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Dilemmas in fetal medicine: premature application of technology or responding to women's choice?

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Abstract

It is argued that innovative health technologies (IHTs) may be changing the roles of both patients and health practitioners, and raising new issues, including ethical, legal and social dilemmas. This paper focuses on the innovative area of fetal medicine. All fetal treatment necessitates accessing the fetus through the pregnant woman's body, and non-surgical treatments have long been a part of pregnancy care. However, recent developments in this area, including the increasing routinisation of sophisticated antenatal ultrasound screening and the introduction of treatments including fetal surgery, may mark a shift in this specialty. The paper explores such shifts from the perspectives of medical and midwifery practitioners working in two Fetal Medicine Units. It examines the apparent effects of the orientation of fetal medicine on prevalent conceptualisations of the maternal-fetal relationship, and some of the consequences of this. It is argued that new forms of uncertainty, including complex risk and diagnostic information, and uncertain prognostic predictions set within the rhetoric of non-directive counselling and women's choice, are leading to unprecedented ethical dilemmas within this area. More widespread debate about such potential dilemmas needs to take place before, rather than following their introduction.

Keywords: Fetus, Antenatal screening, Innovative health technologies, Fetal surgery

Introduction

Innovative health technologies (IHTs) such as new imaging techniques and genetic diagnostics may have the potential to diagnose, treat and possibly even prevent illness and disease. However, it has been argued that much of the promise of IHTs relies on mobilising optimistic claims about their future therapeutic benefits whilst concurrently failing to draw attention to possible uncertainties (Webster, 2002; Williams, Kitzinger and Henderson, 2003). Webster argues that these technologies are redefining the scale, scope and the boundaries of medicine, with the potential to:

. . . re-invent the boundaries of the body in space and time . . . [they] can both reduce the body to its basic biochemical constituents and reconstruct them in novel ways (2002: 446).

Others have highlighted the ways in which, particularly in fields such as genetics, not only are bodies reconfigured, but the relationships people have with each other are changed (Franklin, 1997; Edwards, 1999). Such analyses complement a broad-ranging literature which explores how new reproductive technologies might impact on the status of the fetus, and consequently, on women (e.g. Spallone, 1989; Duden, 1993; Casper, 1998; Williams, Alderson and Farsides, 2001).

Such technologies also raise new issues, including ethical, legal and social dilemmas. Fox (2000) argues that recent advances in biomedicine and medical technology lie at the very centre of the uncertainty that underpins the recent development of bioethics, stating:

. . . . US bioethics implicitly deals with uncertainty – fraught questions of value, belief, and meaning that are as religious and metaphysical as they are medical and moral. What is life? What is death? When does a life begin? When does it end? What is a person? What is a child? . . . Is it better not to have been born at all than to have been born with a severe genetic defect? How vigorously should we intervene in the human condition to repair and improve ourselves? And when should we cease and desist? (2000: 422).

Such uncertainty also carries through into the forms of diagnosis that IHTs are able to generate, particularly those in the areas of genetics. As Webster argues, these are 'more likely to depend on the language of risk and probabilities than the language of causality' (2002: 447). One key area where risk language predominates is that of antenatal care, specifically prenatal screening. Rapp's (1999) seminal work in this area highlights many of the dilemmas that pregnant women currently face within the predominant Western biomedical model of pregnancy, where choices and decisions are often based on uncertainty:

At once conscripts to techno-scientific regimes of quality control and normalisation, and explorers of the ethical territory its presence produces, contemporary pregnant women have become our moral philosophers of the private . . . important cultural and political tensions concerning the limits of individualism, privacy, and bodily integrity have been represented by and played out in our potentially reproductive bodies (1999: 306).

In contrast, this article examines the development of an innovative specialty, fetal medicine, from the perspective of health practitioners, exploring their views of the work they perform, and how they perceive the decisions taken by women and their partners. In so doing, it aims to add to the growing number of sociological and anthropological studies which explore the ways in which ethical dilemmas and reasoning occur in the clinical situation (Haimes, 2002; Hedgecoe, 2004). Such studies contrast with the dominant, disembodied ways in which ethical reasoning is traditionally presented in philosophical bioethics. For example, partly in order to dissociate itself from eugenics, antenatal screening values the principle of nondirectiveness as a key feature. It is believed that client autonomy can best be encouraged within this approach, with only the client's values being discussed within the counselling process (Fine, 1993). Doubts, however, have been expressed about how achievable non-directive counselling is in clinical practice. Williams, Alderson and Farsides (2002a) describe ways in which the boundary between choice and coercion is not a clearcut one for health practitioners, with slippage occurring between these concepts. Similarly, Corrigan's (2003) work on informed consent in the context of clinical drugs trials illustrates how the focus on patient autonomy may be experienced by patients as abandonment. More specifically, this paper aims to explore the possible consequences of what Getz and Kirkengen (2003) recently described as the 'unprecedented ethical dilemmas' occurring as a result of the increasing routinisation of ultrasound screening in pregnancy. It should be stated at the outset that although the paper focuses on the fetus, I place this topic within the overall framework of women's health issues (Casper, 1998; Michaels and Morgan, 1999).

Method

This paper reports on one aspect of an ongoing project which focuses on the extent to which genetic developments and new reproductive technologies might be changing practitioners' and policy makers' perceptions of the fetus, women and the maternal-fetal relationship. Following Ethics Committee approval, part of the research project has involved observation in two London hospitals, in a variety of clinical settings which pregnant women attend. Twenty in-depth interviews have been carried out with a variety of practitioners working within these hospitals, selected because their work brings them into contact with pregnant women and fetuses in different, often contrasting settings. In order to set the study within a wider context, interviews are also being carried out nationally with individuals selected as having particular perspectives on women and fetuses, for example, representatives of disability rights groups, and eight such interviews have been completed.

The paper draws on the interviews carried out with the 13 practitioners who worked in, or were specifically linked with the two Fetal Medicine Units (FMUs). The interviews were conducted as 'guided conversations' (Lofland and Lofland, 1984), in order to encourage respondents to give their own accounts and meanings. Interview themes vary according to the individual, but core themes include topics such as the values and beliefs which inform the individual's thinking in relation to fetal status; the influences on their thoughts about fetal status, including any specific policy documents and articles; and whether genetic and other technologies are changing maternal-fetal relationships. With permission, all interviews were taped and transcribed. Transcripts were analysed by content for emergent themes (Weber, 1990), which were then coded (Strauss and Corbin, 1990). To protect anonymity, each individual has been allocated a number.

Themes

The findings section will look briefly at the rise of fetal medicine, and the possible effects of its orientation on prevalent conceptualisations of the maternal-fetal relationship in FMUs. It will then explore the ethical dilemmas and decisions that are arising in this innovative area and some possible reasons for its expansion, before looking at the potential effects on practitioners.

The development and current orientation of fetal medicine

To understand its current orientation, it is important to look briefly at the historical development of fetal medicine. In the 1960s, the successful treatment of previously fatal haemolytic, or rhesus fetal blood disease, combined with the expansion of ultrasound use, marked a distinct rise in this medical specialty. All fetal treatment necessitates accessing the fetus through the pregnant woman's body, and non-surgical treatments have long been a part of pregnancy care. It is however argued (Williams, 2005) that recent innovations in this area, including the increasing routinisation of sophisticated antenatal ultrasound screening and the development of treatments including fetal surgery, which requires the pregnant woman to undergo surgery (usually under a general anaesthetic) may mark a further shift in this specialty.

At the time this study was undertaken, a variety of fetal procedures were offered in the two FMUs. These included fetal surgery for diaphragmatic hernias; fetal blood sampling; the use of catheters to drain excess fluid from fetal organs; fetoscopy, used to diagnose and treat fetuses; laser surgery for twin to twin transfusion; selective termination of a

fetus in multiple pregnancies, where the other fetuses were at risk; feticide (which usually involves injecting the fetal heart with potassium chloride under ultrasound guidance, leading to almost instant death of the fetus) for fetal anomalies. In terms of the current United Kingdom law in relation to termination of pregnancy for fetal anomalies, for any anomaly identified in the first or second trimester (up to 24 weeks gestation), termination can be offered. Before the passing of the Human Fertilisation and Embryology Act in 1991, parents were not given the option of terminating a pregnancy if a fetal anomaly was discovered after viability, although labour could be induced early. UK law now allows termination of pregnancy on the grounds of serious fetal anomaly at any gestation up to term (40 weeks) (Statham, Solomou and Green, 2001), although late terminations for fetal anomaly make up a very small percentage of total terminations performed.

The majority of fetal procedures are performed using ultrasound, which requires specific skills of the practitioner. In the two FMUs where this research was carried out, practitioners felt that factors such as this may have had implications in terms of the development and orientation of the specialty:

Obstetrician 15: I think the impetus for what is now maternal-fetal medicine as an accredited sub-specialty came largely from fetal medicine doctors, because for a long time it was recognised that you had to have special skills to do it, because you needed to know how to scan, how to needle, etcetera, and that was clearly something that not everybody could do, whereas dealing with sick mothers, of course everyone can do that to some extent, because you don't need a special skill with your hands to do it ...

Midwife 7: I think it's interesting that a lot of the training of doctors in the maternity speciality has focused on the fetus, so we've got sub-speciality trainees in maternal-fetal medicine, but a lot of the emphasis is on the fetal medicine bit.

In these FMUs, the orientation of the specialty, with its focus on the fetus, appeared to have implications in terms of how the maternal-fetal relationship was envisaged, and this will now be explored.

Conceptualising the maternal-fetal relationship

The maternal-fetal relationship is a unique one, characterised by some as a symbiotic relationship (Getz and Kirkengen, 2003); by others, as a relationship between two separate entities (Chervenak et al., 1999). Within the dominant Western tradition of biomedical ethics, the four major principles of justice, respect for autonomy, beneficence and non-maleficence are predominately individualised concepts, containing little capacity to balance the competing needs of patients (McLean, 1999). Zussman (2000) argues that we know little about how physicians handle conflicts arising from commitments to more than one patient. However, he is referring to possible conflicts between two or more individual patients. It could be argued that even less is known about how practitioners working in the innovative area of fetal medicine manage possible conflicts between the fetus and mother. The practitioners interviewed highlighted specific issues in terms of managing the different needs of mother and fetus:

Midwife 6: . . . we call it the Fetal Medicine Unit, but in fact that's not true because you actually have to go through the mother in order to get to the fetus, and everyone is so preoccupied with what's OK for the fetus that we actually

forget what the mother has to go through . . . consideration is given to the mother, but not to the same extent and maybe that's not a good thing.

FMU consultant 8: Obviously we are focused very much on the fetus because that's what we do but you can't ignore the parents in all this and you have got to involve them in absolutely everything and keep them informed of everything . . . so you can't really separate one from the other.

Midwife 7: And the babies that are being discussed, or the fetuses I suppose is technically what they are, again the focus is very much on the fetus and when it can be born and what's the optimum time for the baby to be born, and there is very little mention in those discussions about the mother . . . Of course those are babies that not so long ago you wouldn't have been planning for at all because they wouldn't be surviving. So in terms of planning and managing the service the needs of the fetus in their own right are considerable really.

FMU registrar 14: It's a very glib term, the fetus as patient. I think the fetus is obviously a patient, but I think that most of us think in a way of the fetus as a subsidiary patient to the mother, if that makes sense? . . . the fetus becomes an integral part of it, and whether that's in overlapping pie charts or as a subsidiary, I don't know.

As might be expected, this unique relationship set within the developing specialty of fetal medicine led to specific dilemmas in the clinical context.

'Unprecedented' ethical dilemmas and decisions?

Gertz and Kirkengen (2003) argue that the implementation of advancing biotechnology places clinicians in obstetrics and fetal medicine in a situation where medicine, social values and culturally determined meaning are closely intertwined, whereby practitioners find themselves presenting unprecedented ethical dilemmas to parents, which might involve diagnostic options such as amniocentesis, that endanger the lives of 'normal' fetuses. Practitioners certainly acknowledged these decisions as being particularly difficult for women and their partners, as illustrated below:

FMU consultant 13: A good example is parents we see at 20 weeks where there is a mild dilatation of the cerebral ventricles where we could say, 'look, there is something like an 85–90 per cent chance that this fetus is going to be OK', but we may not be able to explain during the pregnancy why these ventricles are enlarged. It can be a normal variant, but if they are unlucky they will have a baby that's going to be mentally handicapped. Most couples, given the odds of 10 per cent that the baby is going to be handicapped, most will take a risk, but they would be very, very anxious obviously. On the other hand with severe ventricular dilatation we would say there is a 90 per cent chance that the baby is going to be handicapped in which case most couples will terminate but they feel very guilty about the possibility that their baby might have been the 10 per cent that would be OK . . . I think our counselling is better, but I'm not saying that's easier, I think it's often more difficult for parents.

In other situations, a definitive diagnosis may be possible, but only following an invasive test such as amniocentesis. However, these procedures are not without risk, including a generally-cited miscarriage rate of one per cent, and this can lead to further dilemmas:

FMU consultant 8: I think there must be a lot of people that we worry unnecessarily, however much we try not to, and we always leave it very much up to the parents whether they have an invasive test or not, but I think it's hard . . . I think it's more the ones where there are minor things and people feel perhaps they should do something and have an invasive test where perhaps they don't want to. Or you get the situation where it's usually the partner, the husband says, 'Have a test', and the wife says, 'No, I don't want one', which is awful for them because they totally disagree and you get the situation where one is saying one thing and the other is saying the other, and they can't agree and they want you to tell them what to do and you know you can't.

It should also be noted that for conditions such as Down's syndrome, a diagnosis gives little indication of the severity of the condition. Consultant 13 goes on to indicate why she believes these decisions may be more complex than other healthcare decisions:

FMU consultant 13: We are dealing with patients who have more options, they have more things to consider than maybe a patient being offered bypass surgery for coronary heart disease. They are having to make decisions for themselves and for their children, and not only for the child that's unborn, but for the children that they already have . . . for many parents the issues are about, 'how am I going to feel about my other children having the responsibility for this individual 20 years down the line?'

It does appear that in a variety of ways such ethical dilemmas and decisions may indeed be 'unprecedented' (Gertz and Kirkengen, 2003), supporting Rapp's notion of pregnant women becoming 'moral philosophers of the private' (1999: 306). Some of the immediate inter-related factors which help make such decisions unprecedented include: the uniqueness of the maternal-fetal relationship; decision making based on what is often risk and probability-based information; the option of obtaining a definitive diagnosis which may itself result in miscarriage; the influence of enhanced visualisation technologies; decision making in a highly-charged moral area, where both partners may have differing views about available options; the rhetorical emphasis within prenatal screening of non-directive, value-free counselling and informed choice. Obviously there are wider influences on such decisions, including prevailing social values and the cultural meanings of, for example, disability. Getz and Kirkengen (2003) argue that: 'Medical information about the unborn child, considered as value neutral within the biomedical paradigm, is thus transformed into a profound and private moral dilemma' (2003: 2051). However, practitioners are also closely involved in presenting the information and options to women and their partners, and in addition, have their own moral views and boundaries to contend with.

Imperative to 'do something'

Following a diagnosis, the felt imperative to 'do something' was an issue practitioners discussed a great deal, both from their own perspective, and from the perspective of mothers and their partners. Fox (2000) draws attention to the work of Parsons, who argues that 'the combination of uncertainty and the doctor's strong emotional interests' in successfully treating the patient can often lead to medically 'ritualised optimism' and bias in favour of active intervention (1951: 428–70). 'Doing something' in this particular setting could range from women having a late termination of pregnancy because of a fetal anomaly, to undergoing fetal treatment with a reasonable chance of success, to

experimental fetal surgery with a low chance of success. In terms of practitioners' perspectives, there was a commonly-held view that practitioners themselves often found it difficult to cease, or not commence, treatment:

Midwife 6: It's trying to put something right that maybe can't be put right, but because we have the technology we really feel that we should have a go, and the mother is so focused on her baby and trying to do the right thing for it that that's what she's going for at her own expense, her own discomfort, her own sense of not knowing what is the right thing to do . . . because sometimes you just have to say, 'Well, actually, we can't help this baby'. We're not very good at that.

FMU registrar 10: I think that's because the professionals are in a permanent state of feeling that they have to do absolutely everything, even though absolutely everything is not only pointless but also extremely expensive . . . and they are prognoses that you just know are going to be awful, but you pursue them, and the mother is too scared to say no, or feels that because you want that she should too . . .

One consultant obstetrician felt that she had a different approach, partly because of her combined professional focus on both the mother and the fetus:

Obstetrician 15: I suppose I am more cautious, although in a way it's actually quite radical to stand back and say 'No', because people very much often feel that any intervention has to be a good thing . . . and I do think there is an element among some practitioners in fetal medicine to just have a try at something, almost for the sake of it, because the situation is so dire without, which is not something that appeals to me at all . . . Some people will say that's pushing the field forwards and I accept that it may well be, but I think there is also an issue of uncontrolled experimentation because the situation is desperate, of which I'm very wary . . . I think there's a limit beyond which the fetus is not salvageable and we should accept that, and unlike a lot of fetal medicine doctors I also deal particularly with maternal medicine as well, so I am perhaps more focused on the mother and the fetus together, rather than just the fetus.

The notion that the technology seemed to have a momentum almost of its own echoes the work of Williams, Alderson and Farsides (2002b) and Brown, Rappert and Webster (2000), who draw attention to the ways in which agency may be attributed to actual technologies, so that they are seen to be developing 'naturally along identifiable lines' (2000: 9). In terms of a medically 'ritualised optimism' and bias in favour of active intervention (Parsons, 1951), it seems that many practitioners working within the FMU setting felt an obligation to offer intervention, particularly within the context of non-directive counselling and informed choice.

Practitioners also recognised that women themselves might find it difficult to decide against treatment, as can be seen from the following quote in relation to a woman opting for experimental fetal surgery:

FMU consultant 13: Because she [mother] is clutching on to a hope at the moment but the chances of us saving this baby are small . . . for this particular baby because of the severity of the diaphragmatic hernia we said to her that we thought it was about a 10 per cent chance of the baby surviving. She was offered the option of termination of pregnancy or continuing knowing those were the

odds, or trying the experimental procedure, and we were very honest with her, that there were very small numbers and that to date we had had two survive and two had died . . .

Within the context of non-directive counselling and informed choice, such decisions could lead to ethical dilemmas for practitioners:

FMU registrar 14: With scanning and the ability to see and diagnose and actually offer treatment for many conditions, I think obviously mothers become more focused on that and they understand that something can be done, so they want more to be done for the baby . . . I think ethically it's very hard when you've got mothers wanting to do everything they possibly can.

Midwife 7: I am amazed at what some women put themselves through, and I always wonder if I was in that position would I have done the same? For some women who are not even living in this country there is a high cost and there is a high emotional distress . . . and what are we saying to women about the need to have a child? A lot of these women see it as their last resort, but maybe we should be encouraging them to see other possibilities of having children . . .

As with other prenatal technologies, it is possible that the very offer may be seen as a recommendation by women (Press and Browner, 1997). Again, this indicates the difficulty of providing non-directive counselling, and one of the possible ways in which slippage between choice and subtle, if unintentional, coercion can occur (Williams, Alderson and Farsides, 2002a).

Particular groups of women were seen as possibly more likely to opt for, or to be offered, experimental procedures:

FMU consultant 13: You do get some women who have fundamental Christian or other moral values so that for them, termination would never be an option, in which case we may try difficult procedures if we feel that a couple are psychologically prepared for it not to be successful perhaps, and the same thing applies to parents who have had a very long history of infertility. I remember very well a couple who had had 15 years of infertility, and it was almost a last-ditch effort to try and conceive and she did and the baby unfortunately had an obstructive hydrocephalus which was going to result in a severe handicap, and it had never been tried before but we tried to do a procedure that involved putting a telescope into the brain and actually making a hole in the ventricular system to drain that. It wasn't successful and the baby died, but that was an example where any other couple for whom termination would be morally acceptable would usually choose that, if the odds were so poor.

This study does not directly explore the views of women making decisions about fetal treatment. However, the views of practitioners about women and the choices they make bears some relation to the work of Franklin (1997) on in vitro fertilisation (IVF):

IVF is described as a 'hope technology' because it is the hope it promises, as much if not even more than a 'successful' outcome, which leads it to be seen as a desirable option, even when it is expected to fail . . . Women who successfully give birth to IVF babies will feel in their relationship to those children the sense of achievement that child literally embodies. Women who are unsuccessful can feel a

different sense of achievement, of having tried everything possible and having determinedly persevered to the extent of their endurance or their emotional, physical or financial limits (1997: 192–3).

Although there are similarities with the work of Franklin, in that aspects of fetal medicine can be seen as a 'hope technology', one of the key differences is the specific consequences that decisions about the fetus can have, particularly in relation to late terminations of pregnancy. This was recognised by practitioners as being a potentially difficult part of their work, as can be seen in the following section.

'Detached concern'

Drawing on the work of Merton (1976) to describe the work of nurses, Chambliss (1996) argues that nurses routinely care for their patients in the form of a 'detached concern', holding their personal feelings 'in check', whilst remaining open to the feelings of the patient. In difficult circumstances this can be more challenging, and a 'special effort' is required for nurses to keep a 'professional' detachment. All the practitioners interviewed described situations when they were struggling to maintain 'detached concern':

Midwife 6: Oh yes, yes. Particularly when it comes to very late terminations, those at 28 weeks onwards, it's horrendous. It's just – whilst I say I can separate myself intellectually I still come out and cry because it's just so awful.

FMU registrar 10: I find it [observing terminations of pregnancy] really hard, even being faced with the most hideous abnormality . . . even then, it's so hard to watch the procedure being done. I know ultimately I will even have to do them, and I think it's the right thing to do in those circumstances, but no, that child could be yours. It's so hard and you can't think like that, you can't imagine it until you're there.

FMU consultant 13: I think the interesting thing is how little we consider these issues on a day-to-day basis until somebody cracks through the veneer and it's obviously there, because we have all caught ourselves, our eyes welling up occasionally, completely out of the blue, and you think, 'God, how did that get to me, they got through my defences . . .'.

Obstetrician 15: I don't think very much about the fetus in the form of a little baby when I'm scanning or doing procedures but completely illogically I usually say, 'Sorry baby', when I'm doing a feticide [silence followed by tears].

Michaels argues that 'the morality of abortion cannot be contingent on some stable conception of what the fetus is (or is not), but rather must be established on the basis of granting women reasonable license to kill' (1999: 132). There is, however, no mention of the possible impact on the practitioners who carry out these procedures. To varying degrees, these practitioners were all in favour of women's choice. Although practitioners were able to – and did – opt out of procedures to which they were morally opposed, on some occasions they found carrying out particular procedures difficult, even though they were morally supportive of the procedure. Related to this is the rhetorical importance of being non-directive in such circumstances. Again, practitioners commented on the difficulty of this:

FMU registrar 14: I think by counselling and information, informing patients and allowing them to make the choice, they are going to make choices that you disagree with and occasionally they are going to make choices that you find a bit on the abhorrent side, but if they have a legal right to that then you don't have any right to say no, or argue, or try and convince them otherwise . . . we should try not to be happy or unhappy with what people are doing, but it's hard not to because the more you look at the fetus as a patient, the more you look at the fetus as life and those sorts of things.

FMU consultant 8: There's a young girl at the moment, her baby's in a terrible state, basically, it doesn't have a brain. Yes, things like that happen and you think, 'Well, you should have a termination or you should do this or that' . . . and you have to say it's their decision at the end of the day. I think to start with I used to get more worked up about it . . .

FMU registrar 10: In a sense it's also our role a little bit to be the fetal advocate . . . [name of colleague] has done quite a lot of invasive fetal surgical procedures . . . and the best these kids can hope for is getting through their fetal life, being born, only to be on [kidney] dialysis for three days a week for the rest of their lives until they maybe find a transplant, so are you really giving someone quality of life – but then, how do you know?

Midwife 7: It is more the professionals coming to realise that they do need to try and accommodate all the ranges of possible actions that women will make. I have seen many people I work with really trying to accommodate that, I think they struggle to accommodate it because at the end of the day it does make life more complicated.

Discussion and conclusions

Casper (1994) draws attention to the ways in which those working in Science and Technology Studies (STS) have recently expanded their work to include an array of 'non human participants'. One consequence of this was that the terms 'human' and 'non human' became conceptually polarised. However, based on her work in experimental fetal surgery and fetal tissue research, she concludes that fetuses are positioned:

at the margins of humanity, illustrating the fluidity of hybrid identities and continuities across the constructed categories 'human' and 'non-human', thus challenging this conceptual dualism (1994: 317).

In the FMUs in which this research took place, practitioners dealt with fetuses across constructed categories. They might carry out potentially life-saving fetal treatment, and then move straight on to perform a late feticide – or indeed, the same fetus might, at varying stages, be conceptualised at different points along this human/non-human continuum, by women, partners and practitioners. Previous research in the general antenatal setting (Farsides, Williams and Alderson, 2004) commented that it should not be assumed that there is a homogeneity of moral views amongst practitioners working in this area. Although many of the practitioners working in antenatal care did espouse following a non-directive approach, they might hold moral views which could make it difficult to accept some of the choices made by women. Within the FMUs, alongside the expressed commitment to women's choice, there was also a diversity of moral views, as might be expected. However, this leads neonatologist John Wyatt to argue that:

doctors cannot be expected to maintain a careful neutrality about whether the fetus survives or is destroyed. Health professionals cannot be expected to maintain an artificial equipoise between the options of life and death. Since Hippocrates, the practice of medicine in the West has always enshrined moral commitments that include a primary orientation to protect vulnerable life. This is one reason why raising the option of late feticide can cause such deep ambiguity and sense of ethical conflict amongst professionals (2001: 19).

He believes that in such circumstances the role of the professional could become limited to attempting to provide technical information in a non-directive manner, and subsequently carrying out any medical procedures that are requested, in line with the autonomous choices of the client – what he describes as a client-technician model of professional relationship. Freidson (1988) commented on this issue, stating:

When decisions are at bottom moral or evaluative rather than substantive, laymen have as much if not more to contribute to them than have experts. This assumption reflects the substance of equality in a free society, equality not of ability, knowledge, or means, but moral equality (1988: 338)

. . . In order to provide a truly human service, practitioners must have a significant degree of autonomy within reasonable limits dictated by patients' rights, official standards, and accountability. This does not mean a return to medicine's position of irresponsible license . . . but it does mean stopping well short of reducing practitioners to passive cogs in a rationalized system (1988: 391).

More recently, Brown and Webster (2004) have commented on such potential difficulties specifically in relation to complex IHTs and the clinical encounter. They argue that negotiations and differences between participants may relate in part to the relative importance given by each individual to the social, clinical and ethical aspects in shaping clinical decisions.

So what might be the role of practitioners in this particularly complex area of innovative fetal medicine, both now and in the future? First, in relation to the management of uncertainty, Bosk (2000) draws on the work of Davis (1963), Roth (1963) and Fox (1959) to highlight different approaches. He argues that both Davis and Roth focus on how control of information serves organisational needs and quietens patient resistance, emphasising the potential divergence of self-interest between patient and doctor. In contrast, he states, Fox's analysis emphasises the convergence between doctor and patient, with doctors never using uncertainty as a tool for advantage. Each of these approaches appears to assume that uncertainty can be managed by practitioners however they choose, but I would argue that the current situation in fetal medicine is more complex than either of these approaches allow. Within the context of informed choice (and increasing litigation), practitioners are expected to highlight the risks, negative side-effects and uncertainties that might be involved in risky procedures. Mothers and their partners then have to make 'unprecedented' decisions based on this partial information, which practitioners may feel obligated to act on, within the rhetorical non-directive ethos which pervades the whole prenatal screening area. The findings support the work of Brown and Webster (2004), who argue that a new type of uncertainty might be involved in IHTs:

less a form that is 'managed' by the medical expert, but one that creates problems as much for the medic as for her or his patient . . . The lack of clear clinical guidelines and yet-to-be-determined standards of normality and abnormality complicate the expert-lay encounter here (2004: 25).

In terms of predicting prognosis, Christakis (1999) argues that traditionally, diagnosis and therapy have received more attention than prognosis in patient care, medical research and medical education. However, Fox (2000) predicts that the emergence of novel reproductive technologies which either directly or indirectly produce prognostic data will place doctors under increased pressure to make clinical predictions:

In turn, they will be confronted with added problems of uncertainty and limitation, such as what to tell the parents about the future clinical course of a baby diagnosed in utero with polycystic kidney disease . . . (2000: 415).

In addition, Fox comments that end-of-life medical care, which has many similarities with care in the FMU setting, is an area in which prognosis profoundly affects the discussion that takes place around decisions such as whether to initiate or terminate the life-sustaining treatment of patients:

Making the kinds of forecasts about suffering and pain, and about the quality of life and of death that this implies, carries all the participants in such decisions beyond medicine and into the realm of questions of meaning and of spiritual beliefs and uncertainties (2000: 416).

Although this research project did not directly seek the perspectives of pregnant women, the decisions taken by women are central to the future role of practitioners working in this area. Webster (2002) argues that the ways in which lay people engage with innovative 'high tech' medicine from the earliest stage of development demands much more of them as active participants in the mobilisation of such technologies – a process he calls 'the socialisation of medical innovation' (2002: 448). More generally, Brown and Webster (2004) believe that the repositioning of expert-lay relations, in addition to other factors, has led to more demands being placed on patients, including being treated as active partners in consultations. Although this may be so, within the FMU setting in particular, there are other factors which may influence how women in particular engage with IHTs. In the antenatal setting, the links between behaving 'responsibly' and being a 'good' mother have long been recognised as very powerful, with blame being attributed to women who fail to act in what is deemed to be an appropriate manner (Ehrenreich and English, 1978; Oakley, 1984). As Armstrong (1995) argues, the screening of women has to be seen as 'a very particular perspective on women and their bodies . . . Being screened is a duty; evasion is tagged as irresponsible behaviour, a moral dereliction' (1995: 167). In addition, Layne (2003) states that the women's health movement itself, with its emphasis on the ethic of individual control, has meant that:

If they [women] are not morally vigilant, women may 'fall from grace' and slip from 'low risk' to 'high risk'. If a pregnancy ends with a less-than-desired birth experience of birth outcome, it is hard to imagine a woman who could not go back over that daunting list and find at least some areas in which she should have done more, could have tried harder (2003: 1888).

So although I am not stating that women are 'passive victims' of reproductive technologies, I would argue that women's choices and the roles that they play as active

participants in the socialisation of medical innovation, are made within the context of familial, social, cultural and economic constraints (Henry, 2003). For example, practitioners can have a powerful ideological impact in 'shaping the understanding women have of what their experience of pregnancy should be, and how 'responsible' women should act' (Kent, 2000: 179). As practitioners in this study noted, pregnant women (and practitioners themselves) could feel an imperative to 'do something', including undergoing fetal surgery with a low chance of success.

The future role of practitioners in this area is of course also closely linked to more fundamental questions about the seemingly inexorable expansion of prenatal screening and the possible impacts this might have on society. Porter (1999) states that:

medicine has become the prisoner of its success. Having conquered many grave diseases and provided relief from suffering, its mandate has become muddled. What are its aims? Where is it to stop? Is its prime duty to keep people alive as long as possible, willy-nilly, whatever the circumstances? (1999: 717).

He concludes:

Today, with 'mission accomplished', its [medicine's] triumphs are dissolving in disorientation. Medicine has led to inflated expectations which the public eagerly swallowed. Yet as those expectations become unlimited, they are unfulfillable: medicine will have to redefine its limits even as it extends its capabilities (1998: 718).

This, however, begs the question as to who should be involved in redefining the limits of medicine, and how different voices get 'heard'. Kerr, Cunningham-Burley and Amos (1998) state that currently 'a narrow and privileged' group of individuals are making decisions about genetics, including prenatal screening programmes, and other research supports this (Williams, Alderson and Farsides, 2002b). In his paper, Webster (2002) describes one example of lay groups challenging the biomedical model and professional power, in relation to how 'high-tech' medicine defines the nature of the 'problem' (deafness), and the design of the clinical intervention (cochlear implants) that is seen as its solution, calling this 'the socialisation of clinical implementation'. Although encouraging, it would appear that in the area of innovative fetal medicine women and their partners are still playing a larger part in the socialisation of medical innovation than in the socialisation of clinical implementation.

In conclusion, within the antenatal setting it is recognised that, rather than being strategically introduced, screening programmes tend to 'creep in' (Bricker et al., 2000: 82). Once under way, this subtle but often rapid cycle of incorporation, routinisation and consequent consumer demand is difficult, if not impossible, to interrupt (Press and Browner, 1997). Getz and Kirkengen (2003) argue that profound moral dilemmas arise as a direct consequence of the premature introduction of an advancing medical technology in a routine medical setting. This paper has explored some of the unprecedented ethical dilemmas which are resulting from the increasing routinisation of fetal ultrasound screening and recent developments in fetal medicine, from the perspectives of health practitioners working in FMUs. One key aim is to encourage more widespread debate about the potential dilemmas which may arise from IHTs, before, rather than following, their introduction. Such dilemmas are accurately summed up by Anker and Nelkin (2004), who state:

The monsters and mutations of contemporary culture and visual art are expressing the ethical dilemmas and the ambiguities that are inherent in science and technology – activities that can cure or kill, create or destroy, provide benefits or cause harm (2004: 76).

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