Process and consensus: ethical decision-making in the infertility clinic—a qualitative study

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Clinical ethics

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ABSTRACT
Infertility treatment is a speciality that has attracted considerable attention both from the public and bioethicists. The focus of this attention has mainly been on the dramatic dilemmas created by these technologies. Relatively little is known, however, about how clinicians approach and resolve ethical issues on an everyday basis. The central aim of this study is to gain insight into these neglected aspects of practice. It was found that, for the clinicians, the process by which ethical decisions were made was of key importance. It will be argued that this focus on the process of decision-making is more than just empty proceduralism but is based on and facilitates certain substantive ethical principles. In conclusion, suggestions as to how ethical decision-making processes can be supported and improved in infertility practice will be made.

Infertility treatment is a speciality that has attracted considerable attention both from the public and bioethicists. The focus of this attention has mainly been on the dramatic dilemmas created by these technologies: the status of the embryo or the creation of saviour siblings for example. Relatively little is known, however, about how clinicians approach and resolve ethical issues they encounter in their everyday practice. The central aim of the study presented here is to gain insight into these neglected aspects of practice.

Much of the empirical work that has been done on ethical decision-making in medical practice has used standardised tools that seek to measure subjects’ responses to hypothetical situations. The drawback with such tools is that they might not accurately reflect reality. Hurst et al. point out that while there are studies done on ethics consultations and the use of ethics committees, “[t]here has been no systematic, empirical examination of strategies actually employed by physicians to deal with the ethically problematic situations they face”. This is not entirely correct, the work of Braunack-Mayer and Ehrich et al. and Farsides et al., for example, considers these very issues. A lot of interesting work has also been carried out within medical sociology that studies how doctors approach decision-making in what are seen as contentious ethical areas. However, despite these related studies, there is still little empirical work carried out on how ethical decisions are made in practice and even fewer studies conducted in the infertility treatment setting.

The study discussed in this paper is a qualitative investigation into infertility clinicians’ approaches to ethical decision-making. The data on how they made ethical decisions in their everyday practice will be considered: demonstrating that, for the clinicians, the process by which ethical decisions were made was of key importance, rather than trying to reach agreement over substantive ethical issues. It will then be argued that this focus on the process of decision-making is more than just empty proceduralism, but is based on and facilitates certain substantive ethical principles. This discussion will use different philosophical theories of consensus decision-making and democratic deliberation to analyse and critique the data. In conclusion, suggestions as to how ethical decision-making processes can be supported and improved in infertility practice will be made.

METHODS
Sample
Twenty-two interviews were conducted with infertility clinicians from the UK between 2005 and 2007. The study received ethics committee approval from the regional Multicentre Research Ethics Committee. Clinicians were selected from the list held by the Human Fertilisation and Embryology Authority and were approached by a letter that outlined the study and invited them to participate. The participants received no remuneration for taking part in the study. A theoretical sampling approach was used, which, rather than aiming for a representative sample, sampled interviewees until the categories reached theoretical saturation. This was an iterative process, “one in which there is a movement backwards and forwards between sampling and theoretical reflection”.

Interviews
The interviews were semistructured, with the interviewer (LF) broadly following a topic guide that was sufficiently flexible to give the informants the opportunity to expand and elaborate on different areas and the interviewer to probe interesting responses. The interviews lasted for an hour on average and were taped and transcribed with pseudonyms given to the clinicians to ensure their confidentiality (see table 1).

Data analysis
Data were collected until theoretical saturation was reached, when 22 interviews had been completed. Theoretical saturation can be defined as stopping data collection when no new data are emerging in the thematic categories and the relationship between categories is stable. A thematic analysis was undertaken, coding the transcripts for concepts and the relationship between those explored using the constant comparative method (inspecting and comparing all the
data to test the emerging hypotheses. From these concepts overiding themes were generated that exemplified how the informants conceptualised and approached ethical decision-making. To check the validity of the results a number of strategies were used. One of the sampling criteria was to build up a picture of particular clinics and a number of clinicians from each clinic were interviewed to get a more detailed understanding of the clinics’ ethos and approach to ethical issues (note that some clinicians were the only ones interviewed from their clinic). This produced a form of respondent validation: an understanding of the clinic ethos from a number of different perspectives. Furthermore, to provide a check on the interpretations made the transcripts were read and coding categories were discussed with members of the research team (see Acknowledgements for details of the research team).

**THEMES FROM THE DATA**

**How the clinicians made ethical decisions**

Traditionally, in a substantial amount of ethical literature, the locus of decision-making is seen as the individual: an autonomous person thinking through a moral problem and reaching a decision they believe to be right. Certain ethical theories lend themselves well to this kind of view (Kantianism and virtue ethics for example). This study found that in infertility practice the locus of decision-making was seen as the clinic/group rather than the individual. The involvement of colleagues in difficult decisions did not generally take place in an ad hoc way, but was part of a formalised system. Every unit that was visited had a regular clinic meeting at which all members of staff (doctors, nurses, embryologists and in most cases the counsellors) would discuss problematical cases. The majority of units also had access to a form of clinical ethics committee (CEC) and used them for problematical cases. The informants couched their decision-making in terms of reaching a group decision (consensus) and the corresponding group responsibility for that decision. In this way it is clear that the locus of decision-making was seen as the clinic/group rather than the individual.

Most informants thought that the clinic meeting was the most useful place to discuss ethical issues. These meetings were not just discussion forums—they were places where decisions were actually made. Dr Francis stressed that they would come to a unit decision about a particular case:

“We have a meeting every week, which isn’t an ethical committee, it’s our clinical meeting, any patient that we feel is slightly difficult, with whatever issue they go to that meeting, and we discuss it between us and we would very much come to a kind of unit decision really.”

Dr Orben made a similar point,

“We always take decisions collectively, but, as I say, we reach a consensus view as to the way forward.”

The decision to refuse treatment to a couple or individual was almost always taken by the clinic or a CEC. For instance, Dr Adams said,

“Yes, so nobody’s refused treatment without going—well, refusing to treat is done by the Ethics Committee.”

Drs Jenson and Novack remarked that if treatment were refused, the letter would come from the clinic rather than one individual. Dr Jenson recognised that this might be seen as a way of hiding behind the group, but justified it on the following grounds:

“That may be hiding behind a faceless organisation saying the Unit says no, but I think it does show that you’ve taken a lot of other people’s opinions into account, rather than sending the patient to five different people you’ve sat down together and a multi-disciplinary approach is important in fertility treatment.”

**Table 1** Sampling matrix

<table>
<thead>
<tr>
<th>Clinician pseudonym</th>
<th>NHS or private</th>
<th>Length of practice</th>
<th>Sex</th>
<th>Seniority/position</th>
<th>Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Adams</td>
<td>Both</td>
<td>20 Years</td>
<td>M</td>
<td>Consultant</td>
<td>5</td>
</tr>
<tr>
<td>Dr Brown</td>
<td>Both</td>
<td>14 Years</td>
<td>M</td>
<td>Consultant</td>
<td>5</td>
</tr>
<tr>
<td>Dr Case</td>
<td>Private</td>
<td>16 Years</td>
<td>M</td>
<td>Director of unit</td>
<td>1</td>
</tr>
<tr>
<td>Dr Down</td>
<td>Both</td>
<td>25 Years</td>
<td>M</td>
<td>Clinical director</td>
<td>1</td>
</tr>
<tr>
<td>Dr Evens</td>
<td>NHS</td>
<td>29 Years</td>
<td>F</td>
<td>Consultant</td>
<td>1</td>
</tr>
<tr>
<td>Dr Francis</td>
<td>NHS</td>
<td>10 Years</td>
<td>F</td>
<td>Consultant</td>
<td>1</td>
</tr>
<tr>
<td>Dr Grant</td>
<td>NHS</td>
<td>2–3 Years</td>
<td>M</td>
<td>Senior registrar, just finished speciality training</td>
<td>1</td>
</tr>
<tr>
<td>Dr Havers</td>
<td>Both</td>
<td>25 Years</td>
<td>M</td>
<td>Consultant</td>
<td>2</td>
</tr>
<tr>
<td>Dr Inman</td>
<td>Mostly NHS</td>
<td>20 Years</td>
<td>F</td>
<td>Consultant</td>
<td>2</td>
</tr>
<tr>
<td>Dr Jenson</td>
<td>Mostly NHS</td>
<td>12 Years</td>
<td>M</td>
<td>Consultant, head of unit</td>
<td>3</td>
</tr>
<tr>
<td>Dr Kilm</td>
<td>Both</td>
<td>15 Years</td>
<td>M</td>
<td>Consultant</td>
<td>3</td>
</tr>
<tr>
<td>Dr Lovate</td>
<td>Mostly private</td>
<td>35 Years</td>
<td>M</td>
<td>Consultant semi-retired</td>
<td>2</td>
</tr>
<tr>
<td>Dr Marsh</td>
<td>NHS</td>
<td>Infertility 3 years</td>
<td>M</td>
<td>Subspeciality trainee</td>
<td>2</td>
</tr>
<tr>
<td>Dr Novack</td>
<td>Both</td>
<td>16 Years</td>
<td>M</td>
<td>Consultant head of unit</td>
<td>4</td>
</tr>
<tr>
<td>Dr Orben</td>
<td>Both</td>
<td>24 Years</td>
<td>M</td>
<td>Consultant</td>
<td>3</td>
</tr>
<tr>
<td>Dr Percy</td>
<td>NHS</td>
<td>3 Years</td>
<td>F</td>
<td>Subspeciality trainee</td>
<td>2</td>
</tr>
<tr>
<td>17–Dr Quest</td>
<td>NHS</td>
<td>3 Years</td>
<td>M</td>
<td>Subspeciality trainee</td>
<td>4</td>
</tr>
<tr>
<td>Dr Robin</td>
<td>NHS</td>
<td>Infertility 3 years</td>
<td>F</td>
<td>Subspeciality trainee</td>
<td>4</td>
</tr>
<tr>
<td>Dr Street</td>
<td>NHS</td>
<td>3 Years</td>
<td>F</td>
<td>Subspeciality trainee</td>
<td>4</td>
</tr>
<tr>
<td>Mr Tarn</td>
<td>Mostly NHS</td>
<td>20 Years</td>
<td>M</td>
<td>Consultant, head of unit</td>
<td>5</td>
</tr>
<tr>
<td>Dr Urban</td>
<td>NHS</td>
<td>5 Years</td>
<td>F</td>
<td>Subspeciality trainee</td>
<td>5</td>
</tr>
<tr>
<td>Dr Vance</td>
<td>NHS</td>
<td>26 Years</td>
<td>M</td>
<td>Consultant head of unit</td>
<td>5</td>
</tr>
</tbody>
</table>

Impartiality
The informants thought that a “good” ethical decision was a decision that could be seen to be impartial and the process of consensus decision-making just described facilitated this. By making ethical decisions group decisions they were less likely to be made on the basis of personal prejudice or bias.

“because we all have our prejudices, even though we like to think we’re all good honest people, but there are things that I approve of and don’t approve of, and only by taking into account a lot of people’s feelings do we get it right.” Dr Jenson

Impartiality consisted of the non-imposition of the doctors’ own views on their patients, detachment of the decision-maker from the situation and a robust process of decision-making. For the informants, it was the impartiality of process that conferred ethical legitimacy on the decision (see table 2 in the supplementary data published online only for additional illustrative quotes from the data).

Consensus and disagreement
While the dominant theme in the data was that the clinicians generally managed to reach an agreement and that a consensus could be formulated, some informants mentioned disagreements taking place in unit meetings, when a consensus could not be reached. For instance, Dr Vance mentioned a case in which the clinic meeting disagreed with him and refused to treat a 54-year-old woman.

The group dynamics of a clinic could mean that everyone’s opinion was not always heard or taken into account. Clinic meetings were not perfect democracies in which all members debated freely and all views were equally respected. Power relations within the clinics played a role in how decisions were made. Dr Lovate said:

“To some extent, we do have senior people and junior people at the meeting and I think, at the end of the day, decisions are usually accepted if most of the senior people are in favour of a particular issue.”

Dr Novack also mentioned that clinic meetings were not perfect forums and some people might talk louder and be more dominant in discussion.

The structure of medical responsibility also meant that the final decision would always be taken by a particular consultant, and this point came out very forcibly when interviewing subspeciality trainees at clinic 4: they said that, as they were trainees, they would not take any decisions themselves. As the head of clinic 4 said,

“it’s a pseudo-democracy because more often than not, actually, on talking things through we reach a consensus.”

So, although the consultant made the actual decision, it would be taken on the basis of the deliberations that took place in the meeting and with the agreement of the team.

Procedural consensus
The main focus for the informants was not on whether everyone could reach agreement on the substantive ethical issues, but rather on the ability of the unit to make a decision that everyone could support and manage in practice. Dr Marsh said:

“Based on the fact that although you might not be giving them the treatment yourself because you have some reservations, your colleague would, in that situation it’s acceptable because there’s no point just transferring to a colleague just for the sake of getting it ethically right. If the majority feel okay about it probably you’ll go ahead.”

Here Dr Marsh argues that, in effect, a compromise would be reached not by convincing the other person of the rightness of your views, but by a practical acceptance of the other’s opinion with a view to agreeing on a course of action. Dr Kilm said when asked:

“How do you manage disagreement with your colleagues, has there ever been a case of you disagreeing with colleagues over anything?”

“Not desperately, no. The medics are usually fairly good, they sort of disagree or argue and they just move on. Life’s too short really isn’t it?”

Therefore, reaching a consensus was not always a consensus over substantive ethical issues, rather it was a consensus over what particular course of action to take. For example, one doctor thought that offering treatment to same-sex couples was ethically acceptable, whereas others in his unit did not, so there was a unit agreement not to treat such couples. Dr Kilm, Dr Grant and Dr Marsh did not actually have to agree with their colleagues on the substantive ethical issues (such as the ethical acceptability of treating same-sex couples) they just had to agree over what should be done in practice. The aim was to reach a consensus (or joint decision) over what to do, rather than try and reach a consensus over what was ethically right. In certain situations the clinicians (as exemplified by Dr Marsh) would accept and act on another’s ethical stance even when they disagreed with it.

The informants were, arguably, concerned about the process of decision-making rather than the product, the outcome of the deliberation. For the informants a consistent, transparent and, generally, uniform process was the key to making “good” and “acceptable” ethical decisions. They did not argue that what they had decided was incontrovertibly “right” but simply claimed that they had followed an appropriate process of ethical decision-making.

This consensus over the process is not just empty proceduralism devoid of any ethical value, the process itself is an ethical commitment to making “good” decisions. The deliberative process conferred an element of substantive value on the decision—impartiality. There might be disagreement over whether to treat a particular couple (for instance one clinic debated whether to allow a couple to use the husband’s father’s sperm in their treatment), or there might be disagreement over whether the clinic should treat single women. However, they did all agree on substantive ethical values at a deeper level, the values that underpinned the processes by which they made ethical decisions.

EVALUATION OF THIS FORM OF CONSENSUS DECISION-MAKING
The clinicians in this study utilised a concept of consensus in which attention is paid just as much to the process of decision-making as the product of that deliberation.10-20 This process account of consensus has been criticised on the grounds that it does not provide the ethical justification for decisions that a more robust concept of consensus would. Jennings makes the point that such “thin” or purely procedural values are not sufficient in themselves to give a consensus any moral force,
the focus is on the final decision, the product of the deliberation. A contrasting conception of moral consensus that seeks to address this criticism of process-based consensus is what has been called the “resting state of opinion account”. Consensus is reached when there is agreement over substantive issues and the focus is on the final decision, the product of the deliberation. Caws argues that consensus involves, “something more than acquiescence or compromise”, therefore consensus should be, “agreement of opinion on the part of all concerned”. Caws makes much of the distinction between procedural and substantive consensus.

“...agreement of opinion on the part of all concerned”. Caws 23

The important element for this position is agreement over substantive ethical issues and this agreement is the basis for a “genuine” or morally robust form of consensus. The “resting state of opinion” position views process accounts as problematic because, in placing more emphasis on consensus over procedures for decision-making rather than consensus over particular ethical values or principles, substantive ethical values could be neglected.24 The worry here is that without any agreement over substantive issues, there is just a procedure and procedures alone do not confer any ethical acceptability on the decision. Ethical decisions could be reached by any means (poetic reverence or tossing a coin) but what matters is if these decisions are justifiable.18

These are important criticisms. If the clinicians’ consensus decision-making is just a form of thin proceduralism that does not rest on or incorporate any ethical values then, as Jennings notes,19 this form of consensus does not provide any moral justification for their ethical decisions.

These criticisms of process accounts of ethical decision-making have been considered in another context—Norman Daniels’ work on priority setting. How Daniels approaches these criticisms can be used to inform this debate over the infertility clinicians’ ethical decision-making. Daniels has argued that, due to the lack of consensus over the principles that should govern healthcare rationing in a pluralist society, there is a need to develop “publicly acceptable processes for making these decisions”. Daniels has sketched such a fair process—accountability for reasonableness—a model that puts the emphasis on the process of decision-making rather than seeking to draw up a list of foundational principles on which to base these decisions. The way the clinicians in this study made decisions could be seen as a form of an “accountability for reasonableness” process: there was no agreement on substantive issues but an agreement over what constituted a “good” process for making ethical decisions.

The key issue for such process accounts is whether they will produce better decisions, as judged by some conception of ethical acceptability that is independent of the decision-making process itself. This is an issue frequently debated in political philosophy in the context of theories of democracy. Daniels says:

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Procedural values, it is argued, are not enough on their own to legitimise a decision.

A criticism that, “goes to the heart of democratic theory!”.26 Plato, for instance, thought that moral authority rests on moral expertise that enables one to make the right decisions—the philosopher kings of The Republic. However, democrats think the “majority” should be the decision-makers regardless of their expertise. The problem with the democratic view is that we have to accept whatever the majority decide and, as we know, this might not necessarily be morally “right”.

Daniels answers this briefly by saying that his account,

“...improves the quality and coherence of the decision-making process and... this improvement makes it more likely that such deliberation will lead to correct answers”.26

Daniels (p 111–12)26 stresses that his “accountability for reasonableness” process:

“...emphasises the deliberative component of the democratic process, [and is] not merely a procedural appeal to majority rule.”

David Estlund’s account of democratic authority (which Daniels cites) can be used to develop this point. Estlund argues that the process of democracy confers epistemic value (or authority in Daniels’ terminology) on the decisions made. In the same way that juries’ decisions are based on deliberation and a consideration of evidence, the democratic process weighs and judges reasons and, “has a tendency to make correct decisions.” Estlund calls this “epistemic proceduralism”. The process generally leads to the correct decision—the process produces epistemic value. There is not space to consider these claims as they relate to democratic theory in general, but this argument can be applied to the clinicians’ decision-making processes in this study.

The clinicians debated and reasoned about cases and it is this deliberative process that helped them make “good” decisions. Rosamond Rhodes argues that,

“...the discussions [in medicine] are limited to sharing facts and employing the principles of medical ethics that are supported by public reason... Because the discussants... all start with a common view of what counts as a fact and what counts as relevant reasons, consensus... emerges.”

Rhodes takes Rawls’ idea of a reasonable citizen, who has the virtue of fair-mindedness and will put their own prejudices and personal views to one side to make “fair” and “reasonable” decisions, and applies this to medical decisions. Doctors act as reasonable “citizens”, “on the basis of mutually recognisable reasons and evidence” (Rhodes, p 502). She argues that in medical decision-making personal views do not hold sway and, “consensus flowing from public reason is the rule and professionalism points the way.”23 In this way, this process has a “tendency” to produce “good” or acceptable ethical decisions. The process does help us get things right as judged from a perspective independent of the process of decision-making itself: the process confers epistemic value to use Estlund’s terminology.

To make a rigid distinction between substantive and procedural consensus is thus unwarranted. This distinction can be broken down. Procedural elements can incorporate substantive ones; procedural standards have substantive implications. That is, in following certain types of procedures certain ethical values and principles are employed. Moreno (p 44)22 argues that making a distinction between the process (the way the decision was made) and the product (the actual decision) is unwarranted:

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Clinical ethics

“At least in the realm of actual social practices,… it is patent that the admission of intellectual arguments as sound is itself an unavoidably social process.”

Therefore, the process of decision-making, the way the decision was made, is inextricably linked to whether the decision is thought to be acceptable. For the clinicians in this study, a consistent, transparent and, generally, uniform process was the key to making “good” ethical decisions. This process of decision-making thus facilitated the making of impartial decisions and this gives them ethical legitimacy.

Some criticisms can be made of this conclusion that the clinicians’ decision-making has some ethical legitimacy. First, it could be argued that it is idealising this form of medical decision-making. To argue that in order for doctors to make acceptable ethical decisions they have to conform to some abstract notion of Rawlsian public reason would be doomed in practice. People are not always reasonable and it is difficult to put aside one’s own feelings and moral views when dealing with patients.

Second, there could be a tendency for it to lead to conservatism; for instance, some clinics’ reluctance to treat same-sex couples because not everyone agreed meant that sometimes the more “reactionary elements” directed clinic policy. Third, it may be seen as a means of hiding behind the majority and allowing the clinic to make unpopular decisions rather than the individual. Finally, not everyone’s views and position will be able to be taken into account, sometimes an individual’s views will be subjugated and group dynamics will play a role in who gets heard and what decisions are made.

However, as Winston Churchill said: “democracy is the worst form of government except for all those other forms that have been tried from time to time”. Often in the literature ethical decision-making is given impossibly high, abstract standards to meet in order for it to be deemed acceptable. The standards of these processes might not reach the exacting ones that are envisaged by some moral theories, and in practice few ways of making ethical decisions can meet these stringent criteria. Therefore, a weaker standard might be all that can realistically be achieved. This is, in essence, the justification for the form of consensus decision-making the clinicians used—it is the best we can do when faced with the realities of medical practice.

PRACTICAL IMPLICATIONS

Having examined how clinicians make ethical decisions, it is possible to suggest ways that this type of decision-making can be supported and improved. CEC can be one mechanism that can fulfil both these functions. The informants thought that ethical decisions should be taken as a group and therefore a CEC can fulfil both these functions. The informants thought that consensus decision-making is, in practice, a reasonable and effective way to make ethical decisions and in the words of one clinician, although this process may have its flaws, “what’s better?”

CONCLUSION

It was the process of ethical decision-making that legitimised the decision for the clinicians. The process and the product of decision-making were inextricably linked. It has been argued that this form of consensus decision-making does produce robust ethical decisions. The process is built on and facilitates particular substantive values and the procedure itself has some epistemic warrant. Therefore, criticisms of process accounts of consensus that contend it is merely empty proceduralism can be rebuked in this context. Consensus decision-making is, in practice, a reasonable and effective way to make ethical decisions and in the words of one clinician, although this process may have its flaws, “what’s better?”

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REFERENCES


