relatively unheard.

Further, is the issue of human rights. The United Kingdom is statutorily committed to respecting the rights enshrined in the European Convention on Human Rights.¹⁸ A number of these rights, such as the right to life¹⁹ or the right to private and family life²⁰ will be at issue in many healthcare decisions, for example in questions about withholding or withdrawing treatment or its provision. For our purposes, however, one further right – the right to a fair hearing²¹ – is of particular interest. Although the Human Rights Act 1998 only technically covers the actions of "public bodies", and it is unclear whether or not CECs would qualify as such, it is not unreasonable to anticipate that when a particular body or organisation has some – even limited – authority over the lives of others, those who are affected by their decisions (most importantly the patient whose situation has been considered by the committee) could expect that any such consideration would stand up to scrutiny from a human rights perspective – that is, that their rights have been respected in a fair hearing.

This can be broken down into several constituent parts. The first returns us to the question of due process. A fair hearing must meet the expectation that any conclusion will follow adequate consideration of the "quality of the procedures and processes by which it is reached."²² Irrespective, then, of the legal status of CECs or their recommendations, the spirit of due process should inform they way they reach their conclusions. Given the make-up of UK committees, this is asking a great deal. Equally, attention to formal justice – the certainty and consistency of decision-making – also has a role to play in the deliberations of CECs. Yet few have the capacity to take this seriously, not least because they do not have a body of individual or shared experience on which to draw and no widely agreed methods of working.

However, while attention to the concepts of due process and formal justice are important for the external ethicality of CECs and their decisions, Annas points

¹⁸ Adopted into UK law by the Human Rights Act 1998.

¹⁹ Article 2.

²⁰ Article 8.

²¹ Article 6.

²² McLean [2008] p. 99.

out that this is not unproblematic in terms of the internal job of "doing ethics". As he says:

If they are to provide a forum for dispute resolution, ethics committees must follow some basic due process guidelines. Once these are provided, however, the committee becomes 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.²³

Agich and Youngner also propose that even this perceived need for ethics committees to "mimic the legal process" does not guarantee the protections that true legal process incorporates.²⁴ In addition, they note that "[w]hile the potential for resolving conflict is undoubtedly one of the more significant factors underlying the acceptance of ethics committees, there are also problems associated with administrative case review; it can implicitly give recommendations the status of binding decisions, and families may find it more formal and impersonal."²⁵ While it must be agreed that as committees continue to function and develop "the need to attain knowledge about benchmarks, best practices, and measures of effectiveness becomes increasingly significant...",²⁶ there is limited evidence that much effort has gone into doing so. Interestingly, although there was limited support for legal status to be given to CECs in our research, "85% or respondents believed that guidelines would...assist in directing CEC agendas, enhance practice and ensure a degree of consistency between committees with regard to standards, CEC membership and training of members."27 However, writing of the US experience, where such committees are infinitely more powerful and experienced than they are in the United Kingdom, Wolf concludes that they are in fact a "due process wasteland...".28

While the need to take account of due process, formal justice and the requirements of human rights seems self-evident, this is, however, problematic for ethics committees at a number of levels. First, it is not clear whether or not they have available to them the necessary expertise on such matters. If they do, the responsibility for ensuring adherence to these norms will fall to (often) one member,

²³ Annas [1991] p. 19.

²⁴ Agich, Youngner [1991] p. 18.

²⁵ Agich, Youngner [1991] p. 18.

²⁶ Godkin et al. [2005] p. 511.

²⁷ McLean [2008] p. 103.

²⁸ Wolf [1992] p. 84.

whose authority within the committee might become disproportionate as a result. Second, attention to due process in particular might render the committee overly legalistic, making "doing ethics" problematic. Third, a more legally aware and formal committee decision might be taken as carrying an authority that is not merited. The fact that the process may appear quasi-judicial raises questions about the weight to be attributed to any recommendations made and may thereby even affect the potential liability of committee members or of clinicians who ignore or reject any CEC recommendations provided.²⁹

There is no guarantee that the pattern that has emerged from the United States, where courts have on occasion seem comfortable in essentially ceding responsibility – even for life and death decisions – to ethics committees, irrespective of the quality of their decisions or their attention to fundamental legal rules developed over centuries of jurisprudence,³⁰ will be repeated in the United Kingdom. However, the more a CEC came to resemble a mini-court, the more plausible it would be to argue that its decisions should be accorded enhanced respect. This would, of course, have implications for the patients whose care is affected by CEC deliberations, for the clinicians at whom they are directed and for committee members themselves.

Individual Case Consultations

It will be apparent from what has gone before that ethical decision-making in the United Kingdom is essentially *ad hoc*, and arguably lacking either in sufficient ethical expertise or in attention to legal process. It is also clear that CECs are probably not routinely used by the majority of healthcare professionals; while the quantity and quality of ethical issues confronting the contemporary providers of healthcare are significant, the number of "live" cases heard by CECs is apparently rather small. Proponents of the CEC model, of course, might attempt a robust defence of their role and functions, but they must address the criticisms nonetheless, and this they have, arguably, failed to do. Given that it is often claimed that "many senior clinicians, as well as trust and health authority chief executives, believe that some form of ethics support service is desirable…",³¹ it seems clear that (at least some) doctors or other healthcare professionals recognise their limitations when it comes to resolving the complex ethical (and legal) issues that permeate

²⁹ These issues are considered in a report by the (UK) Royal College of Physicians, *Ethics in Practice* [2005].

³⁰ See, for example, Re Quinlan [1976].

³¹ Slowther et al. [2001] p. i7.

their professional lives. Yet they do not routinely turn to CECs for help, support, advice or adjudication, and as Sokol argues, even if they did, "[c]linical ethics committees cannot alone cope with the demands of ethically troubled doctors at the coalface."³² Thus, he concludes "[t]he use of clinical ethicists would represent an important step forward."³³

Unlike the situation in some other countries, UK ethics consultation – when it takes place – is generally undertaken by committee, and there is no established practice of employing individual ethicists in hospitals. If my critique of the existing CECs in the United Kingdom is taken seriously, then it must be asked whether or not the routine failure to offer specialised individual consultations is at best unfortunate and at worst inimical to appropriate consideration of ethical questions.

Yet, however superficially appealing, the involvement of clinical ethicists rather than "ethics" committees is also not without its detractors. While ethicists have, as might be expected, reportedly been found to "score higher in moral reasoning than clinicians...",³⁴ healthcare professionals may be reluctant to engage with them as they could be seen as usurping clinical authority. Equally, healthcare professionals may fail to identify that a problem has an ethical rather than a purely clinical component. For the ethicist, the challenge lies in the fact that many of the dilemmas in which they are likely to become involved will have legal as well as ethical components. For this, if no other, reason, even when used "...ethics consultants are rarely the last decision makers in a medical situation...".³⁵

Nonetheless, in countries where individual ethics consultations are utilised, it has been argued that the authority of the consultants is considerable, if not excessive, as "they regularly make decisions that profoundly affect others' medical and legal interests."³⁶ A training in ethics, it could be argued, is scarcely sufficient on its own to merit this level of influence. Yet, according to Spielman, in the United States "they secured a great deal of quasi-legal and legal authority. This power to affect others' legal rights includes not only authority to advise and decide, but also to administer patient rights, to act as de facto magistrates, to provide immunity to health care providers, to attest to proper procedure, and to offer legal opinions."³⁷

³² Sokol [2005] p. 742.

³³ Sokol [2005] p. 742.

³⁴ Sokol [2005] p. 742.

³⁵ Spielman 2001] p. 167.

³⁶ Spielman 2001] p. 167.

³⁷ Spielman 2001] p. 168

The call to move towards more case consultation – to be undertaken by people with a formal training in ethics – is therefore not a complete (or even, perhaps, significant) answer to the problem of securing efficient, effective and expert consideration of the dilemmas that perplex, and will continue to challenge, the providers of modern healthcare and their patients. Nor will it necessarily satisfy the requirements of due process, formal justice and attention to human rights which, it has been argued, are also essential components of a decision that is both internally and externally "ethical".

Conclusion

Despite the problems that have been identified with the CEC structure in the United Kingdom, and by implication with that in other countries where the system is similar, it remains the case that some kind of ethical advice is needed for those healthcare professionals who confront difficult and demanding decisions. It is to their credit that the impetus to establish these committees came from them rather than being imposed on them by administrators or by Government. The question remains, however, whether or not they – or their patients – are well served by the system that currently exists. The *laissez faire* approach to ethics consultation that the UK adopted has arguably failed those who have supported its development. For as long as committees are relatively rarely consulted, any benefits they could bring are underused. For as long as membership is predicated on "interest" rather than expertise, their authority is likely to be limited. For as long as they do not operate with adequate attention to the jurisprudence of due process, formal justice and human rights they are open to attack as constitutionally inappropriate. Yet, as Doyal notes:

...clinical life must go on and moral and legal indeterminacy within medicine cries out for practical resolution. When negotiation about acceptable professional conduct breaks down between individuals, clinical policy should be formulated through a respected forum of wider debate, discussion and conflict resolution. If a particular "hard case" poses dilemmas for clinicians and health care teams, good clinical practice requires a procedural means to generate the most rational course of action in the circumstances.³⁸

Just what form this should take, however, is much more difficult to state than is the need for it. For patients and clinicians alike, the current system argua-

³⁸ Doyal [2001] p. 46.

bly offers little more than a "lowest common denominator" approach to problem solving. Sokol proposes that this could be resolved by restricting the responsibilities of CECs to the responsibility for "reviewing and developing hospitals' policies...".³⁹ In parallel, "individual ethics consultants [should be used] for the micro issues."⁴⁰ Using committees, such as CECs, for all "ethical" issues that arise in the United Kingdom seems to have come about as a result of the desires of healthcare professionals for support and the enthusiasm of participants in committees to accept this responsibility. Coupled with a level of academic and professional endorsement, there seems no obvious way radically to improve the system, yet arguably the questions raised in this paper need to be resolved and probably should have been considered *before* the system became established. As has been said:

Before one can make the decision to embark upon the establishment of such a facility *a strategic plan* is needed. The plan should contain a road map of how to proceed, and include matters such as an assessment of local circumstances and current conditions. Ethics committees should not come into being simply because someone, one day, decided that it was a "good thing" to have one, or because there happened to be some ethical emergency that needed acute attention. This approach is analogous to running before one has learned to walk.⁴¹

Making decisions that are ethically and legally robust, internally and externally, is no easy task. While it seems possible that no perfect system is available, it is evident that ethical (and legal) issues will continue to emerge in healthcare. Wiping the slate clean, returning to basic principles and starting again – although unlikely – seems desirable. Nonetheless, washing one's hands of the problems associated with creating a system which more closely resembles a "good" one is also not an option. One vital component of any such system would be the recognition of the skill base of other disciplines. Ethicists and lawyers don't "do medicine" – on what basis should healthcare professionals be expected or permitted to "do ethics"? Meritocracies have become increasingly unpopular over recent years, but they can serve a valuable purpose – arguably, this is one situation in which this is the case. Without recognition of the appropriate skill sets needed, any system is doomed to fail both those whose treatment depends on the recommendations

³⁹ Sokol [2009].

⁴⁰ Sokol [2009].

⁴¹ Van der Kloot Meijburg, ter Meulen [2001] p. i37.

made and those who have the humility to recognise their need for help in decision-making. As has been said:

The healthcare of the future demands that decisions are accountable, transparent and can stand up to legal and ethical imperatives. Legal and ethical awareness is critical to the development of the sensitive and robust policies which are needed to achieve this.⁴²

This is unlikely to be achieved by the mere repetition or entrenchment of mistakes that have already been made. The consequences of mature reflection on these mistakes could be manifold. As Sokol proposes, a committee system could run in tandem with individual case consultations - each arm of the structure requiring discrete skills and being subject to specific ethical and legal constraints. Were this accepted, then committees themselves might gain increased authority in those areas in which they have expertise, their recommendations would merit weight, their deliberations would be in congruence with jurisprudential and human rights requirements and ethicists would be free to "do ethics" given direct engagement with patients. To satisfy the aspirations of both patients and healthcare professionals, this would surely be a step in the right direction. Of course, other issues also remain to be resolved. Any country contemplating establishing a system of ethical review would also need to decide on whether any advice emanating from committees or individual ethicists should be advisory or mandatory for those to whom it is addressed, and whether any appeals system should be established. The legal liability of the advisors (committees and individuals) would need to be resolved, and the concurrent role of policy makers and courts decided upon, as would the role of patients and their families in the deliberations. These are difficult, but nonetheless worthwhile, endeavours.

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⁴² McLean [2005] p. 5.

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