

CHOICE, CONTROL AND ISSUES OF INFORMED CONSENT:
THE NEW REPRODUCTIVE AND PRE-BIRTH TECHNOLOGIES¹

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In Australia, particularly in Victoria, there has been heated public debate about the social implications of the new reproductive technologies. One of the initial arguments put forward by the medical researchers for introducing this technology was that 'women want it'. This catchcry has been slightly rephrased recently by both the medical researchers and the users of this technology. The emerging argument is that a woman should have 'the right to choose' to use the technologies. Feminists have argued that women have been used as experimental subjects and living laboratories on reproductive technology programs. The very evidence of women's experimental status which has been produced by feminists, is now being used to argue an informed consent theme by users of the technology and civil libertarians. Inherent in this line of debate is the assumption that if women are fully informed, there are no problems with the technology and all is well.

I will analyse both these claims: a woman's right to choose, and the demands for informed consent. I argue that at the base of both is an individualism which conflicts with the social implications of the technologies which themselves impact on all members of society, but particularly on women as a social group.

I agree that women should be fully informed of the outcomes, risks and implications of these technologies, and will present the information which they should be given. But by examining this information we can see that full informed consent is not possible considering the social context within which the medical profession operates. As Bernard Barber writes:

First by social and self- selection, then by their training both in medical schools and in internships and residencies, and finally by the structure of medical practice, physicians engaging primarily in therapy are strongly pushed toward and become committed to the value of individualism... Steeped in individualism, the physician naturally resists standards set by outsiders, whether they are medical peers, patients, private or public bureaucrats, or government legislators.²

I conclude that the social implications of the new reproductive technologies must take precedence over the individualistic notions of choice and consent. Informed consent cannot be used to validate experimental research which uses women as living laboratories and gives medical science control over our social destiny.

Choice and its constraints

Feminist debates and activism around abortion, sexuality and contraception have had as a slogan 'a woman's right to choose'. But we need now to closely consider this issue of choice within the new dilemmas posed by the reproductive technologies through which women are being slowly but surely divorced from control over procreation.³ What feminists really mean by 'a woman's right to choose' is 'a woman's right to control'. Women claim the right to bodily integrity, to autonomy, and to respect as moral beings capable of making difficult decisions in this area. If 'choice' with respect to abortion means control, we have to ask the same question with respect to reproductive technology. Does it necessarily increase the control of women over their lives or over that technology.

I argue that it does not, and that in fact the desire of some individual women to 'choose' this technology places the social group 'woman' at risk of alienation from the procreative process.

Civil libertarians and liberal feminists have argued for 'rights' and 'free choice' for women. The development of this position within feminism comes from the liberal theory stream. Whereas socialist feminism has dealt with reproduction through the Marxist concept of production, and radical feminism has held that women own their bodies and should therefore control them, liberal feminism has stressed the issue of rights. It was the liberal feminist stream which was strong in the resurgence of the women's movement in the sixties, stressing an individual woman's right to paid work and education.

But there is a basic problem with the concept of rights in general in that it is a static concept 'abstracted from social conditions'. It does not challenge social structures of inequality, nor the relations of production and reproduction. Through its stress on individual rights, liberalism places these rights in the private sphere. This contributes to the split between the private and public spheres which many feminists have seen as responsible for reinforcing women's oppression.

An important element in feminism has been the slogan that 'the personal is political', acknowledging that the experiences of women in private (for example, an act of rape in marriage) are political acts representing the relationships of power between one social group (men) and another social group (women). But though it is an important part of feminism, the personal alone is not enough as I

have argued elsewhere.⁴ Individual women live out our lives within a social context. We are constrained and shaped by the forces of economics, social ideology, personal psychology, and the various power structures which mould our actions.

There are social constraints operating upon choice, many of which are concerned with the social control of all persons, but in this case of women. The world operates on the basis of power inequities. There is no equality in the alternatives offered to people as 'choices' and there is not equality between those who are 'choosing'. Decisions made between undesirable or negative alternatives hardly amount to free choice. The choices of some individuals are firmly based upon the lack of choice of others.

Choices are impinged upon by ideological constructions, for example the pressure on women to be mothers, which we will address later. In addition the forces of capital and commerce blur for people a clear delineation of their needs as individuals and the needs which are socially constructed for us. People are expected and encouraged to choose socially acceptable alternatives. This makes it very difficult for women during pregnancy and birth, for example, to resist the use of new technologies. They can be accused of being selfish if they are not thinking of the child first. The 'maternal' consciousness is shaped to be responsive to these arguments and to be responsive to science and medicine as 'problem-solvers'.

Choices are hedged around by structured constraints depending on a woman's race, class, age, marital status, sexuality, religion, culture and sometimes disability. We do not live in a world with no power imbalances. We live in a world structured along hierarchies, with some people deliberately given more advantages over others.

Within the oppressive structures of race, class and so on, it seems naive to discuss the right to have 'free choice'. By whom and for whom is this right claimed? It is understandable that women make this claim on an individual basis, coming as we do from a society which denies us autonomous will in most spheres of our lives. But the individualism it represents is often in conflict with genuine community. We cannot constantly talk about allowing individuals to maximise their desires without any understanding of the dramatic impact these particular desires will have for other women and for society in general. And we should argue for equality of access to the technologies, but stress that there is a selection process operating with respect to women which divides women into 'fit' and 'unfit' mothers or 'worthy' or 'unworthy' of access to assisted motherhood.

So the discussion of 'choice' and 'rights' is based in an individualism linked to the private sphere; relies on a 'just world hypothesis' where 'all things being equal' people can exercise their choice; is simplistic, ignoring the complexities of the constraints around choice; and is divorced from the social context. Feminism, though it has stressed the right of the individual to fulfil her potential, and has stressed the personal as political, has also stressed the

accountability of women to other women and the need to foster women as a social group.

Informed consent and its limitations

We come now to the concept of informed consent. Informed consent is usually discussed in two settings: the medical situation where a person needs to make a decision about medical intervention; and the situation where a person is to be a research subject and has to make a decision about whether to allow themselves to be such a subject. There are two points worth mentioning here with respect to reproductive technology. The first is that infertility itself is not a life threatening situation. So the person is not making a life and death decision. The second is that it is very difficult when looking at in vitro fertilisation, for example, to determine whether the person fits into the first or the second category with respect to consent. There is evidence to suggest that we are in fact not discussing 'therapy' as it is often called, but in fact experimental procedures. I will explore this later in the paper.

There is considerable debate within the legal and philosophical literature about the concept itself. The characteristics of an informed consent are identified as: competence, voluntariness, the disclosure of information about the diagnosis and therapy, its risks, benefits and alternatives; and comprehension of such information. Meisel and Roth write:

At its best, the decision making process involves conversation, negotiation, reflection, and debate among the patient, the doctor, and possibly many other persons. At its worst, the doctor makes a recommendation and announces it to the patient in the manner of a fait accompli and obtains the patient's signature on a piece of paper, thus formally ratifying the decision.⁵

A number of problems have been seen to arise with the concept. Many writers acknowledge that it is difficult for the person to exercise the right to withhold consent.⁶ There is also a difference between an informed and an educated consent. For example, in one study, only half of the families given genetic counselling had actually grasped its impact.⁷ In addition, it is difficult to ascertain whether a person makes a free consent or is intimidated by a variety of aspects of the procedure. A person can hardly exercise freedom of choice when hospitalised, frightened and/or in pain. She or he often relinquishes power to the person who may heal them or solve their problem. Writers point out the difficulty of obtaining consent when experimental procedures are involved. Richard Simpson writes:

The possibility of exploitation is even greater where experimental treatment is involved. Physician concern for advancing medical knowledge can blind the doctor to the patient's best interests.⁸

Informed consent itself has as one of its historical sources the standards for research and treatment which are derived from the Nuremberg code involving voluntary, competent, and informed consent. In his analysis of an excellent

example of medical experimentation without social accountability, George Annas looks at the 'Baby Fae' case where the heart of a baboon was transplanted into a new born baby. Annas successfully argues that consent was not adequate in this case and that the Nuremberg code itself was violated as well as the necessary prerequisite for human experimentation, that there be sufficient prior animal experimentation. This example is very similar to that of women on IVF programs where procedures have not been tested on primates first.⁹ A Federal Ethics Board in the United States of America in 1979 which held hearings on IVF noted that there had been insufficient controlled animal research 'designed to determine the long range effects of in vitro fertilisation and embryo transfer'¹⁰. The board commented that this was noteworthy because there were available primate models. 'Models' now being used, of course, are women.

In general, the literature supports the push for further informed and educated consent from both medical research subjects and patients. However there is cynicism with respect to whether the medical profession will take part in this exercise. As Ingelfinger has written:

... the process of obtaining "informed consent", with all its regulations and conditions, is no more than an elaborate ritual, a device that, when the subject is uneducated and uncomprehending, confers no more than the semblance of propriety on human experimentation.¹¹

Bernard Barber has extended the concept of the risk-benefit ratio involved in informed consent by including moral injury as part of the damage which may

be done to the individual. Injury may include not just the results of medical or experimental intervention but ‘an injury to the social or moral person’.¹² As we will see from the accounts of the humiliating and debilitating procedures of IVF, this technology itself creates such an injury.

Barber points out basic flaws within the analyses of informed consent. One is the individualistic error which assumes that the transaction occurs between only two people, the doctor and the patient. In fact a variety of other people may be involved in the decision. And again we cannot look at that decision without looking at the structure of the social system which determines a person’s’ behaviour when dealing with informed consent. Barbour warns about medical researchers who

... display all the individualism and autonomy of therapists and add to those values the prerogatives of those who strive to be creative and original scientists. Their goal is to conduct research in their own terms. They too are impatient or contemptuous of calls for informed consent from their peers, their subjects or government regulation.¹³

Though the doctrine of informed consent has been operating for over twenty years in North America, doctors are failing at this new skill. ‘Failure to inform’ has been behind the bulk of all ‘wrongful birth’ law suits.¹⁴

The informed consent debate places a great deal of faith in the individual’s ability to make choices, in the doctor’s beneficence and in patient autonomy. But as Janice Raymond has written, it ‘seldom addresses the context in which choices are made, the patient’s motivation to choose in certain ways, and the conditions

that are necessary for a genuine autonomy to be exercised in the informed consent process'.¹⁵ The patients themselves may be unwilling to hear the information delivered. The condition of being in need of help makes a person vulnerable to manipulation, and the socialisation of doctors is not conducive to empathic negotiations.¹⁶ Again too, the concept is individualistic.

New Reproductive technologies

We can now consider whether choice and informed consent could operate within the new reproductive technology framework. I have written extensively on these technologies and will not detail them here.¹⁷ But for our purposes let us consider the most simple of them: in vitro fertilisation.(IVF) This is a procedure in which an egg and sperm are put together in a Petri dish to become an embryo. This embryo is then placed back inside the woman who may be the woman the egg came from or may be another woman.

I agree with Janice Raymond's comments that the social context of decision-making needs to be considered. So let us consider the social context of informed consent on IVF programs. This context must include that of the development of reproductive technology itself. This development has taken place within the increased medicalisation of life. Richard Taylor has clearly outlined the way that social problems are now becoming medical issues. He also talks of the 'diseasification of pregnancy and childbirth'. He writes:

Normal people are being patientised, social problems are being individualised and medicalised, and the individual is being blamed for maladaptation to society rather than the present social and economic system being held culpable for such maladaptation on a grand scale.¹⁸

There are a number of contextual elements worth elucidating here: the scientific ethic; pronatalist ideology; the experience of infertility; and the relationship between medicine and commerce.

Science, which forms the basis of medicine, has presented a masculine face. The scientific ethic is based on exploitation and domination.¹⁹ It is concerned with the control of, rather than a collaboration with, nature; is narrowly focused, dealing with small segments of information and knowledge; and is characterised by a neglect of the wider social implications of its actions.²⁰

Scientific researchers more and more are concerned with making reputations and with making money, exemplified in the development of IVF Australia.²¹ Rather than working in the less glamorous areas of community health and the prevention of infertility, doctors race for hi-tech fixes for the problem. In so doing they neglect to deal with infertility caused by their own technologies, for example IUDs, and by their own medical mismanagement as in post-operative infection. Dr. William Keye of the American College of Obstetricians and Gynecologists discussed the 36 percent rate of iatrogenic (doctor caused) illness in one hospital service noting that 'our experience also suggests that iatrogenic infertility is common'.²² Some doctors are becoming increasingly concerned about the damage

to the pelvic area followed by infertility, which occurs as the result of gynecological or obstetrical surgery, or even from the more 'simple' procedures.

A further characteristic of the context in which these developments are taking place is that of pronatalist ideologies. Inevitably the question of why people have children arises. Jalna Hanmer points out that women's choices in the reproductive area are related to women's reproductive consciousness.²³ This consciousness is socially created. There is a Strong pronatalism operating which says that having children is good. People parent because it draws social approval: it satisfies their need for a sense of continuity and immortality; because of structures from religion and government to psychological structures which deem parenting to be good; or because they like children. It marks the status passage from childhood to adulthood: a mature person is a parenting person.

For women, motherhood is deemed to be the true fulfilment of femininity. For many women internationally, it brings little power in real terms, but for many it is the only power base from which they can negotiate the terms of their existence. Women learn to like themselves in the motherhood role because it allows them experiences of love and power, not easily found in other situations. The ideology of romantic love also deems that it is a woman's greatest desire to present her husband with his offspring. These kinds of ideological pressures to 'choose' motherhood, create a strong need within women. This ideology and this need are reinforced by economic structures, for example within capitalist countries, the consumption of goods is focused within the family unit.

The strength of the ideology of motherhood is reflected in the constant pursuit of it by women in the face of mounting evidence that men are relinquishing responsibility for their children while increasing their rights over women and children.²⁴ It is seen in the queues of women awaiting IVF which is known to be an unsuccessful technology. Part of the ideology of motherhood has been a self-obliteration and self-sacrifice. Mothers are encouraged to put their own needs last. We could argue that this self-sacrifice in the name of motherhood is lived out through women on IVF programs, who constantly undergo an assaultative process which they themselves describe as humiliating and emotionally draining.

This brings us to the third aspect of the context behind IVF: infertility. I have described elsewhere the painful experiences of infertile people.²⁵ The knowledge of infertility is a shock to the individual because we all assume our fertility, protecting ourselves against it showing itself at unwanted times. The testing process to detect infertility is intrusive, exhausting and has been described as 'assaultive', because women are required to 'expose their bodies for tests and procedures' and to 'expose the intimate details of their sexual lives and their motivations for pregnancy'.²⁶

The experience of infertility in a pronatalist context can be a life crisis. Something over which a person thought they had control was in fact not within their control. Many women feel particularly frustrated and resentful if they have been using a contraceptive device for many years for no good reason or if the

device itself caused the infertility. The lack of control a person feels can lead them to experience low self esteem. The experience itself is similar to grief after the death of a loved one. Barbara Eck-Menning discusses the woman's experience of being isolated through infertility and of suddenly seeing fertility everywhere in the world except within herself.²⁷ There is no loss for us in validating the pain of infertility. This should not, on the other hand, lead us to collaborate in maintaining women on IVF programs, because the social implications of those programs are far broader reaching than the site of the individual.

The fourth characteristic of the context for the development of the new reproductive technologies is the increasing relationship between commerce and medicine. There are many financial institutions which have a power base rooted in women's biology. These include the reproductive supermarket systems being established in North America;²⁸ the drug companies who are manufacturing the fertility drugs used in reproductive research; commercial enterprises being established in Australia such as IVF Australia; and at times the state acting as entrepreneur.²⁹ Petchesky has written that:

... this conjuncture of medical, corporate and state interests in the "management" of reproduction has defined the choices of all women, but in a way that is crucially different depending on one's class and race.³⁰

The relationship between medicine and commercial enterprise has its own history. As Gallileo and then Darwin's explanations of the world became accepted, the power of religion was exchanged for the power of science. Science

became the new authority and developed within the market place, emerging within a capitalist framework. 'It took the most revolutionary aspects of the business mentality - its loyalty to empirical fact, its hard-headed pragmatism, its penchant for numerical abstraction - and hammered them into a precision tool for the understanding and mastering of the material world'.³¹

In her analysis of 'the captured womb' Ann Oakley has considered the increasing medical control over pregnancy, with the division of medicine into various specialties, representing the segmentation of women's bodies: obstetrics, gynecology, pediatrics, neo-natal pediatrics, fetal medicine, and reproductive medicine. She points out that 'womanhood and motherhood have become a battlefield for not only patriarchal but professional supremacy'.³² But all of these sub-specialties are supported by enormous commercial enterprises, feeding them with technological assistance and drugs. So women's bodies are also a battle-field for commercial profit-making enterprises.

Associated with this is the increasingly articulated attitude to babies as products. This is true within so-called surrogate motherhood transactions, but also in reproductive technology programs. Commercialization has made this point crassly. For example there has been the 'floating' of a public company called PIVET-Australia. (Programmed In Vitro Fertilisation and Embryo Transfer) and 'soon the general public will be able to buy shares in the test-tube baby business'.³³ As one newspaper report stated: 'Test-tube babies are about to hit the stock market'.³⁴

Apart from being seen as ‘products’ babies are falsely seen as a ‘cure’ for infertility, which they are not. They are the ‘fix’ for the problems of infertility and the resulting trauma. Should we allow children to be used to meet the needs of adults? Is this symptomatic of other uses/abuses of children, for example, sexual abuse? An article in the Los Angeles Times in 1979 indicated that one couple had decided to conceive a child for the purposes of using it as a bone marrow donor for its sibling. Will this process ultimately lead commercial enterprises to the creation of children for spare parts?³⁵

So within reproductive technology we have a socially constructed need expressed by one group of women which is taken up and validated by the medical profession for their own purposes. They then introduce a technology based on this need for the production of drugs and specific technological implements. Now, through IVF Australia, they even sell their expertise.

Throughout this process women scramble to maintain control. Although constrained as we all are by ideological beliefs and by power structures, the women on IVF programs themselves are maintaining a resistance to the encroachment of medicine. They argue for a place within policy making and for improvement in the conditions for users of IVF, for example introducing stricter regulations about informed consent. But these attempts to improve conditions do nothing to change the material, social and ideological conditions in which the relationships between medicine, commerce and users is taking place. (Note I do

not use the term consumer, as within the new reproductive technologies we are all consumers. They impact on all members of society).

IVF and informed/educated decision-making.

I want now to consider some of the information which women on IVF programs should be given if they are to make a fully informed consent or informed choice. I would argue that they should first know the context analysed above in which the technology is being developed and marketed. Women should then be told what the 'simple process' of IVF entails. The practical experience of the IVF program is painful, costly, and emotionally exhausting. Within in vitro fertilisation, after infertility testing itself there is again a series of tests which the woman must undergo. An IVF cycle lasts for at least two weeks. Mao and Wood write:

This involves about a week of outpatient monitoring by the daily estimation of plasma 17-Beta-Oestradiol levels, the daily scoring of cervical mucous, and one of two ovarian ultrasound examinations. This is followed by another week of inpatient care, involving frequent hormonal assays, the laparoscopic collection of oocytes and, in the event of successful oocyte collection and fertilisation, the embryo transfer.³⁶

A laparoscopy is carried out to collect 'ripe' eggs for fertilization. This is an operation done under general anaesthetic with all the attendant risks. The women's abdomen is inflated with inert gas. A fine suction needle and a guide are

inserted into the uterus and led to the ovary where collection takes place. Most women on the program are super-ovulated. This means that they are given doses of hormones or fertility drugs to increase the number of eggs produced per cycle. They are given these drugs even though such a use is contraindicated in the MIMS, 1985.³⁷ A woman's body normally produces one egg per month, but medical researchers need to replace more than one -embryo in order to have a chance of a successful pregnancy. They therefore super-ovulate the woman so that she produces more than one egg per cycle, usually five or six, but on occasion up to eleven.³⁸ Her body is being asked to produce at least five or six times the normal number of eggs for that month.

The drugs most commonly used are clomiphene citrate and a gonadotrophin usually going by the brand name Pergonal. The possible detrimental side effects of constant use of these hormones are yet to be investigated. There are, however, some dangers which have already been discussed in the literature. Hyper-stimulation of the ovaries is one problem.³⁹ An article in The Medical Journal of Australia has indicated other potential problems: the body's defence mechanism against super-ovulation is overridden, and there may be maternal risks associated with ovarian hyper-stimulation, such as 'Meigs'-like' syndrome and thrombosis.⁴⁰ The higher rate of multiple births can cause concern, as does an unexpected low pregnancy rate and a higher incidence of ectopic pregnancies.⁴¹ Henriët et al comment that 'super-ovulation is not a simple multiplication of a normal ovulation'.⁴²

So we are yet to find out the long term effects of super-ovulating women in these ways.

Women on programs themselves comment on the side effects of these hormones, though their statements appear to be ignored. One woman on a program, who was a doctor herself, said that the hormones had induced enormous emotional turmoil even though she was told there would be no side effects.

Another woman said:

the Professor tells us that according to the labels in his books, they don't have side effects. Once someone comes out and is brave enough, to say "you get side effects" other women say so too. I think that's what he's worried about - that side effects are catching.⁴³

There is, therefore: the pain and discomfort; the risk of the anaesthetic under which a laparoscopy takes place; the risks from super-ovulation drugs; and the possible disappointment if failure ensues in terms of a pregnancy. Women should be warned that they are in fact experimental subjects on these programs. The work is to a large extent unsuccessful and successes are not always replicable.

Doctors have been concerned about the risks of laparoscopy and have been developing new forms of egg 'harvest'. For example, one new method of egg collection is TUDOR (Transvaginal Ultrasound Directed Oocyte Recovery). It was supposed to be a method which avoided general anaesthesia, and which would be cheaper and safer. The woman's bladder is emptied with a catheter, then

refilled with a sterile saline solution. A needle is introduced through the vagina, a hole is made in the bladder and the needle guided in the direction of the ovary, via ultrasound.⁴⁴ But there are problems with this technique as it is very difficult to grip the ovary. For the woman, the experience is 'very difficult' too. Renate Klein writes:

as for the alleged ease and painlessness, women undergoing TUDOR report that it is painful and when the ovary is touched they report some sort of a "cramping sensation". Many doctors go back to using general anaesthesia or trying out "various medications" to numb the pain.⁴⁵

To date this form of egg harvesting has not been as successful as laparoscopy. Indicating the experimental nature of the technique Dr. John Kerin, at that time working in Adelaide, said: 'all of us had to develop - and are still developing - operator skill with this technique'.⁴⁶ The technique itself is not without risk. 'Broad ligament hematomas have resulted from rupture. The method requires an experienced operator who can penetrate the follicle without disturbing the veins in the uterus, Dr. Kerin said'.⁴⁷ This article in OGN, (Ob.Gyn News) indicates that a decision to use this method for collecting eggs should only be made 'after considering the medical facilities, ovarian accessibility, and the physician's expertise'. Where, we might ask, is the consent of the woman?

Women should also be told that the technological fix offered them is a false promise. The 'success' rates of IVF should be called the 'failure' rates. Of every hundred women who go onto an IVF program, at least 86 percent of them

will fail to become pregnant. Yet a recent article in the New England Journal of Medicine discussed a study of couples who were treated for infertility and couples who were not. Of the 589 couples treated for infertility, 41 percent became pregnant. Of the 548 untreated couples, 36 percent became pregnant. The authors concluded 'that the potential for a spontaneous cure of infertility is high'.⁴⁸

The figures from the Perinatal Statistics Unit at Sydney University indicate that until December 31st 1984, 909 pregnancies were achieved in 11 centres throughout Australia and New Zealand. 45 percent only resulted in live births. Five percent of pregnancies were ectopic, 19 percent resulted in spontaneous abortions, and there were 22 still births. Perinatal mortality was four times that of the normal population. Thirty four percent of the babies were born with low birth rate, which again is four times that of the normal population.

The programs also have an unusually high cesarean rate of 43 percent. Doctors seem very keen to have these babies delivered by the medical profession and kept tightly within their control. This in itself is an interesting statistic for women to ponder. The risk of maternal death with cesarean section is increased two to five fold compared with vaginal delivery. Ob.Gyn News reports that 'one of the most important preventable causes of maternal mortality appears to be the use of general anaesthesia, . . . such deaths account for almost one fourth of deaths related to cesarean section.'⁴⁹

In an interesting survey recently published in The Medical Tribune. Corea and Ince give results which indicate that many U.S. IVF hospitals use misleading

statistics in order to attract patients. Many clinics quote a 20 percent success rate using what they see as the world-wide average. Yet of the 54 clinics which responded to the questionnaire, half had never sent a patient home with a baby. 'These zero success clinics have been in business from one month to three years and have treated over six hundred women and collected, by conservative estimate, over \$2.5 million in patient fees.'⁵⁰ Corea and Ince detail the way statistics are manipulated in these hospitals, explaining that some of the so-called pregnancies were in fact just chemical changes which may or may not indicate an early sign of pregnancy. Many hospitals cite pregnancies as a success rate, instead of live births, and many hospitals include their twins and triplets in the reported totals of live births.

This kind of manipulation of statistics, and indeed the giving of false statistics, which lures patients to clinics to undergo extensive medical interventions with little possibility of a baby at the end of the process, has been severely criticised by Dr. Michael Soules in an editorial of the journal Fertility and Sterility. He writes: 'The truth with regard to the expected pregnancy rate after IVF procedures has been widely abused (primarily by IVF practitioners)'.⁵¹ He goes on to say that the 'widespread practice of exaggerating the IVF pregnancy rate appears to be a marketing ploy' and that it is competition which is encouraging this as 'many IVF programs in this country are struggling to treat a sufficient patient volume to maintain the program'.⁵² Medical researchers obviously do not look at the experience of IVF

itself as a cause for dropping patient numbers. Could the process itself be turning people off?

Women should also be told about the costs involved in IVF: the financial and other costs to the couple and to the woman involved. The financial cost is considerable. In Australia it amounts to between \$2,000 to \$3,000 per cycle attempt, two thirds of which is refundable on medical benefits. But this is not the only cost for the couple, as many have to travel from interstate and lose work time. Many of the women have to give up full time paid work because the process is too time consuming.⁵³ In the study of 228 patients who withdrew from programs in Australia in 1983, Mao and Wood found that financial cost was the primary reason for withdrawing. The emotional costs were the second reason and in order of importance were: anxiety, depression, disruption of a normal life and of work-career patterns and the strain on the marriage. The drop-out rate in this study was high according to the researchers.⁵⁴ Interestingly, drop out figures appear to be impossible to obtain because programs do not keep or release them.

We can now look to the experiences of women on IVF programs themselves. Two recent studies give us some interesting insights.⁵⁵ The women indicate the lack of dignity involved in the process, commenting as one woman did that 'it affected my sexuality, I felt powerless'.⁵⁶ Many of them comment on the lack of information given to them about the program and in particular about the lack of success on IVF programs. Just as the public has been impressed by

pictures of happy babies and happy couples, so too women on the IVF programs have been influenced by this media presentation of IVF.

Some complaints have been similar to those of women in relation to other medical procedures. As one woman said:

I would like the doctor to participate more. They just pick up the eggs and put them back, the rest of the time you never see them, it's rush, rush, all the time. You don't like to ask questions. Even when they inform you you don't take it all in. You don't like to phone them and make a nuisance.⁵⁷

The experience of so-called 'failing' is a devastating one for women who go through programs. As you can imagine, after the experience of infertility itself, the testing for infertility and then the IVF procedure, there is a lot at stake for the woman involved. As one woman said after failing to become pregnant: 'I just wanted to sit in a corner and die'. Another said: 'My husband went to pieces, I felt I was dying, I was really crook but I didn't let any emotions come out, I had to look after him'. The lack of caring and information given by the medical researchers after a 'failure' is enormous. The women commented on this and one said:

I would really have liked to have gone back and talked to (my gynecologist) after it didn't work out, but as the IVF scientist says: "You're history, we're on to the next one, we haven't time for you now, we want to get on with it".⁵⁸

This IVF scientist referred to in the above comment said: 'One way the teams cope with failure is to avoid follow-up contact with failed patients'.⁵⁹

These kinds of experiences are repetitions of the relationship which medical researchers have traditionally had with women. Helen Roberts has traced the hidden dimensions of power which operate between doctors and women patients.⁶⁰ She points out that the woman's so-called subjective experience is often ignored by the doctor, and this happened with the many reports on headaches, lack of libido and so on for the pill, all of which were assessed as too subjective to be useful. Medicine, on the other hand, is said to have the scientific experience and evidence.

One of the common complaints which Roberts found from women about 'bad' doctors was that they did not listen. Many of the comments of women on IVF programs are resonant of descriptions of the relationship historically that women and medicine have had. Their anxieties and their concerns are not given validity by the researchers. One patient expressed her concern for the potential results of all of this super-ovulation in ten to fifteen years time. As she pointed out: 'Our generation were guinea pigs for the Dalkon shield and now we're guinea pigs for the new form of modern technology'.⁶¹

Patients themselves indicate that they are unable to wield any power in the traditional doctor/patient relationship, and are too involved to consider the wider social implications of IVF. Informed consent then becomes a dubious concept.

One patient wrote:

We as patients, are not in a position to comment objectively about many IVF issues. Always we are conscious of the fact that we are in the “comprising position”. For most couples our dearest wish is to have a child so we do not publicly complain about the endless experimental procedures, the dehumanised method of treatment, the pain, cost and emotional strain that is an integral part of IVF. I have known some to complain, but only to incur the wrath of the IVF team.⁶²

The possibility of informed consent and choice

We have seen the scepticism about the potential of medical researchers to fully inform patients and if my criteria for educated decision making are followed, this likelihood recedes further. But other issues are also involved. In analysing the obligations of researchers to patients, Davis writes:

The scientist and the clinician both have ethical obligations to provide disclosure of information that includes the proclamation of benefits, the warning of risks, and the discussion of quandries in order to obtain a truly informed consent from a subject-patient. In the last analysis, only the integrity and ethics of such groups as drug companies, the health care professions and researchers will safeguard the rights of the subject-patient-consumer.⁶³

We must discount the so-called ethics of drug companies, as experiences with, for example, the Dalkon shield, have led women to be very suspicious of the care which such companies might give to women when deeply involved in the profit motive. We have yet to see a systematic analysis of what information is actually given to IVF patients. It does seem too that researchers continue to fail to

recognise the rights of patients to full information, if the figures on claims for wrongful birth are any indication.

If full information is presented to a potential IVF client, it is possible that they would withdraw immediately. This may be one of the reasons why the information is not forthcoming. Some patients, however, would still proceed with the techniques, willing to 'sacrifice all' for the possibility of a baby. But with such a strong context of pronatalist ideology discussed earlier, we can question whether that person is exercising 'choice'.

And if such a choice is allowed to the individual, what are the wider social issues involved here? The first question is who is paying? We have already seen that the cost to individuals is substantial. In most instances the woman has given up paid work because of the extensive time and energy needed for such a program.⁶⁴ The cost of IVF procedures to the community is difficult to estimate because figures on the financial details are unavailable. Recent figures in the report of the Family Law Council tabled in the Federal Parliament in Australia indicate that one pregnancy can cost the community from \$10,000 up to \$1,000,000 depending on the care required for the mother and the post-natal care of premature babies.⁶⁵ Costs to society also include the use of hospital expertise, staff, research funding and the hospital facilities. In addition, hospitals will now be required to provide counselling services.

The cost to women may also be enormous in the long run. The history of medicine indicates a growing control by a male dominated profession over

women's bodies through the birth process and now through procreation. Mary O'Brien has argued that within her conceptualisation of reproductive consciousness, men feel alienated from the procreative process.⁶⁶ Having once delivered the seed, they are no longer necessary for the life of the child to come. In order to assuage their alienation they have developed structures to control women and children. These structures include ideological, economic and religious principles and the nuclear family. Men envy women's procreative power. Psychoanalysts have developed a theory of womb envy to account for this. Many cultures have symbolic representations of envy and myth itself carries the tale. For example, Athena sprang from the head of Zeus after he swallowed her mother, and she was known to be a goddess who was not kind to women.

Not only are there symbolic appropriations of women's procreative power by men, but science itself has constantly created theories to disempower women in this area. In the seventeenth and eighteenth centuries sperm was claimed to have carried miniscule versions of man, and woman was merely the vessel that housed the seed. The gradual consumption by male medicine of midwifery and the introduction of the harsher elements of birth, such as forceps or 'hands of iron', have evidenced man's attempts to stop himself from becoming dispensable within the procreative process. This desire by men to be the creators is carried through to IVF scientists. Language constantly betrays this fact. One of the Steptoe and Edwards team was named 'Father of the Year'. And when discussing the role of John Yovich in Pivet, the Bulletin noted that 'He produced his first

pregnancy in 1981'.⁶⁷ We are talking here about the social control of women's bodies, and the encroachment of men into women's procreative power.

The beginning of the alienation of women in terms of reproductive consciousness has begun with the harvesting of eggs from women's bodies. Women who give up their eggs for fertilization must now face the possibility that the 'wrong' embryo is placed back inside them. If the widespread genetic screening of embryos takes place, women's alienation will increase.

The use of women as living laboratories should be a concern for all members of society. Yet constantly the discussions of reproductive technology focus on experimentation on the embryo, or that new character the 'pre-embryo'. Few people stop to ask where the embryos come from? They come from eggs. Where do the eggs come from? They come from women. Women should be the focus of concern.

Women have ceased to have faith in the 'experts' because they:

betrayed the trust that women had put in them. Claiming the purity of science, they had persisted in the commercialisation inherent in a commoditised system of healing... They turned out not to be scientists - for all their talk of data, laboratory findings, clinical trials - but apologists for the status quo'.⁶⁸

The history of the relationship between medicine and women's bodies does not give us faith for the future of a program of informed consent. We have only to look to our history again and again for precedents.

The DES controversy (diethylstilbestrol, a synthetic estrogen) is one example. It was used from the early 1940s until 1971 as a prescribed drug for pregnant women who were prone to miscarriage. Some of the women took the drug as experimental subjects and were not told the truth about what they were taking. They were told it was a vitamin tablet.⁶⁹ But there was time bomb effect with DES and years later some of the daughters of these mothers are suffering cancer of the vagina and cervix at a rate higher than that of the female population of their own age. Problems have also been detected in some sons of DES mothers. There is also occurring a higher than normal rate of infertility in both sons and daughters. For DES daughters, there is an 'increased incidence of spontaneous abortions, premature deliveries and ectopic gestations'.⁷⁰ Though no longer described as the drug for miscarriage, DES in general is still prescribed as a morning-after pill. There is no evidence established which indicates that DES does prevent miscarriage or conception so Diana Sculley points out that women who were given it as a morning-after pill will still conceive sometimes and rape victims who are given it as a pill to stop pregnancy may end up being pregnant. It is in the 'natural progression of science' that in vitro fertilisation is now hailed as a solution to the problems of DES. DES daughters are being offered IVF pregnancies to overcome their infertility caused by medical mismanagement and experimentation on their mothers.⁷¹

Experimentation continues to go unchecked. Gena Corea discussed in detail what she considers to be the malpractice of physician James Burt who does

what he does 'love surgery'.⁷² He believes that the female anatomical system is faulty because women do not orgasm during penile penetration. Therefore he reconstructs the woman's vagina and genitalia dragging the clitoris closer to the vagina. Four thousand women have so far been treated by this man, many of them without informed consent. Burt himself has written that 'in many hundreds of these patients, the patient had not been informed that anything more had been done to her than delivery and episiotomy and repair' after the birth of her child.⁷³ So Burt has 'redesigned' the bodies of hundreds of women without their knowledge and continues to do so. Even though he is shunned by his colleagues, the medical profession has done nothing to stop him from performing this surgery. It would seem that there is an inherent contradiction between the operation of medicine and the concept of women's control.

It will be interesting to see if the new chorionic villus biopsy (CVB) technique being introduced experimentally with women will be another example of medical mismanagement. This is a technique used for prenatal diagnosis which can be done in the eighth week of pregnancy, searching for genetic defects in the fetus. Amniocentesis is the current method used, but it is done late in the pregnancy at about 16 to 18 weeks. It also takes 2 to 4 weeks to get the results, but with CVB it only takes about 1 day. The debate around this procedure is already occurring in the medical literature. Dr. Homer Chin has claimed at a conference on reproductive health that it is an effective genetic screening

technique which does not carry substantial risk for the mother or the foetus.⁷⁴ To date 10,716 women world-wide have had chorionic villi sampling.

However in a conference sponsored by the American Society of Law and Medicine, Dr. Aubrey Milunsky, Director of the Centre for Human Genetics at Boston University School of Medicine said that he is 'troubled by the three near-fatal cases of septic shock reported thus far ... associated with passage of the catheter through an infected vaginal field'⁷⁵. One case resulted in a hysterectomy. Dr. Milunsky comments that 'to perform a 'chorionic' biopsy and entertain maternal mortality as a possibility lends a completely different complexion to the matter'. He also argues that because the body spontaneously aborts defective fetuses in 90 to 97 percent of cases, CVB may be coming into effect before the body can rid itself of the defect, 'interfering with the process, and introducing a set of iatrogenic [doctor induced] complications'. He also comments that another concern is the occasional diagnostic discrepancies.

In addition, Dr. Brambate has reported a fetal loss rate of 13 percent when CVB is performed before nine weeks gestation and a 17 percent loss after twelve weeks.⁷⁶ So the cumulative incidents of complications, fetal loss, and diagnostic discrepancies is 6.9 to 14.7 percent. For amniocentesis the range is 0.7 to 3.3 percent. Dr. Rodeck, Director of the Harris Birth Right Research Centre for Fetal Medicine, King's College, London, has also considered the increased risk of maternal infection and the risks involved. He says:

we're on the verge of doing the procedure on thousands of women, most of whom will have a normal pregnancy. I suspect we'll find it safe ... [but at this point] chorionic villi sampling is a procedure about which we don't really know the long-term consequences.⁷⁷

To date we do not have statistics on how many women in Australia are being experimented on in this way. In Perth in July this year however, one woman who was carrying twins underwent CVB and had one of the twins, a boy, destroyed because he was at risk of carrying haemophilia.⁷⁸ Apart from the psychological impact on the woman of carrying the dead twin through the pregnancy, and potentially on the twin born, we can wonder whether this woman knew of the possible risks involved in CVB. How do we get any guarantees that women on whom this experimental procedure is being performed, know of the debates carried in the medical literature?

Future dilemmas.

Two possible problem areas which we can locate with respect to choice and informed consent may be useful to consider here. The first is the developing area of fetal surgery, sometimes called fetal 'therapy'. The area of fetal surgery is a good example of both woman and fetus being used as living experimental objects. The literature discussing the fetus as 'patient' is horrifying in its representation of women as merely the capsule or container for the fetus. A new journal to be launched onto the market reinforces fetal status. Titled Fetal Therapy

it will deal not only with the clinical and basic research elements of fetal surgery but also with moral and ethical issues and with ‘the legal rights of the fetus and new concepts of fetal personality’.

The personalising of the fetus has meant that in three instances documented to date, women have been forced to undergo surgery because a judge and a doctor [both male] judged the woman ill-equipped to assess and make decisions.⁷⁹ They decided that the fetus as a patient, had rights over and above the woman. In these two instances the mothers refused caesarean sections but the physicians were able to obtain court orders to perform them. The court orders did not have to be carried out. In one case the woman had refused the caesarean on religious grounds. She gave birth before the order could be executed. In another the mother was described as ‘uncooperative and belligerent’. This mother relented when told of the judge’s order’. In at least two of the three cases, the medical diagnosis was incorrect, based on faulty prenatal screening.⁸⁰ Bear in mind the morbidity risks for caesarean which I gave earlier.

The precedent is unnerving particularly when applied to fetal surgery. At a recent panel discussion on ethical dilemmas in obstetrics at a seminar at Maricova Medical Centre in Phoenix, doctors debated the treatment of a pregnant woman against her wishes. Dr. Frank Chervenak indicated that the woman who refuses to have a caesarean section in labour when the fetus shows signs of distress ‘may not be thinking rationally because of pain and fear of labour’.⁸¹ In

this case, the danger to the fetus overrules the woman's autonomy, and he would be prepared to restrain the mother and do a caesarean.

Questions were also raised in this debate as to whether a woman could be incarcerated if she smoked during pregnancy or be prevented from physical activity if it might lead to a premature delivery. It is becoming clear in these discussions that though the woman is deemed to have prior rights up to twenty eight weeks when most abortions are carried out, it is the last trimester which is now at stake. A situation of conflict is being created by medicine between the mother and the fetus.

'Fetal personhood' challenges the autonomy of women. This challenge can include actions to exclude women from jobs where work may be hazardous to reproductive capacity. The personalisation of the fetus will lead to increasing social controls on women, particularly in the workplace. It has already led to sterilizations of women who wanted to work in certain 'hazardous' places. At Willow Island, U.S.A., a plant of the American Cyanamid Company gave all women in eight of the plant's ten departments the 'choice' of losing their jobs or being sterilized. Five agreed to be sterilized. Ironically the department closed a year later so the women were both jobless and sterile.⁸²

Here is a quote from the National Council on radiation protection which is a private non-governmental organisation which helps to set radiation exposure levels:

The need to minimise exposure of the embryo and the fetus is paramount. It becomes the controlling factor in the occupational exposure of fertile women ... For conceptual purposes the chosen dose limit (of radiation) essentially functions to treat the unborn child as a member of the public involuntarily brought into controlled areas.⁸³

These kinds of female exclusionary protections are problematic because they are focused on female employment in heavy industry and ignore other reproductive hazards to women in traditional occupations, for example, hospital work. It also ignores the fact that harmful mutagenetic and teratogenetic agents may be transmitted to the fetus through sperm. And thirdly, the treatment of all fertile women as potentially pregnant and therefore potentially vulnerable, ties women's destiny as child-bearers into employment rights and makes the rights of women for employment and the rights of the fetus diametrically opposed. So the medical profession in alliance with corporations begins to assert a protective relationship over the fetus. The concept of choice and informed consent within this context seem simplistic and ludicrous.

The questions which arise here for women revolve around choice versus coercion; the status of the fetus in conflict with the status of women; and the ability to choose not to undergo these forms of invasive surgery. But women who do not use such surgery will have to deal with their guilt if something goes wrong, and the possibility in the future of a law suit for 'wrongful birth'.

We should also consider what sort of success rates these forms of surgery are having. According to the International Fetal Surgery Registry, survival statistics after fetal surgery are impressive for the child, but the progress of the

children is not. Fletcher argues that in many cases it 'is difficult to establish that the surgery is more beneficial than waiting until after the birth to treat a disorder. 'Only nine were felt to be "normal", one to eighteen months after birth. Three have "moderate handicaps" and another nine have "severe handicaps"'.⁸⁴ Fletcher questions the difficulty of dealing with the situation in which the mother refuses treatment and comments that 'both surgery and caesarean delivery (which is usually but not always necessary) can limit the mother's future possibility for child-bearing.'⁸⁵

The literature itself seems to indicate that these are clearly experimental procedures. Henig writes 'fetal surgery at this moment resides in an ethical gray zone, not quite research and not quite therapy'.⁸⁶ He points out that doctors do not know which fetus to treat and when. They cannot assess whether they are actually saving a fetus to become a profoundly retarded child or whether the fetus would have survived without the 'assistance' of the medical profession.

What is never addressed within these assessments is what the experience is like for the woman involved. And what are the implications of the rights of women here? Much of this discussion now revolves around what to do if a woman does not consent to this particular kind of surgery and the obstetrician deems it to be necessary for the fetus. Elias and Annas have commented that women could be compelled to undergo the procedure.

... when fetal surgery becomes accepted medical practice, and if the procedure can be done with minimal invasiveness and risk to the mother

and significant benefit to the fetus, there is an argument to be made that the woman should not be permitted to reject it. Such rejection of therapy could be considered “fetal abuse” and, at a late stage in pregnancy “child abuse”, and an appropriate court order sought to force treatment.⁸⁷

But there are strong arguments against compulsory fetal therapy. Feminist discussions would not concern themselves with the rights of the fetus, but with the rights of the woman to bodily integrity, which would be intruded upon by such compulsory measures. It would be forcing the procedure on the woman for the benefit of the fetus, an argument which could then be extended to the forcing of a father to give up an organ for a child. As Fletcher has said: ‘If society has gone that far in requiring parental sacrifice what else might it be willing to do to protect the life of the young?’⁸⁸ Pregnant women should have an autonomy which overrides any claims by potential living beings. As Elias and Annas say ‘the right to make a mistake should continue to be the pregnant woman’s, not the physician’s or the judge’s’.⁸⁹

A second area in which the issues of choice and informed consent appear simplistic and irrelevant revolve around the issue of men, but particularly transsexual men as mothers. In July 1984 a group of at least six male to female transsexuals requested admittance to the IVF program at the Queen Victoria Medical Centre in Melbourne.⁹⁰ How will our attitudes to ‘choice’ change when the reality of a baby for a transsexual man comes even closer? In May 1979 Margaret Martin gave birth to a baby girl having undergone a hysterectomy eight months earlier. The fertilized egg had lodged in her abdomen on her bowel where

it received enough nutrients to grow to term without the aid of the uterus. Dr. Roy Hertz has had success with transplanting fertilized eggs of a female baboon into the abdominal cavity of a male baboon. It appears that a fetus may be able to attach itself to any site which is rich in blood and nutrients. In about one thousand cases, a fertilized egg has worked its way into the abdominal cavity of a woman which can expand to accommodate the growing fetus. Approximately nine percent of these women have actually given birth to healthy babies. The mother runs an enormous risk during this process and can often die from a massive haemorrhage. But the possibility of men bearing children has already been seen in this precedent.⁹¹

One possibility is the implantation of a fertilized egg in a male abdominal cavity, administering hormones to the 'male mother' to 'mimic that of a pregnant woman' and delivering the baby through a laparotomy. It has even been suggested that a woman could conceive a fertilized egg which would be flushed out of her womb and implanted in the man. There have been suggestions that transsexuals could have their sperm frozen before their conversion operation and use a donor egg with their own sperm. They would then be both mother and father to the child - the patriarchal dream. As Dr. Shettles, who has done pioneering work in in vitro fertilization, comments: 'I don't think it's going to take as long as it did with the in vitro program. I think anyone who really wanted to get on with it now could achieve success'.⁹²

Published interviews with transsexuals who are desiring to be involved in these kinds of programs are constantly reappearing. It is clear that what they want is to fulfill a stereotyped view of feminine identity. One article in 1984 said: 'Phillip McKernan wants to give birth to prove something to himself - that he has finally made it as a woman'.⁹³ But more recently in a 1986 article the issue was raised again by Professor William Walters, who runs the transsexual conversion clinic at Queen Victoria and is part of the Monash IVF team. He claimed that he could quite understand the demand of transsexual Estelle Croot to have a baby. Said Walters, 'it is a natural corollary that they should want to have children'. Estelle himself said: 'I am a woman. And like any woman I want to feel complete. I want to fulfilled and for me that means having a baby'.⁹⁴ Transsexuals too are influenced by stereotyping and pronatalist ideologies.

I will be interested to see how the civil libertarians will deal with the 'right' of transsexuals to have babies. Feminists would do well to heed the chill winds of colonisation here. Janice Raymond has argued convincingly in her book The Transsexual Empire that transsexualism represents the final colonisation of women.⁹⁵ Through transsexualism, which is mainly 'male-to-constructed-female' sex change, men are able to possess women's bodies, women's creative energies, women's capacities. These are the most 'feminine' women. It is a woman made by a man to be as feminine as man deems fit. As one transsexual said: 'genetic women are becoming quite obsolete'.⁹⁶ And soon, the male-created-woman may be able to have the male-created-baby.

Concluding Statements

I have given you in this paper some examples of the complexity involved in reproductive technologies and the social issues which arise from them.

Although we must encourage all individuals to fulfil their potential and maximise the choices available to them, we cannot do this without concern for the social implications and impact of the new reproductive technologies.

Women particularly should resist the continuing use of our bodies as living laboratories for ambitious and commercially motivated researchers. We should learn from history. Roberta Steinbacher's comments on the contraceptive pill still ring true:

Who invented it, who manufactures it, who licensed it, who dispenses it?
But who dies from it?⁹⁷

End Notes

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