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Calculated Risk:

Constructions of Risk in Biomedical, Feminist, and Lay Perceptions of Conception-Assisting Technologies

BY

STEPHANNIE CHARLOTTE ROY ©

DEPARTMENT OF SOCIOLOGY
LAKEHEAD UNIVERSITY
THUNDER BAY, ONTARIO

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Abstract

This thesis explores how different social and political interests frame interpretations and assessments of the risks of conception-assisting technologies among biomedical clinicians, infertile women seeking treatment, and feminist analysts--three important groups involved in the debate over the efficacy, safety and acceptability of conception-assisting technologies. Through a review of interdisciplinary secondary source data on risk and conception-assisting technologies, I detail the prevailing theories on risk, risk assessment and risk acceptability. I elaborate the particular perspectives on risk held by each of the three groups and the social and political influences which shape them. I also explore how differing conceptions of risk affect decision making and the acceptance of technology. I argue that to understand differing risk constructions it is necessary to understand the social, political, economic and cultural framework within which these risk determinations are made. This discussion of risk and conception-assisting technologies should be viewed and analyzed as part of a wider debate about socializing technology. It also makes way for more comparative sociological analyses of different groups' risk assessments of technological innovations.

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Chapter One

Introduction

It would be strangely innocent nowadays to imagine a society in which the discourse on risk is not politicized. Such a society would have to be lacking free debate without values. It would have to be without a forum for generating a shared ideology.
(Douglas, 1992: 13)

In our society, reproduction is seen as a central aspect of women's lives. Our biological capability to reproduce is shaped by our social and cultural values about conception, pregnancy, birth and child rearing, and on a societal level choices are made as to how reproduction is enacted and regulated (Overall, 1993). Reproduction is seen as "women's work" but the scientific and medical establishment, the agents of our social notions of procreation, see women's bodies as unfit for the task--imprecise, unpredictable, imperfect--and in need of improvement.

This assumption leads to the expansion of reproductive technologies as a way to improve on nature. Our societal view of procreation as of prime importance and even definitive of womanhood is reinforced by current medical practice which focuses on the enhancement of fertility through new reproductive technologies (Overall, 1993). Technologies created to assist conception, for example, have been presented in the media and by the biomedical establishment as a panacea for infertile couples.

Yet, the expansion of conception-assisting technologies is contested by many groups because with these technologies new risks are created which may cause detrimental effects to women's health and autonomy, to the offspring born using new technologies, and to our societal structure itself. The debate over the use of conception-assisting technologies and their efficacy as treatments for infertility centres on questions of risk surrounding their use.

Risk is generally defined as the likelihood of some adverse outcome (Becker & Nachtigall, 1994; Palmer & Sainfort, 1993; Short, 1984). Risk is also an action--to chance the possibility of danger. In contemporary society, questions about risk encompass much of the debate surrounding the acceptability of new technological developments, and analyses of risk are undertaken by experts and lay persons to anticipate, avoid, lessen or change the extent of uncertainty involved in making decisions about technological use (Hayes, 1992).

The debate over technological acceptance and the risks we face is about conflict over who has the authority to declare a particular conception of risk as the truth (Beck, 1992; Hayes, 1992; Kaufert & O'Neil, 1993). Defining risk in our society is therefore a struggle among rationality claims, and ideological commitments (Beck, 1992; Otway & von Winterfeldt, 1982). It is about public support for technological advances, and trust in the institutions which develop and manage technology. And, it is about power, who has the power to decide which risks society is willing to accept, and for what social, political and economic ends (Perrow, 1982).

According to Nelkin, defining risk is a way of "...explaining the failure of existing political or social relationships, of voicing mistrust, [and] of delegating blame" (1989: 98). Discussions of risk are about more than danger to health and happiness. They are also about credibility, trust, responsibility, and fairness; going beyond the statistics of the experts to the arena of public debate: "Instead of asking how much risk is acceptable to you, the general question would be what kind of society do you want?" (Douglas, 1985: 14-15).

AIM OF THE THESIS: CALCULATING THE RISKS OF CONCEPTION-ASSISTING TECHNOLOGIES

The aim of this thesis is to examine the differing constructions of risk in biomedical, feminist and lay conceptions of conception-assisting technologies to better understand the ideological underpinnings of each groups' perspective. Conception-assisting technologies like *in vitro* fertilization and fertility drugs typify the risk and technological acceptance debate, and yet remain an area largely unexamined in current debates on risk. According to Mary Douglas (1992), social scientists have not undertaken the task of analyzing comparative conceptions of risk to explain differences in risk perception in our society. There have been few academic studies on the differences between medical and non-medical conceptions of risk, or on how different groups in society define and construct the risks to society, and in their lives. In the case of conception-assisting technologies, there are varied discourses on risk from ethicists, philosophers, clergy, feminist analysts, physicians, bureaucrats, pharmaceutical companies, and the infertile women who use the technologies.

Analysis of differing conceptions of risk is important to understanding perceived choices and consent to use conception-assisting technologies. Three main groups in the debate: biomedical clinicians, feminist analysts, and infertile women seeking treatment, all evaluate the risks of conception-assisting technologies, but their notions of risk are constructed differently. Their expressions of risk represent political interests--those who are for it minimize the individual risks and dangers to society, while those who contest its use bring the risks to the forefront of the debate. In their constructions they: "...affirm or challenge existing relationships of power and control" (Kaufert & O'Neil, 1993: 32). Each group wants to maintain, or promote, a particular world view in their assessment of the risks of conception-assisting technologies.

To understand the constructions of risk surrounding conception-assisting technologies formulated by each group I will detail the prevailing theories on risk, risk assessment, and risk acceptability which will guide the analysis of each group's risk conceptions. I will discuss the risk construction of each group revealing the influences on, and reasons for, their particular construction--the social, cultural, and political context in which they construct risk. I will also detail the risks each group highlights surrounding the use of conception-assisting technologies and explain how these affect decision making and acceptance of the technologies. Through this analysis I hope to contribute to a broader understanding of risk, risk analysis and technological acceptance, and the social context in which feminists, infertile women seeking treatment, and biomedical clinicians evaluate the risks arising from the use of conception-assisting technologies.

CONCEPTION-ASSISTING TECHNOLOGIES AND THEIR USE IN CANADA

Before detailing the technologies available in Canada to aid conception, it is important to have an understanding of the prevalence of infertility in Canada. The Royal Commission on New Reproductive Technologies conducted the first comprehensive Canadian survey of infertility and found that eight and one half percent of couples (approximately 300,000 couples) aged 18 to 44, who were married or had been cohabiting for at least one year at the time of the survey, and who were not using contraception for that year, failed to have a pregnancy. Not using contraception for two years, seven percent of couples (approximately 250,000 couples) failed to have a pregnancy. The one year time frame, commonly used by the medical profession, represents the time period in which most couples are expected to conceive. It is disputed by many, however, including the World Health Organization, because some couples who do not conceive in the first year, will in the second year. Thus, the Royal Commission used both time frames for clarity (Royal Commission on New Reproductive Technologies, 1993).

There are many causes of infertility including sexually transmitted diseases, exposure to harmful agents in the environment or the workplace, and smoking. Fertility also declines with age (Royal Commission on New Reproductive Technologies, 1993). Infertility can also be iatrogenic, resulting from previous medical interventions: drugs, surgery, diagnostic tests, or medical devices like IUDs (Corea, 1985).

There are a number of conception-assisting technologies used in Canada to help infertile couples have babies. Many women use fertility drugs dispensed by a specialist or their family physician. Fertility drugs are hormones that affect the reproductive system, generally helping to induce ovulation in women, or increase the production of sperm in men. The number of women who use fertility drugs to treat infertility is difficult to ascertain because most often the drugs are not dispensed at specialized centres, but instead, by a couple's general practitioner. Fertility drugs are usually the first treatment used to combat infertility (Royal Commission on New Reproductive Technologies, 1993).

One of the most advanced conception-assisting technologies is *in vitro* fertilization (IVF). IVF has received most of the attention in the critical discourse on new reproductive technologies. IVF is a technique which involves the surgical removal of mature oocytes (eggs) from a woman's ovaries, usually after the administration of a fertility drug to induce ovulation (or hyperovulation). The eggs are then fertilized with sperm *in vitro* (in glass) in a laboratory. Fertilized eggs are placed in the woman's uterus, where ideally, they will implant allowing normal pregnancy and delivery to occur (Stephens & McLean, 1993).

Two variations on IVF are also used in Canada. The first, gamete intrafallopian transfer (GIFT) involves the same removal of a woman's eggs, but instead of being mixed with sperm in a laboratory, the eggs and sperm are reintroduced into the fallopian tubes in a surgical procedure called laparoscopy. Fertilization, if it occurs, takes place *in vivo* (in the body), and requires fewer laboratory facilities. It is however, only suitable for women who do not have blockages of the fallopian tubes (Stephens & McLean, 1993). The second, zygote intrafallopian transfer (ZIFT) involves taking a fertilized egg, obtained through IVF, and transferring it to the fallopian tube usually via a catheter threaded through the uterus under ultrasound guidance (Stephens & McLean, 1993). The three procedures vary only slightly, so for simplicity the term IVF will be used to encompass all three techniques throughout the thesis.

It should also be noted that throughout this thesis the term conception-assisting technologies will only refer to fertility drugs and IVF. It does not include artificial insemination, any use of donated gametes, or any conception-assisting technology that does not result in genetically-related children.

Stephens and McLean (1993), in their survey of Canadian fertility programs for the Royal Commission on New Reproductive Technologies provided a detailed picture of the provision of conception-assisting technologies in Canada 1991 (1993). They found seventeen clinics offering IVF services in Canada, including both teaching and other hospitals, and one independent clinic.[1] Geographically, the services were clustered in central Canada with one third of all clinics located in Ontario (all of which were located in Southern Ontario). This distribution would suggest disparities in access to IVF procedures, evidenced by the fact that of the approximately 2,900 couples using IVF, 70

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[1] There were 15 programs offering IVF, 6 offering GIFT and 2 ZIFT programs in 1992. The programs were not static however, with some clinics adding and removing procedures when they felt it was necessary (i.e. due to availability of laboratory facilities, or personnel) (Stephens & McLean, 1993).

percent were from Ontario, though Ontario accounted for only 37 percent of Canada's population in 1991 (Stephens & McLean, 1993).

Couples generally had to wait four weeks or less for an initial assessment, though the wait was as long as thirty weeks in clinics outside of central Canada. It would seem that the demand for IVF services is high. In addition to medical unsuitability for IVF, some clinics rejected women for treatment on other criteria: being a lesbian, or a single woman, or through demonstrating "doubtful parenting ability", though how this was assessed is uncertain. Certainly, some clinics do exercise the power to decide who is socially suitable to reproduce (Stephens & McLean, 1993).

Stephens and McLean (1993) report that the protocols, procedures and actual practices of conception-assisting programs vary a great deal, despite the fact that there have been standards and guidelines established for some treatments by Canadian biomedical governing bodies. This is evidenced by the variability in definitions of success for IVF. In 1991, half of the IVF clinics defined success through the achievement of pregnancy, determined by a chemical test. The birth of a live child (the definition of success for most infertile couples) was a distant second definition of success by the programs. What was communicated to patients was a statistical success rate, but this was not accompanied by any indication of how the rate was determined in many cases. It could be the number of pregnancies per treatment cycle (which has varying definitions), or the number of live births per couple, or some other rate, leading Stephens and McLean to question how fully informed couples are about the possibility of success. In fact, they found that generally, IVF is not successful. In 1991, 18 to 26 percent of attempts resulted in pregnancy, and 10 to 20 percent of attempts resulted in a live birth. There were 609 pregnancies in 1991, which resulted in 189 live births--this out of approximately 2,900 couples enrolled in IVF programs (Stephen & McLean, 1993).

The findings of the Royal Commission on New Reproductive Technologies concerning IVF and fertility drugs are also worthy of note here. It concluded that the way IVF is currently offered is unacceptable:

- It was being used for indications for which there was little evidence that it was effective.
- There was a marked difference in how services were offered in different clinics, often without the provision of clear and understandable information for patients.
- Record keeping was found to be unsatisfactory and insufficient to assess the outcomes: i.e. number of children born, and the long-term health of women and children.
- Voluntary guidelines for practice were not being adhered to (Royal Commission on New Reproductive Technologies, 1993).

The Commission also found that fertility drugs are being dispensed for unapproved indications and dosages, there are possible unknown long- and short-term side effects which have not been assessed, and some drugs are being prescribed which have not been found effective in treating infertility. It recommends better regulation, and licensing through the creation of a National Reproductive Technologies Commission to ensure the provision of safe and effective technologies for Canadians (Royal Commission on New Reproductive Technologies, 1993). To date, none of the recommendations of the Commission have been enacted in law by the Federal government, though legislation to curb the commercialization of certain new reproductive technologies has been introduced in the House of Commons in 1996.

METHODOLOGY

Determining Differing Constructions

The main focus of this thesis is an analysis and interpretation of what is detailed and what is omitted in the conceptions of risk put forward by feminist analysts, biomedical clinicians, and women seeking infertility treatment, to better understand the moral, social and political interests each group conveys about the use of conception-assisting technologies. Feminist analysts, infertile women seeking treatment, and biomedical clinicians are three important groups involved in the debate about the efficacy, safety and acceptability of these new reproductive technologies. Their conceptions of the risks both reflect and reinforce their values and beliefs about biomedicine and technological acceptance, and lend understanding to the roots of their ideological positions.

Secondary source literature which addresses the use of conception-assisting technologies in terms of the risk conceptions of each group is reviewed. A variety of secondary sources were used in the analysis of each group's construction of risk. These include:

1. An interdisciplinary collection of feminist writings on conception-assisting technologies, infertility, and biomedicine which provide detailed critiques of patriarchal attitudes about reproduction and the use of conception-assisting technologies. The feminist literature represents a wide array of perspectives on the development and use of conception-assisting technologies, and reflects the main arguments of feminist analysts on this subject.
2. Writings on risk, risk assessment, and risk perception from a number of fields including epidemiology, anthropology, economics, sociology, geography and psychology to provide an understanding of the prevailing theories of risk.
3. Works examining infertility, medicalization, and the culture of biomedical practice to detail how biomedical clinicians construct risk. Current literature predominately from biomedical journals detailing the risks of conception-assisting technologies in clinical settings was employed. The aim was to detail

biomedical clinicians' conceptions of risk based on how conception-assisting technologies are actually used since clinicians necessarily construct risk based on their experiences with the technology.

4. Selective accounts by feminist, sociological and anthropological researchers summarizing the experiences of infertile women (and couples) with infertility and conception-assisting technologies. Also used were accounts from infertile women themselves (which should not viewed as representative of all infertile women seeking treatment) and informational books directed at infertile couples to help them understand the options available to them. While interviews with infertile women would have provided the best data on their conceptions of risk, this was beyond the scope of the thesis.

Using these secondary sources, the following themes were explored to determine each group's construction of risk:

1. The experiences of each group with health care, infertility, conception-assisting technologies, and their attitudes toward biomedicine were evaluated.

2. The ideological stance of each group was examined. Each group has a vested interest in portraying the risks associated with conception-assisting technologies the way they do. What is the motivation for each group's conception of risk?

3. Views on risk in general were evaluated. Is it an individual's prerogative to take risk, or should risk taking have a social dimension?

4. What does each group believe are the important components to weighing the risks of conception-assisting technologies? What knowledge do they rely on about the technologies used?

Additional data and insights were gained from primary sources including the Royal Commission on New Reproductive Technologies which provided recent Canadian data to supplement secondary sources. Also, I visited IVF Canada, a Toronto IVF clinic, and attended a Lakehead Infertility Awareness Group meeting which featured a presentation on conception-assisting technologies and infertility by a physician and nurse from the Thunder Bay Assisted Reproduction Centre. Written information given to patients at the IVF clinic and those attending the infertility awareness group meeting was collected and used to supplement secondary sources.

In using secondary sources, I am in fact "constructing" each group's construction of risk. Many of the sources cited in this thesis do not address risk directly, but instead discuss the political, social, and cultural values of each group. This thesis provides a basis from which primary data may be obtained. It is a comprehensive first step toward a fuller understanding of the conceptions of risk in biomedical, feminist and lay perceptions of conception-assisting technologies. It also provides a framework for the comparative analysis of other risk constructions as part of a critique of the societal acceptance of technological innovations.

Plan of the Thesis

Chapter Two provides a theoretical background on the notion of risk. Beginning with an explanation and critique of technical risk assessment methodologies, it posits an alternative to this form of risk assessment which takes into consideration the social constructions of risk conceptions. The chapter concludes with an explanation of how people generally construct notions of risk, and make decisions about taking risks.

Chapter Three outlines the risk construction of feminist analysts surrounding the use of conception-assisting technologies. It begins with an explanation of the social context and ideological underpinnings which guide feminist analysts' extensive critiques of biomedicine, reproduction, and new reproductive technologies. It continues by delineating the risks detailed in feminist writings beginning with the risks to individual women who use conception-assisting technologies. This is followed by an examination of the technologies in a wider social context and the risks they may hold for women as a group--a group whose status is shaped by existing patriarchal social relations. The chapter concludes with a discussion of the debate among feminist analysts on how to respond to these risks in an effort to promote women's reproductive autonomy.

Infertile women's conceptions of risk are detailed in Chapter Four. To get a better understanding of the influences on this group's risk construction, typical experiences of the involuntarily childless and the parenthood motivations of infertile couples are examined. The decision-making process of infertile couples surrounding their options is discussed, centring specifically around the medicalization of infertility and the decision to seek treatments using conception-assisting technologies. This is followed by a discussion of infertile women's conceptions of risk before and during the treatment process.

Chapter Five examines the risk construction of biomedical clinicians and the important role they play in influencing lay risk conceptions. It begins with an explanation of the culture of biomedical practice and the particular perspective of infertility specialists. Biomedical definitions of infertility and the treatment process are then detailed to show the biomedical lens through which infertility is viewed. The construction of risk by biomedical clinicians is explored through an investigation of the risks of conception-assisting technologies found in biomedical literature.

The conclusion (Chapter Six) details the research findings, showing how the vested interests of each group influence their constructions of risk. It is followed by a discussion of something all three groups neglect in their risk constructions--the current mechanisms of societal technological choice and acceptance, and how they can be transformed to better socialize technology. The thesis concludes with suggestions for further research and a statement concerning the significance of this study.

Chapter Two

Conceiving Risk

How are assessments of risk made? What does it mean to say a particular activity or technology is risky? Most scientific and social scientific disciplines study risk and each is constrained by its choice of methods (Douglas, 1985). According to Hayes (1992), this results in a lack of conceptual coherence leading to definitions and uses of risk which vary within and across disciplines. In this chapter the concept of risk will be elaborated in order to create a framework which will guide the analysis of varying constructions of risk surrounding conception-assisting technologies in subsequent chapters.

TECHNICAL RISK ASSESSMENT

The most conventional model[2] of risk analysis--technical or expert assessment--is a product of statistics, epidemiology, engineering and economics, and uses quantitative, probabilistic methods (Firoino, 1989). Emerging out of the need to examine the risks of new technological discoveries, in order to make recommendations to policy makers and business people about

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[2] For example, the May 1996 issue of *Discover* magazine, devoted entirely to the topic of risk, discusses various risks almost solely from a technical assessment perspective.

potential hazards, it epitomizes the hegemony of positivistic science, especially through its desire to eliminate uncertainty by predicting the risks we face (Hayes, 1992).

In technical constructions of risk, the danger has to be quantifiable so the probability of hazard can be determined. Measures like death and disease rates, lost work days and economic cost/benefit analyses are favoured (Short, 1984; Starr, 1994). Usually the analyses involve some comparison of the derived social benefit (converted into a dollar or numerical value) with the risks of a particular activity (typically defined as fatalities per person per hour of exposure) (Cutter, 1993; Starr, 1994). In epidemiology, risk is a statement of statistical probability--the estimated frequency of an event (usually disease or death) under certain conditions of exposure in the population (e.g., one in nine women will get breast cancer over their lifetimes) (Becker & Nachtigall, 1994). Risk is therefore conceptualized as the expected number of fatalities, or other adverse consequences due to a particular activity or use of a technology--it is numerically defined, and scientifically derived (Firoino, 1989).

To quantify risk in a world that is often complex and unpredictable, technical assessments rely on sophisticated models of the 'real world' through the creation of artificial scenarios requiring many simplifying assumptions:

> [A]dult human beings live exactly 70 years, stay indoors all day in radon-contaminated homes, drink precisely seven cups of water a day, smoke very heavily or not at all, and exercise while inhaling abnormal quantities of airborne pollutants (Jasanoff, 1993: 124).

The reliability and validity of these models is absolutely important for accurate measurement of risk, so generally technical risk methodologies are designed to provide overestimates rather than underestimates of risk (Lave, 1994; Short, 1984).

The use of quantitative data and probability statistics gives technical risk the aura of objectivity, rationality and legitimacy (Firoino, 1989). Assessments are based on hard "facts", statistical data, and tested scientific assumptions. "Experts" assert that technical assessments represent the risks we face as they really are: unbiased and objective (Jasanoff, 1993; Nelkin, 1989; Starr, 1994).

Criticisms of the Technical Risk Model

The creation and maintenance of expertise places technical risk conceptions at the top of a hierarchy which ultimately reduces the value of other constructions of risk, and ignores the political and emotional motivations experts have for constructing risks the way they do (Beck, 1992; Cutter, Tiefenbacher & Solecki, 1992; Douglas & Wildavsky, 1982). This inevitably leads to conflict usually with the public, though it occurs within the technical risk community as well. The public is viewed by "experts" as being motivated by more than the facts. Individuals are condemned for making judgments about risk based on their emotions and political motivations. Some experts believe lay people should defer judgment on issues of technological acceptance and management to experts (Cutter, Tiefenbacher & Solecki, 1992; Otway & von Winterfeldt, 1982). Experts view members of the public who question their objectively ascertained facts as irrational, prey to their emotions, weak in probabilistic thinking, ignorant and motivated by subjective political goals (Gillick, 1988; Douglas, 1992).

Conflicts between expert and lay conceptions of risk demonstrate that risk cannot solely be determined using the technical model. Some important criticisms of technical risk assessment further illustrate this point. First, technical risk calculations neglect what is referred to as higher order impacts--risks beyond death and disease rates. These risks include: damage to the public's faith in institutions or politicians; the aesthetic value of the physical environment; social changes resulting from technological advances; emotional distress; or quality of life issues (Kasperson, et. al., 1994; Nelkin, 1989; Slovic, 1994). The range of risks examined in technical assessments is exceedingly narrow, focusing on very few of the things people value (Short, 1984). Also, technical models cannot assess risks that are completely unknown at the present, only those which enter the sphere of the research: How can one examine the risk of a cancer which has not yet been discovered? (Douglas & Wildavsky, 1982).

A second criticism of technical risk assessment is that it assumes only one kind of rationality for thinking about risk. Risk is treated as a unidimensional, technical, probabilistic concept, thus ignoring the many other layers of meaning the term has in popular discourse (Hayes, 1992). The contention that knowledge gained from technical methods is sufficient for making decisions about technological acceptance reflects scientific imperialism in conveying what risks it is in the public interest to know (Otway & von Winterfeldt, 1982; Short, 1984).

The assumption of a single risk rationality leads into the third criticism, that technical risk assessment's claim to being apolitical is false. By asserting objectivity and rationality, technical risk analyses also ignore the social, cultural, and political influences on the scientists themselves. Monetary or reputation pressures, company policies and ideologies, for example, all influence which questions are pursued and how results are used in the assessment of risks. Also, risk assessment is often plagued by incomplete information requiring guesswork and judgment calls by scientists themselves (Freudenberg, 1994). Expert risk assessors assert they are bracketing out "...the grime and heat of politics....to get at the real essence of risk perception before it is polluted by interests and ideology" (Douglas, 1992: 11). They are, in fact, asserting an ideological stance of their own; that risk assessments and societal technological choice can be achieved through clearly measurable, objective means.

CONFLICT WITH THE PUBLIC

In our society, organizations generally set the terms of debate concerning risk acceptability. Technical risk experts assess the magnitude of danger, and influence the choices policy makers, business and industry make concerning the allocation of resources and risks (Clarke & Short, 1993). The apolitical, objective stance taken in technical risk analysis is precisely what leads to conflict between experts and lay people over the risks we face. Experts fault the public for assessing risk based on the very notions they themselves purport to ignore: social, cultural and moral ideals about our world. Also, according to the experts, the public is merely uninformed; if people had all of the facts, they would understand that the risks they fear are no worse than the possible dangers of smoking, driving or skiing (Beck, 1992).

So why do members of the public fear toxic waste storage in their own neighbourhoods, seek compensation for failed medical devices like silicon breast implants, or demand that dairy products using bovine growth hormone be clearly labelled, when experts assert they pose no risks to health? Raynor and Cantor (1987), suggest that the central question is not solely the technical assessment of "'How safe is safe enough?'", but a larger assessment of "'How fair is safe enough?'" (1987: 5). Because decision making is held in the hands of very few, the validity of technical risk claims, and processes under which risky decisions are made fuel public concerns about risk. Those who will be exposed to risk must feel they were consulted, that courses of action were collectively determined, and that those who will regulate the technology are worthy of trust (Raynor & Cantor, 1987). This means confidence in institutions, and the credibility of the information given to the public, are often the issues in debates over risk and technological acceptance (Clarke & Short, 1993; Wildavsky & Drake, 1994).

Also, according to Slovic (1994), lay people can assess risks very much like technical risk experts when asked. They know and understand annual fatality rates surrounding the use of various technologies and understand concepts like the use of nuclear power plants result in fewer deaths annually than driving a car. Lay people's constructions of risk are not built from micro-world simulations however, catastrophic potential threats to future generations and other characteristics are taken into consideration. To lay people, risk is more than annual fatality rates.

Moreover, members of the public have become experts when particular technological hazards affect them. Even armed with the experts' studies, they often still refute their claims. They combine technical and theoretical knowledge with knowledge about their particular situation often giving them a fuller knowledge of the situation (Jasanoff, 1993). Clarke and Short (1993) explain that lay people are in fact very rational, but in non-obvious ways which are neglected by technical risk methodologies centring on probabilistic and cost-benefit approaches to determining risk.

Finally, in disputing the experts, the public is saying: "This is not how we want to live":

> The non-acceptance of scientific definition of risks is not something to be reproached as 'irrationality' in the population; but quite to the contrary it indicates that the cultural premises of acceptability contained in scientific and technical statements on risk *are wrong* [original emphasis](Beck, 1992: 58).

The lay public's risk assessments are very rich and detailed, not irrational, and illustrate the political nature of risk assessment and technological acceptance as a struggle between differing knowledge claims. It would seem that "...just as scientists' estimates may need to be treated with something less than reverence, the views of the public may need to be treated with something better than contempt" (Freudenberg, 1994: 250-251). This suggests that a better model of risk is necessary to understand how differing constructions of risk occur.

AN ALTERNATIVE MODEL OF RISK

Mary Douglas, a pioneer in the study of risk, asserts that conceiving risk as a social construction is the best way to understand risk perception by all groups in society because it provides the widest view of the possible range of goals that people are trying to achieve in constructing risk the way they do (Douglas, 1992). A cultural theory of risk was originally introduced by Mary Douglas and Aaron Wildavsky in *Risk and Culture* (1982). They asserted that people do not have objective risks flung upon them which they merely perceive, but are instead active organizers of their perceptions and thereby construct risks (Wildavsky & Dake, 1994). For them, perceptions of risk reflect underlying assumptions and values, and are shaped by social and cultural mechanisms like blame, social criticism, world views and ideology. These deeply held values and beliefs which defend social positions are what Douglas and Wildavsky (1982) call cultural biases.

The cultural theory of risk is premised on the notion that individuals construct risks (or what is considered hazardous) to support their way of life (Douglas, 1992; Douglas & Wildavsky, 1982; Wildavsky & Dake, 1994). Risk does not exist solely as an objective feature of our physical world; it is a construct which we use to characterize parts of our society (Jasanoff, 1993).

This means hazards are an interpretation of events that are observed, then characterized as unwanted, and communicated to others (Clarke & Short, 1993; Renn, et al., 1992). Risks are made no less real by their social construction. In fact, it makes many of the differences between experts and various constituencies of the lay public more clear: "This argument is not about the reality of the dangers, but about how they are politicized" (Douglas, 1992: 29)

That risk is an interpreted subjective experience means risk conceptions are shaped by social, political, economic, and cultural forces (Cutter, 1993; Dutton, 1988; Kaufert & O'Neil, 1993). What information people choose to believe, trust in the information provider, personal values, social experiences, institutional affiliations, and the social and historical context in which decisions are being made are some of the myriad of influences shaping risk construction (Jasanoff, 1993; Otway & von Winterfeldt, 1982).

It is argued that conceiving of risk as socially constructed better reflects how risk is assessed. It represents a sophisticated attempt to integrate information about risk into meaningful blocks of information (Jasanoff, 1993). And, it allows us to discover and analyze the assumptions or omissions of the variables necessary for risk assessment. For example, in their analysis of a verbal exchange between an Inuit woman and a physician about the risks of childbirth, Kaufert & O'Neil (1993) found that the physician at first cited "objective", scientifically-derived risk statistics to emphasize the fact that he viewed childbirth as risky in the far north. When the Inuit woman questioned the relevance of his statistics, he illustrated the dangers by using case examples from his personal experience--that he had seen seven women die in childbirth. His conceptions of risk were then shaped by the statistics, his experiences, and his interpretation of them. His risk construction also reinforced his political view that childbirth in the remote north without a physician present is full of risks and should not be allowed (Kaufert & O'Neil, 1993). The physician took the statistics about maternal mortality, interpreted them and used them to support his claim about the risks. His dialogue on risks was full of emotions and politics; it was not wholly objective and scientific.

Constructing Risk

Following this inclusive model of risk perception, the mechanisms people use to construct risk can now be delineated. When faced with situations which have elements of risk, people incorporate many different variables in their assessments, and subsequent construction of the risks of technologies or activities. Constructions of risk are shaped by one's experiences and the context of one's life, and the circumstances and constraints that impinge upon them and shape one's view of the world (Becker & Nachtigall, 1994). It is important to note that views of risk are therefore not homogeneous. The debate about the acceptance of technology, risks, and choice is not only between the experts and the public, but also within the public and the expert realms as well.

To construct risk, information about the activity or technology is needed. People rely on formal information from experts, advertising, media, product labelling, self-help books, and pamphlets and advocacy group information. They also have access to informal information through personal contacts: family, friends, and co-workers (Cutter, 1993; Douglas, 1992; Nelkin, 1989).

According to Otway and von Winterfeldt (1982), attributes of technologies themselves also influence the construction of risk. People generally make the following assessments when faced with decisions about risk and technological acceptance:

- Is exposure to risk involuntary as opposed to taking risks at one's own choice?
- Is there personal control over the outcome of the risk exposure, or is one at the mercy of others?
- How certain is one about the probabilities or consequences of exposure? Do the experts agree?
- How much personal experience with the risks of the technology does one have?

- How difficult is it to imagine the risks of exposure?
- Are there delayed somatic effects of present risk exposure?
- Are there genetic effects of present risk exposure which will threaten future generations?
- What is the likelihood of catastrophic accidents?
- Is the burden of the risks fairly distributed? (i.e., Will the benefits go to others, but the risks to us?)
- What is the likelihood of accidents caused by human failure rather than natural causes? (Otway & von Winterfeldt, 1982).

Economic, social, political and cultural considerations are also integrated into constructions of risk: Does the new technology provide jobs? Will it increase our standard of living? Will it concentrate power and create dependence on a small elite group? Does it meet the purported need? These wider social questions come into play, but which questions are asked is dependent on one's cultural framework and motivations (Douglas & Wildavsky, 1982; Otway & von Winterfeldt, 1982).

Taking Risks

In deciding to use new technological advances, individuals and groups have decided to take risks. Risk taking involves more than just danger, however, because the outcomes of technology have both positive and negative possibilities. Douglas (1992) asserts that risk was originally deemed neutral--the probability of an action occurring, taking account of the magnitude of losses or gains that would result. According to Hayes (1992), the present conception of risk as danger is problematic since it assumes the risk-taker has not fully understood the possible negative outcomes (as assigned by an external risk-assessor), allowing her/his actions to be judged as irrational or bad. Analysis of both the negative and the positive aspects of a particular action allows for a better understanding of the risk-taker's motivations because the real or perceived benefits of the activity may more than compensate for its dangerous aspects in the individual's calculation of risk. Risk, therefore, does not only mean hazard, but also is an assessment of both the losses and gains that could result from a particular activity--it may have both good and bad outcomes.

This means decisions about risks are taken by weighing and comparing many good and bad possibilities, and choosing what we can and cannot live with (Douglas, 1992). Decisions about the risks of a particular technology are put in context with all of the other risks we face (from nature, society and all other technologies we are exposed to). The risks of inaction must be weighed against the dangers of action; the benefits of a technology may be high enough for its hazards to be accepted (Becker & Nachtigall, 1994; Otway & von Winterfeldt, 1982). Even a very high likelihood of danger may be accepted if the results are conceived of as very desirable (Douglas, 1985).

Risk-taking decisions are best conceptualized as a gamble, since the ultimate outcome is unknown when the decision is made (Palmer & Sainfort, 1993). The assessment of both gains and losses from a particular action allows the risk-taker to actively construct and evaluate the risk. Risk assessment is therefore not something thrust on the actor by an external expert, but is something constructed using one's own knowledge base, and the variety of political, social, cultural and economic elements which influence it (Hayes, 1992; Palmer & Sainfort, 1993).

CONCLUSION

Differing models of risk assessment have led to many conflicts both within the academic community, and between the "experts" and the public as well. A predominant method of risk assessment is technical, in which objective, scientific, usually statistical methods are used to determine the risks of particular activities or technologies. While proponents of technical risk assessment assert that they represent risks as they really are, such models have met with criticism. Critics assert that technical risk assessments neglect to measure risks outside death and disease rates, and that these statistical abstractions have little meaning in the "real world". They also contend that technical risk constructions are themselves not objective, but are influenced by social, political and ideological beliefs and constraints, including the contention that risks can be objectively ascertained.

This objective apolitical stance of technical risk assessors leads to conflict with the lay public as it is often their lives which will be affected by the possible risks of technology. Technical risk assessments often neglect things which are important to the lay public who question the credibility of evidence which is not collectively determined in a truly democratic decision-making process.

In response to these conflicts between the so-called experts and the lay public, social scientists have put forth a more inclusive model of risk assessment. This model is premised on the belief that risk assessments are shaped by the underlying assumptions and values of the risk assessor. This makes the conflict between the experts and the public not one about facts and statistics per se, but rather about how facts and statistics are interpreted and politicized. Determinations of risk therefore are constructed; shaped by social, cultural, political and economic forces, and varying sources of information, including attributes of technologies themselves.

Decisions about technological acceptance mean that individuals and groups have decided to take risks. Risk taking has both negative and positive possibilities, and means there must be an assessment of both losses and gains. This is done by weighing the good and bad possibilities, their likelihood, and their magnitude in context with all of the other risks we face. The risks of inaction must also be considered, as deciding not to take risks may have negative and positive ramifications as well. Decisions about taking risks are not merely determined for individuals by external experts, but are the result of a myriad of influences.

The construction of risk surrounding the use of conception-assisting technologies parallels other debates about technological acceptance. The next three chapters will explore the risk constructions of three influential groups in society--feminist analysts, infertile women seeking treatment, and biomedical clinicians. Each group assesses the risks of conception-assisting technologies differently because of their particular societal view on the technology, especially their ideological stances. These point to a number of vested interests of each group. Through their risk assessments all three groups make pronouncements about the acceptability of conception-assisting technologies.

Chapter Three

Feminist Conceptions of Risk

Shulamith Firestone, in her book *The Dialectic of Sex* (1970), was the first feminist analyst to assert that reproductive technology would eventually be the means through which patriarchal control of women's bodies would crumble. Firestone argued that patriarchy is rooted in the biological inequality of the sexes and that: "The heart of woman's oppression is her childbearing and child rearing roles" (1970: 81). According to Firestone (1970), the distinction between men and women, fundamentally based on this inequality, would only disappear through artificial reproduction which would inevitably undermine the whole family structure and division of labour in our society, alleviating women from the burden of childbearing and child rearing. The biological differences between the sexes would no longer matter if conception, gestation and birth occurred outside of women's bodies.

Firestone's naive trust in technology to achieve women's liberation has been vigorously criticized by feminists re-examining her earlier arguments from the vantage point of two decades of reflection on the development and impact of new reproductive technologies like IVF and fertility drugs on women

(Sydie, 1988; Tong, 1989). While present day feminists contend that her vision of women's liberation has not come to fruition, it is also likely Firestone herself would be less idealistic about the benefits of technology were she writing today. And as with most feminists, she would likely argue that the development of reproductive technologies has created new risks for women. Skepticism over the development and use of conception-assisting technologies, in particular fertility drugs and IVF, is evidenced by the extensive critical writings by feminist analysts in which the many risks entailed in the use of conception-assisting technologies are exposed.

Generally, feminist research and activism has at its core the goal of ending the sexist oppression of women through change to our cultural concepts, language and ways of knowing the world (Sydie, 1988). Because of their goals, feminist theorists' analyses of risk, according to Cutter (1993), differ in many ways from traditional risk assessment. First, feminists have broadened the discourse on the differential burden of risks that are placed on particular groups, especially women. Second, they have incited action to influence how risk acceptability is determined. Third, feminists have changed how hazards are identified and assessed. And fourth, they have organized outright resistance to new technologies which have, in their view, unacceptable risks.

But, while the feminist construction of risk surrounding the use of conception-assisting technologies has been both unique and thorough, within feminism there are differing views on, and responses to, the threats posed by reproductive technologies. These differences have led to distinct forms of critique and political praxis, and stem from ideological disagreement amongst feminist analysts concerning the roots of women's oppression and the changes which are necessary to achieve women's liberation.

One of two key groups[3] analyzing conception-assisting technologies are liberal feminists (e.g., Birke, Himmelweit & Vines, Overall, and Warren) who emphasize the expansion of individual women's autonomy. Liberal feminists are aware of the physical, social, and emotional risks of conception-assisting technologies but feel they can be managed or regulated using legislative means. Their response to the risks is to create a structure in which women can make free and informed choices about using conception-assisting technologies. They believe that women should be given the opportunity to use conception-assisting technologies if they choose, and that access to the technologies should be expanded to all women who desire them.

The other group, radical feminists, view the risks quite differently. Radical feminists like Corea, Klein, Raymond, and

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[3] For heuristic purposes I am using the labels "liberal feminist" and "radical feminist" to delineate the two main feminist perspectives on conception-assisting technologies. These divisions are in some ways artificial since the perspectives of each group sometimes overlap, and because there are divergent views within each group as well.

Hanmer, believe that conception-assisting technologies threaten the autonomy of women as a group. They assert that those in the male dominated biomedical sphere place the safety and interests of women behind their own desire to make babies using reproductive technologies. They assert that women are being made test-sites for dangerous pharmaceuticals and technological interventions which threaten to further entrench male control over women. Radical feminists also assert that legislative structures are unreliable for instituting change for women. Their evidence is the state's long history of failing women through its complacent acceptance of biomedical doctrine.

These differing ideological stances within feminism do not detract from feminist analyses of the risks of conception-assisting technologies. All feminists analysts are guided by the same goal of ending the sexist oppression of women. Their differing ideological stances demonstrate how change can occur on many different levels, and how political views motivate risk construction, and subsequent action.

However, it is important to remember that while feminist analysts' writings on the risks of conception-assisting technologies are innovative and thorough, they do not comprehensively examine all possible risks. Risk assessment is shaped by ideological assumptions, cultural and social forces, and political motivations. This means feminist analysts' constructions of risk are shaped by their views of women, biomedicine, our society, and their vested interests--they are mainly concerned with risks that threaten women's autonomy and liberation--either collectively or as individuals (Strickler, 1992). The ontological status of the embryo, threats to the structure of the family, and religious objections, for example, are either discounted or ignored completely by feminist analysts, because these risk constructions are counter or tangential to their goal. Feminist interpretations of the risks of conception-assisting technologies are unique in that they cover topics that are generally neglected, and they challenge other risk constructions by looking not only at the risk to the users of the technology, but also to women as a group, and often society as a whole (Overall, 1987; Strickler, 1992).

This chapter begins with a comprehensive review of the risks of conception-assisting technologies detailed by feminist analysts. I concentrate on IVF[4], beginning with the risks of the procedures themselves, and then moving to the risks of conception-assisting technologies when their use is examined in a wider social context. The radical and liberal feminist responses to these risks will also be outlined. These range from calls for an outright ban on technologies like IVF, to liberal feminist models of a caring, risk lessening provision of conception-assisting technologies.

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[4] IVF is considered by feminist analysts to be the most invasive and risky conception-assisting technology which is why most writings concentrate on this procedure. See for example, Corea, 1985; Klein, 1989; Spallone, 1989.

RISKS ARISING FROM THE USE OF CONCEPTION-ASSISTING TECHNOLOGIES

Undergoing any medical treatment carries some risk. With this in mind, feminist analysts have provided an extensive detailing of the physical risks of conception-assisting technologies. In so doing they hope to inform infertile women of the dangers which could arise from undergoing conception-assisting procedures. Liberal feminist analysts feel that in order for women to exercise free and informed choice about using these interventions they must have *all* the information about the treatments, long- and short-term side-effects, and possible future complications. In contrast, radical feminists feel that with all this knowledge of risks, many infertile women will reject the technologies because the risks to themselves are beyond what is normal and acceptable for other medical treatments.

Fertility Drugs

For each IVF cycle, numerous intensive medical procedures are performed, starting with daily hormonal treatments to stimulate hyperovulation. Hyperovulation involves a woman's ovaries being chemically manipulated so they produce more than one egg per cycle. The more eggs produced, the more that can be harvested, and the greater the opportunity to continue the cycle. The process is not risk free and must be closely monitored using ultrasound and frequent blood tests, often requiring a woman to go to the medical facility twice a day (Williams, 1989).

Fertility drugs carry a number of side effects: hot flushes, ovarian enlargement resulting in abdominal discomfort or pain, breast tenderness, dizziness, headache, nervousness, nausea or vomiting, fatigue, and visual disturbances, all of which range from mild to severe (Royal Commission on New Reproductive Technologies, 1993; Williams, 1989). There is also a chance of a serious side effect, ovarian hyperstimulation syndrome which can cause the ovaries to rupture causing further infertility or even death (Spallone, 1989; Williams, 1989).

The risks do not end there; fertility drugs are also related to known carcinogens, are associated with high rates of miscarriage, and the effects of their long term use are unknown (Spallone, 1989). This has been particularly troubling to feminist analysts who feel that fertility drugs have not been adequately tested before being used on women (Corea, 1985). Findings of the Royal Commission on New Reproductive Technologies do not alleviate feminist concerns. The Royal Commission found that fertility drugs were used in dosages that exceed recommended levels and some drugs were prescribed for uses unapproved in Canada. For example, Lupron a frequently prescribed drug used to induce ovulation has only been approved in Canada for the treatment of prostate cancer, yet it is being given to women to treat endometriosis, and is used in conjunction with IVF (Royal Commission on New Reproductive Technologies, 1993).

Medical Invasiveness

If the egg follicles develop without side-effects which necessitate the cessation of treatment, the eggs are retrieved using one of two surgical interventions. The first, laparoscopy, involves putting a woman under general anaesthetic which carries its own risks. Small openings are then made in the abdomen from which a viewing instrument and aspirator are used to obtain the eggs (Spallone, 1989). The second technique, ultrasound needle aspiration, or Transvaginal Ultrasound Directed Oocyte Recovery (TUDOR), has the advantage of requiring only local anaesthesia to numb the vaginal walls, but it is extremely painful and involves other risks. There is the possibility of damage to the bladder and the uterus since a needle is put in the vagina, and through the bladder to pull out the mature eggs (Boston Women's Health Book Collective, 1992; Spallone, 1989).

Egg retrieval marks the end of the most dangerous part of IVF, but further medical intervention is necessary. Next, the eggs are mixed with sperm, and resulting embryos (if conception occurs in the petri dish after twenty-four hours) are inserted into the woman's uterus. If any embryos implant, the resulting pregnancy is closely monitored using ultrasound and amniocentesis. The birth is not permitted to occur vaginally; to avoid any alleged unknown risks, a caesarean section is routinely performed (Boston Women's Health Book Collective, 1992; Corea, 1985).

It is important to note that the procedure can go wrong at any time, and frequently does: not enough eggs mature to make the retrieval worthwhile; fertilization does not occur; embryo implantation fails; or pregnancy does not result, is ectopic, or ends in miscarriage (Williams, 1989).

The high degree of body invasiveness, the constant monitoring and the side-effects from the fertility drugs and surgeries make IVF physically and emotionally taxing for most; the stress has been described by users as "unrelenting" (Williams, 1989). Other stresses from the treatment include: the emotional turbulence, ranging from hope to disappointment, felt by women undergoing treatment; the disruption of paid employment necessary for most because treatment is time consuming; strain on a woman's personal life; and the depersonalization that may result from the "painful and embarrassing invasions of their bodies" during the treatment process (Warren, 1988: 38).

Multiple Pregnancies

In the unlikely event that IVF is successful there is a high probability that a multiple birth will result (Klein, 1989). In the general population one percent of all deliveries are for multiple births, compared to thirty percent of all IVF deliveries (Royal Commission on New Reproductive Technologies, 1993).

Multiple births pose serious health risks for both mothers and children. There is a higher risk of problems during pregnancy including anaemia, miscarriage, toxaemia, high blood pressure, kidney trouble, difficult delivery, and post-birth haemorrhage. Multiple births are usually performed using caesarean section, a surgical procedure which carries its own risks. The babies born are more likely to be premature and therefore of lower birth weight, which may result in other long-term difficulties. Multiple births are also much more stressful for the parents because all of the costs and demands of parenthood are increased (Royal Commission on New Reproductive Technologies, 1993).

Risks to IVF Children

Feminists also assert that there are unknown risks to children born from IVF beyond those resulting from multiple pregnancies. As previously noted, babies conceived through IVF are more likely to be born premature and have lower birth weights. Also, some authors suggest that the infant mortality rate may be four times higher for IVF babies than babies conceived under normal circumstances (Raymond, 1991).

Other long-term risks to children remain unknown, as the oldest IVF child (born in 1978) is just reaching adulthood (Overall, 1993). This leads feminist analysts to make important analogies between IVF and other medical "breakthroughs". Recent history is littered with often untested "advances" in reproductive medicine--the Dalkon Shield IUD, thalidomide, and forceps, for example--which though ostensibly meant to help women and children, have often lead to great harm since side- and intergenerational effects may remain unknown for many years. DES (diethylstilbestrol), for example, is a synthetic estrogen that was given to pregnant women in North America and Britain from 1940 to 1970 in the belief that it prevented miscarriages. It was discovered in 1971 that many women whose mothers took DES developed clear-cell vaginal cancer, had higher rates of breast cancer, and had abnormalities of the reproductive organs which cause infertility (Dutton, 1988). The effects of DES did not appear for close to twenty years after the drug was administered. Feminists are justifiably skeptical about the safety of IVF when any long-term ill effects may not be visible for decades (Mayrand, 1981; Overall, 1993; Simand, 1989).

THE RISKS TO ALL WOMEN: CONCEPTION-ASSISTING TECHNOLOGIES IN THEIR SOCIAL CONTEXT

While feminist analysts provide a detailed explanation of the risks of the conception-assisting technologies to individual women who undergo treatment, what best distinguishes their critique is their examination of the effects of these technologies in a broader social context. Technological developments do not exist in a vacuum--their development and use are influenced by, and reflective of, existing social relationships. Feminists assert that our society is a male-dominated system characterized by power, dominance, hierarchy and competition (Sydie, 1988). This system sees women's bodies as inadequate for the tasks of conception, pregnancy and childbirth, making medical and technological intervention necessary to "fix" women's bodies (Overall, 1987).

Many feminists believe technological intervention in reproduction promotes male-dominated institutions taking control of women's reproductive capabilities--women's sole and autonomous source of power (O'Brien, 1981; Tong, 1989). The technology would not be seen to be malevolent to women if we lived in an egalitarian society, but because the power to create and shape technology has been historically removed from women's influence, the social context of patriarchy means reproductive technology is unlikely to benefit women as a group (Birke, Himmelweit & Vines, 1990; Corea, 1985). This perspective is supported by feminists' extensive detailing of the risks of conception-assisting technologies to women who use them, and the potential risks they hold for all women.

Therapy or Experimentation?

While the IVF procedure itself is fraught with many risks, some of which are inherent in many medical procedures (e.g., drugs and surgery), when the technology is placed in the wider social context other risks also become apparent. The first, according to feminist analysts, is the lack of clinical trials for the procedure, leading critics to assert that IVF is still an experimental technology. According to feminist biologist Ruth Hubbard:

> I see no way around the fact that every *in vitro* fertilization and implant, and every person who results from it, is an experiment and a different experiment: both the women who bear these babies and the babies-on-into-adults themselves are guinea pigs (1981: 260).

Not much has happened since 1981 to alleviate these concerns. The findings of the Royal Commission on New Reproductive Technologies suggest that the current way IVF is being offered in Canada is unacceptable. Evidence suggests IVF is being used in situations which have not been found to be effective in helping women deliver healthy babies. According to the Royal Commission, IVF is only effective in cases of complete fallopian tube blockage, the original indication for the technique. While IVF is used for other indications[5], all other uses should be considered experimental until their efficacy is demonstrated in clinical trials

> As IVF and related technologies have developed, they have sometimes been referred to as 'innovative therapy'....A procedure is not 'therapy' unless it has been shown to be of demonstrable benefit; experimental treatments should not move from the realm of research to the realm of therapy unless and until effectiveness and risks have been identified (Royal Commission on New Reproductive Technologies, 1993: 557).

While findings of the Royal Commission are not based solely on feminist critiques of new reproductive technologies, they do provide good, current evidence to support the claims of feminist analysts that IVF still remains, in many ways, an experimental procedure. Like similar government investigations in other countries, the Royal Commission on New Reproductive Technologies is becoming an essential source for Canadian feminist analysts, for current Canadian information, and as an indication of the path new reproductive technologies will likely take--a path which must be traced and analyzed to assess its potential impact on all women's lives.

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[5] According to Spallone, other indications (generally at the physician's discretion) are suspiciously growing (1989). IVF is often used when the woman has no infertility problems, but her partner has a low sperm count, in idiopathic (unexplained or natural) infertility, in cases where the tubes are only partially blocked, or where the woman has endometriosis (Royal Commission on New Reproductive Technologies, 1993).

Success Rates

Feminists' assertion that IVF is experimental is based on more than the lack of clinical trials; the poor success rate of the technology also adds credence to this contention. Attempts to have children using IVF are usually unsuccessful. Success rates might not be at issue if the technology was neutral or harmless, but IVF is not a benign technology and women undergo many risks when using IVF whether it is successful or not.

Objective success rates for IVF have been difficult to ascertain. Success rates often range from five percent to as high as fifty percent with the variance in quoted success rates reflecting whose interests are being served by the data. Success rates are often constructed by practitioners through the use of statistics centring around successful implantations or chemical pregnancies, and there is a reluctance to disclose rates to the public at all (Boston Women's Health Collective, 1992; Burfoot, 1989; Raymond, 1991; Spallone, 1989).

A survey conducted as part of the Royal Commission on New Reproductive Technologies concurs with feminist analysts. Stephens and McLean (1993) found that ten to twenty percent of IVF attempts resulted in a live birth in 1992. IVF resulted in 189 births in Canada in 1991, but there were approximately 2,900 patients seeking treatment that same year. The survey also found the same lack of standard definitions of "success" making it impossible to calculate "true" success rates.

Distrust of Biomedicine

The risks of IVF multiply beyond the risks of the procedure itself, despite its wide international use, according to feminist analysts. To further delineate the risks of IVF and other conception-assisting technologies feminist analysts emphasize the connections between old and new reproductive technologies. Feminist theorists have a lengthy and profound distrust of the advances of biomedicine in light of the legacy of technological innovations which were ostensibly meant to help. Many of these advances--drugs like the aforementioned DES, and thalidomide, and inventions like forceps and IUDs--had the impact of further medicalizing women's bodies and reproduction, often causing iatrogenic illness (Corea, 1985; Culpepper, 1981; Dutton, 1988; Hubbard, 1981; Simand, 1989).

Conception-assisting technologies are being hailed as new cures for infertility when they are often attempts to resolve problems caused by older technologies (Holmes, 1981). For this reason, feminist analysts assert that conception-assisting technologies represent the pinnacle of medical exploitation of women; technology often causes their infertility, and then further experiments on their bodies are necessary with risky technologies to "cure" that infertility.

Feminist analysts have also shown that the term cure is a misnomer. Fertility drugs and IVF are a temporary, technological fix--not curing infertility, but merely bypassing the problem to help a woman bear a child (Burfoot, 1989; Crowe, 1985). Infertile women must use the technology each time they wish to conceive, concretizing the increasing role medical intervention for conception, gestation and birth is having in women's lives.

Feminist analysts assert that if biomedicine really wanted to cure infertility it would put more resources into the less professionally and financially rewarding arena of prevention of infertility, much of which is iatrogenic in origin, or caused by sexually transmitted diseases (Birke, Himmelweit & Vines, 1990; Warren, 1988). They also argue that the largest cause of infertility in the world, the mass sterilization of women in developing countries, is wholly preventable (Raymond, 1991). Feminists contend that if biomedical practitioners were truly concerned with the plight of infertile women, they would avoid medicalizing women's reproductive lives. This would allow women to exercise their reproductive autonomy, without being reliant solely on biomedicine.

Pronatalist Ideology

Considering what we know about IVF, it is difficult to comprehend why women would participate in the process. However, this must be balanced against the tremendous social pressure for women to reproduce:

> Women frequently believe they must have children to be 'real' and 'full' women because they are not valued as autonomous human beings, but only as servicers to men, primarily as wives and mothers (Hanmer, 1984: 445).

Women in our society are socialized to believe their true fulfillment and value comes from being mothers. Being infertile makes this socially-valued norm impossible to achieve, unless one tries conception-assisting technologies--the choice is to take the risks of using the technology, or risk the stigma attached to childlessness (Crowe, 1985). Historically, the duties of mothering have been used as justification for limiting women's public sphere opportunities, therefore, feminist analysts are very apprehensive about the development and promotion of technologies which reinforce this as women's primary role (Strickler, 1992).

Our social and economic structures are currently constructed to favour motherhood within the patriarchal family. The lack of good abortion services and the limited range of contraceptives, divorce laws which leave many women living in poverty, and poor employment opportunities for women, reinforce our societal belief that motherhood, in the context of the male-headed family, is women's best and natural social role. While most women in the 1990s have children and work outside the home, the lack of day-care facilities and beliefs of some that working mothers are unreliable, again reinforce this ideology of motherhood as women's primary occupation (McDaniel, 1993). Women's individual choices are shaped by these social and economic factors. While women may not consciously recognize or consider these social and economic factors, their development from childhood has been influenced by such ideological constructions, and they shape women's individual choices. For a woman who wants to have children, the discovery of infertility can be devastating.

Consequently, the use of conception-assisting technologies does nothing to address the underlying social impact of infertility and why it represents a crisis for many women who experience it. The use of conception-assisting technologies, both reflects and reinforces the patriarchal belief that women's primary role is motherhood. The risk for feminists is that conception-assisting technologies do not allow for the option of being childless and therefore hinder their efforts to expand the choices women have for self-determination (Sandelowski, 1991). Instead of making societal change towards alternative forms of parenting which allow infertile women to experience the social aspects of mothering, and providing other choices which expand acceptable roles for women, technology is created that reinforces the notion that mothering is women's natural role.

The technology of IVF also reinforces the social message that women are only fulfilled through the birth of genetically-related children. The preoccupation with having genetically-related children is equated by feminists with the devaluing of the social aspects of parenting: the life of the child after she/he is born. Adoption becomes the last resort, meaning children are not appreciated for their own sake, but as possessions of their biological parents (Crowe, 1985; Overall, 1987). The desire for genetically-related children may lead some women to take unnecessary risks and use IVF in cases where, for example, a partner is infertile, and therefore donor insemination would be much safer.

According to feminist analysts, conception-assisting technologies by their very existence increase the pressure on infertile women to keep trying to have a biologically related child until they have exhausted every available means. This in turn strengthens the pronatalist ideology and thereby increases the stigma and suffering infertile women endure (Warren, 1988). Infertile women have not tried hard enough, unless they have tried everything, regardless of the personal costs to health and emotional state which they may endure in the process.

Deciding Who is Fit to Reproduce

The social control of women promoted by the pronatalist and patriarchal notion of the "proper" role for women is further entrenched when one looks at who uses IVF services. In most countries (even many with socialized medicine) conception-assisting technologies (especially IVF) are paid for by the couple. With treatments being priced at approximately five thousand dollars per cycle for IVF, and with some insurance plans not covering fertility drug prescriptions, the services will be primarily utilized by middle and upper income couples (Holmes, 1991; Raymond, 1991; Stephens & McLean, 1993). Also, the enormous physical demands on women who undergo IVF make pursuing or continuing paid employment difficult, so generally, only those couples who can afford to live on one income are able to utilize the technology (Crowe, 1985; Williams, 1989).

In the case of IVF, those who administer the service have tremendous control over which infertile women are allowed access. Generally IVF is only available for heterosexual couples--the classic patriarchal family (Corea, 1985; Raymond, 1984). The medical establishment furthers its control of women, by unquestioningly maintaining the idea of woman as mother, and by defining who is fit and unfit for that role. The nature of the technology itself, and the ideological values of its providers take control of reproduction away from the couple, and secure it in the medical realm. Conception-assisting technologies, according to feminists, are not operated with the best interests of women in mind, but for those who will gain financially and benefit from maintaining the heterosexual, patriarchal family structure: physicians, and the pharmaceutical and technological industries--generally upper-class white men (Corea, 1991).

RESPONDING TO THE RISKS

While feminist analysts are in agreement about the risks of conception-assisting technologies as detailed above, there has been considerable disagreement among them about other possible dangers. All feminist analysts believe that the current use of conception-assisting technologies carries a number of risks which are not in women's best interests, but they diverge in discussions of the extent of these dangers, and in how to deal with them to ensure women's reproductive freedom and general safety and autonomy. The following will detail both radical feminist views that call for an outright ban on the use of conception-assisting technologies, and liberal feminist ideas for reforming the use of conception-assisting technologies to make them more woman-centred to lessen the risks they hold for individual women.

Ban the Technology

Radical feminist analysts maintain that the development and use of conception-assisting technologies are not in the best interests of women as a group, and should be banned. On top of the risks already mentioned, radical feminists detail what *could* result from the use of IVF, and related new reproductive technologies to further their claim. IVF is predicated on the removal of ova from women's bodies and the creation of embryos outside the womb; resulting embryos are therefore available for experimentation. This experimentation could lead to technological developments which could be devastating to women, and to all of humanity.

Embryos are already being screened for their sex and some other genetic traits, and experiments are being performed which could allow genetic manipulation to correct certain diseases and disabilities before the embryo is implanted in a woman's uterus (Raymond, 1991). Advocates of a ban worry that "quality control" will become mandatory for all women who conceive to ensure that "imperfect" babies are not born. This would have profound negative effects on the already poor status of people with disabilities, and for the women who bear these children, as they could be blamed for not using the technology to avoid these "problems" (Corea, 1985).

The desire to exercise "quality control" is already occurring in the contracting of surrogate mothers. If the surrogate is to be the biological mother of the child, she undergoes intense screening to ensure her biological fitness, with some couples choosing surrogates based on characteristics like eye and hair colour, and IQ. A surrogate's life is very regulated during the pregnancy and she must undergo genetic testing using amniocentesis, often being forced to have an abortion if some genetic defect is found. Many surrogacy contracts also state that the surrogate will not be paid if she has an abortion (even though she is compelled to by her contract) or miscarriage, if the child is born with "defects" or is stillborn (Corea, 1985).

Radical feminist critics also fear the possible development of new technologies, especially ectogenesis, or the gestation of fetuses in artificial wombs. As a substantiation of their concerns, they cite writings by male scientists who argue for ectogenesis on the basis that it would protect fetuses from the "hostility" of the uterine environment and birth; from the increasingly poor physical environment marked by industrial waste, pollution, and food additives, which is harmful for gestating fetuses; and from mothers who "abuse" their children through alcohol and drug use, poor nutrition and smoking (Corea, 1985, Overall, 1987). These feminist theorists contend that ectogenesis would be the ultimate manifestation of male control over reproduction leading to the elimination of women altogether.

Radical feminist analysts advocating full scale resistance to reproductive technologies also assert that the historical precedent of men attempting to control nature and women's bodies could lead to profound manipulations of human genetic material in the form of cloning and animal-human hybrids, and result in devastating effects on our biological structures, the natural environment and the social organization of humanity (Corea, 1985; Overall, 1987; Tuana, 1989). They believe that male scientists and physicians are motivated to develop these procedures because of their own inability to have children. Through the technologies they can extend their role in reproduction, ensure that children are genetically "theirs", and maintain their power over women (Sandelowski, 1991; Warren, 1988).

However, radical feminists also see the potential for intensive control over women with the present range of reproductive technologies. The ability to remove ova from women's bodies means they can be put into the wombs of poor women, so that rich and powerful women do not have to undergo the discomforts or inconveniences of pregnancy and childbirth. Scientists are also trying to devise ways to retrieve eggs from dead women, and from aborted female fetuses to make them available for women without functioning ovaries. Some feminists fear that women's reproductive capabilities could be controlled in ways similar to animal husbandry through the creation of "reproductive brothels" where some women are forced to produce eggs for other women whose wombs would be used to gestate babies for men (Corea, 1985).

Radical feminists, in calling for a ban on reproductive technologies not only oppose the physical, psychological and social risks to women from the procedures themselves, but also the potential uses to which these technologies could be put. They see the overwhelmingly male-controlled biomedical and scientific institutions developing technological interventions which crystallize women's primary role as mothers, and increase male control over reproduction, creating risks for the women who undergo the procedures and for all women. To the critics, these risks are unacceptable; they jeopardize the gains women have made for reproductive autonomy and must be resisted for the sake of all women.

What about the concerns of infertile women? Where do their desires to have children fit into this analysis? Gena Corea, a radical feminist who supports a ban on conception-assisting technologies writes:

> The suffering infertility causes women is enormous and deserves to be treated seriously. I do not think that those who respond to the suffering by offering to probe, scan, puncture, suction and cut women in repeated experiments are taking that suffering more seriously than I. They are not asking how much of women's suffering has been socially structured and inflicted and is therefore not inevitable (1985: 6).

Feminists like Corea assert that infertile women's reproductive choices are conditioned by the patriarchal, pronatalist social structure which these technologies help to further entrench. Their desire for children is socially constructed, not biologically necessary, and therefore can be overcome through methods other than these dangerous technologies (Corea, 1985; Hanmer, 1984; Klein, 1989; Raymond, 1984).

Because women's only socially acceptable status is to be gained through childbearing and child rearing, many will accept the physical and mental risks of treatment. Radical feminists contend that these women are being duped by patriarchal values and institutions to make choices which could cause great detriment to their well-being (Denny, 1994). Feminist analysts who wish to ban conception-assisting technology do not want to leave infertile women without any recourse. They prefer to work toward social change that would raise the consciousness of women and enable other alternatives--the acceptance of child free living, alternative forms of family and social structure which would allow for non-parents to nurture children, and a valuing of women for themselves and their abilities beyond mothering (Hubbard, 1981; Klein, 1989).

Questions and Alternatives

Liberal feminist analysts are questioning the position of radical feminists who wish to prohibit the use of conception-assisting technologies. Many contend that a new analysis of women's relationship to reproductive technologies must be undertaken (Birke, Himmelweit & Vines, 1990; Overall, 1993; Sawicki, 1991; Warren, 1988). These feminists agree that conception-assisting technologies like IVF carry many risks for individual women and for women as a group, but they also assert that the technologies will not be abandoned because there is too much at stake both politically and financially (Poff, 1989; Sawicki, 1991).

Even if it was possible to ban these techniques, they question whether it is necessary. Infertile women who have used conception-assisting technologies have not called for halting their use, and infertile women seeking treatment are welcoming the development of anything which could help them conceive (Koch, 1990). If the very women who are directly affected by the technologies welcome them, then feminists who advocate prohibition might be seen as equally patronizing--imposing their own values and stifling the reproductive rights of infertile women (Denny, 1994). Liberal feminist analysts assert that it is the bodies of infertile women which are at risk, and if they, after being properly informed of these risks, wish to use the technologies then their choices should be respected (Denny, 1994; Warren, 1988). Simply advocating a ban on technology does not help women become informed about the risks and benefits, and therefore does not empower them to make sound choices--a main tenet of feminism (Sawicki, 1991).

In advocating an individual's right to choose, liberal feminist analysts recognize that women's desires to have children are socially constructed. However, they assert that this does not mean infertile women seeking treatment are suffering from a 'patriarchal false consciousness'. Infertile women's desires, they contend, are not "...faulty versions of the theoretician's categories" (Stanley & Wise, 1990: 24). Understanding where the desire to have children originates does not remove the desire, nor does it make it less real (Birke, Himmelweit & Vines, 1990; Koch, 1990; Overall, 1993; Warren, 1988).

Liberal feminists also state that even armed with information about risks and alternatives, women do not necessarily change their choices--they do not always become, "self-emancipating" (Denny, 1994: 63). They contend that analyses by radical feminists who wish to ban conception-assisting technologies do not allow women to exercise choices about their reproductive lives. Rather, they reflect a paternalistic approach of protecting women from their own desires, ignoring their lived experiences: "Women are portrayed either as innocent and ignorant victims of the medical establishment or as inviting colluders in a horrifying extension of patriarchal control over women's bodies" (Sawicki, 1991: 72).

Liberal feminists also disagree with the "slippery slope" arguments of radical feminists who call for a ban on the technologies. They feel that radical feminist analysts who have presented frightening future scenarios have not provided convincing arguments as to *why* men would want such things as cloning and animal-human hybrids (Denny, 1994). Liberal feminists also point to the high cost of these techniques. They assert that ectogenesis would also be unlikely because there is no reason to invent new wombs, when control over women's wombs is far less expensive, and less technically sophisticated--technology is not necessarily needed to control women (Birke, Himmelweit & Vines, 1990; Warren, 1988). The pronouncements of some feminists about a possible "Brave New World"[6] scenario also assume that the course of reproductive technologies will inevitably lead down the slippery slope of increased male power and control. This analysis is a form of technological determinism itself, and assumes that women (and many men) will not resist these developments (Birke, Himmelweit & Vines, 1990; Denny, 1994; Warren, 1988).

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[6] *Brave New World* written by Aldous Huxley in 1932 is a dystopian novel about a society dominated by technology where babies are created *ex vivo* (outside the body) and gestated in bottles.

Jana Sawicki, a post-modernist/post-structuralist feminist, asserts that there are "multiple centers of resistance" engaged in better determining the current form of new reproductive technologies (1991: 187). In her book *Disciplining Foucault* (1991), she is critical of the perspective of radical feminists like Corea who have ignored efforts already underway to reshape the provision of new reproductive technologies. In their focus on dominant groups (especially biomedicine) radical feminists ignore the resistance and struggle already taking place. Sawicki states that feminists and other critics have and do play a role in the development and use of new reproductive technologies. She points to changes to the medical control and definition of pregnancy and childbirth resulting from challenges by the women's health movement as examples of resistance which have led to the redefinition of medical practices concerning women. These successes show that medical control over women and childbirth is not absolute and is constantly being challenged (Sawicki, 1991).

Wholesale rejection of conception-assisting technologies and other new reproductive technologies does not identify what feminists should *do* to organize around and possibly against these technologies (Birke, Himmelweit & Vines, 1990). There are, however, many liberal feminist analysts who are fighting for better social policies and participation by women in the policy-making process. Rejection of conception-assisting technologies is also a rejection of the potentially liberating aspects of these developments. Technologies which help women conceive can be used to expand the definitions of family and motherhood. For example, lesbians and single women, by demanding access to these technologies, are challenging societal norms about the definitions of family and motherhood. Also, not all reproductive technologies are harmful for women. Most feminists extol the benefits of other reproductive technologies like contraceptives which have given women greater autonomy. Clearly there are things to be gained from technological developments if feminists participate in their development and implementation, and continue to identify and resist dangerous medical procedures (Sawicki, 1991).

Numerous ethical and policy frameworks have been initiated by liberal feminists to help direct the path reproductive technologies take. They contend that if technologies like IVF have to exist, there is a form they should take in order to represent the best interests of women (Eichler, 1989; Holmes, 1981; Poff, 1989; Sherwin, 1989). The caring, woman-centered approach to infertility treatment that liberal feminist analysts advocate incorporates the following principles:

- At the macro-level steps need to be taken to ensure greater participation of women in all areas of medicine and biomedical research. Women are also needed on government and other bodies which regulate the technologies. This may help to break the male hegemony of biomedicine, and may lead to better, woman-centered solutions to the problem of infertility (Warren, 1988).

- For women undergoing treatment, truly informed choice and consent are essential. Counseling should be provided (outside the treatment context and by an impartial third party) to give full information about the treatment, and alternatives like adoption and child-free living (Holmes, 1981; Overall, 1993).
- Treatment must be provided on a fair and equal basis. This means there cannot be discrimination based on marital status, sexual orientation, geographic location or ability to pay, or any other criteria besides medical fitness (Holmes, 1981; Overall, 1993; Royal Commission on New Reproductive Technologies, 1993).
- There must be adequate record keeping, follow-up and research. Techniques that are experimental must be used in the context of clinical trials, and all patients, and resulting children, must be monitored for long-term side effects (Overall, 1993; Royal Commission on New Reproductive Technologies, 1993).
- Support systems must be available for all participants to help them through the entire infertility treatment process. This support would not only help them continue treatment, but also would ensure that women are active participants in their

treatment; asking questions, re-evaluating their goals, and making sound treatment decisions (Overall, 1993).

CONCLUSION

Feminist analysts assert that true liberation for women will only occur when we have absolute control over our bodies. The notion of choice necessarily assumes that there is a balance of power and a freedom from coercion. The question facing feminist analysts who address the risks of conception-assisting technologies is how choices are made by infertile women. What are the constraints, shaped by male control and patriarchal agendas, on infertile women's informed choice? And, are conception-assisting technologies liberating for infertile women, or do they, in the context of our sexist society, further enslave women to the role of childbearer and childrearer?

Most feminist analysts agree on the risks which conception-assisting technologies like IVF hold for the women who use them. They agree that the techniques are still untested, and that their long-term safety for women and any resulting children is unproven. They recognize that the provision of conception-assisting technologies is financially, physically and emotionally costly for women, and that many are denied access by biomedical clinicians who act as social gate-keepers, deciding who is most fit to reproduce. Most feminist analysts also concur that conception-assisting technologies medicalize infertility, devising heroic, invasive procedures instead of preventing many of the causes of infertility before they occur. They see that these technologies entrench the ideology that woman's primary role is mothering genetically-related children in the context of the nuclear family.

The split between feminist analysts is their response to these risks. Here the differing social and political practices which reflect their views on what is needed to secure the liberation of women becomes apparent. Radical feminists assert that conception-assisting technologies will allow for greater control of all women's reproductive capabilities. They assert that the collective interests of women as a group are harmed by the use of conception-assisting technologies, and that they should be banned to ensure the safety of women as an oppressed group. Conversely, liberal feminists while recognizing the physical, social and emotional risks of conception-assisting technologies, feel that these risks can be managed through a better, woman-centred approach to their use. They feel that women have the ability to shape the use of conception-assisting technologies in ways which will give individual infertile women greater reproductive autonomy.

An impoftant criticism of both liberal and radical feminist perspectives is that very little of the analysis of conception-assisting technologies focuses on the women who use the technology. Feminist analyses do not examine how infertile women understand and assess the risks of using the technology, and in what instances they perceive the risks as worth taking. The next chapter will examine the conceptions of risk by infertile women seeking treatment to see if they correspond with feminist assessments of the risks, and how their social and political views influence their risk constructions, and decision-making process about using conception-assisting technologies.

Chapter Four

Infertile Women's Conceptions of Risk

It may be difficult to understand why women would use conception-assisting technologies like IVF and fertility drugs, knowing the risks that feminist critics detail. However, infertile women seeking treatment reject many of the arguments put forward by feminist analysts about the risks conception-assisting technologies hold for women's autonomy. Infertile women especially reject risk conceptions which label users as being dominated by patriarchy through their husbands and the biomedical establishment. In contrast, they assert they are quite able to make rational decisions about the management of their fertility (Royal Commission on New Reproductive Technologies, 1993).

Writings by and about infertile women show that many are cognizant of the risks of the technologies themselves, yet they continue to use these procedures and even demand their expansion. One reason for their differing perspective on the technologies is their conceptualization of the risks. It is important to analyze conception-assisting technologies within the context of infertile women's lives as this makes their risk constructions more apparent (Becker & Nachtigall, 1994). The experience of infertility, and the pressure and desire to conceive shape infertile women's constructions of risk surrounding the use of conception-assisting technology. Couples weigh the costs of technological intervention with the possible benefit of having a much desired child. For couples seeking treatment, the promise of a child makes most risks seem negligible.

This chapter details the risk constructions of infertile women seeking treatment. Using selective accounts of how other researchers summarize women's (and couples') conceptions of risk and conception-assisting technologies, typical experiences with infertility and motivations for parenthood will be detailed, to better understand infertile women's risk constructions. The decision-making route taken by couples will be analyzed to show the various constructions of risk that emerge throughout the infertility treatment process. This will include an exploration of infertile women's views of conception-assisting technology and medical treatment for fertility, to better understand how their conceptions of risk are constructed.[7] The focus of this chapter is primarily the risk construction of infertile women seeking treatment, but an explanation of couples' risk construction is also essential. Most often the decision to pursue infertility treatment--like the decision to have children--is made by

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[7] It is important to remember that the experiences and risk constructions detailed are those of infertile women seeking treatment. Their perceptions may be quite different from infertile women who do not use conception-assisting technologies.

couples. Becker and Nachtigall (1994) found that because women had a greater involvement in medical treatment for infertility they made the final decision about what constituted risk, and what risks to take. However, they do not examine the possible influences on a woman's decision making by her partner. Women may *voice* the final decision about pursuing treatment, but it is important to recognize that there may be subtle and not-so-subtle ways in which a partner may shape or significantly influence the decision which she ultimately voices.

EXPERIENCING INFERTILITY

Clinically, infertility is defined as the inability to conceive after one or two years of trying. Infertility usually remains undetected until a couple attempts to have a child. It is therefore a dysfunction located between bodies, and does not have to be cured for good health.[8] It is generally defined as an illness only by virtue of one symptom: the inability to have a child (Sandelowski, Holditch-Davis & Harris, 1990). Infertility is also not solely a woman's ailment; male reproductive dysfunctions are the cause for almost half of all cases (Royal Commission on New Reproductive Technologies, 1993). It is important to note that clinical definitions of infertility only

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[8] Women with illnesses like diabetes or cancer may know they are infertile before they attempt conception since infertility is sometimes a result of their illness or treatment (i.e., menopause caused by chemotherapy).

consider those who desire children, so social factors shape what is considered a medical problem. There may be couples who are infertile, but are unconcerned about their infertility. In this thesis discussions of infertility include only those couples who feel their "condition" is a problem, because it obstructs their ability to have children.

The clinical, scientific definitions understate the trauma of infertility for most women. It has been described as a devastating experience, interfering with almost all aspects of life (Strickler, 1992), and a chronic illness with the continuing reminder of loss and the continuing hope for a cure (Lasker & Borg, 1987). The experience of infertility is a profoundly difficult experience for many women. It involves a disruption in the personal normal course of life which challenges their assumptions about their own identities and abilities (Sandelowski, Holditch-Davis & Harris, 1990). It also has significant personal costs which may include lack of fulfillment and diminished quality of life, psychological distress, and conflict with family and friends (SPR Associates, 1993).

Alison Solomon (1989) has likened attitudes toward infertility to those toward rape. Both crises are directly related to the status of women in a patriarchal society, and reactions to them are very similar: There is ignorance in the general population about the crisis; there is a stigma attached to the victims; the feelings experienced (shock, denial, guilt, anger, depression) are similar; there are many stereotypes about the victims; and the reactions of women to the crisis situation are comparable (Solomon, 1989).

Most infertile women grow up with the presumption they are fertile, and that they will have a child with their partner (Lasker & Borg, 1987; Sandelowski, Holditch-Davis & Harris, 1990). Discovering their inability to conceive, women feel shock and denial, followed by feelings of anger and failure since an important aspect of their lives is not within their control (Becker & Nachtigall, 1991; Eck Menning, 1984; Lasker & Borg, 1987; Williams, 1988). Infertile women may also feel guilt over past actions which they believe may be related to their infertility. They are suspicious that their use of contraceptives caused damage to their bodies. Others feel they are being punished for past actions including elective abortions, sexual pleasure, masturbation, or a failed marriage (Sandelowski, Holditch-Davis & Harris, 1990).

Infertility also affects women's self-perception. Having children is considered a central aspect of women's lives, and this ideology permeates women's conceptions of themselves. The ability to have children is often viewed as synonymous with femininity itself (Becker & Nachtigall, 1991; Williams, 1988). Many writing about the experiences of infertile women have found that the discovery of infertility negatively affected how women felt about themselves--it was not an element or part of the body which was faulty, rather, they perceived their entire being as "incapable", "abnormal" or "defective" (Sandelowski, Holditch-Davis & Harris, 1990; Whiteford & Gonzales, 1995). Feelings of guilt, and these negative self-perceptions, lead many women who are infertile to offer to leave their partners so they can find another woman to have children with (Crowe, 1985).

Where do these self perceptions originate? Infertile women's negative feelings partly arise because they cannot proceed with their lives as others in society do, by having children. They have internalized our social norms regarding reproduction. In North American society it is commonly believed that married couples should have children, and that they should want to have children. These societal norms are reinforced by "pro-birth" government policies, such as income tax deductions, which reward married couples who have children (Whiteford & Gonzales, 1995). Our society is strongly pronatalist despite declining birth rates over the last century. And this societal exalting of parenthood and the desire for children is not profoundly altered by sexual, ethnic, religious or social class divisions (Miall, 1994).

Our pronatalism leads us to view with suspicion married couples who do not have children. Voluntarily childless couples are often viewed as immoral, selfish, unfulfilled, prone to divorce, or unhappily married (Miall, 1994). These characterizations often follow those who are involuntarily childless as well since infertility is a "secret stigma", physically invisible and usually hidden from even close friends and relatives (Whiteford & Gonzales, 1995). Even when infertility is known, couples are stigmatized; they are characterized as being sexually, psychologically and physically inferior, though these feelings are often mixed with sympathy (Miall, 1994). Infertile women are also often blamed for the couple's infertility; people assume it was caused by promiscuity, previous abortions or psychological problems. Women are blamed for putting off childbearing for too long, and putting their careers ahead of their most important role, motherhood (Inhorn, 1994; Solomon, 1989).

Experiences of infertility and social stigmatization may change a couple's relationship with family and friends. Women often feel excluded from their friends who have children since parenting is a common experience around which friendships are developed and maintained (Crowe, 1985). Friends and family often do not understand the difficulty of infertility and misunderstand its origins. Their attempts to provide social support in response may further the couple's sense of stigmatization (Miall, 1994). Their solutions to the problem of infertility are usually considered unsupportive; they give useless advice ("relax"), religious pronouncements ("it is God's will"), and continue to put tremendous pressure on the couple to have a baby (Koch, 1989). Couples often become isolated and lonely, since being around those with children is too painful (Lasker & Borg, 1987).

PARENTHOOD MOTIVATIONS OF INFERTILE COUPLES

It is important to remember that the desires of the infertile are not very different from most other Canadian couples. A study by Linda Williams (1988) found that the parenthood motivations of infertile couples seeking treatment are similar to all couples who want children: (1) they feel it is part of marriage--something that couples do; (2) there are pleasures and advantages to having children; (3) they want to see a child grow and contribute to his or her development; (4) they want to love and nurture a child; and (5) there is a wish to recreate themselves, and leave a legacy of their existence in the future (Williams, 1988).

A fundamental question remains, however: If infertile couples want to have all of the experiences of raising children, why not adopt? There are very few domestically born, white[9] infants available through either public or private adoption mechanisms in Western countries including Canada, and these are generally the children which infertile couples desire. There are also many restrictions on adoption related to a couple's age,

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[9] The experiences of white couples dominate the literature on infertility. This may be because they are more likely to have financial resources to utilize conception-assisting technologies and pay the high costs of private adoptions.

their assumed parenting ability, their financial position and in some cases, whether they have tried everything possible to have their own children (Royal Commission on New Reproductive Technologies, 1991).

There is, however, another reason why couples do not choose adoption; like couples who conceive easily, many desire biologically-related children. Infertile couples value a genetic link with their children. For men, genetically-related children are often seen as proof of their virility, and they may define "fatherhood" by their role in conception, or their genetic paternity (Crowe, 1985; Lasker & Borg, 1987). For women, genetically-related children are also important. Many women feel that they must "give" their husband a biological heir, or that biological motherhood is an essential aspect of fertility. Some women also value the experiences of pregnancy, birth and breast-feeding--things which adoption cannot provide (Williams, 1988).

For many couples adoption just does not carry with it the same benefits as having genetically-related children. Having a child is not enough; infertile couples endure the strains of conception-assisting technologies not only to have a child, but also for all of the benefits of genetically-related children (Strickler, 1992). Adoption does not become an option for most infertile couples until all of the possible biomedical routes using conception-assisting technologies fail. Many couples choose not to adopt because of strong objections to adoption centring around the concept of raising children that are not genetically their own (Williams, 1988). Many couples believe that adoption is risky because they cannot be sure of the "kind" of child they will get. Using biologically deterministic arguments, some couples feel they may receive a child who may be in some way deviant, unintelligent or too much unlike themselves (Lasker & Borg, 1987). Couples who are against adoption sometimes believe they can be more sure of the future characteristics, both social and physical, of children genetically related to themselves.

WEIGHING THE RISKS OF INFERTILITY TREATMENT

Upon discovering they are infertile, Canadian couples are faced with two possible courses of action: they can either do nothing and see what happens, or they can seek treatment. Decision making for infertile couples is a balancing act: they must weigh the possibilities of action against those of inaction and calculate whether the costs of each route outweigh the benefits. Therefore, their constructions of risk surrounding conception-assisting technologies take into consideration both positive and negative outcomes of both options.

Upon diagnosis, infertile couples understand there is an almost one-hundred percent risk of remaining childless[10] if they

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[10] Some couples have conceived many years after being told they will never have children.

do not use conception-assisting technologies. This means they risk facing the stigmatization attached to infertility, the lack of resolution of their infertility problems, and possible regret in the future (Menning, 1981). For many infertile couples these are risks they are not willing to take, because their desire for a child is so strong, as is their faith in biomedicine and technology. There really is no decision to make--if they want to have a child, they have to undergo treatment.

Infertility treatment is like a high-stakes gamble: the risks of treatment are high, but so is the potential reward. A couple can only "win" if they use conception-assisting technologies. It also means that one must ignore the success rates because the goal is to defy the odds. Conception-assisting technologies are like lottery tickets, one has to play the game in order to win (Koch, 1990; Lasker & Borg, 1987). For infertile couples, the potential rewards are worth the risk.

CHOOSING CONCEPTION-ASSISTING TECHNOLOGY: THE MEDICALIZATION OF INFERTILITY

Infertile couples who seek treatment feel very strongly that infertility is a medical problem, therefore they look to the biomedical establishment and its technological interventions for answers. In so doing they take the culturally-prescribed route of seeking biomedical solutions to their infertility problems.

Pursuing medical treatment for ailments is considered socially responsible behaviour, and is reflected in the individualistic ideology of North American society which prizes taking active, personal control in problem solving.

Infertility disrupts couples' plans for personal success, and they feel that their suffering, which is not adequately addressed in society and through the medical system (i.e., not covered by Canadian Medicare) abrogates their "right" to reproduce (Strickler, 1992). Many infertile women feel that conception-assisting technologies are a human right which should be available to all who need them, with some advocates asserting that infertile couples are "owed" access to reproductive technologies because infertility often has iatrogenic origins (Koch, 1990; Menning, 1981; Royal Commission on New Reproductive Technologies, 1992). They view conception-assisting technologies, and especially IVF, as their last hope to have genetically-related children. To infertile couples, the controversies surrounding new reproductive technologies are irrelevant and insensitive to their needs, and they are against any ban or moratorium which would impede their access to the technologies (Lasker & Borg, 1987; Royal Commission on New Reproductive Technologies, 1992). In fact, they are so focused on using conception-assisting technologies that, for example, it has proven difficult to find couples willing to participate as a control group in clinical trials to determine IVF's efficacy (Collins, Burrow & Willan, 1993).

Once infertility is medically designated as a disease, couples (now patients) pursue a "cure" only through biomedical means (Becker & Nachtigall, 1994). The knowledge of infertility, while suspected by many couples, must be confirmed by biomedicine before it becomes a reality--a couple's true state of being (Sandelowski, Holditch-Davis & Harris, 1990). The medicalization of infertility means that options like child-free living and adoption disappear, because the narrow focus on infertility as a disease state limits the types of solutions possible.

Infertile couples have high expectations of the biomedical establishment and its technological interventions. Couples believe strongly that biomedicine has the ability to "cure" their infertility (Becker & Nachtigall, 1991). Several studies of infertile couples' expectations from treatment state that most, if not all, couples feel confident that the treatment will work for them and that they will have a successful pregnancy (Koch, 1989; Lasker & Borg, 1987; SPR Associates, 1993; Stewart & Glazer, 1986). This, however, runs counter to the actual success rates of conception-assisting technologies--only about half of all couples who seek treatment will be successful, and the success rate for techniques like IVF is only about ten percent (Eck Menning, 1984).

CONCEPTIONS OF RISK

At the outset, treatment using conception-assisting technologies holds little risk in the minds of infertile women (Becker & Nachtigall, 1991). As treatment progresses, risks become more apparent and important, invariably because the invasiveness of the treatment becomes more obvious once one is experiencing it. The Royal Commission on New Reproductive Technologies (1993) found that many women expressed concern about health risks, wishing they knew more about long- and short-term effects. Some were afraid to ask questions fearing they would be viewed as trouble-makers and be asked to leave the treatment program (Stuart, 1989). With long waiting lists, those with access to conception-assisting technologies, especially IVF, feel they are in a privileged position and do not want to do anything to jeopardize their treatment.

Other sources confirm the Royal Commission's findings; ultimately, regardless of their fears, most couples felt the risks of the treatments were secondary to the possibility of having a child. For many women, no risk was too great, and they would continue as long as they could with treatments to achieve their goal (Becker & Nachtigall, 1994; Koch, 1990; Lasker & Borg, 1987; Royal Commission on New Reproductive Technologies, 1992). There are many stories in the literature of women enduring incredible side-effects or having near-fatal complications from treatment, and yet continuing with treatments using conception-assisting technologies because their desire for a child was so strong (Becker & Nachtigall, 1994; Koch, 1990; Williams, 1988).

For these women, the ethic: "You are never a failure until you stop trying" prevails. The risk of giving up is not an option, their desires to have children are too great (Kozolanka, 1989). Not using biomedical interventions has the potential to lead to regret later in life, with some women fearing they have not tried everything possible to have a child (Becker & Nachtigall, 1994; Crowe, 1985; Sandelowski, 1991). Fearing the later regret of making a wrong choice now, many women continue to use medical technology.

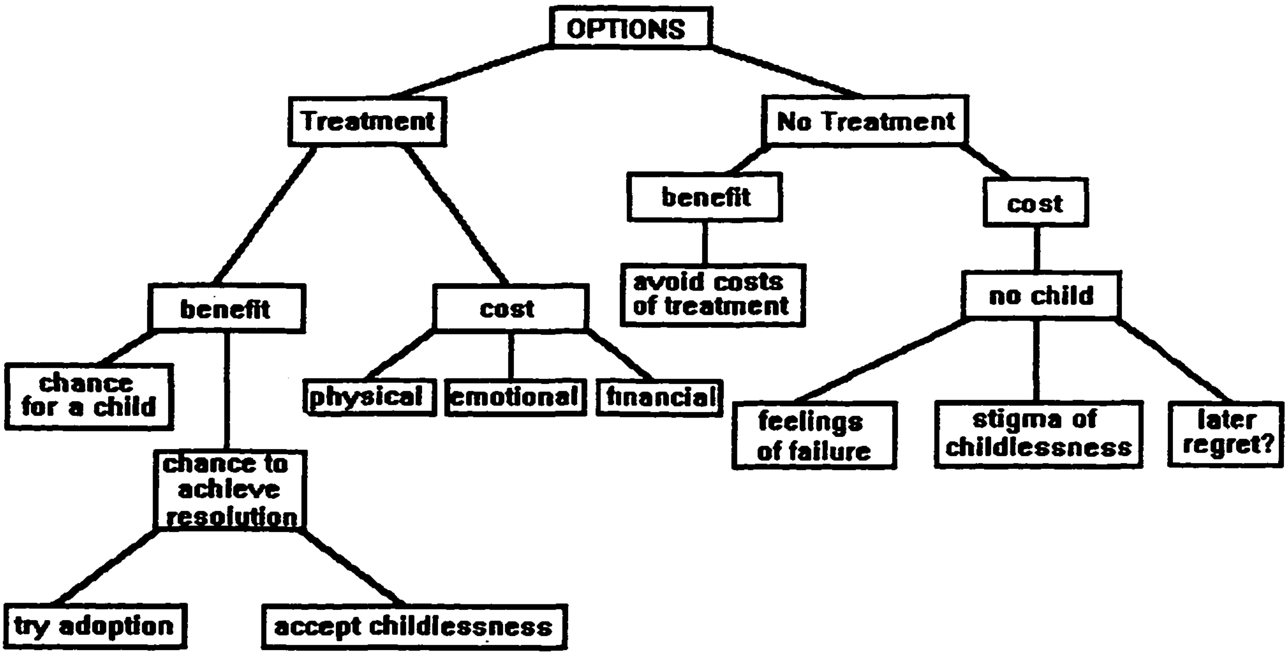
> You cannot say no to IVF. It's a question of responsibility to one's own conscience. I think I would blame myself for the rest of my life if I said no to this last cycle because it *might* result in a child (quoted in Koch, 1990: 109).

For most women not using conception-assisting technologies, not trying, or even not trying hard enough, is equated with failure.

This also helps to explain why true success rates are often ignored by many women. If infertile women believe treatment is not going to work they will find the physical and emotional strains they had to endure unbearable. Koch (1990) believes women use subjective, "magical" beliefs like being particularly suited to techniques, or invoking luck, to help them psychologically cope with continuing treatment. Infertile women are motivated by the possible end goal; the benefits of having a child will surely outweigh the extreme costs involved in treatment (Williams, 1988).

From this description it may sound as though all infertile women fanatically endure incredible strains, and try anything and everything to attempt conception. This may be the case for some women, but many stop treatment earlier. Treatment for infertility is a process, not a discrete medical procedure and women, generally in consultation with their husbands, are constantly weighing the risks of these treatments. Most women are initially treated with mild fertility drugs, increasing to more intensive ones if they do not conceive, and if still unsuccessful, they may decide to try IVF. At the initiation of each new treatment couples must go through the risk-weighing decision-making process, balancing the pros and cons (see Figure One). For each woman there is a point at which the risks become too great for treatment to continue.

Figure 1: Decision-Making Process of Infertile Couples



Many factors part of, and external to, the treatment of infertility may result in couples going through some or all of this decision-making process many times.

The point at which women decide to discontinue treatment is shaped by many factors. These include: (1) the amount of money they have to spend on treatments; (2) the wishes of their husbands who may be fearful that treatment may affect their health; (3) the physical and emotional strain of the treatments; (4) experiences with physicians and staff conducting treatments; (5) the experience of dangerous side-effects from treatments (e.g., hyperstimulation syndrome); (6) being offered a child for adoption; or (7) being told there are no further medical actions that can be taken (Becker & Nachtigall, 1994; Williams, 1988). These factors will shape what women consider as doing everything to attempt to conceive. Some women try all available treatments feeling the risks are worth it, while others stop after taking one drug, or after one cycle of IVF. For those who do not try everything, there may be some resentment, or the inability to accept their childlessness, especially if external factors like finances, or the unwillingness of their husbands to continue force them to stop treatment before they are ready.

Other Benefits of Treatment

Women who do not have a child with the help of conception-assisting technologies often report that they do not regret the treatment experience. Aspects of the technologies themselves provide infertile women benefits outside of their supreme goal of having a child. Most women are satisfied with their treatment experience, and have very few regrets, though some wished they had sought treatment sooner and others wished they had tried to adopt earlier, in both cases to increase their likelihood of having a child (Lasker & Borg, 1987; Strickler, 1992).

Many women felt treating their infertility allowed them to gain control over what would otherwise have been an uncontrollable situation. Their bodies failed them, and by pursuing medical options they were able to take advantage of existing opportunities instead of passively accepting their situation (Strickler, 1992). Couples who try conception-assisting technologies achieve a psychological reward, they can now come to a resolution point--they know there is no possible way for them to have biological children. This means they can choose to try adoption, or try to live without children, and they know that they have fulfilled the socially acceptable state of doing everything they could (Koch, 1990; Williams, 1988).

For couples with unexplained infertility, seeking treatment using conception-assisting technologies also may help them find the cause of their ailment. In these cases, conception-assisting technologies not only hold the possibility of a child, they also serve as a diagnostic tool. For some women, finding out why they cannot conceive becomes almost as important as conceiving itself. Finding the cause of their infertility often leads women towards resolution of their infertility crisis (Williams, 1988).

CONCLUSION

In our society, most people believe that having children is an essential part of being an adult and of marriage. This is especially true for women, for whom mothering is thought to be a central role. Discovering infertility is therefore devastating for many women. Infertility represents a crisis which profoundly disrupts women's conceptions of themselves and their abilities. They experience a wide range of emotions including: shock, denial, anger, guilt, depression and grief, and they feel their bodies have betrayed them. People who are involuntarily childless are also treated differently by family and friends. They are often blamed for their problems, and stigmatized. This, coupled with the strain of being around those with children, makes the experience of infertility one often undergone in isolation.

For infertile couples who wish to have children, the roots of their desires are essentially similar to those who have no trouble conceiving. They feel that they have much to give children, and would like to benefit from that relationship by creating a legacy. They also feel that having children is essential for moving from being merely a couple to becoming a family. Infertile couples are similar to couples with no fertility problems in that they desire genetically-related children. Our society values a genetic link between parents and children; it is equated with virility in men and femininity in women. For women, the experiences of pregnancy, birth and breast-feeding also fuel the desire for a genetically-related child. There is also a belief that adopted children are a risk because one cannot be sure of their genetic makeup and their future social and physical disposition. These cultural constructs, and the scarcity of domestically born, white infants, makes adoption an option to be tried only after all attempts at conception have failed.

The decision to attempt infertility treatment using conception-assisting technologies involves weighing the costs and benefits of undergoing treatment, or doing nothing. Infertile couples therefore take into account both the negative and positive outcomes of all options. They must decide if the risks of not undergoing treatment, and possible feelings of regret and failure, outweigh the risks of the treatment itself. And, they must weigh the risks of treatment against the small likelihood of having a biologically-related child. It would appear that infertile women are very much aware of the physical, emotional and financial risks of treatment, but these concerns are generally overshadowed by their desire for a child. Infertile women, by deciding to use conception-assisting technologies are participating in a gamble. The price of trying may be high, but the possible reward is considered priceless.

By electing to utilize conception-assisting technologies, infertile women are participating in the medicalization of infertility. In so doing they carry with them the strong belief that infertility is a medical problem and therefore requires medical solutions. Seeking "cures" through the biomedical establishment is culturally sanctioned behaviour. We prize taking active control over medical problems, especially those, like infertility, which have a social as well as a physical dimension. Infertile couples have high expectations of the biomedical establishment and believe they will beat the odds and have a child.

Infertile women who seek treatment are also often empowered by their experience. They are able to exercise control over what would otherwise be an uncontrollable situation, perceiving themselves as active agents in the decision-making process. For these women, choosing conception-assisting technologies may mean choosing risks, but it also means actively resisting the stigma of childlessness.

The cost of treatment means that not all infertile couples have access to conception-assisting technologies. In Canada, conception-assisting technologies like IVF and fertility drugs are not covered by Medicare. This means that those who do use conception-assisting technologies reflect an elite group in society (Becker & Nachtigall, 1994). A study conducted for the Royal Commission on New Reproductive Technologies found that the majority of couples pursuing treatment in Canada have annual incomes of over fifty thousand dollars, with both partners being employed full time. Nearly all the women in treatment were between the ages of thirty and thirty-nine. The majority of women also had some form of post-secondary education (SPR Associates, 1993).

The fact that it is the woman who receives treatment in almost all cases, reflects another cultural construction: that women are responsible for all aspects of conception and contraception (Inhorn, 1994). This often means fertile women undergo procedures using conception-assisting technologies for their male partners "...on behalf of a fertile marriage" (Sandelowski, Holditch-Davis, & Harris, 1990: 198). Medically it is not the woman who has a problem, so infertility often is seen as a problem of couples, not individuals (Royal Commission on New Reproductive Technologies, 1993). But, while infertility is a disease of the couple, it is women and women's bodies which remain the dominant site of intervention. Women generally make the final decision about using conception-assisting technologies, what constitutes risk, and what risks are worth taking to have a child (Becker & Nachtigall, 1994). But, their decisions are likely to be shaped by many influences, especially the desires of their partners.

Women generally feel that the risks of conception-assisting technologies are minimal at the beginning of treatment. This perception changes with time and experience with the treatments themselves. Many wish they knew more about the long- and short-term side-effects, and are surprised at how emotionally- and physically-exhausting procedures are. Throughout the treatment process women continually re-evaluate the risks and balance the positive and negative aspects of their experiences, stopping treatment when the risks, in their opinion, become too high. For many, however, regardless of their state, and their fears, their overwhelming desire for a child overrules any thought of stopping treatment. Using conception-assisting technologies allows infertile women to exert control over their bodies, and allows them to try all the options they choose before accepting their childlessness. The technology holds out the potential for hope, and fearing later regret and "what ifs" women continue, until all options, finances, or they themselves are exhausted.

Characteristics of the IVF process may compel women to keep trying. For example, IVF moves all of the micro-processes contributing to conception (ovulation, fertilization, and implantation) into view, allowing women to chart "how far along" they are in each treatment cycle. Women therefore feel they are making progress in treatment with each stage they successfully complete. If a woman moves past egg retrieval to fertilization for example, she has moved "closer" to a pregnancy. The visibility of a usually invisible process psychologically pushes women into trying for higher levels of achievement, making it very difficult to stop trying (Sandelowski, 1991; Williams, 1988).

Women do stop trying though. They either have a child, or some eventually decide that using conception-assisting technologies will not help them have a child. Most women report being satisfied with their experience with conception-assisting technologies, and they feel that it was worth the risks for even the possibility of having a child.

The risk constructions of infertile women seeking treatment are extraordinary in the fact that they are so ordinary. They very much reflect the dominant ideologies of our society, the high value we place on married couples having children, the importance of motherhood, the stigma of infertility, and the central place given to biomedicine to resolve problems that are both physical and social in origin. Infertile women's constructions of the risks of conception-assisting technologies are shaped by these social influences and demonstrate why to these women, almost any risk is worth taking to have a child.

Chapter Five

Biomedical Clinicians' Conceptions of Risk

Primum non nocere
(Above all else do no harm)

(Ancient medical maxim)

As biomedicine is responsible for the development and use of conception-assisting technologies, constructions of risk employed by biomedical clinicians must also be explored. Biomedical clinicians control medical knowledge and technology. They also decide who is ill and who is not ill thereby controlling patients' access to treatment (Becker & Nachtigall, 1991; Lasker & Borg, 1987). In so doing, they play an important role in structuring information for patients, and the treatment choices they make (Deber, Bouchard & Pendleton, 1993). Biomedical risk construction ultimately shapes lay risk constructions, in both positive and negative ways.

The power accorded biomedicine is socially defined. We have been socialized to believe that these methods of defining and treating illness are correct, and that physicians' judgments should be trusted (Lasker & Borg, 1987). As was demonstrated in the previous chapter, when faced with infertility, couples seek a solution through biomedical means because they have been socialized to identify infertility as an illness and believe biomedicine holds the solutions. This power did not always exist. Biomedical clinicians worked to gain exclusive control over the definition and treatment of illness at the beginning of this century by, among other things, discrediting other competing healers and paradigms (e.g., midwives and homeopaths), and through government legislation. Now their hegemony is maintained by a thoroughly medicalized society which often demands that biomedicine have an unlimited authority to define, diagnose and treat illness. The medicalization of infertility represents a recent example of this phenomenon.

With so much power over the diagnosis and treatment of infertility, it is essential that the risk construction of biomedical clinicians be detailed. To do so, the social context in which biomedicine is practised must be explored. This chapter outlines general features of biomedical culture including basic assumptions of the field, and typical characteristics of clinicians. This will be followed by an elaboration of the biomedical treatment of infertility to demonstrate the particular nature of these treatments. Finally, how clinicians construct risk will be detailed including the particular risks of conception-assisting technologies outlined in biomedical journals. Throughout this chapter, recent literature, primarily written by biomedical clinicians, which outlines treatment procedures and possible complications in a clinical setting will be used to construct biomedical clinicians' conceptions of risk.

BIOMEDICAL CULTURE

Biomedicine shapes and is shaped by our society--it mirrors and helps legitimate our capitalist, scientized, individualistic society. According to Berliner (1982), one of the main functions of biomedicine is to ensure that people maintain a level of productivity decided by our society. Biomedicine reaffirms our social mores by defining what constitutes wellness and disease, and affirming individuals' responsibility for their own health (Becker & Nachtigall, 1992).

Biomedicine can be defined as:

> [T]he theory and practice of healing in which: (1) invasive manipulations are used to restore/maintain the human organism at a statistically determined equilibrium; (2) the patients' role is largely passive and the healing is accomplished through external means; (3) ill health and disequilibrium are assumed to be materially generated by specific elements such as bacteria, viruses, genetic malformations, parasites, etc. and can be empirically observed (Berliner, 1982: 62).

The idea that disease is caused by biological agents which affect individual bodies works to ensure that other causes of illness, including environmentally and socially generated agents, are ignored (Berliner, 1982). Biomedical ideology also maintains clinicians' hegemony. Patients must rely on them to define and alleviate their illness since the causes of disease are invisible to the naked eye and unknown to those without the necessary education.

Biomedical clinicians are trained to be objective and rational, guided by the principles of scientific evidence. This is customary and common despite the fact that the practice of biomedicine is full of emotionally-charged experiences, as the example of a physician's risk assessment previously described in Chapter Two showed (Kaufert & O'Neil, 1993).

One emotion which is definitely discouraged is uncertainty. The social organization of biomedical practice has within it the obligation to heal; to find out what ails a patient, and to cure it. Biomedicine, however, is not wholly scientific--there is much art to the science--and there are many illnesses which cannot be diagnosed or cured. Regardless, patients expect physicians to alleviate their suffering, and relating uncertainty to patients is discouraged in biomedical training. Certainty in medical decision making maintains professional power and the aura of biomedical competence (Katz, 1984). If biomedical clinicians admitted that they could not solve patients' problems these patients would soon be looking elsewhere for help.

Certainty also makes action possible. Biomedical ideology asserts that action is better than inaction. The obligation to alleviate patients' suffering means that decisive action must be taken through rapid diagnosis and the initiation of treatment (Becker & Nachtigall, 1991; Katz, 1984). There can be negative consequences to the concentration of biomedical knowledge: First, physicians may believe that patients are not capable of making decisions about their care, and may make decisions for them (Becker & Nachtigall, 1991; Dutton, 1988; Gillick, 1988). Second, people may become patients when it is unnecessary. There are high costs to unnecessary treatments for insurers, in lost time from work and from iatrogenic complications, and to patients' and their families' emotional states (Katz, 1984).

In our society, biomedicine has been accorded a great deal of autonomy through professional organizations and government legislation. The implementation of new biomedical techniques and technologies is governed by regulatory bodies comprised of biomedical clinicians and researchers who set their own standards most often in isolation from outside monitoring and questions (Beck, 1992). This means developments in biomedicine often occur without public consent, and we are left to deal with the consequences of their implementation. In what Beck calls a "noiseless social and cultural revolution" (1992: 207) biomedicine has the power to change our social structure through technological developments of which new reproductive technologies are a poignant example.

It is important not to assume that the power of biomedical ideology rests solely with individual physicians. While they can and do exercise power in the diagnosis and treatment of disease, their training, professional certification, and treatment options are shaped by many factors. Individual physicians are subject to internal and external regulation and direction from researchers, hospitals, government, insurance companies, and pharmaceutical companies, as they are dependent upon these groups for their licensing, liability insurance, and their income (Beck, 1992; McCormack, 1996). While it is far beyond the scope of this thesis to examine the organization of the biomedical power elite, it is important to note that individual physician decision making and action is influenced by many factors.

THE INFERTILITY SPECIALISTS

Biomedical practice is also far from monolithic. A physician's specialization highly influences his or her diagnosis and treatment of illness (Frankenberg, 1993). According to Jay Katz (1984), specialization tends to narrow physicians' scope for diagnosis to areas covered by their training, and engenders confidence in the methods of the particular specialty to the exclusion of other methods. Couples seeking help with infertility may not be able to explore all biomedical and non-biomedical options because once treatment has started it will take a particular course prescribed by the infertility specialist.

In the recent past, the treatment of infertility was considered low status work in biomedicine. With the advent of conception-assisting and other new reproductive technologies, however, specializing in infertility and reproductive endocrinology has become quite prestigious and financially lucrative (Scritchfield, 1989). In their study of conception-assisting technologies, Lasker and Borg (1987) described those who worked to help infertile couples in flattering terms saying they work very hard to help, sharing in the joys and disappointments of their patients. They also caution that many are highly ambitious physicians who are motivated by the challenges of being on the "frontiers of science" and are trying to gain prestige by reaching the top of their field. These clinicians feel there is no need to worry about present and future risks of using these groundbreaking technologies.

With conception-assisting technologies being imperfect solutions to the problem of infertility, physicians face emotional stresses and technological challenges. Biomedical clinicians invest a great deal of personal energy and money into the treatment of infertility. As a result they find failures frustrating and disappointing, not only because they know their patients have paid a great deal for the treatments (not only financially, but physically and emotionally) but also because it represents a personal failure to master the technology and the pathology which is making pregnancy impossible (Scritchfield, 1989; Strickler, 1992). Another source of pressure is from members of the lay public who question the use of conception-assisting technologies. Clinicians must prove the efficacy of these technologies through their safe usage and resulting healthy babies to those who seek their help, and to their critics as well (Becker & Nachtigall, 1992). The pressure for success is intense, and physicians are often targets for the anger and disappointment of the couples they are trying to help, and members of the general public who question the use of these technologies (Lasker & Borg, 1987).

THE TREATMENT PROCESS

It is within this context that women enter infertility treatment. It is a context which is highly technological, with ambitious physicians who have been trained to treat women, who are not really ill (Becker & Nachtigall, 1991). Biomedical training and practice has socialized clinicians to frame the problem of infertility in biomedical terms--with intervention towards the goal of pregnancy as the appropriate response. This medicalization of infertility has the result of closing off discussion of the non-medical context of infertility and possible solutions which do not fall into the biomedical realm (Solomon, 1989; Strickler, 1992).

Infertility specialists view themselves as relieving a disability--a couple's inability to have children (Becker & Nachtigall, 1991; Overall, 1993). They assert that infertility is a disease, an abnormality, which requires a biomedical cure. Diagnosis of infertility involves the identification of physical "defects" through the detection of one or more infertility factors. An infertility factor is a clinical term for a physiological discovery which may cause the infertility, usually consisting of physical deviations from a specified biomedical norm (Becker & Nachtigall, 1992). The diagnostic process can be quite invasive, including surgery and testing which may result in further reproductive impairments.

Once a diagnosis is given, action to overcome the ailment becomes the immediate next step. The obvious goal of treatment is to bring about a pregnancy and the birth of a healthy child. However, the norms and values of biomedicine train clinicians to see success only in terms of a pregnancy--not necessarily the birth of a healthy child (Scritchfield, 1989). This can and does result in disappointment for infertile couples whose only measure of success is a baby.

The diagnosis shapes which particular treatment is to be undertaken (Becker & Nachtigall, 1992). In many cases an infertility factor cannot be identified, but treatment is usually initiated because physicians (who have much at stake professionally and financially) are reluctant to tell a couple nothing can be done. Usually in such cases physicians rely on their past experiences and successes to shape treatment options, having the couple go through a progression of treatments until everything is attempted, the couple decides to stop, or they achieve a pregnancy.

The lack of controlled studies as to the efficacy of treatments for particular infertility practices reinforces this process since the physician cannot say definitively which treatments are successful (Becker and Nachtigall, 1994). Also there are inconsistencies in the delivery and success of treatments between clinics. Blackwell et al. (1987), in their evaluation of IVF programs, state that half of the IVF programs established in the United States at the time of their study had no pregnancies. Also there is no specific credentialing process, and a lack of treatment standards, for IVF practice. Many practitioners have "learned" IVF procedures from visiting other practices for a short time and then attempting to open programs of their own.

In all cases, the treatment process is confined to the workings of the reproductive cycle. The process is therefore spaced out over time without the final results--a pregnancy--being known until several weeks after the final intervention. This also means that the couple and the physician are unable to bring about a rapid closure to the treatment process. This is especially true of IVF which has a low success rate. Upon its likely failure, both parties must wait until the next cycle to try again (Becker & Nachtigall, 1992). In a field which emphasizes mastery of the body and its systems, capitulation to natural reproductive cycles is partially viewed as a failure. With each part of the reproductive process controlled, the specialist moves closer to the goal of achieving mastery over the complex machinery of the body--a goal dictated by the tenets of biomedical training and ideology (Scritchfield, 1989).

Both clinicians and their patients believe infertility can be overcome through medical intervention. Both also favour taking action over pursuing other options such as waiting, or adoption. Physicians often point to the pressure to take biomedical action which they feel from couples who wish to have children. However, they themselves also play an important role in creating couples' expectations about treatments and their efficacy (Becker & Nachtigall, 1991). This happens in part because many of the treatments using conception-assisting technologies are consumer driven, paid for by the couple, and if a physician does not accommodate the couple's wish for another cycle of IVF or another test, they can always try the services of a competitor (Blackwell et al., 1987). This can happen at any point in the treatment process with physicians urging patients to try new techniques, or drugs, or continued IVF cycles. A recent article in the *British Medical Journal* states that there is no medical reason to limit the number of IVF cycles a woman undergoes if she has favourable indications for treatment. For these clinicians: "[the] main limiting factor is the emotional, physical, and financial cost, and most couples seem to feel satisfied that they have tried hard enough after two to three cycles" (Hull et al., 1992: 1468).

This does not necessarily mean these infertility specialists are ambitious researchers, or that they are simply motivated by professional prestige or financial gain. The ideology of biomedicine promotes the idea that if there is something to be potentially gained from a treatment (and these researchers assert that the likelihood of success increases with the number of IVF cycles attempted) then there is no *medical* reason not to attempt it. However, many physicians while encouraging patients to pursue a pregnancy through biomedical intervention are also instrumental in applying limits to treatment (Becker & Nachtigall, 1992; Paulson & Sauer, 1991). Many infertile couples find it difficult to cease treatment because of their all-encompassing desire for a child, or because they fear later regret over the decision to stop. Physicians often help set boundaries on treatment options and sometimes cease treatment when patients do not. However, this does not mean patients will not go to other clinicians, even internationally, to undergo further treatments.

INFERTILITY SPECIALISTS' RISK CONSTRUCTION

Biomedical risk construction takes two forms: The first is a determination of relative risk for a particular illness which helps in the diagnostic process (Becker & Nachtigall, 1994). For example, a woman who has had difficulty conceiving, has a malformed uterus, and was born before 1970, may be a DES daughter, meaning it is likely her physician will investigate this as a potential cause of her infertility (Boston Women's Health Book Collective, 1992). The second involves the risks of tests and treatments which may have their own adverse outcomes. My discussion will focus on the latter of these risk determinations as it relates more centrally to the broader issues addressed here.

Biomedical determinations of risk involve both scientific, epidemiological calculations of risk probabilities, and interpreted, subjective constructions. Epidemiological risk involves using scientific methods to determine probabilities of adverse occurrences from the use of certain technologies or procedures. The risks are explained as a probability statistic, (i.e., there is a ten percent chance of an adverse outcome occurring from a particular medical intervention, or one in ten people are at risk of this outcome during a treatment cycle). Clinical decision making based on these probabilities is also expressed scientifically in medical literature using the tools of economic analysis, decision trees, and cost-benefit analyses (Bunker, Barnes & Mosteller, 1977).

Proponents of epidemiological risk construction assert that while there is no truly scientific way of making decisions, these models provide a useful framework for decision making for individual physicians. They also aid in the development of standard methods for medical treatment, a starting place from which physicians can begin diagnosis and treatment (Bunker, Barnes & Mosteller, 1977).

There are a few caveats to epidemiological determinations of risk. The first is that they have little predictive power: "Risk calculations almost always use historical data and mask the dubious assumption that the future will behave like the past" (*Discover*, 1996). This is why they are often challenged by the lay public, and competing scientific communities. The second is that proper interpretation of these risk determinations requires an understanding of the dictates of probability statistics, something which both physicians and patients are often lacking (Gillick, 1988; Kaufert & O'Neil, 1993).

Biomedical decision-making models have also been criticized for neglecting the conditions under which decisions are really made. They are a confluence of many factors in which the epidemiological statistics play only a minor role, and social and cultural factors are most important (Katz, 1985). Statistical determinations of risk are merely numbers which require interpretation by the biomedical clinician in order to be relevant to individual patient care, and the development of their own risk constructions (Kaufert & O'Neil, 1993). Physicians rely upon empirical and clinical evidence in diagnosis and treatment decision making because their own experience is much more compelling than abstract medical literature (Lock, 1985).

With experience the decision-making process becomes automatic in routine cases. But when options are obscured, or a novel situation arises, non-medical criteria influence decision making (Katz, 1985). For example, a physician who encounters a particular problem will be more likely in the future to look for it in other patients no matter how rare its occurrence may be statistically (Gillick, 1988). Both personal and organizational attributes, from which physicians develop a style of practice and a working model for particular pathologies, are of influence.

Pearl Katz (1985), in her analysis of surgical decision making found that colleagues, hospital organizational structure, departmental hierarchy, competition, the lure of increased referrals, and ideas of appropriate income were all non-medical influences on physicians' medical decisions. In her study, Lock found that personal attributes of individual physicians also affected their conceptions, diagnosis and treatment of menopause. She cites many influences including age, gender, subspecialty, type of training, professional literature read, proximity to teaching hospitals and the demographics of the clinical population, which shape biomedical clinicians' conceptions of illness (1985). These influences also shape infertility specialists' constructions of the risks of conception-assisting technologies.

Non-medical influences on biomedical clinicians' risk constructions should not be underestimated. These are the people who decide which treatments will be used for infertile couples, and help shape patients' determinations of acceptable risks. Their interests in the technology shape its development and use. Being both financially and professionally lucrative, conception-assisting technologies will not likely be abandoned. Proposed new Canadian legislation to curb the commercialization of the technologies, which will also limit their use, is meeting with resistance from practitioners, as does much government regulation of biomedical technology.

Those in control of conception-assisting technologies demonstrate some of the characteristics Dutton (1988) found in her analysis of medical innovations. Biomedical clinicians show technological optimism, believing that biomedicine has the ability to overcome obstacles to the success of the technologies through continued research and mastery of the techniques. They also believe the full benefits of the technology are nearer and greater than imagined at the outset. For example, some physicians believe that IVF will soon replace regular human reproduction through the development of safer and more predictable artificial wombs (Corea, 1985). Those in biomedicine also tend to underestimate the risks of conception-assisting technologies. Some practitioners feel that more studies, or a moratorium on techniques, will hurt infertile couples, and are unnecessary since significant risks have not been detected. Such thinking leads them into a statistical trap of believing that *no* *evidence* of risks is the same as evidence of *no risks* (Dutton, 1988).

Those making decisions about the safety of conception-assisting technologies are doing so on tenuous ground evidenced by the dearth of medical literature on their risks. Biomedical clinicians using these technologies assert that scientific evidence has not been compelling enough to curb the use of fertility drugs and IVF. The overriding risk construction for infertility specialists is that despite the paucity of controlled research into its efficacy and safety, the benefits of conception-assisting technologies outweigh the costs (Scritchfield, 1989). They will proceed with the use of conception-assisting technologies and insist that they are safe until scientific evidence definitively proves otherwise.

The adoption of conception-assisting technologies despite a lack of evidence proving their efficacy is, according to McKinlay (1982), a normal part of the "career" of medical innovations. In his examination of how innovations become part of established biomedical practice, he delineates seven stages through which medical innovations typically pass. These stages are useful in explaining the adoption of conception-assisting technologies as standard procedures of the treatment of infertility.

Typically, medical innovations begin as "promising reports" in the mass media and medical journals (like the birth of the first IVF baby in 1978) (McKinlay, 1982: 235-236). This leads to the use of the innovation on a small group of patients in a few medical institutions, and if somewhat successful allows the innovation to proceed through subsequent stages.

In the second stage professional adoption of the innovation by a wide range of physicians, biomedical associations and biomedical institutions occurs. It is fueled by physicians' desires to respond to the needs of their patients, peer pressure from the early users of the innovation, and the desire to appear more up-to-date, scientific and professional in the delivery of care. In the case of conception-assisting technologies, they were likely adopted because there were few other options available to physicians to help infertile couples conceive. But, McKinlay states that the information used for the decision to adopt medical innovations at this stage is still seriously deficient. It is generally based on small observational studies, the experience of early users, and information provided by the manufacturer of the innovation itself (who have a vested interest in widening its use). Decisions to adopt innovations are rarely done on the basis of randomized controlled trials which are considered the best way to judge efficacy (McKinlay, 1982).

The wide-spread biomedical adoption of an innovation leads to the third stage marked by public acceptance and state endorsement (in terms of insurance coverage and regulation). With general acceptance of the innovation comes the entrenchment of the procedure or technology in the biomedical armamentarium.

But it must be remembered that this adoption has been guided by biomedical interests.

> Having once fostered acceptance and even a demand among the public, these interests are in a position to satisfy it, while appealing to a demand that they may have created as justification for their activities with respect to the innovation [sic](McKinlay, 1982: 244).

And, even at this stage there has still been little formal evaluation of the innovation. This is true of conception-assisting technologies which are generally accepted (though not unquestioningly) but still have not had their efficacy and safety rigorously evaluated. Also, physicians now have a constituency they can appeal to (infertile couples in the case of conception-assisting technologies) to further advance the career of the innovation since they will demand that use of the innovation continue.

When these three stages have occurred the innovation moves into the fourth stage becoming a standard procedure. It is now generally accepted as the most appropriate way to deal with a particular problem. Now it becomes difficult to question its effectiveness since there is ample observational evidence (e.g., babies born using conception-assisting technologies) to support its use. According to McKinlay (1982) though these still do not replace methodologically sound random controlled trials.

This is the stage conception-assisting technologies have reached. From here, their career should move on to stage five, randomized controlled trials, when the technologies will finally be evaluated for efficacy and safety. They will then likely proceed to stage six, professional denunciation, where trials finding negative results are attacked by those who wish to maintain the use of conception-assisting technologies. Their future will be decided based on the most compelling evidence. Regardless, the career of conception-assisting technologies will eventually move on to the seventh stage of erosion or discreditation. At this point the technologies will either be abandoned because they are unsafe, or ineffective, or because a new innovation has been found to replace them. The latter consequence is most likely because unless there is a scandal (e.g., as in the cases of DES or thalidomide) biomedical clinicians will only abandon the use of conception-assisting technologies if there is a replacement therapy (McKinlay, 1992).

It would seem then that the use of unproven (using methodologically sound random controlled trials) medical innovation is part of the normal course of "doing medicine". This is further exemplified by the ideology of biomedicine which favours decisive action to remedy illness. Risk-taking to achieve that end is often rewarded, especially when it is successful (Becker & Nachtigall, 1994). Medical aggressiveness is favoured over inaction, so the biggest risk for biomedical clinicians may be doing nothing to help infertile couples who seek their help.

In summary, biomedical clinicians' risk constructions are a complex amalgam of many factors. Epidemiological calculations and scientific evidence mingle with empirical and clinical evidence and the personal situation and characteristics of the clinician to form his or her determination of the risks of conception-assisting technologies. It is important to remember that there may be quite a split between what appears in medical literature and the actual working lives of physicians. However the overriding risk construction of those using and writing about conception-assisting technologies is one of optimism and minimization, with many texts not pointing to risks at all, or representing them as routine (Becker & Nachtigall, 1994; Dodson, et. al., 1986; Scritchfield, 1989). For the woman experiencing side-effects which have an impact on her daily life, or requiring hospitalization, they are hardly routine; however, her individual experience of health in an intimate, longitudinal sense stands in opposition to the experience of her physician who sees a large number of people and handles complications as part of the work of providing care (Frankenberg, 1993).

THE RISKS OF CONCEPTION-ASSISTING TECHNOLOGIES

Not all biomedical clinicians writing about conception-assisting technologies entirely underestimate their risks. A few articles discussing complications and risks can be found in biomedical journals published in the last decade or so. Blackwell and his colleagues in an article called "Are We Exploiting the Infertile Couple?" (1987) contend that the current practice of infertility treatment is not free from medical and non-medical problems. They believe that the technologies themselves have not "withstood the test of time" to become established in the biomedical armamentarium (Blackwell et al., 1987: 737). They also believe that many physicians are misrepresenting their credentials and their training, to offer infertility treatment, and others are not providing couples with true success rates. While they do not speak of the risks of the treatment for couples, they certainly point out that the current organization and practice of treating infertility makes risks more likely, as those using the techniques may not be adequately trained or monitored.

Most of the biomedical literature on the risks of conception-assisting technologies has been biomedically centered, being drug and process related (Becker & Nachtigall, 1994). Among the most comprehensive is a recent study by Schenker and Ezra (1994) which details the complications which may arise from the use of conception-assisting technologies. Though they caution that there is a wide range of complications, they nonetheless endorse the use of these techniques as a potential solution to infertility. In a previous study they concluded that, "...IVF/ET [embryo transfer] is not an empirical treatment any more and is a relatively safe procedure, although it should be used only when properly indicated" (Ezra & Schenker, 1993: 127). By relatively safe they mean in comparison to surgical infertility treatments (which have many risks as well), and they caution that because of the many risks to IVF, less invasive measures should be used if possible (Ezra & Schenker, 1993).

The risks they do detail in their 1994 article appear quite extensive to the non-biomedically trained eye. Using the jargon of the discipline (which I have tried my best to avoid) they go on to list numerous complications which can occur during the use of IVF. These include:

- Ovarian Hyperstimulation Syndrome (OHSS) which can be either moderate or severe. OHSS can cause many complications including blood clots, renal disorders, pituitary complications, cancer and death. The reported incidences of moderate OHSS is three to four percent, and severe OHSS is 0.1 to 0.2 percent. In data collected through world registries (in which many practitioners do not participate) it was found that nearly 100,000 hyperstimulated cycles occur every year (Schenker & Ezra, 1994: 412-413).
- Complications from the use of anesthesia including pneumonia, gastric perforation, hypoxia and death (arising from general anesthesia); bladder dysfunction, neural injury, backaches and inadvertent spinal insertion (from regional anesthesia). While these risks are not specific to the use of conception-

assisting technologies, they are nonetheless present (Schenker & Ezra, 1994: 414-415).

- During egg retrieval injuries can occur to the abdominal wall, blood vessels, intestine, uterus, or bladder. The process can also result in severe injuries resulting in additional surgery or death (Schenker & Ezra, 1994: 414-416).
- There can be risks resulting from the infestation of the culture medium used to house the ova and sperm once removed from the body. This can result in the woman receiving those gametes or embryos infected with hepatitis or AIDS (Schenker & Ezra, 1994: 414, 416).
- There can also be complications from any resulting pregnancies including an increased rate of spontaneous abortions, ectopic pregnancies, multiple pregnancies, toxaemia, bleeding, anaemia, gestational diabetes, low birth weight and hypertension. Other complications include preterm deliveries, and higher perinatal illness and death rates (Schenker & Ezra, 1994: 416-418).

Another area of risk highlighted in the biomedical literature results from the use of fertility drugs. In 1992 a group called the Collaborative Ovarian Cancer Group (COCG) found that white women with fertility problems who used fertility drugs had a higher risk of certain kinds of ovarian cancer and borderline tumors (Spirtas, Kaufman & Alexander, 1993). The studies however were not enough to persuade physicians to discontinue their use. Instead a biomedical debate is beginning as to the safety of fertility drugs.

> Although the provocative findings of the COCG papers justify an increased level of concern about the possible causal relationship between fertility drug usage and ovarian cancer, more basic and epidemiological research is needed to put them into perspective (Spirtas, Kaufman & Alexander, 1993: 292).

This is a particularly telling example of biomedical conceptions of risk; instead of using preliminary and imperfect research as a basis to protect the safety of patients, they prefer to continue with the use of techniques until more definitive information proving safety or risk is available. While Spritas and his colleagues advise that patients be informed of this possible increased risk, they feel there is no cause for alarm (1993). However, ignoring early concerns raised about other medical innovations has led to many people suffering iatrogenic complications (Dutton, 1988).

Another risk identified in biomedical writings relates to the costs of conception-assisting technologies. The financial, physical and emotional costs to couples undergoing treatment while certainly mentioned, were not considered paramount. The costs warned of were to physicians--the considerable financial costs, time commitment and resources needed to sustain a viable IVF program (Dodson, et. al., 1986). While these are certainly important factors for physicians to consider, these risks must surely be weighed against the enormous benefits these physicians receive.

Other non-medical risks were rarely discussed in the biomedical literature. Social, ethical, political, and economic risks were usually only briefly mentioned, if at all. The unequal distribution of these services to predominately white, well-educated, upper-income, heterosexual couples, is not discussed. The impact on society of treatments which have the power to fundamentally alter human reproduction is seldom mentioned. Risk appears to be viewed only through a narrow biomedical lens, abstracted from the workings of our society. This is so despite the fact that those who control conception-assisting technologies have considerable influence over the development and directions of these innovations, right down to controlling information given to patients, and subsequently their risk constructions.

CONCLUSION

In our society biomedical clinicians are accorded a great deal of prestige, and they possess a great deal of power. They are responsible for our standards and definitions of illness and health, and the treatments necessary to ensure our well-being and societal productivity. As a society we rely on biomedicine to provide these services, and are often quite accepting of its privileged position. This is reflected in the level of autonomy physicians have to make decisions about the development and use of technologies like those which aid in conception and the medicalization of infertility.

The power of biomedicine over the definition and treatment of infertility is not uncontested. As was discussed previously, action by feminists (and indeed other interest groups like patients' rights groups and health care worker trade unions) has led to significant changes in biomedical practice. Specifically in Canada, critique and resistance to some technologies led to the Royal Commission on New Reproductive Technologies. The Royal Commission served as a form of societal comment on conception-assisting technologies, and laws are currently (albeit slowly) being proposed to better reflect the public's wishes regarding the development and use of these technologies. Resistance by the biomedical community to such reforms is often strong, however, and as long as infertile couples choose conception-assisting technologies some of the power of biomedicine will remain. But not all physicians agree with the current provision of conception-assisting technologies, meaning challenges and changes from within biomedicine are also occurring.

Once couples begin exploring biomedical options for the diagnosis and treatment of their infertility, non-biomedical options effectively are shut off. Instead, a particular course of action dictated by an infertility specialist will take precedence. This reflects the ideology of biomedicine, which encourages practitioners to take decisive action, moving rapidly from diagnosis to treatment or cure whenever possible. The use of conception-assisting technologies to "cure" infertility not only potentially helps an infertile couple, but also places the physician in a high-tech, prestigious and lucrative biomedical specialty where he or she has much to gain.

The poor success rates of these technologies also make this position a difficult one for physicians who have been trained to master the machinery of the body in order to find pathologies, and bypass, or eliminate them. The inability to bring about a pregnancy in an infertile woman is often viewed as a personal failure. It also makes infertility specialists targets of the anger and frustration of the couples they are trying to help, and the general public who question the successes and safety of these technologies.

The treatment process for infertility has as an underlying premise the notion that infertility is a disease which must be found and bypassed (since the available technology cannot eliminate it). The diagnostic process seeks to identify infertility factors which are physical deviations of the reproductive cycle and organs from a predetermined norm. Diagnosis shapes which treatment will be undertaken. But since infertility is often difficult to diagnose and the efficacy of many treatments for particular problems has not been identified, treatment is often empirical, based on a physician's previous successes.

With both biomedical clinicians and their patients believing in the efficacy of infertility treatment using conception-assisting technologies, the potential for an unlimited scope to treatments is likely. Biomedical clinicians play an important role in their patients' expectations, however, often urging them to continue with treatments, hoping, for instance, that the next IVF cycle will work for them. Physicians can also play an important role in helping couples stop treatment. Their influence is tempered by many factors including their belief in the efficacy of treatment, financial and reputational issues, and the user-pay system which gives patients the power to take "their business" elsewhere.

All of these factors also influence their construction of risk. Biomedical determinations of risk involve both statistical epidemiological estimates, marked by scientific rationality, and interpreted subjective constructions in which many societal and individual factors play an important role. Epidemiological calculations, empirical and clinical evidence, and physicians' financial and political interests all influence biomedical clinicians' construction of risk.

In its risk construction, biomedicine asserts its optimism about conception-assisting technologies. Despite the fact that there have been very few studies into the safety of these technologies, it is contended that there are no significant risks to women or any offspring. There is a confusion of the findings of no proof of risks with proof of no risk. Just because risks have not been found, does not mean that they do not exist; however, biomedical ideology dictates that technologies which can help alleviate suffering should be used, since the benefits outweigh the costs, at least until the costs become known. To date, the biomedical literature on risks has not been compelling enough for practitioners to curb the use of these technologies.

Biomedical writings have identified some risks to conception-assisting technologies, centring almost entirely on biomedical concerns and complications arising from the treatments themselves. These include: (1) the practice of treatment itself, from the credentials and methods of clinicians, to reported success rates, and the many costs of offering IVF programs; and (2) side-effects of various interventions like ovarian hyperstimulation syndrome, complications from anesthesia, injuries to the body from egg retrieval, and embryo insertion, and complications from any resulting pregnancies. Detailing of risks is tentative though, because in all cases the authors assert that conception-assisting technologies are very useful and important methods to help infertile couples. Again, the benefits seem to outweigh the costs.

Writings in biomedical journals also neglect important risks which have been identified by other interest groups--the emotional and financial costs for patients, and social, political, and ethical risks. They do not discuss the social context within which conception-assisting technologies are invented and used, and the larger risks to society as a whole from their use. The reason for this is that while the sphere of influence of biomedicine is quite great, these conceptions of subjective, non-individualistic, unscientific concerns are not seen to be central to biomedical decision making and practice which is ostensibly based upon objective, scientific, unemotional rationality. It is a discipline which views technology as largely benevolent, and one whose members are heavily invested in the use of conception-assisting technologies.

Chapter Six

Conclusions

RESEARCH FINDINGS

The major purpose of this research was to analyze and interpret the conceptions of risk constructed about conception-assisting technologies by feminist analysts, infertile women seeking treatment and biomedical clinicians. I have argued that each group holds rich and complex conceptions of the risks of these new reproductive technologies--which both reinforce and reflect the social context of their concerns and interests.

Probably the most influential risk construction is that of biomedical clinicians who are responsible for the development and implementation of conception-assisting technologies. Clinicians are part of a self-regulating, highly powerful group which controls much of the information about these technological developments. They are responsible for the so-called objective and rational technical determinations of risk which frame most of the debates concerning the acceptability of their technologies. They are also largely entrusted with defining our societal notions of illness and health, and the treatments necessary to ensure we maintain our standard of well-being. This power and autonomy makes for an environment where the development and uses of technologies are given almost unlimited scope.

Biomedical clinicians themselves are trained to reinforce these norms by taking decisive action and using technology to treat and cure illness. The use of conception-assisting technologies is a good example of this ideology in action, as a social condition--involuntary childlessness--is medicalized and turned into an illness. In using biomedical treatments for infertility, practitioners are part of a high-tech prestigious occupation where there is much to gain. Reputations and finances are enhanced for biomedical clinicians who are responsible for ensuring that infertile couples attempt to fulfill a potent societal norm--procreation.

The overriding concerns of infertility specialists are two-fold: First, they wish to help infertile couples have the children they desperately desire. Second, they have much to gain personally and professionally from the use of conception-assisting technologies--a good salary, prestige, research publications and funding, and personal satisfaction. These things all influence how they construct the risks surrounding the use of conception-assisting technologies. Their notions of risk are an amalgam of technically derived epidemiological statistics, clinical experience, personal characteristics and information gained from biomedical journals. They are heavily influenced by biomedical ideology which dictates that everything that can be done to alleviate suffering should be, and that technological interventions are extremely beneficial to assist in conception for infertile couples.

Biomedical conceptions of risk are also narrow, encompassing only strictly biomedical concerns. Their risk assessments only deal with the health risks which may arise as complications to the treatments, such as side-effects from anesthesia or ovarian hyper-stimulation. They do not discuss the many emotional and financial risks to couples, the societal risks arising from the potential of conception-assisting technologies to change the nature of human reproduction, or the risk that the medicalization of infertility entrenches our pronatalist social mores.

This narrow conception of risk occurs precisely because these are the values which biomedical clinicians themselves hold. If child-free living were more acceptable, many infertile couples would not be bothered by infertility. If many causes of infertility were prevented through basic public health initiatives such as education about sexually transmitted diseases and better environmental safety provisions, there would be few people in need of biomedicine's technological interventions. Biomedical assessments of the risks of conception-assisting technologies reflect biomedical beliefs in the efficacy of these technologies and reinforce physicians' control over definitions and treatments of infertility.

The power and control of infertility treatment has been rather easy for biomedical clinicians to secure. Infertile couples who seek treatment share many of the same beliefs as the clinicians who help them. They see their infertility as a disease which they need biomedicine to cure. This conception of infertility does not merely arise from the influences of biomedicine, but is also a product of our pronatalist society. We strongly believe that married couples should, and should want to, reproduce. This is especially true for women, for whom mothering is thought to be a natural and preferred role. Many of our beliefs, and indeed our social structures are built around the importance of having and raising children. These beliefs help make childlessness (both voluntary and involuntary) a stigmatizing condition.

For infertile women the fact that they cannot have children makes this stigma more profound, as they also hold pronatalist beliefs. They internalize others' beliefs that they are abnormal, and that they should be blamed for their inability to have children. Infertile couples who seek treatment also share with couples who can have children the same parenthood motivations and the desire to have genetically-related children to nurture.

The intense desire to have children, coupled with the stigma of infertility, leads to contemplating using biomedical treatments to help find a solution--that is, have a baby.

Infertile couples who seek treatment willingly participate in the medicalization of infertility because the pervasiveness of biomedical ideology makes this the culturally-prescribed route. Infertile couples who seek biomedical solutions have high expectations of conception-assisting technologies.

This social context informs the decision-making process for infertile couples seeking treatment, and their construction of risk. Decisions to use conception-assisting technologies involve weighing the costs and benefits of action and inaction. This means contemplating the risks of doing nothing to have biologically related children--stigmatization and regret at not trying biomedical treatments. For those who seek treatment, these are risks they cannot live with. While they understand the physical, emotional and financial risks of treatment, the benefit, a baby, is considered priceless. By choosing to use conception-assisting technologies infertile couples are participating in a high-stakes gamble, where the risks are high, but so is the possible reward. The decision is not a fixed one, and is constantly being re-evaluated throughout treatment. Eventually the benefits--a child, or acceptance of infertility--or the risks, which become too great, lead to the end of treatment.

The risk constructions of infertile women seeking treatment very much reflect and reinforce the dominant ideologies of our society, and the great value we place on married couples having children. The stigma of infertility and the central place medical solutions occupy in this social and physical problem, all shape their risk constructions. Those who seek treatment take great risks to their health, and their emotional and financial well-being, to fulfill the goals they have been socialized to desire.

Both infertile women seeking treatment and biomedical clinicians' risk constructions help maintain a way of life which reinforces existing social relations and ideologies about reproduction, biomedicine and technology. Feminist analysts, by contrast, assess the risks of conception-assisting technologies with the goal of achieving social change. Feminist analysts have written extensively about new reproductive technologies and their effects on women as a group. The overriding goal of the feminist movement is to eliminate the sexist oppression of women through change to our cultural concepts, language and ways of knowing the world, which currently maintain the practice of male power over women. They assert that true liberation for women will not occur unless and until we have absolute control over our bodies.

Feminists argue that the choices made by infertile women to use conception-assisting technologies must be analyzed to assess the constraints to their free and informed decision making. The risks of conception-assisting technologies are constructed by feminist analysts with an underlying question guiding the assessment: Do conception-assisting technologies aid in women's autonomy, or do they further enslave women to the role of childbearing?

To answer this question means assessing more than the risks to the individual women who use the technologies, though the feminist literature includes an extensive analysis of these dangers. It also means evaluating these technologies within their broader social context to examine how their use perpetuates certain ideas about women, their capabilities and their proper roles. Feminist constructions of risk therefore differ significantly from more traditional risk analyses.

Feminist analysts assert that conception-assisting technologies are full of known and unknown risks. The women who use them are "living laboratories" since many of the techniques and drugs remain untested, and their long-term safety remains a mystery (Rowland, 1992). Also, using conception-assisting technologies involves many financial, physical and emotional costs to women, since they are very expensive, involve vast amounts of time and energy, and are quite invasive.

They also see risks to women as a group arising from conception-assisting technologies. The high cost of treatments means that they are available to only those who can afford them. Lesbians and single women are also often denied treatment as biomedical clinicians who control the technology act as social gate-keepers deciding who should, and who should not, be able to reproduce. Conception-assisting technologies also perpetuate the medicalization of social problems and take attention away from the prevention of infertility which is often much less heroic, invasive and expensive, and would mean that women would have the freedom to reproduce without medical intervention. Finally, feminist analysts assert that the provision of conception-assisting technologies entrenches women's primary role as mothers to genetically-related children in the context of the nuclear family; that is, it does nothing to change the current social relations which make infertility a stigmatizing condition. Instead of changing society to accommodate the involuntarily childless, conception-assisting technologies change the infertile to accommodate society.

Feminist analysts' discussions of risk do not end with their assessment of the technology. An integral part of feminist analysis is the organization of resistance to the current state of affairs by responding to these risks with prescriptions for change. Feminist analysts are not trying to maintain our current way of life, they want to transform it. How this is to be achieved, however, is a point of contention among feminists writing about this area.

One group feels that the risks of the technologies are too great for women and the technologies should be banned. They feel that infertile women should overcome their socialized beliefs about child-bearing and reject these developments. These feminist analysts also assert that the path new reproductive technologies are currently taking is leading to dangerous new innovations which will place ever increasing control over reproduction in the hands of male-dominated scientific, pharmaceutical and biomedical organizations. This will continue to inhibit the reproductive autonomy of all women.

Another group of feminist analysts disagree with this response. They see it as denying infertile women the opportunity to procreate since this desire, regardless of its roots, is quite genuine. They also assert that women and many men will not allow the full-scale technological take-over of reproduction prophesied by those advocating a ban of the technology. They assert that there is a historical precedent of women's resistance to incursions on their reproductive autonomy which is sure to continue. They do agree with those advocating the ban that the current provision of conception-assisting technologies is quite risky and that changes must be made to ensure that infertile women make free and informed choices, and that the development and use of these technologies promotes and ensures women's full reproductive autonomy.

WHAT IS MISSING: SOCIETAL-INFORMED CHOICE

While feminist analysts advocate necessary changes to the delivery of conception-assisting technologies to promote the goal of women's informed and autonomous decision making, they too neglect an important element of the debate on technological acceptance. How do decisions about the development of technology occur in the first place? In the case of conception-assisting technologies, no government or biomedical professional body has approached the public, asking if they want technologies like these to be developed. There was no societal debate about the risks and benefits of conception-assisting technologies *before* they were implemented as standard biomedical treatments. Instead, the technologies were thrust upon us, touted as medical miracles, leaving the public, and our governments to then deal with the many ethical, physical, financial, and other dangers these new techniques presented (Beck, 1992; Dutton, 1988).

As individuals, we have little control over the creation of technological developments, which means we initially have little control over the risks. Biomedical and scientific institutions take a paternalistic attitude toward the lay public, creating technologies which are "for our own good", and they assume there is a societal consensus about the importance of technological developments. They have decided what we need, and in so doing have the power to radically alter the nature of human reproduction.

When groups in society decide that the risks of a particular development need further exploration, or are too great, we as a society have a dialogue about the technology usually only *after* it is in use. The Royal Commission on New Reproductive

Technologies is a good example of this. The Royal Commission arose from the intensive lobby efforts of the Canadian Coalition for a Royal Commission on New Reproductive Technologies, a nation-wide coalition of women's, health and other groups and individuals who were concerned about the course new reproductive technologies were taking in Canadian society (Eichler, 1993). Conception-assisting and other reproductive technologies were already in widespread use by the time the Royal Commission was launched in 1989. As a society we could only react to these technologies after their implementation since we did not have the opportunity to shape their creation.

Feminist analysts and others concerned about the risks of conception-assisting technologies need to analyze the decision-making structures in biomedical, scientific, and corporate organizations. If we are to have control over the nature of technological developments then there must be mechanisms of societal-informed choice in place. This means having knowledge about the risks and benefits associated with these innovations, and ensuring that those who will bear the major burden of the risks (in this case women) and the general public have a greater voice in the direction and regulation of new forms of reproductive technology. Societal-informed choice means more than reacting to existing technologies; it involves the democratic shaping of new innovations, and achieving "...social control over the welfare of the body politic" (Dutton, 1988: 252).

SUGGESTIONS FOR FURTHER RESEARCH

While much was learned from this analysis of the risks of conception-assisting technologies constructed by biomedical clinicians, infertile women seeking treatment, and feminist analysts, the findings lead to many more questions and possibilities for further research in the following areas.

- The limitations of a literature review could be overcome through research which asks members of each group directly what their conceptions of risk are, and the sources of their risk information.
- Infertile couples are the group that is most directly affected by the risks of conception-assisting technologies. More research is needed to understand their views about the technologies and their risks. Also, longitudinal research which follows them through and beyond the infertility diagnosis and treatment process would be beneficial as it would illuminate the influences on their risk constructions and decision-making to see how these change over time.
- All of the groups in this study had reasons for participating in the risk and technological acceptance debate. Research about the risk constructions of the lay public surrounding

conception-assisting technologies would also be useful for seeing whether the risk constructions of biomedical clinicians, infertile couples, and feminist analysts influence and/or reflect more general or societal viewpoints on these technologies.

- The decision-making process regarding the use of conception-assisting technologies by infertile women is a complicated one. More research is needed to understand the many factors which influence women's decisions to use conception-assisting technologies. Determining the role a woman's partner plays in shaping treatment decisions is especially important. Longitudinal research following couples through the process of diagnosis and treatment would be very beneficial.
- There is also little research into couples who choose not to treat their infertility. Do they feel the treatments are too risky? Are their parenthood motivations different than infertile couples who seek treatment? Do they adopt instead? Understanding the risk conceptions, and decision-making processes of couples who do not seek treatment using conception-assisting technologies would provide further depth to the existing research in this area.
- The biomedical constructions of risk also need more detail. This analysis discussed infertility specialists' risk constructions without fully delineating the complicated organizational influences on their risk decisions. How do

powerful groups like pharmaceutical and insurance companies, professional regulating bodies, and the scientific research elite construct the risks of conception-assisting technologies, and what are their vested interests for doing so?

- Is the feminist message about the risks of conception-assisting technologies reaching infertile women? Research is needed to gauge the influence of feminist writings and activism on new reproductive technologies to see whether the message is reaching individual women and shaping their decision making.
- While feminists certainly talk about risk, they have not yet developed a feminist method of assessing risks and analyzing risk construction. Such theoretical models need to be developed so technological and environmental dangers can be identified, assessed and explained in terms of how they affect women as a distinct group in society. A good starting place for this may be found in the emerging literature on feminist ethics, especially writings focusing on biomedical practices (for example, Overall, 1987; Overall, 1993 & Sherwin, 1989).

SIGNIFICANCE OF RESEARCH

To the best of my knowledge, this study is the first comprehensive analysis of the risk constructions of biomedical clinicians, infertile women seeking treatment, and feminist analysts--three important groups involved in the debate over the efficacy, safety and acceptability of conception-assisting technologies. This comparative analysis of differing risk constructions also makes way for more comparative sociological analyses of different groups' risk assessments of technological innovations.

In examining the social, political, economic and cultural influences on each groups' risk constructions, this study illuminates the type of society each group wants to promote or maintain, and their reasons for doing so. It shows that assessments of risk are not merely statistical proclamations, or lay opinions about safety. They are about technological acceptance, and they reflect the many vested interests individuals and groups have for constructing risks the way they do. Exploring the risk constructions of various groups demonstrates that risk is political; it is not just about the amount of danger we are willing to accept, but about the kind of society that we want to live in.

Infertile women seeking treatment and biomedical clinicians assert that the risks of conception-assisting technologies are well worth the benefit; the possibility of a child. Their risk construction reflects and maintains our pronatalist, medicalized society which seeks technological fixes for social problems. Feminist analysts, by contrast, feel that the risks of conception-assisting technologies are unacceptable for the women who use them, and for the reproductive autonomy of all women. Some feminist analysts feel that conception-assisting technologies, especially IVF, should be banned. Others do not want to take this drastic measure since infertile women do benefit from these technologies. Instead they advocate massive reforms to the organization of biomedicine and the delivery of conception-assisting technologies. These feminist analysts do not fear technological innovations per se, but instead see that technology can benefit women as a group if the social relations which govern its development and use are radically altered. But they neglect in their analysis the notion of societal-informed consent, where democratic institutions not only react to technological innovations, but also shape their development and implementation so that debates over the acceptability of technological innovations occur before women's well-being and autonomy are put at risk. In contrast, I suggest that we need a broader basis for decision-making about technology where the often difficult political debate about risks and acceptability are at the forefront, enabling full societal participation in the creation and use of technological developments.

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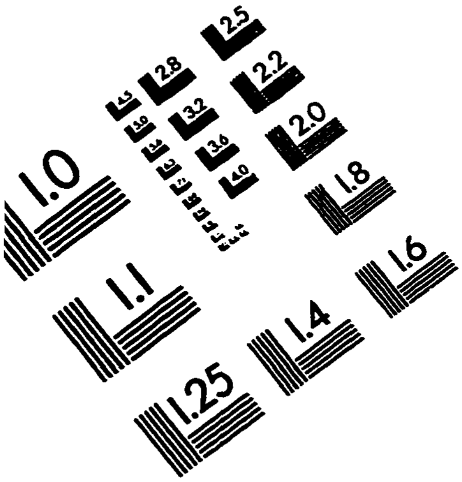
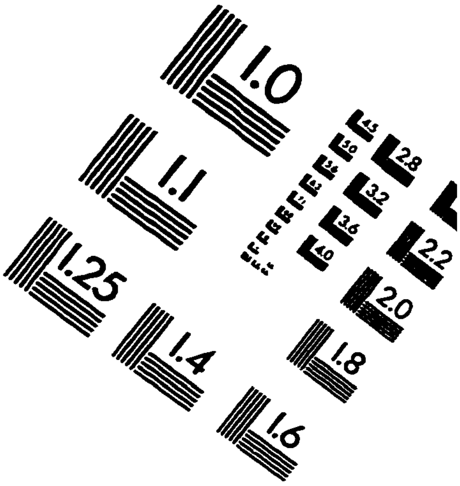
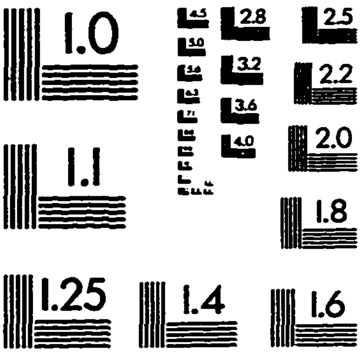
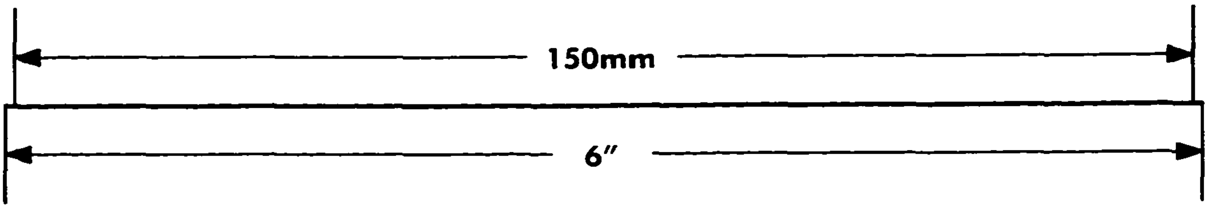
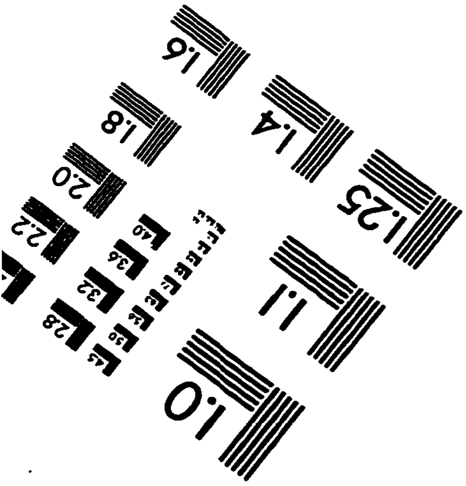
IMAGE EVALUATION TEST TARGET (QA-3)

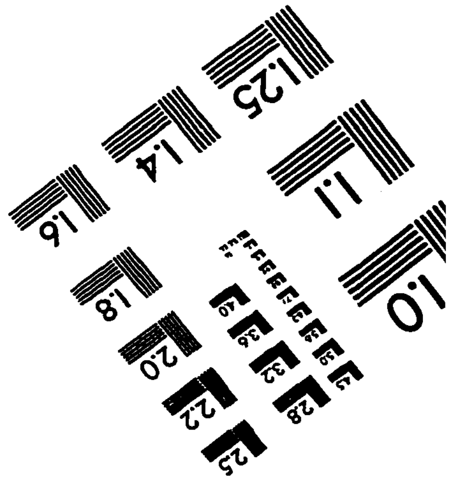












APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989