Use or ornament? Clinical ethics committees in infertility units: a qualitative study

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Abstract

This paper examines the role of clinical ethics committees (CECs) in infertility clinics in the UK, focusing on whether they usefully support infertility clinicians' ethical decision-making. The overall aim of the study reported here was to investigate how infertility clinicians approached and handled ethical problems in their everyday practice and this paper reports on one aspect of these data – what they thought about the use of CECs. This paper gives an overview of what arrangements there are for such committees in infertility clinics; considers why the clinicians used CECs; and examines how these committees provided a useful function in the infertility setting and contributed to making 'good' ethical decisions. Finally, the paper examines how the form of ethics support can be developed and strengthened, and concludes with recommendations for a particular model of CECs in infertility units – a designated CEC for each infertility unit.

The development of clinical ethics committees

Clinical ethics committees (CECs) are a relatively recent feature of medical practice in the UK and are more established in the US where, since the early 1980s, it has been recommended that hospitals have a CEC as a way of addressing ethical issues raised by patient care. 1,2 CECs have also developed in Europe,³ again more slowly than they have in the US.⁴ The functions of CECs are various: Slowther et al. summarize these as falling within three areas: providing ethics input into Trust policy and guidelines; organizing ethics education within a Trust; and providing advice to clinicians about individual CECs differ from research ethics committees in that their decisions do not have any legally binding status, Trusts are under no obligation to have such committees and their operation is not governed by government regulation. The number of CECs in the UK is steadily growing. In 2001, only 20 Trusts had a formal CEC;6 by 2004 68 CECs were registered with the UK Clinical

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Ethics Network;⁵ and in 2008 there were approximately 82 CECs registered with the Network.

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'. This increasing focus on the ethical aspects of medical practice has been well documented.^{8,9} The 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'. 10 One of the main ways the working party envisaged this support being provided was by CECs.

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. There is no formal requirement for infertility clinics to have a CEC. Recommendations over the use and formulation of CECs have never been included in the Human Fertilisation and Embryology Authority's (HFEA) Code of Practice. The current guidance simply states that, 'the HFEA encourages licensed clinics to make use of ethics committees [to aid the person responsible in their decision-making]'. This paper examines the utility of CECs in infertility clinics, arguing that this form of ethics support

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can be a useful mechanism for aiding clinicians' ethical decision-making.

Study design and conduct

The study presented here aimed to build up a detailed picture of how ethical decisions were approached in infertility clinics. The main research questions were

- What aspects of their practice do infertility clinicians find ethically troubling?
- How do they approach and think about these aspects of their practice?
- How do infertility clinicians make ethical decisions and/or resolve ethical issues?

Infertility clinicians working in licensed centres were selected from the list held by the HFEA and sent a letter that outlined the study and invited them to participate. The aim was to get a broad geographical spread throughout the UK and length of clinical practice: both of these sampling aims were achieved. The study received research ethics committee approval from the relevant Multi-centre Research Ethics Committee. The participants received no remuneration for taking part in the study.

Twenty-two interviews were conducted (by the author) with infertility clinicians and data were collected until theoretical saturation was reached (defined as stopping data collection when no new data were emerging for the categories and the relationship between categories was stable). The interviews were semi-structured, with the interviewer following a topic guide that allowed the informants to expand and elaborate on different areas and the interviewer to probe interesting responses. Once an interview had been

conducted the interviewee was asked if they could suggest any other clinicians in their clinic who might be interviewed. This was a form of snowball sampling, whereby the researcher used the informants to establish contact with others. ¹³ This method can have the disadvantage of recruiting like-minded people and therefore, possibly, 'biasing' the sample. However, this method was only used within each clinic and new clinics were approached by an introductory letter.

The interviews lasted for an hour (on average) and were taped and transcribed, with pseudonyms given to the clinicians to ensure confidentiality (see Table 1). One interview did not record and the interviewer made detailed notes after the interview: therefore the responses of this doctor are included in the analysis but not with verbatim quotes. A thematic analysis was undertaken, with the transcripts coded for concepts and the relationship between concepts explored using the constant comparative method. The overall aim of the study was to investigate how infertility clinicians approached and handled ethical problems in their everyday practice, and this paper reports on one aspect of these data – what they thought about the use of CECs. The type of CEC available to the clinics visited for this study are summarized in Table 2.

Results

Why the clinicians used CECs

Disagreement

Dr Marsh explicitly stated this as a reason for using what was, in his clinic, a Clinical Ethics Group:

'There will be areas where we will disagree, and there will be a debate. It's just in those, if there's a big disagreement then,

Table 1 Sampling matrix

Clinician pseudonym	NHS or private	Length of practice (years)	Sex	Seniority/position	Clinic number
Dr Adams	Both	20	М	Consultant	5
Dr Brown	Both	14	М	Consultant	5
Dr Case	Private	16	M	Director of Unit	
Dr Down	Both	25	M	Clinical director	1
Dr Evens	NHS	29	F	Consultant	1
Dr Francis	NHS	10	F	Consultant	1
Dr Grant	NHS	2–3	М	Senior Registrar, just finished specialty training	1
Dr Havers	Both	25	M	Consultant	2
Dr Iniman	Mostly NHS	20	F	Consultant	2
Dr Jenson	Mostly NHS	12	M	Consultant, head of unit	
Dr Kilm	Both	15	M	Consultant	3
Dr Lovate	Mostly private	35	M	Consultant, semi-retired	2
Dr Marsh	NHS	3	M	Subspecialty trainee	2
Dr Novack	Both	16	M	Consultant, head of unit	4
Dr Orben	Both	24	M	Consultant	3
Dr Percy	NHS	3	F	Subspecialty trainee	2
Dr Quest	NHS	3	M	Subspecialty trainee	4
Dr Robin	NHS	3	F	Subspecialty trainee	4
Dr Street	NHS	3	F	Subspecialty trainee	4
Mr Tarn	Mostly NHS	20	М	Consultant, head of unit	
Dr Urban	NHS	5	F	Subspecialty trainee	5
Dr Vance	NHS	26	М	Consultant, head of unit	

Table 2 Organization of CECs in the

Clinic	Structure of clinical ethics committee
Clinic 1	Had a designated one for their unit, organized by the hospital trust. Used to ratify any guideline and policy changes and discuss difficult cases
Clinic 2Dr HaversDr InimanDr LovateDr MarshDr Percy	Did not have one organized by the hospital but had an informal Clinical Ethics Group organized by consultants and interested parties
Clinic 3 Dr Kilm Dr Orben	Did have one but as it was used so infrequently it has now been disbanded
Clinic 4 Dr Novack Dr Quest Dr Robin Dr Street	There is a hospital-wide clinical ethics committee
Clinic 5 Dr Adams Dr Brown Dr Urban	Had a designated one for their unit, organized by the hospital trust in which all ethical cases and discussions took place
Dr Case	Could use a central one that served a number of private units
Dr Jenson Dr Tarn Dr Vance	There is a hospital-wide clinical ethics committee There is a hospital-wide clinical ethics committee Have a committee designated for their unit, organized by the Trust

obviously, our effects are very grave, you can seek help from the local ethical committees'.

In the same unit Dr Iniman also stated that if it was a 'moot' decision they would take it to the ethics group. Dr Vance and Dr Percy said if their units could not decide how to respond to a case they would take it to the CEC. Disagreement is often seen as a common reason for taking a case to a CEC; for instance Larcher et al. ¹⁶ found that the lack of a forum to resolve disagreements and tensions within units was a reason advanced for using CECs. Watson, ⁹ in his clinic's guidelines for ethical decision-making, recommended considering consulting a CEC if a consensus could not be reached.

Complex cases

Dr Novack summed up the use he made of the CEC when contrasting two cases. The first case was of an Asian couple who wanted to use a friend of theirs as an egg donor because of the shortage of Asian donors. The issue was that the donor was 40 years of age, which was older than the normal guidelines for donors. He said:

'That couple I won't take to the ethics committee because I don't think its complex enough. That couple, I mean I could take the decision myself, but what I would tend to do and what I plan to do is discuss it in one of our clinic meetings'.

Whereas another case, concerning whether to freeze the eggs of a 16-year-old girl who was likely to undergo very early menopause, raised more complex issues and he thought it should be taken to the CEC. This points to a view that the CEC might be a better place to engage in a more involved discussion than the clinic meeting.

Guidelines and precedence

The CEC was often seen as the more appropriate forum for setting general guidelines and clinic policies than a clinic meeting. ^{17,18} Dr Adams illustrated how his CEC had formulated guidance on a particular issue:

'With the Human Rights Act, we revisited the question in the Ethics Committee. The Ethics Committee felt that we were discriminating against single women and lesbians, and that we should treat them, so we do now'.

Dr Grant talked about using the CEC to formulate unit policy on age limits for male partners.

CECs were also used if it was thought that the decision might set a precedent and the CEC opinion might be useful for the clinicians to refer to in future cases. Dr Iniman described a case where a couple had wanted to use the husband's father's sperm for treatment because the husband was unable to produce any himself:

'We might take it to [the ethics group] anyway actually, even if we can clearly make an in-house decision on it, we might take it to them because it's such an interesting point and there might be similar future referrals'.

How CECs helped in making ethical decisions Wider discussion

The main benefit that the informants thought could be gained by using CECs was the opportunity to discuss issues and cases more widely and to get a range of opinions from a broader spectrum of people. Dr Urban summed these points up when she said:

'Yes, but it's sort of, these meetings are for that reason that you listen to everybody's views, and it's very good in that three of four lay persons are there that have nothing to do with that. They don't know how we work, and getting their views is useful'.

Dr Down and Dr Novack saw the CEC as an intelligent sounding board. Dr Francis thought that CECs could give 'a more balanced view'. The informants saw this process as one that would facilitate the making of more balanced and considered decisions.

Dr Orben thought that CECs could help keep clinicians' decisions in line with 'everyday' thinking and could act as a kind of 'check' on the acceptability of their decisions to the wider community:

'What do they bring? Well, you hope they bring common sense and a view of what's representative and what's acceptable to society. I suppose because we are so close to it and do it all the time, you view things differently from the man on the street, I guess, and so you want to test that out with normal people instead of strange people I suppose'.

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Thus CECs were, for the clinicians, forums where one could get a wider range of opinions and a greater sense of perspective on issues. This sharing of decision-making gave the clinicians a sense of safety in numbers. Dr Brown said, 'It also gives you some protection in the final decision' and others found it reassuring to know that the CEC was there (Dr Percy).

Detachment

Another particular feature of CECs that the informants valued was that such committees were not involved in the case and did not know the participants. This detachment helped the decision to be made more 'impartiality'. Dr Francis commented:

'Which links into what the ethical committee does, because they've not met the patient, they're not, so they can look at it in a slightly more as a problem to solve rather than just to kind of get the action done because we're there at the time'.

Dr Brown said committee members could 'look dispassionately at a situation'. Dr Evens agreed with this and said it is useful, 'to ask a sort of a wider group of people who are not connected with the actual delivery of service what their views are'. Dr Percy argued that CECs could aid the transparency of decision-making:

'And I think it's often helpful to talk to people from different clinical backgrounds as well. You can get very focused in your own, and I think it's often quite helpful to have to spell out actually how do we make this sort of decision and why is this one particularly difficult?'

The clinicians thought that others who were either not involved with the particular case or the specialism as a whole could make more impartial and hence more defensible decisions. CEC members were less likely to have become inculcated into the dominant thinking of the clinic – the CEC could provide a fresh view of the problems and issues.

Limitations of CECs

Although CECs were often mentioned as useful bodies to aid ethical decision-making, there were a number of concerns about their use. These concerns were different depending on the organizational structure of the committee available to the clinic. In this study the units visited had three main ways their CEC or ethics group was organized (see Table 2).

- (1) There were those units without a CEC at all (Clinic 3 and Dr Case's unit); they relied on either taking difficult cases to their PCT (Clinic 3) or using a central ethics committee that served a number of private units in their region;
- (2) There were those units (Clinics 4, Drs Jenson and Tarn) who used the general hospital CEC to take any cases they wanted to discuss. Unit 2 had an Ethics Group, which was not a formal CEC;
- (3) There were three units (Clinics 1, 5 and Dr Vance) who had a designated CEC for their infertility unit;

this was a committee organized by the Trust that only dealt with issues from the infertility unit.

Those in clinics with the first form of organization were not overly concerned that they did not have access to a CEC based at their place of work; the CEC in both Clinic 3 and Dr Case's unit had disbanded due to lack of use. Dr Kilm said:

'Well, I think it's sort of, for what use it was, it sort of folded up. Because it was used very, very infrequently it sort of stopped, we just stopped using it, I think it just. So if there is a problem, I guess now we would probably just discuss it as a group and then take it from there'.

Those clinics with the second form of organization raised a number of problems with this arrangement. Members of Clinic 4, that used the hospital CEC, had a very low awareness of the existence of such a committee and that ethical cases could be taken there. It appeared to be mainly used by the head of the unit if a case was sufficiently complex to merit extended discussion. Dr Novack said the reason he did not use the hospital's CEC much was due to the lack of regular meetings that meant the committee could not be responsive enough. Dr Orben, when talking about when his clinic used to use the hospital CEC, pointed to their lack of experience:

'We used to use the hospital one but they were so sort of knocked sideways when we asked them anything that now we tend to leave it to the PCT who seem to have a better formed group, and they [hospital committee] really struggled very hard to come to a conclusion with anything we would ask them to do'.

In Clinic 2 they had a Clinical Ethics Group rather than a committee as such, that was run by 'keen consultants' and a philosopher from the university. Dr Iniman raised the problem of the ambiguous status of the clinical ethics group in her clinic. This meant that she was not sure where to go to for advice and what 'status' that advice had. Dr Havers from the same clinic also felt that he did not have access to adequate ethics support.

Clinicians from the clinics that had designated CECs (1, 5 and Dr Vance) appeared to be more aware of their existence (which is not surprising) and used them more frequently. But Dr Urban from Clinic 5 and Dr Vance both mentioned that meetings had to be cancelled due to the lack of anything to discuss. An explanation for why CECs were not frequently used could be that the first port of call was often the clinic meeting and it was in this forum that most of the difficult cases could be resolved. This is something that has been reported in other studies:^{6,19} Hurst et al.²⁰ noted, 'ethics consultation appears to be perceived as a last resort rather than as the primary source of help in cases of ethical difficulty'. However, the clinicians from Clinic 1 – which had a longestablished CEC that they had formed themselves and subsequently asked the Trust to take over - reported many long discussions over cases and policies in their CEC and did not report the cancellation of meetings due to lack of material to discuss.

Discussion

The informants in this study thought that ethical decisions were best taken by a group trying to reach a consensus. 21,22 The CEC extended this consensus decision-making by giving them a wider group of people with which to discuss issues. The CECs provided a useful function in fostering a greater awareness of ethical dimensions of practice. This increasing awareness can give the CEC a role akin to a Greek Chorus.²³ The objective of the CEC is not necessarily to make quick decisions or indeed the 'right' ethical decision. 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.²⁴ It is this facilitation of the process of ethical decision-making that can be strengthened by CECs, 1,6,22 and this process is important for making 'acceptable' ethical decisions.²¹

This greater input from others could act as a check on the informants' decisions and ensure they were in touch with wider public opinion on ethical matters. Whether or not CECs can fulfil this role fully is a moot point. As one clinician mentioned, the membership of CECs is not always representative of a population, so they could be just as out of touch with public opinion as the clinicians. Further, it can be asked whether being aligned with public opinion should, necessarily, be the aim for ethical decision-making? This criticism captures an important worry about consensus decision-making over moral matters – that the majority view might come to dominate without any further moral justification. Clearly, simple coherence with public opinion would not fully justify a decision, but clinicians who work for public bodies (such as NHS Trusts) do have to bear in mind the public's reaction to their work. There were also a number of limitations with the use of CECs raised by the informants: that they were not often used; that they lacked expertise to advise on issues; and that it was unclear what status their decisions had.

What kind of model of CEC?

From the data on the benefits and uses of CECs and the issues raised by different structures of CECs, a tentative proposal can be put forward as to how best to organize CECs for infertility clinics. The key question is how to set up CECs so that they can be useful and offer genuine ethics support to clinicians rather than simply being an increase in bureaucracy. The three models of CECs described in the infertility clinics taking part in this study offer a useful opportunity to compare and contrast different forms of CECs.

It will be argued that having a CEC designated for a unit can overcome some of the limitations of CECs discussed above and has a number of advantages over other ways of organizing this form of ethics support.²⁵

First, there would be a greater awareness of a designated CEC's existence and therefore a greater likelihood of it being used. One of the issues that arose out of the data was that in the clinic that used the hospital CEC

(Clinic 4), some of the clinicians did not know that it existed and thus did not know there was a forum for discussing ethically troubling cases. For those clinics that did not have close links or access to a CEC, a designated committee can provide a clear forum for discussing difficult cases.

Second, a designated CEC would provide a clear structure as to where ethically troubling cases should go, thereby avoiding the ambiguity that clinicians in Clinic 2, for example, had over where to take such cases. Third, a designated CEC would be able to respond promptly when asked to consider a case. One drawback of using a general hospital CEC that came out of the data was that hospital CECs were thought not to be responsive enough. Dr Novack put this down to the hospital CEC being, 'busy and the cases are complex and it takes a lot of time'. Therefore they might not have the time to discuss all cases or be able to meet sooner enough to provide timely feedback (although this might not be true for all hospital CECs). A designated committee could give the unit more control over the CEC's caseload.

Fourth, guidelines and clinic policies could be debated in more detail in a designated clinic CEC than might be possible at a general hospital CEC. In Clinic 1 their designated CEC was used profitably to formulate guidelines and clinic policies and gave the Clinic a forum where these issues could be debated in depth. Fifth, one concern about the use of CECs that came out of the data was that hospital committees might not be able to adequately advise on issues arising in an infertility setting. This was the experience of clinicians in Clinic 3, who felt their hospital CEC did not have the necessary expertise to support them in their ethical decision-making. As Dr Orben noted, they were 'knocked sideways' by requests for advice from his unit. The relationship between a general hospital CEC and the unit might not be sufficiently close for it to be a valuable resource for the clinic. Whereas, a designated CEC could build up an expertise in the area of reproductive technologies and be able to give more nuanced and specialized advice than a general committee called upon to service all specialties. Finally, a designated CEC could organize and be responsible for ethics training in the unit. This is extending the role of the CEC from the predominant form it had in the clinics visited for this study (a forum for discussing difficult cases) to having a more educational one. Developing this function of CECs is something that fits in with HFEA policy which states that awareness of the ethical issues raised by infertility treatment is something that both the 'person responsible' and those working in the unit should have. 26 Here a clinical ethicist could be useful in advising and supporting the committee in its educational role.

However, there are also disadvantages of such a designated CEC:

 Amount of use of CECs: As mentioned, it was often said that CECs of any kind were not frequently used and meetings of those with designated clinics were sometimes cancelled. 96 Frith

- In response to this it can be argued that, first: those clinics that had designated CECs used them more than those who had other forms of CECs. Hence, having a designated CEC did increase the amount they were used. Second, this lack of use might reflect the current organizational structures of CECs in infertility clinics and if clinics had a clearly specified forum for discussing ethical issues the CEC might be used more. Finally, as just mentioned, discussing individual cases is only one of the functions of the CEC,⁵ and if the CECs also took on a greater role in providing education and ethics information for clinicians then meetings would not have to rely solely on case presentations;
- (2) Those who did not have any form of committee were not overly concerned, and some clinicians did not perceive this lack of ethics support as disadvantageous.
 - Again, this lack of concern over not having a
 CEC could, arguably, reflect the problems with the
 current organization and function of CECs.
 A CEC that had a greater role in the unit: of
 providing staff development activities; writing
 guidance and policy; and considering difficult
 cases could provide more extensive support to
 clinicians. Therefore, having a more appropriate
 form of organization of CEC a designated CEC
 could improve their usefulness in the infertility
 clinic and better support ethical decision-making;
- (3) Some units were very small and it would be difficult to have a designated committee for this type of unit.
 - This is an important practical problem and a solution to this would be a CEC that would serve a number of units (similar to the model in Dr Case's clinic); this would at least ensure that there was some clearly defined forum to take problematic cases.

It has been argued that a designated CEC for the infertility unit has a number of advantages as a way of organizing ethics support in the infertility setting. As Slowther and Hope note: 'Ethics support at unit level is valuable despite the existence of a national statutory body [the HFEA]'.²⁷

Further issues for CECs

Even if it is accepted that infertility clinics should have a designated CEC, there are still a number of practical problems that need to be considered. The membership of CECs is often contentious. One important benefit that the informants thought CECs brought to ethical decision-making was hearing opinions from a wider range of people, other professions, different clinical disciplines and lay people. Therefore, as the RCP's report recommends, such committees should be 'genuinely multidisciplinary'. It is important that a designated CEC for a unit is made up of a sufficient variety of people, both lay and professionals, to provide the breadth of experience necessary.

Of course, having a diverse membership does not necessarily ensure pluralistic discussion of issues. ¹ Good training for members of CECs could play a role in ensuring that the breadth of perspective and quality of decision-making are 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. ²⁹

The clinicians were sometimes uncertain about the legal status of the CECs' decisions and this is a matter that needs to be clarified. ^{7,30,31} Some of the informants argued that CECs could provide 'protection' for them when making a difficult decision – but exactly what this protection might consist of was, in practice, uncertain. The HFEA is clear that the responsibility for any decision is that of the 'person responsible' and therefore CECs can only give guidance and advice – they do not have any legal standing as a decision-making body. ¹¹ Consequently, educating clinicians about the role and remit of CECs is also important.

Conclusion

The participants in this study thought that CECs could perform a useful function in supporting and strengthening ethical decision-making in the infertility clinic. Having a clear process and a place to discuss cases, the CEC could make the decision-making processes of the clinic more transparent – cases would not be decided behind closed doors but in a more open forum. All these factors contributed to making 'better' ethical decisions for the clinicians, decisions that were made on the basis of a stronger consensus and were in turn more impartial. In this way the committee could act as a check and balance on the decisions made in the unit, ensuring the consensus was subjected to discussion and justification. I have argued that a committee designated for an individual unit could overcome some of the limitations of CECs raised by the clinicians.

some of the limitations of CECs raised by the clinicians. As many authors have noted, 7,30 more research is needed on the efficacy of CECs, but the results from this study, while recognizing the limitation that it did not survey a large number of doctors, indicate that there is a need for such committees and the challenge is to develop these in ethically and practically useful ways. This type of qualitative data can provide an invaluable insight into why the clinicians used CECs, why they found them useful and the limitations of such committees. From this it is possible to make recommendations as to how best to organize such committees in infertility clinics. Further, this discussion has relevance for the use of CECs in other areas of clinical practice: the issues raised here are unlikely to be unique to the infertility clinic. Uncovering these deeper perspectives on CECs can provide another strand in the evidential base on the utility of CECs in medical practice.

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