Ethics in the Infertility Clinic: A Qualitative Study

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by

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Appendices

Please note that in this electronic version the page numbers of the tables and figures are different from those in the Contents and that some of the Appendices are not included as they were photocopies of original documents (Appendix 2 and some of Appendix 6). The hard copy held in the library has the full appendices.

Abstract

ETHICS IN THE INFERTILITY CLINIC: A QUALITATIVE STUDY

This thesis is a qualitative study of infertility clinicians in the UK, exploring how they manage ethical issues: a study that uses empirical methods to explore ethical questions. I use a broadly Aristotelian conception of the relationship between theory and practice to develop a methodology for considering practical ethical issues. I then show how this approach, when allied with contemporary qualitative methodologies, can provide particularly valuable insights and produce practical recommendations. An important element of my approach is that a close attention to actual practice can also result in refining and developing our ethical theories and principles – practice informs theory just as theory can inform practice. This account of the ethical decision-making processes of infertility clinicians can not only highlight new ethical problems, but also develop more nuanced moral norms and ethical theories to deal with the conflicts and issues that arise in the clinical setting.

Infertility treatment is a speciality that has attracted much attention from the public and bioethicists. The focus has been predominately on the dramatic aspects such as the status of the embryo or underlying issues such as the ethical boundaries of procreative liberty. Relatively little, however, is known about the everyday moral workings of infertility clinics: how clinicians approach ethical issues on a daily basis; what for them are troubling issues; and how they resolve ethical conflict. This study aims to gain insight into the way clinicians actually make ethical decisions. Moving on from this, it critically evaluates such processes and offers both an analysis of the strengths and weaknesses of the clinicians' ethical decision-making and considers how this form of decision-making can be extended and supported in practice.

The aims of this thesis are to contribute to the debate on both how ethical decision-making in the infertility clinic can be improved and, more generally, how bioethics can make a useful contribute to practical problems.

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Declaration

This thesis is the result of my own work. The material contained in the thesis has not been presented, nor is currently being presented, either wholly or in part for any other degree qualification.

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Finally, I would like to acknowledge my partner Mark's contribution to this thesis. His support has been above and beyond the call of duty.

Abbreviations

AI – Artificial Insemination

AID – Artificial Insemination by Donor

AIH – Artificial Insemination by Husband

DH – Department of Health

CEC – Clinical Ethics Committee

IVF – In vitro fertilisation

NHS – National Health Service

NICE – National Institute of Clinical Excellence

PCT – Primary Care Trust

PGD – Pre-implantation genetic diagnosis

SET – Single Embryo Transfer

INTRODUCTION

This thesis is a qualitative study of infertility clinicians, exploring how they manage ethical issues in their everyday practice: a study that uses empirical methods to explore ethical questions.

I use a broadly Aristotelian conception of the relationship between theory and practice to develop a methodology for considering practical ethical issues. I then show how this approach, when allied with contemporary qualitative methodologies, can provide particularly valuable insights and produce practical recommendations when applied to ethical issues in practice. An important element of my approach is that a close attention to actual practice can also result in refining and developing our ethical theories and principles – practice informs theory just as theory can inform practice. The aim is to contribute to the debate on both how ethical decision-making in the infertility clinic can be improved and, more generally, how bioethics can make a useful contribute to practical problems. This account of these ethical decision-making processes can, as Caplan (1982) suggests, not only highlight new ethical problems, but also develop more nuanced moral norms and ethical theories to deal with the conflicts and issues that arise in the clinical setting.

RESEARCH INTO INFERTILITY PRACTICE

This thesis crosses a number of different disciplines as it uses empirical methods to explore ethical issues in medical practice. Consequently, there are many areas of literature that are relevant to this study and it would be impossible to sum up or consider all the research that has been conducted in these disciplines on infertility

practice. The aim of this introduction, therefore, is to locate this study very broadly

in the body of ethical literature and research that has been conducted on infertility

treatment and to demonstrate how my study contributes to an area that has not

received sufficient attention.

Research on ethical decision-making

There has been little empirical work on how infertility clinicians make ethical

decisions. Much of the empirical work that has been done on ethical decision-making

has used standardised tools that seek to measure subjects' responses to hypothetical

situations.[1] This cannot always tell us what might actually happen in practice.[2] Hurst

et al argue that although there are studies done on ethics consultations (a feature of

decision-making that is much more common in the US than in the UK) 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.'(2005:7) [3] This is not completely correct, Braunack-Mayer's

work (2001, 2001a, 2005), for example, considers these very issues. There is,

however, a paucity of empirical work done on ethical decision-making and even

fewer studies conducted on decision-making in infertility treatment.

Research on ethical aspects of infertility provision

Infertility treatment is a speciality that has attracted much attention from the public

and bioethicists, it is one where the focus has been predominately on the dramatic

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[1] See Frederick, *et al* (2000) for a review of the literature on this type of approach.
[2] See Chapter Four for problems with this approach.
[3] The quote goes on to say, 'without help from ethics committees or [ethics] consultants.' (2005:7) Although my study does consider the use my informants made of ethics committees there is not a systematic structure of such committees in the UK, as there is in the US, to aid decision-making see Chapter Nine.

aspects such as the status of the embryo or underlying issues such as the ethical boundaries of procreative liberty. Thus, although there is a substantial body of research on reproductive technologies from a bioethical perspective, the vast majority of this concentrates on more the general issues raised by these technologies.

Reproductive technologies have fascinated bioethicists since their inception and the ethical debates on artificial reproduction go back at least 60 years (Caplan, 1988). ten Have (1995) argues that there are two main sorts of ethical questions that can be directed at reproductive technologies: the first are, '[m]oral questions that concern the technology itself' – these are questions that address the very underpinnings of reproductive technologies, asking the fundamental question, should we be carrying out these technique at all?; the second are, '[m]oral questions that arise within the framework of the technology' – these are questions that, 'remain within the framework of the technology, they proceed from a basic acceptance of the technology….their underlying concern is how its responsible and appropriate use can be defined.' (ten Have, 1995:143). ten Have argues that when evaluating a new reproductive technology most of the ethical questions raised are of the second sort and not enough attention is paid to considering if we should be doing it in the first place. However, I would argue, contrary to ten Have, that a pattern in the ethical debate over reproductive technologies has been an initial discussion over whether we should be doing it at all and then the debates develop into considerations of how such techniques can be employed ethically and then the specific ethical dilemmas that arise out of their use.[4]

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[4] I conduced a literature search in Web of Knowledge by searching the term 'ethics and reproductive technologies.' I then scanned the abstracts of relevant articles from 1975 to get a sense of the changing debate over these issues. It must be recognised that Web of Knowledge does not index books or all

This can be seen in the debates that followed the birth of Louise Brown in 1978 by IVF. There was much initial discussion over whether IVF and AID were techniques that should be allowed on the grounds that they were unnatural (Singer & Wells, 1982. Walters & Singer, 1982. Caplan, 1988. Rothman, 1989). *The Warnock Report* considered many submissions to its inquiry that argued that such reproductive technologies were immoral on the grounds of their unnaturalness, that they represented the introduction of a third party into the reproductive process and, 'this was held to be morally wrong in itself, whatever the motives of those involved might be.' (Warnock, 1985:20) These concerns were often voiced by religious commentators, in particular the Catholic Church (see Rothman, 1989). *The Warnock Report* took the view that, '[a]s a question of individual conscience, there will be those who will not wish to receive this form of treatment nor participate in its practice, but we would not rely on these arguments for the formulation of a public policy.' (Warnock, 1985:31) This was, in effect, directing the debate to the second of ten Have's questions, how can reproductive technologies be employed ethically?

There was a parallel debate in the feminist literature that mirrored this wider discussion of reproductive technologies. One school of feminist thought, represented by writers such as Corea (1988) and the Feminist International Network of Resistance to Reproductive and Genetic Engineering (Spallone & Steinberg, 1987), viewed reproductive technologies as intrinsically harmful to women. Reproductive technologies were practices constructed by a patriarchal medical and technological establishment to further control and colonise women's bodies. Reproductive technologies were seen as reinforcing a biologically deterministic view of women that encouraged a kind of

journals that are relevant in bioethics. Included in this literature search was a search of COPAC for relevant books on the subject.

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pronatalism, that subordinated women's identity to their reproductive role, rather than seeing them as full human persons with a range of interests. It was the social context in which the technologies were developed that made them inherently harmful to woman. Reproductive technologies were not benign techniques that could possibly be harmful to women – they were deliberately constructed mechanisms of control.

This view was criticised by other feminist authors, such as Stanworth (1987), who saw reproductive technologies as benign forces that could be used inappropriately but were not inherently harmful to women. The crucial issue for these authors[5] was that reproductive technologies should operate in an ethical framework, to ensure that women were protected from abuse and exploitation.

Whether or not the debate for allowing IVF was 'won' or scientific developments carried on regardless is a moot point, but nevertheless much of the ethical literature is now concerned with issues that arise from the conduct of the techniques rather than whether we should have them at all. Within the consideration of this second question, different issues are pertinent at different times. For instance, the development of techniques to create embryos outside the body led to much ethical debate on this in the early days of IVF (Dyson & Harris, 1990. Singer *et al*, 1990). The appropriate treatment of the embryo was one of the main concerns of the Warnock Committee and this was one of the predominant impetuses behind calls to license infertility treatment centres providing treatment with embryos or conducting embryo research. The case of Diane Blood in 1996, who wanted to use her deceased husband's sperm for treatment, prompted a debate on the ethics of posthumous reproduction (Delany,

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[5] See Stanworth's (1987) collection of essays on reproductive technologies.

1997). Recently, there has been a lot attention paid to the ethical issues raised by people travelling abroad to get infertility treatment, either due to funding restrictions in their own country or due to regulatory restrictions (such as non-anonymous gamete donation) that they wish to avoid (Pennings, 2002. Blyth & Farrand, 2005). [6]

The is not to say that debates over the acceptability of reproductive technologies are no longer conducted in the literature (there are still questions over the ethical acceptability of IVF and the possible effects on society), and when new techniques are developed, such as pre-implantation diagnosis, questions of their ethical acceptability are raised again. This changing focus of ethical debate can be illustrated by the evolution of concerns raised by artificial insemination (see Appendix 1). As a technique, AID, was once seen as immoral and therefore carried out in secret (Frith, 2001). Donors were anonymous to any future offspring and it was thought best that the circumstances of conception were kept secret from the child. Now, with changing views and a greater focus on the rights of the child, the law regarding donor anonymity was changed in 2004, gamete donors are no longer anonymous to any future offspring and it is generally recommended that it is good practice to tell the child how they were conceived (HFEA,2007:G.5.4.6).

In this way, debates move, not seamlessly, but in fits and starts from considering the fundamental acceptability of a new technique (IVF, Pre-implantation genetic diagnosis (PGD)) to discussing how such techniques should be employed ethically and a consideration of specific ethical dilemmas that might be raised by their use. With the development or modification of new techniques this process starts again.

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[6] See Baird (1996), Fasouliotis & Schenker (1999), Frith (1998) and Harris & Holm (1998) for good overviews of ethical issues raised by the application of reproductive technologies.

This thesis is an extension of this process. Rather than considering general dilemmas that arise in the conduct of infertility treatment, it examines how clinicians make particular decisions in their everyday practice. This can be seen as akin to a funnelling process. The issues becoming focussed down onto the specificities of practice: looking at how clinicians actually approach and think about the many troubling ethical issues they face on a day-to-day basis.

In sum, relatively little is known about the everyday moral workings of infertility clinics: how clinicians approach ethical issues on a daily basis; what for them are troubling issues; and how they resolve ethical conflict. One of the main aims of this study, therefore, is to gain insight into this – an area that has received insufficient attention.

CONTENT AND ARGUMENT OF THE THESIS

Having discussed the gaps in the literature, which this study seeks to address, I will now outline the general structure of the thesis.

Chapter One places this study firmly within the 'empirical turn' in bioethics and looks at the different ways in which empirical data has been employed in ethical analysis. It highlights the similarities and differences this study has with other works in empirical ethics.

Chapter Two looks critically at two of the main approaches to bioethics and how they conceptualise the relationship between theory and practice. First, the

engineering model, where the principal focus is on theory, and second, contextualism where the principal focus is on context/practice.

Chapter Three advances the conception of bioethics that will be used in this thesis. It proposes an Aristotelian notion of the relationship between theory and practice to develop a methodology for approaching ethical issues in practice.

Chapter Four outlines the qualitative methods I use in this thesis. The justification for choosing this type of qualitative research methodology is discussed. I then detail the methods and rationale for the data collection and the strategies of data analysis employed.

Chapter Five gives a broad picture of the regulatory and organisational context of infertility treatment in the UK and how such treatment is funded. This discussion delineates the context in which the infertility clinicians make ethical decisions and the external constraints that shape such decisions.

Chapter Six, the first of the data chapters, examines what the informants saw as ethically troubling in their practice. It develops theories of 'settled' and 'controversial' moralities to account for the complexities and contradictions revealed in the way the clinicians understood their everyday practice.

Chapter Seven examines how the informants dealt with these ethical issues in practice. I show how the attempt to reach a consensus was a central aim of their decision-making processes. I then go on to develop a theory of consensus

showing how the process of decision-making itself, rather than reaching

agreement over substantive ethical issues, was of central importance to the

clinicians.

Chapter Eight is an evaluation and critique of this form of decision-making. I argue

that the informants' consensus decision-making process can be morally justified, as

there is a firm moral basis that underpins it; a 'moral vision' shared by both doctors

and the wider community.

Chapter Nine draws out the practical implications of this study and discusses how

ethical decision-making can be best supported in the infertility clinic. I bring together

the data on how the informants thought about and used clinical ethics committees

(CECs). Then, recommendations for how CEC support could be strengthened are

made.

The Conclusion summarises the main findings of the thesis and discusses the utility

in adopting this theoretical approach to ethical issues in practice.

TERMINOLOGY

Throughout the thesis the term 'bioethics' will be used as a generic term to denote

the disciplines of applied and practical ethics, such as medical ethics and health care

ethics for example, recognising that it can encompass many different approaches to

ethical issues. The term 'empirical research' will be used to denote research

conducted largely in the sociological, anthropological and psychological disciplines

using qualitative and quantitative methodologies. It is recognised that although there are vast conceptual differences between these methodologies and disciplines, the similarity is that they all seek to gather empirical information to make some type of claim about the world.[7] I will use the term 'data' broadly to refer to the products of such studies. I will use the terms 'context' and 'practice' interchangeably to mean wider features of the world, the 'empirical contingencies of life'. These features are anything that could be said to have an impact on or relevance to the situations in which ethical decisions are made.

Further, I will use the term 'principle' to refer to the type of mid-level principles that people often deploy in ethical discussions, such as the imperative not to lie, patient autonomy, beneficence, fidelity, non-discrimination, fairness, sanctity of life etc. I shall use the term ethical theory rather than moral theory as this does not suggest the separation of human life into the moral and non-moral (see, Nussbaum,1990:169). Ethical theory will be used to denote not just comprehensive ethical theories such as utilitarianism, but less all-encompassing theories such as theories of justice or theories of consensus decision-making.

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[7] See Bennett & Cribb (2003) for a discussion of the problems of characterising 'empirical research' as a homogenous whole. It is recognised that empirical research can be grounded on many different theoretical stances and ways of approaching and conceptualising 'reality' or the 'outside world'.

INTRODUCTION

This chapter places this study firmly within the context of the 'empirical turn'[8] in

bioethics. It traces the increasing use of empirical studies in bioethics and places

such studies within three broad categories which are used to shed light on the

different ways in which the relationship between ethical theory and empirical data

can be conceptualised. The position of this study in relation to this question and the

literature in the area is then explored.

THE EMPIRICAL TURN IN BIOETHICS

Like any discipline, bioethics is a developing form of academic inquiry and recent

trends in scholarship have been towards more engagement with empirical research

and ethicists carrying out such research themselves. Bioethics is changing as it

engages with wider currents in contemporary thought, 'the discipline of bioethics

itself is confronted with a sudden shaking at its core and a questioning of its actual

identity and methodology.' (Borry *et al,* 2004:1) Bioethics has been subjected to a

number of critiques that have, possibly, had an impact on the way the discipline is

conducted (see Chapter Two for a discussion of this).

Borry *et al* (2006) have charted the rise of this 'empirical turn', conducting a

quantitative analysis of peer-reviewed journals in the field of bioethics in the period

1990-2003 to analyse the evolution and nature of published empirical research in

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[8] This phrase is borrowed from Borry *et al* (2005).

bioethics.[9] They found that the proportion of empirical research rose in these journals from 5.4% in 1990 to 15.4% in 2003 and concluded that, 'it is likely that the importance of empirical methods in medical ethics and bioethics can only be expected to increase.' (2006:254) This has led some authors to argue that a new form of ethics paper is emerging (Arnold & Forrow,1993). The *Journal of Medical Ethics,* for example, has given guidance on submitting empirical papers since 1997.

This statistical increase in the amount of empirical work conducted in bioethics has been matched by an increasing interest in the relationship between bioethical inquiry and the social sciences (used here in the broadest sense). There have been a number of special issues of journals devoted to discussing such a relationship: for example, *Health Care Analysis*,2003. *Medicine, Health Care & Philosophy*, 2004. *Sociology, Health & Illness,* 2006; and a growing literature on the subject (Hoffmaster,1990. Hedgecoe,2004. Haimes,2002, Holm & Jonas, 2004. Haimes & Williams,2007). In the UK there has been an increase in funding programmes for empirical work in bioethics. The Wellcome Trust, for example, began a programme for encouraging empirical and multi-disciplinary research in bioethics in 1997.

Borry *et al* (2005) have argued that this 'empirical turn' in bioethics can be attributed to three factors. First, the rise of evidence-based medicine, where ethical arguments should either be tested by empirical evidence or ethical decisions should be grounded in the best scientific evidence. Second, the development of clinical ethics as a distinct field, which has a greater focus on the specificities of actual practice than mainstream bioethics. Finally, the increasing dissatisfaction with the discipline of

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[9] Sugarman *et al* (2001) conducted an earlier study that pointed to the rise of empirical research in bioethics during the 1980s.

bioethics as exemplified by the social science critique has contributed to the 'empirical turn'. Draper & Ives (2007) argue that it is this critique that has been the main motivating factor behind the increase in empirical research conducted by bioethicists.[10] It is beyond the remit of this thesis to consider in depth why bioethics as an academic discipline is changing,[11] this is more a topic for a sociology *of* ethics (Haimes,2002). However, it is reasonable to say that there is an increasing focus on the role of empirical research in bioethics and more empirical studies conducted within the discipline. This study is a part of such a trend: a study that uses empirical methods to explore ethical issues.

EMPIRICAL WORK IN BIOETHICS

I now want to give an overview of the empirical work conducted in bioethics to illustrate where my current study sits within current literature and scholarship.

To do this I will draw on Ives and Draper's (2007) categorisation[12] of the different ways empirical research has been employed in ethical reasoning. The three broad categories are a: sociology *of* bioethics; sociology *for* bioethics; and sociology *in* bioethics.[13] It is possible that some studies could fall into more than one category – the categories are not mutually exclusive and, as will be argued, my study has elements of all three categories.

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[10] See Ashcroft (2003) for a different analysis of the development of empirical ethics, that analyses it from a Foucauldian perspective, seeing it as a form of politics, 'a set of ways of arguing and making decisions and representations to maintain a sort of civic stability while changing it in the interests of the competing or co-operating agents making up society.' (2003:12)

[11] It could also be argued that a trend in academia in general is towards inter-disciplinarily work. For example, the funding council for philosophy, Arts and Humanities Research Council, launched an inter-disciplinary funding stream on religion and society in 2007. The growth in the discipline of experimental philosophy which uses the methodologies of psychology is another area of such interdisciplinary (see Appiah, 2008).

[12] There are obvious limitations with constructing any typology of this nature, the intention is to broadly group approaches that share certain characteristics for clarification purposes.

[13] These categories are similar to those often used in medical sociology (White,2002).

In using this categorisation I will draw attention to the different ways in which the relationship between empirical data and ethical theory can be conceptualised. Does empirical data leave ethical theory unaltered? Or does empirical data have some influence on the actual content and structure of ethical theory itself? These are central questions in the development of my own use of empirical research.

Sociology *of* bioethics

The first way empirical data has been used in the study of bioethics is in sociology *of* bioethics. This incorporates two aspects: seeing bioethics and bioethicists as objects of study; and examining the social context of bioethical issues or problems.

A sociology *of* bioethics takes bioethics as another area of society to study, bioethics becomes a social phenomenon rather than an abstract philosophical discipline. Bioethics and ethicists become the object of study, just as doctors have been the subject of study in medical sociology. For Haimes (2002), ethicists are a fascinating occupational group and she argues that even if one sees ethics as an abstract discipline the same cannot be said for ethicists, they are members of a professional and social group. Hence, there is a utility in studying them in their social context - to understand more about ethicists, to understand how their social identity affects the influence they have or do not on the conduct of ethical matters.

Bosk (1999) argues that social scientists can contribute to bioethics by studying the discipline itself. As the role of 'bioethicist' is relatively new, little is known about how this role actually functions and Bosk calls for research on the following questions: what do bioethicists do? For whom? Under what conditions? How are bioethicists trained? How do those in the field define their domain of responsibility?

How is orthodoxy established? How is dissent managed? Thus, social scientists should undertake a, 'description and analysis of the everyday work of people in the new social role we now call bioethicist.' (1999:66)

Fox is a sociologist who has attempted such work and has written widely on bioethics as a social and cultural phenomenon (Fox, 1989, 1990). She argues that bioethics is an important subject as it, 'deals with nothing less than beliefs, values, and norms that are basic to our society, its cultural tradition and its collective conscience.' (1999:11) However, Fox argues that bioethics is unaware of the wider social and cultural context in which it and the 'ethical issues' that are debated in bioethics are located. This is a failing in Fox's view and is not helped by bioethics' focus on the individual clinical encounter between doctor and patient. Bioethics approaches such an encounter, 'with sparse reference to their respective social and cultural backgrounds, their "lived lives," the psychodynamics of what transpires between them, and the social milieu of the hospital in which these doctor-patient encounters take place.' (1999:12) A sociology *of* bioethics, for Fox, can bring these issues to the fore and profitably locate bioethics in its social context.

The second focus of a sociology *of* bioethics is examining what may (or indeed may not) get categorised as ethical areas. What gets constituted as an ethical problem and the way dilemmas are constructed in the ethical literature all become a form of social interaction to be studied by the sociologist.

> Social scientists provide just the kind of context bioethicists so often obscure when we produce ethnographies of medical settings that describe as thickly as possible how ethical problems are ignored, unattended, recognized, managed and resolved in medical settings….the goal is not to show how these problems are properly or improperly resolved. Rather the focus is on how the problems are structured. (Bosk, 1999:64-65)

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Further, ethical issues may be studied by the methods of social science. The papers in de Vires *et al*'s edition of *Sociology of Health & Illness* (2006), for example, are largely an attempt to put bioethical issues (such as the ethics of research and social policy) into a social context.[14]

A sociology *of* ethics can engage with ethical theory to a greater or lesser degree. Bosk's (1992) study of genetic counselling in a paediatric hospital, for example, although looking at an area of great ethical concern, does not explicitly employ or consider ethical theory in his analysis. Other studies and authors critically engage with ethical theory and use their studies to demonstrate what they see as failings in the traditional bioethical engineering model. Anspach (1993), for example, in her study of decision-making in an intensive care nursery explicitly engages with the bioethical debate over life and death decisions in intensive care. Alderson (1990) also uses her empirical findings to advance a form of the 'social science critique' of bioethics.[15]

Braunack-Mayer's study of general practitioners in Australia reached a different conclusion from the studies just mentioned and argued that forms of ethical reasoning found in bioethics did have some purchase in the 'real world'. Her project was concerned with, 'how do the styles and approaches used in bioethics scholarship relate to moral deliberation?'(1998:3) She argued that bioethicists assert that moral theories match real life and in part they are, 'systematising every-day moral activity.' (2001:71) Her project investigated whether this was the case. For example, she

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[14] See also Haimes' work on genetic databases discussed in Haimes & Williams (2007).
[15] See the discussion in Chapter Two of these authors.

argued that her empirical research, 'suggests that there is a role for casuistry in every-day moral reasoning.' (2001:80)

A sociology *of* bioethics is a valuable form of inquiry that has produced many fascinating studies of what constrains and influences ethical decision-making in practice.

Sociology *for* bioethics

A second way in which empirical data has been used by bioethics can be grouped under the term a sociology *for* bioethics. Used in this way empirical research produces data for bioethics. In practice, says Weisz, social scientists, 'can provide ethicists with data, ranging from descriptions of the historical origins or current ethical debates to information about how people in different cultures and at different social levels actually behave in ethically problematic situations.' (1990:5)

One way empirical research could be used is to identify moral issues that need to be studied. Baruch Brody argues for this sort of role for empirical research in bioethics: 'It can identify issues that actually arise and processes actually used for dealing with them, thereby suggesting where normative analysis is most needed.' (1993:218) Musschenga (2005) gives the example that doctors rarely have to choose between prolonging life and euthanasia. More often the primary decision is whether or not to do everything to prolong life rather than whether euthanasia is acceptable in this circumstance. Thus, ethicists need empirical research to tell them what is going on and what are interesting and relevant ethical dilemmas in practice.

A further example of sociology *for* bioethics is that empirical data can be used as the

factual component of ethical arguments (Ashcroft, 2003. Holm, 2005). Many ethical

arguments are based on particular facts, even though these facts do not have any

normative value. 'Good ethics depends upon good facts.' (Sulmasy &

Sugarman,2001:11) Moral arguments often have the form:

1. Whenever situation X occurs, it is permissible to do Y
2. If Z is true, then I am in situation X
3. Therefore, if Z is true, it is permissible to do Y (Sulmasy & Sugarman,2001:11)

Proposition 1 is the moral premise, proposition 2 is empirical. Empirical studies can

contribute to ethics by showing when proposition 2 is true and under what conditions,

and this information is needed to establish one's obligations under proposition 3.

Sulmasy & Sugarman give the example of the argument that one should not give liver

transplants to alcoholics, because the chances of them relapsing into alcoholism are so

high that the prognosis of such transplants is unacceptably low. If it turns out that the

survival of alcoholic patients with liver transplants is as high as transplants for other

conditions, then the argument against such transplants on the grounds of low prognosis

is disproved. Sulmasy and Sugarman argue, 'many normative arguments depend on

factual information, even though these facts themselves do not confer normative status

upon these arguments.' (2001:11)

Empirical research can also be used to assess the likely consequences of actions, so

important for utilitarians (Zussman, 2000. Sulmasy & Sugarman,2001). Brody (1993)

gives the example of this type of study where the consequences of commercial organ

donation were evaluated. The study concluded that due to the extremely poor prognosis

of those who had purchased organs, commercial organ donation was morally wrong.[16]

Birnbacher argues that, 'most controversial debates in applied ethics are not so much controversies in principle but about matters of empirical consequences.' (1999:327) He gives the example of debates over voluntary active euthanasia. Here the controversy is over whether allowing this form of euthanasia will risk a 'slippery slope' to non or involuntary euthanasia. Active euthanasia is rejected on, 'contingent [the slippery slope reasons] rather than categorical reasons [it is wrong to kill].' (Birnbacher,1999:329) Therefore, empirical research can contribute to the contingent solution of ethical issues by providing data on the possible consequences of particular policies.

In their study of withdrawing treatment in neonatal intensive care, McHaffie *et al* (2001) provides an example of how sociology for ethics can meet all the above objectives. They argue that empirical research is useful as it can identify and describe important ethical issues, see how they are resolved and assess the consequences of current management. They conclude that the research cannot answer 'ought' questions, moral judgments are still required. 'Knowledge acquired from this research then brings us closer to what we ought to do because it sheds light on the important issues and aids ethical reflection, even if it cannot of itself provide a resolution to the issues.' (2001:109)

Sociology *in* bioethics

The models of sociology *of* and *for* bioethics largely keep the disciplinary boundaries between ethics and sociology separate. There is ethical theory on the one hand and there is sociologically gathered evidence on the other. A third approach, a sociology

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[16] Although Brody argues that this does not settle the matter and ethical analysis is what is needed to determine the acceptability of the practice.

in ethics, attempts to break down the boundaries between empirical evidence and ethical theory (Hedgecoe,2004).

In a special issue of the journal *Medicine, Health Care and Philosophy* devoted to the use of empirical research in bioethics, Molewijk *et al* (2004) outlined a form of sociology *in* bioethics that they called the Integrated Empirical Ethics approach (IEE) that seeks to combine ethical theory and data. 'IEE refers to studies in which… ethicists and descriptive scientists try to integrate moral theory and empirical data in order to reach a normative conclusion with respect to a specific social practice.' (2004:57) This approach, IEE, contends that the distinction that is commonly held to demarcate bioethics and social science are not two distinct modes of understanding but, 'can be, and often are, complementary and mutually illuminating.' (Jennings, 1986:215)[17] Molewijk *et al* (2004) argue that the distinction between what is considered a fact and what is considered a value cannot be unproblematically upheld.[18] They argue that 'facts' produced by empirical science are not value neutral, as values play a role in how they are constituted.[19] Therefore, ethical theories are based on 'background empirical assumptions'. As Jennings states, 'ethical theorizing …builds on substantive sociological, psychological, and anthropological assumptions.' (1986:213) Molewijk *et al* argue that although the distinction between empirical data and ethical theory can be questioned: 'IEE does not aim to achieve a radical integration in order to create one comprehensive theoretical unity in which there is not reference to any distinction between the empirical and the

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[17] For a critique of an IEE approach see Levitt (2004) who argues the two disciplines (ethics and social science) should be complementary rather than integrated.

[18] Hedgecoe argues, 'There is empirical evidence that the fact/value distinction is at best overstated, and at worst a figment of philosophical imagination.' (2004:131)

[19] As they mention this idea is based on Bruno Latour's work on the social production of scientific facts. See also Chapter Seven of Lincoln & Guba (1985) where they give examples of how values influence scientific inquiry.

normative….however, making the distinction into an irreducible gap between intrinsic (i.e. essential) meanings is erroneous.' (2004:58 & 57)

Van Thiel and Van Delden's (2001) study on the use of the concept of autonomy in nursing homes is an example of the sociology *in* bioethics approach.[20] This was a project that aimed to formulate guidelines on respecting autonomy in nursing homes. They first ascertained what the caregivers' views on autonomy were by formulating four conceptions of patient autonomy from the literature and asking respondents which they preferred for their nursing home. They then tried to formulate a coherent view by taking the aspects of the different views of autonomy and balancing these to produce a theory on how to respect autonomy in that situation.[21]

In all these studies the attempt is made to use empirical data to directly alter and shape ethical theory. 'For example, one might wish to modify the theory of patient autonomy towards the social practice of surgical decision making in elderly men on the basis of empirical data.' (Stigglebout, *et al* 2004:269) Thus, 'bioethical theorizing…is not removed from lived experience – it is based upon it.' (Draper & Ives, 2007:325)

THE APPROACH IN THIS THESIS

This thesis combines elements of all these ways of using empirical evidence in ethical discussion. It is partly a sociology *of* ethical decision-making in the infertility clinic, an investigation into the way the informants thought about, approached and

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[20] See also Widdershoven & Sohl's (1999) study on a supported employment programme and make concrete suggestions as to how such a programme could be improved. Also Ives, *et al*, (2008) study on fatherhood.
[21] See also van Delden & van Thiel (1998).

dealt with what they perceived to be ethical issues. It incorporates elements of a sociology *for* bioethics in that it seeks to provide information on what the informants thought was ethically troubling (see Chapter Six) and how they approached problems (see Chapter Seven) so that an ethical analysis can take into account how issues are resolved and assess the consequences of current management (McHaffie *et al*, 2001). The thesis also has elements of a sociology *in* bioethics as it attempts to say something about how certain principles may be formulated and used in practice (see Chapter Seven and Eight) and thus how empirical data could change our formulations and understandings of ethical principles and theory (see Chapter Three).

Even if one accepts that the use of such empirical methods is a good thing for bioethics, are ethicists, trained in philosophy, the best people to carry out such research? Levitt (2004), for example, argues that bioethics and sociology should remain complementary rather than seeking to become more integrated. Appiah, who despite being very sympathetic to the use of empirical findings in the discussion of moral deliberation says: 'Philosophy should be open to what it can learn from experiments; it doesn't need to set up its own laboratories.' (2008:3) This is in effect what I have done, set up my own laboratory.

I want to give two arguments why I think it is worthwhile for ethicists to be involved in actually conducting empirical studies. First, a study designed by an ethicist and therefore driven by predominately 'ethical' concerns could have a different emphasis and focus from those conducted by sociologists. This is not to say that this sort of investigation is the only way to approach ethical issues or areas, but that there is room for studies of this type alongside more conventionally conceived sociological

ones. Second, ethicists might (and this is a controversial claim) be better able, as a specialism that is predominately concerned with ethics, to design studies that produce data that are of more help in conducting an ethical analysis.[22] Even if this second argument is not accepted (which it probably would not be by many sociologists), my central claim is that there is room for a distinctive type of empirical study: a study that uses ethical theory and principles in the analysis of the data and that seeks to say something about the theories and principles themselves.

Perhaps there is not any difference between the two types of research project. Harman's (2003) response to the question of what is the difference between moral psychology and moral philosophy can be applied here, when he says there may be no interesting difference or only one that is of interest to university administrators. Such a difference might be construed as one of the degree: both disciplines use theory, but it is the way that they use theory in their deliberations that can differ. But as Harman says, 'psychologists also theorise and increasingly philosophers join with psychologists in doing experiments and considering how that evidence…may be relevant to philosophical theories.' (2003:11) Therefore, an empirical study carried out by an ethicist may only differ from a social science one in the sense that it will always incorporate references to moral attitudes (van der Scheer & Widdershoven, 2004). Hence, I would argue that it valuable for ethicists to carry out their own empirical studies and these studies can make a distinctive contribution to the literature.

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[22] See Brody's (1993) critique of empirical studies carried out on ethical issues on these grounds.

CONCLUSION

The 'empirical turn' in bioethics is undoubtedly one of the most significant developments in the field in recent years. It has both challenged traditional ways of doing ethics and produced a range of studies that have enriched our understanding of ethical practice. Barriers have been broken down and new challenges and questions posed. The very emphasis on the empirical has led many to question and re-evaluate the importance of ethical theory. It is this relationship between ethical theory and empirical data and which lies at the heart of this thesis.

In the next chapter I will look at two of the main approaches in bioethics and how they have conceptualised this relationship. Then, in Chapter Three, I will develop my own approach to the relationship between theory and data.

CHAPTER TWO

DIFFERENT MODELS OF BIOETHICS

INTRODUCTION

Conducting any form of empirical study into ethical issues immediately raises

questions about the relationship between the data and ethical theory. Sometimes the

nature of this relationship is implicit at other times it is articulated explicitly. In this

chapter I will look at the way both 'traditional' and contextualist bioethics have

understood this relationship. The problems – as I perceive them – with each approach

help lay the groundwork for developing my own position, which is explored in

detailed in Chapter Three.

'TRADITIONAL' BIOETHICS

Bioethics has generally been associated primarily with the discipline of philosophy.

'Bioethics is characterised as the "investigation of ethical issues arising in the life

sciences…by applying the principles of moral philosophy to these issues"'. (Bennett

& Cribb, 2003:10) At the 'birth of bioethics' philosophy and theology shaped the

discipline with their methods and structures of abstract universal foundationalist

theorising (Jonsen, 1998). Foundationalist moralities provided a justification for why

certain beliefs are true and from there proceeded to tell us what to do (Harman, 2003).

For example, utilitarianism sought to justify its ethical theory on the foundationalist

principle of utility; Kant employed the foundationalist principle of the categorical

imperative, which tells us what must be done independent of our desires. Such

foundational beliefs were the type of belief that could be directly (by observation), or

self-evidently (by rational argument), be justified. From these foundational principles

all other moral beliefs and prescriptions for action follow.

Consequently, bioethics has become characterised as a discipline that seeks to apply ethical theories or principles to a particular set of ethical problems. In this 'traditional' model ethical principles and theories are constructed in an abstract way, without recourse to the context in which they arise and are held to be universally true for all of humanity. They are applied in a top-down rationalist deductive way – theories and principles are constructed and then applied in a value-neutral way to the problem at hand (Jennings, 1986). This form of bioethics has been called the 'engineering model' (based on abstract, universal, foundationalist reasoning) and is generally determined to be the dominant methodology in bioethics (Hedgecoe, 2004). [23] According to Caplan this model, 'presumes that application in ethical contexts is akin to application in such scientific contexts such as engineering.' (1982:8) This model has three attributes:

1. There is a body of knowledge that we can be more or less knowledgeable about, in the case of ethics this is moral theories or principles;

2. This knowledge becomes applied by mechanically deducing conclusions from theories in light of empirical facts, such as those supplied by social scientists. This would be a form of sociology *for* bioethics;[24]

3. The deduction can and must be carried out in an impartial and value-free manner. (Caplan, 1982:8)

Therefore, under the engineering model, bioethicists master normative theories and deductive logic and then combine theory with empirical data to get the solutions. Like a computer properly programmed with ethical theory, various bits of data can be fed in

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[23] Although bioethics has been associated with a particular type of philosophical enterprise, one that stems from a foundationalist tradition, there are of course many different types and forms of 'philosophy', and an association with these would not have to lead to a commitment to foundationalism (pragmatism, postmodernism for example).
[24] See the discussion in Chapter One.

and after logical operations have been performed the definitive moral conclusions will be produced (Caplan, 1982:9). MacIntyre puts it this way: 'Applied ethics derives its conclusions from a set of premises in which the conclusions drawn from ethics are conjoined to factual findings about some specific...social area.' (1984:499)

Harris in his Introduction to the *Oxford Readings in Philosophy on Bioethics* (2001) argues forcefully that the central methodology of bioethics should be philosophy and, more than that, a certain way of doing philosophy. It should not be construed as a multi-disciplinary area but a sub-set of applied philosophy.[25] If one takes this to be what bioethics *is* then, according to Harris, empirical research is only of interest in establishing facts (like one would need to establish the 'scientific' facts about cloning before being able to start commenting on the ethical aspects of such a development). Empirical research, under this model, can produce rich and interesting information about what "is" but it is not able to tell us anything about what "ought" to be the case (Pellegrino, 1995). Facts do not tell us what to do, we cannot, as Hume famously said, derive an ought from an is.[26]

Criticisms of this model – the 'social science critique'

One of the most recent and influential critiques of this model of bioethics has been what has come to be known as 'the social science critique' (Herrera, 2008). It is the notion of bioethics as a philosophical enterprise based on rational, universal 'top-down' theorising and its relative neglect of the social context that has been the focus of many of the social scientists' criticisms of bioethics (Hoffmaster, 1990, DeVries &

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[25] See Bennett & Cribb's (2003) discussion of models of bioethics. They argue that bioethics can and should also be seen as a multi-disciplinary area of inquiry.
[26] Both the claim that you cannot derive an ought from an is and if indeed Hume wanted to make a cognate distinction between facts and values are both disputed. On the first claim see Searle (1964) and on Hume's position see the short summary of the debate in Appiah (2008:212).

Conrad, 1998. Haimes, 2002). I will now consider the main points of this 'social science critique'.

Ignores social and cultural aspects of ethics

Light & McGee argue that bioethics suffers from having it roots in analytic philosophy and this, 'dominance of analytic philosophical approaches to ethics and medicine' (1998:2) has produced 'bad habits' which bioethics should try to rid itself. One of the main 'bad habits' is the decontextualisation of moral problems. 'Bioethics is constructed in such a way as to ignore the role of social and cultural factors, partly since it champions an "ideal of universal ethical principles".' (Hedgecoe, 2004:125) One result of this is that bioethics, as a discipline, is frequently said to have no real sense of what actually goes on in practice. 'Ethicists [are] criticised for being too far removed from clinical reality, insensitive to peculiarities of specific situations and unable to adequately consider the nature of diseases and the clinical contexts in which clinicians and patients are confronted with ethical problems.' (Borry *et al*, 2005:64)

According to this criticism, ethicists might suggest solutions that are unworkable in a clinical setting, or be addressing the 'wrong' problem by focussing on the exciting or extreme rather than the real and everyday (Turner, 2004). To take an extreme example, John Harris (1986) in his paper 'The survival lottery' suggested that everyone have a ticket and if their number came up they would be killed and their organs distributed to those who needed them. Leaving aside whether Harris was seriously suggesting this as a solution to organ shortages and was just pushing certain arguments to see where they would logically take us, these kinds of discussion lead clinicians to view

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bioethics as rather superfluous to their everyday practice and bioethics as of little use in practical problem solving (Kleinman, 1999).

Under this interpretation of bioethics, an ethicist is a creature who has no direct, practical knowledge of the subjects about which they write and thus, 'bioethics as a discipline doesn't seem to be in possession of the realities of practice. Bioethics is seen as, 'an abstract exercise carried on over sherry in the tutorial rooms of academic ivory towers.' (Wilkie, quoted in Bennett & Cribb, 2003:11) This criticism encapsulates two different definitions of relevant 'fact' that bioethics is claimed to ignore.

First, the bioethicist is ignorant about facts about clinical practice and does not fully understand what actually happens in the clinic. In talking about why doctors often feel let down by bioethics, Baron comments, 'bioethicists tend to leave the "facts" of clinical medicine to the doctors; their task is then to apply elegant and compelling arguments drawn from first principles of ethics.' (Baron, 1989:41)[27] Second, the bioethicist does not take into account an appreciation of the social and cultural context of bioethics: a particular type of 'fact' that social scientists argue to be important for any full understanding of ethical issues. This is seen as a troubling omission in bioethical discussion (Fox, 1999. Haimes, 2002).[28]

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[27] For example Chambliss argues that despite the great attention that ethics pays to informed consent (and respecting autonomy) in the bioethics literature, in practice 'informed consent represents at best a polite fiction.' (1993:651)

[28] For example, Anspach argues that it is imperative to know about the social dynamics of communication between patient and professional or, 'informed consent is likely to remain an elusive ideal rather than a practical reality.' (1993:37)

The application gap

A further element of this 'social science' critique is what has been called the 'application gap'. The engineering model presupposes that moral principles are specified independently and prior to their application (MacIntyre, 1984. Caplan, 1982. Jennings, 1986. Hoffmaster, 1994, 1992, 1990). As stated above the engineering model rests on the logical sequence of: the formulation of universal (ethical) principles; social situations empirically described; then moral principles applied to possible courses of action (Jennings, 1986). MacIntyre states the problem:

> in applied ethics the rules or principles which on the dominant conception [the engineering model] constitute morality *cannot* be being applied in the way that is commonly supposed. For the relationship between a rule and its applications cannot be what on the dominant view it is taken to be; that is, it cannot be the case that we can first independently comprehend the rules of morality as such and then only secondly enquire as to their application in particular specialized social spheres. For, were this to be case, the rules of morality as such would be effectively contentless. (1984:501)

According to MacIntyre: 'Moral rules exist only in and through their range of applications and the history of moral rules in key part is the history of the changes in their application.' (MacIntyre, 1984:508) There is an 'application' gap.

Hoffmaster makes a similar point when he argues that there is an, 'application gap between general norms and specific facts that can be bridged only by considerations external to moral theory.' (1990:242). Although conceptual analysis can clarify different meanings of a concept, such as autonomy, it cannot resolve substantive issues as it cannot tell us what that concept "really means"'. (Hoffmaster, 1992:1423) Moral rules have to be given substantive content through their application and by considerations that are external to the moral theory.

Hedgecoe (2004) gives an exposition of what factors might be necessary to give moral theory 'substantive content', that are in Hoffmaster's sense 'extra-theoretical'. He says there is important 'moral work' being done before it is possible to apply theory or principles as, 'applied ethics relies on the assumption that the categories in a moral problem (e.g. 'patient', 'informed'…) mirror those in the ethical theory being applied.' (Hedgecoe, 2004:127) This 'moral work' of categorising concepts, deciding which concepts are relevant and how they apply to the specific situation are matters that have to be done prior to the application of the ethical theory, and as Hoffmaster notes this, 'moral work can determine how issues are resolved.' (1994:1157)

Hedgecoe gives the following example of this 'moral work': 'Deciding whether children of a particular age are competent to give informed consent is a categorisation that can only be made on the basis of empirical evidence. Yet it has serious implications for ethical medical treatment, and thus such empirical research is basic "moral work"'. (2004:127) This type of research could be the measurement of children's understanding of certain concepts or how much information they are able to absorb. Hence, the problem here is two fold: first, this important moral work is not made explicit and this can lead to assumptions and premises that have not been justified being incorporated into the argument; second, if this type of work is not conducted empirically (i.e. studies to see how much children could actually understand), then it could be based on philosophers' unsubstantiated intuitions and assumptions.[29]

Appiah puts this point in the following way: 'In the real world, situations are not bundled together with options. In the real world, the act of framing – the act of

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[29] See Draper & Ives (2007) for a discussion of the problems with philosophers' intuitions.

describing a situation, and thus determining that there's a decision to be made – is itself a moral task. It's often *the* moral task.' (2008:196) He goes on to say: 'In life, the challenge is not so much to figure out how to play the game; the challenge is to figure out what game you're playing.' (2008:197) Thus, to take Appiah's analogy, once you have decided what game you are playing – the relevant principles may then be applied. However, for Hoffmaster the decision of what the game *is* is external to these principles. It is this decision that crucially frames the problem, determines what sort of principles one uses and therefore produces a certain type of answer.

Data from sociological studies

Certain studies on ethical decisions made in a medical context also draw attention to problems with a 'traditional' engineering model of bioethics. Anspach (1993),[30] for example, in her study of decision-making in an intensive care nursery, explicitly engages with the bioethical debate over life and death decisions in intensive care. She uses her findings to criticise traditional bioethical concepts such as autonomy, by arguing that in practice such concepts have little meaning, 'bioethics individualizes the decision-making process….[however] life and death decisions are not private matters, but rather take place in the context of organisations, institutions, and power relations.' (1993:164)

Alderson (1990) also uses her empirical findings to advance a form of the 'social science critique' of bioethics. She devotes a chapter[31] of her book on children and informed consent to discussing the shortcomings of the main theories and methods of bioethics. She takes issue with the use of abstract conceptions such as personhood,

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[30] See also Anspach's (1989) discussion of the limitations of the four principles of health care ethics in medical practice.
[31] Chapter Nine.

for example, that are used in the bioethics literature. Alderson argues that the notion of personhood is of limited use in solving practical dilemmas, a notion often used by bioethicists such as Harris, Singer and Tooley. She argues that the assumption that children are not rational and therefore not persons can prevent them from being involved in the process of gaining consent for their treatment. Whereas, her research found that some children could, in certain circumstances, participate fully in medical decision-making. Further, Alderson argues that the personhood debate in bioethics focuses on the wrong question, namely, 'does this human being have a right to treatment?' [32] A possible answer being: no, because they are not a person (1990:196). She says that this question 'makes no sense' for those caring for handicapped neonates: 'Their central question is: What is appropriate treatment for [the neonate]? Leading on to the tentative question: What will help him have a tolerable life now and in the future?' (1990:196) Thus:

> The "rational person" debate overlooks children's needs and capacities. It lends a spurious certainty to the most complex, tentative questions, but contributes little to real discussion. It is therefore not a useful basis for discussing medical dilemmas involving children. (Alderson,1990:196)

For Alderson, the concept of personhood does not have any practical 'grip', it does not do any useful moral work in helping health care professionals or parents make decisions or think about the problems they face. [33]

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[32] It could be said here that the bioethics are not addressing the right 'game' in Appiah's sense (discussed above) and the bioethics commentary misses the important debates that those working in the field need to address.

[33] It could be argued, contrary to Alderson, that the problem is not with the concept of personhood but rather in the situation she describes practitioners are more concerned about beneficence for the child and this is the important ethical principle here. Therefore, her findings can be used to point traditional bioethics in the right direction rather than suggesting the whole project of traditional bioethics is flawed.

Rebuttals

There are a number of rejoinders that can be made to this 'social science critique' of bioethics. First, it is worth noting that this is not the only way bioethics is practised, and to characterise bioethics as a monolithic discipline is simply wrong. There are other ways of doing ethics - casuistry, virtue ethics for example - that do not rely on such a methodology (Callahan, 1999). It is, however, often argued that other models are 'in the minority' in academic bioethics (Hedgecoe, 2004). The point of highlighting these alternative views is merely to indicate that there is disagreement over what constitutes 'bioethics' methodology and therefore any criticism levied at one conception is bound to fall foul of critics who can reply that 'this is not what we do anyway'. The authors who are most associated with this method of bioethics, Beauchamp & Childress, have developed their views on the role of principles in moral deliberation and in the fifth edition of their *Principles of Biomedical Ethics*, explicitly state they reject such a 'top-down model' (2001:408).

Second, in response to these critiques of a 'traditional' model of bioethics it might be replied that it is not surprising that studies find no support for such a model as this model is a straw man. Herrera (2008) mounts a case against the social science critique of bioethics along these lines. He argues that bioethics is already a multi-disciplinary area and the idea of bioethics as populated by abstract philosophers is an outmoded one. Herrera gets a 'sense of unfamiliarity' (2008:140) when reading criticisms, such as Hoffmaster's. He asks whether any bioethicist would seriously dispute that the social context of ethical problems are important or that ethical problems cannot be solved solely on rational grounds?

Jennings also makes a similar point when he argues that:

> [f]or while the engineering model is often used by applied ethicists as a second-order methodological account of their enterprise, it does not in fact accurately describe what these studies are doing. The engineering model, I contend, is best seen as an ideology of applied ethics and not as an accurate reconstruction of the nature of applied ethical analysis. (1986:212)

As Nussbaum notes when discussing those who are hostile to the use of ethical theory, 'anti-theorists take mediocre and excessively simple targets. Does any distinguished ethical theorist believe, for example, that a theory is simply a system of rules?' (2001:xxvii) Thus, the model of bioethics that is criticised by the 'social science critique' could be said not to represent what bioethics really is and what bioethicists really do.

There is, however, one element of the 'social science critique' that has some value, the recognition of the problem raised by the 'application gap' – that principles and ethical theories need to get their content through application and it is an attention to this process that is important for any approach to bioethics (Birnbacher, 1999). My approach to this problem will be discussed in the next chapter.

A common response to the 'social science critique' is to posit a more self-consciously contextual meta-ethical theory and it is to this that I will now turn.

CONTEXTUAL BIOETHICS

Out of perceived deficiencies in the 'traditional' engineering model of bioethics has grown an interest in a contextual morality, a move away from foundationalist theorising towards an approach that sees the context of moral or political theory as being important. Contextualists generally view "contexts" not only as *a field for*

applying ethics, but also as *a source of morality*.' (Musschenga, 2005:468) Contextual

morality pays careful attention to the context in which decisions and dilemmas are

played out and therefore gives a central place to social science research in

discussions of moral issues. This concern to reinstate the particular context in moral

reasoning has been a growing trend in philosophy and political theory in recent years.[34]

Contextualism is a broad term that can embrace many different positions depending on

the role that context is seen to play in determining the morality of the situation. Some

forms of contextualist morality reject the claim that morality can be expressed in

explicit propositions, moral theory or principles (Bader & Saharso, 2004). These

'strong' contextualists would claim that it is not possible to make ethical judgements

that have any wider application beyond the case in question, as morality rests solely

in each individual context (MacIntyre,1988).[35] This approach would jettison

'traditional' forms of ethical theory and concentrate on description and mapping the

moral terrain, without seeking to make any general normative claims beyond the

particular context.

Other forms of contextualism would retain ethical theories but view the nature of this

theory as different from the universalist, foundationalist conception. Carens (2000), for

example, advances a form of moderate contextualism that has a notion of context-

transcending principles, but attempts to see how the circumstances of particular cases

determine the content of these principles. For the purposes of this discussion I want to

concentrate on one formulation of contextualist morality advocated by Hoffmaster.

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[34] This has been a general trend and has occurred within the discipline of philosophy see Dancy (2004) and political theory see (Carens, 2000. Bader & Saharso, 2004).
[35] Although in later works MacIntrye has made his use of context-transcending principles more explicit.

Hoffmaster considers the relationship between social science research and bioethics and his account has been very influential in the literature (see Hedgecoe, 2004. Haimes, 2002. Herrera, 2008).

Hoffmaster's contextualism

Hoffmaster's contextualist morality rejects the claim that morality can be exhaustively expressed in explicit propositions, 'traditional' ethical theory or principles and the focus is on understanding the context of ethical issues rather than debating ethical theory.

> Moral philosophy and its adjunct "applied ethics" movement run into trouble because they remain stubbornly acontextual….Reading books and engaging in arm-chair speculation, does not supply contexts, however. (1992:1427)

Hoffmaster while rejecting universal ethical theory does not reject all theory completely, '[a] contextual understanding of morality does not mean that there is no room for moral theory or philosophizing about morality, simply that the nature of this theory must be different.' (Hoffmaster, 1992:1428)

However, for Hoffmaster the use of theory is much more limited:

> The focus of contextualist morality, rather than being theory, is practice. Its concern is accounting for the phenomena of morality. But understanding the practice of morality requires that this practice be located in its social and historical contexts. Morality becomes intelligible only when the background that makes it possible is considered. (1990:25)

Hoffmaster explains this background consists of three elements:[36]

1. *Vorhabe* (fore-having) – the totality of cultural practices that when applied to morality are the 'set of cultural beliefs that delimit the moral realm and thus determine what comes to be identified as a moral issue.' (1990:251)

2. *Vorsicht* (fore-sight) – the vocabulary or conceptual schema that is brought to a problem. Thus the way moral issues are formulated.

3. *Vorgriff* – a specific hypothesis which can be refuted or confirmed by the data, which in morality is specific judgments about moral issues.

He argues that traditional bioethics ignores the *Vorhabe* and the *Vorsicht*. Theories such as utilitarianism and Kantianism focus on one moral insight from practice and ignore the rest to create a moral theory that, 'reflects a truncated understanding of what morality is.' (1990:251) For Hoffmaster problems such as those created by reproductive technologies and genetic engineering cannot be solved by a traditional bioethics, 'because they call into question the presuppositions that structure the context within which positivist moral theories operate.' (1990:252) The *Vorhabe* and *Vorsicht* of morality need to be altered to reach resolution of these types of problem.

Thus, ethical theory, for Hoffmaster, arises out of practice rather than underlying it, and is not abstract, universal or context independent (1992:1428). In this contextual morality social science research would have a pivotal place as it is about understanding what happens in practice, rather than purely a focus on normative theories or principles. Hoffmaster outlines some of the benefits of such approach. A contextual morality in bioethics would move bioethics away from purely theoretical concerns making it more realistic and helpful (Hoffmaster, 2001:7). By putting bioethics in context it can expose

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[36] These elements are based on Dreyfus' discussion of Heidegger's understanding of science. Such scientific understanding requires 'pre-understanding' which consists of these three elements.

the gap between theory and practice, for example although informed consent is seen as theoretically important studies show it is a fiction (Hoffmaster, 2001:8). Studies can show that moral prescriptions of what ought to be done can be blocked by decision-making procedures and power relationships in hospitals. 'Putting bioethics in context helps to expose the institutional, social, and cultural forces that create gaps between theory and practice and points bioethics in directions more likely to produce moral reform.'(2001:9) Bioethics should be more circumspect in judging (making normative judgments) and attempt to understand morality as a lived experience (2001:10).

Hence, for Hoffmaster, there is no one universal method to problem-solving; it becomes one of seeing which approach is appropriate and the challenge is to see which approach fits the issue under consideration: 'There is no method of morality, let alone a 'rational' method of morality. Moral decision-making is, instead, a matter of 'muddling through.' (1990:250)

Criticisms of contextualism

Are people contextualists?

As a way of strengthening his position Hoffmaster argues that a contextualist morality better reflects how people think about ethical issues in practice and that principles do not feature in peoples' moral decision making. He uses examples of research into how ethical decisions 'actually get made' to illustrate how people 'muddle through' rather than apply or use principles (1990:253).

One example is a study of genetic counselling (Lippman-Hand & Fraser, 1979 in Hoffmaster), which examined parents' choices over what steps to take in response to

genetic counselling. Hoffmaster says that this study shows that these are not decisions taken on the basis of ethical theories or principles but ones in which the parents 'muddle through'. These are highly individual decisions that may not be right for others.

However, an alternative interpretation of this study can be made. While this 'muddling through' may be true of how individuals make these decisions, there is a prior decision taken by society/medicine that that the defective foetuses can/should be aborted and that this is an acceptable choice to be made and counselled for in these circumstances. Therefore, the principle that it is ethically acceptable/tolerated to abort defective foetuses is in operation and this gives individuals that choice to make – it becomes an individual moral choice. So even in Hoffmaster's example, there are still ethical principles that are employed. His example merely shows that sometimes these ethical principles operate at the level of society rather than at an individual level. What it does not show is that ethical principles are not used. Therefore, Hoffmaster's example of the occurrence of a contextual morality in practice could be interpreted in a way that actually illustrates, rather than disproves, the use of ethical principles.

Other research has shown that in some areas ethical principles have been used to make ethical decisions. Braunack-Mayer's study on general practitioners in Australia found that forms of ethical reasoning employed in bioethics do have some purchase in the 'real world'. One of her findings was that the GPs she interviewed, 'did have and use moral principles.' (1998:239) These moral principles were 'principles-in-use', that is they were not developed with the rigour or consistency found in the bioethical literature, but nevertheless, her GPs did have a sense of principles such as beneficence and autonomy and sought to use them in their ethical deliberations.

Normative judgments

Any account or inquiry into moral life needs to have some normative leverage, ethics needs to be able to judge or at least have some 'methods of criticism', so that we can say that something should not continue on moral grounds.

Contextualism is often criticised for falling into relativism, that is adopting a position where any thing goes (Kukathas,2004). The worry here is that if we abandon ethical theory, the foundationalist belief systems that have tried to give us guidance over what to do, we are left with no way of making moral judgements (Rachels, 2003). Contextualist morality, in order for it to be a distinctive consideration of ethical issues rather than just description needs to have some 'normative leverage'. It needs to be able to say that such and such practice should not continue on moral grounds. So how does Hoffmaster deal with this issue?

For Hoffmaster moral judgments do not depend on ethical theory, they depend on what he calls 'rational criticism'. This form of criticism has two distinctive features. First, such criticisms are directed at moral judgments that are situated in particular social contexts, 'they assume that morality changes and that rational criticism can contribute to that change.' (1990:253) Second, the notion of rationality is more modest in contextual morality than that used in what he calls positivist morality, one that is satisfied with saying that judgments are embedded in moral practices rather than universal rules.[37] Therefore, in Hoffmaster's view: 'Contextualist morality has ample room for critical normativity.' (Hoffmaster, 1990:252) Whether this form of rational

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[37] In the 1990 paper he uses Geuss' criteria for criticising ideologies and argues that morality can be criticised along the same lines (1990:252-3).

criticism can adequately perform a normative role is debatable.[38] However, I want to consider the wider claim that ethical theory has no role to play in contextualist ethics.

A contextualist morality does raise the important point that any ethical theory or deliberation must be sensitive to the context in which it is played out. However, in certain formulations, the rejection of any form of ethical theory makes it difficult to make judgements about practices that we might be unhappy about. Molewijk, when commentating on a problem he sees with conceptions of ethics that leave no role for ethical theory in the production of normative judgments, says, 'I am not suggesting that moral theory should function as the final arbiter, but no role at all is (at least in my opinion) really a waste of ethics' critical and constructive knowledge.' (2004:86)

The danger of positions like Hoffmaster's is that they reduce our power to make ethical judgments. Ethical theory can play a significant critical role and to not employ such theories in ethical deliberations can make those discussions all the poorer.[39] Ethical theory and principles gives us a way of criticising such practices that go beyond simple remonstrations of 'I don't like that'. It allows us to say some things are unjust, unfair or simply wrong. A rejection of any form of ethical theory could lead to the inability to criticise the status quo. Thus, ethical theory's critical facilities are both useful and, arguably, necessary to be able to advance moral judgments.

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[38] Hoffmaster does not elaborate on this method of rational criticism in any later papers, so this method is not particularly well elaborated.

[39] See Nussbaum (2000, 2000a & 2006) for a seminal discussion on why we need ethical theory in modern life. See also next chapter for a discussion of the role of ethical theory in the approach to ethics adopted in this thesis.

CONCLUSION

This chapter has critically appraised two different approaches to bioethics. First, the 'traditional' or engineering model where the principal focus is on ethical theory and where context, if it plays any role at all, usually plays a secondary role. Second, contextualism, where the principal focus is on context, and where ethical theory, as traditionally understood, plays little or no role.

There are, I have argued, problems with both these ways of seeing bioethics: problems that are principally concerned with how they conceive the relationship between theory and context/practice. In the next chapter I will develop a theoretical approach that focuses on both theory and practice equally. An approach based on an understanding of their interdependent relationship. Ethical theory is important in this approach but the provenance of it is different from a foundationalist conception of theory. Such ethical theories arise out of practice, as a contextualist might argue, but can still retain their wider applicability, as a traditional approach to bioethics would claim. This, I believe, enables bioethics to both retain its normative function and be attentive to the particular contexts in which moral decisions take place.

CHAPTER THREE
THEORY AND PRACTICE IN BIOETHICS

INTRODUCTION

In the previous chapter I looked at the two dominant ways of conceptualising

bioethics and examined their limitations. In this chapter I now want to explain the

way that the relationship between ethical theory and practice (contexts) will be

conceptualised in this thesis. From this I will develop a methodology for approaching

ethical questions in practice.

Stephen Toulmin (1992) advances an argument that, since the Renaissance, ethics

has been increasingly seen as a discipline that should emulate the natural sciences

and leave behind its Aristotelian concerns with the particular, concrete diversity and

localised judgements. Philosophy was to be concerned with issues of theory and not

with practical matters.[40]

> After the 1650s, Henry More and the Cambridge Platonists made ethics a field for
> general, abstract theory, divorced from concrete problems of moral
> practice….Modern philosophy was concerned not with minute "case studies" or
> particular moral discriminations, but rather with the comprehensive general
> principles of ethical theory. (1992:32)

Toulmin argues that these core beliefs of modernity are now being questioned.[41]

'Today, this theoretical agenda is wearing out its welcome, and the philosophical

problems of practice are coming back into focus.' (1992:186) The movements of

post-Renaissance thought from the oral to the written; from the particular to the

universal; from the local to the general; and from the timely to the timeless are no

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[40] This is, of course, a view of one strand of, largely Western, philosophical thought, but it has had a
profound influence on the way ethics has been carried out in the Anglo-American tradition.
[41] However, some beliefs of modernity are, arguably, worth keeping, human rights, freedom of speech
etc (see discussion in the previous chapter).

longer seen as unproblematic. One conclusion of this critique of modernism is, obviously, post-modernism which in some formulations does away with any form of (ethical) theory. At this extreme there is a danger of adopting a position that allows no critical faculty and slips into relativism. This can be seen in the developments discussed in the previous chapter, a contextualist morality that seeks to replace a traditional (modernist) bioethics.

Toulmin, however, argues that, 'we can neither cling to Modernity in its historic form, nor reject it totally – least of all despise it. The task is, rather, to reform, and even reclaim, our inherited modernity, by *humanising* it.' (1992:180) For Toulmin the way to humanise philosophy is to 'recover practical philosophy', 'a renewed acceptance of practice, which requires us to *adapt* action to the specific demands of particular occasions.' (1992: 192) The rejection of foundationalism does not have to mean the rejection of rationality for Toulmin, just a different conception of it that reinstates Renaissance concerns for the particular and does not solely focus on abstract theorising. We need to, 'reappropriate the wisdom of the 16th-century humanists, and develop a point of view that combines the abstract rigor and exactitude of the 17th-century "new philosophy" with a practical concern for human life in its concrete detail.' (1992:xi) This is, in effect, advocating a middle way between the purely theoretical concerns of 17th century philosophy and the more contextual concerns of the 16th century humanists. Toulmin terms this a '*pre*-modern' rather than a *post*-modern approach. My approach could be said to be a way of conceptualising a middle way between these two forms of philosophy.[42] I will argue that using Aristotle's account of the relationship between theory and practice

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[42] Toulmin argues that casuistry is a useful 'middle way' for making ethical decisions.

can help us develop an approach which, while paying due attention to context, retains universal principles and theories and therefore avoids the pitfalls of more relativistic accounts (such as strong contextualism). This will enable bioethics to both retain its normative function and be attentive to the particular contexts in which moral decisions take place.

ARISTOTLE ON THEORY AND PRACTICE

My concern here is to draw on elements of Aristotle for a conception of, 'a more inclusive conception of what moral philosophy is' (Nussbaum, 1983:204). The importance of the particular circumstances in which the moral decision takes place are more fully recognised and the empirical contingencies of life are not seen as separate from the ethical enterprise. However, in this enterprise ethical theory still has a role to play. The attempt here is not to give a full systematic account of Aristotle's thought or provide a historical or textual analysis, but to pick out and use some features of Aristotle for my own purposes.[43]

I shall draw on Jonsen & Toulmin (1988) and Nussbaum's[44] work on Aristotle in regard to the relationship between theory and practice, recognising that this is one interpretation of the role practical wisdom (*phronesis*) plays in Aristotle's ethics and its complex relationship to theory. As Barnes says, 'on many issues in the interpretation of Aristotle's philosophy it is not plain where the orthodoxy lies.' (1995:xi) However, I shall endeavour to indicate alternative interpretations of key

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[43] See Dunne (1993) who approaches the study of Aristotle (and indeed other philosophers) in a similar way. Also Flyvbjerg (2001) who advances a form of 'phronetic' social science based on a broadly Aristotelian foundation.

[44] Nussbaum has also modified and changed her views over time. See the discussion in *Fragility of Goodness* (2001:278-282) and in the preface of this updated edition of *Fragility*.

points that have caused particular controversy and locate the debate in the wider
literature on Aristotle as far as possible.[45]

Theory and practice

Aristotle saw a difference between different types of theory. For example, geometry
was seen in classical Athens as a proto-type of theoretical reasoning, statements
about the state of world from which, by deduction, conclusions about particular
instances could be reached. Aristotle held that theoretical knowledge could be
divided into two kinds: formal or analytic argumentation such as geometry; and
theories about the natural world, such as Aristotle's work in zoology and the
categorisation of natural types.[46] Ethics, however, did not fall into either of these
categories. Jonsen & Toulmin argue that:

> the *absence* of any such pre-existing divisions in the subject matters of Ethics
> – the fact that the circumstances and cases that human conduct deals with *do
> not* come neatly packages in "natural kinds" – is precisely what prompted
> Aristotle to deny that ethics can be a science: that is, a field for "universal and
> external" principles and quasi-geometrical argumentation. (1988:64)

Hence, according to Aristotle not all knowledge could be subject to this kind of
'scientific' theorising, practical fields, such as ethics and medicine for example,[47]
have a different form of knowledge[48] – one that is the product of experience.

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[45] I say 'as far as possible' because as Broadie notes, 'scholarship on Aristotle's *Ethics* is a vast and thriving industry.' (2002:81)

[46] See Barnes (1995) for a succinct introduction to Aristotle's work in general and his inquiries into zoology and the categorisation of species. And Hughes (2001) for a discussion of Aristotle's biological studies impact on his ethical thought.

[47] See Nussbaum (1994) Chapter Two for a detailed analysis of the analogy Aristotle makes between medicine and ethics and where Aristotle sees such an analogy breaking down.

[48] See Reeve (1992) on the relationship between scientific knowledge and ethical knowledge, who disputes this contention (Chapter One). He argues that, 'Aristotelian ethics is much more like a science than it is usually represented as being.' (1992:27)

Ethics was a practical activity that differed from 'science'[49] in the following ways:

1. Scientific theories attempt to formulate general and universal truths whereas ethics is about particular facts and circumstances.

2. Scientific knowledge lays claim to certainty by the soundness of its theoretical principles, whereas practical knowledge certainty is grounded in knowledge of the particulars.

3. Scientific theories are a temporal, whereas ethical judgements are specific to their time and place. [50]

Therefore, we cannot expect the same amount of precision in ethical knowledge as other forms of inquiry.

> But our account would be adequate, if we achieved a degree of precision appropriate to the underlying material; for precision must not be sought to the same degree in all accounts of things, any more than it is by craftsmen in the things they produce.(*Nicomachean Ethics* (EN), 1094b13) [51]

Hence,

> It is the mark of an educated man person to look for precision in each kind of inquiry just to the extent that the nature of the subject allows it. (EN, 1094b24)

Therefore, for Aristotle there are two ways of knowing. *Episteme* which can roughly said to equate to what we mean by scientific knowledge today and *phronesis* – the kind of wisdom that is relevant for ethical deliberation – an articulation of judgement, experience and deliberation about what is the right (in the ethical sense) thing to do.

> Nor is wisdom[52] only concerned with universals: to be wise, one must also be familiar with the particular, since wisdom has to do with action, and the sphere of action is constituted by particulars. That is why sometimes people who lack

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[49] It is not at issue here whether this is an accurate reflection of what science is.
[50] These are taken from Jonsen & Toulmin (1988).
[51] All quotes from the *Nicomachean Ethics* are taken from the Rowe translation (Aristotle, 2002), unless stated otherwise.
[52] Wisdom in this context is *phronesis* – practical wisdom.

universal knowledge are more effective in action that others who have it – something that holds especially of experienced people.[53] (EN, 1141b15-20)

Aristotle goes on in this passage to give the famous example of why chicken is good to eat. There may be a scientific explanation of why chicken is good to eat (he suggests that as it is a light meat it is easy to digest); however, direct experience tells us it is good to eat – we do not need this kind of theory to tells us what is good to eat. For Aristotle, then, the realm of practice requires a different form of knowledge, an accumulation of experiences that gives one a particular kind of wisdom – *phronesis* – and ethics is included in this realm.

For Aristotle ethics cannot be reduced to simply following or applying a series of abstract rules as might be possible in those disciplines that are more properly seen as scientific. 'Practical wisdom…cannot be acquired solely by learning general rules. We must also acquire, through practice, those deliberative, emotional, and social skills that enable us to put our general understanding of well-being into practice in ways that are suitable to each occasion.' (Kraut, 2007)

> Things in the sphere of action and things that bring advantage have nothing stable about them, any more than things that bring health. But if what one says universally is like this, what one says about particulars is even more lacking in precision; for it does not fall under either expertise or under any set of rules – the agents themselves have to consider the circumstance relating to the occasion, just as happens in the case of medicine, too, and of navigation. (EN, 1104a4-10)

Hence, for Aristotle practical reason is both understanding and experience and each particular situation one is confronted with enhances that understanding.

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[53] Dunne quotes this passage and gives a commentary in parenthesis that make the point about the importance of practical knowledge clearer: 'But phronesis is practical and therefore one needs both kinds of knowledge [i.e. of the universal and the particular] *but particularly the latter* [i.e. of particulars].' (1993:313)

> Everything which is done is particular, that is to say an ultimate. So the person of practical wisdom [*phronesis*] needs to recognise particulars, just as understanding and judgement too are concerned with things which are done, and so with ultimates. (EN,1143a32)

> These [particular insights] are origins of the end one has in view, since universals are derived from particulars. Of these particulars, then, we must have a perception, and that is insight. (EN, 1143b5)[54]

Aristotle is concerned with how a general understanding of the virtues is to be applied and used and it is here that *phronesis* plays an important role. Practical universals (such as the virtues, directions on how we should act) are known to us by seeing instances of them. There are no hard and fast rules over what to do in a specific situation[55] – there is a difference between scientific universals and practical ones. Practical universals are flexible and inexact and we need experience to build up our picture of what they are.

Ethical theory and principles play a role in Aristotle's ethics. Aristotle formulates what can be seen as an ethical theory, one that examines how we are to live well and concludes that the practicing of the virtues (such as justice, courage etc) can fulfil this aim. Ethics, for Aristotle does have universal rules or principles, but these universals cannot be applied to a problem and an answer derived in the same way as scientific universals. Ethical theory cannot offer a definite answer to a problem by the application of certain universals. It can offer some guidance, on things to be considered, but how these will be balanced with and against each other will be a matter decided by looking at the particular case and employing one's practical

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[54] These two translations are taken from Hughes (2001:101-102)
[55] As Appiah says, 'Normative theories, if they are sensible, do not offer algorithms for action.' (2008:193)

wisdom (*phronesis*).[56] Thus, universal rules or principles play a role in Aristotle's ethics but he does not abstract them from the case in hand, he posits *phronesis* as a mechanism for getting from a universal rule to its application in practice. For my purposes the important point is not the acceptability of Aristotle's ethical theory – a virtue ethic – but the way he conceptualises the relationship between ethical theory and the particular case.

This relationship between theory and practice or between the universal (generalities) and particular[57] is important for my account. Aristotle's conception of this relationship distinguishes his ethics from Plato's, who saw the Form of the Good as a purely abstract entity.[58] Jonsen and Toulmin interpret Aristotle as holding that ethical generalities were important, but these generalities differed from the Platonic Ideal: first, 'the relevance of such generalities [ethical theory] must always be criticised in the light of detailed facts of the particular situation.' (1988:71) And, second, these generalities are based on the wisdom and experience of human beings. This type of theory will not meet the criteria of theory as *episteme* or *sophia*, its subject matter will not permit the same level of exactness, as we would find in maths for example. 'Human affairs…contain so much variety and fluctuation, that a theoretical account of it can only be given "roughly and in outline" and can do no more than suggest what is true, "for the most part".' (EN,1.3 summarised in Dunne,1993:243)

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[56] Kraut interprets Aristotle as holding that, 'although he [Aristotle] holds that ethics cannot be reduced to a system of rules, however, complex, he insists some rules are inviolable.' (2007) Rules of this nature, for Aristotle, are theft, malice, adultery and murder. These are not actions that one can exercise appropriately or apply ethically, 'it is not possible, then, ever to get it right with affections and actions like these, but only to go astray.' (1107b14-15, EN quoted in Kraut)

[57] Defined as: a universal is a type or kind of thing (doctors); whereas a particular is one of such a type (Dr Smith).

[58] Aristotle argued that this abstract 'ideal of the good' is not something that man can, in practice, achieve (1096a11-97a14, EN). See also Devereux (1986) for a discussion of the difference between Plato and Aristotle's views on the universal and the particular.

Nussbaum has written extensively on the relationship between theory and practice in Aristotle's thought. She argues that for Aristotle, 'universal statements are posterior in ethical value to concrete descriptions, universal rules to particular judgments.' (2001:301)[59] Rules can be used as a form of a rule of thumb, as summaries rather than, 'the ultimate authorities against which the correctness of particular choices are assessed.' (Nussbaum,1990:68) For Aristotle it is not possible for any universal formulation to cover all the particulars that might arise – any law is the summary of wise decisions – and laws should be corrected when they are not in accord with good judgment. 'General principles are authoritative only insofar as they are correct; but they are correct only insofar as they do not err with respect to particulars.' (Nussbaum,1994:66)[60] In this way, 'that is why it remains important for [ethical] theories to consult good practice.' (Nussbaum,2000:246)[61]

This attention to the particularity of a situation, as Crisp notes, can be accepted by, 'ethical theorists of any stripe.' (2000:28)[62] Any ethical theory faces the problem of generalisations running out when confronted with particular situations – moral rules

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[59] This claim that judgments about particular situations are normatively prior to general rules in Aristotle has been questioned by Irwin (2000) for example. He argues that, 'Aristotle believes he can find theoretically significant generalizations.' (2000:129) The debate here for Irwin is that Nussbaum (among others) is trying to press a particularist interpretation onto to Aristotle, particularism here is defined as particulars are normatively prior to generalities. This turns the debate into one about moral metaphysics – reasons are not determined by principles (Vayrynen, 2002). This is one interpretation of particularism, a further one is that a particularist would have no time for moral principles (at whatever stage they were employed – i.e. Dancy (2004)) in this respect Nussbaum is not a particularist (see her discussion of this point in the Preface to the revised edition of *Fragility of Goodness* (2001)).

[60] See Nussbaum's *Therapy of Desire* for good account of Aristotle's methodology and goals of ethical inquiry.

[61] For a more detailed elaboration of Nussbaum's interpretation of Aristotle on this point, that is beyond the bounds of this chapter, see 'The Discernment of Perception' in Nussbaum's *Love' Knowledge* (1990).

[62] Arguably Kant would not agree with this, but argue that the problem was a lack of theory, 'It is therefore not the fault of the theory if it is of little practical use….The fault is that there is *not enough* theory.' (Kant, 1793/1991:61)

are indeterminate.[63] However, it is the formulation of the moral rules and how they can be revised and interpreted in the light of experience and situations that is important for my account and where it differs from the 'engineering' model of bioethics based on foundationalism. The contention that the moral rules arise out of experience, as Nussbaum puts it, 'the discernment rests with perception', is key in my account.

> The particular case would be absurd and unintelligible without the guiding and sorting power of the universal….Nor does particular judgment have the kind of rootedness and focus required for goodness of character without a core of commitment to a general conception – albeit one that is continually evolving….There is in effect a two-way illumination between particular and universal. Although the way we have described the particular takes priority, they are partners in commitment and share between them the honors given to the flexibility and responsiveness of a good judge. (Nussbaum,2001:306)

Thus, this account does not reduce ethical theory to a superfluous and meaningless enterprise,[64] it has a key role to play in moral deliberation. This point is summed up by Nussbaum when she responds to critics who have charged her with being 'anti-theory' in the Preface to the revised edition of *Fragility of Goodness*:[65]

> Theories can and should incorporate a decent respect for judgements based on experience and cultivated perception; Aristotle's is one that does so. But the whole of his theory is ready to be wheeled on stage at any time, in order to criticise perceptions that are deformed….Judgments will test theories as theories test judgment. (2001:xxvii)

In this way, theories arise from practice, experience and perception. They are useful ordering principles, rules of thumb for conduct and they can be criticised by practice and good judgment.

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[63] This is a debate akin to the discussion of Kant's maxims – what maxim covers a particular situation?
[64] As some formulations of the social science critique of bioethics would do.
[65] See also Nussbaum (2000) for an elaboration of these views.

The position that I am adopting can be seen as a form of 'philosophy from the inside out' as opposed to philosophy outside in (which would correspond to the engineering model of bioethics). Dworkin argues:

> We can begin with practical problems….and then ask which general philosophical or theoretical issues we must confront in order to resolve those problems…When we reason from the outside in, a practical issue must shop from among ready-made theories on the racks to see which theory asks and tries to answer questions that best fit its own dimensions. When we reason from the inside out, theories are bespoke, made for the occasion, Savile Row not Seventh Avenue. (1993:29)

Thus, ethical theories can arise out of the practical problems, context and dilemmas that face us in bioethics. The practice can inform theory just as theory can inform the practice – the two are symbiotically related. It is this explicit attempt at ethical theory creation and modification that distinguishes this approach from more sociological approaches. Although such approaches do influence ethical theory (i.e. Alderson's critique of the concept of personhood might lead to such a concept falling out of use)[66] there is no explicit aim to engage with ethical theory and attempt to, out of the practice, construct theories that more closely match the circumstances, theories that therefore may be more likely, 'to succeed in the political forum.' (Dworkin,1993:29)

Nussbaum argues that a reflection on practical problems can result in the reshaping of ethical theory. Although ethical theories such as justice should be able to have a theoretical power to reach beyond the specific case, 'they must also be responsive to the world and its most urgent problems.'(2006:1) She argues that certain problems facing theories of social justice such as doing justice to those with physical or mental impairment cannot be solved by, 'merely applying the old theoretical structure to the new case.' (2006:4)

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[66] See previous chapter.

The problem of extending education, health care, political rights and liberties, and equal citizenship more generally to such people seems to be a problem of justice, and an urgent one. Because solving this problem requires new ways of thinking about who the citizen is and a new analysis of the purpose of social cooperation (one not focussed on mutual advantage), and because it also requires emphasizing the importance of care as a social primary good, it seems likely that facing it well will require not simply a new application of the old theories, but a reshaping of the theoretical structures themselves. (2006:2)

Nussbaum's work on women in developing countries (2000a) and the practical problems facing women in these situations has led both to different perspectives on existing theories of justice and to the need to think in terms of constructing new theories of justice as a way of approaching such practical issues.

Carens (2000) gives an analysis of how practice can change or influence ethical theory. He argues: 'The idea is to engage in an ongoing dialectic that involves mutual challenging of theory by practice and of practice by theory.' (2004:123) Empirical research or practice can challenge theory for Carens in the following way. In attempting to apply theory to 'real cases' it can highlight conflicts between theory and practice, 'that may not be apparent if one stays within the framework of the theory and considers only the examples that theorist himself or herself puts forward.' (2004:120)[67] Souder, for example, conducted a detailed analysis of thought experiments that have been used by philosophers and argues that there is a, 'reciprocal influence between the assumptions of the arguer's position and the details that describe the thought experiment.' (2003:216) In his view the thought experiment contrives to back up the theorist's position by the subtle choices of detail (not an unsurprising conclusion as the experiments are designed to do just that). Thus,

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[67] As Wittgenstein said, 'a main cause of philosophical disease – a one sided diet: one nourishes one's thinking on only one kind of example.' (1968:593)

empirical research can be more challenging to ethical theories than the made up cases and hypothetical scenarios that characterise some ethical discussions.[68]

It is this conception of the relationship between theory and practice, which draws on Aristotle, that will form the conceptual basis of my use of empirical research in ethical discussion. An analogy can be drawn here between Nussbaum's use of literature in ethics[69] and my use of empirical research. For Nussbaum literature can, 'show us, in a way that isolated philosophical examples cannot, what it means to organize a life in pursuit of what one values, and what conflicts and obstacles beset such a search.' (1999:175) Nussbaum seeks to use the study of literature in ethics in three main ways. First, to provide a richer conception of the circumstances and context in which moral decisions are taken; second, ethical theory can bring analytic tools to the study of literature that can be productive; and finally, novels can be used as places in which different conceptions of the good life (Kantian, Utilitarian for example) can be played out, to exemplify what morality looks like and how characters exemplify this. The third use is, arguably, the most important to her project – but for mine it is the first two uses of literature that mostly closely mirror my use of empirical research in ethics.

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[68] For instance, Judith Jarvis Thompson's (1986) famous example of the violinist illustrates the problem with using hypothetical cases to generate moral theory. In her paper about the morality of abortion she discusses the question of the pregnant woman's obligation to the foetus she is carrying. As an illustration of such obligations she makes an analogy between being pregnant and being wired up to a famous violinist who needs the use of your organs for nine months to survive and then you will be disconnected and free to go your separate ways. The problems with this example is that is does not really tell us anything about the actual obligations one might or not might not have towards a foetus one is carrying and introduces many extraneous matters (such as obligation to strangers and what counts as a reasonable level of help) that, to my mind, does not help settle the issue of the morality of abortion. However, Thompson is using the example to make clear the differences between different moral obligations and as an exercise in using counterfactual thought experiments to highlight theoretical concerns the article is a worthwhile project. See Appiah (2008) who has a lot to say on such thought experiments and the problems of 'trolleyology.' He makes an important and neglected point that there is an assumption that peoples' reactions to these hypothetical examples mirrors our responses to real cases, and this assumption might not be warranted (2008:100).
[69] See *Love's Knowledge* (1990), a collection of her essays on philosophy and literature.

The conception of ethics advanced here shares many similarities with casuistry, the use of a case-based approach in moral deliberation. In Jonsen & Toulmin's *The Abuse of Casuistry* they chart casuistry's roots in Antiquity, paying particular attention to the work of Aristotle and the role *phronesis* plays in ethical deliberation. Ethical issues are approached by considering the outcomes of previous deliberation and using procedures and techniques that were successful in the past to solve the problem. Casuistry plays down the importance of principles or any universal considerations but seeks to build up a store of paradigmatic cases that can be used to throw light on new dilemmas – as case law does.[70] Jonsen & Toulmin (1988) argue that although casuistry has its roots in Aristotle, Aristotle could not be said to be a casuist. The main differences between casuistry and the view of ethics that is being advanced here are that: first, there is no 'paradigm case', a key element in classic casuistry; and second, my position does not do away with any form of universal values – rather there is a concern to see how these theories are influenced by practice. This concern with ethical theory also distinguishes my approach from a strong contextualist position that would reject any form of ethical theory in seeking to make ethics more contextually based.

APPLYING THIS FRAMEWORK

Having outlined the broad conception of ethics, drawn from Aristotle's understanding of the relationship between theory and practice, that underpins the work conducted in this thesis, a broad methodology for approaching ethical questions in practice will be developed. This introduces the approach that will be used to analyse my data and draw normative conclusions. The elements of this approach are

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[70] There are, of course, different formulations of casuistry see Strong (1999).

not, necessarily, applied sequentially to ethical issues, but are rather used when relevant and appropriate to the analysis being conducted.

Setting out the *endoxa*

A starting point of this method is to set out what Aristotle calls the *endoxa* – the phenomena. The phenomena are those aspects, views, opinions of the matter under consideration and also the world as it appears to us in the broadest sense. There has been much discussion and controversy over what Aristotle meant to include in a definition of the phenomena and whose views Aristotle thought important to take into consideration.[71] This strategy would be uncontroversial in most bioethical discussions and Allmark argues that explaining the *endoxa* in bioethics, 'is perhaps beyond dispute.' (2006:71) Most ethical discussions begin by setting out of different views and arguments. A common approach in bioethics papers is to focus on the views or a particular aspect of a philosopher's work and subject that to criticism and possibly out of that critique develop one's own stance.

However, Aristotle, arguably, had a wider conception of the phenomena than this (Nussbaum,2001:244) and therefore simply summarising the 'views of the wise' could, arguably, not be enough. Attention to the way the dilemma is played out in all its facets, a more detailed description of the issue than is commonly found in (some/many) ethical discussions, would enable the circumstances and particularities of a situation to be adequately described. Hence, a full description of a problem, area, dilemma, and the circumstances in which it is located could be usefully uncovered and discussed. Thus, for my purposes the *endoxa* will be interpreted in a broad sense.

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[71] See Bostock (2000) Chapter Ten.

This element closely resembles a sociology *of* bioethics, that is examining the social context of bioethical issues or problems.[72] What gets constituted as an ethical problem and the way dilemmas are constructed in medical practice all become a form of social interaction to be studied. A close attention to the circumstances of an ethical problem can be just as illuminating as the writings of bioethicists on the matter.

Using ethical theory as a tool of analysis

Using this method, ethical theories and principles can be used as tools to analyse the data (part of the *endoxa*). Here, ethical theories are used to discern the areas of disagreement, to clarify terms that are used and reveal ambiguities. Callahan argues that ethical principles, the formulation of which are an important part of ethics, should be seen as, 'ways of organizing our moral thought, giving it a shape and formal structure.' (1999:291) Therefore, ethical theory is a body of knowledge that can be brought to bear on different issues and used as an analytic tool.

Caplan makes this point when he says that ethical theory and principles are, 'tools by which moral issues can be examined from a variety of perspectives.' (1982:15) For Caplan, those trained in ethics have a set of traditions and theories that enable them to deliberate about and judge moral issues. 'A fully developed applied ethic would afford the moral philosopher an opportunity to examine the delicate interplay that occurs among fact, social roles and prescriptive principles in reaching moral decisions.' (Caplan,1982:16) An ethicist has an expertise in both normative theories and concepts and should be an expert in the descriptive ethics of their chosen area (the *endoxa*). Thus,

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[72] See Chapter One for a discussion of this.

the ethicist has the role of diagnosing moral problems rather than simply offering solutions. An important aspect of this role is not just accepting the moral problems as presented by, say, doctors, '[a] knowledge of ethical theories, traditions and concepts allows the moral philosopher to see the normative aspects of ordinary events in ways that those more directly involved do not and sometimes will not.' (Caplan, 1982:14) Using ethical theory could highlight and clarify the areas of disagreement more clearly and discern underlying ethical issues. Thus, theories and principles can be a tool for elucidating and analysing the data, just as sociologists use theories of social interaction to approach their data for example (Maxwell, 1996).

It could be questioned in response to this, that it appears here that the ethical theory used to analyse the empirical data is preformed, a given in a foundationalist sense, and then used to analyse the data. Whereas, previously it had been argued that the specifitivities of theory were developed in a particular context. Therefore, exactly *what* is being used to analyse the data? Where have these particular ethical theories come from and what gives them their warrant? I would argue that this is construing the relationship between theory and practice as a linear one, whereas it is better characterised as more akin to a symbiotic relationship. Theory can be used to approach the data and it can also arise from the data itself. Then the theory might be modified or extended – theory interprets data and data interprets theory – and the two processes can occur in the same study. As Alasuutari says when talking about studies in the social sciences, '[i]t is very difficult…to make a clear distinction between the "empirical" and "theoretical" parts of a study…. Ideas that surface with empirical data cannot be separated from insights that are gained while reading theories and earlier research.' (1995:175)

Specifying theories and principles

Empirical findings contribute more than just descriptive information to which the ethicist applies their theories. They contribute to our very understanding of the principles themselves. As discussed in the previous chapter, for the engineering model of bioethics sees moral principles as specified independently and then applied to actual problems. As MacIntyre states, if this were the case, 'the rules of morality as such would be effectively contentless.' (1984:501) And have no power to direct action. Therefore, 'moral rules exist only in and through their range of applications.' (MacIntyre, 1984:508) Formal principles take on their content through successive applications and interpretations (Jennings, 1986). This is the Aristotelian point that it is the particular situation that is the measure of an ethical principle and the principle needs to be 'specified' to both fit the situation and to be made meaningful.

One way that this can be done is by specification of principles (Richardson, 1990. Beauchamp & Childress, 2001). The specification of ethical principles provides one account of the way in which they can be made less abstract and therefore can be applied meaningfully to particular cases. Principles may be formulated abstractly, such as the principle one should not harm others, but for them to have any meaningful content they need to be specified in a particular context. Formal moral principles take on their content through application and this is how they direct action.

Richardson (1990. 2000) gives a detailed account of how ethical principles need to be specified in order to bridge the 'application gap' and therefore be practically useful. This specification should not be the introduction of an exception to the

principle (P), but a qualification (q) that makes it fit the case in hand. So for instance, 'repeated cycles of IVF are harmful and should not be performed' could be a practical specification of the principle 'do no harm'. *P* is specified by *q*, 'by adding clauses indicating what, where, when, why, how, by what means, by whom or to whom the action is to be….done.'(1990:295) To use an example of Richardson's, the norm 'euthanasia is generally wrong' could be specified by, 'it is generally wrong to shut off the respirator of a patient in a potentially reversible coma.' (1990:296) What would not count as a specification of a principle would be the move from 'torture is always wrong' to 'torture is sometimes wrong', as specification proceeds either, 'by setting out substantive qualifications that add information about the scope of applicability of a norm or the nature of the act or end enjoined or proscribed.' (1990:296) The move from prohibiting torture to allowing it sometimes would therefore be a revision of the principle,[73] it would alter its force rather than giving more detail on how it was to be applied. In this way principles are under-determined, for instance, 'liberty or equality may not exactly formulate what is positively required in different contexts and cases but clearly excludes any serious lack of freedom such as slavery or serious inequality.' (Bader & Saharso,2004:110) For Richardson specification is always needed as, 'the complexity of moral phenomena always outruns our ability to capture them in general norms.' (1990:294) Thus, specification is the refining and tailoring of the principle to fit the precise circumstance.[74]

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[73] This move would be prohibited by one of his clauses that for it to be a specification of a norm, 'every possible instance of the absolute counterpart of *p* would count as an instance of the absolute counterpart of *q*.' (Richardson, 1990:295) (Where *p* is the specification of *q*)

[74] See Verweij (1998) who gives a useful example of such specification when he considers a case of getting informed consent for a drug trial, in this case he argues, 'the principle of autonomy is not *revised*; the moral institutions and the morally relevant facts of the case are considered to be the reasons to propose a specific understanding of the principle.' (1998:37)

A product of specification is to clarify and convert ethical theories and principles into practical guides for action. Birnbacher sums this up when he says, 'applied ethics deals with the "translation", as it were, of theoretical principles into workable practice rules, making them available for everyday judgements and decisions.' (1999:321) If we see the meaning of principles specified in the context of application then they can be useful for directing action. This is taking a more Aristotelian view of ethical theory where the construction of a 'practice rule', in Birnbacher's sense, is given a more central role. It is in practice that such theories become meaningful.

There are of course limitations to specification. Moral conflict may never be totally avoided however closely one seeks to specify a principle. Further, specification may, 'be arbitrary, lack impartiality, or fail for some other reason.' (Beauchamp & Childress, 2001:17) Beauchamp & Childress (2001) argue that the specification of principles needs to be used alongside the balancing of principles.[75] The balancing of principles, deciding which principle takes precedence in a particular case, making a judgment over the relative weight to be given to potentially competing principles, is part of my approach – an exercise in *phronesis*. Furthermore, in a close attention to the particular context as set out by a sociology *of* the practice, this balancing of principles is an important component of ethical decision-making.

Making normative judgments

A final of element of my methodology is to make normative judgments about the practice under study. For bioethics to be a distinctive and, I would argue, a useful discipline this normative element is important. I will first consider how this issue is

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[75] See DeMarco & Ford (2006) who advocate the use of balancing *instead* of specification, because, they argue, it more clearly displays the reasons behind the decision.

approached in Aristotle's ethics and then, following on from this, the way such

judgments are made in my approach.

Normative judgments in Aristotle

One of the key criticisms of Aristotle is that if such an emphasis is placed on

phronesis and the individual judging and responding to situations how can one ever

be sure that a 'right' solution has been reached? Aristotle puts much store on

problems being resolved when an agreement is reached. At the beginning of book

VII of the *Nicomachean Ethics* Aristotle begins a discussion of, 'lack of self-control,

and softness or weakness for comfort' (1145a35-6, EN) – *akrasia*. It is in this

discussion that his method is most clearly illustrated.[76]

> As in other cases, we must set out what appears true about our subjects, and,
> having first raised the problems, thus display, if we can, all the views people hold
> about these ways of being affected, and if not, the larger part of them, and the
> most authoritative; for if one can both resolve the difficult issues about a subject
> and leave people's views on it undisturbed, it will have been clarified enough.
> (1145a3-8, EN)

In essence this method sets out what the relevant opinions are and then considers

what puzzles they may give rise to (such as contradictions for example), and finally

these puzzles are resolved. This Aristotelian method has caused a lot of

controversy.[77] What has been termed a 'dialectical' method should, hopefully, move

us towards a 'better' resolution in some way. A critic, however, could simply say that

just because agreement has been reached, this does not indicate anything – all parties

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[76] This is not to say that Aristotle always employed this method. Bostock, for example, argues that,
'very little of the *Ethics* can be explained as *simply* an application of the method set out in [book]
V11.' (2000:219)
[77] See Allmark's (2006) discussion of this criticism of Aristotle that the dialectic cannot deliver first
principles, namely that it cannot move us towards the truth. And Irwin (1988) who argues that
Aristotle's dialectic can produce first principles.

may be wrong, there is nothing in Aristotle's ethics against which competing

solutions can be judged, no first principles on which to base justification.

In response to this criticism it can be argued that Aristotle is not trying to set up *a*

priori ethical theories against which 'progress' can be judged. Aristotle does not

posit the existence of any systematic theory on which solutions can be judged and it

is not possible to formulate truth in ethics in any exact way. Thus, ethical truth does

not consist in the formulation of abstract theories, but in the nuanced application of

ethical theories using practical wisdom *phronesis* (rationality) and an appreciation of

the specificity of each situation. Aristotle's method is a form of dialectic moving

between what is agreed and areas of disagreement to try and formulate a resolution.

Nussbaum argues that there are no rules about how to do this but the aim is, 'to

arrive at a view that is internally coherent, and also one that is broadly shared and

shareable.' (1990:174)[78] Aristotle argues that there is something true in most

opinions and therefore by considering all commonly held opinions it is possible to

whittle them down to something that approaches the 'truth'. For Aristotle this notion

of truth, 'insists on a rigorous scrutiny of appearances and on the fundamental role of

consistency. It claims correspondence, too, with the deepest human beliefs and

desires.'[79] (Nussbaum,1994:65)

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[78] This has similarities with Rawls' (1972) method of reflective equilibrium, see later discussion in this chapter.

[79] This approach could be underpinned by adopting a version of Aristotle's functionalism argument in which what counts as a fulfilled life and certain human capabilities can be used as standards against which our ethical theories and beliefs can be judged. Nussbaum has, in her later work, defended a capabilities approach (2000a,2006) that has its roots in Aristotle. Nussbaum argues that her capabilities approach holds, 'that certain universal norms of human capability should be central for political purposes….[in] making cross-cultural comparisons and to developing a defensible set of cross-cultural categories.' (2000a:35) Hence, this approach attempts to provide a universal theory upon which to make ethical judgments. This account has been criticised on many grounds, see Flax (2001 & 2001a) for a critique of Nussbaum's use of universal values. For my purposes agreement with this kind of approach is not crucial, my approach can also be justified on the more pragmatic grounds of producing useful and better accounts.

Hence, Aristotle's method can be seen, not as a way of delivering the 'truth', as would be understood in the sense of a recognition of a Platonic form, but of moving towards 'better accounts.' As Hughes (2001) argues, Aristotle is not concerned with justification in ethics as modern moral philosophers are. There might not be any *proof* that the products of *phronesis* are 'right' but there can still be an explanation of the outcome; the person can, 'invite us to see the situation as they saw it, in the hope that we too will agree that they read the situation alright.' (2001:115) This way of moving forward seems the best we can do, 'the universal account always has to be responsive to particulars and is to that extent provisional; but it is a theory nonetheless.' (Nussbaum, 2001:xxvii)

Normative judgments in my approach

Having examined the debate over the ability of an Aristotelian approach to come to normative conclusions, the implications for my approach will now be discussed. This symbiotic relationship between theory and practice can raise the problem that such mutual adjustment between theory and practice does not provide any means of adjudicating between the two claims in any *a priori* way. In response to this it is argued that while it is true that there is no way of ranking theory or practice so that one 'trumps' the other, this is accepted and any adjustment of either element needs explicit justification (Molewijk *et al*, 2004). This type of decision cannot be made abstractly: which element (ethical theory or the practice or both) would have to be adjusted would depend on the context and the delicate interplay between theory and practice. Like Hughes' point above, about the conclusions of employing *phronesis*, what is required is a careful justification of why one element was modified. I would argue that in reality, this is the best that can be done.

In my approach it is not argued that we can reach the 'true' or ultimately justifiable account, it is rather to gather a finely grained description of the problem (using all our resources, empirical research and those of ethical theory) to produce a defensible (on the basis of reason and argument) solution or recommendation. The emphasis in my approach is on how useful ethical theories are, rather than how 'true' or 'right' they are. This is not a new conception of the role of theory or principles in bioethics. Many philosophers such as Beauchamp (2000), Strong (2000), and Jonsen (1998) have argued that there is no generally agreed theory of right and wrong, no ethical theory that is sufficiently well established as to be able to provide some kind of system within which to address moral problems. 'Bioethics, for them, is about resolving cases in ways which can be justified to those involved but not in ways that are necessarily right.' (Smith Iltis, 2000:273) Hence, reasoning can be judged by how useful it is in the public sphere and how acceptable it is to the 'public' or the groups it might affect, rather than how 'close' it is to the truth.

This type of aspiration for bioethics has been viewed as a move towards pragmatism in bioethics (Arras,2001): so how does my approach to ethics stand in relation to (philosophical) pragmatism? Many of the elements of my position have a distinctly pragmatic flavour: seeing principles as tools and attention to what works in practice rather than what is true or right. It has been argued that bioethics has incorporated many pragmatist features without being a self-consciously pragmatist movement (Schermer & Keulartz,2003).[80] Arras (2003) argues that much of Beauchamp & Childress' work could be categorised as pragmatist in a Dewian sense. In *Principles*

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[80] Jonsen (1998) contends that bioethics has its roots in American pragmatism from the beginning.

of Biomedical Ethics, 'principles function very much like Dewey's tools, helping us sort out what to attend to in a morally freighted situation.' (Arras, 2003:608) In this way Arras argues that modern bioethics embraces a form of freestanding pragmatism, one not based on the cannon of pragmatist thought such as Dewey, James etc, and therefore in a sense, 'we are all pragmatists now.' (2001:70).[81]

Therefore, although ethical theories and principles are not held to be 'true' in any straight forward foundationalist way, in my approach they can still be used to reflect on and make judgments about ethical issues. General ethical theories or principles can be useful in that they give us guidance on what to look for and how to appraise a situation, but close attention has to be paid to how they relate to that specific situation. And further, such theories can arise out of practice. In deciding, does a practice respect patient autonomy?, for example, the theory of patient autonomy would have to be a more nuanced one, one that had been developed by an attention to the specificities of a situation as well as the prevailing theory.

OTHER METHODOLOGIES IN EMPIRICAL ETHICS

My broad methodology for approaching the study of ethical aspects of practice is an amalgam of elements based on an Aristotelian conception of the relationship between the theory and practice. There are, of course, other methodological approaches that seek to provide a methodology for empirical ethics, the most popular of these are: reflective equilibrium and pragmatic hermeneutics. I shall briefly outline the main elements of these methodologies and discuss why I have used my approach in this study as opposed to these other methodologies.

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[81] For a critique of Arras' views see (Schermer & Keulartz,2003). For an overview of the debate over the role of pragmatism in bioethics see (Tollefsen & Cherry,2003).

Reflective equilibrium

This is an approach in empirical ethics that attempts to integrate theory and practice (Musschenga, 2005. Van der Scheer *et al*, 2004). It is based on Rawls' notion of reflective equilibrium that he used to build and provide justification for moral theories and principles. As Daniels defines it:

> The method of reflective equilibrium consists in working back and forth among our considered judgments (some say our "intuitions") about particular instances or cases, the principles or rules that we believe govern them, and the theoretical considerations that we believe bear on accepting these considered judgments, principles or rules, revising any of these elements wherever necessary in order to achieve an acceptable coherence among them. (2003)[82]

Beauchamp and Childress in *The Principles of Biomedical Ethics* use this method, uniting it with their version of a common morality theory, they state that: 'Method in ethics properly begins with our "considered judgments", the moral convictions in which we have the highest confidence and believe to have the lowest level of bias.'(2001:398) These considered judgements are, as Rawls argues, subject to revision: 'The goal of reflective equilibrium is to match, prune, and adjust considered judgments in order to render them coherent with the premises of our most general moral commitments.' (Beauchamp & Childress, 2001:398)

When applied to empirical ethics there are various ways of incorporating this into empirically answerable questions. The research would attempt to find out what were peoples' considered judgments. Once these judgments were mapped, as Musschenga (2005) notes, ethicists would be concerned with finding the right answers to practical

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[82] See also Daniels (1996) a collection of essays addressing reflective equilibrium in theory and practice and van der Burg & van Willigenburg's (1998) edited collection.

problems and this could be done in various ways. The ethicist could aid the people whose views they had studied to formulate 'a well considered judgment' that was consistent with their views and beliefs on other issues, or: 'Empirical ethicists [could] also use the method of reflective equilibrium for determining whether a set of principles that forms the core of an ethical theory is in alignment with the well-considered judgments of a particular community.' (Musschenga, 2005:481) An example of a research project in empirical ethics that used this methodology is Van Thiel & Van Delden (2001). They used the methods of reflective equilibrium to try and formulate guidelines on respecting autonomy in the nursing homes.[83]

There have been many criticisms of reflective equilibrium: some focusing on the philosophical problems with the claim that our considered moral judgments carry weight; problems with the vagueness of the concept of coherence; and that reflective equilibrium idealises human rationality – that in practice people will not modify their views in light of critical pressure (Daniels, 2003). There is not space to fully debate these issues, as they do not strike at the heart of the reason why reflective equilibrium was not used in this study. The reason is that the research questions posed in the study described in this thesis were not answerable by employing this methodology. I did not set out to examine the ethical 'considered judgments' of the clinicians and then to see if these could be revised to, eventually, form a coherent moral view. Reflective equilibrium, as a method, would have not answered my research questions.[84] As Daniels says, 'we do ethics to solve many different kinds of problems and that the methods we use plausibly vary with the problems we want to solve and the interests we have in solving them.' (1996:333) He goes on to say:

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[83] See Chapter One for an outline of this study.
[84] See detailed discussion of my research questions and the use of research methodologies to 'fit' one's research questions in Chapter Four.

'*There is no one thing we do that is always central to solving an ethical problem for there is no one paradigmatic ethical problem.*' (emphasis in the original. 1996:339) Therefore, this methodology was not appropriate for 'solving' the ethical issues I wanted to examine.

Pragmatic Hermeneutics

The overriding aim of pragmatic hermeneutics is to not simply to find out what the moral beliefs of people are but to, '*reconstruct* the practice's internal morality.' (Musschenga,2005:482) Van der Scheer *et al* (2004) give an overview of this methodology that is a combination of pragmatism and hermeneutics as found in the work of John Dewey and Hans Georg Gadamer respectively. The significance of pragmatism is its theory of meaning. The meaning of a theory derives from the practical consequences of its usage, concepts and theories, 'do not represent any a priori or absolute authority, but they owe their value to their mediation in achieving that for what they were intended to be. Thus, their value is determined by their context.' (Van der Scheer *et al,* 2004:93)[85] Hermeneutics is the attention to communication and especially dialogue as a form of interaction, knowledge is always a matter of interpretation rather than objective truth (Widdershoven, 2005). This approach aims to, 'make explicit the normative orientation in daily life.' (Van der Scheer *et al,* 2004:93). It is not merely descriptive but aims to see how specific practices can be improved, in so far as theories are used they are directly related to the practices under consideration. Hence, theories are valuable if they can do what they are supposed to do (i.e. a theory of autonomy could be evaluated by considering whether it actually promoted autonomy in particular situations).

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[85] Hence, this could be seen as a form of contextualism, see Chapter Two for a discussion of this.

Widdershoven & Sohl (1999) study is an example of this methodology. This study focussed on one case of supported employment and collected stories from all the participants. The overall aim was to improve concrete practical situations, by taking into account all the diverse elements that go to make up someone's experience of a supported work programme. In doing this, they argue that it is possible to see that some concepts such as integration and autonomy are too crude and that, 'participants use concepts that are more subtle, and therefore might be more adequate to get hold of the intricate nature of processes of care for people with mental handicap.' (Widdershoven & Sohl, 1999:127) Hence, this method pays close attention to participants' constructions and use of terms and their understandings of the situation.

This methodology would have been more fitted to answering my research questions than reflective equilibrium. However, a problem with this methodology is a similar one to the main criticism made against contextualist forms of ethics, that it gives a lesser normative role to ethical theory and this can reduce the critical force of ethical deliberation.[86] This is a criticism made by Molewijk (2004) of Widdershoven & van der Scheer's (2004) pragmatic hermeneutic method. An important aspect of the methodological approach that I have proposed is that it seeks to both use and say something about ethical theory. Theory construction and criticism are central aims of my approach. Ethical theory is useful to criticise practices and to guard against any serious contraventions of particular principles, for example, liberty or equality.[87]

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[86] See Chapter Two for criticisms of contextualism.
[87] See previous discussion in this Chapter.

Thus, I would argue that in trying to integrate theory and practice in a more sustained way, for certain tasks, my approach has certain advantages.[88]

CONCLUSION

In this chapter I have given an account of my approach to the relationship between theory and practice and how this impacts on using empirical data in ethical deliberation. From this I have developed a broad methodology that can be applied to examining ethical issues in practice. As will be seen later in the thesis this methodology can produce not only theoretical contributions to the debate but practical suggestions for improving the practice under study. The next chapter will focus on the qualitative methods used in conducting my study of infertility clinicians' approaches to ethical decision-making.

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[88] See The Conclusion for an evaluation of the usefulness of my approach.

<div align="center">**CHAPTER FOUR**</div>

<div align="center">**METHODS**</div>

INTRODUCTION

In this chapter I will outline the research methods used in the thesis for conducting and analysing the interviews with the infertility clinicians. These are the social science methods that I combined with my approach to conducting empirical research in bioethics as outlined in the last chapter. First, I will give an overview of definitions of qualitative research. Then the justification for choosing this type of research method for studying my research questions will be developed. Second, I will discuss the evolution and subsequent progression of my research project detailing the methods and rationale for the data collection. Finally, the analytic strategies I used to approach and make sense of my data will be elaborated.

WHAT IS QUALITATIVE RESEARCH?

An initial difficulty in defining qualitative research is that authors often begin discussions by stating that there is little consensus over what qualitative research actually *is* (Mason, 1996. Marshall & Rossman, 2006). 'Qualitative research methods are a complex, changing and contested field – a site of multiple methodologies and research practices. "Qualitative research" therefore is not a single entity, but an umbrella term which encompasses enormous variety.' (Punch, 2005:134) However, despite this rich diversity there are a number of features that, gathered together, can be seen to constitute qualitative research. Mason, for instance, argues that it is useful to look for some common elements, 'so that we can develop a sense of what is *qualitative* about qualitative research' (1996:4). Such elements include:

- Qualitative research is based, broadly, on an interpretivist approach that attempts to seek meaning in the social world. Where this meaning lies and how it is interpreted are highly contested questions but nevertheless some derivation of meaning from the social world characterises qualitative research.

- Description of the settings and a close attention to the context of the subjects of study. A strength of qualitative research is that it can often provide fine grained description of social worlds about which there may not be very much known.[89] Qualitative research pays close attention to the context in which the phenomena under study arise and unlike quantitative research that attempts to isolate and manipulate variables, qualitative research attempts to provide explanations that are based on rich, contextual and detailed data that takes place in the natural world.

- Qualitative research is based on data collection methods that are flexible, rather than seeking to impose rigid structured or standardised forms of data collection on situations. There is a hesitation in imposing *a priori* frameworks before data collection and study designs can sometimes 'emerge' during the research process.[90]

Therefore, with these common elements in mind, it is possible to talk of a qualitative research 'genre' (Marshall & Rossman, 2006). The term is a well-used heuristic device that delineates a type of research methodology and approach to social research.

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[89] This can be a useful methodology for the first stage in the examination of ethical issues discussed in Chapter Three, that of considering the *endoxa*.
[90] These points have been adapted from Mason (1996), Murphy *et al* (1998) and Marshall & Rossman (2006)

The relationship between qualitative and quantitative methodologies

In this section I want to discuss why I have chosen to use qualitative rather than quantitative research methodologies to approach and study my research questions.

The debate over the relationship between qualitative and quantitative research traditions is long and fraught and there is not space to give a comprehensive account of the minutia of this debate.[91] Indeed, it has been argued that qualitative researchers should no longer have to justify their approach to data collection and analysis as though it was a poor relation to quantitative inquiry and a deviation from the 'normal' way of conducting social research (Wolcott,1990).

The relationship between qualitative and quantitative research can be seen, broadly, in two ways: one that sees the two research traditions as fundamentally different; and one that sees them as complementary and amenable to possible collaboration. I shall base this discussion on Murphy *et al's* (1998) very useful literature review of this area. The first approach, the 'two paradigm approach', argues that the philosophical beliefs of the two traditions are fundamentally different; qualitative research is 'anti-positivist' and constructivist and holds, 'there exists multiple, socially constructed realities.' (Guba & Lincoln, 1989:86) Whereas, quantitative research is positivist and grounded in realism. Thus, qualitative and quantitative research methods are based on two fundamentally different philosophical paradigms.

There have been numerous critiques of the approach that sees quantitative and qualitative research as fundamentally different (Silverman,1993). This has led to a

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[91] See Hammersley (2005) for a useful synopsis of this debate.

move towards an approach that chooses the research methodology on grounds of the problem or question to be investigated. This second approach sees the two methodologies as possibly complementary. Within this approach methods are seen simply as research techniques that can be used when and where they are relevant, rather than seeing such techniques as arising out of a particular philosophical system (as the two paradigm approach does). This approach of choosing between methods on instrumental grounds can be further divided (Murphy *et al,* 1998), into those that see:

- qualitative research as the junior partner (for instance using qualitative research to generate hypotheses that can then be tested by quantitatively)

- qualitative research as the senior partner, where it is seen as a methodology that is better able to capture social processes and meaning

- and the 'horses for courses' approach that rejects any pre-determined hierarchy of methodologies. 'Different kinds of information about man and society are gathered most fully and economically in different ways, and that the problem under investigation properly dictates the methods of investigation.' (Trow, quoted in Murphy *et al*, 1998:59) Therefore, research methodologies are a tool-kit that can be used when and where they are needed.[92]

In this thesis a broadly 'horses for courses' approach will be adopted in the sense that my justification for using qualitative methodology is that it best fits my research questions and is the most appropriate way of 'finding out' about the elements on which I want to focus.

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[92] This approach has a pragmatic flavour to it, the methodology used is the one most useful for answering a specific set of questions.

My research questions were broadly to look at how doctors thought about ethical issues: to gain insight into the way clinicians talked about how they made ethical decisions, and to see how the informants approached and managed ethical issues in their everyday practice. Further, I was also concerned with what constituted an ethical issue for them, rather than using preconceptions of what they might find ethically troubling. My research questions focused on understanding how clinicians thought about different types of situations and therefore a quantitative methodology would not be a viable vehicle for fully exploring and answering these kinds of questions. Silverman states, 'in choosing a method of research, everything depends upon what we are trying to find out. No method of research, quantitative or qualitative, is intrinsically better than any other.' (2005:6) Therefore, the research questions have driven the choice of methodology in this study rather than formulating questions to match a prior methodological commitment (Punch, 2005).

QUALITATIVE RESEARCH IN BIOETHICS

It has been argued that qualitative research is particularly suited to studying ethical issues in practice (Fox & DeVries, 1998. Hull *et al*, 2001). Such research can enrich bioethics, 'by emphasizing and examining the contextual and situated nature of morality and moral choice. We should focus more on process and outcome and see how what we call bioethics is accomplished by human beings interacting in a social context.' (DeVries & Conrad, 1998:250) Arnold & Forrow (1993) also argue that studies in empirical ethics could usefully incorporate 'rich descriptions'[93] of actual practice and that qualitative methods could, 'shed light on the most serious normative questions in clinical ethics.' (1993:196)

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[93] Descriptions that a full and penetrating picture of what is going on (Maxwell, 1996).

Jennings (1990) in a paper on ethnography[94] and ethics examines the contributions that ethnography can make to the study of moral issues. He argues that ethnography can be useful for bioethics in a number of ways and I shall consider two of these that are relevant for my purposes. First, he says that ethnography can lay bare a 'moral phenomenology' that shows how moral concepts and categories are, 'embedded in ongoing forms of social practice and experience and are structured via particular institutional patterns.' (1990:269) This was a central aim of my research to see how clinicians actually discussed and approached ethical issues. Second, ethnography can show bioethics better ways of effecting social change. Bioethics' strategy has been a philosophical one that seeks to bring about change by rational persuasion and argument. Jennings argues that change often needs to be more organisational and structural and that ethnography can point us in the right direction to affect such change. For my research purposes it is useful to see how decisions were actually made in practice and therefore what processes are necessary to bring about change. Although my research methods are not those of ethnography and I did not carry out any participant observation,[95] Jennings' points about the value of ethnography can also hold for my chosen method of interviewing.

ten Have and Lelie put the case for more qualitative research in bioethics in the following way, 'the proper type of empirical ethics research will have more affinity with the qualitative methods of anthropology or sociology, than with the quantitative methodologies of epidemiology and decision analysis.' (1998:271) They claim that an important part of the morality of medicine is missing in contemporary health care ethics, the internal morality of medicine. This internal morality is, 'the value, norms

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[94] Ethnography is broadly a set of methods that involve the ethnographer participating in peoples' lives, watching and observing social phenomena (Hammersley & Atkinson,1995).
[95] See later discussion of why I did not carry out any observations of practice.

and rules intrinsic to the actual practice of health care [and these have] special significance for the interpretation and solution to moral dilemmas.' (ten Have & Lelie,1998:263)[96] The external morality of medicine is the values and social rules prevailing in society and culture in general. Thus, '[i]n order to identify the internal morality of practices, in-depth description of cases as well as participatory observation studies of behaviour in "real-life" situations are more appropriate than quantifying responses towards hypothetical case vignettes or questionnaires.' (1998:271)

In this thesis I will concentrate on the features of ethical decision-making that lie within the clinicians' remit, decisions that they are able to make about their practice in the clinic (although obviously influenced by external factors such as wider cultural norms and regulatory restrictions and funding criteria.) In order for these to be fully understood there needs to be greater attention paid to the, 'particularities of the practical setting.' (ten Have & Lelie, 1998:267) Through the use of qualitative methods, my project is a way of obtaining a greater understanding of the 'particularities' of the practice of infertility treatment.

Such particularities of practice have often been neglected. Although infertility is a speciality that has attracted much attention from the public and bioethicists, it is one where the focus has been predominately on the dramatic aspects such as the status of the embryo. Relatively little is known about the everyday moral workings of infertility clinics.[97] It has been argued that describing in detail aspects of our social worlds is a central aim of qualitative research (Mason, 1996). Qualitative

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[96] See discussion of the concept of an internal morality of medicine in Chapter Eight.
[97] See The Introduction for a discussion of research carried out on the ethical dimensions of infertility practice.

methodologies are often said to be useful if little is known about the area to be studied and it is argued that this kind of research can provide a description of, 'the apparently superficial trivia and minutiae of everyday life.' (Bryman, 1988:63) Thus, one important aim of using qualitative research in this thesis is to provide 'thorough description' (Dey, 1993) of this setting to illuminate how ethical issues and decisions are approached in infertility practice.

Despite there being a growing body of literature that highlights the particular relevance of qualitative research for bioethics, Borry *et al* (2006) found that most of the empirical research published in bioethics journals used quantitative methodologies (64.6%). This finding was mirrored in an earlier study on empirical research in bioethics conducted by Sugarman *et al* (2001) who found over half of the research conducted in this area during the 1980s used survey research methods. Sugarman *et al* (2001) attributed this to medical ethicists' lack of familiarity with and expertise in qualitative methods, methods that require, 'substantial expertise and resources that might not be available to those conducting empirical research in medical ethics.' (2001:25) This thesis is, therefore, an attempt to readdress this imbalance and utilise qualitative methodologies (in combination with my theoretical approach as outlined in the previous chapter) to explore ethical issues in practice.

THE RESEARCH PROCESS

Any research project, once completed, can be reconstructed to look as though it followed a smooth trajectory from start to finish. However, in this section, I want to give an account of my research project in the form of a 'natural history' (Silverman, 2005. Alasuutari, 1995). This is a means of giving an account of the research as it

progressed, the thinking behind the decisions taken in the organisation of the research and the dead ends and false leads that, probably, happen in all research projects. Silverman argues that, 'by asking your readers to engage with your thinking *in process*, they are in a far better position to assess the degree to which you were self-critical.' (2005:306) By making the process of the research explicit, the reader is able to, 'trace the route by which you came to your interpretation.' (Mason, 1996:150) The researcher gives both a clear exposition of data collection and the process of data analysis and this can enhance the validity of the study (Murphy *et al* 1998).

This can be seen as a form of narrative account of the research process. Anspach (1993) used this approach in her study of neo-natal intensive care units. She described how she had conducted the research and the practical decisions she took that influenced the data she collected and her findings to produce an 'analytic narrative.' (1993:183) Such a narrative or natural history is designed to make clear the theoretical assumptions, the choices made and the interpretation of the data. This account of my research process is designed to provide such a 'clear exposition' and contribute to strengthening the validity of the research.

The research project

As a health care ethicist working in a medical school I became increasingly interested in the medical profession and how they thought about the ethical issues that they faced in their practice. Through my teaching of ethics to both medical students and qualified health care professionals I had to think about how ethics as a discipline could be made more accessible to practitioners. Further, the ethical aspects

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of reproductive technologies was one of my long-standing research interests and this coupled with an interest in the growing use of empirical research in bioethics all contributed to my decision to conduct an empirical study on infertility clinicians.

Initially my research interests were focussed on how clinicians thought about gamete donor anonymity. The debate over gamete donor anonymity was something I had written about from a purely ethical perspective. In this debate there were often claims that the majority of clinicians opposed moves towards making gamete donation non-anonymous. Haimes (1993) wrote a paper arguing that there was little known about clinicians' views in this area and I thought that it would be interesting to explore this hitherto neglected area. After talking to a number of infertility clinicians informally at a conference, I began to wonder if this topic would sustain a PhD thesis. Restricting the study to the debates over donor anonymity seemed to neglect more general discussions of how they made ethical decisions and other topics that might be fruitful. Therefore, I decided to broaden my study to examine these wider questions and the main purpose became to build up a detailed picture of how ethical decisions were made and approached in infertility clinics. The main research questions became:

- What aspects of their practice do infertility clinicians find ethical 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

I applied to the Multi-centred Research Ethics Committee for ethics approval, as the study would take place in different regions and received approval (see Appendix 2).

Interviews

I decided to use semi-structured interviews[98] as my data gathering method.[99] This
form of interviewing has the following characteristics:

- there is a list of the range to topics to be covered in the interview, but not a
  structured list of questions

- they are relatively informal, rather than a formal question and answer format
  (Mason,1996)

There are, broadly, two types of research interview: the standardised and the
unstructured (Murphy *et al*, 1998). The standardised interview is the type commonly
used in quantitative research where respondents answer from a pre-determined list of
questions. This form of interview is meant to try and control bias by asking
respondents for the same information in the same order in the same way.
Unstructured interviews are more difficult to define and Murphy *et al* say that, 'it is
more accurate to see interviews as ranged across continuum…from standardised to
non-standardised.' (1998:112-113) Therefore, there can be varieties of non-
standardised interviews ranging from those that have a list of topics or questions to
those that do not use topic guides but ask respondents to reflect on certain areas
(Denzin, 1970).

There has been much criticism of the standardised form of interview. The aim of
such interviews is to eliminate bias in attempting to gain access to 'facts' that are out
there waiting to be elucidated, a form of positivism. The main criticisms of this view
of interviewing have been on the grounds that such 'bias' cannot be eliminated and

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[98] This form of interview can also be called 'the long interview' (McCracken, 1988).
[99] For an overview of the increasing use of interviews as a research tool see (Gubrium & Holstein,
2002. Fontana & Frey, 2000).

further that there is no need to see bias as a bad thing in itself. It has been argued that to try and strip the context away from an interview can lead to a loss of meaning (Mishler, 1986).

Qualitative interviews have often been seen as a solution to the shortcomings of the standardised interviews and it is argued they can have the following benefits.[100]

1. Exploring the way respondents themselves define their experiences and practices and uncovering the insider's perspective.
2. Penetrating respondents' public accounts – unstructured interviews are more likely to produce 'truer' accounts (Denzin,1970).[101]
3. Flexibility – they are useful in hypothesis generating or exploratory research, researchers can open up new dimensions that they had not anticipated in advance.

Rationale for data collection methods

All decisions made about how to design one's research project should be made on principled grounds (Mason, 1996. Coffey & Atkinson, 1996). Therefore, I want to elaborate the reasons why I chose this method of data collection in preference to other methods that social scientists have at their disposal.

My first overriding reason for choosing to interview my research subjects was that it was, arguably, the best way to answer my research questions. My concern was with

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[100] These are adapted from Murphy *et al* (1998).
[101] The notion of being able to produce 'pure' description, a direct reflection of reality has been criticised (Hammersley, 1992). Hammersley argues that it is not possible to have a theoretical description and that descriptions are always made from a particular (value-based) point of view.

how clinicians thought about and conceptualised ethical issues in practice, how they approached the ethical aspects of their work and what they saw (and defined) as an ethical issue. Hence, I thought that the best way to elicit data on these concerns of sufficient depth was to interview them.

I did not use vignettes in my interviews although this has been a popular approach in some empirical research in bioethics.[102] Presenting a formulated 'ethical dilemma' for clinicians to discuss would have pre-judged what they actually thought were dilemmas, an issue that I wanted to explore in the research. Further, as Hurst *et al*, note situational features such as time constraints and inter-professional relationships can influence ethical decision-making and these features are lost to analysis if studies use, 'hypothetical or otherwise standardised cases.' (2005:7)

It could be argued that there are a number of benefits in using a semi-structured interview format to elicit information from doctors. First, doctors can be seen as 'an elite' and there can be useful information to be gathered from such 'expert' subjects (Marshall & Rossman, 2006).[103] Second, doctors are familiar with the interview format as a way of gathering and conveying information (Braunack-Mayer, 1998). A semi-structured interview can be seen as similar in certain respects to a medical consultation (although generally much longer!) in that the general purpose is to gather information but the interviewer (or the doctor) needs to be flexible so that they

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[102] See Goldie *et al* (2004, 2004a, 2005) in their Ethics in Health Care Survey they used 12 vignettes to examine medical students' attitudes and potential behaviour. For a discussion of how it might not be possible from a response to a vignette to determine what the respondent's own normative views are or how they would respond in practice see Finch (1987). Also Appiah (2008) makes the point that people might respond differently to hypothetical examples than they would if actually confronted with such a situation.
[103] For a discussion of the challenges of interviewing elites see (Undleim,2006. Odendahl & Shaw,2002).

can pick up important pieces of information that the informant (or patient) does not realise are pertinent. Third, doctors are very busy and an interview that only requires an hour of their time is preferable to other methods that might be more time consuming for them (i.e. to organise access for a researcher, or to travel to other places for focus groups).

The argument that doctors are busy could of course be turned around and it could be argued that a postal questionnaire would have been a time saving device and would have enabled me to get a greater number of responses. However, such a questionnaire would not have allowed me to fully explore my research questions. I wanted to probe and develop my informants' answers and this would have been impossible in this format. Further, it was not an aim to produce a representative sample, in the sense of getting a statistically significant number of responses. Therefore, the possible increase in numbers of informants produced by this format would not have been of significant benefit.

Using observation as a method was also considered. I could have chosen to observe clinic consultations between clinicians and patients and/or group or team meetings between clinicians and/or meetings of ethics committees to determine how ethical decisions were made and approached. Dingwall (1997) has argued the problem with interview data is such that observation should always be the method of choice. This reflects the view that 'naturally occurring data' is always preferable to that that has been 'artificially' constructed. Silverman, however, argues that, 'the attempt to erect a polarity between "natural" and "artificial" settings is spurious.' (1993:29)

Therefore, methodologies should be chosen on the grounds of what one is trying to find out rather than any prior ideological preference.

There were a number of reasons why I choose not to do an observation study. First, my research questions focussed on how doctors thought about their practice, what accounts they gave to explain and conceptualise ethical issues and dimensions. My view was that observing them would not elucidate these questions. Second, it was unclear what and where I would have to observe to 'see' ethics happening. Would it take place in the consultation with patients or in meetings with colleagues or in ethics committees or in corridors, or in the hospital canteen? As a result of my interviews I now have a much clearer idea of where it might be said that ethics 'takes place'[104] and so would now have a more focussed approach to observation. But before I began the research this focus would not have been possible and I would have been in danger of generating a lot of data that was not relevant to my research questions. Third, practical aspects of time and access would have been difficult. I have done my PhD while having a full-time job in academia and long periods in 'the field' would simply not have been possible for me. All projects will have some practical limitations imposed on them: funding body criteria; time frame; resources – time and money. Therefore, it is important to recognise the practical context in which a research project takes places (Maxwell,1996). Finally, access issues and consent could have also posed difficulties in trying to negotiate observing clinics (though they probably could have been overcome if I had decided to do such a study).

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[104] Discussions and team meetings with colleagues and in some instances CEC meetings now appear to be possible sites where ethics 'takes place'.

Sampling

With any study one of the key questions to address is who to observe or interview. The sampling frame for this study was, in certain respects, straightforward. As it was a consideration of infertility clinicians' views about the ethical aspect of their practice, the population from which I sampled was infertility clinicians in the UK. Every infertility clinic in the UK providing treatment that falls within the category of 'licensed' treatment is regulated by the HFEA.[105] There are 115 clinics offering licensed treatment in the UK (HFEA,2008) and I took this as my sampling frame (see Appendix 3 for the details of the clinicians I interviewed). I used a theoretical sampling approach which, rather than aiming for a representative sample, aims to sample interviewees until the categories reach theoretical saturation, in order to, 'make key comparisons and to test developing theoretical propositions.' (Mason, 1996:93). In my research this was an iterative process, 'one in which there is a movement backwards and forwards between sampling and theoretical reflection.' (Bryman,2001:324)

Mason argues that it is important to think how meaningful conventional categorisations (such as age, gender, social class) are in your sampling (1996:87). I started off unsure if there were any particular variables such as age, gender, length of practice, or geographical location that might be relevant to my research questions. At the beginning of the study I thought that gender might be a relevant variable, that women might have a different perspective on ethical issues and reproductive health matters.[106] As the study progressed I did not find any significant difference in the responses between the female and male informants, so I abandoned using gender as a

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[105] See Chapter Five for a discussion of what is covered by the HFEA licensing regulations.
[106] See Gilligan (1982) and Noddings (1984) for example.

sampling variable.[107] One aspect that did become important was the length of practice and consequent seniority of informants. A central question was how the informants made decisions and those who were consultants had different decision-making responsibilities than those who were registrars.[108] Therefore, I decided to include in the sample some informants who were not consultants and interviewed six sub-speciality trainees.[109]

I began my sampling by contacting infertility clinics reasonably near to where I lived and worked. This was a practical measure to minimise both the costs and time it would take to conduct the interviews. Once I had interviewed someone from a clinic I asked them if they could give me the names of any other clinicians in their clinic that I might talk to. This could be seen to be a form of snowball sampling, where by the researcher makes contact with people and then uses them to establish contact with others (Bryman,2001). This method was useful as the HFEA website that lists all the clinics only includes the name of the licence holder, the 'person responsible', so other doctors who work in that clinic are not listed, and not all infertility clinics have their own websites where details of the staff can be found. Once I had interviewed several members from a particular clinic I began to get a sense from the data of a clinic ethos and approach to issues. Therefore, I thought it would be useful to get a reasonable number of clinicians from each clinic to explore this notion of a clinic ethos further. This was a form of theoretical sampling based on emerging themes from the data. I interviewed all the clinicians in Clinics 1, 2/3rds of the clinicians from Clinics 2 and 4, and half of the clinicians from Clinic 5, some of the

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[107] I interviewed 7 women and 15 men, see Appendix 3 for the sampling matrix.
[108] This is discussed in Chapter Seven on consensus.
[109] I stopped specifically sampling sub-speciality trainees when I had reached theoretical saturation.

clinicians were the only ones I interviewed from a clinic so do not have a clinic number (Drs Case, Jenson, Tarn and Vance).

I wrote to the clinicians asking them to participate in the project. I sent them a letter asking if they would participate including, a tear off slip to sign, an outline of the study and a consent form and a stamped addressed envelope (see Appendix 4 for this material). I received a response rate of about one interview to every eight letters sent. Once the informants had responded I contacted them and arranged an interview date. The clinicians who responded could, of course, be seen as a self-selected group who might have a prior interest in ethics. However, unless the purpose of the study, to get their views on the ethical aspects of their practice, was concealed from the informants (i.e. I portrayed the study to be about something else and this would be, arguably, an unwarranted form of deception) that was inevitable. However, I avoided contacting any clinicians who had published on ethics or who had a clear academic or policy interest in the subject to try and minimise this kind of bias.

Logistics of the interviews

The interviews were semi-structured, I had a topic guide that I followed broadly, but which still allowed the clinicians to direct the focus of the interview. The topic guide was made up of general questions (see Appendix 5) such as: what do you see as ethical issues in your practice?; How do you approach such issues?; How do you resolve them? I probed and asked additional questions to get the clinicians to elaborate on issues that I thought were interesting and relevant to my research questions. The topic guide evolved over the course of the interviews, as I altered and revised it in light of both efficiency (some questions did not produce useful

responses) and theoretical aspects that developed as I gathered more data. I tape-recorded the interviews with the informants' consent. Recording the interviews had been mentioned in the information I sent with the interview request and I asked them at the beginning of the interview if they were still happy for me to record it. None of the informants refused. One interview (with Dr Street)[110] did not record. I realised this as soon as I had left the room and went to the hospital canteen and made detailed notes on her interview. I have included this interview in the analysis, but there are no quotes from her due to the recording failure.

The interviews lasted on average for an hour. All of the interviews took place in the informants' places of work. Nearly all the interviews were interrupted at some stage by phone calls and bleeps. The interview with Dr Grant was particularly disrupted and I had to finish it on the telephone, although I was able to record the telephone conversation as well. The interview with Dr Case was interrupted three times while he went and did embryo transfers. All the breaks and interruptions were marked on the transcripts. Immediately after the interview I went and made notes on how the interview went, any initial ideas, thoughts and impressions so that I would have a contemporaneous account of the interview.

I conducted 22 interviews. I stopped at this point as I felt I had reached theoretical saturation (Strauss & Corbin,1998) in that no new categories or themes were emerging and I was beginning to hear similar accounts and stories of how the informants approached ethical decision-making.

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[110] All informants were given pseudonyms, see discussion below.

Reflexivity

Holstein & Gubrium in their consideration of what they call the 'active interview' argue that, 'all interviews are interpretively active, implicating meaning-making practices on the part of both interviewers and respondents.' (1995:4) Therefore, the interviewer does not just gain access to respondents' beliefs, views or opinions, but in interviewing people the interviewer actually creates a particular reality. This has implications for the analysis of the data (see below) and means that attention has to be paid to the way the interviews were conducted, the questions and form of questioning used, the background knowledge and expertise of the interviewer. All these factors shape and construct 'the interview'.

My position of going into the interviews as a health care ethicist[111] and asking doctors questions about ethics clearly influenced the way the doctors approached and positioned themselves as 'experts' in ethics. In my day job I teach a Masters in Health Care Ethics that largely attracts existing health care professionals and so I have a lot of experience in talking to health care professionals about ethics. The interviewees often positioned themselves as non-experts, that they were medics and as such had no particular ethical knowledge or expertise. My role in the interviews was to get them to talk about how they saw the ethics that arose for them in practice rather than how well they could talk about ethical issues in terms of an academic dialogue. Further, by the very asking of the question, 'how do you approach ethical issues in your practice', I was influencing and constraining the debate into particular ways of seeing these features of our social world.

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[111] See Richards & Emslie (2000) for a discussion of the effects of the interviewer's professional on the interview interaction.

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Transcription

The interviews were professionally transcribed. The recorder I used was a digital one and the voice files were saved on to my computer. Once I had received the transcripts I read them while listening to the interview, this enabled me to correct mistakes and misunderstandings in the transcription and add my own notes of the pauses, tone of voice and emphasis. Having the voice files easily accessible meant that I was able to replay key bits of the interviews when I was analysing the data to hear the interview and to more fully understand the context of the discussion.[112] Both the voice files and transcripts were anonymised by giving each doctor a number and any identifying references in the transcript were replaced (such as a mention of a place was replaced with Anytown). The transcripts were stored in a locked filing cabinet and the voice files on the university server (more secure than an individual computer as it cannot be stolen and it is password protected). The doctors were then given both numbers and pseudonyms. The pseudonyms are used in the presentation on the data as it was felt that this would give the informants more personality that just using numbers, i.e. Dr 1 (Appendix 3 gives details of these).

The transcripts were then uploaded into ATLAS qualitative software and this programme was used to manage and code the data. The quotes from the informants therefore have a unique identifier (for example 1:11), the first digit refers to the doctor's number, the second to the quote number of the transcript stored in ATLAS. Thus, anyone could find the quotes quickly if they had access to my ATLAS database (see Appendix 3 – the sampling matrix for the tabulation of doctor numbers

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[112] There is a body of thought that says you should always transcribe your own data (Seidman,2006). However, I would argue that with new technology that enables interviews to be saved onto computers it is possible to work closely with the data without having to have transcribed it initially. Also see Bailey (2008) for a discussion of issues raised by the transcription process.

and pseudonyms). When quoting the informants the unique identifier will always be used to reference the quotes and when I am speaking in the transcripts (my questions to the informants) this is highlighted in bold type.

DATA ANALYSIS

I shall now discuss how I have analysed my data by detailing how I conceptualised my interview data and then outlining my analytic strategies.

The status of interview data

In this section I want to elaborate how I 'saw' my interview data and draw out the implications this has for how the data were analysed. The question can be formed in such a way as to ask, 'is interview data a topic or a resource?'[113] This is framing the debate in a particular way and it is a debate within qualitative research that I want to discuss, drawing out implications for this research project.

The approaches that have arisen in response to the positivist paradigm can generically be put under a heading of naturalism[114] (Hammersley & Atkinson, 1995). In one formulation interactionalists see interviews as providing access to the interpretations that people give to stimuli and as, 'encounters between humans beings trying to understand one another.' (Silverman,1993:95) For interactionalists the context of the interview is crucial to understanding the data, the interview is a 'social event' and to understand it, it needs to be described as such. The key is to understand

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[113] Here the terminology 'topic' and 'resource' is that used in the literature on this issue, see Murphy *et al* ,(1998) and Hammersley & Atkinson (1995).
[114] This term does not have the same meaning as when it is used in philosophy. See Miller (2003) for a discussion of the use of this term in meta-ethics.

how individuals interpret and give meaning to the world around them so unstructured interviews allow respondents to define the world in their own way (Denzin, 1970).

Both types of interview, the standardised form based on positivism and the less structured form based on naturalism, have been subject to criticism. It is argued that they both struggle with the same problem: as they both try to understand social phenomena as something that exists independently of the researcher (Hammersley & Atkinson, 1995:10). How can researchers be sure that what respondents produce in interviews represents reality? (Murphy *et al*, 1998:120) Both traditions respond to this question in a different way. As noted above, positivism tries to eliminate bias, or distortions of reality by capturing sufficient numbers of respondents and using a fixed questionnaire design and rigid protocols. Naturalism constructs this problem as one of possible misunderstandings between the researcher and respondent. Such misunderstanding can therefore result in the interview not producing an accurate account of their reality (Denzin, 1970). This can be solved by building a rapport with respondents (Rubin & Rubin, 2005), developing a relationship over the course of the research to, 'obtain intersubjective depth between both sides so that a deep mutual understanding can be achieved.' (Silverman, 1993:95) In sum, within both these approaches, '[t]he validity of interviews is to be judged in terms of how carefully the interview has overcome the biases that are seen to be inherent in the situation, whether through standardisation or digging deeper.' (Murphy *et al*, 1998:120)

The contention that research should be about representing phenomena in some literal sense has been criticised at a deeper level and Murphy *et al* (1998) call this the 'radical critique'. This critique sees interview data in a different way and is based on,

'the understanding that interviews are essentially contextually situated social interactions.' (Murphy *et al*, 1998:120) In this perspective interviews are no longer seen as more or less accurate reports of an external reality. Rather, they are occasions when individuals produce accounts of their actions, feelings or views and so on. Dingwall sees interviews as involving a 'dance of expectations' and these accounts are a time when the respondent is, 'required to demonstrate their competence in the role in which the interview casts them'. (Dingwall, 1997:58) For instance, in these accounts respondents may present themselves as competent members of a community (i.e. Baruch (1981) found people constructed a notion of parenthood, or in my research as doctors who practice ethically).

There are two main implications that can be drawn from seeing interviews as contextually situated social interactions rather than as representations of reality:

1. Interviews can never be seen as a source of anything apart from knowledge of that interview itself – here interviews are treated as a topic. This position is adopted by ethnomenthodologists who would see the interview data as only telling us about the reality of the interview itself (Baker, 2003. Silverman, 1993).

2. Interviews can be seen as displays of respondents' perspectives. For example, Baruch (1981) treated interview data as 'local accomplishments' in his study of parents' responses to congenital illnesses in their children. He examined what the parents could be said to be doing in the interviews, what *account* they were producing, arguing that in the interviews the parents were displaying their moral responsibility. In this way Baruch is not interested in the truth or not of these accounts, 'he is focussing on how, in telling their

story to a stranger, mothers skilfully produce demonstrably 'morally

adequate' accounts. [Thus] human subjects actively participate in the

construction of social and psychological realities.' (Silverman, 1993:110)

Based on this 'radical critique' of interview data, I shall now outline what approach I

shall take to my data and how this has influenced my strategies for analysis.

Resource and a topic

My approach will follow that of Hammersley & Atkinson (1995). In response to the

'radical critique' they agree that interview data should be placed within the context

of its production and treated as evidence of the perspectives of those who produce

them. However, they do not infer from this that interviews cannot tell us anything

about the setting in which they occur. 'Everyone is a participant observer, acquiring

knowledge about the social world in the course of participating in it….such

knowledge on the part of people in a setting is an important resource for the

[researcher].' (Hammersley & Atkinson, 1995:125) Hence, my position, like

Hammersley & Atkinson's, rejects the idea that just because you do not see interview

accounts as simple representations of the world does not mean that interviews can

never be read for what they tell us about the phenomena to which they refer or tell

'plausible stories' (Strong, 1979).

While data should not be 'accepted at face value', it is not necessary to abandon the

use of data to tell us something about reality altogether. Dingwall, although arguing

that we cannot be certain that interviews represent literal descriptions of an

individual's reality and taking the problems of interviews to be so great that

observation should be treated as the method of choice, acknowledges that, 'in real life we recognise that the accounts we receive every day contain some mix of the real and the representation and there seems no good reason why the accounts we receive as sociologists should be essentially different.' (Dingwall, 1997:60) In certain respects it could be argued that my interviews with the doctors 'mimicked' the clinical encounter. They took place in the clinic where the doctor would see patients, I was asking for information and an account from my informants as to what they did and how they felt. In this way there is a parallel between the research and clinical dialogue and although the clinical dialogue is a place where the different meanings and power relations between participants is rife, it is still a place where information is given that is trusted and used in practice.

Hammersley & Atkinson do not just see interview data as representing reality in the way that the interactionalist position does. They also see interview data as producing *accounts* from respondents that are able to tell us something about those who produced them. As Silverman says, 'we need not hear interview responses simply as true or false *reports* on reality. Instead, we can treat such responses as *displays* of perspectives of moral forms.' (1993:107) Hammersley & Atkinson say that it is possible to see interview data in two ways: information and perspective. Interview data can be analysed from both these angles and these forms of analysis are complementary (1995:126). Thus, 'Separating the question of the truth or falsity of people's beliefs as social phenomena allows us to treat participants' knowledge as both resource and topic.' (Hammersley &Atkinson, 1995:126)

Interviews as accounts

One aspect of my analytic strategy was to analyse my data in terms of seeing them as accounts produced by my informants in the context of the interview. In doing this I will follow a position outlined by Hammersley (2003), who argues that although attention to what happens in the interview is important, 'this focus cannot tell us all there is to know about human social life.' (Hammersley, 2003:773) We need to pay attention to the context, the general knowledge we have about, 'social forces and institutions that structure human social life.' (2003:772) This involves taking other factors, our knowledge of the social context, as well as what the informants tell us and incorporating this into our analysis. My data analysis incorporated a knowledge of the social context in which infertility clinicians practice (see Chapter Five) and utilised the ethical literature on decision-making to enrich the data analysis as set out in my methodology discussed in Chapter Three.

My interest in thinking about the interview data as 'accounts' arose when, having looked at my transcripts of the interviews as a whole I became worried that there was no cohesive story being told. I was unsure how to manage all the different accounts and how to construct explanations that would reflect such a diversity. Further, in some of the interviews the interviewee did not advance a 'coherent' position, they might contradict themselves or give conflicting examples or appear to be in favour of certain things but against others when, to my mind, there were no distinguishing reasons. This 'instability' of respondents made me wonder, at first, if that was a fault with my interview technique and I should have pressed them further to produce what

I would term a 'coherent' account.[115] I had these worries in mind when I read Gilbert and Mulkay's (1984) study on scientists' accounts of scientific practice. I thought that this work might be useful for my project as it had similarities with mine, in that they were interviewing highly specialised professionals about their practice in a work setting. Gilbert & Mulkay argued that trying to present a definitive version of an account of a particular social setting, or trying to theorise one way social life operates is mistaken and a mistake that characterises much of sociological analysis (1984:2). Instead they say that in trying to produce such a definitive account sociologists ignore and select particular parts of their data and give these the label of the right or best representation of what the respondents are 'really saying'. In doing this the analyst misrepresents the respondents. 'This is not only because different actors often tell radically different stories; but also because each actor has many different voices.' (1984:2) This had parallels with what I had found in my data and gave me another way of approaching the analysis of my data.

Seeing interview data as accounts can enable us to, 'think of talk itself as socially meaningful text. That is, as individual social actors recall and retell events or describe past experiences, they may be performing particular types of speech acts.' (Coffey & Atkinson,1996:100) Baruch sees these sorts of speech acts as types of recipes, 'that are culturally or personally prescribed sequences of typifications involving typical problems, typical solutions, typical actors.' (Baruch,1981:278) By using the 'recipes' social life can become stable and routine. Thus, part of the aims of my examination of my informants' accounts was to uncover and make explicit these

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[115] By coherent account I really mean one that would stand up to philosophical debate and have the same kind of rigour. Obviously, to expect 'ordinary' people to produce this kind of account is naïve.

'recipes' that they use to order and stabilise their reality.[116] In analysing the data in this way, it was possible that the informants were portraying themselves in a certain way – as ethically competent practitioners – and this was a competency constructed within the interview. However, while bearing this in mind, I 'bracketed' such concerns (Gubrium & Holstein, 1997) and largely concentrated on the interviews as a resource.[117]

Strategies of analysis

Once the interviews had been loaded into ATLAS I read and listened to the interviews several times, to check the accuracy of the transcription and to get a feel for the interview. I made notes on each interview, ideas it provoked, thoughts, general themes and so on. Then I coded the interviews within ATLAS. I began coding after having done the first two interviews and then coded each new interview as I went along. After coding a new interview I then went back to the previously coded interviews and revised them in the light of any new ideas or codes. For example, after I had done six interviews I saw a theme developing of different clinics having a particular ethos, a particular clinic view on certain issues and ways of approaching issues.[118] I then went back and coded the previous interviews in light of this category. I discussed my coding with my supervisors and they read a number of transcripts to provide a checking mechanism for the coding. During this process, that I carried out until I had completed all my interviews, I kept memos of thoughts and ideas on different interpretations of the data. I kept these memos both as Word documents and within ATLAS, which allowed me to link memos to particular quotes

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[116] See Chapter Six for a discussion of how the informants thought about the role of ethics in their practice – an example of such an ordering of reality.
[117] Gubrium & Holstein have developed this method of 'analytic bracketing' see their work for a more detailed discussion (1997 & 2000).
[118] See discussion in Chapter Six.

and codes, this was a useful strategy in developing my analysis. For example, I

grouped together a selection of quotes on resource allocation and fairness and linked

them to a memo. See Figure 1 below:

FIGURE 1

Resources
Here the point is very much that the funding constraints are unfair on people. This again could be linked to the principle of justice, in different areas like are not being treated as like and people are unable to have treatment due to dubious criteria, like if they already have a child. Or have one with Downs.

[4:62][151] Yeah, I think it is highly uns..

Yeah, I think it is highly unsatisfactory and probably unethical that people get IVF treatment, within the NHS, by where they live. I think it is untenable that because you live here in Anytown and you can get IVF treatment, but if you live in some other parts of the country you can't get treatment.

[6:17][29] But I think it's really diffic..

But I think it's really difficult in the NHS: we don't treat anybody over 40; we don't treat anybody who's got a child. Say if we've got a couple who've got a child with catastrophic Downs Syndrome, we can't offer them IVF, so there are a lot of things that aren't fair about it.

[10:72][19] Dr 10: Adopted, if you have ad..

Dr 10: Adopted, if you have adopted a child you're outside the criteria for NHS treatment. If you're female and your partner has a child in a previous relationship that's not living with you, they still wouldn't qualify for treatment. Right, okay because some places construe it as living with ...?
Dr 10: No, it's not, which seems very unfair.

[11:6][58] Dr 11: I suppose it depends on..

Dr 11: I suppose it depends on which way you look at it because what I would - I don't know whether it's how I feel about it because what would be nice is if there was just a rule that suits all, so it didn't actually matter what your postcode was. But I think that's probably the hardest thing, you know, if you lived in Anytown where we have a contract to do some treatment, if you do have a child from a previous relationship you can actually be treated but if you live over here then you can't be. I have a problem with it in that

When I had finished coding and re-coding my data I had created 102 codes. I then re-

organised these codes into broader categories and began to think about links between

the codes and the relationships between categories (Dey, 1993) (see Appendix 6 for a

more detailed discussion of the development of my coding and strategies of

analysis). At the end of this process I had reached, 'a position where [I had] a stable

set of categories and [had] carried out systematic coding of all the data in terms of these categories.' (Hammersley & Atkinson, 1995:213)

I analysed my data by using the following ways of validating qualitative research:

- The constant comparative method

- Deviant cases analysis

- Comprehensive data treatment

- Using appropriate tabulations (Silverman,2006:303)[119]

I shall consider these in turn.

Constant comparative method

The constant comparative method, first developed by Glaser & Strauss (1967), involves trying to find another case with which to test out an 'emerging hypothesis'. The way that this was accomplished in my project was after particular codes were initially developed they were tested and the relationships between them explored by the new data that was gathered. Further, as I re-visited the codes after each interview existing codes and interpretations of interviews were revised in the light of new data. Thus, 'the mutual relationships and internal structures of categories [became] more clearly displayed.' (Hammersley & Atkinson,1995:213) For example, I began with some initial thoughts about how the informants thought that it was important to avoid discrimination in making decisions about patients and decisions should be made on a case-by-case basis. For example, not having a policy on treating certain groups. However, other informants thought that a blanket policy was fairer and less

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[119] The first two of these elements can be part of the method of analytic induction. I have not fully embraced this method as my approach began with some theoretical assumptions so was not totally inductive and analytic induction presupposes phenomena are governed by deterministic laws, a form of naturalism (Hammersley & Atkinson, 1995:236).

discriminatory. Thus this formed a hypothesis that the informants were concerned about discrimination and felt it was important to treat patients 'fairly'. As I gathered more data I tested this hypothesis and it developed into a more general account of the informants' concern with impartiality and the strategies they employed to facilitate it.

Deviant case analysis

A further analytic strategy that is designed to improve the quality of qualitative research, by developing and strengthening the emerging ideas, is the search for negative instances or deviant cases (Becker, 1998). 'Willingness to seek out disconfirming evidence, and to allow this to modify general ideas, constitutes the essence of a scientific attitude.' (Seale, 1999:73) Clearly, cases are deviant in relation to the theory or explanation being put forward (Silverman, 2006:299). In this project cases were judged to be deviant if they contradicted a hypothesis that had been previously put forward on the basis of the data. As Coffey & Atkinson say: 'It is never enough to illustrate good ideas with supportive examples. The grounding of theory on empirical evidence requires comprehensive searching and systematic scrutiny.' (1996:191) The main discussion of a deviant case is in Chapter Seven where one informant did not fit into the general account of decision-making that I advanced. Further, throughout the discussion of the data instances that did not support particular interpretations have been discussed and quotes provided, rather than leaving them out of the analysis. The aim was to give a sense of the data as a whole. This point leads to the next element of producing a 'credible qualitative research' (Silverman,2006:271), comprehensive data treatment.

Comprehensive data treatment

As Silverman says, 'All parts of your data must, at some point, be inspected and analysed.' (2006:298) All the data that I collected was transcribed and analysed and although certain topics such as ethics education that were discussed in the interviews have not been presented in this thesis, I have attempted not to leave out any elements that could contradict the theories I have developed from the data. This is the issue in qualitative research that Seale calls 'showing the data' (1996:158) In an ideal world the reader could have access to all the data and the coding schemes and would be able to assess the validity of making any inferences from the data themselves. However, this is clearly unrealistic, as even if people had the medium to present their full data set (CD-Roms and memory sticks for instance), few readers would have the time to read it all; and Seale points out that this is akin to researcher expecting the reader to do their work for them. As Seale (1999) says we need to develop 'shorthand procedures'. In this thesis two main ways have been used as such procedures. First, each point of data interpretation has been illustrated with a number of quotes so that the reader gets a taste of the data and enough of it to see the evidence for the interpretation. The second procedure is using appropriate tabulations, or, as Silverman terms it, 'simple counting'.

Using appropriate tabulations

At various points in this thesis I have used tables to set out the informants' views on a particular issues or area of the data. For example, the informants' views on what counted as an ethical issue for them have been put into a graph so that the number of

times each issue was mentioned can be ascertained.[120] The benefits of this approach

are that, according to Silverman, '[s]imple counting techniques, theoretically

derived…can offer a means to survey the whole corpus of data ordinarily lost in

intensive, qualitative research. Instead of taking the researcher's word for it, the

reader has a chance to gain a sense of the flavour of the data as a whole.' (2006:301)

Seale, for instance, used this in his study of elderly people living alone where he

counted instances of particular occurrences for example, '33 speakers gave 44

instances where they stressed the independence which this indicated.' (1996:128)

This is a way of overcoming anecdotalism. Bryman argues that: 'There is a tendency

towards an anecdotal approach to the use of data in relation to conclusions or

explanations in qualitative research. Brief conversations, snippets from unstructured

interviews…are used to provide evidence of a particular contention.' (1988:77) By

showing the reader how widespread particular instances were, this charge of

anecdotalism can be avoided. It must be stressed, however, that this 'counting' is not

the same as the numerical justification that would be employed in quantitative

methodologies (the sample is not representative or large enough to generate

statistically significant results). The purpose of this 'simple counting' is just to show

the data and give the reader a better sense of the data set as a whole.

Limitations

The methods outlined above were designed to produce a research project that could

be said to be credible. However, there are a number of other methods that have been

suggested for promoting the quality of qualitative research (Seale, 1999) that I have

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[120] In other places tables have been used to present more data on particular topics, such as informants' views on impartiality (Chapter Eight) and their views on particularly contested ethical issues (Chapter Six).

not fully engaged with or made limited use of and in this section I want to discuss why this was the case.

Respondent validation

Respondent validation uses the tool of feeding back the interpretation of interview data to respondents to ascertain whether the analyst has understood them correctly (Bryman, 2001). Lincoln & Guba (1985), for example, see this as one of the most important checks on the validity of a study's findings. In this study I did not carry out respondent validation in a systematic way as, for example, Bloor (1976) did in his study of doctors' decision-making in adeno-tonsillectomy. I did not conduct second interviews with my informants due to practical difficulties. It was hard to arrange times to come and interview the informants in the first instance and the interviews themselves were quite lengthy; therefore it would have been almost impossible to expect them to give up further time to talk to me. Further, I did not send them my interpretations of the data for checking. I took a decision not to do this on the grounds that respondent validation presupposes that there is some 'truth' out there that can be reached and the researcher needs the respondent to check they have comprehended it in the right way. This did not fit in with my way of seeing my interview data (see above) and therefore I did not think it would add significantly to the project. Further, there were practical difficulties with doing this as a number of authors have noted (see Silverman, 2006). As Bloor argues, 'The main requirement for the validation exercise seems to be an adequate level of involvement among respondents in one's research or a degree of commitment to the research project.'(1978:551) Initially, I asked the informants if they would be interested in

reading through preliminary findings, but the response was that they had no time to do this.

There have been criticisms of respondent validation as means of ensuring validity of research (Bryman, 1988). Bloor (1978), although finding the technique useful for generating further areas for research, found a number of problems with member validation. He argued that this technique cannot be unproblematically used to establish the validity of a project and that such responses should be treated as data and not as a test of validity.

However, there were two ways that I did use a limited form of respondent validation in my research. First, in my last interview with Dr Vance I asked him to reflect on one of my findings, to in effect get an 'informant's view' of my interpretation of a particular point of my data. One of the themes that had arisen from the data was that although the informants often mentioned ethical issues, they generally felt that their everyday practice did not present vastly challenging ethical issues. I asked Dr Vance to reflect on this, on whether it was a reasonable interpretation, he agreed with my contention and therefore this in one specific instance was a form of respondent validation (see discussion in Chapter Six).

Second, as mentioned above, one of my sampling criteria was to build up a picture of particular clinics and I sampled a number of clinicians from each clinic. This produced a form of respondent validation as I was able to build up a picture of the decision-making process in the clinic from a number of perspectives. I could check my understanding of that clinic's ethos with other informants from that clinic.

Triangulation

This is the combination of different methods of provide a 'better' picture of what is being studied (Seale, 1999). This method has been subject to criticism in the same way that respondent validation has (as respondent validation can be seen as a form of triangulation). As Hammersley & Atkinson say: 'What is involved in triangulation is not the combination of different kinds of data *per se*, but rather an attempt to relate different sorts of data in such a way as to counteract various possible threats to the validity of our analysis.' Therefore, triangulation may not add up to ' a more complete picture.' (1995:232) Due to these reasons and practical difficulties of conducting observations of clinics, I did not produce data sets from different sources.

I did perform a form of triangulation in the data analysis by having my supervisors read a selection of the transcripts and look at my coding of these to provide a further check on my interpretation of the data.

CONCLUSION

This chapter has been an exploration of my research methods: how the research was carried out and some of the theoretical assumptions that I made in both organising the data collection and analysing the data. In the next chapter I shall examine the regulatory and organisational features of infertility treatment in England, to introduce the context in which the informants (the infertility clinicians) in this current study made their ethical decisions.

CHAPTER FIVE
THE ORGANISATION OF INFERTILITY TREATMENT IN THE UK

INTRODUCTION

In this chapter I will give a broad account of the regulatory and organisational context of infertility treatment in the UK and how such treatment is funded. This discussion delineates the context in which the infertility clinicians made ethical decisions and the external constraints that shaped such decisions.

REGULATION

Before 1990

Discussions of the regulatory framework in infertility often begin with Louise Brown, the first baby conceived by in vitro fertilisation (IVF) (Steptoe & Edwards, 1978). However, artificial insemination (AI), either by donor (AID) or by the husband (AIH) was an assisted conception technique that predated IVF. AID was first used in clinical practice in England in the late 1930s and was generally practised in secret (Nachtigall, 1993). In 1945 Mary Barton, a gynaecologist, published an article in the *British Medical Journal* (Barton & Walker, 1945) about her AID programme, that prompted a public outcry that accused her of performing an immoral procedure.

With the development of the creation and manipulation of embryos outside the body and related treatments such as IVF, ethical concerns over these procedures became more marked. Louise Brown's birth in 1978 in the UK[121] sparked controversy and debate over the ethical acceptability of interfering in human reproduction (Deech & Smajdor, 2007). As a response to these scientific developments the Government

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[121] For an overview of the early days of IVF treatment in countries other than the UK see Cohen *et al* (2005).

established the Committee of Inquiry into Human Fertilisation and Embryology

chaired by Mary Warnock, in July 1982, to debate the correct societal response to

these developments. The terms of reference for this Committee were as follows:

> To consider recent and potential developments in medicine and science
> related to human fertilisation and embryology; to consider what policies and
> safeguards should be applied, including consideration of the social, ethical
> and legal implications of these developments; and to make recommendations.
> (Warnock, 1985:4)[122]

The Committee reported its findings in June 1984 and it became known as *The*

Warnock Report. Its main recommendations were: that the embryo deserved some

protection under the law; that new legislation was needed to set out the legal limits of

embryo research and reproductive technologies; and that a licensing authority be set

up. The Report provoked debate and controversy, *The Times* for example, ran a

headline 'Warnock: Ethics Undermined' for an article that heavily criticised the

Report's conclusions (Warnock, 1985:viii).

In 1985 the Voluntary Licensing Authority (VLA) was set up, chaired by Mary

Donaldson, as an interim measure to monitor and regulate reproductive technologies

until legislation based on the findings of the Warnock Committee was passed. This

body was made up of scientists, health professionals and lay people, who carried out

inspections of clinics and issued licenses to practice. Any centre wishing to carry out

research or treatment in this area had to apply to the Authority for a license. The

Government then carried out a consultation and published, in 1987, a White Paper

Human Fertilisation and Embryology: A framework for legislation that committed it

to legislating in this area and became the basis for the Bill that was put before

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[122] References to the Warnock Report are taken from an edition published in 1985 that contains the
Report and two commentary chapters by Mary Warnock.

parliament. In 1989 the VLA changed its name to the Interim Licensing Authority to reflect its temporary status.

The need for legislating in this area was succinctly put in the parliamentary debate over the Human Fertilisation and Embryology Bill. Legislation was needed, 'to regulate research on embryos, to protect the integrity of reproductive medicine and to protect scientists and clinicians from legal action and sanction [and] introduce statutory control of a new form of clinical practice.' (Morgan & Lee, 1991:22-23) The detailed regulation of an area of clinical practice did not receive the large amount of attention that other clauses of the Bill (embryo research and abortion – one area of the Bill was to amend the 1967 Abortion Act) received. However, it is this element of the 1990 Act that is important for my discussion.

With the passage of the 1990 Act, infertility practice became governed by a comprehensive piece of legislation. Although this legislation gave clinicians a role in interpreting, carrying out and organising infertility practice it did impose some limitations to their clinical freedom and how they organised their practice. For example, the HFEA has recently brought out a consultation document (HFEA, 2007a) on single embryo transfer, to consider changing policy to (generally) allow only one embryo to be transferred. Such a policy would clearly restrict a doctor's freedom to make a clinical judgment over how many embryos to transfer in a particular patient. Organisational aspects of clinical practice are also governed by national policies. For example, record keeping of those who have had treatment and the child born from such techniques, is now kept by HFEA in a standardised format. Whereas, in countries where there is no legislation, such as the US, the studies conducted indicate that there is no standard

system of record keeping and clinicians organised it according to their own preferences and views (Office of Technology Assessment, 1988).[123] In the UK, however, in the area of infertility treatment legislation has meant a greater standardisation of practice and a change in the role of doctors. They have gone from the being the sole mediators of the practice (Noveas, 1998) to facilitators of a predetermined policy and this clearly affects the way they can control and influence their clinical practice.

The role that the state via legislation should play in medicine is a contested one, some argue that medical decisions should remain outside the public sector (Bonnicksen, 1992). For example, in a study conducted after the Warnock Report but before legislation, Walker et al (1987) found that among clinics, donors and recipients there was little support for any change in the way AID was organised, hence little support for legislation. Others, however, maintain that in an area like this, where so many of decisions are not clinical ones but reflect society's attitudes to family structures, legislation is both useful and necessary (Brahams, 1983).

Regulation under the 1990 Act

The Human Fertilisation and Embryology Bill received royal assent on 1st November 1990. One of the main problems with a piece of legislation such as the 1990 Act was that in this area (as in many other areas of medicine) what is scientifically possible changes so rapidly that legislation will quickly become out dated. The 1990 Act established the Human Fertilisation and Embryology Authority (HFEA), which began its statutory duties in August 1991, to partly address this problem of rapid

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[123] Despite there being no national legislation infertility practice in the US is not an 'ethical free for all.' There are professional guidelines that delineate 'good practice'. The Ethics Committee of The American Society of Reproductive Medicine, for example, issues ethical guidance in this area and publishes this on its website as open access articles from *Fertility and Sterility*.

scientific development outstripping regulatory structures. One of the HFEA's duties was to regulate new techniques that would arise as technology developed.

The HFEA has a duty to regulate centres providing treatment and conducting research, publish a Code of Practice and maintain registers of those born from such procedures and those receiving treatment. The first two of these functions is how the HFEA provides the context for ethical decision-making in the infertility clinic. The Code of Practice (and associated policy documents) determines what constitutes 'good practice' in the licensed centres and what limits are put on procedures on ethical and clinical grounds. The HFEA grants licenses to clinics to allow them to practice in this area and these licensing procedures ensure that such regulations are adhered to. A licensed centre is one that provides IVF or donor insemination, stores gametes or embryos, brings about the creation of an embryo and/or carries out research on embryos.

The Code of Practice is now in its seventh edition (HFEA, 2007), and contains guidance for licensed centres for the proper conduct of their activities. As the Code of Practice is only revised periodically new guidance is given to clinics by Chair's Letter, Chief Executive Letter or Directions and these are incorporated into later editions of the Code of Practice. [124] The Directions are rules that licensed centres must comply with and non-compliance could result in the suspension of the clinic's license and thus an inability to continuing providing such treatment. New guidance on policies and ethical responses to 'new' techniques are usually preceded by a

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[124] The HFEA's website has a full list of the Directions and guidance given to clinics since the creation of the HFEA.

public consultation to ascertain general views on the ethical and/or clinical acceptability of certain procedures. For example, there have been previous consultations on sex-selection in 1993 & 2003, pre-implantation genetic diagnosis in 1999, modernisation of regulation and the new fee structure in 2002 and concerns over multiple births in 2007.[125]

Hence, via the Code of Practice and the further guidance the HFEA directs the position and approaches clinics are to take. There are elements of treatment that are not allowed in the UK and therefore patients and doctors cannot 'choose' to utilise them. For instance, sex-selection for social reasons is prohibited; the HFEA stipulates the numbers of embryos to be transferred; and consent forms and procedures are set out in the HFEA Code of Practice. Therefore, clinicians' choices over how to conduct their clinical practice are circumscribed by a tight regulatory framework.[126]

One area of regulation that merits particular discussion is the guidance offered by the HFEA on 'welfare of the child', as this was an area that all of the informants in this study had to address in their practice.

Welfare of the child

Current legislation provides that: 'a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born

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[125] Details of these consultation documents can be found on the HFEA's website.
[126] Such restrictions of choice in this way has led, arguably, to what has been called 'reproductive tourism.' (Pennings, 2002. Blyth & Farrand, 2005).

as a result of the treatment (including the need of the child for a father), and that of any other child who may be affected by the birth.' (s 13 (5), HFE Act, 1990) This welfare of the child provision has, arguably, been one of the 1990 Act's most controversial provisions (Blyth, 2007). The 1990 Act did not define precisely what was meant by 'welfare of the child' in this context (BFS, 1999) but the HFEA, in the first edition of its Code of Practice, issued broad guidance that clinics should consider:

- The commitment to raising the child

- The ages and medical histories of the family

- The needs of any child to be born, including any possible multiple births, and the ability of the parents (or parent) to meet those needs

- The risk of harm to any child/children to be born, inherited disorders, problems during pregnancy, neglect or abuse

- The effect of a new baby or babies upon any existing child of the family (HFEA, 1991)

Clinics found this guidance very hard to implement due to the difficulty in interpreting risk factors and the British Fertility Society, when issuing its own interpretations of the guidance in 1999, argued that: 'A definition of the meaning of 'the welfare of the child' has not been agreed and in its absence, implementing the assessment is, in practice, the subject of confusion and debate.' (BFS, 1999:85) Further, as Blyth, notes many clinicians saw such a provision of welfare of the child as an unwarranted incursion in an area that should be a matter of clinical judgement. The welfare of the child provision was unnecessary, as it was 'good medical practice' to take it into account and clinicians did not need vague legislative provisions to ensure that they did (Blyth, 2007). Welfare of the child provisions were

also criticised on other grounds, that such provisions were unfair to infertility patients.[127] Jackson, a professor of medical law, has argued that the provision should be removed from legislation as it is, 'unfair to deprive some people of the zone of privacy that surrounds most individuals' reproductive decision-making.' (Jackson, 2007:49)[128]

As a result of these problems with the welfare of the child provision, the HFEA, in 2004, began to review the welfare of the child requirement (HFEA, 2005) and produced new recommendations on how infertility clinics should implement the provision (HFEA, 2005a). This new guidance provided that, 'there should be a presumption to provide treatment, unless there is evidence that the child to be born, or any existing child of the family, is likely to suffer serious medical, physical or psychological harm.' (HFEA, 2005b) There are in effect two main changes to the guidance. First, only serious risk of harm needs to be taken into account, thus, arguably, making the judgments easier to make. Second, information given by the patient is to be the first port of call and GPs only contacted if the clinician thinks that there are particular issues to be addressed, whereas previously GPs were contacted as a matter of course.

Many clinicians and commentators have argued that, even in the light of this new guidance, it is time to remove any form of welfare of the child provision from the regulatory requirements (Harris, 2000), while others have argued that the provision can have some utility in making fair decisions about who should be allowed to have

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[127] The RCOG also argued against welfare of the child provisions on these grounds in their evidence to the House of Commons Science and Technology Committee (2005).
[128] This is a later version of an article first published in 2002.

infertility treatment (Parker, 2005). Nevertheless, the HFEA seems committed to some explicit form of welfare of the child assessment and thus, although, with the new guidance, clinics are able to adopt a slightly more laissez-faire approach to welfare of the child assessments, clinicians are still guided and constrained by national policies and rulings on the issue.

Review of the 1990 Act

As seen in the case of welfare of the child provisions, the HFEA continually reviews and monitors the guidance it offers. However, the flexibility to do this is limited by the need to stay within the confines of the 1990 Act. As Biggs notes: 'Legislative drafting can never be sufficiently flexible to keep pace with the rate of scientific progress in this area.' (Biggs & Horsey, 2007:xi) The Act has also been subject to a number of legal challenges, such as the case taken against the HFEA to allow the creation of a 'saviour sibling' in 2005. The 1990 Act is bound by its roots and Morgan & Lee argue that the 1990 Act is 'a Warnock Act':

> This is true not only in its following the report of the Warnock Committee, but also in the more important sense that the science in question is that of 1984, updated in an ad hoc and piecemeal way. The Act represents a limited attempt to capture or to understand the exponential technological leaps since then. (Morgan & Lee, 1991:4)

In light of these problems and the changing scientific and technological developments, the Government decided to conduct a full review of the 1990 Act in 2004. The House of Commons Science and Technology Committee began an inquiry into the Act that reported in 2005. As a result of this and Department of Health consultations, a revised HFE Act is, at the time of writing, going through Parliament. However, the interviews with the clinicians were carried out before the new

legislation was debated in parliament, so the regulatory structures were those of the 1990 Act and associated guidance.

THE FUNDING OF INFERTILITY TREATMENT

One of the enduring controversies in infertility treatment has been the way it has been funded and who can and cannot be given treatment. The two issues are inter-twined as often certain groups such as single women and those in same-sex relationships have been denied treatment on the NHS, but can get treatment in some private centres. There are no definitive figures for the percentage of infertility treatment carried out in the private sector. Riley (2007) estimates that only 25% of infertility treatment is carried out in the NHS. The HFEA does not keep figures on this but has an anecdotal impression from its Fertility Views Patients' Panel that around 80-85% of treatment is privately funded (Woodward, 2008). Only one clinic in my sample (Clinic 1) solely did treatment on the NHS, one clinic was solely private and the others did a mix of private and NHS. The purpose of this section is to give an overview of the funding criteria that operate for NHS funded treatment, and the consequent limitation this places on the clinicians' practice.

NHS funding

As Morgan & Lee note the 1990 Act drew attention to, 'questions as to the provision and payment for assisted conception services. The Government's refusal to commit more resources to the area [has been] repeatedly criticised.' (1991:23) The issues surrounding whether infertility treatment should be offered on the NHS at all and if so, how much treatment (generally how many cycles of IVF should be given) and to

whom, have seldom been out of the public eye since the inception of the 1990 Act

(Shenfield, 1997. Lord *et al*, 2001). It might be thought that with so little of infertility

treatment provided on the NHS, any restrictions on funding and the imposition of

eligibility criteria for patients has little effect on infertility clinicians. However,

although the majority of their practice is private there is still approximately a quarter

that is funded by the NHS. Further, the restrictions on NHS funding for such

treatment has had a profound influence on infertility provision in the UK as a whole.

The UK has one of the lowest numbers of IVF cycles per million of the population.

Data from the European Society of Human Reproduction and Embryology (ESHRE)

in 2004 put the UK far down the list of amount of IVF provision in Europe.

TABLE 1

Country	Cycles per million of the population	Cycles per thousand of females of reproductive age
Denmark	2128	9
Belgium	1847	8
Finland	1765	8
Sweden	1432	7
France	1154	5
The Netherlands	942	4
Germany	755	3
UK	**663**	**3**
Austria	551	2
Macedonia	252	1

(Data adapted from a table in Andersen *et al* (2008))

Clinicians' ability to provide a service that meets the populations' needs is, arguably, compromised by the lack of NHS funding. Further, their ability to select patients in a quarter of their practice is determined by the willingness of their local Primary Care Trust (PCT) to fund treatment.

Primary Care Trusts and IVF

At the time of the interviews NHS funding for infertility treatment was administered and distributed by PCTs. PCTs replaced Health Authorities in 2002, with a further reorganisation in 2006, and there are currently 152 PCTs in England. Each of these PCTs issues criteria about who they will fund infertility treatment for and how much and what type of treatment will be provided. Inevitably this system has given rise to variation in how much and to whom infertility treatment is given. This regional difference in provision in health care has become known colloquially as a post-code lottery and the 'lottery' in infertility provision can be significant. In the South and West area there was 0.3 IVF treatments per 100,000 population, where as in Anglia and Oxford there was 21.3 per 100,000 (Lord *et al*, 2001). Infertility campaigners (such as the National Infertility Awareness Campaign (NIAC))[129] argue that there are two problems: first, regional variation in infertility provision and eligibility criteria that they see as unfair; and second, a general lack of funding for such treatment across the country.

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[129] The NIAC are a well-respected body which has organised surveys of PCT provision with government bodies and their chief executive Claire Brown works closely with the British Fertility Society.

In response to the former problem, in 2004, the National Institute of Clinical Excellence (NICE) issued national guidance on what PCTs should provide for those seeking fertility treatment (NICE, 2004). The main recommendation of this guidance was that couples should be offered up to three stimulated cycles of IVF and the woman should be aged between 23-39. Although this guidance was greeted with some enthusiasm by patient groups and fertility clinicians (BFS, 2005), it was not accompanied by any commitment from the Government for additional funding to enable PCTs to provide this additional service. NICE subsequently commissioned two surveys in 2005 to see how the implementation of the guidance was progressing, one with PCT commissioning managers and the other with fertility experts from licensed clinics. Sixty-eight percent of fertility experts thought that the guidance would be hard to implement and that the major barrier to this was lack of PCT funding and competing priorities (NICE, 2005:19). When announcing the new guidelines the Health Secretary, John Reid, said he expected all PCTs to, 'offer at least one full cycle of treatment to all those eligible,' – a statement that would hardly encourage PCTs to stretch themselves to give the full three cycles recommended by the guidance. The survey of PCT commissioners found that in 2005 63.5% of PCTs were offering only one cycle, 31.7% offering two and none offering three (NICE, 2005a:12). The NICE recommendation of providing three IVF cycles is not being met. This inability to provide as many cycles as the clinician deems appropriate is a further curb on clinicians' freedom to make their own clinical judgments. It is argued to be highly inefficient to only offer couples one cycle and there are concerns that with the move towards single embryo transfer, these problems will become more severe (BFS, 2008).

Social eligibility criteria

A further problem with the NICE guidance was that it did not address the other part of the problem of IVF provision, namely that eligibility criteria for NHS treatment could vary across PCTs. The guidance says it does not address, 'social criteria for treatment (for example, whether it is single women or same-sex couples who are seeking treatment, or whether either partner in a couple already has children).' (NICE, 2004:34) This was highlighted as an issue in the post-guidance survey carried out by NICE that,[130] 'the majority of PCTs also regarded the lack of social guidance as either a major or minor barrier.' (NICE, 2005a:16) It is often these 'social eligibility criteria' that seem most unfair about the unequal distribution of resources for infertility[131] and cause infertility clinicians the most difficulties. Ashcroft argues that by leaving out a consideration of social eligibility criteria NICE were attempting, 'to demarcate 'medical' from 'non-medical' uses of IVF, and that this rested on contested value judgements about the borderline between the medical and non-medical, and about who was deserving of treatment and under what circumstances.' (2006:136)

The debates over NHS funding of infertility treatment are underpinned by ethical questions of how one sees the status of infertility. One justification for providing treatment for the infertile on the NHS, is that infertility is the kind of condition that merits medical treatment. Robert Winston, a British fertility specialist, said, 'infertility is actually a terrible disease affecting our sexuality and well being.' This position appeals to a particular definition of what it means to be healthy. If health is defined as

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[130] See also the survey carried out on infertility specialists on the new guidance (NICE, 2005).
[131] See Ashcroft (2003a) who argues to the contrary that as such criteria are judgements about priorities and values, local variation need not always be unjust.

the optimal physical functioning of an organism then it could be argued that where infertility is caused by some form of physical malfunction then this should be treated. A wider definition of health could be employed to support the claim that infertility is a disease such as the World Health Organisation's (WHO) definition, that health is a complete sense of wellbeing. It could be said that infertility treatments are enabling the infertile to function as fully healthy individuals and should be part of health care provision.

Conversely, it has been argued that infertility is not a disease, it is rather the effect of other conditions, such as fallopian tubal blockage. Infertility treatments do not 'treat' infertility they only ameliorate the effects of other conditions. Nevertheless, many established medical treatments fall into this category, for instance diabetes is not treated but its unpleasant side-effects managed, so this in itself does not constitute an argument against the merits of medical treatment for infertility. Infertility can also be seen as purely a social problem and one that does not need medical intervention. Couples could have counselling to come to terms with the inability to have children, which is an inability to participate in social customs rather than any specific medical problem. NICE, however, have avoided addressing questions of whether infertility should be seen as a medical need by framing the debate solely in terms of clinical effectiveness.[132] NICE has left the difficult decisions to PCTs and, in doing this, has offered little guidance to health care professionals – when offering guidance is one of its stated aims (Riley, 2007).

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[132] See McMillan (2003) for a discussion of the limitations of focussing solely on clinical effectiveness to determine treatment criteria.

In a Department of Health survey of PCTs and IVF provision undertaken in 2006, criteria that fall under the social eligibility heading are listed as:

Age of woman

Age of male partner

Weight of woman (BMI)

Smoking/health

Previous children

Couple's relationship

Previous assisted conception

Follicle stimulating hormone level or poor cycle response

Previous sterilisation (treatment is often refused on these grounds)

Other (which included conforming to welfare of the child criteria – in which their GP would be contacted – and sharing anonymised data with the commissioners) (DH, 2007)

Clearly, some of these criteria can be argued to be more clinically based than others. Follicle stimulating hormone level or poor cycle response could be seen as a purely clinical criterion that would lead to the assessment that a patient has little chance of conceiving. Other criteria such as weight, age and smoking can be justified on the grounds that the older you are, the higher the BMI and the greater the amount you smoke can all affect the success rates of the treatment.[133] However, these criteria also

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[133] However, most PCTs will not treat with a BMI of over 30, where as the British Fertility Society recommends not treating when the BMI is over 35 (BFS,2006).

carry with them a sense that there are some non-clinical value judgments at play (Kennedy, *et al* 2006), in that these might be groups seen as less deserving of treatment, raising the problem of how much success rates must fall before it is deemed appropriate to preclude someone from treatment?

It is difficult to get conclusive data on all PCTs' social eligibility criteria. The survey carried out by the Department of Health in 2006 (DH, 2007) was conducted just after the re-organisation of PCTs and this data does not always refer to the PCT in its re-organised form. The MP Grant Shapps requested eligibility criteria for infertility treatment from PCTs in 2007 and has presented the data on his website.[134] Some PCTs' eligibility criteria are available on the web as part of PCT documentation, but it is not always clear if they are the most up to date policies. It appears from Shapps' data that PCTs are gradually moving towards general criteria of women's age between 23-39, no previous children and a body mass index (for the woman) below 30. Only three trusts stipulated that couples must be in a heterosexual relationship.[135]

However, there still are differences. In terms of maximum age some PCTs (such as Luton) have a lower maximum of 35 years. Lincolnshire PCT, for instance, reduced its maximum age to 35 in 2006 and estimated that this would save them £100,000 per year. However, they have now increased the age limit to 39 to bring them into accord with their neighbours (Lincolnshire PCT, 2008). Not all PCTs will not fund smokers, but the trend is towards a greater exclusion of smokers. These variations give rise to

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[134] www.shapps.com. This data was also reported in *The Telegraph*, 3rd March 2007.
[135] South Hams and Devon PCT (2005) for example restricts access to heterosexual couples.

concerns that they are not based on 'clinical effectiveness' but rather on an attempt to reduce the pool of potential recipients, as the example of Lincolnshire illustrates.

PCTs again vary on the definition of no previous children: some will not fund couples who have a child living with them, whereas others couch it in terms of having a child at all. There is also often a distinction drawn between children from a previous relationship and children from the current relationship. Only two PCTs, Bristol and South Gloucestershire, specifically fund treatment if the couple had a child together, three others did not mention such a criterion and the rest would not offer treatment (Shapps, 2007). This type of criterion is clearly a form of social criterion and has been argued to be purely about reducing the numbers eligible for treatment. It cannot even be cashed out in terms of welfare of the child (however dubious some of those welfare of the child judgements may be) as no one generally believes having siblings is harmful. Further, already having a child could be seen as an indicator for successful treatment.

NHS provision for infertility treatments is still subject to regional variation both in amount of treatment offered and the social eligibility criteria employed. Clinicians are constrained by PCT policies and funding criteria over who they can offer treatment to and how much they can give them. Thus, such funding structures have an important impact on the context of infertility provision in the UK and parameters within which infertility clinicians make ethical decisions.

CONCLUSION

This chapter has illustrated the frameworks in which infertility clinicians make

ethical decisions, from regulatory structures to funding limitations. These

frameworks set the context in which ethics is carried out in the infertility clinic and

parameters and possibilities of clinical ethical decisions. The next four chapters form

the core of this study and explore and analyse the way the clinicians made and

approached ethical decision-making.

CHAPTER SIX

ETHICAL ISSUES IN INFERTILITY PRACTICE

INTRODUCTION

This research project was driven by the overriding aim of seeing how infertility

clinicians managed and resolved the ethical issues in their everyday practice. To

begin this discussion it is necessary to have an understanding of how the informants

thought about the ethical issues they encountered and indeed what these ethical

issues were. This is setting out the *endoxa* (as discussed in the Chapter Three), to see

what gets constituted as an ethical problem, what the different views are of the

practice and where the conflicts are to form the basis of discussion.

Generally, the informants viewed their infertility practice as a medical speciality

fraught with ethical difficulty. However, there was a contrasting view that they were

not constantly troubled by ethical difficulties in their everyday practice. This chapter

is an exploration and examination of this apparent contradiction. I then apply the

element of my methodology that seeks to develop theory, in this case a theory of

'settled' morality that arose out of the data, to explain how the clinicians thought

about the ethical issues that arose from their practice.

I will argue that the informants operated within a 'settled' morality, within which

they sought to normalise their practice so they could develop a framework in which

to go about their everyday clinical duties. The ethical issues that informants brought

up in discussion will then be considered to provide a backdrop to the kinds of

problems and concerns the informants thought ethically troubling. Particular issues

will also be discussed throughout the thesis when considering how practitioners approached and made ethical decisions.

INFERTILITY PRACTICE AS AN ETHICALLY CONTENTIOUS AREA

In this section I want to consider how the informants saw the relationship between their practice and ethics. In response to a question on how they (the informants) saw the role of ethical issues in infertility practice, 17 of the informants thought that the area of infertility medicine raised many difficult ethical issues. The view that infertility practice is an area of profound moral and ethical importance is one reflected both in the literature and the regulatory context of reproductive technologies in the UK.[136] This is an area of medicine that has attracted considerable debate and exploration in the academic literature and is closely regulated by a specific act of parliament and a regulatory body. In their guide to the 1990 Act, Morgan and Lee say, 'within [the Act] are some of the most difficult, most intractable and fundamental moral questions of which any society has become seized.' (1991:1)

This view of reproductive technologies has not changed in the years since the passage of the Act. For example, in the Government's review of the Act in 2006, the White Paper recognised the continuing complexity of ethical issues raised by this area of medicine: 'The development and use of human reproductive technologies continue to raise a range of complex and profound social, legal and ethical questions. Addressing those issues and questions goes to the very heart of our existence as

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[136] For a more detailed overview of the regulatory context of infertility practice in the UK see the previous chapter.

individuals, families and society.' (DH, 2006:1) Hence, that informants viewed their practice as raising a substantial number of ethical issues was not an unexpected finding. The high ethical profile of this area of medicine was one of the reasons why I chose the infertility clinic as a site to conduct research on how doctors made decisions and approached the ethical aspects of their practice.

One aspect of this view that reproductive technologies raised many difficult ethical issues was that ethics was an integral part of medicine. Drs Marsh and Down thought that generally ethics was a part of medical practice, the two could not be separated:

> So everything in every aspect of medicine, all decisions are ethical to some extent, or to a large extent. (13-37)

> I think ethics is a part of medicine. I think, I think they are intimately involved with one another. In all areas of medicine there is ethics. (4-90)

Other informants thought that obstetrics and gynaecology and by extension infertility practice was, as a medical discipline, more ethically fraught than other areas of medicine. Drs Grant, Jenson and Havers' comments were typical of this view:

> Yes, I did obs & gynae as the speciality, in the medicine field it's got more ethical commitment than others. (7-69)

> I think fertility and ethics, we are dealing with probably the most important part of medicine, in my view, or ethically important part of medicine. (10-68)

> As you are aware in this field, more than probably in other fields on the medicine, ethics is very important. (8-88)

Dr Grant saw infertility medicine as the place where ethics and medicine had a closer relationship than in other areas of medicine:

> I see them as two, in medicine, yes, not in infertility. I think in infertility, or assisted conception, I think ethics and medicine begin to come close together. That's the reason why we can turn a patient down on ethical grounds, not only on medical grounds. (7-19)

Dr Urban reiterated this view:

> Yes, it's just I think it's a part because, as I said, ethics is a big part of this IVF treatment, part and parcel. (21-29)

Thus, infertility practice, by its nature, had the potential to raise a substantial volume of ethical issues. Dr Quest summed this up when he said:

> if you sit and think how many ethical problems we have every day, I think that it's impossible to count them. (17-44)

Dr Evens said:

> Now the interesting thing for this kind of work obviously with fertility, is because there are so many ethical issues. (5-109)

And Dr Vance:

> And ethical problems, plus plus plus plus. Because I'm lead for the Assisted Conception Unit, but I'm also lead for the Termination of Pregnancy service. So I've got a very sort of, there's ethics just coming out of my ears basically. (22-1)

Twelve of the informants (Drs Case, Down, Evens, Francis, Havers, Iniman, Lovate, Novack, Percy, Quest, Street and Vance) talked easily about the large numbers of issues that arose from their practice.[137]

Whether or not infertility practice is particularly fraught with ethical difficulties is not the substantive issue here – palliative care doctors might disagree for instance. What is important is that the informants thought that their practice raised complex ethical issues by its very nature. The account they gave of their practice was one of an ethically contentious area. Hence, generally, the informants viewed their infertility practice as a medical speciality fraught with ethical difficulty. However, there was a

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[137] For details of these issues see the section on controversial morality in this Chapter.

contrasting view that in everyday practice ethical issues and difficulties did not arise frequently.

FEW ETHICAL ISSUES IN EVERYDAY PRACTICE

Although the informants did mention a wide-range of ethical issues that they faced in their practice, the overall impression from the interviews was not one of their everyday clinical practice being suffused with difficult ethical dilemmas and issues. Some informants did not find it easy to think of ethical issues when asked the general question, 'what issues do you see as ethically challenging in your practice?' Dr Robin, for instance, in response to this question said:

> Do I have to say something?' (18-29)

Dr Urban, having mentioned a problem with lack of anonymity of egg donors, then said:

> I can't sort of think off the top of my head what other ethical issues, I need to sort of think very hard and I need some time. I just can't sort of think at the moment what other ethical issues are. (21-14)

Dr Tarn asked me, as the interviewer, to provide some guidance:

> So otherwise I don't think there are really, which other issues have you got in mind, which?' (20-23)

Dr Orben also asked for some guidance on what I might be looking for when asking about what challenged them ethically in practice:

> Well I don't know, because my perception of it is obviously different from yours. I don't see it as particularly difficult from an ethical point of view at all. You give me some examples of what's difficult ethically. (15-11)

Twelve of the informants explicitly talked about how, generally, their practice did

not raise or did not frequently raise ethical issues. Dr Marsh responded to a question

about how he dealt with controversial ethical issues by saying:

> Just, like I said, if it's contentious - if it's straightforward, which is 90% or 99%,
> even 95% of the times it is straightforward. (13-45)

Dr Tarn said:

> I just think on an everyday basis there are no huge ethical issues. (20-24)

Dr Lovate also made this point

> I mean I think that I actually, mostly one isn't faced with ethical issues,
> mostly it's just mundane sort of medicine. (12-43)

Dr Orben, when discussing issues that might cause controversy, said that it was

unusual for such issues to arise:

> One or two cases in, and how long have we been doing it here? Well, I think
> I started my infertility practice in, I came in '85 and I think within a year it
> was up and running. So in 20 years of practice here, probably the number of
> cases where we've had to really scratch our heads and think you could count
> on the fingers on one hand. (15-7)

He went on to explain why he thought that this was the case:

> Well, again it doesn't because a lot of it's at the margins, we're talking about
> pre-implantation diagnosis aren't we, and we're talking about having siblings
> in the hope that you're going to match for a bone marrow donor and those
> kind of things which, of course, make up a very small number of the total
> number of patients undergoing fertility treatments. It doesn't really impact
> on our practice at all. (15-18)

Dr Grant also made the point that difficult cases were infrequent:

> I think, again I don't know if it's our clinic practice, but I think it's quite easy,
> infertility because, as I say, some couples have got a problem and they know that
> their problem is going to stop their treatment, they will just leave it, they will not
> pursue treatment. So it's difficult to find couples who've got a problem, it's a real
> problem, and we'll discuss for long. So generally apart one or two cases a year,
> no more than one or two cases per year. (7-59)

Dr Brown said:

> We have a few single women who come for treatment and a few lesbian couples. It's a number that I think is often looked at in sort of the press or whatever and is blown up out of proportion as being some big problem. I mean most of the people that we see coming for infertility treatment are ordinary heterosexual couples. You might say well, it's because the lesbian couples or the gay couples don't get treated or the single women won't get treatment, but in fact a lot of clinics will offer treatment to those people. It's just that I think most of them actually don't actually pursue treatment. Our view in our clinic is if you want treatment and you fit the current criteria then you get NHS treatment or you have to pay for it. (2-76)

A further element of this view, that there were few troubling ethical issues in everyday practice, was that funding criteria precluded some ethical issues for NHS clinics.[138] Dr Evens made this point about funding issues:

> And in relation to the fact that we're National Health Service, we don't pay for the treatment, it's the primary care trust that pays for the treatment, so we're going on their guidance as to what they feel is appropriate, so that's where that comes in. (5-16)

Potentially 'controversial' groups who might come forward for treatment (such as single women, same-sex couples, older women for example) would be precluded from receiving treatment by the funding criteria. Thus, in a NHS clinic certain cases would never present themselves for ethical debate.[139] A further aspect of the implications of funding structures on ethical aspects of practice was that some difficulties arose that the informants saw as purely funding problems rather than ethical issues. Dr Francis made this point:

> Well, I think the difference with us, and there are lot of ethical issues with infertility, but our ethical issues are slightly different because we're NHS, so most of our ethical issues aren't actually about ethical issues, they're about funding. (6-70)

Dr Lovate, whose clinic also did a lot of NHS work, gave two examples where they would not treat a couple due to funding restrictions. First, women over 40 would not

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[138] See Chapter Five for a more detailed explanation of funding for infertility treatment.
[139] Different PCTs had different funding criteria (see Chapter Five) and criteria would also change depending on how tight budgets were. For example Dr Tarn said that the age for accepting women for treatment has just been reduced from 39 to 38 by his PCT, solely to cut numbers of people eligible for IVF treatment.

be treated and second, couples who had already had children by infertility treatment would not be treated to try for a third child.

> **Yes. I mean is it a funding issue why you wouldn't treat, or an ethical one, or would you see it as a combination?**
>
> No, it's not an ethical one, it's funding, it's resources. (12-21)

One such problem created by funding criteria that Dr Francis's unit faced (Clinic 1) was whether to give treatment to a couple who had a child but that child had very severe Downs Syndrome. Her local PCT did not fund treatment for those who already had a child under 16 living with them and therefore this couple were technically prohibited from getting treatment funded by the PCT. This was a matter that was discussed at this Clinic's CEC, not because the informants from that Clinic has any issues with offering treatment to that couple, but to see whether that couple could be construed to fall into the PCTs' funding criteria. That is, could such a child (with severe disabilities, who would be unlikely to live to majority) be discounted as a 'child living with you' for the purposes of the funding criteria. The boundary between whether an issue is an ethical or a resource concern can be unclear and funding restraints often force us to prioritise on the basis of criteria such as need or who is most deserving and hence become ethical issues. However, for NHS clinics there were some groups who they could not treat purely on financial rather than ethical grounds.

These two ways of seeing the role of ethics in infertility practice, that on the one hand practice raised many ethical issues and on the other there were few ethical issues, could be held by the same informant. For example, Dr Urban who said ethics

was a big part of IVF (21-29) also found it hard to give examples of ethical issues raised by her practice and said:

> Yes, for the clinicians. Because I feel personally we don't sort of get much involved in these difficult ethical issues. (21-11)

Dr Grant also combined these two views, saying ethics and infertility were closely linked (7-69) and also that difficult cases were infrequent (7-59).

In sum, the informants recognised that infertility practice was an area that raised many difficult ethical issues, but they also thought that, generally, in their everyday clinical practice they were not constantly beset by ethical difficulties. Difficult cases might arise once or twice a year, but generally their practice was routine and straightforward.

SETTLED MORALITY

This raises an interesting question. How can we explain why clinicians, working in what is arguably one of the most ethically controversial areas of medicine, report that on a daily basis they have few ethical issues to contend with? This apparent anomaly − that there are few ethical issues in everyday infertility practice − can be explained by seeing it as an articulation of a 'settled morality' rather than as the expression of the view that infertility practice did not raise any ethical issues. This settled morality is the broad moral framework in which infertility practice is conducted (in the UK).[140]

A settled morality can be contrasted with 'controversial' morality. Hoffmaster outlines a version of this distinction, 'morality is largely settled. Morality

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[140] See further discussion of this in Chapter Eight.

encompasses the commonplace as well as the controversial, and it is only a preoccupation with the latter that creates the unwarranted impression that moral issues are, by their very nature, disputatious.' (Hoffmaster, 1990:244) In general terms, settled morality is something that most serious minded people would agree on, such a murdering children is morally wrong.

The informants alluded to a notion of a settled morality when talking about obvious ethical decisions, or as one informant put it, 'barn door' (2-15) decisions, where they thought that most people would agree with that decision. Dr Brown gave an example of this type of decision:

> But from a personal point of view, I know two people who I've been involved with where we've turned down treatment, and I would say that the bulk of the population, whatever that sort of means, but a broad body of people would have agreed with that decision. It wasn't seen as sort of being vindictive at all in any way or … (2-16)

Dr Iniman also referred to decisions to refuse treatment for a couple in these terms:

> It would have to be, it has to be something pretty barn door, such as a psychiatric history of the current admission for psychosis and difficulty in coping with day-to-day life.(9-43)

Dr Percy made a similar point:

> So in order to be able to refuse treatment when it's a clear-cut barn door case, I think we have to have some form of assessment. (16-8)

When ethical issues are part of a settled morality they can be rendered invisible by the lack of discussion, so that it is easy not to think of them as ethical issues at all. Dr Marsh illustrates this point very well:

> And the framework helps when you are making difficult decisions, for common decisions probably just it's very straightforward you wouldn't bat an eyelid and think, "Oh, I've made an ethical decision", but you have. (13-38)

Here, decisions made within the settled morality, or 'common decisions' as Dr

Marsh puts it, are often not even seen as ethical ones. Issues in settled morality do

not attract the intensive discussion that controversial moral issues do, but they are

moral issues nevertheless. As Smith & Churchill say there are generally, 'enough

shared assumptions about our values and their expressions in action that we do not

need to articulate the process explicitly.' (1986:7)

A lack of appreciation of the distinction between settled and controversial morality

has sometimes resulted in a confusion over what an ethical issue actually *is* and this

is evident in some critiques of bioethics. For instance, Turner (2004) argues that

bioethics ignores important problems such as global inequities in resource and this is

because bioethicists do not see them as ethical problems.[141] I would argue that it is

not that such a problem is seen as not ethical, rather it is an issue over which there is

broad agreement. It is generally agreed that it is wrong that people starve in poorer

countries while those in the developed world consume the majority of the world's

resources.[142] Therefore, while there may be disagreement about the solution, there is

no need to debate the rights and wrongs of it, it is part of settled morality.

The notion of a settled morality can be seen as analogous to the discussions over

what has been called the 'agenda problem' for applied ethics (Cribb, 2005). Cribb

uses Brock's formulation of this, '[t]he problem is what is to be taken as fixed or

given for the purposes of setting or changing policy and what is to be taken as open

for modification and so on the policy agenda.' (Brock, 1987:790) One way the

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[141] See also DeVries & Conrad (1998) who make a similar mistake in arguing that the reason bioethics
does not attend to certain 'mundane' problems is because they are not seen as ethical issues.
[142] The key moral debate in this example is over what we do about this problem, not whether it is a
problem in the first place.

agenda is fixed in infertility practice is the necessity to act within the regulatory

framework. In this way, the regulatory context of infertility treatment sets

parameters within which ethical debates in the clinic take place. Certain procedures,

such as sex-selection for social reasons, are not allowed in the UK (HFEA, 2007) and

therefore, in the everyday clinical practice it is not a matter of ethical contention.

Thus, settled morality is partly informed by the regulatory structures under which

such technologies operate and, in the case of NHS clinics, PCT funding criteria. Dr

Orben made the point that IVF practice in the UK operates within tight boundaries.

> **So you said you don't find a lot of your everyday practice contentious, is that a fair statement?**
>
> Well I don't, perhaps just because I've been doing it, you know, it's bread and butter, I've been doing it for almost since the first IVF successful pregnancy, that was more or less the time when I was getting involved in it. So, yes, one's watched the controversies and the difficulties that various sections of the community have had with various aspects as treatments have developed. But within the UK we've been pretty closely regulated, either voluntarily or compulsorily, over the years so that some of the excesses that hit the newspapers which are mostly about treatments that take place abroad, that's just not part of our practice. (15-15)

Further, different clinics set their own agendas of ethical practice. So some clinics

did not treat same-sex female couples (Clinics 1,4 and 3) because it was not felt to fit

within that clinic's ethical framework. For example Dr Grant said:

> We haven't treated same sex couples yet, and the reason why is because there is a discrepancy on what people think, or some of my colleagues think different than what I think, and so there's not unanimous decision about it so we have not started treating these couples. And we won't do it until we all agree on it. (7-41)

So, in this clinic although they did not agree on whether it was ethically acceptable to

treat same sex couples, they agreed not to treat them as a clinic policy.[143] This was

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[143] For a further discussion of this point see the Chapter Seven and the discussion of conscientious objection.

mirrored in other clinics where agreements were reached as to what the clinic would

do. This can be seen as a form of clinic 'ethos' and informants talked about the

'ethos' of their unit, that the unit shared a particular moral stance on an issue. For

instance, Dr Case's clinic had come to joint decisions (reached consensus) over

whether to treat single women and same-sex couples:

> Latterly in this clinic we have accepted treatment of single mothers. That
> includes women whose partners have given consent for posthumous use of
> sperm, or posthumous use of embryos because they've had a death or
> whatever. And, subsequent to the acceptance of that situation, acceptance of
> the single mother who doesn't have a partner, and doesn't intend to have a
> partner, who might need donor sperm or even assisted reproduction using
> donor sperm. In this clinic we haven't treated same sex couples.
>
> **Is that a policy of your organisation or this particular clinic?**
>
> That's a policy of this particular clinic, and the feeling of the staff in this
> particular clinic. And it was the feeling of the staff in this clinic that made us
> latecomers to treating single mothers as well. (3-8)

Informants from Clinic 1 were very in favour of non-anonymous gamete donation

and portrayed that as being part of the 'ethos' of their clinic. Dr Evens said:

> Because we've always, since 1980s, had this ethos that children have a right
> to know how they were conceived. (5-39)

And:

> The scenario pretending it never happened has never sort of sat easily within
> our unit; it's not sort of been our ethos. (5-44)

Dr Francis (also from clinic 1) reiterated this view:

> we're also quite unusual that we've been a unit that's done an awful lot of known
> egg donation for years, and we've had very little anonymous egg donation; nearly
> all our egg donation's known. So I think we've always felt very comfortable with
> that. You know, quite a lot of units don't do known donation, whereas we've
> always done it.(6-31)

In this clinic there was a strong agreement on a particular ethical issue – that gamete

donors should not be anonymous. Therefore, settled morality can be located at a very

localised level of the particular clinic. Other clinics, as is pointed out in quote 6-31, could think very differently.

A further explanation for the view that their practice raised few ethical issues could be that the questioning of the informants was specifically directed at their everyday practice, rather than asking them what ethical issues in general they thought were troubling. Dr Orben implicitly makes a distinction between everyday issues and unusual ethical issues:

> Well, again it doesn't because a lot of it's at the margins, we're talking about pre-implantation diagnosis aren't we, and we're talking about having siblings in the hope that you're going to match for a bone marrow donor and those kind of things which, of course, make up a very small number of the total number of patients undergoing fertility treatments. It doesn't really impact on our practice at all. (15-18)

Dr Evens makes a similar point:

> I think the issues we're coming on to now, the more ethical issues that I think are more important are the genetics, and creating the perfect baby, and pre-implantation genetic diagnosis and selection, or whatever. I think those are huge ethical dilemmas, far more important than the issue of trying to assess who or who wouldn't be able to provide the appropriate parenting skills. (5-122)

Dr Francis gave the following examples of issues she thought could be ethically troubling but were outside current practice:

> Oh, you know, things that could potentially affect the germ line in an embryo, you know, I mean, god, it's like light years away but things like cloning and, yeah, things that you know and just being driven at all costs to produce the baby without thinking of the long-term affect on that child, you know, both emotionally but also physically, you know, changing the kind of genes that make up that child, which could potentially then be passed to future generations. I think it's right that we're quite cautious really. (6-86)

Hence, it could be argued that everyday ethical issues could be those that are not, now, at the cutting edge of medical science, they arise out of 'bread and butter' IVF practice. These everyday issues might be ones that are familiar and there is a reasonable level of broad agreement over how to approach them. There are a range of issues that are no longer debated and seen as 'ethical issues' in everyday infertility practice, such as: the morality of the practice of IVF itself; creating and manipulating embryos outside the body; the practice of sperm donation itself; and creating a family with the assistance of reproductive technologies.[144] Of course, these issues are still debated by some people 'outside' infertility practice, and people would not work in that area if they fundamentally objected to such practices. However, now that infertility practice is based on a clear legal framework it could be said that the acceptability of reproductive technologies as a legitimate way to form a family has entered the settled morality of society in general.

Ethical issues can change their positioning and move from controversial to settled or visa versa. There can be movement between controversial and settled morality, an issue can start of as part of controversial morality (as most aspects of reproductive technologies did) and as it gains greater acceptance become part of the settled morality. The changing attitudes towards artificial insemination by donor (AID) and sperm donor anonymity is an interesting example of how the ethical issues raised by a technique change over time (see Appendix 1).

Thus, what issues are seen as ethically controversial change over time, 'what counts as an ethical problem *in the first place*…is socially constructed.' (Hedgecoe,

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[144] See The Introduction for a discussion of these issues.

2004:126) Ethical issues are entities that arise out of a particular social context

(Cribb, 2005)[145] and what is a pressing ethical issue for one generation might not be

seen as such by another. As Warnock said in her introduction to *The Warnock*

Report:

> I do not believe that there is a neat way of marking off moral issues from all others; some people, at some times, may regard things as matters of moral right or wrong, which at another time or in another place are thought to be matters of taste, or indeed matters of no importance at all. (1985:viii)

Some of the informants held this view that contentious ethical issues could change

over time.

 Dr Vance, for instance, said:

> I mean the whole thing's a moveable feast isn't it. I suppose that's the other thing I've learnt, I mean the ethics of today are not necessarily going to be the ethics of tomorrow. You know, it is quite a bit about, it's got to be a shifting sands sort of thing. (22-53)

An example used by two informants, Dr Lovate and Dr Jenson, that illustrates the

changing status of particular issues, is treating female same-sex couples. Both these

informants argued that this was no longer an ethically contentious issue and therefore

did not need to be the subject of ethical debate. Dr Jenson said:

> It's changing. I suppose five-six years ago, same sex couples would have been sent to the ethics committee should we treat them. I am now of the opinion, and have been for some time, that a same sex couple doesn't need to go to the ethics committee. (10-75)

Dr Lovate argued:

> But if you want to know my personal views about that, I would have no hesitation in treating a lesbian couple…. But, society has changed and gay couples have come out, and I think a quarter of the population are gay and when a child goes to school I think that if the child has two mummies rather than a mummy and a daddy, I don't think it'll make a damn of difference to the child's acceptance at

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[145] See also Haimes (2002) for a discussion of how ethical problems are 'produced' by social factors.

the school. So I think in a way my views have changed because society has changed. (12-8)

The view that there were few troubling ethical issues in everyday practice was an unexpected finding, as infertility treatment and reproductive technologies are generally seen to be areas where ethical issues arise with great frequency. Seeing the informants' responses as fitting into either a settled or controversial morality (see next section) elucidates something that was initially troubling during the data analysis: how can some informants hold both that there are (some/many) ethical issues raised by infertility practice and at the same time also find it difficult to think of issues that trouble or affect them? Issues that were highlighted can be seen as an expression of controversial morality (which was a less frequent occurrence), while finding it difficult to think of ethical issues can arguably be seen as an indirect articulation of a settled morality.

In the last interview (with Dr Vance) I wanted to reflect back my understanding of this to an informant[146] and solicit his view on this and how he understood this.

> **I've found from my interviews that while people say there's lots of ethical dilemmas in infertility, when it comes to their everyday practice they actually feel quite happy what they're doing and they seem not to be vastly challenged ethically all the time.**
>
> Well life would be a bit painful if it was wouldn't it really. I mean what you tend to have is little crises every now and again, somebody comes up with something new you hadn't thought of, because you do tend to make sort of an ethical environment you work in and then everything fits in generally, and then every now and again somebody comes up with something you really hadn't thought of before. (22-55)

Thus, it is this ethical environment that the informants work within that is their settled morality. The informants' view that there were few ethical issues raised by

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[146] See Chapter Four for a discussion of respondent validation.

their practice can be seen as an articulation of this settled morality, that they were not frequently troubled by ethical issues, is because much of their practice fell into the sphere of settled morality. Further, this settled morality could sometimes been seen as an absence of ethical issues, rather than an articulation of ethical issues over which there was broad general agreement.[147]

CONTROVERSIAL MORALITY

The ethical issues that informants raised in discussion, controversial morality, will now be considered, to provide a backdrop to the kinds of problems and concerns the informants thought ethically troubling. As discussed, controversial issues came up less frequently. They were issues on which there was less agreement and where there was greater uncertainty over what to do. Controversial morality is more easily articulated than settled morality – a morality that can be rendered invisible. So by setting out what the informants thought to be controversial issues, it is possible – by default – to see what their settled morality looked like.

In the interviews an open question was asked, 'what issues do you see as ethically challenging in your everyday practice?'[148] This gave the informants a free range to answer the question in terms of their own priorities and concerns. Hurst, *et al* (2005) argue that allowing informants to articulate what they see as ethically relevant is an important way of exploring how ethical issues are actually resolved in practice. This eliciting of informants' own categories was one of the reasons why a qualitative methodology was chosen, rather than conducting a larger scale postal survey that

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[147] See the next chapter for a discussion of the levels of agreement over ethical issues in the informants' practice.
[148] With the exception that they were all asked how they approached welfare of the child issues, in the guise of how they screened potential recipients (as this was a useful way into discussing how they made ethical decisions).

sought responses to pre-set categories and cases chosen by the researcher.[149] Framing the question in this way by asking the informants about their everyday practice was designed to focus the discussion more on the routine and possibly mundane aspects of practice, rather than asking questions about what issues might be raised by reproductive technologies in general. This was intentional as one of the aims of the research was to get clinicians' responses to build up a picture of how everyday practice functioned and its ethical dimensions. The responses to this question (and other related questions and probes) are tabulated in Figure 2.[150]

Every informant discussed in detail the ethical problem of trying to ensure welfare of the child produced by any infertility treatment (see footnote 13). This was an assessment that had to be undertaken when considering all patients for treatment, so was an issue that was likely to be frequently encountered. The non-anonymity of gamete donors was seen as unethical by 11 informants, largely due to the fall in donor numbers since the law was changed to only allow non-anonymous donors in 2005 (HFEA, 2004). The ethical problems raised by egg sharing were issues over which there was little consensus. Some clinics (Clinics 1, 2 & 4) did not have such a scheme due to the problems they saw with the egg sharers giving fully, un-coerced informed consent. Treating female same-sex couples (SSC) was also an area where there was some disagreement and which has, in the past, been the source of great controversy (Donovan, 1993). Five of the informants were not happy about treating SSC and one informant (Dr Down) would take a request for treatment from this group to the CEC. The responses to the issues of egg sharing, donor anonymity and the treating of female same sex couples have been tabulated (see Table 2) to give a

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[149] For further discussion of this point see Chapter Four.
[150] See Appendix 7 for a detailed commentary and explanation of the categories of ethical issue used in Figure 2.

sense of the concerns that the informants had over these issues. These three issues could be said to be clear examples of the issues over which there was little agreement amongst the informants.

Some of the issues mentioned such as PGD, the treating of same-sex female couples and the treatment of post-menopausal women have received a lot of attention in the ethical literature. Others such as age difference between partners, whether to treat recipients with health problems and when to stop IVF cycles have received less consideration. As an example, it is interesting to contrast the debate over older versus post-menopausal mothers. Post-menopausal women require egg donation to achieve a pregnancy and therefore can be significantly older than women who can produce their own eggs (e.g. the 64 year old British woman who had a baby, although she was not treated in this country). Cases such as this have received a lot attention, particularly in the media. In contrast, amongst the informants in this study a more important concern was the issues raised by women, usually between 40-45, who came for IVF (without egg donation). The success rate for these women is so low that the informants thought it was unethical to offer them treatment. It was giving false hope and, as women in this age group would not receive NHS funding, involving them in futile expenditure. Dr Case, for example, summed up the dilemmas faced by this group of patients very well:

> The age limit's 45 in this clinic. But, you know, after the age of 42 the chances of success are so remote that that in itself is an ethical issue, whether a patient should be given hope when there is very little hope. Whether we should take money off them when we know the chances of success is relatively small, you know, and even when you discuss those issues and the couple still say we still want to take the small chance there is, whether it's right to say, to accept it. (3-62)

Dr Lovate's clinic has also discussed whether they should treat this age group:

> So, the decision was made because we get a lousy pregnancy rate in couples with unexplained infertility where the woman is 40 years or older, the policy of the clinic is that we don't treat those patients.(12-18)[151]

He went on to explain why this policy had created a dilemma for his clinic:

> But what happens if - and this is exactly what happened - if a woman comes and she's met someone last year but she doesn't ovulate. So her fertility has never been tested but she's never ovulated, she's only recently married, she doesn't ovulate, so she might be very fertile, there are lots of women of 40 who are very fertile, so this is a situation where the dilemma was well, should we go against our policy and treat this particular patient because she might be pregnant, if you induce ovulation she might fall pregnant with the first ovulatory cycle. Now, that issues was discussed six months ago and we didn't minute what we decided, so when the same issue came up a second time with another patient, half the people remembered one thing and the other half remembered something else. (12-20)

Therefore, this issue is both less dramatic and news worthy but, nevertheless, an issue that troubled the informants more than the issue of post-menopausal women seeking egg donation.

Categorising ethical issues

There is a debate to be had over precisely how to categorise different cases and points into distinct 'ethical issues'. Although a commentary on how the categories were formulated is included in Appendix 7, there is clearly over-lap between different issues. When informants talked about particular cases they often raised a number of inter-related ethical issues and therefore these could have been categorised in a number of ways. For example, many cases could be reduced to welfare of the child considerations, but could also include concern for the health status of the person undergoing treatment and the impact of gamete donation on the couple. Further, such placing of issues into different categories could be viewed to be putting

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[151] It could also be argued that he might be concerned about his clinic's success rates and their position in league tables as well as the poor prognosis for the patient.

pre-conceived and artificial categories onto the data (Strauss & Corbin,1998), as every issue in some senses presents its own unique ethical dimensions. As Hedgecoe notes applied ethics often, 'assumes that social reality cleaves down neat philosophical lines, with theoretical categories matching those in social reality.' (2004:130) Hence, the listing of ethical issues does not provide an unproblematic reflection of what ethical issues the informants raised. However, in the ensuing discussions the kinds of issues and areas that the informants found troubling will come out in relief when the question of how they managed and resolved such tensions is discussed.

CONCLUSION

This chapter has been an attempt to set out the *endoxa*, map the moral terrain in the form of a sociology *of* ethics to get a detailed perspective on how the informants saw the place of ethical issues in their practice. Not only this, the terrain was analysed using the tools of ethical theory (in Caplan's sense, see Chapter Three) to illuminate the way the informants' thought about ethical issues. This was done by developing a theory of 'settled' morality that arose from the data. It was argued that the informants operated, largely, within an area that could be defined as a 'settled morality'. Subsequently, a broad overview of the issues that they found troubling was given, to provide a backdrop to later discussions. The next chapter will consider how the informants managed and resolved ethical issues and difficult cases in their practice.

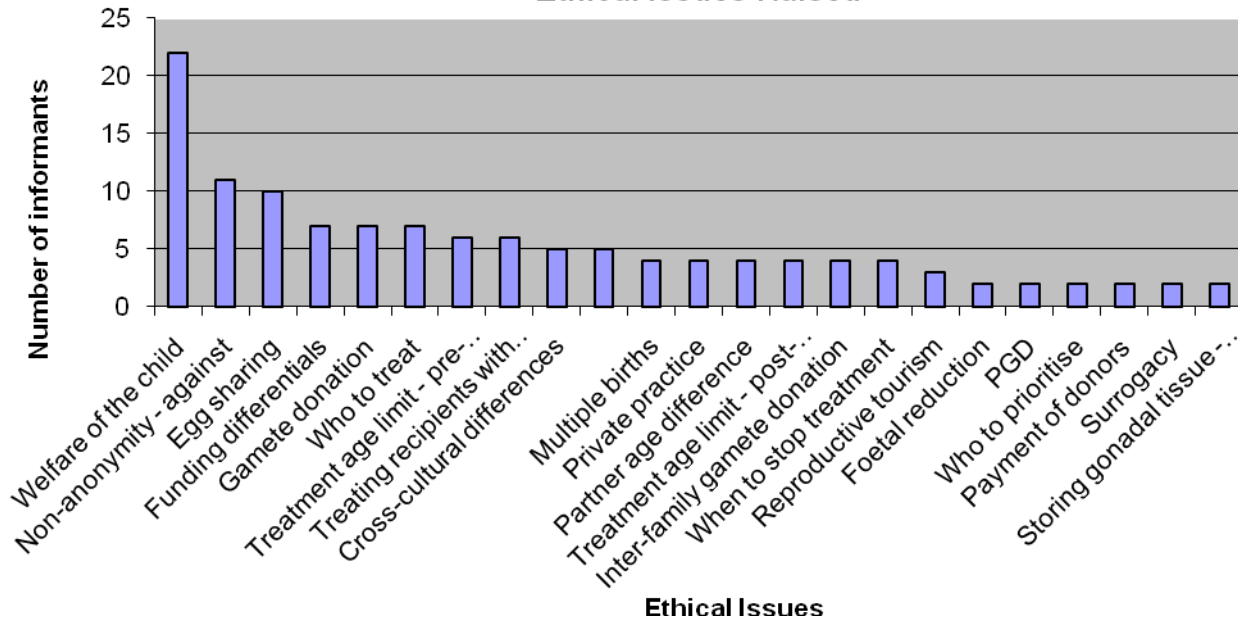**Figure 2**
Ethical Issues Raised

TABLE 2

VIEWS ON THE CONTESTED ETHICAL ISSUES

Clinician	Egg Sharing	Treating same-sex female couples (SSC)	Anonymous gamete donation
1 - Dr Adams	Not at moment	Yes, some in unit disagree and opt out	For anonymous donation
2 – Dr Brown	Doesn't do the donated gametes in that clinic	Yes happy with it	For anonymous donation
3 – Dr Case	Yes – but aware of the pitfalls	No, very morally against	In favour of anonymity – but in favour of telling the child
4 – Dr Down	No – very against as thinks women are being in effect forced into it called it an abomination	In NHS hasn't treated, nothing against it in principle, but would take a request to the ethics committee	Against anonymity – and would actively encourage recipients to tell the child. All members of Clinic 1 were
5 – Dr Evens	Not keen	Not keen, thought each request should be treated on a case by case basis (although mentioned research to say children did less well in such families)	Against anonymity – very in favour of the child knowing and non-anonymity.
6 – Dr Francis	Not keen	As a NHS clinic didn't do it, but happy in principle	Against anonymity – and would actively encourage recipients to tell the child
7- Dr Grant	Has no objection to egg sharing	Happy to treat SSC	Against anonymity – wouldn't treat if the recipients were not going to tell

			the child
8- Dr Havers	*	Did not treat SSC, clinic policy and happy with that	For anonymity, but also favoured a double-track system (of allowing both anonymous and non-anonymous donation)
9 – Dr Iniman	Against, as sees it as a form of coercion	Happy to treat, but would prioritise sub-fertile heterosexual couples first	Against anonymity – in favour of disclosure to children
10- Dr Jenson	Has no objection to egg sharing – if managed appropriately	Treats and is happy to	In favour of anonymity due to sperm shortages
11 – Dr Kilm	No objection to egg sharing	Their unit does not do donor sperm privately and NHS doesn't fund SSC, and he is not in favour of treating them.	For anonymity – doesn't see reason for knowing donor identity and concerned over the fall in numbers, change in the law is 'appalling'
12 – Dr Lovate	*	Unit doesn't as NHS but would be happy to treat	Against anonymity – thinks it important children know, if numbers can be kept up
13 – Dr Marsh	*	*	Against – but thinks that not having any system for ensuring child is told makes it meaningless
14 – Dr Novack	Clinic does not do egg sharing, that is a clinic policy that he endorses	Treats SSC	In principle against anonymity, in practice in favour due to fall in donor numbers
15 – Dr Orben	No objection to egg sharing	Treats SSC	Against anonymity – important things are out in the open
16 – Dr Percy	Clinic does not do egg sharing	Thinks in this day and age ok to treat SSC	For anonymity, thinks donors should be uninvolved, but should tell the child how they were conceived

17 – Dr Quest	Not keen on egg sharing	No objection to treating	For anonymity, as fall in donors and no need for the child to know
18 – Dr Robin	Disagrees with egg sharing	No objection to treating	For anonymity, does not see why the child should know, thinks it makes it all too complex
19 – Dr Street	Disagrees with egg sharing	Her Unit treats SSC	For anonymity but thinks couples should be open with the child
20 – Mr Tarn	Against egg sharing, sees it as selling eggs which is wrong	Very uncomfortable about SSC, doesn't treat	For anonymity thinks the law change is dreadful
21 – Dr Urban	*	*	Ambivalent
22- Dr Vance	Against egg sharing, sees it as selling eggs, but might do it in the future, due to changes in anonymity law	Happy to treat	Against, felt very passionately that children should be able to find out the identity of their donor.

* Any gaps in the Table indicate that the informant did not mention this issue in the interview.

THE MAKING OF ETHICAL DECISIONS

> We try and discuss as much as possible if there are sticky cases between ourselves at our meetings that we hold weekly, or on a regular basis, to take things forward, see what other people feel about the same situation. And yes, the decisions are never right or wrong, it's just probably best to get the group views, a consensus view of what everyone feels about the subject of a difficult case. Dr Marsh (13-3)

INTRODUCTION

One of the main aims of this research project was to gain insight into the way clinicians actually make ethical decisions.[152] The previous chapter discussed how the informants thought about the ethical issues that arose in their practice and what these troubling and difficult ethical issues were. This chapter will examine how the informants approached and dealt with controversial ethical issues in their practice. After seeing what happens in practice I go on to develop a theory of consensus based on the data and the ethical literature.

First, I will argue that the attempt to formulate some form of consensus was a central aim of the informants' decision-making processes. Second, ways the clinicians managed disagreement in practice will be discussed, looking at what happened if agreement could not be reached. I then use my findings to refine a theory of consensus, which is more closely tailored to the specific situation. Finally, a deviant case to this analysis will be considered as a way of showing that the consensus model of decision-making was the dominant way that the informants conceptualised their approach to ethical decision-making. An evaluation and critique of this form of decision-making will be undertaken in the

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[152] Or rather, how they account for their ethical decision-making. See Chapter Four for a discussion of this point.

next chapter, the purpose of the current chapter is to demonstrate how the

clinicians actually made ethical decisions.

HOW THEY MADE DECISIONS

Traditionally many ethical theories have put the locus of decision-making on to the

individual.[153] This model of how ethical decisions are made is that of the

autonomous individual thinking through a moral problem and reaching a decision

they believe to be right. This study found that in infertility practice this was rarely

the case. A predominant theme in the data was that ethical decisions were, largely,

seen as the kind of decision that should be made by a group of people reaching some

form of consensus. Twenty-one of the twenty-two informants said that they would

not take a decision on a difficult case alone and would want to involve colleagues in

the making of that decision. Ethical decisions were best taken by a group or number

of colleagues, a single individual making such a decision would be seen as highly

inappropriate – that was not how ethical decision-making was approached by the

informants.

The involvement of colleagues in difficult decisions did not generally take place in

an ad hoc, informal way dependent on the individual doctor, but was part of a

formalised system. Most infertility treatment is provided by relatively small clinics

or units,[154] and even the largest units in urban teaching hospitals may only have three

or four consultants working in them. Every unit that was visited had a regular unit

meeting where all members of staff (doctors, nurses, embryologists and in most cases

the counsellors) would discuss any problematic cases. This was the first port of call

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[153] See Chapter Two for a discussion of this criticism of bioethics.
[154] These terms will be used interchangeably.

for most of the units to discuss ethically difficult cases. The majority of the units also had access to some form of CEC and used them for a number of reasons to support and aid their decision-making.[155] Only one unit, Clinic 5, which had a CEC specifically set up for their unit, saw this committee as the main forum where ethical cases were discussed. Dr Brown said:

> I mean if I saw a patient in my clinic on Thursday who I thought there was an ethical issue round this patient being treated here, then I would take that to the Ethics Committee, I wouldn't go and ask my colleagues about it, because all you'll get is a number of, you'll get polarised views one way or the other. (2-71)

Dr Urban, who also worked in this unit, agreed with this and thought that ethical issues should be discussed in the CEC rather than the general clinic meeting. However, the CEC decisions were then discussed at the Unit meeting to make sure the rest of the team were happy with them.

Most informants, however, thought that the clinic meeting was the most useful place to discuss ethical issues and generally this was where decisions were taken and cases resolved. Hence, these meetings were not just discussion forums – they were places where decisions were actually made. Dr Francis outlined how her unit approached decision-making and 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, anybody, that anybody feels, any patient that we feel is slightly, with whatever issue they go to that meeting, and we discuss it between us. Or, god, I'm trying to think of things, people who we're not sure of, you know, about cohabitation, we basically bring it all together, and we would all decide. Or if there's somebody that we thought oh actually shall we give them a go at IVF…. and we would very much come to a kind of unit decision really. (6-39)

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[155] See Chapter Nine for a detailed discussion of the use of ethics committees. In this Chapter the underlying principles of their ethical decision-making will be considered incorporating both the informants use of unit meetings and CEC.

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. (15-6)

Dr Quest:

> I think that in all ethical problems it's not good to make the decision alone, you need to have meetings, committees or whatever, but you need to have at least five or six different opinions. (17-33)

Dr Marsh:

> We try and discuss as much as possible if there are sticky cases between ourselves at our meetings that we hold [weekly], or on a regular basis, to take things forward, see what other people feel about the same situation. (13-3)

Dr Jenson:

> I think fertility and ethics, we are dealing with probably the most important part of medicine, in my view, or ethically important part of medicine and I don't think it can be approached by individuals, it has to be a group thing because we all have your 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. (10-68)

The decision to refuse treatment to a couple or individual was almost always taken by a unit 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.' (1-76) Dr Jenson said if treatment were refused the letter would come from the unit rather than one individual. Dr Novack also made this point:

> If it's a positive response I won't belabour the thing, I just say sure, we'll treat you. If it's a negative response I would usually say to them, and have this in writing, that your case was discussed at a meeting of our unit, present at which were - and I won't list the names but I'll say X number of doctors, nurses or whatever, and this is our decision, and you have a right to appeal if you like. (14-13)

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. (10-37)

It was not only doctors who were involved in making difficult or contentious

decisions. There was a strong emphasis on the importance of involving other

professions and disciplines so that decisions were not made solely by doctors but

by members of a multi-disciplinary team.[156] Twenty of the informants thought

that getting the views of other professions (rather than just medics) was very

important when making difficult decisions. Dr Percy made this point very

clearly:

> I mean I certainly think the first port of call should always be the
> multidisciplinary team, and more and more medicine now is multidisciplinary
> which, you know, the opinion of our nurses and HCAs [health care assistants]
> to me is just as important as the consultant who's been here for a long
> time….So I think it is appropriate that we should seek opinions from other,
> you know, not just doctors talking to doctors, I think you've got to involve
> other people. And also, especially with things like fertility, obstetrics, nurses
> and midwives are independent practitioners and they're going to be involved
> in the care in just the same way as another doctor is, so they have a right to be
> able to say I'm happy with this or I'm not happy with it. (16-46)

Counsellors were thought to be particularly important as they often had more

contact with the patients and were able to shed light on areas that the doctors had

not been able to uncover. Drs Grant, Jenson, and Evens specifically mentioned

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[156] It is always the consultant who takes the decision, who is 'responsible' (legally at least) for that
decision (see discussion later in this chapter). However, the point here is that decisions were discussed
with the whole health care team and the input of other professions into the decision-making process
was seen as important.

the benefits of working in and as a team. Dr Grant indicated the benefits of

having a widely discussed decision:

> Obviously we've got lay[157] people as well, and you learn from non-medical
> people how to approach a case, or why sometimes you as a doctor could be
> advised by certain things. Other lay people in the committee could help you
> to look at things from a different perspective and different side. And I believe
> personally in teamwork, and teamwork in this case is then all members of the
> team have something to say, have a say, and in the ethics committee it's not
> one person deciding but just a group reaching a conclusion. (7-25)

Dr Jenson:

> so the counsellors' opinions are incredibly important, the embryologists and
> nurses. The nurses who see patients on a day-to-day basis are incredibly
> important because they know far more than me. Patients come in and see the
> man in the suit in best behaviour but actually will unload things to the nurses
> who they feel more at home with. And that's what I like about this type of
> medicine is that you do have a group of people that you can sit down and
> bounce ideas off and you're not alone. (10-40)

Dr Evens, in answering a question on how she made ethical decisions, said:

> Looking at case conferences in relation to a particular couple and trying to
> look at it from different angles, and obviously getting the background of
> social workers' views, counsellors' views, psychiatrists' views, physicians'
> views, across the board.(5-73)

Dr Novack stressed that in his unit everyone felt they could play a part in decision-

making and that they worked in a very inclusive environment:

> We're actually quite a close-knit clinic even though we're a very big clinic.
> … We're quite a social clinic, we go out with the team a lot, so there's
> always somebody either going off on maternity leave or leave, coming and
> going, whatever, a big Christmas do, various do's throughout the year. So
> we're on first name terms with everybody, there's a hierarchy but not an
> overt hierarchy, and I think the atmosphere amongst the staff is reasonably
> informal. (14-57)

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[157] Dr Grant is referring here to lay people on his CEC.

High levels of agreement

The majority of informants gave accounts of the high levels of agreement between members of the team.[158] Dr Orben, for instance, who had been working in the area of infertility for 24 years and said:

> But, as I say, we reach a consensus view as to the way forward.
>
> **Has it ever happened that there's been a difficulty in reaching that consensus?**
>
> Very infrequently. One or two cases in, and how long have we been doing it here? Well, I think I started my infertility practice in, I came in '85 and I think within a year it was up and running. So in 20 years of practice here, probably the number of cases where we've had to really scratch our heads and think you could count on the fingers on one hand. (15-7)

Dr Iniman said when talking about if she and her colleagues ever disagreed over particular cases:

> Well, it wouldn't be very frequent. I can only think of one example, which was a transsexual couple, but I'm struggling to remember the details actually. (9-53)

Dr Robin, who had been working in her clinic for two years said:

> I mean within the past two years I don't think there's ever been a situation where we disagreed. (18-12)

And Dr Novack, who was the head of this clinic, reiterated this view:

> Yes. I mean I don't know if we have - I'm trying to think. We don't tend to have major disagreements. [Mobile phone interruption]. Sorry, how do we manage disagreements? Well, we talk things through. As I said, I don't think we have any really. (14-26)

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[158] See Chapter Six for the discussion of settled morality that could account for these levels of agreement.

Dr Kilm made the point that practice is 'probably fairly standard' across units,[159] so the consensus could extend beyond the individual clinic to infertility practice in general:

> I don't imagine that there are such major significant differences between units. I'd be surprised if there were. Because I think that's the thing, that's probably because, that's probably the thing that comes out when you go to meetings and you all get together and you hear everyone has the same sorts of problems and they're dealing with the same sorts of issues, and they're probably more or less dealing with them in fairly similar ways. (11-51)

When asked to account for this level of agreement, informants gave the following responses. Dr Grant thought there was a professional construction of common views:

> I think we tend to agree on most of the ethical issues…

> So, I mean you said most of the time you agree, why do you think you agree?

> Well we agree because I think we've got, well I think the main reason why we agree is because in the UK the HFEA regulates the fertility treatment, and so we've got some sort of standard guidelines. The other reason, because I think we all are from the same background in terms of accepting patients for treatment and we all agree on the same principles. (7-35)

Here Dr Grant explicitly said that he thought that he and his colleagues shared the same principles and that this formed the basis for their high levels of agreement.[160] He went on to say, 'And, as I say, what makes it easier is the fact that HFEA has got the standard of practice or a code of practice which we all look at.' (7-39) Dr Robin also talked about 'HFEA ethics' as something that could be referred to and used to inform decisions (18-17).

Informants also looked to colleagues and others in their profession to formulate their views.

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[159] It must be noted, however, that as discussed in Chapter Six practice is not always the same across different units, i.e. some units did not treat same sex-couples.

[160] See discussion in Chapter Eight on the values of the medical profession.

Dr Evens, in answering a question on how she made ethical decisions, said:

> Well, it's experience in actually looking at other people in the profession when you're going to meetings or to HFEA conferences or doing inspections at the HFEA, and seeing how things are managed, and actually looking at case conferences in relation to a particular couples. (5-73)

This pointed to how she went about forming her own opinions on a particular case and how she looked to other units and opinions expressed at conferences to gauge the 'general view' or approach to a particular issues. The informants used the clinic meetings and discussions to help them formulate their opinions and responses to particular cases and often their opinions could be influenced and changed by discussions at the meetings. Dr Grant made this point:

> Obviously, as often happens, you vote for it and see what the people think is the best thing. But I must say that I've never been involved in any case where there was not unanimity, so even people, or perhaps myself when you're not quite convinced about one aspect of what's going to happen or which kind of decision you have to make, perhaps thinking about it and listening to other people have made me change my mind. (7-26)

Dr Percy said:

> I think it's very useful. I think it's very useful and I think, I mean I've certainly found myself, I mean I think of myself as being quite broad minded but I'm sometimes surprised when I'm actually talking about things. I think gosh, actually that's quite narrow minded, or I hadn't considered it in that viewpoint and, yes, now I see you say that, yes, actually maybe the decision I made was wrong and I would rather change my mind on that one. So I find talking about things quite helpful. I think it clarifies what the issues are, because I think very often with these cases, the issues are more than just what meets the eye. (16-42)

Dr Quest put the point like this:

> Yes, yes. But as I said, again, it's important to have this clinic or team meetings, because you can have different points of view. So in order to make the right decision you need to have all the points of view, to take all the views and make the right decision. So it's - if you take the decision alone, I think most of the time you're going to fail. You need to have all the points, you need to see the black,

the white, the pink, the green and the red, all the colours in order to make the right decision. (17-33)

Informants looked to colleagues to check that their ethical views were 'acceptable'.

Dr Tarn also stressed the importance of finding out the consensus on ethical problems:

> I think the basis of my ethical outlook is if I do have absolutely clear views on any one specific situation, I would certainly see what other people think about it before imparting my views. My views are that on any one ethical problem, to see whether I was the odd one out or the odd one or within the group. But within that, when you talk to people, some will disagree with what you say, but they might be the odd one out, it's others, you need to decide what is the reasonable and what is the normal ethical approach to this, or the sensible ethical approach to this particular issue, without being an extremist or maverick or a fascist or, you know. (20-32)

Dr Percy also said:

> Because again, it's all about getting - I suppose really, most of the discussion is actually about making sure you've got a sensible considered majority opinion, that a sensible considered majority of people think that we should not be treating or we should be treating. I guess it's sort of safety in numbers and reassuring yourself that your line of thinking is not way out there and that this is acceptable. I mean let's face it, most things we do in our society are based on laws and laws are passed by a majority. That's sort of how we work in our society, so I think it's a good way of doing it. (16-40)

Thus, the clinic meetings and CECs were the ways the informants used not only to check and validate their opinions, but also as ways of developing and constructing their responses to a particular situation. As Dr Marsh put it, 'And yes, the decisions are never right or wrong, it's just probably best to get the group views, a consensus view of what everyone feels about the subject of a difficult case.' (13-3)

MANAGING DISAGREEMENT

While the dominant theme in the way that the informants talked about making ethical decisions was that they generally managed to reach an agreement, that a

consensus could be formulated, some informants mentioned disagreements

taking place in the unit meetings and thus a consensus could not be reached. For

example, disagreement over a particular case was a reason why some informants

said that they used their CEC. Dr Marsh gave 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, obviously, our effects are very grave,
> you can seek help from the local ethical committees, or every institution has got
> its ethical committee, or you can discuss it with an ethicist just to tease out the
> …(13-10)

In the same unit Dr Iniman also stated that if it was a 'moot' decision they would

take it to the ethics group (9-35).[161]

The main 'tactic' employed if a consensus of opinion could not be reached over a

particular case was conscientious objection. This was used, often as a last resort, to

manage disagreement. There is a conscientious objection clause in the 1990 Act. 'No

person who has a conscientious objection to participating in any activity governed by

this Act shall be under any duty, however arising, to do so.' (Section 38 (1)). How

far this extends and what activities can be covered by this clause is unclear (Morgan

& Lee, 1990). Riley argues that it would not cover doctors refusing to treat particular

individuals or patient groups on the grounds of personal prejudice (2007:88).

However, the informants used conscientious objection to justify opting out of

treating particular cases and individuals for reasons that might be construed as

prejudicial.

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[161] See Chapter Nine for a detailed discussion of the use of CECs.

Dr Iniman recounted one of few times she could remember having any

disagreement with colleagues about a treatment decision:

> I can only think of one example, which was a transsexual couple, but I'm struggling to remember the details actually.[162] Anyway, I wasn't at all happy about it but some of my colleagues were. So we kind of amicably decided that people who weren't happy didn't need to have any involvement in that particular couple's treatment. I don't think it came through in the end, but that's the only example I can think of where my feelings differed from some of the other people within the department.
>
> **So you can have a sort of opt, there is enough of you to opt out if there is a situation where …**
>
> Yes. (9-55)

Here the substance of the disagreement was not resolved, Dr Iniman did not

change her mind nor was she persuaded of the morality of taking on that

particular case. Rather, it was managed in practice by Dr Iniman opting out of

treating that couple. Dr Iniman's unit was a relatively big one and it was possible

for a doctor to opt out of a particular treatment if they were unhappy about it. In

smaller units this opting out took a different form. Dr Case for instance felt very

strongly that he did not agree with treating female same-sex couples, and

discussed how they approached the decision over whether to treat such couples.

> **I mean because presumably there's small numbers of staff here, its a relatively small clinic? Do you all sit round and discuss issues?**
>
> It is relatively small. Yes, we do discuss and we've asked each other, you know, how do you feel about treating in this situation and that situation, and we respect one another's views really. If we were a larger clinic with a larger number of staff, where some might express an objection on conscience grounds or ethical grounds for a particular treatment situation you've got another member of staff you can call on who would be happy. So you can absorb that sort of difference of opinion. In a small clinic you can't really do that very well. (3-9)

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[162] I have left out the details of this case, as Dr Iniman said it was a unique case and therefore any details might identify the couple. Further, the details of the case are not crucial for the point I am making here.

He went on to say that although the other clinician who worked in his unit was happy to treat same-sex couples, the unit had decided not to treat. The reasons for this were: first, such a small unit could not offer appropriate support to such a couple with effectively 50% of the clinical staff; and second, 'but partly because they respect my position on it and they feel that we want to stay together as a clinic and work together with the same outlook.' (3-35) Here some sense of a unit ethos was invoked:[163] that it is important to maintain a team approach to care. Despite feeling strongly about not treating same-sex couples Dr Case thought that, 'if you feel uncomfortable about the situation in which we're being asked to treat it's better if they move on to another centre that would say yes and they feel okay about it.' (3-72) This was a common approach; Dr Jenson also made this point:

> if we say we don't feel comfortable about treating you and we will refer you on to A N Other and always giving people an option to try somewhere else. (10-36)

This reflects the view that these kind of moral judgements are seen as personal ones. That is, the clinicians are not saying that the couple or person should not be treated at all, or that a particular procedure should never be carried out – they are saying that they do not want to do it themselves. This largely locates their morality as a personal one of what *they* will or won't do, rather than what should be done by the wider community of medics. This embodies the view that they do not have the 'right' to impose that view on others (either their colleagues or patients).[164] The use of conscientious objection as a tool for managing clinical disagreements could also be attributable to the informants' backgrounds in gynaecology, where there is perhaps the archetypal example of conscientious

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[163] See Chapter Six for a discussion of the clinic ethos.
[164] This point will be developed Chapter Eight.

objection in not performing abortions. Conscientious objection gave a practical

solution to intractable cases of disagreement. Dr Adams sums this point up when

he said:

> Yes, it's a bit like abortionists isn't it. Not all gynaecologists have to do
> abortions, so we don't force anybody to do anything they don't want to
> do. (1-50)

It must be stressed that disagreement over ethical issues was not generally

mentioned by the informants and although conscientious objection was seen as a

way of managing disputes, in practice is was not something that happened

regularly.[165] Dr Novack, while mentioning conscientious objection as a possible

way of managing different views in practice, said:

> And, of course, every member of the team, if they strongly disagree with
> a particular treatment plan, are not obliged to be involved, engaged in the
> treatment of that couple, so they have the right not to. Although actually
> we've never really had those sorts of issues.

> **Right, but it's..**

> Yes, we've never had anybody say no, I'm not going to be involved in the
> treatment of the couple. (14-24)

Therefore, although conscientious objection was a possible option when agreement

could not be reached, it was not one that, in practice, was often used.

Conscientious objection was a tactic for managing disagreement in the clinic and for

certain types of situations it was successful. If a doctor did not want to treat a certain

group, as in the case of Dr Case, he could get his clinic to agree that they would not

treat as a matter of clinic policy. In a way the whole clinic conscientiously objects.

Dr Case's ethical view on treatment of same-sex couples was respected. In contrast,

in a situation where a doctor was happy to treat a particular group and their

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[165] See discussion above on 'high levels of agreement'.

colleagues disagreed there could be a situation where someone's views had to be subjugated. Dr Grant, who was happy to treat same-sex couples was not able, due to his clinic as a whole not wishing to treat, to treat that group, his views in this sense were not respect. However, Dr Grant he did not seen unduly concerned about this:

> **But you'll wait until your colleagues, until everyone in your unit agrees before doing it?**
>
> Yes, I think, I believe in the teamwork and team decisions so we cannot take different decisions on different patients.
>
> **If someone else in the unit wasn't happy with treating couples like that, you would go along with that decision, you'd be happy to abide by that?**
>
> Yes until, as I say, until a unanimous decision is taken, yes. (7-74)

A similar situations happened with Dr Vance quoted below (22-57), however he was also happy to accept the majority view and move on. Thus, this way of managing disagreement allowed people to opt out of an activity if they felt sufficiently strongly but did not necessarily enable people to positively do something if they wished.

GROUP DYNAMICS

This portrayal of ethical decision-making being made by the group and on the general basis of consensus is possibly a representation of an ideal type of decision-making. As discussed in Chapter Four, the data is seen as the informants' account of their practice, how they represent and account for their actions. As I did not do any observations in the clinics it is not possible to compare this to what 'really' happened. However, interviewing informants from the same clinic enabled me to gain a sense of how that clinic made ethical decisions. The informants discussed how sometimes a decision might be reached that was not a consensus of the whole group. Group dynamics could mean that everyone's opinion was not always heard or taken

into account. Clinic meetings were not perfect democracies where all members debated freely and all views were equally respected. Power relations within the clinics, therefore, 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.' (12-16).

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

> It's an interesting one because team meetings, sometimes it could be a question of who speaks the loudest, and we do have one or two sort of quite vocal self-assured young embryologists, for example, who may not necessarily have lived life broadly or have a feeling of the ways of the world, and are not necessarily seeing patients in clinics in the way that I do day to day, and the clinicians and nurses and, of course, counsellors are dealing with all sorts of scenarios. And you can have people who are little bit quiet who don't say anything. (14-23).

The structure of medical responsibility also meant that the final decision would always have to be taken by a particular consultant and this point came out very forcibly when interviewing sub-speciality trainees at Clinic Four (Drs Quest, Robin, and Street). These doctors said that as trainees they would not take any decisions themselves. However, their clinic meetings were a place where a process of dialogue took place, a process of consensus making, and the consultant would take the decision on the basis of that discussion. 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.' (14-23) So, although the consultant made the actual decision, that decision would be taken on the basis of the deliberations that took place in the meeting and with the agreement of the team. Dr Jenson sums up this point when he said:

> But I know that an inclusive unit where everybody's opinion is equal is a much happier unit than one where somebody saying you do as I say because I'm in

charge. Although I don't like management by a committee. Eventually the buck has to stop with somebody, but if people feel included in the decision-making process it works a lot better, and that's simple management I think. (10-47)

Therefore, as far as possible there was an emphasis on group rather than individual decisions. The informants, generally, saw their ethical decision-making as something that was best tackled by a group. 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 unit rather than the individual.

THEORIES OF CONSENSUS

Having considered how the informants made and approached ethical decisions, a definition of consensus can be formulated – one that is based on how the informants, implicitly, defined their notion of consensus decision-making and drawing on the ethical literature in this area. This is using the data to develop ethical theory, as discussed in Chapter Three, a close attention to actual practice can aid in refining and developing ethical theory and principles. Philosophical discussions can help clarify meanings, terminology and advance important distinctions between different forms of consensus decision-making. The data can not only show *how* in practice consensus decision-making was seen by the informants but also elucidate these philosophical distinctions, to see if they are meaningful in practice and point out other facets and aspects that may be lacking in the theory. Hence, this theory of consensus is developed not solely by considering the philosophical literature on the subject but also by examining how the notion is used and formulated in practice.

The role consensus plays in moral deliberations has increasingly become a topic of discussion for bioethicists, with John Rawl's *A Theory of Justice* bringing the concept of consensus into general debate (Hester, 2002). There have been various edited collections on the role of consensus in bioethics (Ten Have & Sass, 1998. Bayertz, 1994) and special editions of journals (*Journal of Medicine & Philosophy*, 1991. *Cambridge Quarterly of Healthcare Ethics*, 2002). Moreno has noted that, 'appeals to consensus are so common, and the relations embodied in consensus so ubiquitous, that we have become largely inured to them.' (1995:3) However, there is no consensus over definitions of consensus (Engelhardt, 1994. Trotter, 2002). I shall first outline the debate in the bioethics literature about definitions of consensus and then advance a definition that is based on the literature and the way the informants in this study made their ethical decisions. Whether this is an ethically acceptable way of making such decisions will be discussed in the next chapter.

Consensus as a process

A key issue in the philosophical debate over definitions of consensus decision-making is whether consensus is seen as a process (Moreno, 1995. Jennings, 1991. Spicker, 1998) or as a resting state of opinion (Caws, 1991. Trotter, 2002). For the latter position consensus is reached when a decision is made that all agree with and the focus is on the decision reached, the product of the deliberations. Caws argues that consensus involves, 'something more than acquiescence or compromise,' therefore consensus should involve, 'agreement of opinion on the part of all concerned.' (1991:378) The focus for these accounts is agreement over the substantive ethical issue, the product of the deliberation.

In the process accounts, rather than everyone having to agree to a substantive ethical conclusion, a resting state of opinion, lack of serious dissent is enough to call something a consensus (Moreno, 1995). This account of consensus attends just as much to the *process* of decision-making as the *product* of that deliberation. Process and outcome are seen as part and parcel of the same entity. Moreno argues that making a distinction between the process (the way the decision was made) and the product (the actual decision) is unwarranted and such a distinction, 'is no longer taken to be decisive in contemporary philosophy….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.' (1995:44) Therefore, in Moreno's account the process of decision-making, the way the decision was made, is inextricably linked to whether the decision is thought to be acceptable. For instance, in public life decisions are often defended on the grounds that they were made in an unbiased way[166] and if the way that the decision was made was thought to be corrupted in some way then, 'this is widely taken as a prima facie reason to think that the result of that process is likely to erroneous in some way.' (Moreno, 1995:44)

This notion of consensus as a process has been criticised,[167] the main issue is that it is contended that there is a difference between procedural and substantive consensus and what is at the heart of debates over consensus is the means and possibilities of getting a consensus over substantive issues.[168] Caws makes much of the distinction between procedural and substantive consensus, arguing that the latter is what is

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[166] This is something the informants often referred to; see discussion on impartiality in Chapter Eight.
[167] See also Trotter (2002).
[168] There is a large literature on consensual rationality and how groups make decisions that cannot be considered here. See Caws (1991) for a broad overview of the debate.

important and this is what marks a 'genuine' form of consensus. 'If the process is to have any chance of converging there should form the beginning be *some* degree of substantive consensus as well. (1991:382)

This account of the importance of a process of consensus decision-making was something that was mirrored in the data. The informants were, arguably, concerned about the *process* rather than the *product*, the outcome of the deliberations. They did not argue that what they had decided was incontrovertibly 'right', but that they had followed an appropriate process of decision-making. Moreno makes this point, '[t]he point of ethical deliberation is not to reach consensus but to attain a desirable end, an end that settles controversy without further disagreement.' (Moreno, 1988:428) For the informants a consistent, transparent and, generally, uniform process was the key to making 'good' and 'acceptable' ethical decisions.[169] The informants did not claim that the decisions they made were 'right' in the sense of invoking some objective notion of what a good decision should be based on,[170] they saw their decisions as the best that could be done in the circumstances. In this sense they were not focussed on the end product, the actual decision itself; rather, the focus was on the process used to reach that decision. This can be seen in the data when the informants wanted to check their ethical opinions were in line with others and used meetings to formulate and refine their opinions. In this sense their ethical decisions were often formed by the process of consensus rather than them bringing preconceived ethical stances to the table.

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[169] See Slowther, *et al* who quote a chairman of a CEC who stresses the importance of procedural aspects in ethical debate, 'We didn't get ethics training, lets be clear about that, what we got was a procedure a community of inquiry.' (2001:41)
[170] Such a notion could be an ethical theory, applying certain principles or even adopting a particular religious doctrine.

It is this process that, using Moreno's analysis, can be seen to legitimise the decision for the informants. The process and the product of decision-making are inextricably linked. It is the due process, the taking of the decision out of the hands of one clinician and making it a clinic or CEC decision that gave such decisions their legitimacy. Thus, the informants sought consensus over what to do (in a particular situation) rather than a consensus on underlying ethical principles or theories that might justify the action.[171]

Consensus and compromise

This raises the issue of whether the informants reached a consensus or a compromise and the distinction between these two terms has also been extensively discussed in the literature. In some cases, it could be argued, that it would be more accurate to say the clinicians reached a compromise over how to act rather than an actual consensus on an issue. For instance, Dr Vance gave the example of a case where he did not agree with the majority decision and therefore had to compromise and go along with that decision.

> But I'll tell you one that recently happened that shocked me. We had a woman who wanted to use donor eggs and she was, I think she was 54, and I couldn't get my lot to do it at all for love nor money. I thought they were mean and surly actually.
>
> **Right. And did you do it then?**
>
> They said no.
>
> **So you went with them?**
>
> Oh I had no choice. I can't make them do anything. I can only be convincing. (22-57)

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[171] This can be seen to mirror the account given by Jonsen & Toulin (1988) of the deliberations of a national commission. The participants could agree on specific policies, but not the principles that guided them.

The main focus for the informants was not on whether everyone could reach

agreement on an ethical issue, but rather on the ability to make a decision that all the

team could either support or that could be managed in practice. Dr Marsh said:

> So it does help when you have a consensus opinion that at least it's a
> democratic kind of decision and you are giving the couple a chance, based on
> not what you feel but based on what the majority feel. Based on the fact that
> although you might not be giving them the treatment yourself because you
> have some reservations, your colleague would, so 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. (13-6)

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 view. Dr Kilm, for instance 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? (11-48)

He went on to say:

> So I think it's just appreciating other people who may have different views from
> their own and, to a certain degree, they have to be respected even if you don't, you
> just have to agree to disagree. (11-46)

Here a distinction can be made between agreeing with the substantive ethical

decision and agreeing with the practical course of action. For instance, in Dr Grant's

case, discussed above, he thought that offering treatment to same-sex couples was

ethically acceptable. However, others in his unit did not, so there was a unit

agreement that such couples would not be treated. 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. So for Dr Kilm (quoted above 11-46), Dr Grant and Dr Marsh they and their colleagues did not actually have to agree on the substantive ethical issues they just had to agree over what should be done in practice. The resolution of the disagreement was a practical solution in which a course of action was proposed that could be generally accepted. This is, in effect, a consensus over a compromise. This type of compromise was a group decision on how to solve a practical problem. This compromise did not involve changing anyone's ethical views, it just involved an agreement over what to do and in certain situation the informants (as exemplified by Dr Marsh in quote 13-6) would accept and act on another's ethical decision even when they disagreed with it.[172] Thus, it was the *process* of this group decision-making on ethical issues that was more important to the informants than whether they reached a genuine agreement on a substantive ethical issue.

There is much made in the literature of the distinction between consensus and compromise and it is often argued that consensus involves, 'something more than acquiescence or compromise.' (Caws,1991:379). Moreno argues that the distinction between consensus and compromise, 'is critical in social practice' (1995:46). Therefore, it could be argued that the informants did not actually reach a consensus over what to do – rather they compromised so that they could agree what to do in practice. Some clinicians had to put aside their ethical views in order that practical decisions could be made. Whose views get accepted and who has to compromise

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[172] In certain cases, for others they used conscientious objection (see above).

could arguably become a 'political' issue (Engelhardt,2002) and clinic politics could be the defining factor rather than ethical acceptability.[173]

However, although there is a useful distinction to be made between the two concepts. In this study, the issue was what course of action to take, not how can we reach agreement over ethical matters and further, informants thought that it was not their place to pronounce what was right or wrong.[174] Therefore, I would argue that their acceptance of other's practical solutions to the issue at hand can be seen as a form of consensus. Further, there was a mechanism for clinicians to use if they felt that they could not 'go along' with a decision – when even this form of consensus could not be reached, there was the final recourse to conscientious objection as a means of managing disagreement in practice.

On the basis of the data from this study, consensus can be defined along the lines of Moreno's conception, as a lack of serious dissent, a group process that comes to a decision that all the group can support and implement. This might not be agreement over substantive ethical issues, but an agreement over what to do, what course of action to take. For Moreno's process orientated account of consensus, 'the empirical background of consensus expressed in terms of actual social practices is all the more important.' (1995:103) This study is an attempt to elucidate the actual decision-making practices of the informants to adjudicate their acceptability.

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[173] See Chapter Eight for a discussion of this critique of consensus decision-making.
[174] See the discussion of impartiality in Chapter Eight on the informants' views on the unacceptability of imposing their own ethical views on their patients.

A DEVIANT CASE

The predominant way the informants talked about making ethical decisions was as a group process designed to produce a consensus on the way forward. However, one informant, Dr Lovate did not give an account of consensus decision-making that conformed to this analysis and his account can be seen as a negative instance of the general hypothesis.

The use of negative instances or deviant cases has been argued to be an important tool for improving the interpretation of qualitative research accounts (Silverman, 1993; Becker, 1998; Seale, 1999).[175] The methodology in this section draws on Seale's study 'Living alone towards the end of life.' (1996) This study interviewed friends, relatives and others who knew people who had lived alone in the last year of their lives. Seale argues that the majority of his informants were concerned to demonstrate their moral identities to the interviewer by justifying their behaviour and actions, but there were five informants who gave accounts that did not conform to this analysis. Seale argues that the consideration of these deviant cases could be instructive:

> I felt these apparently deviant cases, where speakers appeared to locate themselves outside the ideal of accompaniment, were satisfactorily explained as aberrations. The speakers in each instance successfully demonstrated their moral adequacy by alternative means. In doing this, they showed an orientation towards the event as deviant from normal behaviour, requiring explanation, so strengthening the general case that accompaniment of dying people is perceived as a generally desirable norm. (1999:80)

Therefore, these deviant cases give additional support for his theory of moral adequacy (Seale, 1999:78).

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[175] See Chapter Four for a detailed consideration of this method of aiding the validity of qualitative research.

Dr Lovate was the twelfth doctor interviewed and it was just over halfway in the data collection. The analysis of the data that I had conducted before this interview had not given the process of consensus in making ethical decisions any pre-eminence and it was the subsequent analysis of his transcript that prompted thinking in these terms. Dr Lovate did not see the process of consensual decision-making as a useful way of making ethical decisions and this highlighted that the other informants *had* used it in this way. By drawing attention to the problems he thought were created by his colleagues using a consensual decision-making processes, he threw the other accounts into relief. His account suggested that consensual decision-making was the 'dominant model' of ethical decision-making used in the infertility clinic.

Dr Lovate thought that decisions about how to treat and manage a patient should be taken by the individual doctor dealing with them. When asked about how he made ethical decisions Dr Lovate gave the following account:

> I'm interested in the patients. I'm sorry, the patient is my patient and I…I'm a damned good doctor, I know that I'm a good doctor, I know that I give my patients more than what's called of me….So, I know that I have the patient's interest at heart, and just knowing that gives me strength to do what I want to do. But I'm shackled, you know, I can't….And part of the reason I'm pleased that I'm in the twilight of my career is that I'm so bound down and my practice is inhibited by the rules that I have to keep by. And the thing that really upsets me is that I don't believe it's in the interest of the patient. I think a lot of what's happening now is not in the interest of the patient, because it takes the initiative, you know, one's not allowed to have initiative any more because there are guidelines, you've got to stick by the guidelines. And I think that the patient loses out, and that's really what upsets me. So, when you say moral and ethical issues, I always spend a lot of time discussing with the patient what I intend doing. I'm one of the few doctors who on my private consent form in my private practice, when it comes to induction of ovulation I have these are the potential complications, and the sixth one is death. And I actually write on there that patients have died from this treatment, so I tell them everything….So I spend a lot of time explaining in great detail to the patient what I intend doing, what the potential complications are, and if the patient hears that, and then I get consent, you know, written consent, then I would like to treat the patient the way I think that that particular patient expects.(12-31)

His more individual approach to patient care was reflected in his unhappiness with the increasing amount of guidelines in infertility practice. 'You see, I find that I would prefer to have no policy at all. I'd rather we had no policy and that we raised all these issues and discussed it on a personal individual basis, because - but, of course, if you do that then you can be accused of favouritism or, you know, you like this couple so you're allowing them to have a third.' (12-25) Although he recognised that having no policies might lead to a clinician being accused of partiality, he thought that each case should be decided purely on its merits. Guidelines, for Dr Lovate, interfered with his preferred way of making ethical decisions which was, for him, a focus on the particular patient by an individual doctor without outside interference. He thought decisions were best taken by the individual doctor not a unit meeting.

Dr Lovate gave an example to illustrate these points. The amount of super-ovulatory drugs to administer and then how many embryos to transfer back are currently contentious areas in infertility practice.[176] Dr Lovate said, 'I mean I am much more aggressive in my treatment of infertile patients in that I feel that it's important to get a pregnancy even at the expense of it being a multiple pregnancy.' (12-28)

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[176] See HFEA (2007) consultation document on single embryo transfer and Ledger (2007) for a consideration of lower doses in IVF treatment.

His unit, Clinic 2, had a policy on the prescribing levels for drugs:

> I mean for years I used to do battle. Vicky[177] is our, a senior nurse who, because if patients need ovulation induction or super-ovulation, the nurses actually do it, it's a nurse-led clinic, and I for years have said, "Look, when it comes to my patients, I want them to have three ampoules or two ampoules", but that went against the grain because what about the policy of the clinic, and how can Dr Lovate have a - so we used to have wild discussions in these meetings. But it was always settled amicably and I lost.   But I thought it was important to give my views, and there was no blood or anything like that, so its….(12-29)

Thus, for Dr Lovate having to abide by clinic policies and protocols interfered with his ethical decision-making – this should be done on the basis of acting in the best interests of one's patient, without recourse to outside influences.

Dr Lovate's deviant account can be argued to strengthen the analysis of consensual ethical decision-making. Dr Lovate, by drawing attention to his battles with colleagues over patient management and his views on general guidelines, positions himself as going against the grain of the prevailing ethos. In the end, he still had to abide by the clinics' policies and the decisions it made on the basis of a general consensus. So he still participated in the process of consensus decision-making, he just did not see it as a beneficial way of making such decision. Therefore, this account reinforces the analysis that making ethical decisions on the basis of consensus was, generally, seen as the most appropriate and useful way of approaching them in the infertility clinic.

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[177] This is a pseudonym.

CONCLUSION

This chapter has examined how the informants made and approached ethical decision-making in their everyday practice. I have agued that they used group processes to try and reach a consensus over how to handle difficult cases. The cases that were discussed in clinic meetings and CEC were those that were part of a controversial morality, where there was no generally agreed opinion on how to proceed. In these cases the informants had to find a way of managing such cases in practice. For the informants consensus decision-making gave them a consistent, transparent and, generally, uniform process that was the key to making 'good' and 'acceptable' ethical decisions. It is this process that could be seen to legitimise the decision. The process and the product of decision-making were inextricably linked for the informants. It was the due process, the taking of the decision out of the hands of one clinician and making it a clinic or CEC decision that gave such decisions their legitimacy. Thus, having explained how the informants made ethical decisions, it was possible to develop a theory of consensus by both examining how the notion was used and formulated in practice and considering the philosophical literature on the subject.

By focussing on the way that ethical decisions are actually made in practice, it is held that the process of decision-making is of importance as well as the actual decision itself. One of Moreno's key claims in *Deciding Together* (1995) is that, led by his formulation of naturalism, it is imperative to study social process of consensus formulation to see if these specific manifestations of consensus are morally acceptable. Therefore, social science and psychological research are needed to establish how well an actual consensus process functions, it is not a matter that can

be settled by abstract argument alone. This chapter is an attempt to do this, by examining a particular setting where consensus is used to make ethical decisions. As the social production of decisions becomes more important for bioethics alongside a concern for the actual decision itself and if we are to be confident in our ethical decisions, we need to have some understanding of the procedures that were used to make them. This can open up new arenas of inquiry for bioethics: the social production of decision-making.

The next chapter will look critically at consensus decision-making and consider whether it is a defensible way of making ethical decisions in the infertility clinic.

CHAPTER EIGHT

EVALUATING CONSENSUS DECISION-MAKING

Many forms of Government have been tried and will be tried in this world of sin and woe. No one pretends that democracy is perfect or all-wise. Indeed, it has been said that democracy is the worst form of government except for all those other forms that have been tried from time to time. Winston Churchill, 1947.

INTRODUCTION

Having discussed how the clinicians in this study approached and made ethical decisions, it is now relevant to ask whether this is a good way of making such decisions. This chapter will examine the criticisms that have been levied at the use of consensus as a way of making ethical decisions. The concern in this chapter is to consider whether critiques of consensus decision-making are pertinent in the infertility clinic. From the perspective developed in this thesis, this judgment cannot be made abstractly it would depend on the context and the interaction between theory and practice. It will be concluded that, in this particular setting, consensus decision-making can be defended as an adequate way of making ethical decisions.

As stated before, generally ethical theories have treated the individual as the moral agent, who is responsible for his or her own decisions. Moral authority rests with the individual. But an account that locates moral authority with the group and seeks to base ethical decisions on the deliberations and outcomes of a group process and consensus confounds this traditional view of ethical agency. Seeing moral authority in this way is more often found in the realms of political philosophy where concern is focussed on the legitimacy of large group decisions and warrants for government. Correspondingly, there has been much debate and criticism over consensus as a basis

for the authority of political systems (Rawls, 1993.Trotter, 2006. Kukathas & Pettit, 1990) and of those who seek to construct a consensus to provide the basis for bioethical policy making (Engelhardt, 1996 & 2002. Turner, 2003a). However, there has been relatively little attention paid to the utility of consensus as a way of making small group decisions (Moreno, 1994,1995).

CRITICISMS OF CONSENSUS

The two main criticisms that have been levied against consensus decision-making in bioethics are:[178] first, that it can mask dissent, that it can be coercive – views outside the consensus are either suppressed or ignored; and second, consensus is actually not possible as there is a profound plurality of moral values and therefore a real consensus could never be brokered. These criticisms are related, as the greater the moral pluralism the more likely that there will be dissent and dissent of a more pernicious nature – making the issue of masking dissent more acute. The bulk of the chapter will be concerned with addressing the second criticism, as this strikes at the heart of the debate over the utility of consensus as a form of ethical decision-making.

Masking dissent

The concern that a process of consensual decision-making for bioethical issues can suppress, mask or not take into account dissenting views is a common one (Trotter, 2002. Engelhardt, 2002). 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. Just because the majority believe that something is morally acceptable does not, automatically, make it morally right. For

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[178] These criticisms are usually directed at committee decision-making such as CECs or government policy committees such as those often used in the US.

instance, if a particular society held that killing people from different ethnic groups was morally acceptable and this view was held by the majority of the population, we would not wish to simply endorse it solely on the grounds that it was the consensus of the majority. Thus, a common objection to the use of consensus as a decision-making tool is that it can revert to a form of crude utilitarianism, wherein majority opinion will hold sway with no other moral justification offered.[179] As Moreno notes, the moral tradition of Western culture has been to deny that consensus on moral issues has any particular validity (1995:5).[180]

A number of arguments can be put forward as to why, in this study, the criticism that consensus decision-making can mask dissent does not have any great purchase. First, there were, generally, high levels of agreement reported among the informants. The informants considered that disagreement over what to do in particular cases was the exception rather than the norm. Hence, it appeared that there were not many conflicting views to be masked – there was not a high level of dissent in the first place. The informants operated, largely, within a settled morality in which there was agreement about many courses of action.[181] Second, when there was dissent this was not masked. In cases where a workable solution could not be found (i.e. a compromise) the informants could use conscientious objection to enable the dissenter to opt out of being involved in the treatment. Thus, no one was forced to act in a way they felt was unethical, no one's moral values were subjugated by the majority.[182] However, there were some situations where it could be argued that dissent was

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[179] See debates over this in Smart & Williams (1973).
[180] See also Ten Have & Sass (1998) who discuss how consensus formation has not been a topic of concern in western philosophy.
[181] This is not to say that there was never any disagreement but that, generally, in their practice a consensus could be reached. See Chapter Seven for an elaboration of this.
[182] This point was discussed in Chapter Seven.

masked. If a doctor was happy to treat (see discussion of this in Chapter Seven) and the rest of the clinic was not then the doctor, in effect, was not able to treat. Two informants mentioned this, but neither of them felt that this was a profound limitation on their ability to practise in the way that they wished to.

Thus, the problem of masking of dissent was not an important issue in the infertility clinic as the informants were able, generally in their practice, to formulate a consensus on what they should do and to take the decisions 'as a group'. Of course this group decision may not reflect everyone's views and certain groups will have power imbalances and hierarchies that can affect decision-making.[183] Nevertheless there was an attempt to involve everyone in the decision and reach a decision through a deliberative process.

Moral pluralism and consensus

At the heart of the debate over the usefulness of consensus as a way of making ethical decisions is the worry that due to moral pluralism people will never be able to reach a consensus over ethical issues. This problem will now be considered and will be the main focus of this chapter.

Moral pluralism is often seen as a feature of modern life (Rawls, 1993. Parker, 2000), that is often referred to in debates over bioethics method (Strong, 1999) and there is a large and diverse literature on the subject from a variety of perspectives. For clarity I shall focus on Engelhardt's discussion of moral pluralism as he relates this to the possibilities of getting a consensus over ethical issues. Engelhardt's (1996)

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[183] See Chapter Seven, for a discussion of this.

account of moral pluralism and the issues it raises for modern society and the project

of bioethics has been very influential. In essence he argues that the secularisation of

western societies has had a profound effect on the ability of a society to institute any

widespread moral advice or policies.

> The Enlightenment hope of secular bioethics has gone aground on the postmodern recognition of competing moral narratives and accounts, among which choice in a principled fashion has not proved possible without begging the question of which moral vision should give guidance. The question has then become whose moral consensus should be recognized as the moral consensus to guide policy. (2002:10)

Thus, for Engelhardt, as there is no general moral vision or position any consensus

will only be partial to those who uphold the underlying position. Those who hold

another position will be left out of this consensus and what comes to be the

prevailing consensus is largely a matter of power and politics rather than morals.

Consensus as a way of making ethical decisions fails because:

> in the search for consensus in bioethics, such a morally normative account is sought as the basis for clinical and public policy without acknowledging that the consensus first depends on first granting the canonical character of an initial moral vision or point of departure. (Engelhardt, 2002:12)

Hence, consensus needs to be based on a 'moral vision' and as that vision is what is

lacking in the first place, consensus cannot add anything useful to decision-making.

For Engelhardt it is this lack of a shared 'moral vision' that makes moral decision-

making difficult and contentious.

Moreno advances a position in his book on the use of consensus in bioethical

decision-making, *Deciding Together* (1995), that can provide a response to

Engelhardt's concerns over the possibility of moral consensus. Moreno's overriding

thesis is that consensus is a central part of bioethical decision-making, an important

part of the social practice of bioethics. He gives an account of the use of consensus

decision-making processes in national ethics commissions and hospital ethics

committees in the US. While consensus procedures may seem to be obviously

relevant in such forums, he also argues that these procedures are used in clinical

settings (as this study has found)[184]and small group processes. 'Moral consensus is a

natural feature of human affairs, that manifests itself in and emerges from social

practices, and that human experience contains both the conditions that undermine the

quality of a moral consensus and the resources that enable us to improve it.'

(1995:124)

In answer to Engelhardt's problem of a lack of a common moral vision that besets

consensus decision-making, Moreno contends that there is enough common ground

in society to allow the formulation of a consensus. Moreno argues that, 'the moral

authority of consensus in bioethics must be understood within the framework of

liberal political philosophy to which our society subscribes.' (1995:143) Hence, the

'moral vision' arises out of a generally accepted political liberalism and these

consensus processes need to be scrutinised to see if they, 'sufficiently respect

individual self-determination and other principles that are the objects of a society's

settled over-lapping consensus.' (Moreno, 1995:106) Thus, '[u]nder such

circumstances the validation of moral consensus may turn on the extent to which

principles that are the objects of an overlapping consensus have been honored in the

process.' (1995:103)

In Moreno's view bioethical consensus is justified by 'honouring' principles that

arise out of a political liberalism and that such principles are upheld by our

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[184] See The Conclusion for a discussion of other studies on the use of consensus in medical decision-making.

society.[185] Moreno uses Rawls' term 'over-lapping consensus', that members of a pluralistic society will agree on some values, but will not all agree on the same ones.[186] For Moreno, as long as the group broadly upholds liberal values, such as respect of personal autonomy, and accords, 'with the general conditions that govern the conduct of this kind of process' (1995:63) then the group has as much moral authority as is possible in a liberal society. Thus, according to Moreno, this is the 'moral vision, in Engelhardt's sense, on which moral consensus can be based.[187]

If the acceptability of consensus decision-making is judged by whether it attends to principles that are part of the general moral framework of a community, the question becomes, is the consensus formed by the informants in this study based on any such foundations? Is there some sort of more general 'moral vision'[188] that can be used to justify their decisions? It will be argued that there is a form of a common moral vision amongst the informants that is based on their membership of their profession and the regulatory context in which they practice. Therefore, decisions can be made and judged on the basis of this 'moral vision' and this 'moral vision' is defendable in a wider societal context. The informants shared a commitment to the underlying value of impartiality and their decision-making processes were designed to facilitate this. The aim of making impartial decisions was what underpinned their moral vision, what all the informants agreed on and what gave their moral outlook coherence. The relationship of the informants' 'moral vision' to wider society will be considered, examining theories that hold that doctors' morality is largely internal

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[185] Also see Strong (1999) who argues that as a society we share enough moral values to make agreement possible.

[186] A concept that has been widely criticised, see Jennings (1991) and Kukathas & Pettit (1990).

[187] Moreno also bolsters his claims by positing that there is a 'shared moral sense' based on the work of Hume and data from moral psychology. This will not be considered due to space and it is not central to the argument that is being advanced here.

[188] The term 'moral vision' will be used as a short hand for, 'a general moral framework'.

to their practice. In contrast, a theory of doctors' moral vision will be put forward (based on the data and literature), a form of a medical professionalism account, that sees the link with a wider societal morality as central to doctors' ethical functioning.

IMPARTIALITY

The previous chapter established that the informants attempted to make ethical decisions on the basis of group consensus. The overriding goal of this process of consensus decision-making was to make impartial, and therefore acceptable, ethical decisions. The informants' thought that a 'good' ethical decision was a decision that could be seen to be impartial. The process of consensus decision-making led, in the informants' view, to a more impartial decision. By taking the decision out of the hands of one person and locating it with the group, decisions were less likely to be made on the basis of personal prejudice. For the informants, it was the impartiality of process that conferred ethical legitimacy on the decision. The informants might not share the same views on particular ethical issues (such as treating single women) but they all agreed that there was an appropriate way to make ethical decisions and were, generally, prepared to abide by the outcome of that process. Impartiality can be seen as a shared value that all the informants subscribed to and one that can be justified within a broader societal moral framework. In this section how they constructed this concept in practice and how consensual decision-making contributed to the impartiality of decisions will be examined.

Definitions of Impartiality

Impartiality is often seen as one of the features that characterises moral theories and their dictates.[189] Rachels sees moral impartiality in the following way, 'the requirement for impartiality, is at bottom nothing more than a proscription against arbitrariness in dealing with people differently from another *when there is no good reason to do so*.' (1986:10) Gert puts forward the following definition of moral impartiality. He argues that an impartial choice is one in which a particular type of consideration does not influence the decision so: '*A* is impartial in respect *R* with regard to group *G* if and only if *A*'s actions in respect *R* are not influenced at all by which member(s) of *G* benefit or are harmed by these actions.' (Gert, 1995:104) Impartiality for Gert is a property of a particular decision made by a particular person that affects a particular group (or person).

It is of course possible to criticise any formulation of impartiality as an impossibility in reality.[190] Young argues: 'The ideal of impartiality is an idealist fiction. It is impossible to adopt an unsituated point of view, and if a point of view is situated, it cannot stand apart from and understand all points of view.' (1990:104) However, it is not claimed here that the informants were exemplifying some sort of unsituated form of impartiality. Rather, the concern is to elucidate precisely how they attempted to accomplish, what they saw as impartiality in their particular social setting. Thus, this addresses Young's concern that, 'it is impossible to reason about substantive moral issues without understanding their substance, which always presupposes some particular social and historical context.' (1990:104)

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[189] For an excellent overview of the place of impartiality in mainstream moral theory see Jollimore (2006).
[190] The claims that ethical theories represent some form of impartiality have also been criticised by theorists who advance an ethic of care, see for example: Gilligan (1982), Noddings (1984).

Therefore, in order to analyse whether decisions are impartial (or not), there is no blanket, abstract definition of impartiality as such that can be appealed to. Rather, what is needed is some specification[191] of what would constitute impartiality in a particular situation, what are the relevant conditions in that particular situation for saying that action is impartial.

For the informants, impartiality consisted of: the non-imposition of their own views on their patients; detachment of the decision-maker from the situation; and a robust process of decision-making. How the concept of impartiality is actually used and therefore specified in practice by the informants will now be elucidated.

Ethical decision-making and impartiality

The attempt to make decisions impartially, and therefore more acceptably, was the ethical imperative that guided the informants' actions in this area. When asked to talk about 'how do you make ethical decisions?' the informants gave a variety of responses to this, elements that they thought were important when making ethical decision. Twenty of the informants were explicit about the need to avoid discrimination, bias, prejudice or any other form of unequal treatment. Ten of the informants specifically used terms such as bias, prejudice, and discrimination when talking about things to guard against when making decisions. Two informants used the word 'impartial' to refer to the way decisions should be made. Other informants discussed issues that were seen as representing notions of impartiality. Table 3 details the different categories of response that have been put under the rubric of impartiality.

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[191] See Chapter Three.

There were two main ways that informants talked about being impartial. First, that it was wrong to impose one's own views on a patient (or indeed colleagues). Second, decisions were 'better' if the person taking them was detached from the case or situation. These will be dealt with in turn.

The imposition of views

A common view was that it was unwarranted to impose one's own beliefs (ethical or religious) on to patients. Dr Havers provided an example of this. He had trained in Italy and was a practicing Catholic and was concerned that his own religious views might compromise his impartiality when dealing with patients:

> Well, it made me feel more comfortable that I was making the right decision because, you see, I come from another country, which is Italy, Southern Italy, Catholic country, so my culture, although I am a very open minded person is always inside me. So any time I have a patient in front of me with a bit of, where I can see an ethical problem, I always ask to myself whether it is a real ethical problem or it's coming from my personal background. (8-87)

Dr Jenson put the point like this, that it was important to guard against one's personal prejudices:

> I think fertility and ethics, we are dealing with probably the most important part of medicine, in my view, or ethically important part of medicine and I don't think it can be approached by individuals, it has to be a group thing because we all have your 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. (10-68)

The likelihood of such an imposition of one's own personal moral beliefs on to the patient was thought to be increased if the clinician had very strong moral beliefs.

Dr Iniman put the point like this:

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I don't think that it is good to have clinicians who do have very strong religious beliefs, because it makes it very difficult for their patients. I'm thinking back now to the days where I was involved in terminations. I mean I think people can opt out of course, they must have the absolute right to opt out, but trying to put your own beliefs on patients is inappropriate. (9-69)

Dr Kilm made a similar point when he said:

I suppose it's whether the person that is making the judgement is reasonably open-minded and has a broad enough education that they are able to appreciate different views rather than them having only sort of been brought up in a blinkered existence but, you know, they've got a very narrow-minded view on things that only fits in with say one religious type or what have you and everything has to fit into that, and if it doesn't well then they are going to get into trouble at some stage.(11-46)

Dr Kilm thought that an open-minded doctor was less likely to push their views onto others, have less of an axe to grind and was therefore less likely to 'get into trouble.' By being broad minded and not wedded to a particular viewpoint decisions could be negotiated in practice with all view points considered equally. This equal consideration of views (based on an open mindedness that is willing to change or take on board other's views)[192] was seen to make decisions more impartial. This attitude of the informants fits in well with recent guidance published by the GMC, *Personal Beliefs and Medical Practice*, they state: 'You must not unfairly discriminate against patients by allowing your personal views to affect adversely your professional relationship with them or the treatment you provide or arrange.' (GMC, 2008)

Detachment

A further aspect of impartiality for the informants was that a better decision could be made if the decision taker was in someway detached from the situation. This

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[192] This could be seen as a form of 'reasonableness', see discussions of Rawls' notion of public reason below in this Chapter.

'detachment' could mean various things. Dr Francis, for example, when she talked about what ethics training could contribute to clinical practice, exemplified how she was using (specifying) the concept of impartiality.

> I think if you have formal training, actually, it may make you think about it in a slightly more clinical and detached way, because I think the problem with ethics is you kind of think it's so much influenced by the way you were brought up and what you like, that it's very easy to think well of course that's okay, rather than thinking well actually, you know, I wouldn't offer it to somebody because I think oh I might as well do that. I would think well I know that these papers say that this, this and this, and maybe it would make you look at things in a slightly more detached way. (6-51)

Ethics training could help the doctor to be more detached from the situation and this was something Dr Francis clearly thought was valuable. Ethics training could help doctors to transcend their own views and ideas, and training could in someway broaden the mind so to speak, by the reading of academic papers that might point out other ways of looking at things. Dr Iniman also saw this as an important part of the benefits of ethics training for doctors:

> Oh no, I think it [ethics training] does, and again it takes away from personal bias to having a framework, a sort of structure on which you can pin the arguments that help you to make a decision. (9-96)

Dr Kilm put the point like this:

> It's worth them having some kind of training, it's worth them having considered some of the things and maybe make up their own mind, realise what their own views are and hopefully realise or recognise that other people may have different views to their own and sometimes you have to put those views to one side, because we all get involved in things that maybe we prefer not to be involved in but it's just part of the job. (11-63)

So detachment in this sense was being detached from one's own viewpoint (a point that links into the one above), the ability to recognise there are other points of view.

Some informants thought that it was important for the doctor to remain detached from the patients in order to make a better assessment. Dr Evens put it like this:

> Because the other thing you've got to very mindful of too is not to be influenced by Miss Nice or Mr and Mrs Nice or Mr and Miss Nice to say what a lovely couple, wouldn't they make lovely parents, we don't know they're going to make lovely parents. (5-106)

Dr Iniman thought that doctors with their experience were more likely to be able to remain detached from the situation:

> I'm going to say something that you might not agree with at all now, but I think that if a non-clinician meets the patient they are much more likely to be swayed. And clinicians are always swayed because part of the basic tenure to doing medicine is you're doing the best you can for the person in front of you. But over the years you learn how to amalgamate that with looking at the wider perspective and what might really be in their long-term best interests and helping them to go through the implications. And also we've got back up, particularly in fertility medicine, with counsellors who will deal with implications counselling, and we're really fortunate in that. I've got pretty limited experience to base this on but I think that it's difficult for, it's harder for somebody coming in from a different background to hear the patient's story and remain unmoved. (9-37)

A second form of this detachment was that in some situations it was better for someone (or some body) to make the decision that did not know the patients, who was detached from the day-to-day management of the case. This was a common reason for advocating the use of CECs.

Dr Evens made this point:

> we'll take it to the ethical committee, and take it forward from there, to ask a sort of a wider group of people who are not connected with the actual delivery of service what their views are. (5-58)

Dr Francis said:

> Well, I think it's people who aren't involved, people who actually haven't seen the patient so they're not kind of swayed by 'we like them or we don't like them'. (6-44)

Dr Brown and Dr Case also highlighted the fact that the CEC could help make decisions because they would be detached from the actual case and be able to see it in a more dispassionate way.

> Well, that you're given advice by people who aren't necessarily doctors or scientists, or interested specifically in that, and they can look at it from outside, they haven't got a vested interest in saying yes or no. (2-28)

> But now we use Anytown, which is the nearest sister clinic, we use their ethics committee set up, and in fact they do their ethical discussions in-house, but they're a much bigger team and so one part of the team can pass a problem to another group and they can discuss it in isolation. And so we send over to them and they're discussing it as independently of the situation; that's much more practical. (3-44)

The informants saw this process of decision-making as more defensible. In the current healthcare environment this model of decision-making could also be seen as useful to clinicians as it was thought to give them a form of protection. By having procedures for making decisions that were designed to ensure the impartiality of the decision this enabled them to claim that the decision was (more) impartial and therefore less likely to be subject to criticism. Dr Jenson cast the element of protection in the following way:

> And I think you are stronger as a group. 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. (10-38)

Dr Tarn gave this account of his clinic's meetings:

We have regular meetings, you know. Some of us call them business meetings, some of them call them clinical meetings, I don't know what they are really, but a monthly get together. And if there are problem cases we discuss them with the nurses, the consultants, the receptionist, so it's openly aired and discussed really.

So do you find that a useful forum?

Yes, that's useful in two ways. There is an element of self protection for doctors as well now, you know, so I protect my back as well by doing that, say look this wasn't my decision, this was a joint decision, after case discussion at the meeting. So it benefits both sides, I think, the patients, it gets the staff more involved and it protects the final person who will be signing the letter. (20-11)

This type of decision-making was perceived to be better all round, Dr Tarn stated, for example, that he thought it also benefited the patients as well, by showing that they had procedures and mechanisms for making ethical decisions that distanced the individual clinician from the decision, a way of demonstrating that they make reasonable and adequate decisions.

CEC were also thought to offer clinicians some form of protection. Dr Havers said:

The cases are being rejected all the time. But it's good for us because, that was my feeling in these specific cases, but they back us up, which is important. You feel also a bit more, having support from an ethical committee in making such a decision, it's an important thing. Even, I mean first of all ethically for the patient and for the couples, so are you sure that you're doing the right thing for society as well, but also medical and legally, just to make sure that you cannot be liable for anything, for making a decision that can be taken to the court or the human rights or something like that. (8-29)

Dr Brown reiterated this point:

And you get the support of a body that says yes or no, which if you will shares the responsibility. It takes the responsibility off you to a great extent, which you could argue is a bit of a cop-out but I think that that's reasonable if you, you know, if you are deciding something really quite important about a patient. (2-29)

With all these mechanisms for ensuring impartiality: CEC, clinic meetings and the involvement of other professions, the informants were, arguably, concerned about the

impartiality of the *process* rather than the impartiality of the product, the outcome of

the deliberations. For them a consistent, transparent and, generally, uniform process

was the key to making 'good' and 'acceptable' ethical decisions. As Dr Orben said:

> So for me for a decision to be ethical it means that it's open, that it has been
> carefully considered and that the decision has been taken usually by more
> than one person, and preferably by people who don't stand in any way to gain
> from the decision being made. (15-44)

MORAL VISIONS OF MEDICINE

It could be contended by critics of consensus decision-making, such as Engelhardt,

that the informants' shared value of impartiality that guided their decision-making,

was just a 'moral vision' held by doctors. Engelhardt would argue that there are

moral communities who share values (such as particular religious groups) and he

calls these 'moral friends.' Whereas, moral strangers who do not share the same

values, 'will not see the world in the same way.' (Engelhardt & Wildes, 1994:136)

Therefore, doctors are a community of 'moral friends' and members of a wider

society are potential 'moral strangers.' To a wider society that does not hold this

'moral vision', such decision-making would not have any moral validity – doctors'

consensus decision-making would only be a consensus amongst themselves. This is

the view that medicine has its own particular morality, an 'internal morality of

medicine', that is distinctive to the external morality of the wider society (Veatch &

Miller, 2001).

For my defence of consensus decision-making to be successful, I want to argue that

there are important links between the informants' 'moral vision' and the wider

society's. I shall first outline and critique theories of an internal morality of medicine

and then develop my own account. This close attention to actual practice can aid in refining and developing ethical theory and principles.

The Internal Morality of Medicine

The debate over whether there is an internal morality of medicine was stimulated by MacIntyre's concept of 'practice' and the claim that practices had virtues that are 'internal' to them (Veatch, 2001). A practice for MacIntyre is, 'a coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity.' (MacIntyre, 1981:175) A practice has its own goals or *telos* and internal goods are generated by successfully engaging in the practice, by realising and pursuing its unique *telos*.

This notion of a unique good or *telos* of an activity has been applied, by some authors, to the 'practice' of medicine. The accounts that build on this idea of a unique *telos* of medicine have been termed essentialist and have two central tenets. First, that medicine has an essential character, ends or goals that are distinctive to it, for instance, the healing aim of medicine is a distinctive goal. Second, from such conclusions about the nature of medicine and a reflection on the ends and goals it is possible to decide what should be done, to construct a medical ethic for the profession. Kass (1975) was one of the first authors to advance this approach and took an Aristotelian view that medicine had a particular end of producing health and the morality of medicine depended on the advancement of this end. Pellegrino built on this account and is one of the main exponents of this view of the internal morality

of medicine. He argues that the ethics of the medical profession has its source in the nature of the profession,[193] in what is distinctive about the medical profession and the good for which it aims. Medics have generic obligations as healers and aim at health as a good (Pellegrino, 2001).

This kind of essentialist account has been heavily criticised (Veatch, 2001). One criticism points to the difficulty in stipulating what such a *telos* of medicine is. If it is construed too broadly then it fails to differentiate medicine from other activities, if too narrowly then much of what is considered modern medicine (such as cosmetic surgery and even infertility treatment) might fall outside what should properly be seen to be medical activity. A further problem for such essentialist accounts is that even if it was possible to formulate a defendable version of what the ends or *telos* should be, there are still problems of how to derive what should be done, what follows from these ends of medicine. Simply establishing the ends of an enterprise does not necessarily tell you how to achieve those ends in an unproblematic way.

However, the most important criticism of this approach for my purposes is that medical morality cannot be solely internal to medicine as a practice. Veatch (2001) argues that ultimately any decision over what ends of medicine should be pursued are matters to be decided externally from medicine itself and concludes that there is no utility in a concept of the internal morality of medicine.[194] For Veatch, (using the example of the debate over doctors participating in capital punishment): 'the question of whether a physician's behaviour is morally appropriate when he or she participates in an execution is surely not settled by the balancing of two competing

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[193] Pellegrino also include other 'healing' professions in this analysis. So nursing, clinical psychology and dentistry would all be classed as professions with a distinctive *telos*.
[194] See discussion of Veatch's criticisms later in this Chapter.

goals of medicine. Surely it is settled by resolving the more fundamental societal

moral question – the morality of capital punishment itself.' (2001:634)

In response to such problems with an internal morality of medicine, Brody & Miller

(1998. Miller & Brody, 2001) have advanced a version of internalism that seeks to

overcome the difficulties encountered by the essentialist accounts. They put forward

what has been called an evolutionary account that sees the gradual evolution of an

internal ethic of medicine in concert with wider society. Arras sums up this

evolutionary approach as follows:

> Miller and Brody propose a theory of professional medical goals and duties
> conditioned by the evolving demands of history and (external) social/cultural
> influences. They thus want to argue that there is indeed a core ethic developed on
> the basis of reflection on medicine's specific goals and duties, but that this core
> ethic develops historically as a result of a dialectic or conversation between the
> medical profession and the larger society. (2001a:648)

For them, there is an important interaction between medical values and societal

norms that, together, form a medical morality. In light of this criticism of internal

moralities of medicine, that it ignores the relationship between the morality of the

medical profession and the morality of the wider society, I want to advance an

account of a medical morality or a 'moral vision' that builds on this notion of the

relationship between medicine and the wider society in which it is practised.

THE VALUES OF MEDICAL PROFESSIONALISM

The account of medical professionalism that I want to advance is broadly based on a

view that there are specific moral responsibilities and obligations required of doctors

qua their membership of the profession of medicine. This account has two elements:

first, it is a form of a 'practical precondition account', that says there are specific

ethical precepts that all doctors have to broadly share to be able to practice. This gives the medical profession a degree of moral cohesion, a moral vision, upon which a consensus can be based. Second, this moral vision has to be part of and in close relationship with the wider morality of the society in which doctors practice.

The first question for this account is, what norms are binding on doctors by virtue of their membership of their profession? (Ladd, 1983) What are the norms without which medicine, in Arras' words, 'would cease to be a going concern.' (2001:646) Arras gives the example of confidentiality, as a norm that makes the trust relationship between the doctor and the patient possible.[195] This type of account does not need a developed thesis about the goals and essential *telos* of medicine, rather: 'It simply asserts that, whatever we think about medicine's 'true' purposes, the enterprise of medicine as a practical activity won't be able to get off the ground without scrupulous adherence to the duty of confidentiality.' (Arras, 2001:646)

Rhodes (2002) has put forward a theory of medical professionalism, which she calls a contractarian constructivist account and I will build on this to formulate my process-orientated account of medical professionalism. The importance of her version for my purposes is the link she makes between the cohesive medical professionalism that is fostered by medical training and the ability of practitioners to make decisions on the basis of consensus.

> Medical ethics education[196] is…primarily concerned with inculcating medical professionalism. This involves helping students to understand the justification and

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[195] Talcott Parsons (1951), for example, also saw doctors as having specific duties and roles that arise from their professional status. These were: applying a high level of skill and knowledge to the problem of illness; acting for the welfare of the patient, rather than self-interest; being objective, emotionally detached and non-judgemental; and being guided by the rules of professional practice.

[196] For the account advanced in this chapter it is not pertinent whether such values are inculcated by specific ethics training or within general medical training and in practice.

content of their special responsibilities as physicians, to accept their professional responsibilities as important and overriding, to understand principles of medical ethics that are relevant to clinical practice, to learn to apply them and use them in case discussions, to learn how to reach a consensus with peers on difficult cases, and to learn how to tolerate reasonable differences in views and unavoidable uncertainty. (2002:496)

Rhodes uses John Rawls' theory[197] to explain this distinctive form of professional morality. She argues that in medicine the concept of political liberalism and the success of public reason are often more apparent than in political deliberation. This notion of public reason is central to Rhodes and Rawls' account. Rawls argues that there must be a capacity for reason and reasonableness in order for people to participate in the hypothetical construction of political justice,[198] 'all ways of reasoning…must acknowledge certain common elements: the concept of judgment, principles of inference, and rules of evidence…and include standards of correctness and criteria of justification.' (Rawls, quoted in Rhodes, 2002:500) This idea that there can be a common standard of 'reason' is coupled with Rawls' recognition that there are some elements in society that have a distinctive character and autonomy and therefore act from their own principles. Rhodes argues that while Rawls may not have had medicine in mind, 'medicine is clearly a part of society that is ethically autonomous.' (2002:499)

Building on these two elements Rhodes attempts to construct the principles that should govern the social institution of medicine, as Rawls outlined the principles that

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[197] Rhodes draws on Rawls' later work *Political Liberalism* (1993) to ground her account and the quotes from Rawls will be the ones that Rhodes has used to substantiate her account.
[198] It should be noted here that Rawls separates his claims about political liberalism from his theory of justice. Further, in order to advance this account of medical professionalism one does not have to accept the Rawlsian foundations, as in this context it could be argued that we are not taking about hypothetical formulations of principles but actual ethical professional codes that doctors adhere to in their professional practice. It is enough to say that there is a social practice (medicine) that has professional ethical codes that doctors have to follow on moral and indeed legal grounds and these have arisen out of the social context that medicine operates in.

should govern political institutions. These principles, for Rhodes, are drawn from, 'the distinctive character and autonomy of the profession [of medicine].' (2002:500)[199] The principles that Rhodes outlines are not, as she says, unique or distinctive; they are found in many different sets of ethical codes for doctors. She argues that, 'there is genuine consensus on the core content of the professional responsibilities of physicians.' (2002:505) and gives the example of the consistency of the principles she lists to those found in 'The Medical Professionalism Project' (2002).[200]

The two foundational principles for Rhodes are: first, the fiduciary responsibility of doctors, that they should act for the good of their patients; and second, 'physicians and the institutions and profession of medicine must *seek trust and make themselves deserving of trust*. (2002:501) [201] From these foundational principles come basic principles, one of which is *non-judgmental regard,* no one would want to be denied treatment simply because the doctor did not like them. This can be seen as broadly analogous to the imperative of impartiality that the informants in this current study saw as an important criterion for making acceptable ethical decisions. Hence, for Rhodes, these principles arise out of the distinctive character of medicine and put moral duties on to doctors *qua* their being doctors. These duties are different from the kind of moral duties that the person in the street might have, 'because of its distinctive position in society, medicine has its own ethical principles that are in

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[199] See Bosk (1979) who argues that medical training is above all an ethical training where doctors inculcate the ethical values of their profession.

[200] Such values are also consistent with those outlined in the Royal College of Physicians' Report on medical professionalism (RCP, 2005).

[201] From these two foundational principles, the principals of caring, confidentiality, non-judgmental regard, non-sexual regard and respect for the patient's values follow.

some notable respects different from the rules of ordinary morality, and they have a distinctive rationale.' (Rhodes, 2002:499)

For Rhodes, Rawl's public reason characterises medical decision-making. When discussing cases or difficult decisions, 'the discussions 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.' (2002:503) Rhodes takes Rawls' idea of a reasonable citizen, who has the virtues of fair-mindedness and will put their own prejudices and personal views aside to make 'fair' and 'reasonable' decisions, and applies this to medical decisions. Doctors act as reasonable 'citizens' and put aside their own views and act, 'on the basis of mutually recognizable reasons and evidence.' (Rawls, quoted in Rhodes, 2002:502) 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.' (2002:503)

Medical professionalism and process

The account of medical professionalism I want to advance builds on Rhodes and the data from my study. An important precondition for operating 'ethically' in modern medical practice would not only be to adhere to a set of ethical precepts laid out in professional codes, but to be willing to follow a particular decision-making process. This decision-making process is procedural, in that it involves clinics and CECs meetings and builds on a particular conception of public reason. This conception of public reason as found in the data from this study has similarities with Rhodes' account of Rawls. The informants did try to put aside their own moral views when

making decisions and had a set of 'mutually recognizable reasons and evidence' on which to base decisions. The clinicians did, by dint of their membership of the profession of medicine, have a consensus over the procedural aspects of ethical decision-making. The main concern over consensus decision-making was that it was not possible to get substantive consensus – consensus over actual issues. My account places more emphasis on the consensus over procedures for decision-making rather than consensus over particular ethical values or principles. The informants were able to make consensus-based decisions even when consensus over the substantive issues could not be reached. If the distinction between substantive and procedural consensus is broken down, then it can be argued that procedural elements incorporate substantive ones, procedural standards have substantive implications (Moreno, 1995). That is, in following certain type of procedure certain ethical values and principles are being upheld. This is exemplified in this study where the procedure of decision-making was thought to confer a substantive value on the decision – impartiality.

Kuhse puts forward the argument that consensus by groups, such as national ethics committees designed to make ethics policy is, *in practice*, the best way of deciding complex ethical matters. Her argument is that such committees will make policies, 'not by presenting us with 'the truth', but rather presenting society with rational arguments.' (1994) For Kuhse, 'discourse will often reveal that we tend to overestimate moral disagreement. Ethics is not an arbitrary series of different things to different people, and even the most difficult ethical issues are amenable to reason and discussion.' (1994:91-92)[202] Therefore, it is the procedural aspects of a rational

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[202] See Jennings (1991) who also makes this point.

dialogue and discourse that gives committee decisions their authoritative force. Despite arguing for such a procedural form of ethical decision-making she recognises that the authoritative force of committees will be tentative and fallible and does not wish to overstate their efficacy, but concludes that they are, 'the best we can do.' (1994:95)

Thus, my account focuses on an adherence to a particular process of ethical decision-making and this process leads to and incorporates particular ethical values that doctors share by dint of their membership of their profession.

Objections

Veatch argues that there is no cohesive medical 'moral vision' as I have postulated. In order to strengthen my position I want to consider his objections. Veatch (2001) argues that as there are so many different medical roles, 'they therefore have different moralities.' (2001:629) Thus, medical morality is determined solely by the doctor's moral views and not by any aspect of medical practice itself. This is a common criticism of medical professionalism theories. Wurm-Schaar and Fato, in an edition of *The American Journal of Bioethics* devoted to a discussion of medical professionalism argue, 'the medical profession itself appears to lack consensus regarding its core values…is fragmented into various sub-speciality organizations with their own codes of ethics and conduct.' (2004:w1) There have been various rejoinders to this (see Brody & Miller, 1998. Miller & Brody, 2001)[203] but I want to advance one counter argument to this 'many medicines' thesis.

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[203] They argue that if Veatch's contention is true, that there are many different medicines all with a different morality, 'by virtue of what are all these disparate practices…seen as *practices of medicine*.'

This study did not find that the informants all had identical moral frameworks (although it did find an area of 'settled morality' in which they practised and a general adherence to the value of impartiality) what it did find was that they were united by their adherence to the process of decision-making. This process was thought to aid, facilitate, bring about a more impartial decision – a decision that was not based on the individual moral views of a particular doctor. Consensus decision-making can be seen as a means of achieving a particular ethical goal, the goal in this case being a decision that can be argued to be impartial and therefore less likely to be subject to reproach. Thus, the informants could be said to have a shared vision of what acceptable ethical decision-making should be and what that process was aiming to achieve – impartial, trustworthy decisions. Of course, as I only studied one speciality my data cannot conclusively rebut the 'many medicines' objection. However the focus on process rather than substantive ethical agreement points to the possibility of this being a more widely held and unifying position.

It could be further countered that this medical professionalism account of medical morality 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. However, from this research project it is possible to see that there are processes of ethical decision-making that participants agreed on and followed with the explicit aim of making 'acceptable' ethical decisions. The

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(2001:590). For them, Veatch's position reinstates the dichotomy between medicine as pure technique and medicine as a moral practice – a dichotomy, they argue, that needs to be broken down in order for medical ethics to be a meaningful discipline.

standards of these processes might not reach the exacting ones that Rawls envisaged and at times may not have been completely impartial or indeed justifiable, but they are, broadly, the best one can do. This is, in essence, the justification for the form of consensus decision-making the informants used – it is the best we can do in actual practice. In abstract discussions there may be higher standards for ethical decision-making (for instance applying a theory such as Kant's in a rigorous fashion) but in practice a weaker standard might be all that can realistically be achieved.

THE MEDICAL PROFESSIONALISM ACCOUNT AND SOCIETAL NORMS

As stated earlier it now needs to be demonstrated that this medical professionalism account is a conception of a 'moral vision' that could be shared by the wider community in which clinicians practice. While medics might agree on the form of internal morality that governs their decision-making and see it as the basis for making consensual decisions, other people, such as patients for example, might not adhere to this form of morality. This moral vision might not be generally accepted in wider society. If this is the case, then without a more widely accepted moral vision, it could be argued that doctors' decision-making has lost its warrant and we are back where we started with the criticism of consensus based on inescapable moral pluralism. Historically patient groups have been at variance with the medical professions' approach to many issues and this has been well documented. Examples of the medical profession being out of step with a wider morality range from patient dissatisfaction with childbirth practices in the 1970s to the practices of organ retention in many hospitals that came to light at Alder Hey.[204]

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[204] See Lupton (2003:122-127) for a discussion of patients' resistance to medical dominance.

These claims do some have purchase. It would be overstating the case to say everyone in society held the same moral beliefs and therefore it is possible that the medical profession may become inculcated into a particular ethical viewpoint that is not generally shared. However, there are three counter-arguments to this point that can be raised. First, medical decision-making is no longer the sole preserve of the doctors. Other disciplines, patient groups, committees made up of lay members for example, all now contribute to both decision-making and the construction of the morality of the medical profession (or at least there are moves to try and bring this about!). The values and processes of medical professionalism could be said to include not just doctors but all health care professionals. The medical profession are now publicly scrutinised and their decisions and professional ethics are matters for general debate. Therefore, it can be argued that professional ethics have to be in step with a more general consensus and consequently are less likely to impose an alien morality on wider society.[205] Further, infertility treatment is highly regulated and the process of this regulation involves public consultations, parliament and the involvement of interested parties – hence this area of medicine does not operate in an ethical vacuum.[206]

Second, the link between medical values to those of the wider society can be demonstrated by the example of impartiality. It was argued that this was a value that the majority of the informants viewed as an important ethical principle in their practice. Impartiality can also be seen as a value that has gained precedence in the wider moral framework of British society. Although it is difficult, if not impossible,

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[205] For instance, Alder Hey provides an example of public disquiet and scrutiny of a medical practice.
[206] An example of this is the removal of donor anonymity – the professional bodies were against this, but nevertheless it was still removed and hence in some senses this was imposed by external bodies on medical practice.

to pin down the zeitgeist of an age, examples of impartiality as a guiding principle in some recent legislation will suffice as examples of its current employment. The Sexuality Discrimination Act 1975 has been extended under The Equality Act 2006 to require public bodies to actively promote gender equality. Sexual Orientation Regulations 2002 make it illegal to discriminate on the grounds of sexuality; the Employment Equality (Age) Regulations 2006 make it illegal to discriminate on the basis of age in employment; and the Disability Discrimination Act 2005 does the same for disability.[207] All these pieces of legislation seek to make employment practice more impartial and less susceptible to discriminatory practices.

Finally, it can also be argued that this kind of medical morality is dependent on a wider societal acceptance as, at root, it is about the medical profession being trustworthy in the eyes of the community it practices in. Therefore, the morality of medicine both reflects and is reflected in the morality of the wider community. Medicine was traditionally seen as a *moral profession* in the work of Everett Hughes for example. The medical profession was seen as having a set of moral values that it adhered to and this was what gave it its status and prestige (Parsons, 1951). It was largely seen as an altruistic and moral enterprise. Doctors were granted their privileged status on the grounds that they would be moral in their everyday undertakings (Cruess & Cruess, 2000). However, this notion of medical professionalism began to be heavily criticised in the 1960s and 1970s. It was argued that any notion of professional ethics was a cynical ploy, doctors' supposed altruism was really a mask for their own self-interest (Friedson, 1970. Krause, 1996. Starr, 1982).

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[207] See NHS Employers (2008) for an outline of equality legislation governing employment practice.

However, since the 1990s there has been a change in the tenor of the sociological literature and medical professionalism began to be reunited with the notion that medicine has certain values (such as altruism) that are central to its functioning in society. Freidson, for instance, in a latter work (1994) argued that medical professionalism serves an important social function in ensuring that the professions maintain high standards of work and trustworthiness. Freidson argued that there were now 'three logics' for viewing the distribution and organisation of health care:

1. by market forces – where health care is traded like any other commodity

2. by large social organisations – insurance companies or the NHS, bureaucracies that seek to manage health care

3. by the professions themselves with a commitment to the standard of their work and a public service ethos (Freidson, 2001)

In his view it is this third way of organising healthcare that is preferable. We need to bolster medical professionalism in order to best ensure a more ethical and publicly trustworthy health service.

Sullivan exemplifies this trend in arguing that medicine cannot function unless the public has trust in it as an institution, 'the root of the public's trust is the confidence that physicians will put patients' welfare ahead of all other considerations….It is the function of medicine as a profession to safeguard and promote this trust in the society at large.'(2000:675) In a report published in 2005, the Royal College of Physicians defined medical professionalism as follows, '[m]edical professionalism signifies a set of values, behaviours and relationships that underpins the trust that the public has in doctors.' (2005:14); and argued that, 'these values, which underpin the

science and practice of medicine, form the basis of a moral contract between the medical profession and society.' (2005:15) Professionalism becomes associated with ethical values of practice and those values are ones that encourage and facilitate public trust in the medical profession. Therefore, these values need to be shared by the wider society.

It can be argued that this medical professionalism account, which is an articulation of values without which 'medicine would cease to be a going concern', are values that necessarily link the medical profession with the wider community. The criticism of consensus decision-making, that due to moral pluralism any consensus reached was simply a view of particular communities at a particular time and hence did not have any moral authority, can be met by claiming that this medical professionalism account is linked to a wider morality by the need for the medical profession to be trustworthy. Medicine could not be 'a going concern' if it did not have the public's trust.

CONCLUSION

This Chapter has both sought to specify the principle of impartiality that underpinned the informants' consensus decision-making process and to determine if this is an acceptable way of making ethical decisions. Consensus decision-making on ethical issues has been defended as an acceptable way of making ethical decisions in the infertility clinic. However, this form of decision-making is not perfect and, as discussed, there are a number of problems with it. There could be a tendency for it to lead to conservatism; for instance some clinics' reluctance to treat same-sex couples because not everyone agrees. Thus the more 'reactionary elements' may direct clinic

policy. 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.

However, returning to Churchill's opening quote, it can be said that the form of decision-making used by the informants is not perfect. It may be the worst form of decision-making except for all the other forms that have been tried. Often in the ethical literature ethical decision-making is given impossibly high, abstract standards to meet in order for it to be deemed acceptable and in practice few ways of making ethical decisions can meet these stringent criteria. Here, it has been argued that consensus decision-making is, in practice, a reasonable and effective way to make ethical decisions. In the words of one informant, although this process may have its flaws, 'But what's better?' (16-46)

Despite being the 'best we can do in practice' this form of decision-making can be improved upon and strengthened. In the next chapter how this could be done will be discussed by examining their use of CECs.

TABLE 3
CONSTRUCTIONS OF IMPARTIALITY

Elements that contributed to 'good' ethical decisions	Which doctors	Quotes
Decision should be fair - equals should be treated equally - should act justly	Dr Down Dr Evens Dr Francis Dr Jenson Dr Kilm Dr Marsh Dr Percy Dr Tarn	'Well it's unfair, it's that you wouldn't, whether he is a drug dealer or not but if its outside and a couple can achieve a pregnancy naturally no-one says to them you cannot have children because you are going to be unsuitable parents. But here we maybe saying that because they are coming for fertility treatment I think everybody should be treated the same.'(Dr Down, 4-40)
Resource allocation in the NHS was often categorised as unfair	Dr Evens Dr Francis Dr Down Dr Jenson Dr Kilm Dr Marsh Dr Tarn	'So say from Anytown you can have one cycle of IVF but you get it straightaway; if you live in Newtown, you have to wait three years but then you get three attempts. **Right so it varies from?** Yeah, which is very unfair.' (Dr Francis, 6-8)
Lack of bias	Dr Grant Dr Iniman Dr Robin Dr Percy Dr Orben Dr Jenson	'particularly if the person who is directly involved with the management of the couple, it's very easy for them to be biased and give ground in one particular aspect of the couple, whereas a fresh pair of eyes might look at it at a different angle, and I do value that, yes. It's quite useful and, like I said, somebody else might come with a

		different attitude.' (Dr Robin, 18-14)
Better to be detached or not involved in the situation	Dr Francis Dr Brown Dr Evens Dr Case Dr Havers Dr Orben Dr Urban	'we'll take it to the ethical committee, and take it forward from there, 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 Evens, 5-58)
Should not discriminate - or be prejudiced - no unwarranted differential treatment	Dr Adams Dr Brown Dr Down Dr Evens	'The Ethics Committee felt that we were discriminating against single women and lesbians, and that we should treat them, so we do now.' (Dr Adams, 1-48)
Guidelines can help prevent bias	Dr Adams Dr Jenson Dr Percy	'If we are seen to be discriminating on a random basis, you know, I may have a different view to my colleague next door who's seeing another couple. As long as there is a policy across the board as to how we're going to manage people.' (Dr Jenson, 10-74)
Ethics committees can promote impartiality - should not have a vested interest	Dr Brown Dr Case Dr Orben Dr Francis	'Well, that you're given advice by people who aren't necessarily doctors or scientists, or interested specifically in that, and they can look at it from outside, they haven't got a vested interest in saying yes or no.' (Dr Brown, 2-28)
Should not impose one's own beliefs on the patient	Dr Kilm Dr Iniman	'So I think it's just appreciating other people who may have different views from their own and, to a certain

	Dr Percy	degree, they have to be respected even if you don't, you just have to agree to disagree.' (Dr Kilm, 11-47)
Ethics training can help prevent bias	Dr Francis Dr Iniman Dr Francis	'Oh no, I think it does, and again it takes away from personal bias to having a framework, a sort of structure on which you can pin the arguments that help you to make a decision.' (Dr Iniman, 9-76)
Guidelines can be unfair	Dr Lovate Dr Marsh	'but if you have a unit and there are lots of people on the unit, and the people coming in and out of the unit, you do have to have a policy and to some extent you just have to stick to the policy, realising that in certain situations it's unfair, it's …' (Dr Lovate, 12-26)
Try to not be influenced by one's own culture	Dr Havers Dr Percy Dr Novack	'So I think that if we've got a national regulatory body they could be helpful with that sort of issue, sort of helping clarify what's nationally acceptable within those particular [ethnic] communities.' (Dr Percy, 16-90)
Decisions should be impartial - not influenced by financial considerations	Dr Case Dr Havers	'To be impartial because I think the freedom of people is very important. People have to have the freedom on making a choice but within certain limits.' (Dr Havers, 8-25)
Consistency in decision-making	Dr Percy Dr Lovate	'You have to be consistent, I think that's very important.' (Dr Percy, 16-7)

CHAPTER NINE
ETHICS SUPPORT IN THE INFERTILITY CLINIC

INTRODUCTION

In this chapter I want to draw out the practical implications of this study. I will do this by building on the previous analysis of how the informants made and approached ethical decisions and discuss how ethical decision-making can be supported in the infertility clinic. I shall first draw together the data on how the informants thought about the use of CECs. Some of these points have been covered in Chapter Seven, where the general themes of how they made decisions on the basis of a form of consensus were elaborated. However, the purpose here is to give a picture of the specific reasons why they sought to use CECs as opposed to the other forum of decision-making, the clinic meeting. Then, recommendations for how this CEC support could be strengthened will be made, examining the debate over the use of CECs in the literature and the drawing out the implications of my findings.

CEC 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 (Slowther & Hope, 2000). CECs have also developed in Europe, again more slowly than they have in the US (Slowther *et al*, 2004).[208] The functions of CEC are various, Slowther *et al*, (2004a) summarise these as falling within three areas: providing ethics input into Trust policy and guidelines; organising ethics education within a Trust; and providing advice to clinicians about individual cases. Such committees had generally operated in isolation until the formation of the UK Clinical Ethics

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[208] See Hurst *et al* (2007) for a useful discussion of ethics support in a European context.

Network.[209] This network aimed to offer general support to CECs and facilitate the sharing of good practice between committees (Slowther *et al*, 2004 & 2004a).

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. 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 in their decision-making]' (HFEA, 2000:1) In 2005 when the House of Commons Science and Technology Committee 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].' (HC, 2005:150) As a result of this, and other evidence (for example Doyal, 2005), the Committee recommended that, 'there are merits in the creation of a nationally coordinated network of clinical ethics committees 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 clinical ethics committees in the manner recommended is an appropriate role for central government.' (DH, 2005: Recommendation 84).

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[209] See their website www.ethics-network.org.uk/

Consequently, there is no mention of CECs for infertility units in the HFE Bill that is currently going through parliament.

This lack of central organisation is reflected in the patchy provision of CECs in the UK; for instance in 2001, only 20 Trusts had a formal CEC (Slowther *et al*, 2001a). However, by 2004 68 CECs were registered with the UK Clinical Ethics Network (Slowther *et al*, 2004a). The purpose of this chapter is: to examine how these recent developments in the use of CECs have impacted on infertility practice; what the arrangements are for such committees are; if these committees provide a useful function in the infertility setting; and, if they do, how this form of ethics support can be developed.

THE USE OF CECs IN INFERTILITY CLINICS

The type of CEC in the clinics visited for this study are summarised in Table 4. Three of the units had designated CECs for their units, which only considered cases and issues concerning infertility treatments. Some units used the hospital CEC and one unit had access to a clinical ethics group rather than a formalised committee. As discussed in Chapter Seven, Clinic 5 (that had its own designated CECs) was the only unit that saw the CEC as the principle place where ethical decisions were made. Dr Brown said:

> The clinic has an Ethics Committee. So if we have an ethical issue about whether or not we should be treating somebody, then it is referred to the ethics committee, which comprises some outside people and some in-house medical people. (2-12)

And Dr Urban:

> Any ethical issues are discussed in a separate ethics meeting. (21-5)

Therefore, most units mainly relied on their clinic meetings as the place to make ethical decisions and CECs did not really feature as strongly as might have been expected in ethical decision-making.[210]

TABLE 4
STRUCTURE OF CLINICAL ETHICS COMMITTEES

Clinic	Structure of clinical ethics committee
Clinic 1 • Dr Down • Dr Evens • Dr Francis • Dr Grant	Had a designated one for their unit, organised by the hospital trust. Used to ratify any guideline and policy changes and discuss difficult cases.
Clinic 2 • Dr Havers • Dr Iniman • Dr Lovate • Dr Marsh • Dr Percy	Did not have a one organised by the hospital but had an informal Clinical Ethics Group organised 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, organised 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	There is a hospital wide clinical ethics committee

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[210] The reasons for this will be discussed below.

Dr Tarn	There is a hospital wide clinical ethics committee
Dr Vance	Have a committee designated for their unit, organised by the Trust.

The role and use of CECs was a frequently discussed topic in the interviews with the informants when they were asked how they approached ethical decision-making. They were asked if they used CECs and what they thought that such committees contributed to such decision-making. I shall first examine why the informants said that they used CEC and in what circumstances; and then consider what benefits they thought these committees conferred on ethical decision-making. Subsequently, the limitations of CECs will be discussed, examining the problems that the informants raised with the use of CECs.

Why the informants used CECs

CEC were used for a variety of reasons, the predominant ones were: if there was disagreement in the unit; for complex cases; and for setting guidelines or cases that might set a precedent. I shall consider these in turn.

Disagreement

Disagreement over issues involved in a particular case was one reason why some informants said that they used their CEC. Dr Marsh explicitly states this as a reason for using, what is 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, obviously, our effects are very grave, you can seek help from the local ethical committees, or every institution has got its ethical committee, or you can discuss it with an ethicist just to tease out the …(13-10)

In the same unit Dr Iniman also stated that if it was 'moot' decision they would take it to the ethics group (9-35). Dr Vance who worked in one of the larger units in the country said, when asked how his unit made decisions on difficult cases said:

> I mean you take your concerns to the meetings, and everybody discusses it and we try to come to a consensus opinion. There's about 20 of us, nurses, counsellors, doctors, not much in the way of admin staff, they tend not to want to stay behind at night, they don't get paid so much. And we try to get a consensus. Sometimes we just grind to a halt, we can't decide.
>
> **What do you do then?**
>
> Well then we just stop for a week or two and have another go later, and then if we still can't make it we then take it to the ethics committee…(22-21)

Dr Percy also made this point:

> So if, as a unit, we were completely split or if we made a majority decision but a few people said look, very strongly, I think this is the wrong decision, as I say, we've not had that situation but knowing how everybody feels here I think we'd probably all say fine, we'll take it to the ethics group and abide by them. (16-39)

Disagreement might be seen as a common reason for taking a case to a CEC, for instance 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

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consulting a CEC if consensus could not be reached. However, this was only mentioned by four of my informants (Dr Marsh, Iniman, Percy and Vance).

Complex cases

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

> That couple I won't take to the ethics committee because I don't think it's 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. (14-11)

Whereas another case raised, to his mind, more complex issues and therefore should be taken to the CEC:

> Yes. I've got another one here actually that your microphone's on … of a girl who has got a Mosaic Turner Syndrome, so she will go through an early menopause at some stage, but at the moment she's producing eggs. The technology for freezing the eggs isn't that good at the moment and she's requested having embryos created with a donor sperm for her use in the future, but at a time when she may be married with somebody who may not be comfortable with those embryos with an unknown donor's sperm. But it may be her only chance to create embryos. So that's maybe, again it raises ethical issues and, again, looking at it simplistically, it seems like a reasonable request. But I'm going to put that to the ethics committee because I think it's something that just needs a little bit more thought because there are, again, a few layers, there's a number of potential scenarios for the future. So, is it right to create embryos that may never be used. (14-22)

This points to a view that the CEC might be a better place to engage in a more involved discussion than the clinic meeting. The need to discuss complex cases in CEC is also illustrated by this example given by Dr Evens, she says:

> Ethically, we have major dilemmas to say that, when we don't treat, sorry, if we only treat childless couples, if we treat a [couple who have a child with Downs], how can we then say, are we just ignoring the fact that the abnormal child exists. That's a huge ethical dilemma. So that was debated long and

hard in our ethics committee. And in the end we came up with, it might sound a bit like a cop out, but it was decided that if the couple had a child that was not going to reach the age of majority, then they should perhaps be considered for treatment on the basis of saying that the, by opting for fertility treatment it was going to minimise the likelihood of having a similar issue. But that kind of issue is huge. (5-55)

The issue of whether to treat those who all ready had a child if that child was in someway disabled was seen as an important and complex issue and one that they debated at the CEC. Dr Grant also made this point:

We have meetings with our counsellors, and we tend to discuss the ethical problems at this meeting. We've also got an ethics committee, where some of the more difficult cases are discussed. (7-21)

Therefore, issues that were seen as requiring more discussion, that were more complex than usual, were seen as reasons to take cases to CECs. A further reason for taking cases to CECs was that they fell outside the clinic's guidelines. Dr Marsh said,

but there have been previously cases where we've had to say, for example, freeze tissue in pre-pubertal girls for, ovarian tissue for preserving fertility, you know, those kind of things might be taken to ethical committees just to think about because these are not established practices.(13-11)

Dr Down said:

We take that sort of thing which falls outside our guidelines to the ethical committee. If we have any serious reservations about someone's ability to provide some effective parenting, we may discuss it with the ethical committee. If new situations arise which have got ethical connotations like should we do pre-implantations genetic diagnosis? What I am saying is, if there is a new situation where there was an ethical dimension as to how we handle the eggs or the embryos, we would ask them for that. (4-13)

Guidelines and Precedence

CECs were also used for setting the guidance itself and such general policies were often seen as most appropriately made by a CEC than just by the Unit.

Dr Evens said:

> I suppose one of the issues that has changed in our guidelines, is that we used
> to say that our guidelines should mirror those of adoption, and then obviously
> there's been the change where we have a male age limit, and last year the
> male age limit was removed after discussion in ethical committees that we
> have, to say that well, does it matter? (5-48)

Dr Adams illustrated how his CEC had formulated guidance on a particular issue:

> And the Ethics Committee in the hospital decided that we would also apply
> the same to the self-funding patients, so as a Trust we did not treat lesbian
> couples or single women. We didn't feel quite so badly because there was a
> hospital in Anytown that does. 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.(1-48)

Dr Grant also talked about using the CEC to formulate unit policy on age limits for

male partners (7-27). In the literature CECs have also been advanced as the

appropriate place to write and develop ethical guidelines for clinical practice (see

Doyal, 2001. Sokol, 2005).

CECs were also used if it was thought that the decision might set a precedent for

future cases. Dr Iniman outlines how the decision-making process for a difficult case

might be approached. In this case a couple had wanted to use the husband's father's

sperm, as the husband was unable to produce any himself.

> **So what happened with the couple who wanted to use the father's
> sperm?**
>
> That's only a referral this week, so we've got some in-house discussion,
> which is also a practical thing, which of course he will be too old to fit the
> regulations for a sperm donor. Well looking at the husband's age, I think it's
> very unlikely his father would be of the age to be a sperm donor. So we'll
> have the departmental meeting next week, and either the unit lead clinician
> will write on behalf of us, putting all these comments, or if it's a moot
> decision then we'll go up to the Clinical Ethics. We might take it to them
> 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. (9-35)

It was felt that as there might be cases like this in the future then CEC opinion might

be useful for the clinicians to base act as a precedent for other cases.

How CECs helped in the making of ethical decisions

The informants had mixed views on the usefulness of CECs and Table 5 summarises

their perspectives. The informants highlighted a number of benefits of using CEC:

wider discussion of decisions; decisions made by those who were detached from the

case or situation; transparency of decision-making; and protection for the clinicians.

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, to get a range of opinions from

a broader spectrum of people and therefore to have a more balanced and considered

decision. 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. So I think you come out of your infertility, take the hat
> off and then you listen to them. And I think that helps a lot, you know, you
> listen to other people's views. End of the day, yes, it's the consultant
> decision whether treatment's provided, but these ethics meetings are there to
> guide us in the right direction. (21-21)

Dr Down said:

> Well, their decisions aren't binding on us but we value their wisdom in
> discussing the problem, getting other peoples points of view on it. So, it's
> like a, very much a intelligent sounding board for the decisions that we make.
> (4-14)

And:

> What, whatever sort of training, life experience they've got they'll bring to it.
> It ranges from professors of ethics and medical ethics down to people of
> different religious faiths. So it's a microcosm of the community. (4-16)

Dr Francis, Grant and Novack also reiterated this view:

> But it's people from all different sort of backgrounds really who I feel give a
> more balanced view. Because we can, you know, we just get a bit too
> focused or a bit too kind of narrow really because we do it day in and day out.
> So I think it is good to have that, even if they come up with decisions we
> don't want. (6-45)

Dr Grant:

> Obviously we've got lay people as well, and you learn from non-medical
> people how to approach a case, or why sometimes you as a doctor could be
> advised by certain things. Other lay people in the committee could help you
> to look at things from a different perspective and different side. (7-23)

Dr Novack:

> As a sounding board, but they can just advise sort of generically, because
> they're sensible people who are versed in clinical ethical dilemmas I suppose.
> You don't necessarily have to have, require an expert views in reproductive
> medicine. They just have to be able to think things through. (14-9)

Dr Orben thought that CECs contributed this type of common perspective:

> 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. (15-23)

Dr Percy and Vance also thought that CECs could help keep clinicians' decisions in

line with 'everyday' thinking:

> I suppose really, most of the discussion is actually about making sure you've
> got a sensible considered majority opinion, that a sensible considered
> majority of people think that we should not be treating or we should be
> treating. I guess it's sort of safety in numbers and reassuring yourself that
> your line of thinking is not way out there and that this is acceptable. (16-39)

> Have I thought, could I manage without an ethics committee? I have
> actually. There have been times I've thought well quite clearly this is
> wasting their time, you know. But I do find it, I do get some reassurance
> from it really. I mean if you're going out on a completely wild limb they
> would point that out. You know, if somebody's like completely lost the plot.
> But, you know. (22-34)

CECs were, for the informants, forums where you get a wider range of opinions and a greater sense of perspective on an issue. Therefore, CECs are usually multi-disciplinary bodies and can therefore improve decision-making by bringing together the views and standpoints of a diversity of specialisms and people (Larcher *et al*, 1997. Slowther *et al*, 2001a).

Detachment

As discussed in Chapter Eight, another particular feature of CECs that informants valued was that such committees were not involved in the case, did not know the participants and this enabled the decision to be made more impartiality. When talking about how detachment was useful in making ethical decisions, 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 because we're there at the time.(6-50)

Dr Evens and Dr Brown agreed with this:

> It allows us to bounce ideas off the wall, discussing it, i.e. meetings, and then we'll take it to the ethical committee, and take it forward from there, to ask a sort of a wider group of people who are not connected with the actual delivery of service what their views are. (5-57)

> so you may have a religious sort of person and you may have lawyers and you may just have, you know, I shouldn't say academics but people from completely unrelated disciplines just to look dispassionately at a situation. (2-14)

In aiding the making of decisions that could be said to be more impartial, 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? (16-84)

Dr Vance also made this point:

It's politics really, hospital politics. Because if you do something that people in-house are unhappy about it could leak out and that could get a bit sour. If you take it to the ethics committee it's in the open, and if they disagree, I mean nothing's binding about what the ethics committee say but at least you haven't kept it in-house, you haven't done it secretly. That's the important thing. (22-28)

Protection

Finally, informants drew attention to the protection from censure that a CEC might

give them. Dr Brown said:

Oh, yes, very helpful because when you genuinely do have a problem or you think there's an issue, I mean it gives you guidance. It also gives you some protection in the final decision, hopefully, which is going to be in line with the Ethics Committee in that it is a number of people, if you will. It's decision by cabinet rather than one person's 'well my view is this shouldn't be done, full stop'. (2-20)

Dr Havers said:

You feel also a bit more, having support from an ethical committee in making such a decision, it's an important thing. (8-29)

These benefits of CECs all reinforced the form of decision-making the clinicians

thought was appropriate for ethical issues. The CEC extended their consensus

decision-making by giving them a wider group of people to discuss issues with –

more opinions and disciplines to contribute to the debate. CECs also performed an

important function in helping the informants make impartial decisions, by involving

those who did not have any relationship with the patients or cases, those who were

'detached' from the situation and could, therefore, make more impartial decisions.

Limitations of CECs

Not often used

One of the main points that came out of the discussion of CECs was that they were

not used very often, clinicians did not often present cases to the CEC for discussion.

This is something that has been reported in other studies, (Racine, 2007. Hurst *et al*, 2005. Slowther *et al*, 2001a). In Clinic 4, for instance, there was a hospital CEC that was used by the head of the unit, Dr Novack. However, none of the three sub-speciality trainees at this unit (Drs Quest, Robin and Street) knew there was such a hospital based CEC and when asked about it, Drs Quest and Robin said:

> No, most of the time we don't have a committee like that. Sometimes they have a committee but it's just the consultants and the senior nurses in order to discuss a couple of cases, but I never heard about the ethical committee for specific cases. If we have a very complex case the meeting is between the consultants, us, the doctor who saw the couple, sometimes maybe the GP or, and the senior nurses, that will discuss a case. (17-15)

> Ethics committee? Apart from research local ethics committee. No. Not that I'm aware of, no. (18-13)

This indicated that the CEC was not used very often in this clinic and did not have a very high profile. A number of CECs had folded up due to lack of use, Dr Case said:

> We had an ethics committee supporting this, you know, a separate ethics committee constitute as an ethics committee supporting this clinic, but for a long time they hadn't been used, no cases being put through to them. (3-42)

Dr Kilm's committee had also disbanded:

> 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. (11-25)

A number of informants said that they had rarely used their CECs.

Dr Tarn said:

> Yes I've used them, and I think they have been helpful, and in fact I have been to one of the meetings to present a case - that must be about 18 months ago now, I can't remember. But I think yes, I think they have been helpful. But I think that's only back to the wall, certainly from my point of view, from

the fertility point of view, we were able to resolve most of those issues internally I think. (20-16)

Dr Percy:

> So we haven't actually, I haven't personally had to take a case to the ethics but we do have it, and I think that it is always reassuring to know that it is there. (16-41)

Dr Orben said his unit did not often use the hospital CEC:

> **So the ethics committee, how do you use that?**
>
> Very infrequently is the answer…. but, gosh, if we do that once a year I'd be surprised really. It doesn't happen very often. (15-22)

Dr Novack said the reason he did not use the hospital's CEC much was due to the lack of regular meetings and this meant that the committee could not be responsive enough:

> But not that often because they're busy and the cases are complex and it takes a lot of time, and all these people do it voluntarily. (14-10)

However, Dr Urban and Vance, who both had designated CECs for their Units, mentioned that meetings sometimes had to be cancelled due to lack of items for discussion:

> I've attended to so far two. One there was no case to be discussed, (21-7)
>
> It's only once a quarter, and they quite often have been cancelled. The last one was cancelled because there was nothing to talk about. (22-37)

An explanation for why they did not often use CECs could be (as discussed in previous chapters): first, that largely the clinicians operated within a 'settled morality' in which the majority of their practice did not present greater ethical difficulties (see Chapter Six); and second, that frequently their first port of call was the clinic meeting in which to raise difficult cases and it was in this forum that many of the cases could be resolved. Hurst *et al*, noted a similar finding, 'ethics

consultation appears to be perceived as a last resort rather than as the primary source

of help in cases of ethical difficulty.' (2005:13)

Other limitations of CECs

There were also a number of issues that some informants raised concerning the

limitations of CECs. Dr Jenson thought that often CECs were not representative and

therefore this meant that they were not the best place to make such decisions:

> As society changes so should our views, and I think this is where the ethics
> committee's make-up has to be, is very important and there's certain ethics
> committees that I've been involved with I don't think are particularly
> representative because the vast majority of people who would give up the time to
> sit on ethics committees are probably white middle class people who have their
> own strict view, and may not be representative. (10-30)

He also raised the issue of what cases should be taken to an CEC?

> But the numbers of cases that we're referring to the ethics committee are
> becoming less and less. Even egg donation of, inter-familial egg donation used to
> go to the ethics committee. Why? Go and see the counsellor and gradually you
> will think of what should we be sending, and I think it comes down to exceptional
> cases and then having an ethics committee meets once a month for the exceptional
> cases. Is it worthwhile? (10-34)

He went on to say:

> So ethics committees I think are less involved than they used to be, certainly
> in my experience here. (10-33)

Dr Orben pointed to lack of experience of their hospital CEC when talking about

how often he used the committee:

> Very infrequently is the answer, and it's had different forms over the years and 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 that's, because they are more used to taking decisions about
> funding transplants or, I don't know, some other rare treatments, and so we tend
> to use them now to make those decisions and they seem better able to do it than
> our in-house ones, the one that used to discuss research projects and things like

that, and they really struggled very hard to come to a conclusion with anything we would ask them to do. So, as I say, now it's the PCT. (15-41)

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 support in her clinic.

> But in practice I think that it's been of fairly limited help because it's not got a very clear place in the structure of the hospital unit, it doesn't have any place with the PCT, for example, so I've got to go also through all those layers. So, for example, to do a procedure on a child, it wasn't just taking things to the Clinical Ethics Committee, I went to the Clinical Director, I went to the hospital committee that deals with new technologies. You know, there was more complexities. (9-99)

Dr Havers from the same clinic said:

> We have some hospital committees here, but the committee declined the case; they said that they can only advise on medical issues but not on these kind of issues. And they declined the case actually, so they let us down. And we had to use a bit of commonsense. (8-20)

Here he felt that he did not have access to adequate ethics support, the committee 'let them down' and the team were left to their own devices.

THE DEBATE OVER THE USE OF CECs

Having examined the informants' views and perspectives on CECs, I now want to consider how my data impacts on the wider debate over the use of CECs. There appears to be a need for the medical profession to have more support for their ethical decision-making (RCP, 2005a). If this point is accepted the question becomes, 'what is the best way of providing this support?' This question raises both practical and ethical issues: a solution needs to be both practically workable and ethically

advantageous and it is balancing these two goals, goals that are sometimes in tension, that is the difficult task.

The need for ethics support

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.' (RCP, 2005a:ix) This greater focus on the ethical aspects of medical practice has been well documented (Parker, 2004. Watson, 2005)[211] and a number of reasons have been given 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 'evidence' or for good reasons. The medical profession is now much more closely scrutinised by the media, the public and by internal mechanisms such as professional development reviews and institutional audit (Kerr, 2008). This shift in both the organisational delivery of health care and the increasing focus on ethical issues raised by medical practice has resulted in a number of developments, one of which has been a greater demand for some form of ethics support for health care professionals.

The RCP Working Party conducted a survey of specialist registrars to investigate their experiences and opinions on ethics support and training, and found that:

> Ongoing support from senior colleagues and peers is used and valued, but in addition to this trainees would value having access to clinical ethics support from a wide range of sources. The preferred model is through senior colleagues, clinicians with an interest in ethics or clinical ethicists or CECs. (2005a:34)

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[211] See also Fleetwood *et al* (1989) for a consideration of why CECs developed in the US.

On this basis of this survey and their deliberations, the Working Party concluded that: 'Wherever health care is provided we believe, on the basis of current trends, and our findings, 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.' (2005a:37) One of the main ways the Working Party envisage this support being provided is by CECs.[212] 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, 'there is scope for a greater number of UK neonatal intensive care units…to benefit from general and specific advice of a local clinical ethics committee.' (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 is born out by the increase in the formation of CECs in the last 20 years in the UK (Slowther *et al*, 2001. Slowther *et al*, 2004a).[213] This increase can be explained partly by local reasons, a particularly problematic case or a group of clinicians wanting to have a forum to discuss ethical issues in more detail. Other reasons are related to more general changes in modern medicine as noted above.

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[212] The other ways of providing ethics support recommended are: the availability of a clinical ethicist and an increase in undergraduate and postgraduate ethics education.
[213] See the UK Clinical Ethics Network website, www.ethics-network.org.uk for an up to date list of CECs known to them.

My study also found that most of the informants (with the exception of Drs Jenson and Kilm) found some form of ethics support very useful and this support was in the first instance colleagues at clinic meetings and then, if the need arose, they would use a CEC to resolve a problematic case.

How to meet this demand?

As discussed, one of the main suggestions for how ethics support could be provided was the use of a CEC. I shall confine my discussion to this aspect of ethics support as none of the informants had access to a clinical ethicist and many of the benefits they saw in using CECs when consulting on a particular case, that of extending their consensus, would not be met by consulting with one individual. Dr Grant, for instance, said:

> and in the ethics committee it's not one person deciding but just a group
> reaching a conclusion. (7-70)

This is clearly seeing the CEC as an extension of the process of consensus decision-making that was elaborated in Chapter Seven. The informants thought that ethical decisions should be taken as a group and therefore the use of a CEC was extending this group decision-making further. Therefore, although in many circumstances a clinical ethicist could have been useful, they would not have been able to take the place of a CEC, rather they could have to act in concert with the committee.[214]

The key question is how to organise CECs so that they can be useful and offer genuine ethics support to clinicians rather than simply be an increase in bureaucracy

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[214] There is a debate over whether there should be an ethicist on a CEC (RCP, 2005a. Slowther *et al*, 2001a. Slowther *et al*, 2004).

(Slowther *et al*, 2001a). My data on how the informants thought about CECs can be useful in pointing to ways that such committees could be organised, what possible limitations they might have and how these can be overcome.

What kind of model of CEC?

In my study the units visited had three main ways their CEC or ethics support was organised (see Table 4).[215]

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 and had a rather ad hoc structure.

3. There were three units (Clinics 1, 5 and Dr Vance) who had a designated CEC for their infertility unit, this was a committee organised by the Trust that only dealt with issues from the infertility unit.

Those in clinics with the first form of organisation 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 and Dr Orben (15-41) talked about how, when his unit did have a CEC, they were unable to reach conclusions on cases, so were therefore not very helpful.

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[215] See Slowther *et al*,(2004) for a discussion of discussion of different models of CECs and ethics support (Section A9).

Those clinics with the second form of organisation raised a number of problems with this arrangement. Clinic 4, who used the hospital CEC, had a very low awareness of the existence of such a committee and that ethical cases could be taken there. Drs Quest, Robin and Street did not know that there was such a committee and it appeared to be mainly used by the head of the unit if a case was sufficiently complex to merit extended discussion. Hence, the relationship between a general hospital CEC and the unit might not be sufficiently close to enable it to be a valuable resource for the clinic. Clinic 2, which was served by a clinical ethics group, not a formal CEC, found the ad hoc nature of this support troubling. Dr Iniman (9-99) commented that as this group did not have a place in the hospital structure, she had to consult and approach a number of other bodies and committees to get help with a case. This arrangement was unsatisfactory both for getting an adequate resolution and in the time it took. Dr Havers, from the same unit, also mentioned times when he had not been able to get any support and this concerned him.

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. Although Dr Urban from Clinic 5 and Dr Vance both mentioned that meetings had to be cancelled due to the lack of anything to discuss, the CEC did appear to provide a useful resource for the clinics. Those clinicians from Clinic 1, that had a long established 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.

These three models of CECs offer a useful opportunity to compare and contrast different forms of committee. I would argue that having a CEC designated for a unit is the best 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.

2. A very clear structure as to where ethically troubling cases should go, thereby avoiding the ambiguity that clinicians in Clinic 2 had over where to take cases.

3. Time to adequately discuss issues, a disbenefit of using a general hospital CEC being that they were very busy and therefore might not have the time to discuss all cases.[216]

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 be of more help than a general committee called upon to service all specialities. 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.

6. The committee could organise and be responsible for ethics training and dissemination of information to the clinicians in the unit.

There are also disadvantages of such a designated CEC:

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[216] This was the perception of Dr Novack, whether it is the case that hospital based committees are very busy will depend on the committee. Some hospital CECs do have spare capacity.

1. Amount of use, 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.

    a. 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 clinicians then meetings would not have to rely solely on case presentations. Awareness of the ethical issues raised by infertility treatment is something the HFEA recommend that both the 'person responsible' in the unit and those working in the unit have (HFEA, 2007). Hence, CECs could provide a valuable educational role. Here a clinical ethicist could be useful in advising and supporting the committee in its educational role.

2. Those who did not have any form of committee (as in the first way of organising ethics support) were not overly concerned, so some clinicians do not perceive this lack of ethics support as disadvantageous.

    a. However, one problem mentioned by Dr Orben, that the committee had been little help, might be overcome by a designated committee that could build up a better level of expertise.

3. Some units were very small and it would be difficult to have a designated committee for this type of unit.

    a. This is an important practical problem and a solution 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 forum to take problematic cases.

Thus, I would argue that, if possible, a CEC that was a designated committee for the infertility units would be the most advantageous way of organising CECs in the infertility setting.

Issues in CECs

There are a number of practical problems that any CEC needs to confront. The membership of such committees 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, people from other professions and clinical disciplines and lay people. Therefore, as the RCP report recommends, such committees should be 'genuinely multi-disciplinary' (2005a:38). However, there have been concerns expressed about whether such committees have the appropriate level of expertise and training for members is clearly an important priority (see Williamson, 2008).

The role of such committees also needs to be clarified as 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 is, in practice, uncertain. The legal status of CECs decisions is sometimes unclear to the clinicians and this is a matter that needs to be clarified (RCP, 2005a. McLean, 2007). The HFEA is clear that the responsibility for any decision is that of the 'person responsible' and therefore CECs would only give guidance and advice, they do not have any legal standing as a decision-making body (HFEA, 2000). Educating clinicians about the role of CECs is also important.

One underlying issue concerning CECs is what gives them any moral authority? 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.' (1992:298) His solution to this problem is that the CEC becomes a representation of the moral community of the hospital that has, 'the responsibility for and the representation of those values and practices that define the health care institutions as a moral community.' (1992:297)[217] As argued in the previous chapter, the clinicians do have a shared moral vision that is both constitutive of their profession and linked to a wider morality that enables them to function as trusted professionals. Therefore, it could be argued that CECs should aim to use and build on these values and it is this that gives them their moral authority.

CONCLUSION

From my data it is possible to see why the informants used CECs (to manage disagreement, for complex cases and to set guidelines or precedents); why they found them useful (wider discussion, detachment of decision-makers and protection); and the limitations of such CECs (lack of use, not representative and ambiguity in structure). CECs can provide a useful function in providing ethics support to clinicians and this is a role that could be developed and expanded to give a much greater level of support. The role of the CEC could be extended to include ethics education and fostering a greater awareness of ethical dimensions of practice. This increasing awareness can give the CEC a role akin to a Greek Chorus (King, 1996). The objective of the CEC is not necessarily to make quick decisions or indeed the

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[217] See Reiser (1994) for a discussion of the values inherent in health care institutions and how closer attention should be paid to ensuring that these values cultivate a 'humane ethos'.

'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 (Gillon, 1997). It is this facilitation of the process of ethical decision-making, so important to the informants, that can be strengthened by CECs (Fleetwood *et al*, 1989. Slowther *et al*, 2001a).

The CEC can also act a form of 'checking' mechanism on the clinicians' consensus decision-making. The CEC extends the consensus and provides a forum for that consensus to be debate and subjected to further scrutiny: are the decisions being made ethical defensible? Does the consensus produce robust results? These are all questions that a CEC could debate away from the pressures of immediate clinical practice.

As many authors note (McLean, 2007. RCP, 2005a) more research is needed on the efficacy of CECs, but from my study, while recognising the limitation that it did not survey a large number of doctors, there appears to be a need for such committees and the challenge is to develop these in ethically and practically useful ways.

This chapter has examined how the informants thought about CECs and, from this data and the debate in the ethical and medical literature, made some suggestions as to how such support should be organised and how it can be improved. This qualitative data can provide an invaluable insight into why clinicians used CECs, why they found them useful and the limitations of such committees. Uncovering these deeper perspectives on CECs can provide another strand in the evidential base on the utility of CECs in medical practice.

TABLE 5
VIEWS ON ETHICS COMMITTEES

Doctor	Clinic	Ethics committee (CEC)	Clinic meetings (CM)	What found most useful
1 - Dr Adams	5	Would not refuse treatment without going to CEC, was happy to abide by the CEC's judgements.	Not used to discuss or make ethical decisions	CEC was where any ethical cases went
2 – Dr Brown	5	Found it useful. He would not ask colleagues in a clinic meeting. 'Oh, yes, very helpful because when you genuinely do have a problem or you think there's an issue, I mean it gives you guidance.' (2-20)	Not used to discuss or make ethical decisions	CEC was where any ethical cases went
3 – Dr Case		The one for their unit had folded and they have access to a regional one, he did not use it very often.	Clinic meetings where most decisions made	CM
4 – Dr Down	1	Did use their CEC for difficult cases, but would discuss in clinic meetings first. Found it helpful 'Well, their decisions aren't binding on us but we value their wisdom in discussing the problem, getting other peoples points of view on it. So, it's like a, very much a intelligent sounding board for the decisions that we make.' (4-41)	Also used clinic meetings	Both
5 – Dr Evens	1	Did use one for difficult cases but would discuss in clinic meetings first. Found it helpful.	Also used clinic meetings	Both

		'It allows us to bounce ideas off the wall, discussing it, ie meetings, and then we'll take it to the ethical committee, and take it forward from there, to ask a sort of a wider group of people who are not connected with the actual delivery of service what their views are.' (5-57)		
6 – Dr Francis	1	Did use one for difficult cases but would discuss in clinic meetings first, found it useful. 'But it's people from all different sort of backgrounds really who I feel give a more balanced view. Because we can, you know, we just get a bit too focused or a bit too kind of narrow really because we do it day in and day out. So I think it is good to have that, even if they come up with decisions we don't want. '(6-45)	Also used clinic meetings	Both
7- Dr Grant	1	Did use one for difficult cases but would discuss in clinic meetings first, found it useful. 'I think because there is a variety of people, and not only medical, or not only professional people sitting around the table, so not just fertility physician or fertility expert. So other people that are known as being lay people, they provide insightful comments and suggestions, and different occasions have been quite important for the decision making process. ' (7-51)	Also used clinic meetings	Both
8- Dr Havers	2	Found variable coverage, would use it more if more available. 'But it's good for us because, that was my feeling in these specific cases, but they back us up, which is important. You feel also a bit more, having support from an ethical committee in making such a decision, it's an important thing.' (8-29)	Used clinic meetings as sounding boards	CM
9 – Dr	2	Not that helpful, but bring different opinions. As too	Uses these as well, if can't	Both, but mainly CM

Iniman		informal and no clear better if like LRECs. 'I don't think they do help that much actually, but what they bring is a different perspective. Though some of them are coming from a background of philosophy and ethics, the way that they argue the case is very different.' (9-31) 'But in practice I think that it's been of fairly limited help because it's not got a very clear place in the structure of the hospital unit, it doesn't have any place with the PCT, for example, so I've got to go also through all those layers.' (9-33)	agree go to the Ethics group or if seen as interesting	
10- Dr Jenson		Thought they were not representative, only for exceptional cases and is that worthwhile to have a committee just for that. 'Most ethics committees are chaired by a vicar and their make-up is retired teachers and things like that.' (10-32) 'So ethics committees I think are less involved than they used to be, certainly in my experience here.' (10-33)	Used these more now	CM
11 – Dr Kilm	3	Their CEC folded due to lack of use, didn't find it useful. 'I'm not actually that happy and maybe ask for some more information, or you may suggest that maybe an ethics group makes the decision on your behalf, takes that responsibility away from you, but I don't think that it's a particularly good way of doing it.' (11-16)	Discuss issues in these meetings	CM
12 – Dr Lovate	2	Hardly ever used the Ethics Group	Discusses things at the CM main forum	CM

13 – Dr Marsh	2	Nothing had gone there in his time, but can see the utility of a group decision. 'It's just in those, if there's a big disagreement then, obviously, our effects are very grave, you can seek help from the local ethical committees.' (13-10)	Discusses things at the CM	CM
14 – Dr Novack	4	Due to practicalities doesn't use it that often. Only take complex cases.	Mainly discusses things in the CM	Both
15 – Dr Orben	3	Uses it very infrequently, approaches PCTs for help more as have better procedures	Discusses things with colleagues mostly	Colleagues
16 – Dr Percy	2	Found CEC useful, hasn't taken a case personally. If in the unit they are split or feel strongly take it to the ethics group. 'And I think to my mind if you've got an ethics committee there, you have a group of self-selected people who have an interest and are motivated, you can say that's good, you can say that's bad but I don't think it's going to get better, that is the accepted forum for discussing that sort of thing.' (16-43)	Also uses CM, they are the first port of call	Both
17 – Dr Quest	4	In year and half been there never seen something go to the CEC	This is where any ethical issues are discussed	CM
18 – Dr Robin	4	Not seen anything go the CEC	This is where any ethical issues are discussed	CM
19 – Dr	4	Not seen anything go to the CEC	This is where any ethical	CM

Street			issues are discussed	
20 – Mr Tarn		Used it twice in last two years, found it helpful. 'But I think yes, I think they have been helpful. But I think that's only back to the wall, certainly from my point of view, from the fertility point of view, we were able to resolve most of those issues internally I think.' (20-16)	Most issues resolved in CM	CM
21 – Dr Urban		Has found their CEC useful. 'I do find it is very useful and I think you learn quite a lot from it, and you get a perspective of those people who are not involved with the couple's treatment.'(21-6)	Ethical issues went to EC not so much CM	CEC
22- Dr Vance		Yes sometimes. 'I find it reassuring I suppose. But it is quite a lot about politics, yes. I mean the people on ethics committee are a spectrum of the public. They're not trained in ethics, and the discussions are often not very philosophical really, not very ethical. It's quite a lot about them having a feeling for public opinion.' (22-34)	Would discuss ethical issues in CM and then take them to the CEC if disagreement of a complex issue	Both

CONCLUSION

This thesis was an examination of a particular area of medicine and how that speciality approached and made ethical decisions in everyday practice. It was also about bioethics, arguing for and demonstrating how a particular way of doing bioethics could contribute to a greater understanding of ethics in practice. This understanding was then used to evaluate that practice and make suggestions as to how ethical decision-making in the infertility clinic could be improved and supported. In this conclusion I will discuss the key findings of the study and then examine their possible wider applicability.

OVERVIEW

My interest in studying how infertility clinicians made ethical decisions arose out of a general interest in reproductive technologies and the ethical issues and dilemmas this area raised. Although subject to very tight and comprehensive legislation, there is still a large area of infertility practice that is left to the individual clinician or clinic to organise. Furthermore, the interpretations and use of guidelines can vary between different infertility clinics. My interest was to explore how infertility clinicians made and approached ethical decisions within this regulatory framework. How do the clinicians working in this area see the dilemmas? How do they approach them and what tools do they use to solve them? And, importantly, are these tools adequate? Are they morally defensible? These are areas that have not been subject to sufficient scrutiny and, I thought, worth addressing.

THE METHODOLOGY

To consider these questions I adopted a methodology that was based on an Aristotelian conception of the relationship between theory and practice as a way of both analysing the data and developing ethical theory. An important element of my approach is that a close attention to actual practice can result in refining and developing our ethical theories and principles. The practice can inform theory just as theory can inform the practice – the two are symbiotically related. From this engagement with practice the ways that such theories need to be extended and developed can be determined.

This approach had four key interlinked elements. First, a consideration of the *endoxa*. This aspect is akin to a sociology *of* bioethics where a close attention to what happens in practice and the circumstances of the ethical problem can be combined with the bioethical literature to get a fuller understanding of the issues. Second, ethical theories and principles were used as tools for elucidating and analysing the data. Third, these principles and concepts were specified by seeing how they were used in practice. Specifying principles provides one account of the ways in which they can be made less abstract and the meaning they have in that particular context illuminated. Finally, ethical principles and theories were used to draw normative conclusions about the ethical acceptability of the practice under study.

THE RESULTS

Settled Morality

The first part of the project was to find out how the infertility clinicians thought about and approached ethical issues that arose in their practice. This is in essence

setting out the *endoxa* in the Aristotelian sense, investigating the way the dilemma is played out in all its facets, providing a more detailed description of the issue than is commonly found in (some) ethical discussions. This enabled the circumstances and particularities of the situation to be adequately described, to get a picture of what ethical issues troubled the clinicians in everyday practice and what role ethical issues played.

A fascinating, apparent, contradiction arose. Although the clinicians described their practice as being fraught with ethical difficulties, they also reported not being constantly troubled by ethical issues in their everyday practice. This apparent contradiction can be usefully understood from the perspective of a 'settled' morality. In all clinics it was found there was a wide area of common agreement on many ethical questions. This 'settled' morality provided a framework in which they could go about their everyday clinical duties. It also provided the basis for their ethical decision-making process – a process that was based on reaching a group consensus to resolve ethical questions.

Consensus

A commonly held model of ethical decision-making is that it is individuals who make decisions. This study found this did not apply in the infertility clinic. In this study it was found that the informants made ethical decisions on the basis of group consensus. Much ethical store was put on the process of decision-making. The emphasis was not necessarily on getting a consensus over substantive ethical issues but on reaching a decision over what to do and this decision was validated by the process itself. This process fulfilled an ethical function in ensuring (or aiding) the making of a 'good' decision.

Impartiality

The central feature of this process was the ability to make decisions that the informants saw as impartial. By seeing how they defined impartiality, what elements it comprised of and how they used it in practice, the concept of impartiality could be given content. In this way, the concept of impartiality was given a richness that a purely abstract formulation lacks and this enables us to see if that is an adequate or acceptable formulation of that principle. Thus, the concept of impartiality was specified and a definition of impartiality could be formulated that was meaningful in this context.

The doctors employed a conception of impartiality that was very important for their ethical decision-making. This was a key ethical principle for the informants. Ethical decisions should be made impartially without bias or prejudice or undue influence. The procedural and substantive elements of ethical decision-making became merged – the two were not separable. Thus, the informants' form of consensus decision-making focussed on the importance of the process of how decisions were made and how this procedural aspect conferred the substantive ethical principle of impartiality. This shows that theories of ethical decision-making should not only take into consideration the principles on which such decisions are based but also the *way* decisions are made. This procedural aspect, an attention to how the decision is made, becomes an important part of the ethical assessment of that decision. This study shows that this is an important feature of ethical decision-making that is sometimes overlooked.

Normative Judgements

This raises the question as to whether this form of ethical decision-making is defensible? Is it something that should be supported?

One of the main ways in which such a consensus decision-making process can be morally justified is that there is firm moral basis that underpins it, a 'moral vision' that doctors, by dint of being members of the medical profession, adhere to – an important aspect of medical professionalism. This medical professionalism is geared to gaining and keeping the trust of the wider society and informed by the values of that society. The medical profession no longer operates in isolation. It is now scrutinised and judged by the laity and medical professionalism has to be part and parcel of a wider societal morality. It is, I believe, this underlying moral vision, shared with a wider society that primarily justifies doctors' consensus ethical decision-making. This is not to say this decision-making is perfect. It clearly has its flaws, as previously outlined. The question, in practice, is what is better?

Practical Conclusions

From this focus on the process of decision-making it was possible to make a number of suggestions as to how this process could be supported and improved in practice. The study showed how CECs can make a valuable contribution to this. CECs can be a useful way of supporting ethical decision-making in the infertility clinic. They can be used to extend the consensus, by involving more and varied people in the decision-making process. It can also provide a forum for that consensus to be debated and subjected to further scrutiny.

THE WIDER PICTURE

The question now arises as to the relevance of the findings of this study to other areas of medical practice. Have other studies found that practitioners make decisions on the basis of consensus? Are the recommendations about CECs relevant for other settings?

Consensus decision-making

There are obviously a number of important differences between the kind of decisions doctors in other fields of medicine have to make and those in infertility clinics. Infertility treatment is a voluntary decision – it is not, however much importance we give to childlessness – a condition that *has* to be treated like a heart attack or broken leg. This has a number of implications. First, patients can go elsewhere (if for instance a clinic will not treat them, a same sex couple could travel to a centre that did treat such couples), which is not an option for patients in intensive care, or in any other emergency procedure. Second, there is time to make decisions over who or how to treat, thus these decisions can be discussed in clinic meetings or CECs: there is time to develop a consensus decision-making process. Third, there is an option for the doctors of not doing anything at all to the patient, an option that would not be available for other conditions. Doing 'nothing' in other circumstances, for instance if a patient was arresting and it was decided not to perform cardio-pulmonary resuscitation, would arguably be a particular management decision based on quality of life concerns. Therefore, there are important differences between infertility treatment and more acute medicine that limit the generalisability of these results.

The limited evidence that there is on this presents a mixed picture on whether doctors

make group decisions over ethical matters. Some studies have found that consensus

decision-making is used. Zussman's (1992) study on ICU found that this setting was

one where collective decision-making was emphasised and Melia (2001) in a later

study of ICU in the UK found that, '[c]onsensus and the social processes that

promote it are important in intensive care, as agreement, or at least tacit agreement to

disagreement, is the prime means through which the difficult work of intensive care

is effected.' (2001:718) Hurst *et al*, (2005) in their survey of internists, oncologists

and intensive care specialists found that one reason for doctors seeking assistance

with ethical decisions was to 'seek consensus' and they used discussions with

colleagues and families to create a process out of which would, hopefully, arise an

agreement over what to.[218] However, other studies such as Sorensen & Iedema

(2008) found that the lack of consensus among those involved in intensive care

provision created problems for patient care. Saarni, *et* al (2008), who carried out a

quantitative survey of Finnish physicians' reports of ethically problematic decisions,

found that the area of medicine the doctor worked in made a 'real difference' to the

amount and type of ethically problematic situations reported. Thus, it could be

questioned whether findings of studies conducted in infertility practice can be

usefully applied to other areas.

Further empirical research carried out in other medical specialities could shed an

important light in this area. This would enable some comparisons to be made

between specialities and address questions such as: is this consensus form of ethical

decision-making used in other disciplines? What are the differences between

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[218] See also Pool (2003) who argues that decisions over euthanasia in Holland can be seen as
processes in which various people (patients, doctors, nurses) play a role.

specialities? Are some more hierarchical than others? And what can the different disciplines learn from one another in terms of improving ethical decision-making? There are also more theoretical areas of research that could be pursued based upon the findings of this study for instance: a more extensive examination of theories of consensus could be conducted, looking more closely at the moral warrant for consensus decision-making; and a more detailed consideration of how these findings relate to Rawls' theories of over-lapping consensus and public reason.

Wider Use of CECs

Having looked at the use of consensus in other medical specialities I will now ask whether the usefulness of CECs be transferred to another clinical context?

Other studies that have looked at the cases brought before CECs suggest that there is a demand in other specialities for CEC support for specific cases. Slowther *et al* (2004a) list a number issues brought to CECs from other medical areas and Hurst *et al* (2007) in their survey of European doctors also found other medical specialties using ethics consultation. For UK doctors the first most cited issue was disagreement among care givers, followed by euthanasia and doctor assisted suicide. Of the most prevalent six issues none related to reproductive technologies or infertility treatment. Thus, one can argue that other disciplines are faced with ethical difficulties and clinicians in those areas are under the same external and internal pressures as infertility clinicians to make defensible ethical decisions. As discussed above there is research that suggests other medical specialisms make decisions on the basis of a group consensus and would, therefore, presumably, see the same benefits to be gained from the use of CECs as my informants did. However, it has also been argued

that different specialities have different approaches to shared decision-making (Eisenberg, *et al*, 1983) and therefore these conclusions about CECs might just be applicable to infertility specialists rather than to medicine in general. However, the use of CECs has not particularly been confined to the area of reproductive technologies.

The debate over how applicable these findings are to other specialities is one that cannot be conclusively answered without more research comparing and contrasting the ethical decision-making processes of different specialities. The trends in modern medicine for decisions to be made by multi-disciplinary teams, which involve the patient and the closer scrutiny of all aspects of medical practice, all suggest that consensus decision-making with availability of a CEC, if needed, is likely to become the dominant model in health care practice.

LIMITATIONS

There are limitations to this study. As it was a qualitative study only a small number of clinicians were involved, therefore it cannot be said to be a comprehensive survey of infertility clinicians' views. However, I stopped my data collection when I had reached 'theoretical saturation', when I felt I was not getting any new or different accounts of ethical decision-making (see Chapter Four). Thus, I do not think conducting more interviews would have substantially impacted on my analysis. Also the richness and detail of the data, for example not just asking, 'do you use CECs?' but finding out why they used them and the subtle concerns they had, provided an invaluable insight into what was actually important to clinicians and this kind of data can be used to develop policies on how best to organise such committees.

Another limitation was that I did not observe what actually happened in the infertility clinic, I got my informants' accounts of how they made ethical decisions and these could, of course, be their public face and post hoc rationalisation of their decision-making processes. There are two responses to this: first, as discussed in Chapter Four, with employing a form of respondent validation and by a recognition that these are accounts, I would argue that I built up a good picture of how they made decisions; second, this points to an area of further research. I would like to observe the functionings of an infertility clinic, both to see how it compares to the data collected in this study and to get a picture of the patient's role in decision-making and how the consultations are handled. There are, however, problems with this kind of ethnographic research in that being an observer in the consultation and clinic can affect the event one is observing. Therefore, no research methodology is without its limitations. Another way of approaching the study of ethical decision-making in the infertility clinic would be to conduct focus groups with other members of the infertility clinics; nurses, embryologist and counsellors for example, to build up a different picture of how ethical decisions are made.

FINAL THOUGHTS

This thesis set out to develop an approach to the examination of ethical issues that could both provide an insight into actual practice and develop ethical theorising in that area.

This account of infertility practice can highlight new ethical problems and develop more nuanced moral norms and ethical theories to deal with the conflicts and issues

that arise in the clinic setting. This is what this thesis has attempted to do. This approach has proved fruitful in this study and, I would argue, could be used in other areas of practice that raise ethical issues.

In using this approach I am not arguing that it is the only way of 'doing' bioethics. Morality, ethical problems and issues are complex things that can benefit from many different approaches and theoretical schemas. As Daniels says: '"Doing ethics" involves trying to solve very different kinds of problems answering to rather different interests we may have, some quite practical, others more theoretical.' (1996:339)

Despite the obvious limitations that any piece of research has, it is hoped that this thesis has contributed to the debate on both to how ethical decision-making in this setting can be improved and how bioethics can make a useful contribute to practical problems – these were the overriding aims.

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APPENDIX ONE

CHANGING ETHICAL ATTIDUDES TO SPERM DONATION

This is appendix is a detailed consideration of one ethical issue raised by the development of reproduction technologies – the moral acceptability of sperm donation and the changing attitudes towards it and the changing ethical concerns it raises.

Donor insemination was first used in clinical practice in England in the late 1930s and was generally practised in secret (Nachtigall,1993). In 1945 Mary Barton, a gynaecologist, published an article in the *British Medical Journal* (Barton & Walker, 1945) about her artificial donor insemination (AID) programme. The response to the article was one of outrage and wholesale condemnation of the practice. In 1948 a commission was set up to discuss the issue of AID and concluded that it should be made a criminal offence. Reasons for rejecting the practice were a mixture of religious concerns – an objection to masturbation and the perceived intrusion in the holy sacrament of marriage – fears of the possible eugenic implications and the association with its use in agriculture (Pfeffer,1987). Sperm donors were generally regarded with suspicion and the 1960 Feversham Committee – a committee of enquiry set up by the government to look into the legal aspects of AID – said sperm donating was, 'an activity which might be expected to attract more than the usual proportion of psychopaths' (The Earl of Faversham's Report,1960). The Committee reported that while AID might be an acceptable treatment for some couples, it should be generally discouraged. Thus, sperm donation was seen as an activity that was in itself morally wrong and should not be encouraged.

The demand for AID continued to grow, however, and in 1968 it became available on the NHS if recommended on medical grounds. Subsequently, the 1973 Peel Committee – a committee of the British Medical Association set up to consider human artificial insemination – reiterated this view (The Peel Committee,1973). Sperm donation was gradually moving towards being seen as an acceptable medical technique for the alleviation of infertility.

At the time of the Warnock Committee in 1982, set up by the government to examine the ethical implications of reproductive technologies, sperm donation was a practice that, although not unlawful, was carried out covertly without central record keeping or regulation. The donor offspring was illegitimate at law and the husband of the woman receiving the treatment had no legal responsibility or duties towards the child: the donor was considered the legal father (O'Donovan,1989). The usual practice was for the husband to be entered on the birth certificate as the father. This involved the couple committing an offence by entering false information on the birth certificate, although one unlikely to be found out. Thus, the problems with legal paternity contributed to the desire to keep the practice secret. In this context, donor anonymity was the preferred way of organising such treatment as it was seen as a necessary practice both to protect the donor from parental responsibility and allow the husband parental rights (Dewar,1989).

With the development of technology, egg donation became possible and the debate became about gamete donation rather than just sperm donation. The Warnock committee endorsed the practice of gamete donation and recommended that, 'the AID child should in law be treated as the legitimate child of its mother and her husband, where they have both consented to the treatment.' (Warnock, 1985:85). This resulted in a provision in the 1987 Family Law Reform Act allowing the husband of the woman to be entered on the birth certificate as the father of the child. The Warnock Committee also recommended that gamete donation should be anonymous (1985:15). The reasons given for this decision reflected a number of different considerations: 'Anonymity would give legal protection to the donor but it would also have the effect of minimising the invasion of the third party into the family. Without anonymity, men would, it is argued, be less likely to become donors' (1985:25).

In 1990 the Human Fertilisation and Embryology Act was passed which translated many of Warnock's recommendations into legislation. Although enshrining the practice of anonymous gamete donation the Act itself has, arguably, paved the way for the practice to be questioned. As the question of the donor offspring's legitimacy has been addressed couples do not have to keep the practice secret in order to falsify the birth certificate. At the same time, the donor is protected from any legal responsibility for the child (1990 Act, Section 28 (2)) and the legal status of all parties has been clarified (Morgan and Lee, 1991). Most importantly, in recognising that attitudes towards anonymity could change over time, the Act put in place the information gathering structures necessary for a programme of non-anonymous donation. By legislating in this area the 1990 Act has also contributed to the

growing public acceptance of reproductive technologies by legally sanctioning such treatments (Lieberman & Hamer, 1994). The shame and secrecy which previously accompanied AID has been replaced by a much greater openness and willingness to discuss many of the issues involved (Haimes, 1993).

Thus, once the practice of gamete donation became more accepted and accompanied by a form of legal sanction in both the Family Law Reform Act 1987 and the 1990 Act, the ethical debate shifted towards concerns over how to organise the practice ethically. One of the main concerns over gamete donation was that any resulting children born from the donation would be unable to find out the identity of their gamete donor. Many authors have argued that being denied knowledge about one's biological origins can be harmful to donor offspring (Snowden & Mitchell,1981; Turner,1993).

Sants (1964) coined the term 'genealogical bewilderment' to refer to children who had no or only uncertain knowledge of their natural parents and argued that such uncertainty could have a detrimental effect on the child's mental health. Although Sants was considering the issue in relation to adoptive children, McWhinnie (1996) has argued that such 'bewilderment' can apply equally to donor offspring. Donor offspring are curious about the donor's physical characteristics, family aptitudes and have queries and uncertainties about the donor's medical history. However, some have argued that the concept of genealogical bewilderment has not been support by research evidence. Humphrey & Humphrey (1986) conducted a review of empirical studies conducted in the 20 years since the publication of Sants' paper and concluded that the existence of

genealogical bewilderment amongst adoptees has not been upheld by subsequent research.

In 2000, almost a decade after implementation of the Act, and in the absence of any evident government action to address the issue of information for donor-conceived people, Joanna Rose, a donor-conceived adult, and an unidentified donor-conceived minor, jointly initiated a human rights challenge to the legislation in the English High Court. They claimed that the statutory enforcement of donor anonymity contravened their right to 'respect for private and family life' guaranteed by Article 8 of the 1950 European Convention on Human Rights and Fundamental Freedoms (Rose and Another versus Secretary of State for Health and Human Fertilisation and Embryology Authority, 2002).

While this case was being heard, the government launched a public consultation in December 2001 seeking views on what, if any, information should be provided for donor-conceived people. The government reasserted the previous Administration's position that: 'There is no question whatsoever in making any changes in the law which would allow the identification of people who have already donated sperm, eggs or embryos. Such a change – if made – would only apply to donations made after the introduction of new legislation.' (DH, 2001, para 1.3)

The consultation ended in July 2002 and in January 2003 the government made public

both the substance of the responses to the public consultation and its initial plan of

action (DH, 2003 & 2003a). A significant majority of respondents endorsed the

provision of non-identifying donor information to donor-conceived people, while a

smaller proportion of respondents proposed the complete removal of donor anonymity.

Responding to the consultation, the minister for public health, Hazel Blears, indicated

the government's acceptance of, 'a strong argument in principle for children conceived

using donated sperm, eggs or embryos being able to find out the identity of their donor.'

After further consultations in January 2004, Blears' successor, Melanie Johnson,

announced that with effect from 1st April 2005, all new donors would be required to

agree to their identity being disclosed to any individual conceived as a result of their

donation, if so requested, once they reached 18 (HFEA, 2004).

It can be seen that gamete donation moved from being a technique that was seen as

largely immoral and one that should be carried out in secret, to one that was both legally

and morally accepted. In its gaining acceptance a new ethical concern presented itself –

should donors be anonymous to any offspring produced? The view of this enshrined in

the 1990 Act was that they should be anonymous, but since then attitudes have,

arguably, changed and all donor-conceived people born after April 2005 will be able to

apply to the HFEA for identifying information about their gamete donor once they reach

the age of majority.

Clinician Number	Clinician	NHS *	Private	Both	Length of practice	Sex	Seniority/Position	Clinic
1	Dr Adams			Both	20	M	Consultant	5
2	Dr Brown			Both	14 years	M	Consultant	5
3	Dr Case		Yes		16 years	M	Director of Unit	
4	Dr Down			Both	25 years	M	Clinical director	1
5	Dr Evens	Yes			29 years	F	Consultant	1
6	Dr Francis	Yes			10 years	F	Consultant	1
7	Dr Grant	Yes			2-3 years	M	Senior Registrar, just finished speciality training	1
8	Dr Havers			Both	25 years	M	Consultant	2
9	Dr Iniman	Mostly NHS		Both	20 years	F	Consultant	2
10	Dr Jenson	Mostly NHS		Both	12 years	M	Consultant, head of unit	
11	Dr Kilm			Both	15 years	M	Consultant	3
12	Dr Lovate	Some	Now	Both	35 years	M	Consultant semi-retired	2

		NHS	mostly					
13	Dr Marsh	Yes			Infertility 3 years	M	Sub-speciality trainee,	2
14	Dr Novack			Both	16 years	M	Consultant head of unit	4
15	Dr Orben			Both	24 years	M	Consultant	3
16	Dr Percy	Yes			3 years	F	Sub-speciality trainee, just going onto to a consultant post	2
17	17 – Dr Quest	Yes			3 years	M	Sub-speciality trainee	4
18	Dr Robin	Yes			Medicine 1991, infertility 3 years	F	Sub-speciality trainee	4
19	Dr Street **	Yes			3 years	F	Sub-speciality trainee	4
20	Mr Tarn	Mostly NHS	Some		20 years	M	Consultant, head of unit	
21	Dr Urban	Yes			5 years	F	Sub-speciality trainee	5
22	Dr Vance	Yes			26 years	M	Consultant head of unit	

* Sub-speciality trainees never did private work, only the consultants

** Interview did not record

**ETHICAL DECISION-MAKING IN THE INFERTILITY CLINIC: THE
CLINICIAN'S PERSPECTIVE**

Information Sheet

This project is a small scale qualitative study comprising of approximately twenty semi-structured interviews with infertility specialists from around the UK. The interviews will take about one hour.

The purpose of this project is to explore how infertility specialists manage and approach ethical decision-making in their clinical practice. This project will explore how ethical issues are handled in clinical practice and what regulations and policies clinicians see as ethically acceptable.

Aims of the project - The aim of this project is to examine clinicians' views on ethical issues raised by their infertility practice. The project aims to find out what aspects of their practice infertility clinicians find particularly ethically troubling and how they approach and manage such issues.

Background - Although there has been a substantial body of research on ethical issues raised by reproductive technologies from an ethical perspective and sociological studies on doctors' work in particular areas, there has been little research carried out on the attitudes of infertility practitioners. The aim of this project is to readdress this imbalance.

Work which has led up to the project - I have been interested in the ethics of reproductive technologies for many years and have published widely in this area. Further, I am a health care ethicist based in a Medical School and have an interest in how doctors approach and think about ethics.

Confidentiality - The interviews will be audio taped and then transcribed and maintaining confidentiality will be of utmost concern. In order to ensure complete confidentiality all data tapes, transcripts and files will be labelled with a code rather than the name of the doctor. When the data is reported numbers and/or pseudonyms will be used to designate respondents and care will be taken that any information that could lead to respondent identification or identification of the clinic will be removed or changed. Data will be stored in locked filing cabinets in my office at the University and if stored on computers it will stored on the password protected managed network of the University.

Areas to be covered in the interviews – the interviews will, broadly, cover the following areas: what ethical issues clinicians face in their practice, how they approach such issues, how they resolve any ethical conflicts in their practice, what they think about regulation in this area.

Dissemination – the results of the study will be disseminated in standard academic formats (conference papers, journal articles, and a thesis).

Research subject consent form. Version 2, 18th February 2002

**ETHICAL DECISION-MAKING IN THE INFERTILITY CLINIC: THE
CLINICIAN'S PERSPECTIVE**

Consent Form

I have read the Information Sheet on the above study.

 I agree to participate in the project and I agree to the interview being tape recorded.

………………………………
Please print name

……………………………
Please sign name

**ETHICAL DECISION-MAKING IN THE INFERTILITY CLINIC: THE
CLINICIAN'S PERSPECTIVE**

TOPIC GUIDE

(Remember to TURN ON MICROPHONE!)

1. Background of the clinician

- Length of time working in the clinic, length of time practising, role

2. Information on the clinic setting

- What kind of treatments the clinic offers, number of patients

- How is treatment funded - private, NHS, are there any differences between the
  two groups?

3. Screening recipients of treatment

- How do you determine peoples' suitability for treatment, how do you define
  these factors

- The HFEA Code of Practice says clinics considers the welfare of the child -
  how do you do this? New guidelines?

4. Ethical dilemmas in practice

- What do you see as the ethical issues raised by your practice, how do you think
  about these

- Any examples of bad ethical decisions (by you/anyone else?), where systems
  haven't worked

- How do you resolve any dilemmas/problems

5. Decision-making

- Explore influence and role of colleagues, other places worked that are different?

- How could they make better decisions (support, info, structures?)

- How much ethics training have you had, what did it contribute if anything?

Do you use CECs:

- What is the structure of your ethics support
- Who makes up the ethics committees, what gives them moral authority
- How do you think they make decisions, how do they help?

6. Role of ethics in practice

- What are the underlying principles/imperatives that guides your practice?
- What do you think the relationship between ethics and medicine is?
- How do you see the role/place of ethical issues in your practice

7. Regulation

- What are your views on the regulatory structures in this area?
- How do you feel it affects your professional autonomy?
- Do you have any suggestions for policy changes

8. Conclusions

- Ask them if there is anything else they would like to add
- Ask them if there is anything that I have not covered that is relevant or pertinent
- Tell them about the confidentiality of the collected data and data storage
- Tell them about dissemination plans
- Thank them for their time

APPENDIX SIX

ANALYSIS STRATEGIES

In this appendix I want to describe my strategies of analysis in more detail.

After my initial coding of all the interviews, coding that was conducted after each interview and previous interviews revised in the light of the new interview and associated codes, I had 102 codes. Some of these codes addressed quite precise issues such as: their views on altruistic donors; donor anonymity as a good thing; problems with donor anonymity; views on egg sharing; and decisions made by ethics committees. Other codes addressed more general themes in the data such as: how they made ethical decisions; what they saw as ethical issues; ethos of the clinic; and what they saw as non-medical matters. Some codes were based on my interpretations of the data such as: how they talked about ethical issues; what they saw as the basis for their ethical decision-making; where they adopted a laissez-faire approach to decision-making; how they defined an ethical issue; and transparency of decision-making. Other codes were the informants' opinions such as: problems they saw with consensus decision-making; how useful they saw CECs; problems they saw with conscientious object; and their views on regulation. See the list of codes below.

LIST OF CODES

Altruistic donors
Anonymity as a good thing
Anonymity- problems with
Anonymity - who decides
Basis of morality
Bias
Case-by-case
Clinic meetings
Clinic policies
Clinical area
Consensus - problems
Consensus - protection
Conscientious objection
Consensual decisions
Consultation - what is covered
Counselling
Cycle numbers
Decisions - transparency
Decisions how made
Difference ethical/clinical
decisions
Different views in the clinic
Donated embryos
Concerns over donor gametes
Donor child relationship
Donor numbers fall
Double track on anonymity
EBM
Effective treatment
Egg donation
Egg sharing
Ethics - help
Ethics – how they talked about
it
Ethics - procedure
Ethical issues - what is?
Ethical issues
Ethical motivation
Ethics committee decisions
Ethics committee multi-
disciplinary
Ethics Committees - general
Ethics Committees - refusing
treatment

Ethics committees - shared
responsibility
Ethics committees - usefulness
Ethics training
Ethos of centre
Experience
Expertise
Fairness of decision
Gamete donation - ethical issue
Gamete donation - like adoption
Gamete donation - not like
adoption
Genetic relationship
Good medical practice
Impartiality
Laissez faire
Medical criteria
Multi-disciplinary
Role of the natural
Non-discrimination
Non-medical matter
Not an ethical issue
Obstetrics & Gynaecology very
ethical
Obvious ethical decisions
Patient autonomy
Poor sperm quality
Posthumous donation
Private practice issues
Private practise
Professional autonomy
Protection of recipient
Reasons for stopping treatment
Recipient - age limits
Recipient - BMI
Recipient - information on
donor
Recipient - need for screening
Recipient - screening of
Recipient - strain on
Recipient - treating lesbians
Recipient - treating single
women
Recipient - treatment criteria

Referrals
Refusing treatment
Regulation - HFEA
Regulatory remit of HFEA
Relationship between
ethics/medicine
Relationship between patient
and decision-making
Reproductive tourism
Resource allocation
Right to a child
Right to treatment
SET
Surrogacy
Telling non-directional
Telling not
Telling recipient own decision
Telling the child
Too much treatment
Treating for genetic reasons
Waiting lists
Welfare of the child - defer
decision
Welfare of the child - more
information
Welfare of the child - policies
Welfare of child

I adopted, in effect, two ways of coding my data:

1. I coded the data for precise points and issues – for instance I had a collection

    of codes on CECs which picked out different aspects of the informants' views

    and thoughts on CECs:

    Ethics committees - decisions
    Ethics committees - multi-disciplinary
    Ethics Committees - refusing treatment
    Ethics Committees - shared responsibility
    Ethics Committees - usefulness

2. I also coded the data into general codes as well, so the ethics committee codes

    above were also coded as 'Ethics committees - general'. This general code

    included all the other CECs codes. Another very general code was 'how they

    made decisions', this obviously included a lot of material and was sub-

    divided into codes such as: multi-disciplinary decision-making; benefits of

    consensus; clinic meetings.

Thus, I had two levels of coding: the specific and the general. I did this so that I

would not lose any data when formulating my codes. One problem with any coding

scheme is the decision of what category bits of material should be allocated to (Dey,

1993). Often certain parts of the interview address a number of issues relating to say

CECs that could be coded as both shared responsibility and usefulness. In order to

ensure that decisions such as these were not arbitrary I would also code them in the

'Ethics committee – general' code.

When I began to analyse my data I could search it for specific issues, such as the role

they gave to experience in making ethical decisions, and very general issues, such as

how they made decisions. ATLAS allowed me to print all the quotes and associated

memos of a code and would also highlight all the codes associated with the particular quote. For example:

> P 1: Int-1-m.doc - 1:38 [Yes, so nobody's refused treat..] (116:116)   (Super)
> Codes: [Consensual decisions] [Ethics Comms general]
> No memos
>
> Yes, so nobody's refused treatment without going - well, refusing to treat is done by the Ethics Committee, on which there's only one doctor, the rest are all non-doctors. And that's not me; I present the cases, but we have a - there's one gynaecologist, two nurses, two counsellors, an ethicist and a lay member of the public.
>
> P 2: Int-2-m.doc - 2:20 [Oh, yes, very helpful because ..] (75:75)   (Super)
> Codes: [Consensual decisions] [Ethics com decs]
> No memos
>
> Oh, yes, very helpful because when you genuinely do have a problem or you think there's an issue, I mean it gives you guidance. It also gives you some protection in the final decision, hopefully, which is going to be in line with the Ethics Committee in that it is a number of people, if you will. It's decision by cabinet rather than one person's 'well my view is this shouldn't be done, full stop',
>
> P 3: Int-3-m.doc - 3:34 [So if a new situation arises, ..] (82:82)   (Super)
> Codes: [Consensual decisions]
> No memos
>
> So if a new situation arises, and I can't envisage any at the moment, but as each new situation has arisen we've had a request from, say, a same sex female couple, we want treatment with donor sperm, when that first happened we sat down and said did we want to do that in this clinic and how did we feel about it, and we decided not to because we felt since we're a small number of people,

Therefore, I could easily see which codes were associated with which quote.

I used my coding scheme to help me find bits of data and initially to aid me in seeing what was going on and what the general themes of the data set were. When I had finished my data collection and had reached the position of having a stable set of codes I did not embark on further refining of the coding structure. Dey (1993), for instance, recommends slicing and splitting codes to further refine data analysis. I thought that as coding is a tool to organise data and make it more accessible it should not be slavishly followed simple for the sake of coding. When I began writing about the data, a task I undertook along side data collection in the form of memos, I would

look both at the quotes produced from the codes (at their various levels) and also the transcripts themselves. As I conducted all the interviews myself and, although the 22 interviews produced about 660 pages of transcripts, I became very familiar with my data. I read each interview as an event in itself and saw it is a narrative to answer questions such as, 'what does Dr Brown think of CECs? How does this fit in with his views on ethical expertise?'

Coffey & Atkinson (1996) argue that a useful way to see an often mentioned goal of qualitative research, that of producing 'thick' analysis, is to see it meaning the use of multiple analytic strategies. 'We believe that it is important for qualitative researchers to explore their data from a variety of perspectives.' (1996:4) Therefore, I used both a coding strategy to make sense of the data and also a more narrative approach that looked at each transcript and sought to see what stories and themes developed in the interview as a whole.

As a way of making my data analysis more transparent I have include three sections from different transcripts to illustrate how I coded particular segments of data. As discussed in Chapter Four it is impossible to present one's whole data set and coding for approval to ensure validity. However, we can develop 'shorthand procedures' (Seale, 1999) to exemplify the validity of the research.

Notes on the segments

The star symbol is the code.

The hand-writing symbol shows there is a memo associated with that bit of the transcript (see an example of a memo in Chapter Four).

ETHICAL TOPICS - COMMENTARY OF THE GRAPH

Issues or topics that were only mentioned once are not included on the graph. They

are tabulated below.

Posthumous use of sperm/eggs	1
Not giving treatment too soon	1
ICIS interfering with nature	1
Donor embryos	1
Should we do IVF?	1
Single women, treated?	1
Male age treatment limit	1
Embryo donation	1
Social sex-selection	1
IVF league tables	1
Storing gonadal tissue - adults	1
Treating recipients as a couple	1
Older donors	1

EXPLANATION OF THE CATEGORIES USED IN THE GRAPH

Welfare of the child – this was something that was mentioned by all the informants

in some form as a recurrent ethical issue they faced in their practice.

Non-anonymity – this is a reflection of those clinicians that thought that the law

change on donor anonymity (that made donors non-anonymous to any future

offspring) was a wrong and that it affected their practice in reducing donor numbers.

Egg-sharing – this was the ethical problems raised by programmes of egg-sharing,

some clinics did not do this (Clinic 1) as they thought it was unethical.

Funding disparity – this is the differences in funding criteria from region to region

and the unfairness of criteria such as not having any children living with you as a

criteria for getting funding for infertility treatment.

Gamete donation – this category includes worries over whether it should be done at all, how to tell the child and if they should be told, problems with egg donation, such as if donors should be allowed to choose the recipient.

Who to treat – this category could be categorised as an aspect of welfare of the child, but the seven instances that are included in this are specific cases such as: a transsexual using their own sperm; a gay man who had stored his sperm wanting to have a child with his sister's lesbian partner, where the informant deliberated over whether they were suitable for treatment, and any refusal could/would have been couched on welfare of the child grounds.

Treatment age limit – pre-menopausal – this category is those women usually between 40 and up to natural menopause and the informants were unsure if it was ethical to treat them as the success rate would be so low in that age group.

Recipients with severe health problems – here is the issue was should those patients with very severe health problems, one case was a women with cardiac problems, be given treatment due to the risks to their health. Some thought that if the patient accepted the risk why should they refuse, but there was a welfare of the child consideration if life-expectancy was reduced.

Cross-cultural differences – this was ethical issues raised by differences in recipients cultures, such as Jewish orthodox couples not having sex at the right time of the month, one informant mentioned difficulties with couples who could not speak English, two informants mentioned the problem of recipients (Jewish and Muslim) wanting to get a religious representative to inspect the laboratories where sperm was stored.

Same-sex couples – a number of informants (five) thought that it was unethical to treat lesbian couples.

Multiple births – this was the issue over how many embryos to transfer and the problems created by multiple pregnancies and births.

Private practice – four informants highlighted ethical problems that could be raised by practicing privately, for instance giving couples unnecessary treatment and biased advice on treatment options.

Partner age difference – this was the issue of a large age difference between partners, the four informants who talked about this were concerned with older men and younger women and if it was appropriate to treat such couples.

Treatment age limit – post-menopausal – all the informants who mentioned this were against treating post-menopausal women.

Inter-family gamete donation – this was people wishing to use their relatives as gamete donors and the cases the informants found problematic were, fathers acting as sperm donor for their sons and daughters donating eggs to their mothers. These cases were thought to be unacceptable and they would not offer treatment.

When to stop treatment – this was the issue of how many cycles a couple should be given, not on financial grounds, but on the grounds of the couples' best interests.

Reproductive tourism – this was the problem of patients going abroad for treatment, either coming home with problems that would then have to be managed in the UK, or the issue of getting treatments that would not be available here due to ethical concerns.

Foetal reduction – the issues raised by having to reduce multiple pregnancies through selective abortion.

Pre-implantation genetic diagnosis – this was a disquiet with the procedure and what conditions it should be used for.

Payment of donors – this was the issue over much and if at all donors should be paid. One respondent thought it was wrong that private clinics made money out of donors (by charging high fees for treatments using donated gametes) when donors were only paid expenses.

Surrogacy – complex issues surrounding the use of this such as, if the surrogate does not want to give up the baby.

Storing children's' gondal tissue – this was the issue of when to do this, if the child was having chemotherapy for example, and if that was creating problems for the future.

Posthumous use of eggs and sperm – this was raised in context of a woman who wanted to use her dead husband's sperm, the informant thought that this was alright but it was discussed in the CEC.

Giving treatment too soon – this was the issue of giving IVF before it was established that the couple needed it. The example given was of a couple in their very early thirties being given IVF after only a year of trying, the informant thought that this was too early and was harmful to the couple.

ICIS – the informant wondered if ICIS was interfering with nature, as it circumvents male infertility.

Donor embryos – these were thought to be more ethically problematic than simply donating gametes, as the embryo was thought to be more akin to a child and the resulting child would not be genetically related to either of the couple.