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Consultation activities of clinical ethics committees in the United Kingdom: an empirical study and wake-up call

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ABSTRACT

Objective: To identify the consultation activities of clinical ethics committees (CECs) in the UK and the views of CEC chairpersons regarding such activities.

Methods: An anonymous, password-protected online questionnaire was sent by e-mail to 70 CEC chairpersons. The questionnaire contained 14 items.

Results: Of the 70 CECs contacted, 30 responded (a response rate of 43%). There has been an almost fourfold increase in the number of CECs in the past 7 years. Over half of the CECs that responded had considered three or fewer active cases and three or fewer retrospective cases in the preceding year. Eighty percent of chairpersons felt that the number of active cases considered by their committee was too low. Seventy percent of CECs had rapid response teams. Aside from low consultation caseloads, chairpersons identified a number of concerns, including education and training of members, composition of CECs, low profile and lack of funding and support. Although most respondents believed there is a need for clinical ethics support in the NHS, many noted the limited use of the services, even after efforts to increase the visibility of their CEC.

Conclusion: Despite a sharp increase in the absolute numbers of CECs across the UK, the number of cases considered by the majority of CECs is low. The findings presented here suggest we must reflect on the reasons for such low caseloads and pause to consider whether the committee model is most appropriate for the UK context.

Few professions are as fraught with ethical dilemmas as those involved in healthcare. Not only must professionals consider where they stand on notoriously controversial issues such as abortion and euthanasia, but they also face situations on a daily basis that raise less obvious, but perhaps no less important, ethical questions. In light of the ethical complexity of modern medical practice, the Royal College of Physicians, in its 2005 working paper,¹ highlighted the importance of clinical ethics support in hospitals:

Wherever healthcare is provided we believe [...] that there will be a need for formal ethics support which is both timely and informed.

Clinical ethics support is widespread in the USA and expanding in the UK.² Although we do not propose in this article to provide detailed justifications for the need for clinical ethics committees (CECs), Smith and Weise³ have recently suggested that CECs fulfil four functions: (1) to promote an ethical resolution of morally problematic clinical

cases; (2) to support comfortable and respectful communication among the parties involved; (3) to assist those involved in the case to work through future ethical uncertainties on their own; (4) to help the institution or organisation recognise patterns or issues that require attention. An example of the type of case that may be referred to a CEC appears in box 1.

Although there is some literature on the purpose and responsibilities of CECs,⁵⁻⁷ few empirical studies exist on how CECs work in practice. Two major studies investigating the consultation activities of CECs currently exist in the literature: a UK study by Slowther *et al*⁸ in 2001, and an American study, by Fox *et al*,⁹ in 2007. Slowther *et al* interviewed all known CEC chairpersons in the UK. This constituted 20 CECs, 16 of which (80%) had been in existence for less than 5 years.

The Fox study found that the median number of consultations on active cases (ie, cases where the key ethical decisions had not yet been made) in the past 12 months was three. This is mirrored in the findings of Slowther *et al*, where CECs usually had fewer than two requests for advice on active cases per year.

The idea for the present study emerged from informal conversations with members of CECs across the UK. Many of the members lamented the lack of cases referred to their CEC and the disheartening meetings with little to discuss but ways to remedy this drought. Morale in the CEC meeting rooms seemed low. So common were these conversations that we decided to conduct a formal study to shed light on the current state of CECs. The primary aim of this study was thus to establish whether there is any truth behind the anecdotes. We examined the current consultation activities of CECs in the UK, as well as the views of chairpersons about (i) their committee's activities and (ii) the challenges that their committees face.

METHODS

Participants

We contacted the chairpersons of all of the CECs associated with the UK's Clinical Ethics Network operating in acute trusts, mental health trusts and private hospitals, using email addresses listed on the website of the UK Clinical Ethics Network.¹⁰

Questionnaire

The chairpersons were invited to complete an anonymous, password-protected online questionnaire hosted on the KeySurvey website¹¹ (see online appendix 1). Invitation emails were sent out on 27

Box 1 Case example

A 30-year-old woman was admitted to the intensive care unit with a pneumococcal bacterial blood infection. She had had a splenectomy and radiation therapy for treatment of Hodgkin's disease 12 years previously, which induced a remission. On admission, she was in septic shock, with lung, kidney and liver failure. She was treated aggressively, but by day 12 remained ventilated, sedated and on dialysis. Her doctors believed there was a 50% probability of a reasonable recovery, but that she would have permanent paralysis on the left side of her body from a stroke she suffered soon after admission.

The patient was married with three young children. She had no advance directives, and her husband repeatedly stated that he was certain she would not want to live with left-sided paralysis. By day 10, he asked the doctors to withdraw life-sustaining treatment. Initially, the patient's mother strongly opposed this decision, but by day 15, she changed her mind. The doctors believe that life-sustaining therapy should be continued given the prognosis. An ethics consultation is requested. The case is adapted from Prendergast.⁴

March 2008, and reminder emails were sent out on 8 April 2008 to all CECs.

In total, the questionnaire contained 14 items, covering the establishment of the committee, the numbers of retrospective cases (ie, cases where the key ethical decisions had already been made) and active cases considered in the past year, and whether the CEC had a rapid response team. The other questions related to the composition of the committees and the qualifications of their members. Several questions gave respondents an opportunity to describe, in free text, any problems their CEC had encountered, and the measures taken to address these. They were also able to comment on whether they perceived a need for CECs in the UK. Lastly, there was an open-ended question for respondents to add any other thoughts about CECs.

Data analysis

The results of each questionnaire were compiled by KeySurvey, an online survey program, and the total responses to each question were compiled for analysis.

As distributional assumptions in the data could not be made, Kendall's tau-b (test statistic denoted by tau) was used to test for a correlation between the age of the committee and number of (a) active plus (b) retrospective cases in the past 15 months. The critical level of significance was set at 0.05.

The answers to the qualitative questions were examined thematically and incorporated into the discussion section to supplement the quantitative findings and inform the development of possible solutions to some of the problems identified with CECs.

The project proposal was sent to the Chair of the Wandsworth Research Ethics Committee for ethical consideration. It was classified as "audit" and did not require full ethical review.

RESULTS

We identified 73 CECs; 70 were successfully contacted (it was not possible to obtain the address for one committee, and two committees had been disbanded or were in abeyance). A total of 30 out of the 70 (43%) responded.

Of the 30 CECs that responded, 14 were established more than 4 years ago, 12 had been in existence for 2–4 years, three for 2 years and one was established in the past 12 months. Thirteen CECs (43%) held meetings monthly, with nine (30%) holding them every 2 months. Eight (27%) held them at other intervals, although none held them weekly.

Twenty-six (87%) chairpersons out of the 30 who responded believed there is a need in British hospitals for formal clinical ethics support. The remaining 13% were unsure of such a need.

Further findings of interest are discussed below.

(i) Presence of members with an ethics qualification and training of members

Of the 30 CECs that responded, 21 (70%) reported having at least one member with a master's or doctoral degree in medical ethics, bioethics or philosophy. Eight did not have such a member at that time, but one had a member studying for a master's degree.

(ii) Number of consultations

Three (10%) CECs had considered no active cases in the past 12 months, while 13 (43%) had considered between one and three active cases, nine (30%) had considered between four and six, and four (13%) had considered between seven and nine. One (3%) had considered between 10 and 15 active cases.

Three (10%) CECs had not considered any retrospective cases in the past 12 months, whereas 13 (43%) had considered between one and three retrospective cases, and 11 (37%) had considered between four and six. Three CECs had considered seven or more cases.

There were no significant correlations between the age of the committee and number of active cases considered in the past 12 months ($\tau = 0.23$, $p = 0.140$) or the number of retrospective cases in the past 12 months ($\tau = 0.17$, $p = 0.294$).

Twenty-four (80%) chairpersons felt that the number of active cases their CECs considered was too low. The six chairpersons who were satisfied with the number of cases considered by their committees in the past 12 months were either on the committees that considered many cases or on the newer committees who felt that their workload was currently sufficient.

Possible reasons given in our study for the low number of consultations included: lack of awareness or understanding of the CEC among healthcare professionals and Trust managers (mentioned by 14 respondents), the self-regulatory nature of specialties within hospitals (including physician preferences for keeping decisions under their control), the difficulty of providing consultations at short notice in acute cases, and the lack of recognition of ethical issues.

Suggestions to increase the low caseload included more publicity for the committee (including on intranet sites), involvement in the education of healthcare staff in the form of "semi-fictitious case studies", grand round presentations, an "ethics and law interest group" and training evenings. Nine respondents reported already implementing some of these.

(iii) Models for providing ethics support

Twenty-one (70%) CECs had a rapid response service to deal with urgent cases. Seven rapid response teams (33%) had not considered any active cases in the past 12 months, with 12 (57%) having considered between one and three active cases. Only two services had considered four or more.

(iv) Funding and support

Four respondents in this study reported a lack of funding and support from central government, primary care trusts and individual hospitals. However, apart from obtaining funding for salaried ethicists, few respondents could suggest other options.

DISCUSSION

The number of active and retrospective cases considered by CECs in the past 12 months is generally low, even among the well-established committees. Over half of the committees had considered three or fewer active cases and three or fewer retrospective cases in the last year. This means that over half of the CECs surveyed consider no more than one case, whether active or retrospective, every 2 months. It is not obvious how a committee's expertise in case analysis can be developed with such a small number of cases a year. Respondents made several suggestions to explain this lack of activity (see above), but more research is needed to discover the reasons for this low caseload. It is hoped that this study will encourage research into related issues, such as whether increasing publicity about the CEC in the hospital or more ethics education of healthcare staff will increase the number of cases referred to CECs.

Concerns

Our study echoes four particular concerns also raised by Slowther *et al*,⁸ Fox *et al*⁹ and the RCP working paper.¹

(i) Presence of members with an ethics qualification and training of members

In the study of Slowther *et al*,⁸ only three CECs had ethicists as members. Our study did not investigate the exact number of members with ethics degrees in each CEC. However, the fact that 70% of CECs have at least one such member is encouraging.

Given the low number of case referrals to most CECs and the consequent difficulty for members to develop expertise in clinical ethics analysis, the CECs must ideally have members formally trained in bioethics and must encourage members to attend training courses to either acquire or maintain relevant knowledge and skills. Spike,¹² for example, emphasises the need to identify a minimum level of qualification before a member can sit on a CEC and envisions training being completed over a long time to cover the basics of law, ethics and medicine.

The American Society for Bioethics and Humanities (ASBH) has suggested the core competencies necessary for effective healthcare ethics consultation.¹³ These include: the clinical knowledge to understand the medical dilemma and proposed courses of action; the training to recognise the nature of the ethical problem and to identify potential solutions; the ability to communicate effectively both as a team and with the referrer and patient; and the organisational ability to maintain records and analyse outcomes.

Some specific examples of training programmes have been suggested that could be undertaken by CEC members to improve their ability to consider ethical issues. Parsi and Kuczewski¹⁴ have described their success with simulated ethics consultations for graduate students planning to become involved with ethics consultation services. In this course, feedback is provided by tutors and other students. The Portland experience, as described by Tuohey,¹⁵ is also insightful, as he describes a well-defined part-time training programme for small teams of medical professionals which covers basic

components of law and ethics and more specific issues in healthcare ethics.

(ii) Number of consultations

Although the medicolegal climate is different in the USA and clinical ethics consultation has existed in that country since the late 1970s, it is worth noting that the ethics consultation team (consisting of four clinical ethicists, two full-time and two part-time) at Washington Hospital Center, a 900-bed hospital in Washington DC, USA, receives nearly 400 formal ethics consultations a year (as well as 400 informal or "curbside" consultations) (E DeRenzo, personal communication, 25 November 2008). At Portland St Vincent Hospital, in Portland, Oregon, USA, the (full-time) clinical ethicist at the 425-bed hospital conducts around 160 consultations a year (J Tuohey, personal communication, 26 November 2008). This situation does not seem to be typical of hospitals in the USA, however. As mentioned in the introduction, the Fox study⁹ found that the median number of consultations on active cases in the past year was three, with 22% of committees performing none, and over 90% performing fewer than 25. Slowther *et al*⁸ found a similar situation in the UK, with only eight committees out of a total of 20 discussing and giving advice on active cases.

Godkin *et al*¹⁶ have looked at ethics consultation rates in Canadian hospitals. In the nine hospitals they studied in detail, the number of consultations per year ranged from four to 250, depending on the site.

In light of this paucity of cases, it may be worth sharing clinical ethics cases between CECs (while respecting patient confidentiality), thereby giving members more experience of difficult issues and improving their reasoning skills. This more widespread dissemination, however, may dissuade clinicians from consulting the CECs.

(iii) Models for providing ethics support

The most appropriate way to provide ethics support is likely to vary between institutions, and even depending on individual situations. Therefore, many organisations may find it helpful to incorporate more than one model to be used separately or in parallel. Rushton *et al*¹⁷ have described three models for providing ethics support: full committee, small group and individual consultant. Each of these methods may be used in different situations. For example, for policy formation and in cases that are not time-pressured, a larger committee may be useful to provide multiple viewpoints, whereas in acute cases an individual consultant or small group might provide immediate advice, perhaps reporting back to the full committee. The present study reveals the widespread use of smaller teams to supplement CECs. This would allow the flexibility of rapid consultations but with the scrutiny of a multidisciplinary committee. Fox *et al*⁹ found that consultations with fewer participants were more efficient in terms of man-hours spent on each case.

The work of Godkin *et al*¹⁶ is also of interest here since the predominant model of ethics support in Canada is a single ethicist, rather than a full CEC. Godkin *et al* found an average of 184 consultations per ethicist per year (not taking into account one outlying result).

The possibility of a professional clinical ethicist, who could be the point of contact for clinicians in need of ethics support, was also demonstrated in the Portland model.¹⁵ The addition of a professional clinical ethicist, especially in larger hospitals, was recommended by the Royal College of Physicians in the 2005 working paper.¹

(iv) Funding and support

The study of Fox *et al*⁹ found that the amount of publicity and number of different media used to publicise were statistically related to the volume of cases referred for consultation.

Several respondents in our study claim to have tried publicising the CEC around the hospital, but with meagre success. This study also shows that CEC chairpersons feel insufficiently supported financially. CEC members are not remunerated, and chairpersons have little administrative support. Combined with the low activity levels, this perceived lack of support can lead CEC members to feel despondent about their involvement. There is also the risk of a vicious circle: whereas chairpersons may want greater resources to train and publicise their CEC in order to increase the number of referrals, Trusts may wonder why they should inject money into their CECs if most of them have low caseloads.

Limitations and future study

This study examines the provision of clinical ethics support through a formal process. It does not take into account the informal discussions between professionals and committee members ("curbside consultations") which never reach the CEC. Some respondents, however, may have had a more inclusive understanding of "case". It is likely that a far greater number of ethical discussions about clinical cases occur outside of formal CEC meetings.

Another limitation of the study is the relatively low response rate (43%). It is unclear why the response rate was not higher. The chairpersons who did not respond may have been too busy to complete the questionnaire, or were perhaps put off by the online format. It is possible that the chairpersons who responded were those who felt most strongly, whether in a positive or negative manner, about the work of their committee.

One issue that was not raised in our study but which would be an avenue for future research is the authority given to CECs, both in law and by healthcare professionals in practice. Doyal² emphasises the necessity for CECs not to overstep their boundaries. The role of CECs is to provide clinicians with an ethical analysis of a given problem and to offer some advice, but the clinical team caring for the patient makes the final decision about patient management.

Lastly, certain writers, among them McLean,¹⁸ have expressed concern about the possible legal ramifications of CECs recommending courses of action, as well as the lack of scrutiny in the appointment of CEC members.

CONCLUSIONS

This study highlights some areas of concern. Many respondents had similar worries to those raised in the studies of Slowther *et al*⁸ and Fox *et al*,⁹ such as a general lack of awareness among clinicians of, and support for, the CEC. The fact that most committees now have qualified ethicists as members, or are planning to have such members, is an encouraging finding from this study. However, the Fox and Slowther studies draw on data from 7 years ago. It is concerning that, in spite of a significant quantitative growth, the number of consultations brought to the CECs remains low. That over half of the committees had considered three or fewer active cases in the past year, despite earnest efforts to publicise the CEC, suggests it is time to

Main messages

- ▶ The number of clinical ethics committees (CECs) in the UK has increased fourfold in the past 7 years.
- ▶ However, the number of active and retrospective cases considered by CECs in the past 12 months remains low.
- ▶ Studies to investigate the reasons for such low referrals in the UK are needed.
- ▶ The committee model may not be the most appropriate method of ethics support for the UK context.

reconsider whether this model of ethics consultation is most appropriate in the UK context. Clearly, more research is needed to elucidate the reasons for the low number of referrals. Perhaps such research will reveal ways to salvage the committee model. However, it may be that a change in focus from CECs to small "satellite" teams, individual ethics consultants, or both would increase the flexibility, use and value of ethics consultation services. At the moment, the stark reality about CECs in the UK is that clinicians are not using them.

Competing interests: DS is a member of two clinical ethics committees and has spent time in North America working with clinical ethicists.

Contributors: DS had the idea for the study. He devised the questionnaire, collected the data and helped in the writing of the article. The literature search, data analysis, and much of the writing were carried out by JW. DB and PS contributed to the interpretation of the data and the drafting. PS performed the statistical analysis.

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