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## ETHICS COMMITTEES

# The use of clinical ethics committees in infertility clinics

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### Abstract

Clinical ethics committees (CECs) are increasingly used in UK health care (Slowther et al., 2004a). However, there has been little debate about their use in infertility units. Current HFEA guidance on CECs encourages their use in aiding ethical decision making but this is not required by the code of practice or obligated by law. It will be argued that the HFEA should strengthen its guidance on CECs by recommending that all infertility clinics should have a designated CEC (where possible) as a matter of good practice and such a recommendation should be formalised in the HFEA's Code of practice. The article will conclude with recommendations for a particular model of CECs in infertility units.

**Keywords:** *Clinical ethics committees, ethical decision making, ethics, infertility clinics*

### Introduction

Clinical ethics committees (CECs) are increasingly used in UK health care (Slowther et al., 2004a). However, there has been little debate about their use in infertility units. Current HFEA guidance on CECs encourages their use in aiding ethical decision making but this is not required by the code of practice (HFEA, 2000) or obligated by law. It will be argued that the HFEA should strengthen its guidance on CECs by recommending that all infertility clinics should have a designated CEC (where possible) as a matter of good practice. This article will first consider, why ethics support is needed for infertility clinicians. Then, the benefits that CECs can bring to ethical decision making and the possible problems with them will be explored. Finally, the article will conclude by recommending that a designated CEC, where possible, for all infertility units is the best way of organising such committees in this area.

### Background

CECs are a relatively recent feature of medical practice in the UK. They are more established in the US where, since the early 1980s, most hospitals have

established a CEC to address the ethical issues raised by patient care (Slowther & Hope, 2000). CECs have also developed in Europe, although more slowly than in the US (Slowther et al., 2004b; Hurst et al., 2007). The functions of CEC are various and Slowther et al., (2004a) summarise these as falling into three areas: providing ethics input into hospital policy and guidelines; organising ethics education within a trust; and providing advice to clinicians about individual cases. CECs differ from research ethics committees in that their decisions are not legally binding. Trusts are under no obligation to have such committees and their operation is not governed by any central regulation.

The increasing number of CECs are a result of the growing recognition that doctors, generally, need more support for their ethical decision making. The Royal College of Physicians (RCP) established a working party in 2004 to consider what kind of ethics support would be most valuable for clinicians at a local level. This working party arose out of a, 'perceived need to ensure that decisions are ethically as well as clinically defensible' (Royal College of Physicians, 2005:ix). This greater focus on the ethical aspects of medical practice has been well documented (Parker, 2004; Watson, 2005). There are a number of reasons for this trend: the general

shift from medical paternalism; high profile incidents such as Alder Hey and Bristol; advances in medical technology; a general shift to the greater accountability of professions and a demand that decisions are made on the basis of 'evidence'. This shift in both the organisational delivery of health care and the increasing focus on ethical issues raised by medical practice have resulted in a number of developments, one of which is a demand for more formalised ethics support for health care professionals than currently exists.

The RCP Working Party concluded that, 'there will be a need for formal ethics support which is both timely and informed. This can no longer be left to chance or allowed to depend on the enthusiasm of individuals' (2005:37). One of the main ways the Working Party envisage this support being provided is by CECs. This view has also been reiterated by other bodies, for instance, The Nuffield Report on ethical decisions in fetal and neonatal medicine also recommended that neonatal intensive care units could benefit from general and specific advice of a local CEC. (Nuffield Council of Bioethics (NCOB), 2006) The study of CECs in the UK carried out by Slowther and colleagues also found that many clinicians and managers believed that some form of ethics support was desirable and a CEC was favoured by 62% of respondents, 26% favoured an ethicist and 12% suggested some other form of support (Slowther et al., 2001a:i4) This need for ethics support from CECs is born out by the increase in the number of CECs in the last 20 years in the UK (Slowther et al., 2001a, 2004a). Other forms of ethics support could include having a clinical ethicist employed by the trust and increasing undergraduate and postgraduate ethics training. This article will concentrate on the debate over the use of CECs in infertility clinics as, to date, this has been the most prevalent method of ethics support in this area (Frith, 2009).

### **Clinical ethics committees in infertility clinics**

Despite this general trend towards the increased use of CECs in medical practice, there has been little debate over their use in the infertility setting. Recommendations about the use and formulation of CECs have never been included in the HFEA code of practice. The current guidance states that, 'the HFEA encourages licensed clinics to make use of ethics committees [to aid the person responsible (PR) in their decision-making]' (HFEA, 2000:1) In 2005 when the House of Commons Science and Technology Committee (HC) reviewed the HFE Act 1990 they heard evidence on the role and use of CECs in infertility units. Slowther and Hope from the ETHOX Centre in Oxford, who have conducted

much of the current research on CECs in the UK, commented: 'Ethics support at unit level is valuable despite the existence of a national statutory body [the HFEA].' (House of Commons (HC), 2005:150) As a result of this, and other evidence (Doyal, 2005), the Committee recommended that, 'there are merits in the creation of a nationally coordinated network of CECs to parallel the arrangement for local research ethics committees.' (HC, 2005:186) In response the government said, although it recognised the need for such committees, it would not wish to establish national guidelines and regulations for CECs, '[we are] not convinced that attempting to direct centrally the conduct and decisions of local CECs in the manner recommended is an appropriate role for central government.' (Department of Health, 2005a: Recommendation 84). Consequently, there is no mention of CECs for infertility units in the 2008 HFE Act that has been passed by parliament. This is, arguably, a missed opportunity to ensure that all units have a more formalised system of ethics support available.

There are, broadly, three ways that infertility units have access to CECs (Frith, 2008) and the merits of these different models will be considered later in the article.

1. Units who do not have a CEC – they rely on either taking difficult cases to their PCT or using a central ethics committee that serves a number of units in their region.
2. Units who use the general hospital CEC to take any cases they want to discuss.
3. Units who have a designated CEC for their infertility unit, a committee organised by the Trust that only deals with issues from that particular infertility unit.

There is little data that give a comprehensive picture of cases taken to CECs in the infertility setting. One study (that did not survey CECs but interviewed infertility clinicians about the ethical aspects of their practice) gives some indication of the kind of cases taken to CECs by infertility units (Frith, 2008). One case was a 16-year-old girl who was likely to undergo early menopause. The debate was over whether to freeze her eggs for her use in the future. The clinician thought this was a complex case that could generate a number of potential scenarios and merited more detailed and specialist discussion than could be provided within the clinic. Another area debated by a unit's CEC was the relevance of the Human Rights Act (that came into force in 2000) to the practice of the unit. The CEC argued that the unit could be seen to be discriminating against same-sex couples and single women because they did not offer treatment to these

groups. This led to a change in the unit's policy and they began treating these patients. Generally, CECs were used to: discuss complex cases; where there was disagreement in the unit; and to consider cases that might set a precedent for future practice (Frith, 2009).

### **The case for the use of clinical ethics committees**

#### *Strengthen the process of ethical decision making*

One of the main advantages of CECs is that they provide a valuable mechanism for strengthening the process of ethical decision making (Fleetwood et al., 1989; Slowther et al., 2004a). This focus on the process of ethical decision-making can encompass various elements. CECs are usually multi-disciplinary bodies and decision-making can be improved by bringing together the views and standpoints of a diversity of specialisms and people (Larcher et al., 1997; Slowther et al., 2001a). For instance, in the case mentioned above of the 16-year-old girl requesting egg freezing, the views of a number of different specialisms such as paediatricians and those who work with adolescents could be invaluable to the discussion. CECs can also facilitate a transparent decision-making process to ensure that ethical decisions are made openly and appropriately (Slowther et al., 2004b; Frith, 2008). This contribution to the process of decision-making gives the CEC a role akin to a Greek Chorus (King, 1996). The objective of the CEC is not necessarily to make decisions. Rather, it is to act as the place where difficulties, uncertainties and ambivalence can be aired and this reflection can be used to aid the ethical decision-making process for future cases (Gillon, 1997).

#### *Managing disagreement*

CECs can also be a useful forum for taking cases that a unit has not been able to reach an agreement over. Larcher et al. (1997) found that the lack of a forum to resolve disagreements and tensions within units was a reason advanced for using CECs. Watson (2005), in his clinic's guidelines for ethical decision making, recommended considering consulting a CEC if a consensus in the unit could not be reached. Therefore, CECs can provide a forum external to the unit to resolve contested issues. This potentially only removes the problem of getting a general consensus to another level – what if the CEC cannot reach agreement? This is a problem with any form of group decision making. However, the role of the CEC, as noted above, to be an informative discussion forum means that the committee is not necessarily the place

where the final decision is taken. It is rather the forum where competing issues and values are debated to inform the decision taken – a consensus of opinion does not always have to be reached for a decision to be made.

#### *Writing guidelines*

CECs have also been advanced as the appropriate place to write and develop ethical guidelines for the unit (Doyal, 2001; Sokol, 2005). For instance, all units have to have clear policies for assessing the welfare of the child and this could be formulated by a CEC that has the relevant expertise and diversity of views to adequately draft such guidelines.

#### *HFEA and ethical awareness*

In the HFEA code of practice it states that the PR should have, 'sufficient insight into the scientific, medical, legal, social, ethical and other aspects of the centre's work' (HFEA, 2007:G.1.1.1). And further, personnel should be provided with initial training in, among other things, 'the broader ethical, legal and regulatory context of their work' (HFEA, 2007: A.10.11). CECs can also be given an educational role that can further these HFEA requirements. A CEC could be a good forum for co-ordinating the ethical professional development of clinic staff and making sure all staff had access to appropriate training in this area.

### **Limitations of clinical ethics committees**

#### *Bureaucracy*

CECs could be seen as adding another layer of bureaucracy to an already overburdened health care system (Slowther et al., 2001a, b). In response to this it could be argued that CECs can be used as discussion forums to clarify and extend deliberation rather than bureaucratic bodies requiring arduous formalised paper work. Experiences with research ethics committees have led to complaints about the increase in paper work and whether or not an increase in bureaucracy promotes ethical research (Department of Health, 2005b). A danger with such committees is that they become seen as the place that ethics takes place and once approval for the study has been gained ethics can be put to one side. Hence, it is important that CECs do not suffer the same fate and become seen as the only place where the ethical aspects of practice need to be considered. Ethics should be an integrated part of good medical practice (GMC, 2006) and not something that can be 'signed off' by a committee and subsequently forgotten about.

*Legal status of committees' deliberations*

The legal status of their decisions and/or deliberations is sometimes ambiguous and needs to be clarified (RCP, 2005; McLean, 2007). However, the HFEA is clear that the responsibility for any decision is that of the 'PR' and therefore CECs only give guidance and advice, they do not have any legal standing as a decision-making body (HFEA, 2000).

*Do clinical ethics committees have any moral authority?*

It has often been asked what gives CECs their moral authority, why should clinicians take advice from such a body? Blake notes that this is an important question otherwise a CEC is, 'a contradiction in health care: a collection of health care professionals with no moral authority engaged in the practice of ethics' (Blake, 1992:298). His solution to this problem is that CECs should become a representation of the hospital's moral community that has, 'the responsibility for and the representation of those values and practices that define the health care institutions as a moral community' (Blake, 1992:297). Reiser (1994) also argues that health care institutions have inherent values and closer attention should be paid to ensuring that these values cultivate a 'humane ethos'. It could be argued that CECs should aim to use and build on these values and it is this that gives them their collective moral authority. However, there are difficulties in determining what an institutions values are and gaining agreement on a core 'set' of such ethical values (Parker, 2000), so resting the moral authority of a CEC on these grounds might be impossible in practice. It is, rather, the process that a CEC uses in its deliberations that gives them a form of moral authority – the open discussion of cases and the attempt to consider all sides and aspects of an issue. Although this cannot always be guaranteed in CECs' discussions, an attention to the process of deliberation itself and clear committee operating rules can help facilitate a robust and defensible process of ethical deliberation.

Despite these limitations, there is a good case to be made for saying that CECs can bring a more robust procedure to ethical decision-making in the infertility clinic and can be a useful forum for supporting and advising clinicians on difficult cases (Fleetwood et al., 1989).

**Models of clinical ethics committees**

Having established the utility of CECs in the ethical decision making, the key question becomes how to organise CECs so that they can offer genuinely useful ethics support to clinicians without imposing too

many bureaucratic burdens. As noted above, there are three ways of organising CECs in infertility units. The third way of organising CECs, having a designated CEC for a particular infertility unit is, to my mind, the optimum way of organising this form of ethics support for infertility clinicians. The advantages of having a designated committee are:

1. Greater awareness of its existence and therefore a greater likelihood of it being used. A recent study found that those working in units who used their general hospital CECs were often not aware of that forum for discussing ethically problematic cases (Frith, 2008).
2. A designated CEC for the unit would provide a clear structure as to where ethically troubling cases should go, therefore avoiding any ambiguity over where to take such cases.
3. There would be time to adequately discuss issues. A possible disbenefit of using a general hospital CEC was that they might be very busy and therefore not have the time to discuss all cases as promptly as it desirable (although this might not be true for all hospital CECs).
4. Guidelines and clinic policies could be debated in more detail than might be possible at a general hospital CEC.
5. The committee could build up an expertise in the area of reproductive technologies and therefore be of more help than a general committee called upon to service all specialities.
6. The committee could organise and be responsible for ethics training and dissemination of information to those working in the unit.

There are also disadvantages of such a designated CEC. First, a possible problem with such committees is that they might not be frequently used. A recent study found that the meetings of those with designated CECs were sometimes cancelled because there were no cases to discuss (Frith, 2008). However, discussing individual cases is only one the function of CEC (Slowther et al., 2004a) and if the CECs also took on a role in providing education and ethics information for clinic staff then meetings would not have to rely solely on case presentations. Here a clinical ethicist could be useful in advising and supporting the committee in its educational role.

Second, some units are very small and this would make it difficult to have a designated committee. This is an important practical problem: a solution could be a CEC that served a number of units, to ensure that there was some forum to take problematic cases. The proposed change to the HFEA's policy on CECs would state that it is recommended

as 'good practice' to have a designated CEC, recognising that for some units that might not be possible.

Finally, a designated committee for a unit presents its own problems. The membership of such committees is often contentious. One important benefit that CECs bring to ethical decision making is hearing opinions from a wide range of people, people from other professions, clinical disciplines and lay people. One danger is that such a committee might develop a narrower perspective on issues than a general hospital CEC might. The RCP report recommends, CECs should be 'genuinely multi-disciplinary' (RCP, 2005:38). It is important that a designated CEC for a unit is made up of a sufficient variety of people both lay and different professions to provide the breadth of experience necessary. Of course, having a diverse membership does not necessarily ensure pluralistic discussion of issues (Fleetwood et al., 1989). Good training for members of CECs could play a role in ensuring that breadth of perspective and the quality of decision making is maintained. Therefore, it is important that members of CECs are given the appropriate level of training and have sufficient expertise to fruitfully aid ethical deliberation (Williamson, 2008). Further, the operating rules of CECs can be used to encourage 'an open analysis of ethical issues' by for example getting the chairperson to, 'explicitly ask for objections or appointing committee members to raise objections to the majority view' (Fleetwood et al., 1989:140–141).

A further question about the membership of a designated CEC for a unit is the role of the PR. Should they be on the committee and what should their role be if they are? Generally the PR is a member of the designated CEC (Frith, 2008) and it could be argued that there is a danger that the committee could simply become a rubber-stamp for the PR's decisions. There are two possible responses to this. First, as has been argued, a CEC is not a decision-making body rather it is a place for ethical reflection and deliberation and this is used to support and aid decision-making. Second, the PR is the one who is legally the decision maker and hence their influence on any decision is inevitable. It is, however, better that such decisions are informed by a wider debate than taken by the PR alone and this process of debate can improve ethical decision making.

## Conclusion

It has been argued that, if possible, a CEC specifically designated for an infertility unit would be the most advantageous way of organising CECs in the infertility setting. More research is required on

the benefits and uses of CECs (RCP, 2005; McLean, 2007) and, specifically, on their use in infertility clinics. However, despite this need for continuing evaluation, the case for the utility of CECs is a strong one and more infertility units could benefit from their use. Therefore, it is recommended that a designated CEC for a unit can provide both a focus for ethical decision-making and a means of organising ethics education and training for those working in infertility clinics.

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